Improving the health of communities through participation.
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The structure of this resource kit

We have designed this folder as a resource kit for each service and other interested people. The purpose is to highlight the achievements of the doctoral students engaged in this community participation program and to document the learning’s from the program against some of the unanswered questions that we identified at program commencement (see page 3).

This resource kit is structured in three parts:

1. In part one, we present an Executive Summary and a brief outline of the program background, rationale and approach. Short bios are provided for each of the staff and students. At the end of this part is a list of the dissemination activities (e.g. publications, conference presentations and awards) that have been completed as part of this program.

2. In part two, high level summaries of the projects conducted in each community are provided. The students have documented the approaches used, the major activities and the major outcomes/learnings. For each of the cross cutting projects a high level summary is also provided (focus on summary of approaches, activities and learnings).

3. Part three is divided into seven sections:
   - Section one: The purpose of community participation
   - Section two: The challenges of community participation
   - Section three: The link between community participation and health literacy
   - Section four: Methods of community participation
   - Section five: The role of leadership and governance in community participation
   - Section six: Engaging community members in participatory processes
   - Section seven: The ethical implication of community participation

   Each of these sections is presented in a similar way: a summary of the key points, the evidence (all of the articles are provided with this resource), and a summation of what we have learnt. At the end of each section are publications, presentations and documents produced by our whole team to support the summations.
The following table provides a map of how each of the unanswered questions is explored in each part of this resource kit.

<table>
<thead>
<tr>
<th>Unanswered questions</th>
<th>The corresponding part of the report that addresses these questions</th>
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<tr>
<td>• What service models do communities design for themselves given a range of data, information and research evidence?</td>
<td>Part two high level summaries of each service and cross cutting projects</td>
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<td>• What is the role of communities in changing health service delivery models? (co-implementation and co-production)?</td>
<td>Section one – The purpose of community participation</td>
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<td>• What is the purpose of community participation? What are the outcomes from a health policy and service perspective? Can these outcomes be achieved?</td>
<td>Section one – The purpose of community participation</td>
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<td>• What are the challenges in community participation?</td>
<td>Section two – The challenges of community participation</td>
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<td>• Does community participation lead to changes in community health literacy, attitudinal and behaviour change, changed use of health services?</td>
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Executive Summary

In late 2012, staff and students from La Trobe University Rural Health School, Rural Northwest Health, Rochester and Elmore District Health Service, and Heathcote Health embarked on a journey to address some of the unanswered questions related to community participation. The partnership was unique, in that funding was provided by the services to attach a doctoral student to each of the communities. The student would complete all requirements for the award of a PhD and support for the students would be provided from the service and from all researchers involved in the program.

The design for this program was developed from the Scottish work of Farmer and Nineger. In their Remote Services Future (RSF) study, their method of community participation was based on deliberative decision-making. They engaged citizens, healthcare professionals and service managers in a series of structured workshops to produce hypothetical, rural healthcare service plans. Broader community engagement occurred with those who could not attend formal workshops. The workshops focused on perceptions of health in the community, versus evidence of actual health status, consideration of service innovations, and a planning exercise, where local service models were designed within existing budgets.

In our program the RSF process was followed, with projects established across three rural sites. The choice of communities was pragmatic, in that the Chief Executive Officers (CEOs) of three rural health services expressed interest in participating in the study after hearing about the work in open presentations.

The study focus of consumer participation was a direct response to the international policy directive that consumer participation is central to all aspects of service planning, design, delivery, and evaluation. Within the literature there is growing interest in community participation, but numerous authors debate theories, rationale, purpose, approaches and methods. In healthcare: local responsiveness, cost containment, improvements in health outcomes and greater accountability of services and systems are frequently identified as outcomes. However, many of the underpinning propositions for community participation are tempered by acknowledgements that the evidence base for these claims is not strong.

There is government acknowledgement that mandating participation is difficult, when there is lack of clarity on how participation can, and should be enacted, beyond a tokenistic, ‘tickbox’ exercise. Community participation remains a policy aspiration in many Western countries, but has been described as an ‘elusive goal’ at the community level.

Consistent with the Scottish RSF process, members of community organisations, [service and sporting clubs, craft and interest groups and older peoples’ groups], citizens, local service agencies [eg, local government], and health service CEOs and staff were invited to participate in four community workshops in each community. Invitations were sent via letters and newspaper advertisements. Four key topics from the RSF process were used to guide the workshops: identifying local health assets and challenges, comparing citizen perspectives with objective health data from local health service and government published sources, examining evidence of what works to address identified health challenges, and what service models might meet their future needs.

In each of the three services the process worked slightly differently, reflecting the inherent messiness of community participation. Each health service and each community embraced the project in different ways. In Yaniramba, John Atiken (as the PhD student) led a process where there was major buy in from the health service and the community. John’s enthusiasm resulted in engagement with over 500 people. The community worked together to host major mental health forums, design community gardens, and deliver aged care expos and age friendly gymnasium equipment in community spaces. In Heathcote, Elena Wilson (PhD student) led a process that resulted in community forums and a community-working group to establish a health and wellbeing plan. A governance framework was developed to bring together members of the community and external stakeholders, who had not previously worked together. In Rochester and Elmore, Mary Magennis (PhD student) led a process that prioritised young families, drug and alcohol issues, youth, older people, mental health and access to specialist services.

Given significant interest in community participation at a health service level, the Dean of the then Faculty of Health Sciences (now College of Science, Health, and Engineering) provided funding for three doctoral students to pursue cross cutting projects. Nerida Hyett focused on international exemplars of community participation, Diana Guzys, on the link between community participation and health literacy, and Emma Patten on community inclusion.

The students have produced a multitude of publications, key documents, policy papers, and have presented in Australia and internationally. The commitment of the services to this project has been highlighted internationally, with much interest in the unique approach.

As a team we have achieved much, but there have been many challenges along the way. However, everyone is very proud of what has been achieved. We extend our warmest thanks to the services that provided funding, and we look forward to celebrating with you as each student walks across the stage to receive their PhD. We are delighted to present this resource kit as our final report.
The La Trobe Rural Health School research team that led this project

**Professor Jane Farmer**
Professor Jane Farmer is Associate Pro Vice Chancellor, Research in La Trobe’s College of Science, Health and Engineering. Jane’s current research interests are in community and citizen engagement and involvement, co-designing and co-producing health services and measuring outcomes of this as a means to increase health literacy (and therefore health) and civil participation. Jane has written extensively on rural health services, and led groundbreaking projects around working with communities to produce health services. She won a Scottish Government Innovation award for her Remote Service Futures study.

**Professor Amanda Kenny**
Professor Mandy Kenny holds a PhD in rural health policy and is a Professor of Rural and Regional Nursing. She is widely published internationally and is frequently invited as a key speaker at national and international conferences. As an active researcher, she has a strong interest in consumer participation in health care and health service design. Mandy has conducted extensive research and consultancies for Government, with an emphasis on service design, funding models and workforce development.

**Dr Virginia Dickson-Swift**
Dr Virginia Dickson-Swift is a Senior Lecturer in the La Trobe Rural Health School, La Trobe University, Bendigo, Australia. She has a wealth of experience in teaching research methods to undergraduate and post-graduate students throughout Australia. Her research interests lie in the practical, ethical and methodological challenges of undertaking qualitative research on sensitive topics and she has published widely in this area. Currently she is involved in a number of projects using community based participatory research methods to explore aspects of community health and wellbeing in rural communities throughout Australia.

**Professor Peter O’Meara**
Dr Peter O’Meara is the Professor of Paramedicine at La Trobe University. Peter has academic qualifications in health administration and public policy. His doctorate examined rural paramedicine models of service delivery. Prior to his La Trobe appointment he was employed at both Monash University and Charles Sturt University after working in rural ambulance services in Victoria for over 20 years.

Peter’s research publications and research interests focus on rural health and paramedicine models of care, in particular the evolution of community paramedicine models in North America. His research students are further extending this work through their own studies. He is a frequent conference speaker in Canada and the United States where the concept of community paramedicine is gaining traction as a mainstream role to meet the needs of communities and improve the operation of the health system.
In 2011-2012, Professor Jane Farmer, Professor Amanda Kenny, Dr Virginia Dickson Swift and Professor Peter O’Meara worked on a proposal for a research partnership focused on community participation in health service design. The development of this proposal was prompted by discussions held with various health services in 2011 about their interest in developing stronger knowledge and practices for working more closely with their community.

The proposal was for that each health service to fund a PhD student for a period of three years for focused work on community participation. The student would complete all requirements for the award of their degree through this program and would be aligned to the service/community for the length of the program. Staff from the La Trobe Rural Health School would supervise the students, and support for the students would be provided from the service and from all researchers involved in the program.

There was significant interest in a program of this type and a partnership was formed between the La Trobe Rural Health School and three rural Victorian health services: Rural Northwest Health, Rochester and Elmore District Health Service and Heathcote Health.

Proposed benefits

The developed program had extensive input from the services and was designed to involve the ‘community’ (local residents, service providers [including council, health service and other service providers] and local formal and informal groups) in ‘conversations’ about health and health services in the local area. Through a structured process, communities were supported to devise a forward looking plan to address future, local, health and health service priorities. Through this process, the plan was that communities would be supported to collectively plan and implement change designed to improve local health outcomes.

The program was designed to produce evidence for the services on enacting rural community participation at a grass roots level. It was proposed that the knowledge gained from all aspects of this program would make an important contribution to broader understanding of community participation (particularly in the rural context), and would result in learnings that could be scaled across regions, geographic contexts and health care systems.

Staff in the La Trobe Rural Health School were interested in testing community participation techniques, implementing and exploring outcomes from use of the Remote Service Futures method [described below], and community priorities and planning activities.

It was envisaged that the program would provide the opportunity to explore some of the unanswered questions that relate to community involvement [see page 8]. Academic outcomes, including international refereed publications and conference presentations were a priority.

It was proposed that the PhD students would benefit from involvement in a highly practical project, based within a service and community. Each student would complete a PhD with refereed publications and conference outcomes.
The benefits/outcomes for the service were summarised as follows:

- Completion of a well-designed, innovative and rigorous program of research that is supported by staff from the LRHS.
- A supported, structured community participation program.
- A PhD student that is aligned to the service for three years. Under the supervision of LRHS staff, the student will lead the body of work.
- It was envisaged that having a student aligned with the service and having staff from the LRHS actively engaged would build capacity within the service. Participation by local health professionals/staff of organisations would be encouraged, as it would strengthen the potential outcomes. Through this involvement, it was envisaged that a flow on effect would occur with individual skill development in aspects of project management, community development and research.
- Identification of community health and wellbeing priorities for the local community.
- Access to innovative knowledge on what has been done in other communities/what works and what doesn’t.
- A ‘realistic’, measurable and timelined/contingent, community/stakeholder-designed plan to start to achieve a community that is both healthier and has the most appropriate service models.
- Potential changes in health literacy in the community, regarding key local health and service priorities (longer term impact 3–10 years).
- Potentially, a sustainable model of community participation/governance and a community that is engaged and motivated to take the initiative forward.
- External recognition of innovative work within the service through profiling the service and the program nationally and internationally through conferences, publications and nominations for service awards.

The rationale provided in the original proposal

The Declaration of Alma Ata in 1978 was a major landmark in primary health, and established the democratic right and responsibility of the community to participate in health care planning, design, development and implementation. It firmly established the benefits of harnessing broad community action to improve primary health, and identified meaningful participation by individuals, and collectively, as central in building self reliant and self determined communities capable of taking the action necessary to respond to significant health care inequities (World Health Organisation and UNICEF 1978). Since that time, the WHO has promoted the need for the social, economic and health sectors to take inter-sectoral action on health, and community participation has become enshrined in international health policy (Green, Price, Lipp, & Priestley 2009).

Countries have adopted various policies and approaches to community participation, with most underpinned by the notion that empowered communities drive improvements in health and health care, including health literacy (Kilpatrick 2008). In the Australian context, the national health reform agenda is predicated on strong community participation, with Government policy indicating that meaningful community participation is central to the achievement of locally responsive, agile and flexible services (Australian Government Department of Health & Ageing 2009, 2011).
Unanswered questions surrounding community participation

While there is an extensive body of research on community participation in health and health care, there remain key unanswered questions. These questions include:

- What is the purpose of community participation? What are the outcomes from a health policy and service perspective? Can these outcomes be achieved?
- Does community participation lead to changes in community health literacy, attitudinal and behaviour change, changed use of health services?
- What models of services do communities design for themselves given a range of data, information and research evidence?
- Given that a number of processes and models have been trialled and many ‘experts’ herald their own model as ‘best practice’, what are the key aspects of best practice models/processes?
- Is community participation a project, a governance model or both? Is it appropriate to make community participation sustainable and if so, how?
- Given that individual communities have been engaged, how do you engage across communities to design regional plans for health?
- Researchers state that community participation should be inclusive. What does inclusion mean in different rural communities? What models have been tried and what is best practice in rural community inclusion? What mitigates inclusion issues? Does inclusion matter and to what extent? What voices are most often lost and what impact does this have?
- How does community participation relate to other governance mechanisms at different levels in health services?
- To what extent, can and should community participation and other local health governance mechanisms serve to act as general advocacy vehicles for rural communities?
- Given that ‘the best’ community action is assumed to be bottom–up, what is the ethics of top–down processes generating bottom–up activity? What are the ethics of academic/research involvement in community participation? What divisive actions can arise from community participation and what are their current and ongoing impacts on rural communities?
- How can community participation, empowerment, knowledge and health literacy ‘go viral’ – i.e. how can you spread effects from immediate participants, into the wider community?
- What is the role of novel methods in community participation; e.g. visual methods like geographical information systems (GIS) and global positioning systems (GPS) mapping; and narrative methods like storytelling and consumer-accessible systematic reviews.
- What is the role of communities in changing health service delivery models? (co-implementation and co-production)
The appointment of doctoral students aligned with each service.

The program commenced in 2012 through a transparent application process for the service funded PhD students. Service staff from Rural Northwest Health, Rochester and Elmore District Health Service and Heathcote Health were involved in the student recruitment process, with final decisions about the service funded PhD students made by service staff. The following students were recruited into the program:

**John Aitken**

John qualified as a pharmacist in 1976, and initially pursued a career in academic research. John gained a Master of Pharmacy degree studying neurotransmitter pharmacology at the Victorian College of Pharmacy. John then worked as a pharmacist in the UK before returning to work in new drug research and product registration in Melbourne.

In 1982 John bought his first retail pharmacy in Melbourne and in 1987 John sold his Melbourne pharmacy and bought the Amcal pharmacy in Warracknabeal. John subsequently also formed a partnership at the Amcal Pharmacy in Horsham. These were busy pharmacies each averaging 3000 prescriptions per week, and gave John a chance to observe peoples’ health problems every day. Between 2006 and 2010 both businesses were sold and John retired. John worked part-time as a pharmacy locum.

In 2012 a position as PhD researcher for La Trobe Rural Health School, based on study at Rural Northwest Health service, was advertised in Warracknabeal. John began his PhD in October, 2012.

John has since learned a lot more about the causes of peoples’ health problems and the impact of social determinants on health outcomes.

“Researching for my PhD has given me a much better understanding of the health problems, faced by people living in my community, than my previous years in community pharmacy. In the pharmacy, you focus on the problem of the person in front of you; in my PhD I focus on the problems facing the broader community, and particularly marginalised and disempowered community members.”

John’s goal is to finish his PhD in 2016 and continue to work in public health.

“Doing my PhD has been one of my best life experiences. In my research I have met some wonderful people, with all sorts of stories; I have also worked with some great new colleagues, and have enjoyed every aspect of a project that has already been recognised, by health groups, as improving community health and wellbeing.”

**Mary Magennis**

Mary is a retired Professor of Nursing from the University of Tasmania. She spent twenty years in university education and was involved in the transfer of nursing education from hospital-based schools of nursing to higher education. Prior to that time, Mary worked in nursing at St Vincent’s Hospital in Melbourne and studied a Masters degree in primary health care at the University of Rochester, State of New York. She has continued with some casual part time on line teaching and has been a Board Member of a rural Health Service. In her spare time she lives on a farm and runs a Poll Dorset Sheep Stud.

**Elena Wilson**

Elena’s research in this project examines the ethical implications of community-based participatory research. She has a BA Hons. (Sociology) and teaches in the core first year Health Science subjects at La Trobe University while completing a PhD with the La Trobe Rural Health School. Elena has previously had roles in rural health, project management, health service community participation and human research ethics.
Cross cutting projects.

Given significant interest in community participation at a health service level, combined with key policy documents highlighting the need to involve communities at all levels of service design, planning, implementation and evaluation, we approached the Dean of the then Faculty of Health Sciences to provide further funding for the program. Our submission highlighted that services were required to meet the National Safety and Quality Health Service Standards – Standard 2 Partnering with Consumers and the criteria to meet the standard include consumer partnerships in service planning, designing care, measurement and evaluation.

We indicated to the Dean that there were significant unanswered questions around community participation processes and the impact of community participation on health literacy. We argued that Faculty funding to support three staff PhD scholarships would significantly strengthen our ability to establish a strong research program that would lead to significant outcomes and outputs. Our funding request was approved. The following staff were recruited into the program through a transparent application process:

**Nerida Hyett**

Nerida Hyett (B.OT, MHSc) is completing a PhD with La Trobe University. Her research is a qualitative investigation of how and why people participate with community initiatives. By increasing understanding of the issues and challenges of community participation, she aims to develop innovative approaches to improving community health and wellbeing.

**Diana Guzys**

Diana Guzys has spent most of her nursing career in community health roles undertaking health education and health promotion in central Victoria. From this, a passion to better understand how to improve the health literacy of communities and the health care system has developed, particularly for rural communities.

**Emma Patten**

Emma Patten has been teaching with La Trobe for thirteen years in the fields of health promotion and environmental health, as well as working in positions of community development with young people, the aged, and mental health consumers. She is also a PhD student with LRHS, studying inclusion and exclusion of people in community engagement for participation in rural health decision-making and service development. Emma grew up in both the city and the country of Victoria providing a unique insight into the differences and similarities of these regions. Emma is currently on maternity leave from La Trobe and enjoying the experience of being a mum to Eli.
Phase one of the project.

- Engagement of the community using various means.
- Use of the Remote Service Futures methodology (adapted for local circumstances). This 4–5 stage process involved providing communities with iterations of data, information and evidence about health and healthcare services. The process included:
  1. engaging communities in envisioning their future;
  2. engaging the community with local health and social data and encouraging questioning;
  3. introducing service innovations, methods or health interventions used elsewhere;
  4. discussing costs;
  5. establishing priorities and planning for the future.

Figure 1 illustrates the phase one process.
Phase two of the project.

- Provision of feedback to the community on the priorities identified in phase one.
- Harnessing of community interest in taking priorities forward.
- Compilation of detailed information [data and costs] about the identified community priorities and consideration through a participatory research process.
- Completion of a final community prioritisation plan.
- Feedback to the broader community [the process of feedback was tailored to meet individual community need].
- Exploration of whether and what type of ongoing community governance mechanism a community might want and how it fits with existing governance mechanisms like the Board and Community Advisory Committees, if they are in place.

Figure 2 illustrates the phase two process
Dissemination activities completed as part of this program.


Aitken, J., & Knight K. (2014) Improving the health of rural communities with Community Engagement. Poster presented at Rural Northwest Health Strategic Planning Meeting (07/2013 Victoria, AUSTRALIA)


Aitken, J., Morley, C., Casey, L., & Knight K. (2014) Engaging the local community to promote well-being. Workshop presentation Leading Age Conference (10/2014 Nashville, USA)


Guzys, D., Dickson-Swift, V., Kenny, A., & Threlkeld, G (2014) Exploring the complexities in developing a suitable framework to assess the critical health literacy of population groups. Presentated at Higher Degree by Research Festival (12/2014 Victoria, AUSTRALIA)


Part two: high level summaries of the projects conducted in each community and the cross cutting projects

Health service project: Yarriambiack

– John Aitken (Supervised by Dr Virginia Dickson-Swift and Prof Amanda Kenny)

Key facts about the community

<table>
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<tr>
<th>7th HIGHEST</th>
<th>1 in 2 people are overweight or obese</th>
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<td>The Yarriambiack community ranks 7th highest in Victoria for the total number of people with asthma</td>
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<th>1st HIGHEST</th>
<th>1 in 2 people in the Yarriambiack community do not eat the recommended levels of fruit and vegetables</th>
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<td>The Yarriambiack community has the highest per capita consumption of sugar sweetened beverages in the State of Victoria</td>
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| | 1 in 4 people in the Yarriambiack community are over 65 years of age |
| | |

Photograph by Mattinbgn: Wikimedia Commons
Photograph by Mattinbgn: Wikimedia Commons
The process
The process in the Yarrambiack community was designed to achieve the following aims:

• Develop a sustainable mechanism of working with community members to explore and test ideas, and in partnership, design evidence-based approaches to maximise health outcomes.
• Identify priorities and capture innovative approaches that communities design given a range of data, information and research evidence.
• Forge a strong partnership with a leading university to ensure the project reflected world-class best evidence on community participation so that knowledge gained could be translated to the broader sector.

24 workshops were conducted with community members engaging 500 people (in a community of 6500). Agreed health priorities were designed to achieve locally responsive, cost effective solutions to target poor health outcomes.

What the community prioritised

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<tr>
<td>Self-help, connecting people and 'social glue.'</td>
<td>Older people and loneliness</td>
<td>Communication on health issues and services.</td>
<td>Sustainability of community and health services.</td>
<td>Access and transport to health services.</td>
<td>Drug and alcohol issues.</td>
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Community identified health and well-being priorities

Outcomes

• Major mental health forums, including an ICE drug forum attended by 350 people.
• Community gardens in three communities to support intergenerational socialisation and distribution of health information.
• Aged care expos in two communities.
• Age friendly gymnasium equipment in community spaces to promote exercise amongst older people and people with disabilities.
What models of services do communities design when given a range of data, information and research evidence?

Rural Northwest Health previously had an ad hoc approach to conversations with consumers regarding service development – this was not targeted. The community action research group process provided additional information for the health service about consumer experience of their health and well-being and their interaction with health services. The community engagement process identified potential champions within the community who could support appropriate interventions that would improve health and well-being.

The major service gaps that were identified by the research groups included support for young people, support for people with cancer, and gaps in service and health literacy, where community members were not aware of the resources available and appropriate interventions for health problems.

People with cancer were interviewed and identified a number of problems associated with treatment planning, mental health issues, access problems and other health and well-being issues. These problems were addressed by the appointment of a cancer support nurse for Rural Northwest Health, who implemented the following strategies:

- The cancer support nurse has responsibility for managing treatment arrangements in Yarriambiack Shire but also for people travelling to regional centres Horsham, Ballarat, Bendigo and Geelong; and for people travelling to Melbourne.
- Coordinating transport for appointments and ensuring people are aware of government subsidies for both transport and accommodation.
- Coordinating care for people with cancer with community health team members, ensuring allied health support and that laboratory and test results are available when required for appointments.
- The presence of a cancer support nurse meant that people who were discharged to remote rural communities felt that they were still under care and that their condition was being appropriately managed. This provided a psychological benefit for community members who were struggling with the consequences of having a cancer diagnosis even though they were in remission.

Some young people in the community were victims of bullying, social isolation or mental health problems. These young people felt that they could not attend the regular secondary College campus and chose to attend the optional off-campus Victorian Certificate of Applied Learning course that was provided at the Warracknabeal neighbourhood house. A teacher from Warracknabeal secondary College, with assistance from a teacher’s aide, provides this course on one or two days per week. On average approximately 10 to 15 students are registered to attend this program at any one time. Interviewing these students identified the following issues and some potential solutions:

- Lack of work experience for young people attending the VCAL program. RNH and Yarriambiack Shire developed a short-term placement and mentoring program to provide experience and support for students trying to enter the workforce.
- The lack of a permanent youth social worker in the Yarriambiack Shire was identified as a priority and the position has since been filled with a youth worker with local experience who has so far stayed longer than recent appointees.
- A health and well-being program targeting youth was the basis of the launch for ‘Seasons of Wellness’ by a youth worker who specialised in dealing with marginalised young people.
The need to build capacity amongst community members to address health and well-being issues was developed into a program of community events called Seasons of Wellness. These programs aimed to improve health literacy and build capacity for community members to deal with the diversity of issues that affected the health and well-being of local people. Topics discussed in presentations included:

- Prostate cancer at local football clubs
- Arthritis disease management.
- Falls prevention
- Strategies to de-clutter your house and life

To build community capacity and develop better relationships with La Trobe University, university researchers presented at a **Communiversity** at Rural Northwest Health. Presentations related to rural life and included:

- Microbiology for farmers.
- A history of farming and the Mallee region of Victoria.
- Romance literature and rural life.
- Rural streetscapes and city laneways.
- Community engagement in rural health.
- Strategies for ageing at home in small rural communities.
- Classical literature why were World War I soldiers reading the Iliad and Odyssey at Anzac Cove.

To address intergenerational health, the concept of community gardens was developed as a way of improving the therapeutic landscape of the Yarriambiack community by adding health to place. Community gardens were developed in Warracknabeal, Beulah, and Hopetoun. Over 300 community members have been involved in this project and some 20 community organisations have participated in supporting the development of these gardens. This was developed using a coproduction approach with RNH providing administrative support for community organisations to develop the gardens. The gardens in Hopetoun and Beulah have been developed on hospital grounds, however, the Warracknabeal community garden group wished to set up their garden on disused land in the main street of Warracknabeal. Stakeholder consultation has been a key feature in the development of all of these gardens, and the outcomes have addressed community needs.

The key benefits of the gardens can be summarised as follows:

- Intergenerational engagement between community members. All age groups have participated from the very young to the very old. Children’s gardens have been developed within the community gardens to ensure that they participate.
- In Warracknabeal, the disability service Woodbine has been involved in preparing and designing the garden site. Special garden beds for people with mixed abilities have been incorporated into the design of the community garden in Warracknabeal. Clients of Woodbine disability services continue to participate in the garden on a regular basis and are involved in garden bed maintenance, watering, and maintaining the garden site.
- The health service social worker, community health nurse, dietician, and physiotherapist have all been involved in the garden design and presented information to community garden group meetings.
- Fresh food is available for community members to use and this has led to increased food security for marginalised community members.
- The community gardens have received community grants for; sunshades and skin cancer education, water reticulation and recycling, administrative costs, and garden infrastructure.

These gardens continue to develop within the communities and are a key outcome of this project.
Health service project: Heathcote

– Elena Wilson (Supervised by Prof Amanda Kenny and Dr Virginia Dickson-Swift)

Key facts about the community

- 3 in 4 people are overweight or obese
- 1 in 3 people live alone
- 1 in 3 adults in the Heathcote area smoke
- 1 in 3 people tested for blood cholesterol by the Heathcote GP clinic recorded high levels of cholesterol
- 1 in 4 people in the Heathcote area are over 65 years of age

The process
Community members and stakeholders were involved in group discussions to envision the health and wellbeing future of their community. They were provided with health and social data, to make decisions about local health and wellbeing issues in Heathcote. Health and wellbeing priorities were identified by the group through workshops and community meetings.
What the community prioritised

Community identified health and well-being priorities:

- Mental health
- Social isolation
- Access to health services
- Transport
- Ageing population

Exploration of community interest in taking priorities forward

- Two community forums held to review Heathcote and District Community Plan and to gain community participation in development of community governance model for implementation of the plan.
- Community–identified priorities, health data and health service priorities were presented to the broader community at these forums.
- A community working group was established for development of a Health and Wellbeing Plan based on the community–identified priorities.

Production of a final community prioritisation plan:

A community Health and Wellbeing Plan was developed, reviewed and finalised by the Health and Wellbeing working group together with broader community input. This plan sits within the Heathcote and District Community Plan 2014–2017, which was developed as part of the community’s new governance model which became the Advance Heathcote group.

The Health and Wellbeing Plan includes clear objectives, each associated with potential partner organisations and timelines for completion. A governance structure was established to drive implementation and associated reporting to the Advance Heathcote group.

Developed plans (with community and other stakeholders) to engage the broad community:

- Development of a hospital Community Engagement Strategy, the community health and wellbeing working group and the community action research group.
- Community engagement objectives incorporated into the Heathcote and District Community Plan.
- Selection of an ‘Inter-generational project’ (Heathcote Games) for testing locally as priority objective of the Health and Wellbeing plan. Heathcote Games is an intervention, which has emerged from the prioritisation process and included as an objective in the Health and Wellbeing Plan developed by the community. A steering committee was formed to implement the Heathcote Games.

What models of services do communities design when given a range of data, information and research evidence?:

The model designed by the Heathcote community is a social model based on the community working together with a focus on social determinants of health resulting from the community’s recognition of the interrelationship between their health and socio–economic factors. Their model is based on a governance framework that brings together members of the community and external stakeholders, who did not previously work together for a common goal. Accountability, process and community engagement have been built into this framework.
Health service project: 
Rochester and Elmore

– Mary Magennis (Supervised by Prof Jane Farmer and Prof Peter O’Meara)

Key facts about the community

1 in 2 people are overweight or obese

Over a 5 year period Rochester recorded the highest rate of farm injuries requiring admission in the Campaspe Shire

1 in 3 people are over the age of 65

The highest risk to life in the Shire is heart disease

The process

The project was promoted via the media, mail and attendance at community events. Seven community meetings were conducted. Research visits to community groups and organisations resulted in participation of 150 community members. The aim was to involve local people in identifying priorities for local health and wellbeing with REDHS and other local services.
What the community prioritised

Community identified health and well-being priorities:

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<td>Young families</td>
<td>Drug and alcohol issues</td>
<td>Supporting youth</td>
<td>Supporting an older community</td>
<td>Mental health</td>
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<td>Access to specialist health services and amenities</td>
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Major outcomes

The major tangible results were successful grant applications related to mental health (funding not accepted due to the inability of REDHS to attract a suitable staff member) and the successful and ongoing establishment of a Community ICE Action Group. The Community ICE Action Group received funding from the State Government, Bendigo Community Bank and Campaspe Shire and strong buy in from local organisations and community members.
Developing the collective critical health literacy of rural communities through community participation.

What is health literacy?
The knowledge and skills that facilitate the successful negotiation of the daily and exceptional demands of life, to achieve and maintain optimal health.

Background
Three levels of health literacy were conceptualised by Nutbeam (1999), which depict progression in autonomy and empowerment in regards to making health decisions. The first of these is functional health literacy, which relates to basic skills in reading, writing and numeracy. More advanced cognitive, social and literacy skills that enable active participation in decision-making is conceptualised as communicative health literacy. Critical health literacy shifts the emphasis beyond management of disease and illness, to focus on wellbeing and disease prevention to understand the social determinants of health and engagement in collective action for the common good.

The study
The key issue for examination in this project was what community members from rural and regional Victoria, Australia identified as the indicators to assess the health and health literacy of their communities. Three questions guided this process: How would you know if your community is healthy? How would you know if your community has the skills and knowledge to be healthy? What could be done to improve the skills and knowledge to be healthy in your community?
Data collection

Data were collected via multiple methods to facilitate broad community participation.

In the first stage of data collection, the Delphi technique, which is an anonymous iterative survey process, was used with community members on community health service boards of management and advisory boards across the State of Victoria. Participants responded to the three questions and their responses were used to generate statements used in subsequent surveys. The Delphi participants indicated their level of agreement and rationale for their responses. A summary of responses was returned to participants to consider, and then the process of indicating their level of agreement with the statements was repeated. The survey iterations concluded when stability of opinion became apparent.

The second stage of data collection focused on engaging a broad range of community members who live in rural communities of various sizes. Data were collected using opinion post cards, placed at public venues, in communities that varied in population size from approximately 4,000 to 12,000 residents. Participants anonymously placed their response to each question on cards and placed these in a collection box. The three questions were used to initiate discussion with community groups in the final form of data collection. Data from this stage were thematically analysed.

Findings

Healthy rural communities were perceived by community members as providing a diverse range of opportunities for participation for a broad section of community members to engage in community life, building social capital and cohesion. Social networks, friends, families and neighbours are common sources of health information, knowledge and skills. The critical health literacy of the rural communities can be considered a collective resource, which provides an opportunity for leveraging distributed health literacy to benefit of the community, through community participation, to improve and enhance health literacy.

Common indicators used to assess health literacy

Several common indicators used to assess the health literacy of a community were identified through this study:

- Community members are proud to be a part of their community
- Public spaces are well cared for/maintained.
- People are willing to assist others.
- Community members are involved in community planning.
- Community lobby groups exist to influence decision makers
- The community has visible and identifiable leaders.
- People can be seen being physically active.
Cross cutting project: International exemplars

— Nerida Hyett, PhD student
(Supervised by Prof Amanda Kenny and Dr Virginia Dickson-Swift)

**Exploration of international case studies of community participation and health**

**Research problem**
In many Western countries, community participation in healthcare design and decision-making is central to health policy. However, within the Australian healthcare context, policy translation is limited by challenges of enacting ‘meaningful’ and ‘effective’ community participation, and there is a lack of understanding of evidence-based methodologies (or ‘best practice’).

**Research questions**
The purpose of this cross-cutting research project was to address knowledge gaps relating to community participation, which limit health policy translation. The objective was to explore international exemplars of community participation in Western developed contexts, to understand how community leaders and practitioners enact community participation, what challenges they have experienced, and what methods and strategies they have employed to overcome participation challenges and/or barriers. The questions decided by the research team were:

In developed, high-income, Western nations:
- What models of “exemplary” community participation exist?
- How are exemplary models of community participation initiated, developed and sustained, and what challenges are encountered?
- How do people participate in community initiatives that aim to improve community-level health and wellbeing?
- Why do people choose to participate in community initiatives that aim to improve community-level health and wellbeing?
- What are the best methods of outcome measurement and evaluation?

**How do exemplary models of community participation initiated, developed and sustained, and what challenges are encountered?**

**What are the best methods of outcome measurement and evaluation?**

**Why do people choose to participate in community initiatives that aim to improve community-level health and wellbeing?**
The process

Using a qualitative research approach, two case studies of exemplary, or highly-regarded community participation initiatives were completed. The first case study was of a Canadian food security network, which included interviews with five community program leaders, field observations of seven community-based food and gardening program sites, and analysis of documents and social media participation. The second case study was of a rural Australian community banking initiative, which included interviews with five past/current volunteers, field observations of the community bank context, and analysis of historical documents, webpages, and media reports.

All data were thematically analysed to develop case study descriptions and descriptive themes, to understand the reasons why people participate, including motivations and contextual drivers, and how people participate, and the methods and processes used.

Key findings

The findings describe how, within communities, people have diverse participation preferences, and different interests and expectations. Strategies that used to enact and sustain community participation processes are described, including use of multiple methods, leadership networks, online participation via social media, and by leveraging outcomes.

The reasons why people participate are described in the research findings, and the themes highlight interrelationships between people, place and community, which were the ten per centers, benefit to community, and taking control. Motivations for community participation are linked with community sustainability and wellbeing.

In drawing together these findings, sociological perspectives are used to form a conceptualisation of ‘community’ as client for health services.

Implications for health services

- To work collaboratively with communities, health professionals need a shared understanding of community that emphasises inherent diversity and interrelationships with contextual factors (social, cultural, historical, political)
- Communities are more diverse than what might be immediately visible in the leadership sub-group, and this should be considered when health professionals are involved with the design and delivery of participation initiatives
- Community participation can be supported by the use of multiple methods and strategies, which recognises that people have different interests and preferences for participating, and will want to participate in different ways
- It is difficult to enact community participation with health services programs, because the purpose, processes and outcomes are usually defined by institutions and lack meaning for communities.
- Community participation processes and outcomes are different across contexts, which makes it difficult for health professionals to evaluate programs and measure outcomes
- Health services that are focussed on illness/treatment programs may not have sufficient financial/other resources, which are needed to design, implement and sustain innovative, locally-responsive programs
- Critical reflection is needed, to review the purpose and objectives of community participation, and to identify and remove barriers that prevent power sharing (control of decision-making)
Cross cutting project:

Inclusion

– Emma Patten*

* Note Emma is currently on maternity leave. Details of her project for inclusion in this folder will be sent on her return.
* Note Emma is currently on maternity leave. Details of her project for inclusion in this folder will be sent on her return.
SECTION ONE:  
The purpose of community participation

Community participation: What is the purpose?

• Participation is variously defined as individual, personalised relationship, meaningful engagement, active involvement, shared or delegated power.

• Community is commonly defined as people in a bounded geographical area, a social space, people with shared social and cultural customs, and people who have a vested interest in driving local solutions.

• There is a premise of a somewhat cohesive group of people with a shared purpose, vision, goals and focus.

• There is an assumption that community participation will lead to resilient, connected communities, with locally responsive services that meet their needs.

• There is an assumption that giving decision making to communities will improve health outcomes.

Historically, researchers have identified several reasons why community participation has been integrated within healthcare policy and practice (Rifkin & Kangere, 2002):

1. The health services argument: current health services are either under utilised or misused. Involving communities in the development of healthcare services will improve service use.

2. The economic argument: resources exist within communities (human, financial, social), which could and should be used for health services development and provision.

3. The health promotion argument: people’s health improves when they take responsibility for their own health and act for themselves (which produces greater results than medical interventions alone).

4. The social justice argument: all people, especially marginalised groups, have a right and duty to participate in decisions that affect their health and access to publically-funded healthcare services.

5. The ‘people know best’ argument: development advocates argue that people know what works for them and professionals need to learn from people.

6. Sustainability argument: if people are involved in healthcare projects and programs, people become committed to activities that they have helped developed, and they are more sustainable.

7. Capacity building argument: people can develop skills, knowledge and experience that they can use to improve their employability.
### Key points and the evidence

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<th>Key points</th>
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| Community participation is highlighted in key international policy documents as central to healthcare reform | • Committee on the Future of Rural Health Care, 2005.  
• World Health Organisation. 2010.  
• Commonwealth of Australia. 2012. |
| Community participation is mandated by governments in several countries by linking it to quality and safety reporting. | • NHS England. 2013.  
• Accreditation Canada. 2013.  
| There is an assumption that community participation will build resilient, self determining communities capable of responding to complex health care issues | • Organisation for Economic Co-operation and Development. Strategies to improve rural service delivery. 2010 |
| There is an assumption that if you give decision making powers to community members, healthcare will be responsive, cost containment will occur, health outcomes will improve – health professionals and health systems will be more accountable. | • Committee on the Future of Rural Health Care, 2005.  
• National Health Hospitals Reform Commission. 2009.  
• Francis R. 2013. |
| In the rural context there is an assumption that rural communities are appropriate/ ‘ripe’ places of participation. | • Kenny et al. 2013, 2015. |
| There are few examples of community participation in rural areas, and those that do exist, lack critical analysis of the rationale and the challenges that communities face in enacting participation policy at a local level. | • Kenny et al. 2013, 2015. |
| There is an argument that community participation is central to ensure efficient models that are localised and meet community priorities | • Greenhalgh T, Humphrey C, Hughes J, Macfarlane F, Butler C, Pawson R. 2009.  
Community participation: What we have learnt about the purpose

i. The theory of community participation is to facilitate tailoring of health services to the particular circumstances of the local community
   - Strengthen health service and community relations (especially if history of tension)
   - Direct health service planning towards community identified priorities for health and wellbeing
   - Flatten the communication hierarchy between health service providers and the community

ii. Our reviews of the community participation literature have indicated few direct benefits of participation, and that outcomes of community participation are difficult to identify, quantify, measure and compare (Attree et al., 2011; Rifkin, 2014).

iii. From our program we have identified that health services and communities are often confused about the purpose of community participation. It is important to ensure that there is shared understanding amongst all stakeholders.

iv. We have learnt that practitioners and leaders need to communicate the purpose of community participation clearly and openly, that the purpose should align with processes, timeframes and available resources, and that evaluation is needed to understand impacts and outcomes (positive and negative).

v. Community participation is more effective when it is driven by key community members, such as a health service CEO, who is strongly committed to the process and outcomes. There is a tendency for leaders to distance themselves from the ‘community’ and not realise that they are important stakeholders in all activities that occur.

vi. Our greatest successes have occurred in communities where the CEO’s vision has transformed the organisation from the top down with presentations to community stakeholders, health service staff, senior management and the health service board. Ultimately, as the auditor general’s report recommends, community participation has to be embedded within the organisation. This is a long-term strategy that gets easier as results and benefits become apparent.

vii. Developing a governance structure reinforces the role of community participation within the health service.

viii. Community participation provides those with a commitment or agenda to have a voice and feel listened too. However, often people express concern that decisions have already been made external to the community, and the processes in the community are simply tokenistic to muffle potential objections.

ix. Health services are funded to provide specific services, which may not align with community priorities, leading to a dissatisfied and disengaged community.

x. Community participation should focus on community members having a ‘voice’ in decision-making. Realistically, however, much of the focus for services is the outcome of meeting the requirements of Standard two – (service perspective).

xi. There is a risk that the Board and management level staff have little understanding of community participation and that community participation within the service is driven by risk management and compliance agendas.

xii. Community participation should be viewed as a framework for community members to engage with the health service about their ideas for health and wellbeing. Participatory activity needs to be designed to support open discussions in a non-judgemental environment.

xiii. All participants have experience that is relevant to the delivery of health service interventions and services, not just those who are traditionally seen as the ‘experts’.

xiv. Behind the facade of their everyday lives, community members address health challenges in their homes, their parent’s homes and their workplaces, which causes stress and anxiety. Meaningful communication strategies (and research methods) are needed to capture people’s knowledge, begin participation processes to support coproduced new knowledge and better outcomes.

xv. Community participation gives community members ownership of their health and well-being allowing them to understand the role of community spaces, places and assets in maintaining community health.

xvi. The involvement of health service staff in the participation process provides additional communication with consumers, allowing staff to develop empathy and understand consumers’ level of health literacy; as well as their anxieties and the potential social impact of the burden of disease particularly in older and marginalised community members.

xvii. Community participation empowers staff to try new strategies to reach out to marginalised community members.

xviii. Having a definitive topic or issue around which to gather the community is more likely to gain interest than a broader topic. Community members struggle to get excited/involved when the focus is nebulous and not important enough to engage them.
Community participation to design rural primary healthcare services

Jane Farmer 1* and Amy Nimegeer 2

Abstract

Background: This paper explores how community participation can be used in designing rural primary healthcare services by describing a study of Scottish communities. Community participation is extolled in healthcare policy as useful in planning services and is understood as particularly relevant in rural settings, partly due to high social capital. Literature describes many community participation methods, but lacks discussion of outcomes relevant to health system reconfiguration. There is a spectrum of ideas in the literature on how to design services, from top-down standard models to contextual plans arising from population health planning that incorporates community participation. This paper addresses an evidence gap about the outcomes of using community participation in (re)designing rural community health services.

Methods: Community-based participatory action research was applied in four Scottish case study communities in 2008–10. Data were collected from four workshops held in each community (total 16) and attended by community members. Workshops were intended to produce hypothetical designs for future service provision. Themes, rankings and selections from workshops are presented.

Results: Community members identified consistent health priorities, including local practitioners, emergency triage, anticipatory care, wellbeing improvement and health volunteering. Communities designed different service models to address health priorities. One community did not design a service model and another replicated the current model despite initial enthusiasm for innovation.

Conclusions: Communities differ in their receptiveness to engaging in innovative service design, but some will create new models that fit in a given budget. Design diversity indicates that context influences local healthcare planning, suggesting community participation impacts on design outcomes, but standard service models maybe useful as part of the evidence in community participation discussions.

Keywords: Community participation, Primary health care, Rural health, Healthcare reform, Community engagement, Co-production, Population health planning

Introduction

This paper explores the outcomes from inviting community members to participate in designing primary healthcare services for remote rural places. In our study, healthcare models were designed that address communities’ priorities and are affordable within existing budgets. The community participation process we used involves local people in service decision-making as is desired within contemporary healthcare policy.

Internationally, remote and rural places are changing due to conditions of global capitalism [1]. One result is that younger, working age people become concentrated in metropolitan and commuter areas, leaving concentrations of older people in smaller, more peripheral, remote rural settlements [2]. With regard to services, larger regional centres tend to have a range of primary healthcare and a general hospital, while smaller towns might have a hub of more limited primary healthcare services and a community hospital. Suitable service arrangements for small remote settlements are hard to define [3] and remote places are vulnerable to small changes in population and healthcare providers.

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Contemporary advice on how to design primary healthcare services spans a range from providing rational, algorithmic models that suggest workforce based on accessibility to services and amenities [4] or need, combined with evidence of effectiveness [5] through to suggesting population health planning founded on discussing local priorities in relation to need and social determinants [6]. While there is strong direction from governments internationally to use community participation in local service planning [7,8], there is little clarity about what to do, what outcomes to expect and how to incorporate evidence about health innovation [9].

This paper shows outcomes from deploying a community participation process to design healthcare for remote communities. It draws on findings from a study ‘Remote Service Futures’ (RSF), the primary purpose of which was to devise a feasible methodology for remote community members’ participation in health service reconfiguration [10]. In 2008–10, within the action research process to devise the methodology, residents of four remote Scottish Highland communities were invited to participate in planning to identify their local health priorities and design ways to address these. This paper outlines the community participation methodology derived and the healthcare designs produced.

Background

The Scottish Government Urban–rural Classification defines the settlements included in this study as “very remote rural areas” [11]. For shorthand, we call them remote. The Scottish Government defines very remote rural areas as having fewer than 3,000 inhabitants and being over an hour from a settlement of 10,000 or more. There are different categorisations and understandings of the concepts of remote and rural depending on countries’ size, population and geography, but we suggest that, internationally, remote areas share features of sparse population, distance from and therefore inaccessibility to, specialised services [12] and choice of services, and identification as geographically peripheral in the national psyche.

Relative to other UK states, Scotland is well resourced with general practitioners (GPs) and nurses [13] and these are more evenly distributed throughout the country than in other nations [14]. Remote health services are provided by a mix of GPs (either employed as National Health Service (NHS) independent contractors or salaried), community staff employed by regional health authorities, Scottish Ambulance Service personnel, council and voluntary/non-profit organisation workers. NHS24 is a national first response phone triage service and there are after-hours service schemes to see a primary healthcare practitioner. About 6.4% of Scotland’s 5.3 million population live in remote areas [15]. Remote and rural areas are distinguished by higher suicide rates, incidence of alcohol related disease, numbers of accidents and palliative care workload [16]. Compared with its urban areas, remote Scotland does not have severe socio-economic disadvantage, but there are pockets of disadvantage [17].

Internationally, problems of remote and rural healthcare include centralisation, lack of chronic condition care, health worker shortage, failure to adequately address prevention and lack of infrastructure for co-ordinated, integrated care [18]. Decades of policy to incentivise rural workforce and introduce tele-health have had very small impacts in the face of systemic and societal disincentives. Those concerned with redesigning healthcare for remote areas have had to formulate creative ideas about service provision and planning. At the time the RSF study started, a policy document Delivering for Remote and Rural Healthcare (2008) [19] had recently been produced and its goal was to provide a standard framework for how Scottish rural health services would be delivered into the future. It was the culmination of several years of discussion, some of it based on evidence from the NHS Remote and Rural Areas Resources Initiative which had been established in 2000 to address the problems of recruiting and retaining rural health professionals.

There is a spectrum of approaches to deciding what health services a rural community should have. One way is to provide standard service designs for types of places with certain packages of objective characteristics. In Australia, a rural and remote primary healthcare typology has been established, with authors concluding that “a critical minimum population base of about ... 2,000-3,000 people for remote communities is necessary to support a comprehensive and sustainable range of ... services” [3]. How to service communities of less than 2,000 people is not addressed. The Index of Rural Access applies a fine-grained approach to remote and rural healthcare planning [4], including service availability and proximity, population health needs and mobility and claims to be sensitive in describing accessibility deficits. Another algorithmic approach combines need and best practice evidence to design community workforce.

Using chronic disease as an exemplar, it identifies need for condition sub-populations, effective interventions and then calculates the competencies required for the local population [5].

An alternative to standardised models is to customise services to local context within a population health planning philosophy [20], incorporating community participation. Community participation has been described as “…social interactions to influence and localise outcomes” [21]. Variations are community engagement or involvement, which we consider are all about desire to include the views of local people in service planning. Keleher [6] describes population health planning as requiring stakeholder input, being predicated on a social determinants.
understanding and informed by data about care delivery, illness prevention, health promotion, resourcing and effective design and implementation. Community participation has been described as a ‘social process’ and ‘an ideal’ [22]. It has also been discussed as a state on a continuum between community readiness and community empowerment [23]. Experts [21,24] have commented on the need to distinguish between clients and citizens in participation, with clients’ participation based on self-interest as consumers, while citizen participation asks people to reach beyond their own concerns, to what is good for the community as a collective. The way we conceptualise community participation is as an intervention that could extend into a philosophy of working, with the key idea being that it endeavours to bring together the voices of those who have an interest in the community’s health – i.e. it’s a space in which local citizens, health and service practitioners and managers can discuss local health issues and how to address them.

Diverse motivations have been ascribed to why international governments promote community participation. The Scottish Government [25] describes need for: “…a relationship where patients and the public are affirmed as partners rather than recipients of care… where we think of the people of Scotland not just as consumers – with only rights – but as owners – with both rights and responsibilities”.

Here, the Scottish Government is invoking both client/consumer (individual) and citizen/community (for the good of society), perspectives [21,24]. A review found over 100 methods for public engagement [26], including focus groups, participatory appraisal, Planning for Real, citizen’s juries and future visioning. With imprecision about what it is and many methods offered for doing it, it is unsurprising that health managers wrestle with understanding what to do about community participation. While there is general evidence about beneficial effects, few studies evaluate outcomes affecting health service decision-making [27].

Remote and rural settings have been suggested as prime sites for community participation due to a history of rural community development [28]. The OECD [2] has promoted community participation within the “new rural paradigm”, suggesting its centrality to harnessing rural communities’ internal resources. Rural places have been shown to have high social capital [29] and volunteering [30].

While community participation is an established policy concept, it has been suggested that little power or creative input into design has actually shifted to citizens [31]. Some in rural health think that the public would have difficulty making “realistic” decisions [32], presumably because understanding the health system is complex. Given the lack of studies showing whether or how community participation can affect service design, this paper offers new insights and starts to address a gap in knowledge.

**Methods**

**Study design**

The Remote Service Futures (RSF) study developed and applied a community participation process using community based participatory action research (CBPAR) [33]. Community members from four remote settings were invited to participate in four workshops. To include those who would not, or could not, attend workshops, face-to-face individual interviews, email and telephone conversations were also used. The process philosophy was to encourage community members to ask questions about local health and health services, to provide evidence in response, to inform priority-setting and service design, and to include health practitioners and managers as part of the discussion and sharing of evidence. Action research is used to address complex real-world problems by applying cycles of fact-finding, action and reflection [34]. CBPAR involves citizens as intelligent co-participants in tackling research problems, leading to “self-critical communities” [35], community capacity and co-learning between participants [33]. In RSF, a review of international literature informed design of a prototype community participation process. Action research applied, developed and refined the process (see Figure 1). Importantly, although RSF was intended to develop new primary healthcare models, local residents were informed this was a hypothetical situation and new models would not necessarily be implemented. The project was a partnership with a health authority and was approved as a service improvement initiative by NHS Highland Ethics Committee.

Community is defined here as the people living within a more or less bounded territory (islands/peninsulas) – that is community as people in place. This aligns with Cohen’s [36] notion that community members have something in common with each other, but also distinguish themselves from members of other communities. In this study, some participating community members were also service providers, including healthcare workers. In participation terms, this was designed as citizen, rather than consumer, participation [24].

**Community selection**

Four communities defined as remote [11] (<3,000 population and >60 minutes’ drive from a settlement of 10,000) with healthcare delivery models defined as ‘fragile’ by the health authority, were purposively selected (by health authority managers) for the study (see Table 1); two (A and B) were island and two (C and D) peninsula communities.

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**Table 1:** Community selection

<table>
<thead>
<tr>
<th>Community</th>
<th>Type</th>
<th>Population</th>
<th>Distance</th>
<th>Health Authority</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Island</td>
<td>&lt;3,000</td>
<td>&gt;60 mins</td>
<td>Remote</td>
</tr>
<tr>
<td>B</td>
<td>Island</td>
<td>&lt;3,000</td>
<td>&gt;60 mins</td>
<td>Remote</td>
</tr>
<tr>
<td>C</td>
<td>Peninsula</td>
<td>&lt;3,000</td>
<td>&gt;60 mins</td>
<td>Remote</td>
</tr>
<tr>
<td>D</td>
<td>Peninsula</td>
<td>&lt;3,000</td>
<td>&gt;60 mins</td>
<td>Remote</td>
</tr>
</tbody>
</table>
Fragile communities were those where services depended on one or two key local health practitioners who were likely to leave in the next two years, due to retirement or job moves.

Two communities had high proportions of over 65s (relative to the Scottish average of 17% [37]). All are distant from major emergency and specialist health services. Distance is exacerbated by poor roads, sporadic mobile phone and broadband coverage, often adverse weather and sea-crossings - causing accessibility challenges. For the island communities, their remoteness has been countered by having resident single-handed GPs, but this model is regarded as unsustainable [19]. The four communities share consistent common conditions for consulting general practice.

Data collection
Following introductory meetings in each community, a series of four workshops was held (see Figure 1) in the village hall. Workshop foci were: 1) Future health: identifying the role of health in the community’s future and comparing this with current health assets and challenges; 2) Health evidence: Comparing data about community health with local perceptions; 3) Service roadshow: presentations from experts, including health service and voluntary organisations’ employees, about service innovations and initiatives; 4) Planning exercise: where community members identified health priorities, competencies and infrastructure required to address them, and then designed a local service model to fit within the existing budget. The design and use of a game format in the planning exercise

Table 1 Community characteristics

<table>
<thead>
<tr>
<th></th>
<th>Community A</th>
<th>Community B</th>
<th>Community C</th>
<th>Community D</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population size 2008/09</td>
<td>206</td>
<td>126</td>
<td>483</td>
<td>150</td>
</tr>
<tr>
<td>% aged &gt;=65</td>
<td>9.7</td>
<td>25.4</td>
<td>22.7</td>
<td>17.1</td>
</tr>
<tr>
<td>Approximate distance</td>
<td>3 hours by ferry</td>
<td>2.5 hours by ferry</td>
<td>2.5 hours by car</td>
<td>2.5 hours by car</td>
</tr>
<tr>
<td></td>
<td>In situ</td>
<td>In situ</td>
<td>50 mins drive</td>
<td>50 mins drive</td>
</tr>
<tr>
<td>Top 5 issues for local</td>
<td>Smoking related conditions</td>
<td>Smoking related conditions</td>
<td>Smoking related conditions</td>
<td>Smoking related conditions</td>
</tr>
<tr>
<td></td>
<td>Hypertension</td>
<td>Hypertension</td>
<td>Hypertension</td>
<td>Hypertension</td>
</tr>
<tr>
<td></td>
<td>Obesity</td>
<td>Depression</td>
<td>Obesity</td>
<td>Depression</td>
</tr>
<tr>
<td></td>
<td>Hypothyroidism</td>
<td>Asthma</td>
<td>Hypothyroidism</td>
<td>Asthma</td>
</tr>
</tbody>
</table>

Data obtained from local GP practice, local authority website, or QOF (Quality & Outcomes Framework) website.
has been discussed previously [38]. Throughout the workshops, the central ideas of health (described as about physical, mental and social wellbeing [39]) and the competencies required to address health priorities were emphasised rather than structures and institutions (doctors and nurses, health centres and hospitals). This was because we wanted to start the conversation about health issues and then move to solutions in an open, objective way - rather than commencing with discussion about traditional service ‘solutions’.

Community members became involved by: a) being nominated by a local organisation or service, as researchers asked these to identify a citizen to participate in a group to discuss community health issues; or b) self-volunteered attendance, as the process and workshops were advertised widely and participation invited, using community noticeboards and websites, newsletters and newspapers.

Workshops were intended to be interactive, with two researchers (usually AN & JF) facilitating. The local NHS manager was generally present at each workshop. As well as participating in discussion, they were a useful reference source for technical questions e.g. how many hours is a community nurse ‘allowed’ to work per week? What is the scope of practice of a paramedic?

This paper draws on thematic and summary notes from the RSF workshops. Summary notes, rather than verbatim recordings, were taken as it was important to keep the discussion as natural as possible to facilitate participation. Notes were written on flip-charts as workshops progressed, with themes and outcomes summarised at the end. Conscious that there were those who would not, or could not, attend workshops, the researchers also conducted interviews between workshop stages with community members who either contacted directly or were suggested to researchers by service practitioners. A total of 39 informal interviews were conducted with people who did not wish to attend workshops, were disabled or housebound. Interviews tended to focus on the topics of the first two workshops – i.e. the role of health and discussion of local health priorities. Formal evaluation feedback on each workshop was elicited using short questionnaires. Numbers attending varied over the four workshops for each community: A) 3–30; B) 5–30; C) 8–28; D) 6–15, workshop attendees. There was no consistent pattern as to which workshop was best attended, with some sites having higher participation at the start and others having highest participation at Workshop 3. The workshop process occurred over 12 months for each community and all workshops took place within a 17 month period.

**Data analysis**

Themes and decision-making points from workshops were summarised and fed back to participants for verification. Where ranking or selection exercises were conducted, these were recorded. Each workshop’s findings were summarised and reported to the wider community using newsletters, websites and community councils, giving further opportunities for comments and verification. Some interview data were hand-written and others audio-recorded depending on the choice and consent of interviewees and degrees of confidentiality (sometimes other family members, carers or friends were present, meaning recording was inappropriate.) Interview data were incorporated into findings.

**Results**

**Findings**

This paper focuses on workshop discussions so it describes themes arising, decision points, rankings and selections. This section follows the structure of the RSF workshop process.

**Future health**

Community members were encouraged to talk about the role of health in the future of their communities and community health assets and challenges (summarised in Table 2). A strong future was described as requiring young families living locally and this meant that local employment opportunities were important. Health and healthcare had a role as young families and employers would be attracted to places that were perceived to be healthy, vibrant and had local health services. A community where older people could live with quality of life until they died, was another aspiration.

**Health evidence**

Asking to assess biggest local health problems, as they perceived them, community members consistently cited emergency and after-hours call-outs, cancer and alcohol abuse. When presented with anonymised data on the most common conditions for which community members visited their local GP practice (see Table 1), workshop participants were surprised at the prevalence of conditions that they perceived local people could prevent and address, including smoking and obesity. At workshop 2 conclusion, participants were asked to identify local healthcare priorities.

Consistency was found across communities, with priorities: what to do in emergency situations and how to recognise different levels of emergencies; how to improve local health and well-being, particularly preventing and managing chronic conditions; ensuring that older and vulnerable people could live in the community and that crises were anticipated; developing volunteering schemes that could help with transport, basic social support, first response and health promotion. This led to
identifying services and initiatives that citizens would like to learn more about.

**Service road show**

Workshop 3 involved inviting service providers and representatives of different initiatives to speak with communities. This gave community members opportunities to learn about innovations and ask questions. Community members either identified specific services they wanted to hear from or suggested health issues which researchers then investigated to identify initiatives that community members might want to hear about. Researchers found out about initiatives through internet searching (looking particularly for example initiatives in remote or rural communities), local service managers or national government departments and agencies. Thus, these were presented at service roadshows at one or more communities: NHS 24; tele-health and tele-monitoring; volunteering schemes, including lay first responders, time-banks, community transport; health worker roles, including physician assistants, generic health assistants, community nurses, nurse practitioners and paramedics. Community members said it was valuable to meet service providers and representatives of initiatives and to ask questions. They thought this allayed fears, provided ideas and helped to understand the activities of different services.

**Planning exercise**

The final workshop was designed as a game, with cards, instructions and worksheets [38]. It involved stages of designing a service model:

1. Agree local health priorities.
2. Using provided lists of competencies (compiled from existing healthcare and volunteering role descriptions and some additional competencies that researchers constructed in response to previous workshop discussion), identify the top 10 competencies required to address local health priorities.
3. Align competencies with existing or new roles to design a local workforce. This had to comply with: a) a set of rules based on legislation, regulation and registration issues; e.g. what was within a particular health practitioners’ scope of practice or legal working hours; and b) a set budget (an approximation of the community’s current health and social care budget).
4. Identify other things needed to address priorities.

The top 10 competencies recurred for communities B, C and D. These were: basic technical skills, including taking temperature and pulse; minor injury and illness treatment; basic emergency aid; works after-hours; provides health/medical care home visits, when necessary; undertakes specialised care tasks in the home; terminal illness care; dispenses medicines; has intimate knowledge of the community so they can tell if something is amiss and act; supports mothers and young babies.

Only three participants attended Community A’s final workshop. We informally asked several previous participants why they had not attended. One reason given was the poor weather on the day and the old, damp village hall venue. However, others suggested that participation had been discouraged by one or more community members, who portrayed attendance as compliance with assisting the health authority to change local services. Researchers had also previously received an email from a community member stating that, on behalf of the community, he/she was stating that the community did not want to participate.

During the process and culminating at the final workshop, community participants expressed what we have come to regard as a set of key shared principles about

### Table 2 Community health assets and challenges

<table>
<thead>
<tr>
<th>Common assets</th>
<th>Common challenges</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community spirit, people look out for each other</td>
<td>Fears for security in an emergency situation due to remoteness/weather</td>
</tr>
<tr>
<td>Resourceful, adaptable community members</td>
<td>Older people have to leave community if their care needs become too great</td>
</tr>
<tr>
<td>Low crime, beautiful scenery, a safe place to raise children</td>
<td>Lack of affordable housing</td>
</tr>
<tr>
<td>More online working has allowed working people to settle in the communities</td>
<td>Current practitioner about to retire, concern about finding replacement</td>
</tr>
<tr>
<td>Personalised continuous care from local practitioners</td>
<td>Current practitioner provides “above and beyond the call of duty”: fear that</td>
</tr>
<tr>
<td>Local health practitioners are social assets and provide preventative care</td>
<td>replacement will not provide a similar service if not contractually obliged</td>
</tr>
<tr>
<td>Flexible, resourceful health practitioners who think and act ‘out of the box’</td>
<td>For practitioners providing 24/7 service, concern of insufficient support,</td>
</tr>
<tr>
<td>Responsive air ambulance service connecting community to acute care in emergencies</td>
<td>issues of stress and isolation</td>
</tr>
<tr>
<td></td>
<td>Confusion about current health services provision: who does what, who to call, when</td>
</tr>
</tbody>
</table>
that their desired local healthcare model. These are summarised based on themes raised at workshop 4:

1. The healthcare worker(s) should reside and work locally. This provided health security, understanding of local context, continuity and made people feel that, although living in a remote place they were valued by statutory authorities. Living locally was thought to harness commitment and responsibility from a practitioner.

2. Expert emergency triage must be available locally. There was concern that lay first responders would be inexpert in discerning levels of emergency. There was demand for community level knowledge (e.g. through a printed algorithm supplied to remote community members) about levels of emergency situation, how to identify them and actions in response to each.

3. Anticipatory care and monitoring must be available locally. This related to high proportions of older people, often living isolated and/or alone and a desire to keep them living in their ‘home communities’. While good neighbours have a general support role, a formal role in anticipating care needs before a crisis, was identified. This was not necessarily seen as a highly skilled position, but could be partly fulfilled by volunteers or health assistants.

4. Leadership for local community health improvement and mustering volunteering as part of this, was desirable. Key aspects were generating ongoing volunteering; e.g. for first response; and knowledge about useful activities that citizens could implement, to improve local health and wellbeing.

Table 3 compares new designs with original models. Although participants from Community B discussed a range of new roles, they ultimately selected to replicate the existing model. Community C included new nurse practitioner and healthcare assistant roles and also included volunteering, while Community D invented a new combined nursing/paramedic role and were keen to involve non-health workers and to establish volunteer first responders.

Discussion

Findings show that using community participation can lead to designing new service models that fit within existing budgets and address local aspirations and healthcare priorities.

Participant communities were similar on dimensions of rurality, health status, aspirations and health priorities. They proposed a consistent set of requirements for remote Scottish primary healthcare. These were: resident practitioner(s), expert emergency triage, monitoring and anticipatory care of vulnerable people, community volunteering for health improvement, and leadership of community (health) volunteering.

Despite community similarities, community participation led to different service designs for three communities and one community did not participate at the final service design stage. These diverse outcomes suggest the influence of local contextual factors. This implies that different communities do want different things so suggesting the same standard model for all, apparently alike, rural communities is likely to be unsatisfactory and could lead to community disaffection. Community participation appears to allow for the customisation of local service models.

The two innovator communities (C and D) included new types of practitioners and community members as volunteers in their service designs, showing that some communities will be quite bold in a community participation process. Community B did not innovate and Community

Table 3 New and old service models

<table>
<thead>
<tr>
<th>Community A</th>
<th>Community B</th>
<th>Community C</th>
<th>Community D</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service model at start of study</td>
<td>1 ft GP</td>
<td>1 ft GP</td>
<td>Access to GP practice in neighbouring large village 50 mins drive away. Weekly local surgeries (half day), peripatetic nursing service available</td>
</tr>
<tr>
<td>2 pt nurses; one of these also does social care</td>
<td>1 pt nurse Various pt carers</td>
<td>1 ft Nurse Practitioner (working 24/7)</td>
<td>New resident practitioners with these skills &amp; roles:</td>
</tr>
<tr>
<td>Model designed</td>
<td>Insufficient participants attended final workshop</td>
<td>1 ft GP pt district nurse, 3 pt care workers (including some intensive care hours) with some budget left for contingencies</td>
<td>• Health/emergency care worker.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Non healthcare worker(s) to lead community health activities.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Volunteer first responder scheme to provide basic aid and emergency life support</td>
</tr>
</tbody>
</table>

**Legend:** ft = full-time, pt = part-time.
A informally withdrew. While reasons for this behaviour were not explicitly investigated, the literature and previous research suggest a range of explanatory ideas. Previous study has noted that communities are at various stages of receptivity for participation and that some maybe prone to hegemonic power, with prominent local people exerting influence over others [40]. For Community A, there was evidence of community leaders spreading advice not to participate as this would indicate compliance with health service change.

While Community B participated, the outcome replicated their current GP-led model, despite much discussion at their workshops about the value of different types of workers. Actions of A and B could be interpreted as forms of protest or at least non-compliance with, the potential for change.

Communities A and B had ‘rich’ existing service delivery models, each having a resident GP and a nurse despite small populations. A and B are island communities and thus may feel strong insecurity, particularly they might perceive threats to health and community sustainability if they lost their GP. Conversely, C and D may have been more receptive to change due to circumstances. Residents of C were dissatisfied with having no locally resident health professionals and were keen to advocate for improvement in local provision. Community D was about to lose the resident nurse and people were anxious about local service depletion. These circumstances may have made Communities C and D readier to envision innovative services, particularly as their designs highlight local presence as a priority. Community receptivity for change can be understood to arise from different origins. Portes [41] reflects on relationships between local social capital and change, with strong bonding capital (i.e. relationship ties between neighbours that are alike in social group and status, and embedded in the local community) less associated with innovation, compared with the existence of strong local bridging capital (i.e. relationship ties between people in the community and people with access to external resources) which is more associated with innovation [41]. Although we lack evidence about length of time community participants had lived locally, observation in all of the communities indicates that they combined diverse long-term locals and incomers and this was reflected in workshop attendance. This questions the role of social capital as underpinning different responses. Rather, we suspect evidence from a previous study about how remote health services incrementally adapt over time, in relation to their context, might be relevant [42]. Findings of that study indicated that rural health services developed incrementally in relation to inter-linked demand and supply factors of what skills and roles were available locally and how local ‘consumers’ adapted to these. We suspect community members need to be able to envisage and therefore accept, change to aspects of service delivery that are akin to current or known services, as opposed to being asked to envision radical change. That is, Community C wanted moves back to a previous model of a resident community nurse because they remembered this and nurses still lived in the community (though now working peripatetically). Community D saw nurses and paramedics already in their community and thus could envisage a role that combined these two sets of skills. Although we suggest this as a theory, why communities design different models is an issue worthy of future, in-depth exploration.

The composition of the participant group is likely to impact both on choices made, and acceptance of these by the wider community. For all communities, only small proportions of the population attended workshops and outcomes depended on their views. Thus, if the models designed were to become more than hypothetical — and moved to implementation, fellow citizens might protest that they had not participated in decision-making. This issue was raised by a health manager who questioned the status of the designed models and community reactions if the health service moved to implementation? “When and how is a community decision made?” she asked. Inclusion is discussed in community participation literature, with questioning about the credibility of processes involving small numbers. Others suggest that all are offered the opportunity to participate and that not participating is also a choice [43]. Taylor et al. [21] note that community participation implies collective involvement and Alford [24] that true citizen involvement requires representative participants. In practical terms, methods such as Renn and colleague’s citizen panels [44], seem to come closest to an ideal inclusion method. They applied random selection to lists of community residents to invite citizens to participate in community decision-making forums. They say this is a way to ensure marginalised people are invited to participate, but there is still the problem of whether such people feel sufficiently comfortable to turn up in a public setting.

In redesigning rural services, standard models devised for communities with shared characteristics avoid these complications of involving communities that we have described. Their basis is to produce equity for all – “…not ad hoc responses…” [3]. If community participation results in different service designs for apparently similar communities, this could result in some communities being overworked compared with others. An example would be if local people provided lay first response in some communities, but not in others. Hanlon and Halseth [45] have commented on the exhaustion in rural Canadian communities due to service withdrawal and community members having to co-produce services.
But while the acceptability of diversity, with potentially different impacts for local residents, presents a philosophical debate, in fact there are uneven models already present in Scottish remote healthcare, and likely internationally. Taking the example of first response, some communities have already established volunteer first responder schemes, while others have not [46]. Community service models vary as do the skills and experience of individual health professionals [47]. Some recent initiatives in rural health endorse the perspective that it is realistic to draw on existing assets, local needs and rural propensity for adaptation to circumstances, when redesigning local services [48]. As co-production, resilience and resourcefulness become increasingly promoted in government policy, it seems communities will have to increasingly become self-reliant co-producers, with the implications for diverse service accessibility and potentially for outcomes, that brings [49]. The challenges of community participation may make the application of standard models seem attractive when redesigning services; however, there is evidence that rural communities protest if externally conceived plans, into which they have had no input, are inflicted upon them [50,51].

The overall RSF study was about producing a community participation process for remote places that could be used by health authority managers (i.e. was straightforward to understand, produced plans for service redesign, and was relatively cheap). It thus collected limited, mainly observational and informal data about participants, their motivations and experiences. As engaging people in a comfortable and ‘normal’ process was important, most data were not recorded verbatim, meaning that the words of participants cannot be shared here. Since the process was collaborative, it was necessary to ‘go with the community’, rather than being overly directive. This produced messy evidence, but Titter and McCallum [52] note that “users must have agency and the ability to shape the methods used for their involvement”. We do not have formal data about why people participated or not. This would have been useful regarding the apparent withdrawal of Community A at the design stage. As the models derived by communities were hypothetical, we do not know what would happen if the health authority chose to work with the communities to implement the designs. However, in enacting an actual process of community participation to produce designs for future services, a number of issues about rural community participation have been raised.

Conclusions
This paper illustrates that community participation can be used to design rural primary healthcare services, but outcomes may vary from innovative models to passive protest, depending on community receptiveness. That communities produced different responses to apparently similar circumstances and priorities, suggests that aspects of local context affect the choices communities make and therefore that engaging community members should add value when designing acceptable local services. Population health planning incorporates community participation while top-down standard models appear to neglect a community perspective, even though they are underpinned by a desire for fairness. There may be a role for standard models as part of community participation discussions as they are informed by evidence and provide abstractions that community members can use as a basis for discussing adaptations or additions that they deem important given local requirements.

Inviting communities to participate in decision-making produces messy and unpredictable outcomes and this is insufficiently acknowledged by policymakers. More needs to be written on the productive and/or messy aspects of community participation in system change.

Competing interests
The authors declare that they have no competing interests.

Authors’ contributions
JP conceived of and led the RSF study, participated in study design, assisted with data collection and analysis and led on writing this paper. AN organized workshops, led on data collection and analysis and assisted in writing this paper. Both authors read and approved the final manuscript.

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References


RESEARCH ARTICLE

Community participation in rural health: a scoping review

Amanda Kenny*, Nerida Hyett, John Sawtell, Virginia Dickson-Swift, Jane Farmer and Peter O’Meara

Abstract

Background: Major health inequities between urban and rural populations have resulted in rural health as a reform priority across a number of countries. However, while there is some commonality between rural areas, there is increasing recognition that a one size fits all approach to rural health is ineffective as it fails to align healthcare with local population need. Community participation is proposed as a strategy to engage communities in developing locally responsive healthcare. Current policy in several countries reflects a desire for meaningful, high level community participation, similar to Arnstein’s definition of citizen power. There is a significant gap in understanding how higher level community participation is best enacted in the rural context. The aim of our study was to identify examples, in the international literature, of higher level community participation in rural healthcare.

Methods: A scoping review was designed to map the existing evidence base on higher level community participation in rural healthcare planning, design, management and evaluation. Key search terms were developed and mapped. Selected databases and internet search engines were used that identified 99 relevant studies.

Results: We identified six articles that most closely demonstrated higher level community participation; Arnstein’s notion of citizen power. While the identified studies reflected key elements for effective higher level participation, little detail was provided about how groups were established and how the community was represented. The need for strong partnerships was reiterated, with some studies identifying the impact of relational interactions and social ties. In all studies, outcomes from community participation were not rigorously measured.

Conclusions: In an environment characterised by increasing interest in community participation in healthcare, greater understanding of the purpose, process and outcomes is a priority for research, policy and practice.

Keywords: Community participation, Community engagement, Rural health, Health policy, Health reform, Health services

Background

Rural health is identified as a key priority for health reform across the United States [1-3], Canada [4], the United Kingdom [5,6], Europe [7], Asia [8] and Australia [9-13] due to complex access and equity issues associated with geographic distance, socially determined disadvantage, mal-distribution of health professionals, scant resources and poorer health outcomes across key indicators [1-15]. However, internationally, there is increasing recognition that while rural areas share some commonality, health inequalities vary considerably, requiring locally targeted responses that align with local population health need [4,5,11,13,14]. Accordingly, international policy is increasingly identifying the role of communities in healthcare planning, design, delivery and evaluation to avoid an ineffective ‘one size fits all’ approach [2,4,6,12,16].

In 1978, the World Health Organisation [17] identified the centrality of communities in health planning and decision making, yet three decades later, conceptualisations of rural communities as disempowered and distanced from urban centres of power continue [16,18,19]. Calls for meaningful multi-sectoral partnerships with communities recognise that collaboration is central to ensure acceptable, appropriate and effective responses to begin to tackle entrenched rural inequities [18]. Internationally, social, political and economic changes in rural
environments, particularly associated with ‘mechanisation, modernisation and downsizing’ in agricultural industries [4] has impacted on rural social cohesiveness and contributed to the ‘circle of decline’ [7] being experienced in many rural locations.

Rebuilding or harnessing community capacity is integral to developing locally responsive health services [4] and is in the interest of communities and government as it draws together rural social capital, maximises the innate, adaptive, inventive and innovative nature of rural people [12,20] and leads to empowered communities capable of developing local solutions [21,22]. There are shared advantages for communities and government in terms of rural town survival, resilience, sustainability, and fiscal responsibility [23], but consistently, a lack of knowledge on how to build effective community/policy maker partnerships that empower communities and encourage citizen control and responsibility in local decision making is identified [4].

The community participation agenda
Despite the desire to meaningfully engage communities in health care planning, and the adoption of community participation as central in the health agendas of many countries [4,6,7,11-13,24], researchers continue to debate models, approaches, motivations, definitions and operational challenges [22,25,26]. Most commonly, researchers define communities as groups bounded by geographic location [27], and participation as collective actions that harness socio-cultural affiliations, customs, values and beliefs through social interactions to influence and localise outcomes [28]. In theoretical terms, participation is understood to be multi-level, depicted as a ladder by Arnstein [29] (see Figure 1), or as a spectrum (see for example International Association for Public Participation [30]).

![Figure 1 Levels of participation](image)

The seminal work of Arnstein [29] has been extensively cited and is influential in theories of participation and the interaction of power structures in society. Arnstein [29] argued that whilst participation is theoretically the cornerstone of democracy, in reality, large sections of the community are powerless and excluded from political and economic decision making. Participation is described in categorical terms as citizen power, and a typology proposed, illustrated by a ladder of participation, to highlight the divergence of views between those who have power and those who do not. She describes the ladder as an illustration of the different grades of participation, and by understanding these differences there can be greater understanding of citizens demands for meaningful, power redistribution and the tokenistic way in which participation is often considered by those in power [29].

At lower levels, participation is consultation or information provision, and at highest levels is full citizen control that involves the redistribution of power from ‘government to the governed’ [29]. While there is robust debate in the literature about Government agendas for community engagement [16,22], particularly from a neoliberal perspective [21] current policy in several countries [4,6,13,31] reflects a desire to engage communities at the higher level of Arnstein’s [29] ladder; partnership, delegated power and citizen control.

The Australian rural context
As Australian rural researchers, our interest in Arnstein’s [29] higher levels of community participation is driven by the emphasis on community participation in the Australian healthcare reform agenda [11-13,31,32], international recognition of the lack of knowledge on how higher level community engagement is achieved [4], interest in the sustainability and empowerment of rural communities [4,12], and interest in policy agendas that promote local responsiveness [13]. Like many countries, Australian health care reform is driven by increased demand for health services, inequities in health care access and outcomes, issues of quality and safety, workforce mal-distribution and inefficiency and system fragmentation [13]. While Australia has a universal health care system, Medicare, there is recognition that a universal system does not result in universal access, with significant access and equity issues evident in rural areas [12,13]. The increasing emphasis on community participation, consumers, patients and citizens, to develop services that are locally tailored is evident in Australian policy [11,31] and the imperative for community participation to be central to decision making is mandated in National Safety and Quality Health Service Standards [33]. Key Australian reform documents state that policy, system and service reform must result in local responsiveness, flexibility and agility [11], and that ‘public...
voice and community engagement’ [13] is one of the most important levers to achieve a continuously improving health care system:

Consumers should not only be the focus of the health system, they should be at the centre of decision-making in health. Both at a policy level and an individual level, consumer experiences and preferences should help lead health system reforms, alongside the evidence base. The reality of shared responsibility requires not just declaring it but building consumer health literacy and access to quality information and advice [13].

While definitions of rural are debated [34], for the purposes of this article we refer to rural as areas outside capital cities and metropolitan centres. In Australia, community participation in rural areas is described as an important strategy to build self reliant and self determined communities, and in health policy terms, is viewed as central in developing locally, responsive healthcare that is based on rigorous population health needs assessment [10,31]. Researchers note the long tradition of rural community participation in Australian health services [35], that many communities demand involvement [22], and that the sustainability of rural health services is viewed as central to the sustainability of towns [36]. Kilpatrick [22] suggests, however, that there is a wealth of community participation in rural health service planning that is never reported and that given policy imperatives for higher level community engagement, there is an urgent need to capture examples and commit to ‘analysing the processes of community engagement in order to improve them’ [32]. There is a commitment to community participation but ‘reluctance by policy makers to analyse and measure’ [32] and at the practice level, little guidance on how policy is best enacted [4].

Given international imperatives to develop locally responsive services and build sustainable empowered communities, research that investigates process and outcomes of community participation is of central importance for policy and practice. The aim of our study was to identify examples, in the international literature, of higher level community participation, delegating power and citizen control, most commonly clustered as ‘citizen power’. Arkesey and O’Malley’s [37] work on scoping reviews was useful in our conceptual thinking. Consistent with their work, we acknowledged that the first step was to ‘identify gaps in the evidence base’ and draw ‘conclusions from existing literature regarding the overall state of research activity’. Researchers have identified scoping reviews, as an effective means of capturing a range of literature on a topic [38] and for our purpose it was a useful approach to mapping and collating existing literature in a summary format that would be useful for policy makers and practitioners. Scoping reviews differ from systematic reviews, in that the focus is not on the assessment of quality as defined within a biomedical research paradigm [39], rather, the approach enables a broader range of literature to be captured, including all types of study designs [37]. Arkesey and O’Malley [37] propose a methodological framework for scoping reviews to enable replication and strengthen methodological rigour. The five stages of their framework; identifying the research question, identifying relevant studies, study selection, charting the data, and collating, summarising and reporting results were utilised in this study.

Identifying the research question
To guide the search strategy, and ensure that a broad range of literature was captured, the research question: ‘What examples of higher level community participation in rural healthcare exist in the international literature?’ was developed. In defining parameters it is recommended that wide definitions of key terms are initially adopted to ‘generate breadth of coverage’ [37] and we considered the broad terms appropriate for this stage.

Identifying relevant studies
To balance the need for comprehensiveness with pragmatic cost and time limitations, we developed inclusion and exclusion criteria based on our review purpose (outlined in Table 1). A methodological limitation is that choices may have excluded relevant papers.

Key search terms were developed and a search of the Cochrane Library (see www.thecochranelibrary.com) identified one study on consumer consultation [40] and confirmed the absence of registered Cochrane reviews. The existing Cochrane review did not meet the inclusion criteria. A broad scan of Medline located a scoping review by Mitton et al. [41] who had scoped a similar topic, but not with a rural focus. Recognising that qualitative and mixed method studies can be difficult to locate, terms were mapped using SPIDER [42]. The phenomenon of interest was community participation. Linked descriptive terms were used to represent the types and levels of participation, to increase the range and depth of search
Table 1 Inclusion and exclusion criteria

<table>
<thead>
<tr>
<th>Criterion</th>
<th>Inclusion</th>
<th>Exclusion</th>
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<tbody>
<tr>
<td>Time period</td>
<td>January 1990 and February 2012</td>
<td>Any study outside these dates</td>
</tr>
<tr>
<td>Language</td>
<td>English</td>
<td>Non-English</td>
</tr>
<tr>
<td>Type of article</td>
<td>Original research article published in a peer reviewed journal</td>
<td>Any article that was not original research and/or unpublished</td>
</tr>
<tr>
<td>Study focus</td>
<td>Community participation</td>
<td>No reference to community participation, i.e. individual consultation between health professional and client</td>
</tr>
<tr>
<td>Health service</td>
<td>Rural</td>
<td>No reference to rural health care services</td>
</tr>
<tr>
<td>Geographical place of study</td>
<td>International, developed countries</td>
<td>Developing countries</td>
</tr>
<tr>
<td>Population and sample</td>
<td>Mixed population sociodemographic</td>
<td>Reference to only a single sociodemographic factor i.e. gender, cultural group</td>
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results. Table 2 illustrates the search terms used noting that the term rural was used in all searches.

The developed terms were used to search Medline, CINAHL, Proquest, Expanded Academic, Informit and Cochrane databases, with additional searches using Google Scholar.

Study selection

Using the developed search terms 2467 articles were identified. An initial scan of title and abstracts identified large numbers of irrelevant studies, particularly those related to patient consultation and one off engagement activities that did not fit with Arnstein’s definition of higher level participation. Through a process of elimination, driven by inclusion/ exclusion criteria, 99 studies were identified as potentially relevant. Full text versions of the articles were obtained and, as a key parameter for our review was high level participation, each paper was reviewed by more than one team member for evidence of partnership, delegated power and citizen control. Discussion occurred between the researchers to ensure there was consensus on the level of participation identified.

Over one-third of publications found were from Australian rural health journals including the Australian Journal of Primary Health and the Australian Journal of Rural Health. Australian researchers published 40 of the 99 articles retrieved; the United States of America (USA) 16, Canada nine, United Kingdom (UK) five and New Zealand one. After review, 24 studies demonstrated Arnstein’s lower levels of participation [29], with publication dates between 1994 – 2011; 15 were Australian, seven from the USA, one from both the UK and New Zealand. Key topics covered by these 24 articles included consumer representation on health boards and governance, community consultation in strategic planning, strategies to involve community feedback in health care planning and design [43-45], and funding submission [46].

Overall, of the 99 articles located, innovative research methods for rural community participation were an emerging area, with eight articles published from 2006–2011; four were Canadian, with the remainder from USA, UK and Australia. Other topics covered were participatory action research design, development of theoretical frameworks or production of toolkits for consumer feedback and consultation [16], and development of conceptual frameworks for guiding or measuring processes [27]. The exploration of interagency partnerships [47-49] and workforce development [44,50,51] were considered by six articles. Conceptual discussion of community participation, defining key terms and highlighting issues for research and ethics were the focus of eight articles [52].

Table 2 Search terms

<table>
<thead>
<tr>
<th>SPIDER Tool</th>
<th>Search terms</th>
</tr>
</thead>
<tbody>
<tr>
<td>S</td>
<td>(“rural” OR “regional”) AND (“population” OR “healthcare” OR “community”)</td>
</tr>
<tr>
<td>P of I</td>
<td>(“community” OR “consumer” OR “citizen”) AND (“participation” OR “engage” OR “involve” OR “partner” OR “collaborate” OR “develop”)</td>
</tr>
<tr>
<td>D/E/R</td>
<td>OR “cooperative behavior” OR “stakeholder governance” OR “community network” OR “community development” OR “social capital health services” OR “community-institutional relations” OR “community health planning” OR “health service” OR “health planning”</td>
</tr>
<tr>
<td></td>
<td>“qualitative” OR “quantitative” OR “mixed method” OR “community participation action” OR “case study” OR “cohort study” OR “quality assurance”</td>
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</table>

[S AND P of I] AND [D/E/R].
While the identified articles provided important background to our research question, the process of review for evidence of partnership, delegated power and citizen control only yielded six articles; published in the period 2003–2009. Three studies were conducted in rural USA [53-55], one in rural Canada [56] and two in rural Australia [57]. They included community capacity building [55,57], partnership development [35,55], and community involvement in health care design and development [35,53-57]. Figure 2 illustrates the process of study selection.

Consistent with the purpose of the review, to identify examples of high level participation that could be useful for policy and practice, we refined our final article selection to the six articles on rural health that most closely demonstrated higher level participation or Arnstein’s notion of ‘citizen power’.

Data charting and collation
The fourth stage aligned with Arksey and O’Malley’s description of a charting approach. We developed summaries of each article and documented data related to author, year, location, study design, methods and sample (see Table 3).

Summarising and reporting findings
Arksey and O’Malley describe the final stage of scoping reviews as an overview of the located studies. As the purpose of our study, was to identify examples of higher level community participation in rural healthcare, our reporting focuses on the six articles that best demonstrate this.

Results and discussion
The assessment of higher level community participation
The six studies had strong citizen investment, with power balanced in a mutually beneficial partnership [35,53-57]. Decision-making was democratic [35,53-57], with community members equipped and skilled in prioritisation, strategic business and financial planning. In the planning stages, stakeholders had a shared and agreed vision, control and responsibilities and leadership was shared and distributed [35,53-57]. In two studies, the idea for a partnership was initiated and driven by community leaders [35,54]. In all other studies, participation was initiated by government and driven by state initiatives [55] or funding through local council and research partnerships [53,56,57]. Coady [56] described that ‘the decentralisation of health decision making was...
welcomed as a meaningful opportunity to bring the voice of the community fully into the process of setting local health agenda [56]. Community representatives had bargaining influence over planning and outcomes and authority to veto or disagree with proposed plans and actions [35,53-57]. Researchers reported that shared power and leadership, transparency and accountability, enduring relationships, and mutual trust and respect, contributed to service outcomes [35,53,54,57].

In two studies, community members had the majority of decision-making seats [35,57], however, in all studies power was retained by health professionals, paid coordinators, academics or health service managers as they held financial resources and ultimately decision-making powers [35,53-57].

Partnerships were needed to assess community strengths and resources, create management structures, facilitate comprehensive planning and negotiation, and to work through resistance [35,53,54,57]. However, gaining trust and acceptance was important and partners must be committed to long term outcomes for population health, and supportive of community ownership of health issues and solutions [35,57]. Utilising the knowledge, skills, resources and capacity building initiatives of universities and health services supported the achievement of outcomes [35,53,54,57].

Three of the studies reviewed [35,54,57] identified that higher level community participation is influenced by the nature of close knit rural communities and social interactions that support the development of new community sub-groups committed to local health care initiatives. Kegler [55] identified the importance of drawing on existing local leadership, and extending development opportunities to new leaders. In the rural context it was suggested that fewer resources provide a higher incentive for working together [35].

Outcomes of higher level community participation

In the studies reviewed, outcomes from community participation were indicated, though not rigorously measured. Reported outcomes included awareness of the health services provided [35] and improved self efficacy, social capital and accountability [35,55,56]. Benefits to community members included learning new skills [35,53-57], particularly in strategic planning [53,56], meeting facilitation [35], grant submission [53] and leadership [55,56]. It was reported that paid and unpaid leadership positions were created [35,53-57], with benefits for the people employed and the broader community.

It was reported that community participants enjoyed the learning process, the positive impact of contributing to healthcare in the community [56], new and strengthened relationships, reduced isolation, improved social support, and achieved a “strong sense of empowerment” [55]. Outcomes for the broader community included implementation of new public policy [56], new infrastructure and health services [35,54,57], and increased local employment positions [35,55]. Access to grant funding was described in some of the studies for community service development [53], and capacity building activities [35,57], with suggestions of small financial investment to reap large returns [55].
Challenges in community partnerships

Some of the studies demonstrated that delegation of power to the community is challenging for some individuals or groups [56] and power may be shared conditionally and withdrawn in times of conflict [57]. In their study, O’Meara, Pendergast and Robinson described a situation of conflict where “council attempted to become more directive through the facilitators, rather than involving the community in defining their own solutions and strategies” [57]. Despite intentions of authorities to share power and ownership with the broader community, in all studies reviewed, the final decision-making powers were still held by a person or group in a professional, leadership position [35,53,54], such as local government [55-57]. Sustainability was supported by continuity of leadership [35,53,57], with one report of a study being temporarily suspended when a paid community facilitator was lost [57].

Limitations of the studies

While all of the reviewed studies reflected elements of higher level participation, the study by Johns was closest to full citizen control [35], where power was only delegated to the partner health care organisation when managerial responsibilities exceeded the group’s capacity. In all of the studies, only scant details were provided about processes of nomination, election and representation with groups developed through self-selection or from existing leaders within the community [35,39,53-56]. In one study, participants included unemployed or low income volunteer community members [56] but in all studies little description was given about who was included or excluded and the rationale for these decisions. While one study described the community population as vulnerable and underserved [53], consideration of issues associated with working with marginalised populations was absent.

None of the reviewed studies reported the use of web based interfaces or social media to mobilise and engage communities but instead relied on local media to disperse information, raise public perception and acceptance of community action and progress [53,54]. Early release of needs analysis research data in local newspapers and television news was identified as a cost effective method of gaining community interest but none considered the use of the internet to transfer or gather information.

The six studies had a similar study design, using qualitative research methods such as interviews and focus groups for collecting and analysing data on the participants’ experiences of participation [35,39,53-56]. This descriptive information provided an overview of possible outcomes for participants and the broader community, however no quantitative methods were used to measure or validate the outcomes reported.

Conclusion

The limitations of this review related to size, breadth, inclusion and exclusion criteria, article selection and review are acknowledged. The very small number of articles identified is perhaps not surprising given contentions that a great deal of rural community participation is not reported. However, in an environment characterised by increasing interest in community participation in rural communities the need for rigorous research that explores and analyses higher level community participation is needed. Policy promotes community participation as highly desirable, but for many policy makers, practitioners and community members there are major gaps in understanding the purpose, process and outcomes.

Abbreviations

WHO: World Health Organization; USA: United States of America; UK: United Kingdom

Competing interests

The authors declare that they have no competing interests.

Authors’ contributions

VDS, AK, JF and PO conceived and designed the scoping review, and completed the first draft. JS developed the search strategy, completed the database searches and preliminary synthesis of findings; and provided input on early drafts. VDS and AK provided intellectual content to shape the findings and discussion. NH and JS made final decisions about article verification with consensus from all authors. NH collated all materials, completed the analysis of key findings and prepared the manuscript. AK edited the final manuscript, and all authors read and approved the final version prior to submission.

Acknowledgement

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References

SECTION TWO: The challenges of community participation

Community participation: what are the key challenges?

- ‘Community’ and ‘participation’ are debated terms.
- The lack of a shared definition is challenging for those wanting to develop participatory initiatives.
- There is lack of clarity at government level about how participation can actually be achieved.
- At the local level there is a lack of knowledge of how participation can be successfully implemented.
- There is a lack of evidence on community participation in rural areas.
- Rural communities are changing and the bucolic picture of a cohesive, homogenous community does not reflect the demographics of many rural communities.
- People want to define their own terms for what ‘participating’ is. For some reading a newsletter is viewed as participation.
## Key points and the evidence

<table>
<thead>
<tr>
<th>Key points</th>
<th>The evidence</th>
</tr>
</thead>
</table>
| ‘Community’ and ‘participation’ are debated terms. | • Morgan L. 2001  
• MacQueen KM, McLellan E, Metzger D, Kegeles S. 2001  
• Popay J. 2006.  
• Head B. 2011  
• Draper A, Hewitt G, Rifkin S. 2010 |
| There is global debate on why community participation is emphasised in healthcare policy. | • Head B. 2011  
• Head B. 2007 |
| Governments are unclear about how meaningful community participation will actually be achieved. | • Francis R. 2013.  
• Victorian Auditor General. 2012 |
| There is a lack of knowledge on how community participation is enacted at a grassroots level. | • Kenny et al. 2013 |
| Rural health services struggle to identify what meaningful community participation might mean for their organisation, their staff and the communities that they work with. | • Kenny et al. 2013, 2015 |
| There are few examples of community participation in rural areas and those that do exist lack critical analysis of the rationale and the challenges that communities face in enacting participation policy at a local level. | • Kenny et al. 2013, 2015. |
| The demographics of rural communities are changing and the makeup and complexity of communities is an important consideration prior to embarking on community participation initiatives. | • Oakley P. 1991 |
| Assuming that communities will welcome participation opportunities and engage as ‘well behaved’ citizens is at best naïve. | • Oakley P. 1991 |
Community participation: What we have learnt about the challenges

In our research, we have identified a wide range of challenges that impact on practitioners and leaders abilities to enact community participation in a rural context.

i. The lack of evidence of community participation outcomes contradicts the strong policy emphasis. This means that health services should critically analyse policy and carefully evaluate policy implementation.

ii. Community members experience several barriers to participation, including travel distances, competing priorities, over-consultation and participation fatigue.

iii. Different community members may have different participation preferences or abilities; for example, some may enjoy formal meetings, while others would prefer one on one conversation, or participating via social media platforms.

iv. Contextual factors may influence community participation, for example, historical events, cultural values or norms, social networks, political conditions, population demographics.

v. People may not want to participate in ways that suit the health service, and vice versa.

vi. Organisational culture and health professionals values and understanding of community participation may be a barrier.

vii. Social networks and relationships are needed to support community participation and to achieve positive outcomes (e.g. from social learning exchanges), these take time and resources to build and sustain.

viii. Processes that focus on mobilising and building resources (e.g. fundraising) may exclude people who have fewer resources to contribute.

ix. The contested nature of inclusion is challenging ie Working with and accessing the groups that most need services.

x. The burdensome nature of participation need budget support to make sure the service works ‘in’ the community.

xi. Challenges of linking consumer activities to community participation.

xii. Community participation does not appeal to everyone in the community.

xiii. It is not always possible to engage the disengaged.

xiv. Community participation can be ethically challenging.

xv. Expectations of community participation need to be stated for everyone involved.

xvi. A combination of methods of involvement and/or recruitment to community participation activities more likely to be useful than just one method.

xvii. There are many people in our communities who do not fit in with dominant representations of the average community member. The diversity in each community, calls for planning for how to engage with those who have something to contribute but might require special accommodation, (people with mental illness, alcohol and drug use, vulnerable or isolated).

xviii. Community participation and action research by their nature are designed to test existing power structures and organisational frameworks. This can cause conflict if not well managed.

xix. Every voice is valid, stakeholders must be heard, treated with respect by other participants and encouraged to be frank and honest in their opinions to ensure the discussion reflects their knowledge and experience.

xx. The health service must have the capacity to utilise the information and knowledge provided by the community participation process. Health service stakeholders including staff, management and the board must be aware of the value of the knowledge the community participation creates.

xxi. Managing project outcomes is a key challenge to ensure that stakeholders do not feel that they have been treated in a tokenistic manner.

xxii. Health services are moving to health and well-being models which may not be fully appreciated by all the stakeholders within the organisation. This is further complicated by community expectations of a traditional bricks and mortar health service, to which you attend when you are sick, changing to community health outreach which is a traditional model of community participation in the developing world. Health care is now being taken to the consumer, but the consumer may not be ready to accept care outside the hospital/health service environment.

xxiii. Policymakers do not fully appreciate the intricacies of community participation (as identified in the Victorian auditor general’s report) this leads to challenges particularly with accreditation guidelines and staff interpretation of what community participation really means.

xxiv. Community advisory committees may not be representative of the community stakeholders that utilise the health service.

xxv. Some health services focus on consumer feedback without acknowledging potential future users and those consumers who may have health and service literacy problems, which means they do not get the full benefit of the health service facilities, treatment options and support networks.

xxvi. “We don’t know what we don’t know”—consumer participation aims to provide some of the answers to this hypothetical conundrum. However, all stakeholders in this process have knowledge gaps, which must be addressed to ensure the participants have equal capacity to make a meaningful contribution.
Community participation for rural health: a review of challenges

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Abstract

Context Internationally, community participation is highlighted in health policy reform as good for rural communities. Implicit in this policy is the message that the complexities of the rural environment are too difficult for easy solutions and that community participation will somehow build resilient, self-determining communities capable of dealing with complex rural access and equity issues and poorer health outcomes. The underpinning proposition is that by giving decision-making powers to community members, health care will be locally responsive, costs will be contained, and health outcomes will improve. What happens in the practice of enacting community participation in health-care decision making is less clear.

Objective Despite the growing body of work that documents different levels and models of community participation, significant gaps that outline the practical challenges inherent in rural community participation remain. In this article, we draw on a body of literature to outline the practical considerations in implementing community participation policy in health settings in rural areas. Through a critical review, we aim to stimulate debate, progress ideas and provide a conceptual representation of the somewhat 'messy' nature of rural community participation at a grass-roots organizational level.

Discussion and conclusion Based on our analysis of the current literature, we provide a summary of challenges and practical strategies that might mitigate some of these challenges. Our review highlights that despite policymakers suggesting that community participation is good for rural communities, policy enactment must move beyond mandated tokenism for there to be a recognition that meaningful participation is neither easy nor linear.

Introduction

Community participation in health-care design and coproduction is increasingly highlighted in health policy reform in the United States, Canada, Asia, Europe and Australia as good for rural communities. Implicit in this policy is a view that rural settings require...
customized solutions\textsuperscript{2,4,6–8} and that rural communities are appropriate places of participation. There is an assumption that involving citizens will build the resilient, self-determining communities needed to deal with complex rural issues of access, ageing, and poor health and social outcomes.\textsuperscript{9}

Coproduction is a term increasingly evident in key policy documents when referring to participation and is defined as a collaborative approach to bringing together professionals, people using services and citizens to develop and deliver public services.\textsuperscript{10} The underpinning proposition is that by giving decision-making powers to community members, health care will be locally responsive, costs will be contained, health outcomes will improve, and health professionals and health systems will be more accountable.\textsuperscript{1,2,8,11}

Whilst governments across many developed countries are promoting community participation as central to health reform,\textsuperscript{8,12–15} a major policy flaw in the current community participation agenda is acknowledgement by governments, sometimes quite overtly, that they are unclear about how meaningful community participation will actually be achieved.\textsuperscript{11,14,16} Increasingly, there is a move from governments in several countries to mandate community participation by linking it to quality and safety reporting.\textsuperscript{17–19}

As researchers, we work closely with rural health service partners who struggle to enact mandated standards that require communities to participate at all stages of health-care design, delivery and evaluation. Whilst we are located in Australia, it is evident that there is a lack of international knowledge on the enactment of community participation at a grassroots level. This impedes the ability of rural health services to identify what meaningful community participation might mean for their organization, their staff and the communities that they work with.

In a previous review (add reference to our 2013 article following peer review of this manuscript), we sought to identify examples of community participation in rural health care that could support participation processes at a community level. We found few examples, and those that did exist lacked critical analysis of the rationale for rural community participation in health care and the challenges that communities face in enacting participation policy at a local level. There was little discussion of processes, inclusion or health/social outcomes. Our findings were consistent with other researchers who argue that there is limited evidence of outcomes from community participation across all health-care settings, not only rural.\textsuperscript{20,21} Our review revealed a gap in knowledge of the practical challenges inherent in rural community participation, and it is this gap that we seek to address here.

**Method**

Our research question for this study ‘what is known about the practical challenges in enacting rural community participation’ informed our choice of review method. Grant and Booth\textsuperscript{22} provide a useful typology of reviews, and from their work, a critical review aligned best with our question and purpose. Critical reviews are used to source, analyse, synthesize and ‘take stock’ of a diverse range of literature.\textsuperscript{23} The focus is on the conceptual contribution of a broad range of literature, rather than an assessment of the quality of the work.\textsuperscript{22}

Whilst typically critical reviews do not include formal presentation of search strategies,\textsuperscript{22} we believed that a documented search was useful to meet our aim of identifying and providing commentary on the challenges of rural community participation. We identified key search terms reflecting our research question, and the following Boolean search string was used: (rural or regional) AND (population or health care or community) AND (community* or consumer or citizen) AND (participation or engage* or collaborate* or partner*). The use of truncated words and wild cards (*) enabled a broadening of the search to capture terms with the same root. The search was conducted in Medline, CINAHL, Proquest, Expanded Academic and Informit.
Our initial search yielded 2467 articles. Following a scan of titles and abstracts, large numbers were excluded, as most were focused on patient consultation. We focused our study on developed countries, and after excluding literature from developing countries, 99 full-text articles were retrieved. We then hand searched reference lists to capture key additional literature on community participation. Through a process of in-depth reading, we extracted information about challenges in community participation and aggregated these challenges under three main clustered headings: shared understanding, governance and practical application, and sustainability. Consistent with limitations of critical reviews, our ‘interpretative elements are necessarily subjective’, but we did achieve agreement through a team approach of discussing sourced literature, clustering and cowriting.

In presenting our review, we aim to illuminate challenges in the practical enactment of health policy. Our purpose in doing this is to stimulate critical debate, progress ideas and provide a conceptual representation of rural community participation at a grass-roots organizational level.

Shared understanding

Definitional challenges

‘Community’ and ‘participation’ are debated terms, which create challenges for those seeking to start local initiatives. Participation has been variously defined in terms of individual, personalized relationships, through broad collective citizen involvement, ‘meaningful’ engagement, active involvement in policy implementation, shared or delegated power, and coproduction.

Common definitions of ‘community’ include people in a relatively bounded geographical area, a social space with interactions and transactions, people with social and cultural affiliations and common norms and customs, and people who drive locally beneficial solutions. There is a premise of a somewhat cohesive group of individuals with a common purpose and shared focus.

However, whilst rural communities are sometimes characterized as bound by relationship ties and unofficially governed by local hegemonies, classically portrayed in the notion of gemeinschaft, the need to be cognizant of the complexity and changing nature of rural communities is an important consideration prior to embarking on community participation initiatives. Assuming that communities will welcome participation opportunities and engage as ‘well-behaved’ citizens is at best naïve. Oakley’s comments about rural people, whilst almost two decades old, are a timely reminder of rural complexities:

Participation... cannot merely be proclaimed or wished upon rural people... It must begin by recognising the powerful, multi-dimensional and, in many instances, anti-participatory forces which dominate the lives of rural people. Centuries of domination and subservience will not disappear overnight just because we have ‘discovered’ the concept of participation.

Community participation: purpose and rationale

When embarking on community participation at a local level, having a clear understanding of its purpose and rationale would seem a basic starting point. However, globally, there is debate on motivations for policy’s emphasis on community participation. Questions are asked as to why greater community participation is espoused in countries with the democratic right and power to influence political decision making, through free and open electoral voting processes. Normative arguments centre on active citizenship, as key to quality democracy. The focus is on cohesive social capital and good governance, including scrutiny of governments, to increase transparency, honesty and accountability. Instrumental arguments centre on service users having valuable insights into service delivery and improvement, ensuring service efficiency and effectiveness. In complex and controversial situations, it is argued that diverse groups of stakeholders may assist in reducing conflicts, by harnessing collective problem-solving to

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Health Expectations
Our initial search yielded 2467 articles. Following a scan of titles and abstracts, large numbers were excluded, as most were focused on patient consultation. We focused our study on developed countries, and after excluding literature from developing countries, 99 full-text articles were retrieved. We then hand searched reference lists to capture key additional literature on community participation. Through a process of in-depth reading, we extracted information about challenges in community participation and aggregated these challenges under three main clustered headings: shared understanding, governance and practical application, and sustainability. Consistent with limitations of critical reviews, our ‘interpretative elements are necessarily subjective’, but we did achieve agreement through a team approach of discussing sourced literature, clustering and cowriting.

In presenting our review, we aim to illuminate challenges in the practical enactment of health policy. Our purpose in doing this is to stimulate critical debate, progress ideas and provide a conceptual representation of rural community participation at a grass-roots organizational level.

**Shared understanding**

**Definitional challenges**

‘Community’ and ‘participation’ are debated terms, which create challenges for those seeking to start local initiatives. Participation has been variously defined in terms of individual, personalized relationships, through broad collective citizen involvement, ‘meaningful’ engagement, active involvement in policy implementation, shared or delegated power, and coproduction.

Common definitions of ‘community’ include people in a relatively bounded geographical area, a social space with interactions and transactions, people with social and cultural affiliations and common norms and customs, and people who drive locally beneficial solutions. There is a premise of a somewhat cohesive group of individuals with a common purpose and shared focus.

However, whilst rural communities are sometimes characterized as bound by relationship ties and unofficially governed by local hegemonies, classically portrayed in the notion of *gemeinschaft*, the need to be cognizant of the complexity and changing nature of rural communities is an important consideration prior to embarking on community participation initiatives. Assuming that communities will welcome participation opportunities and engage as ‘well-behaved’ citizens is at best naïve. Oakley’s (p. 4) comments about rural people, whilst almost two decades old, are a timely reminder of rural complexities:

> Participation...cannot merely be proclaimed or wished upon rural people... It must begin by recognising the powerful, multi-dimensional and, in many instances, anti-participatory forces which dominate the lives of rural people. Centuries of domination and subservience will not disappear overnight just because we have ‘discovered’ the concept of participation.

**Community participation: purpose and rationale**

When embarking on community participation at a local level, having a clear understanding of its purpose and rationale would seem a basic starting point. However, globally, there is debate on motivations for policy’s emphasis on community participation. Questions are asked as to why greater community participation is espoused in countries with the democratic right and power to influence political decision making, through free and open electoral voting processes. Normative arguments centre on active citizenship, as key to quality democracy. The focus is on cohesive social capital and good governance, including scrutiny of governments, to increase transparency, honesty and accountability. Instrumental arguments centre on service users having valuable insights into service delivery and improvement, ensuring service efficiency and effectiveness. In complex and controversial situations, it is argued that diverse groups of stakeholders may assist in reducing conflicts, by harnessing collective problem-solving to
address ‘wicked’ or complex problems that require collective input.41

Critical questions are posed as to whether community participation is simply governments’ attempts for legitimization39 or neoliberal underpinnings of passing responsibility for design and delivery of services to end-users.39,42

It is argued27,38,43 that democratic governments have been traditionally reticent to delegate any real power in decision making, beyond the political gain that might be engendered through being seen to listen to the ‘voice’ of the people. Whilst these debates centre largely on participation at a macro level, they do provide a cautionary note at the rural community level. Questions could be asked about the purpose, goals and focus of a community’s participation and whether there are local organizational commitments to delegate decision-making power, or whether participation is designed simply to meet statutory requirements (i.e. bureaucratic box-ticking).

Embedding community participation in a meaningful way means to move from ‘symbolic’ or ‘representative’ engagement to direct, cogovernance, involving communities in the planning, design and delivery of health and well-being services and amenities.42,44 When participation is embedded at operational levels, it is expected to define and uncover solutions to complex local problems, create momentum and draw on expertise from diverse sources of knowledge, including practical experiences of those working and living in the proximate field.27

Whilst the concept of participation emerged through international health policy,45 a range of interpretations of community participation and foci of its application have developed, and we argue that confusion has resulted, to an extent impeding more widespread adoption in the rural context. The WHO46 interchangeably refers to ‘participation’ ‘involvement’, ‘engagement’ and ‘empowerment’, and this creates widespread confusion.

In rural policy,2–5 community participation is suggested to be good for rural communities without much explanation of what it means. As Morgan24 (p. 222) explains,

The proliferation of meanings attached to the phrase ‘community participation in health’... has allowed it to be analysed as a political symbol capable of being simultaneously employed by a variety of actors to advance conflicting goals, precisely because it means different things to different people.

Regarding rural places, variation in understanding might be expected due to heterogeneity of rural contexts, nationally and internationally, and the consequent mix of demographics and pertaining policy frameworks. Indeed, participation has been described as an umbrella term, suggesting an on-going, active relationship with shared power and ownership, understood in different ways by different people.15

Lack of shared agreement on theoretical frameworks

Theoretical models or frameworks to underpin community participation are debated. Since 1969, Arnstein’s ladder of citizen participation (Fig. 1) has been promoted as the seminal community participation model. It represents the redistribution of power from ‘government to the governed’.29

However, since the 1990s, critics of Arnstein26,47–53 have identified issues with the ladder, including lack of consideration given to the quality of the participation and limitations associated with the categories chosen. Modifications, refinements and adaptations of Arnstein’s ladder have occurred with those by Burns47 and Wilcox49 most commonly cited.

Despite these refinements, contemporary authors50–53 critically reject the use of Arnstein as the ‘touchstone for policymakers and practitioners’.53 It is argued that refinements to the model have promulgated hierarchical thinking, with uncritical embracing of power as a single dimensional, finite commodity that can be seized by citizens and used to shape health decision making.50–53 Bishop and Davis50 argue that the simplistic, linear notion of participation...
creates a false view that policy problems are static and that different levels and types of participation are needed to address the same problem.

Critics contend that Arnstein’s top rung, citizen control, creates a view that any participation below this level is not legitimate and fails to acknowledge that for different people and different purposes, different levels may reflect successful participation. Tritter and McCallum refer to ‘dangerous snakes’ in Arnstein’s ladder. Using the analogy of snakes, they describe a multitude of issues that limit participation and argue that the ladder is built on the ‘assumption that power will trickle down from involvement’.

Focusing on groups that may be disadvantaged, Tritter and McCallum and others argue that the emphasis on citizen control has a risk of capturing popular opinion without attention to involving disadvantaged citizens. Others contend that hierarchical models assume that all people want to be involved in the same way, rather than capturing the desired level or type of involvement of different community members.

In arguing that the transfer of power to citizens has the potential risk of creating adversarial positions between policymakers, service providers and users (and indeed within these groupings), Tritter and McCallum propose that community participation is more like a ‘vague mosaic’ than a ladder with defined rungs. Collins and Ison argue that the fundamental flaw in Arnstein’s and adapted models is the lack of consideration of how all stakeholders might work together collectively to pursue an issue that is contested or ill-defined. Their proposition is social learning, which they define as learning that occurs through situated and collective involvement with others. They argue that this is more appropriate to reflect interdependencies, complexity, uncertainty and controversy. Whilst they argue for a new policy paradigm of social learning for concerted action, they also acknowledge that lack of a consistent theoretical underpinning for community participation is a challenge for those wanting to embrace different approaches.

The lack of evidence for embracing participation

Health-care providers’ interest in community participation may be provoked by the argument that community participation is useful to manage health-care rationing and decentralization, and thus central to efficiency models that are localized to regions and community priorities. However, researchers argue there is little evidence of widespread policy change to locally appropriate, diversified, health-care delivery models as a direct result of citizen inputs to design.

In a number of case studies, participation has resulted in improved infrastructure, funding and beneficial changes to service provision, and there is some evidence to suggest that participatory processes increase social capital and cohesion. However, there are still gaps in evidence linking participation and health-care service improvements, particularly in the rural context. Study findings are limited in capacity to replicate or generalize, and scalability of small rural projects to larger systems and policy is unknown. There is a paucity of longitudinal research to demonstrate whether short-term efforts are sustained, or whether they result in
cost-effective solutions for rural health improvement objectives, such as reducing the burden of chronic disease and health spending.

When discussing rural community participation, Kilpatrick states that engaging communities in health care is expected to have desirable outcomes for citizens, however, implementation has superseded robust research evidence and more needs to be known about whether participatory methods achieve anticipated results. More broadly, several authors have identified a paucity of research that identifies whether the outcomes of participation meet purported objectives. This gap in knowledge presents a significant challenge when convincing all to participate.

**Governance and practical application**

Improving how government and related organizations work with communities is an international policy interest. Researchers argue that the major challenge in rural areas is unequal positions of power, stemming from differences in social class, knowledge and expertise, societal position, and other educational and occupational advantages. Williamson and Fung describe information gulfs that separate different groups in the community, and knowledge that separates ‘outsiders’ from locals. In the rural context, Kilpatrick argues that strong governance to bridge gaps is a necessary preparatory step for meaningful community participation.

However, evidence of governance models to support community participation is limited, particularly in the rural context. Ethnographic fieldwork in rural Australian communities in three states suggests ‘governance is not a single process in which communities are, or are not, adequately engaged ... governance is comprised of different processes, instigated by different actors for different reasons, both in and out of dialogue with public agencies.’ An important consideration is a pervasive view in many rural communities that those from government are outsiders with little understanding of how local communities actually work.

Inclusion and representation are challenges in establishing governance, and in rural communities, this may mean an inner circle of key community leaders to developing an effective governance environment. As Morgan highlights, the challenge is to develop governance frameworks that enable participation to arise from inside and occur as spontaneous and self-generating, rather than from outside or above. There are a few examples of governance structures that have partnered community members, health care and other service stakeholders to bring together lay and expert knowledge and community resources, but the paucity of evidence-based governance processes provides a major challenge for local implementation.

Additionally, even in situations where governance mechanisms are established, government regulations, for example, that require community organizations to acquire formal bureaucratic processes such as working with children checks, food handling and insurances, present challenges that conflict with ways rural communities have traditionally governed themselves. This can serve to de-legitimize the communities’ own forms of self-organization.

**Considerations of who participates**

Questions of who participates, who does not and whether it matters, are challenging for enacting rural community participation. In participatory activities, community members are generally assumed to share a vested interest in making their community a good place to live. In rural communities, this can mean appointing ‘local champions’ or the ‘usual suspects’ to attend structured meetings and provide opinions or feedback. It is expected that community members, who either self-select or are appointed, are able to set aside their individual interests and develop a shared vision for beneficial community outcomes. Methods such as citizen juries, neighbourhood committees, community forums and community champions are built on this premise.

However, who really represents ‘the community’ is debatable. Community members
may have conflicting interests, and individual conflicts between community members may determine who volunteers to represent others. Representative participation is common in rural communities with consumer representatives on local boards, networks or action groups. However, by only including those who are available, have the capacity to participate in a power-compromised social setting, or who self-elect, participation may exclude others with diverse perspectives. Mechanisms to engage the disadvantaged and marginalized remain elusive. Whilst there are some examples of inclusion involving disadvantaged or marginalized people and subcultures, there is limited evidence to suggest that participatory approaches alone, without specific strategies to target marginalized groups, result in an inclusive model of community participation.

Insider–outsider tensions are widely discussed in the literature. Eversole contends that it is impossible to adequately represent those who are not directly participating. However, she acknowledges the importance of what she terms ‘translation agents’ – those people who are comfortable in the circles of both the powerful and the powerless and who are able to facilitate transactions among groups.

Whose knowledge counts?

There is a need to consider that different forms of community knowledge exist and how to access forms of knowledge. Local community knowledge is grounded in context, which challenges those external to rural communities to accept local knowledge as a legitimate form of understanding as well as to find ways to gain access to this information base. Eversole argues that dialogue is often complicated by ‘the persisting assumption that experts are still holding the only real “knowledge”’.

In the context of the rural community, long-standing community members can dismiss the views of others who are not considered ‘real locals’ as they do not have familial roots within the community. Whilst residents may have lived in the community for extensive time periods, they are not viewed as having legitimate claims to knowledge about the community until they have lived there for decades.

A criticism of rural community participation approaches, is that one group (often endogenous and usually the more powerful), tries to ‘engage’ the other group, using its own processes. This may include having workshops and/or meetings that are presented in a format and language that makes sense to one group but can alienate others. Cornwall criticizes these ‘invited spaces’, highlighting that no matter how participatory groups seek to be, they are ‘still structured and owned by those who provide them’ as compared to spaces that people create for themselves.

Sustainability

Researchers argue that for some people, participation itself may be their goal, that is without the necessity for some punctuating endpoint or output. They suggest that the opportunity that participation offers to come together for social interaction can be highly valued. However, there can be on-going demands for people to participate in various activities in their communities, which can result in what has been termed ‘participation fatigue’. In rural areas with small populations, this can pose a barrier to participation. Community members who have been involved in participation processes have reported negative physical and psychological health consequences including exhaustion and stress.

Issues of sustainability have recently been drawn into the community participation and rural health literature as a measure or indicator of progress, but the issue is problematical. The increasing association of participation, sustainability and rural health services may derive from issues related to service closure and changing rural population demographics. There is a risk in using community participation processes as an outcome or performance measure reported to funding bodies. Desiring sustainable community participation, in this sense,
may be imposing an artificial, indeed unhelpful measure that is useful to outside bureaucrats and not to local citizens. Reinvigoration for the sake of funding may occur, or superficial changes made to programmes to meet requirements, denouncing the idea of ‘full citizen control’ and acting as a reminder to communities of who essentially has the power. Using sustainability as an outcome measure of participation may impose an endpoint to an otherwise continuous process of engagement and cultural change. By compartmentalizing participation as a ‘project’ or ‘product’, political ideals are imposed on what may occur as a spontaneous, naturally occurring process of change.

In tangible terms, researchers have argued that the scale of participation indicates sustainability. Morgan states that ‘in order for participation to be sustainable it must extend beyond the local (or project) level’. Enduring through disadvantage, or disasters, and continuing to function under strain are included in the rural health conceptualization of sustainability. Sustainability as an outcome of community participation might be better viewed as improved community liveability and enrichment, strengthened social connections, and liveable physical space and natural and built resources. Farmer, Prior and Taylor suggest that these dimensions, or resources, can be measured as stocks of types of capital when indicating outcomes for communities, where improvement indicates growth and prosperity in addition to longevity.

**Discussion, practical strategies and conclusions**

In this paper, we have drawn together literature to highlight some key challenges for enacting rural community participation. We are not suggesting that the challenges we have identified represent an exhaustive set. Rather our purpose was to provide a thought-provoking overview. Some issues raised are widely applicable to non-rural settings, but we argue that the rural environment creates a complex context that community participation policy directives fail to acknowledge. Rural communities have small populations that must continue to live in proximity with each other, before, during and after participation exercises, and they tend to have ageing populations, which mean dwindling human capital. Whilst government acknowledges confusion over directions for enacting community participation, we argue that there are many issues beyond simply ‘how to do’ community participation. These make involving communities in health-care design and provision very complex for rural community health service providers.

Whilst the policy environment assumes that community participation is good for rural communities and many authors present arguments for community participation related to active citizenship, democracy, transparency, government scrutiny, collective problem-solving, social capital, and improved efficiency and effectiveness, questions about purpose, goal and focus are fundamental and need, if not resolution, at least acknowledgement and discussion in policy arenas.

The proliferation of meanings of community participation, definitional challenges, and debate surrounding appropriate theoretical frameworks provides a chaotic picture for citizens and health-care providers seeking clarity. Rural health services may be told that participation is central to local ownership and efficiency, but the paucity of evidence to support these contentions presents a significant challenge to convincing local stakeholders.

The intention of governance processes is to produce strategy and order, so the lack of knowledge of governance processes to support effective community participation is a gap. In establishing community participation initiatives, there are complex questions of inclusion, representation, and legitimate types of knowledge. However, even if these issues can be dealt with, there is often tension between innovation and documentation of evidence on what works in the community participation space.

The challenge of enacting community participation and strategic imperatives of organizations results in questions of sustainability. There are risks associated with community
participation processes being viewed as outcomes or outputs, in that community fatigue from being involved in a multitude of projects, impacts on the ability to really harness sustained, long-term participation for change.

In drawing together the findings of our review, we provide a summary of the major challenges and propose some practical ways these might be addressed.

Shared understanding
Before embarking on community participation, it is important that all stakeholders have a shared understanding of the purpose and rationale. Organizations must be clear whether they are delegating real power in decision making or whether participation is simply meeting mandated requirements. Moving from ‘symbolic’ engagement to coproduction requires a commitment if shared ownership is to be developed. Early conversations between all involved are paramount. Importantly, organizations must clearly understand that participatory processes might not lead to solutions that fit with directions of the organization, locally responsive health care or improved health outcomes.

Bucolic, idealized views of rural communities might serve to perpetuate a picture of cohesive groups. However, these same views might serve to ensure that those who do not fit the idealized rural mould are further marginalized. There is a need for communities to have open and honest discussion about changing demographics and develop a number of strategies to engage with populations that are hard to reach. This might involve the use of peers to guide participation, participatory activities in different settings, the use of different participatory processes, including social media, and engaging in different, creative ways. There is a need to spend some time ascertaining the desired level or types of involvement of individuals and different groups.

Governance and practical application
Unequal positions of power are inherent in community participation. Consideration should be given to ensure citizens have practical training in participatory processes and where appropriate citizen advocates are engaged. Whilst inclusion and representation are challenging issues for governance, community ‘champions’ or key community leaders are useful to engage in planning and implementing a solid governance environment. The focus should be on developing strategies that support participation by marginalized population groups.

Sustainability
 Participation fatigue can be a real issue in rural communities. Developing different ways for people to participate might be one strategy, but there is also a need to clearly recognize that all participation does not have to be protracted for a long time period to be sustainable. Sustainability as an outcome might be represented by improved liveability and strengthened social connection. The fundamental message is that organizations should be clear about what they are participating about, and once the issue has been explored and considered, it may be appropriate to cease participation on that issue.

In concluding, we argue that whilst policymakers may present community participation as a desirable process, where people queue in a somewhat orderly fashion, to climb the rungs of a ladder towards citizen control, the reality shows we are not at all sure about solid structures, organization and processes. Rural communities are not homogenous, connected and uniform. The analogy of a ladder suggests safety, careful steps and an upward climb. Our experience of community participation fits with Tritter and McCallum’s ‘messy’ description. Policy might suggest that community participation is good for rural communities, but if policy enactment is to move beyond mandated tokenism, there must be recognition that meaningful participation is neither easy nor linear. Critics of Arnstein refer to the snakes amongst the ladder rungs, but for rural communities, there is a need for fundamental awareness of the key challenges before even taking the first step.
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Health Expectations
Title
How can rural health be improved through community participation?

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Executive summary

Rural Australians generally experience poorer health than their city counterparts. Rural Australia is a vast geographical region, with significant diversity, where there is good health and prosperity, as well as disadvantage. The purpose of this issue brief is to provide evidence on how the health of rural Australians can be improved through community participation initiatives, which are currently being funded and delivered by health services and networks.

Rural Australians need innovative health services that are tailored to the local context and meet increasing healthcare demands, without increases to expenditure. There are community participation approaches supported by research that can improve existing practice. Avoiding duplication, including the current work of Medicare Locals and Local Hospital Networks, is important for ensuring good outcomes from community participation initiatives.

The following recommendations are made to improve practice:

- New ways to contract and pay for health services are needed, which use ideas developed with communities, within current budgets
- State and federal government competitive grants and tenders should prioritise proposals that demonstrate effective community participation approaches
- Community-based services, such as community health centres, Medicare Locals and Local Health Networks, have an important role to play in facilitating community participation, including:
  - Building partnerships between existing services and leveraging existing participation strategies, rather than developing new services or standalone initiatives – to leverage available funds and maximise outcomes
  - Employment of a jointly-appointed, paid community leadership position across existing community-based health services, to avoid duplication and overcome barriers of over-consultation and volunteer fatigue
- Formal and robust evaluation of initiatives is necessary to guide future policy and research

A national innovative online knowledge sharing portal is required to share best practice in rural community participation, save time and money on ineffective approaches, and to support the rural health workforce.
What is the policy issue?

Rural people, one-third of Australia’s population, generally experience poorer health than their city counterparts \[1\]. Rural Australia is a vast geographical region, with significant diversity; where there is good health and prosperity as well as disadvantage. The purpose of this issue brief is to provide evidence on how we can improve the health of all rural Australians, but particularly for people experiencing disadvantage.

Overall, rural Australians are more likely to experience poor health, and their life expectancy is up to four years lower than urban counterparts \[1\]. Preventable health conditions, including obesity and accidental injuries, are more prevalent in rural compared with urban areas; and there are higher rates of unhealthy behaviours, mainly risky alcohol use and tobacco smoking \[3\]. Suicide prevalence is high, particularly for young men and men aged over 85 years old \[1\]; as are rates of chronic diseases, including mental illness.

The distribution of health services in rural versus urban areas contributes to poorer health outcomes. Rural health services are generally small with fewer resources and infrastructure, but at the same time are expected to provide a broad range of services over a large dispersed area \[2\]. There are high demands placed on them because of fewer alternative options, high population needs and persistent workforce shortages \[2\]. In 2011, fewer available health professionals and limited access to specialist services resulted in an estimated $3 billion shortfall in health service provision in rural Australia, primarily for dental, allied health and aged care services \[3\]. Access to timely and affordable health care for rural people is a national problem.

Commentators predict rural-urban inequities will worsen with new challenges to the health sector \[4\]. One reason for this is the increasing privatisation of health services, which makes it difficult for people on low incomes to access care. Health budgets are tightening, while ageing populations and the increasing burden of chronic disease are placing increasing demands on health systems and challenging current capacities \[5\], \[6\]. Recent national health reforms may go some way to improve the health of rural people. However, there is no evidence to date that they have made significant progress in addressing rural health priorities \[2\]. With ongoing rural health inequities and an uncertain fiscal future, it is becoming increasingly important that we find effective, affordable and sustainable ways of improving rural health.

What is the proposed solution?

One way of tackling disparities without large increases in expenditure is to engage rural communities in redesigning health services, so they better address local needs. Community

\[1\] We use the ABS (2011) definition of rural as “outside major cities”, a geographical grouping that includes regional and remote, noting that health varies across these regions
participation\(^2\) is a process of collective action, which takes full advantage of local assets and capacities, mobilising citizens to take control of health at the local level. Communities participate in a partnership with services to deliver health programs and initiatives. There are already instances of this occurring across Australia\(^7\)–\(^10\).

National standards require health organisations to engage consumers and communities in service planning, design, evaluation and governance\(^{11,12}\), and the majority of hospital and primary care networks are releasing community participation plans. ‘Standard 2: Partnering with Consumers’, found within the National Safety and Quality Health Services Standards, notes that consumer participation will improve the “safety and quality of care”\(^{11}\). Primary care reform requires that Medicare Locals coordinate primary health care services “with a greater focus on the specific needs of local communities”\(^{13}\). The aim of policy initiatives is to have consumers and communities participate in the delivery of health services they consume, and to mobilise communities to take action on local issues that impact on their health and wellbeing.

One of the challenges for health services executives charged with meeting these standards is that there is little guidance on how to do community participation so that it improves health outcomes\(^{14-16}\); this lack of evidence extends to the rural context\(^8,17\). Experts suggest that community participation will improve outcomes for communities and health services when it is facilitated effectively, and argue that people have a right to be involved in decisions about publicly funded services\(^{18,19}\). Drawing from the best available research, this issue brief provides recommendations on how to facilitate rural community participation to improve the health of rural communities.

Community participation in the rural context is enabled and challenged by a range of factors. There are numerous examples of successful community participation in Australia, particularly in Indigenous health, which demonstrate that it can be effective (see for example westerndesertkidney.org.au). There are several reasons why, for instance, rural communities tend to have fewer services, therefore people have more incentives to participate in discussions about them\(^9\). Generally, rural communities have higher rates of community connectedness and volunteering\(^1\). There are longstanding traditions of community participation with small rural hospitals and health centres, particularly in times of threat and protest, or natural disasters\(^20,21\). And, outside of mainstream health services, community participation has been integral to rural wellbeing through strong establishments such as the Country Fire Authority and the Country Women’s Association.

Relying on strong rural community bonds alone, however, is not enough. Some rural citizens have no interest in contributing to discussions on how public healthcare services are delivered or run. Research has reported that ad hoc, informal or responsive involvement is enough in some communities; however, at the same time, some people have no desire to

\(^2\) We use Schmidt and Rifkin’s (1996) definition of community participation in healthcare, “social process whereby specific groups with shared needs living in a defined geographic area actively pursue identification of their needs, take decision and establish mechanisms to meet their needs”
take on public healthcare responsibilities. Initiatives that burden volunteers with additional responsibility run the risk of exploiting rural ‘goodwill’ and destabilising existing good community work.

Rural communities with changing demographics might encounter difficulties in facilitating community participation using traditional strategies, for example, a ‘town hall’ style meeting might be insufficient to understand broad community concerns because of the growing diversity of views and agendas. For example, ‘tree-changers’ (people who move inland from metropolitan cities seeking new life styles and opportunities within regional Australia) might have different ideas about local hospital priorities than farming families with young children, or newly-settled refugees. And finally, because rural people have past experiences of services being withdrawn, it is understandable that participation approaches implemented by public institutions may be met with suspicion and resistance.

There is little guidance for health services on how to effectively facilitate community participation in meaningful ways that results in positive outcomes. Without evidence, there is a risk that tokenistic methods or a ‘tick box’ approach will be used to meet legislation and standards on community participation. The challenge policymakers face is finding best practice approaches to community participation that can be implemented across rural Australia, which improve the delivery of services and health outcomes for rural people.

**Best practice approaches to community participation**

The following strategies for effective community participation have been developed from research currently being conducted by the La Trobe University Rural Health School (refer to Building Healthy Rural Communities Research page 13 below for more details). A case study of community participation in Canadian food programs and initiatives, including a national food security network, a provincial-level food and farming alliance and several local community gardens and kitchens, reveal a number of effective participation strategies. The findings of this case study, together with preliminary findings from three rural Australian research initiatives, have been used to develop the strategies outlined in this issue brief. They are designed to improve community participation initiatives that are currently being implemented in rural health care services in Australia and to enhance outcomes for the organisation and the community.

1. **Gather local knowledge with local people**

A comprehensive understanding of local context is required to facilitate participation at a community level—a one-size-fits-all approach to community participation rarely works. Generic approaches underutilise local knowledge, social networks, assets and expertise, and fail to respect historical experiences, cultural context and local health conditions. The diversity of rural communities needs to be understood by examining the local context through a process of gathering experiential and tacit knowledge (lived experiences) as well as scientific knowledge.
The story of Warracknabeal, Victoria, demonstrates how national data can be an inaccurate depiction at the community level (see Box 1 below for more details). This example demonstrates that knowledge of the local context will contribute to more accurate health planning and prioritisation as well as increase awareness of local assets and attributes to support health initiatives, for instance, the availability of volunteers and neighbourhood safety.

**Box 1. Warracknabeal, Victoria**

**Warracknabeal**

Warracknabeal is situated in the Yarriambiack Local Government Area (LGA), about 330 kilometres north-west of Melbourne. Warracknabeal is an affordable place to live, and the LGA has the second lowest median house price in the state, with over 97% of rental housing classified as affordable. This community has a high sense of belonging, trust, and safety; 45% of residents volunteer; membership of groups and parental involvement in schools is above the state average, and crime is low.

Unique to this rural area, population projections indicate an increase in young adult residents, possibly due to affordable housing costs, and availability of public schools (see [www.facebook.com/WarracknabealSecondaryCollege](http://www.facebook.com/WarracknabealSecondaryCollege)) and health services (see [www.rnh.net.au](http://www.rnh.net.au)). Unemployment (4.6% compared with 5%) and welfare dependence (8.8% compared to 9%) are below the state average, although, take home wages are low, and almost half of households live on less than $650 per week (6th lowest of Victorian LGAs).

There are high demands on health services because of an ageing population and high prevalence of disability. The rate of primary health occasions of services is more than five times the state average. Despite cancer incidence being lower in rural than urban areas on a national level [1], locally cancer incidence in males is double the state average, the highest incidence of all Victorian LGAs.

**Digital stories, Warracknabeal, 2012:**

- Katie, nurse, challenges stereotypes to pursue her dream rural health career [http://www.patientvoices.org.uk/flv/0633pv384.htm](http://www.patientvoices.org.uk/flv/0633pv384.htm)
- Peter, feeling powerless due to illness draws from community for wellbeing [http://www.patientvoices.org.uk/flv/0632pv384.htm](http://www.patientvoices.org.uk/flv/0632pv384.htm)

Understanding the local context through local knowledge and lived experiences, statistical information and other relevant sources will support community participation that takes full advantage of local assets and capacity.

**2. A dynamic, multidimensional approach is more effective than a single method**

To effectively facilitate community participation, health services should use a range of strategies that are integrated to form a broad organisational approach. In the Canadian case study, for example, participation strategies were used at all levels of community activities, operations and governance. This included policymaking with community conversations, newsletters to provide community updates, and webinars to share examples of good
Improving the health of communities through participation

Multiple dynamic approaches were used, which meant they could be adjusted to suit the local context, energy levels and available funding. The intensity or demands required of the strategy could be changed—for instance, time, resource investment, efforts, skills, responsibilities and expectations of citizens and staff. Using multiple strategies did not necessarily mean more funding or resources were needed. Engagement from volunteers, interns and students and use of social media were key factors to a successful approach.

Another key to success in community participation is determining the right balance of strategies with the community. In Rochester, Victoria, for example, seeking input from existing, established community groups on local health service priorities was found to be more successful than beginning a new community reference group specifically for this service.

Table 1 outlines how multiple strategies can be integrated to form a broad organisational approach, based on a Canadian case study. High and low demand strategies were integrated to form a comprehensive approach, without a requirement for extensive financial or human resources.

**Table 1. Example of a multidimensional community participation approach integrating different strategies**

<table>
<thead>
<tr>
<th>Participation strategy</th>
<th>Objective</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inform</td>
<td>Provision of information to community</td>
<td>- Newsletter, website, calendar, household canvassing</td>
</tr>
<tr>
<td>Consult</td>
<td>Seeking information from community</td>
<td>- Online, written or photographic submissions - Feedback through community leaders</td>
</tr>
<tr>
<td>Involve</td>
<td>Intentional strategies to engage community</td>
<td>- Twitter feed, Facebook page - Skills workshops and social events - Interactive webinar</td>
</tr>
<tr>
<td>Collaborate</td>
<td>Participating with community, cooperative</td>
<td>- Community food hub e.g. food market, garden, kitchen - Social enterprise e.g. bike shop, meals on wheels, café - Story-making or art workshops - Students placements or internships - Online learning portal, open access resources - School nutrition programs - Community working groups</td>
</tr>
<tr>
<td>Empower</td>
<td>Full decision-making by community</td>
<td>- Participatory policy making, priority setting and strategic planning</td>
</tr>
</tbody>
</table>

3. Leveraging existing community assets and capacity

To encourage community participation with health services, it is important to leverage existing capacity rather than develop a new initiative in isolation. This approach recognises that good community participation may already be occurring and new initiatives are more likely to succeed and be cost effective if they build on what exists. For example, building a community garden on a health service site is a strategy that has been used in Canada and in Australia. It creates a social community space within existing health services, which provides new opportunities for health promotion and recreation while improving awareness and access to onsite primary health care programs [9, 23, 24]. This practical approach means that limited financial and human resources are used to capitalise on existing community activities or assets, energy and motivation. In this example, existing assets and capacity included the health service, spare public land, volunteer gardeners, and local community groups and business sponsors. Leveraging that aims to form new community partnerships between existing entities maximises value, capacity and outcomes for community participation initiatives. Examples of leveraging in Canada are provided in Boxes 2 and 3.

Box 2. Student-led Meals on Wheels by bike, Montreal

In Montreal, Quebec, a youth-driven healthy food delivery program, a ‘meals on wheels’ by bike, makes use of local university partnerships for land use and for student volunteers who deliver healthy meals to elderly residents by bicycle - important for the city because of high rates of elderly residents living alone (see housing profile http://www.fgmtl.org/en/vitalsigns2010/housing.php). The outcomes are three-fold: improved access to healthy meals, youth vocational training in agriculture, hospitality and social care, and intergenerational social interaction through meal deliveries and events. The program is multidimensional and entrepreneurial, volunteers and members can choose what level and type of engagement they prefer, for example newsletter subscriber or board member, and volunteers schedule their own shifts in food preparation or deliveries. The organisation creates stronger neighbourhood connections; the building is a bustling hub for youth and an incubator for innovation, for example urban agriculture projects like bee-keeping, and a bicycle repair shop. See http://santropolroulant.org/

Box 3. Community agriculture, Halifax

Community participation in Halifax, Nova Scotia, utilises local connections with farmers, a community centre car park, and volunteer energy and labour for agriculture projects that have benefits for the broader community. See http://www.youtube.com/watch?v=u34-x26kCYQ

4. Paid community leaders are fundamental

Employing community leaders to generate effective community participation with health services is fundamental. Employing a local person with valuable contextual knowledge and local relationships will contribute to the success of community participation initiatives, as well as reduce volunteer over-reliance and burden. Community leaders, also known in the
literature as ‘community animators’ or ‘community organisers’, are resourceful people who are well connected with linkages within and across neighbourhoods, and with local business and industry leaders. They are keen organisers who bring people together and facilitate participation in community activities. Their responsibilities include organising social events, evaluating local issues, providing education and advocacy, and maintaining stakeholder partnerships with business, health and education. Community leaders are strong advocates with contagious enthusiasm, who are trusted and respected by their community.

In the Canadian case study, community food programs employed a local person who had a good understanding of the local context and existing relationships in the community, and who was able to organise and mobilise people. The majority of community leaders observed in the Canadian case study were paid staff, or volunteers paid an honorarium. Leaders were sought out and invested in through a leveraging and capacity building process. See Box 4 for an example of how community food animators were utilised for a national community participation initiative.

**Box 4. Community food animators**

Community food animators talk food security

Community food animators were responsible for holding ‘kitchen table talks’ during a national citizen consultation strategy implemented in Canada. This involved organising a meeting with citizens in their existing networks, and writing a submission on food security together. Online and written submissions were used to develop a robust policy platform for a national food strategy. See an advertisement from Ontario Health [http://www.ohpe.ca/node/11623](http://www.ohpe.ca/node/11623) and the final report at Food Secure Canada [http://foodsecurecanada.org/policy-advocacy/resetting-table](http://foodsecurecanada.org/policy-advocacy/resetting-table)

Community food animators are currently employed by FoodShare Toronto. See a description of their role at [http://www.foodshare.net/toronto-community-food-animators](http://www.foodshare.net/toronto-community-food-animators)

**5. Use specific strategies to include marginalised community subgroups**

Communities need to develop specific strategies that will enable marginalised subgroups to participate in community activities. Traditional community participation methods can marginalise and exclude people because of age, illness, disability, transport, language or culture. Employees of health and welfare services may have existing trust and legitimacy, and are well placed to develop strategies that encourage marginalised groups to participate. This could involve storytelling rather than surveys, or submitting photos rather than written responses. Methods should be developed in collaboration with relevant community members.

One example of where this has been done well is in Heathcote and Warracknabeal, rural communities in Victoria. In these places digital storytelling was used with different groups to share community experiences. Similar approaches have been used in Canada. In the Canadian community food programs, for example, leaders supported participation with newly settled migrants and people living in social housing by building community gardens together (see Box 5). Social media and webpages can be used with accessibility options to
provide information and to seek comment from people who find it difficult to attend face to face consultations, or in languages other than English.

**Box 5. Community gardening with new Canadians in Halifax**

Community gardening with new Canadians in Halifax

See Herald Magazine, October 25, 2013; ‘Rooted in the community’; gardening with new Canadians in Halifax had positive outcomes for community participants. The community garden is described by two Nepalese refugee women as a place to grow food to feed their families and to meet the local residents of Halifax.


**Box 6. Inclusive community participation in a Halifax community garden**

Inclusive community participation in a Halifax community garden

This video provides a virtual, narrated tour of community gardens across the Halifax municipality, to demonstrate how food and gardening can be used as a vehicle for wide participation that has positive benefits for communities. In this example, food and gardening were used as strategies to include community subgroups that generally might find it difficult to participate. See video: [http://www.youtube.com/watch?v=6OehlMAq73Q](http://www.youtube.com/watch?v=6OehlMAq73Q)

6. Shared decision-making improves outcomes and experience for the community

Involving the community in decision-making with health services staff is more effective than seeking isolated consultation feedback, as this may or may not provide relevant or practical ideas or outcomes. For example, involving community members in a budget and resource allocation meeting with finance officers and managers may result in more practical outcomes than seeking feedback through a survey. This is because community members are likely to find it difficult to provide practical solutions without appropriate information and explanations needed to make good decisions.

The value of the shared decision-making approach is supported by research on citizen juries and participatory budgeting [14, 22]. A good example of where shared decision-making works in practice is in ‘co-production models’ in Australia and the United Kingdom. In these models, service provision responsibilities are shared between management, service providers and service users, and lines between these groups are intentionally blurred [9, 26-29].

In our Warracknabeal study we observed the value of shared decision-making with rural communities. We found that having health staff attend community meetings led to quick decision-making and practical ideas that could be implemented within current budgets. Similarly, across southern Ontario, cooperative working groups including parents, teachers, community food workers and council officials, deliver successful healthy food programs in schools. There are many examples of community programs that have staff and community members working cooperatively and sharing decision-making and other responsibilities to
complete various activities; for example, writing newsletters and online blogs (see for example, Sustain Ontario website www.sustainontario.com and Box 7 for an example from the school nutrition programs delivered across southern Ontario).

Box 7. FoodShare Toronto Farm to Table school nutrition program

<table>
<thead>
<tr>
<th>FoodShare Toronto Farm to Table school nutrition program</th>
</tr>
</thead>
<tbody>
<tr>
<td>This program uses a cooperative model of governance and demonstrates how sharing decision-making and other responsibilities with staff and community members has positive outcomes. See website for program description and a video: <a href="http://www.foodshare.net/field-to-table-schools">http://www.foodshare.net/field-to-table-schools</a></td>
</tr>
</tbody>
</table>

What are the challenges of community participation in rural areas?

Our research points to two challenges associated with community participation with rural health services.

Over-consultation and volunteer fatigue

Over-consultation and volunteer fatigue often impact on community participation in rural places. We found that participation approaches that require a high level of community time and investment are challenging to implement over a prolonged period. This difficulty may increase with smaller populations, and has been confirmed in other rural studies [30, 31]. Participation strategies must be in the community’s best interests over time [9]. Volunteer fatigue can be avoided by using a combination of high and low demand strategies; changing demand in terms of time, resource investment, efforts, skills, responsibilities and expectations of citizens and staff. For example, health services can use high demand options such as community priority setting meetings once a year, alongside low demand options such as ongoing social media information updates and online progress reports with feedback options.

Volunteer fatigue can also be counteracted by balancing paid staff and volunteer labour, and by offering incentives such as transport or food vouchers. In a Toronto-based community food initiative, volunteers at a food distribution centre were given a public transport pass and a box of fruit and vegetables to acknowledge their work. Health organisations are encouraged to regularly celebrate achievements by using social media and local news outlets to acknowledge awards, contributions and investments; food programs in the Canadian case study did this weekly via Twitter and Facebook.

Sustainability of approach

Our research shows that sustaining a consistent approach to community participation is more important than maintaining one particular strategy. High demand participation strategies, such as a community forum, might be more effective if they are used for short periods of time on a regular basis, rather than frequently. Strategies should not be prolonged if they are not in the community’s best interests. For example, alternating community town hall-style meetings with an online webinar or a meeting in an aged care
home would maintain consistency of the participation approach, while also encouraging broader participation beyond the ‘usual suspects’ to different community subgroups. The challenge is to sustain a community participation approach that is dynamic and flexible in responding to local conditions, energy and motivations, and recognises that an extensive, long term participation strategy might not be the most effective or meaningful method of participation for communities\[^32\]. Local conditions and objectives should determine indicators of success\[^9\].

**What happens when you do it well?**

Our research demonstrates that community participation with rural health services can deliver social benefits to the community and improve health literacy.

**Social benefits**

Community participation is a social process that can lead to social benefits such as better relationships and community cohesion. Social benefits of community participation can be difficult to measure, but there are useful evaluation tools such as questionnaires designed to measure social capital\[^33\].

Social benefits reported by key informants in the Canadian case study included improved social connections, trust, belonging, cohesion, safety, and reduced social isolation, which confirms what other studies have found\[^24, 34-36\]. It is too early to determine what the social benefits are from the rural community research initiatives underway as part of this study, however, the Warracknabeal study indicates new positive social connections as a result of attending community meetings. In other studies, researchers looking at rural communities and participation have reported improvements in infrastructure and access to funding to create social community spaces\[^17\]. For example, Men’s Sheds are a well-known social community space, created through participation, which support friendships and belonging in communities\[^37\].

There is good evidence that a higher sense of community ‘belonging’ is associated with good mental health\[^33\]. This indicates that community participation that results in social benefits is one strategy that might be effective for tackling rural health priorities including reducing high rates of mental illness and suicide.

**Improved uptake of health information: health literacy**

Being health literate means having the ability to understand and utilise health information, and apply it when accessing services\[^38\]. Health literacy is a particular requirement for effective use of electronic personal health records and online technologies for managing, accessing and navigating health services\[^39\]. By communicating with services, communities can learn about the health system, the various programs offered, and about appropriate service access for health complaints. In this way, community participation with health services may prevent inappropriate service use; for example, emergency presentations for health complaints that could be managed by a General Practitioner.
In an extensive literature review, researchers reported that improved health literacy was linked with positive health behaviour change [40]. In our study, Canadian community food leaders described the importance of health literacy related to food and nutrition, and linked this with increased healthy food consumption and choices in shopping and meal preparation.

Community participation initiatives that include peer discussions and skill sharing, education sessions and workshops, and information distributed via social media, may improve health literacy. Further research, some of which is under way, is needed to explore methods of measuring health literacy so we can determine which are most effective. Our initial findings suggest cooperative methods that utilise shared decision-making combined with social media are likely to be effective.

**Key messages for policymakers**

- New ways are needed to contract and pay for health services, using ideas developed with communities and within current budgets. Current funding models need to be more flexible to allow this. Solutions developed with communities do not necessarily need more funds, but the inflexibility in current funding arrangements means that they cannot be implemented easily [13].

- State and federal government competitive grants and tenders should prioritise proposals that demonstrate effective participation approaches as outlined in this issue paper.

- Community health services, Medicare Locals and Local Health Networks have an important role to play in facilitating community participation by gathering local knowledge, mapping existing assets, and leveraging capacity at regional and local levels. This should include:
  - Building partnerships between existing services, which have established trust and legitimacy, and leveraging existing participation strategies, rather than developing new services or standalone initiatives. This will result in focussed investment of currently available funds, maximising outcomes.
  - Employment of a joint-appointed paid community leadership position across community health services, Medicare Locals and Local Health Networks, in order to avoid duplication of community participation initiatives, improve efficiency, and overcome barriers of over-consultation and volunteer fatigue. This position, similar to the ‘health animator’ model used in Canada, and the research leader in our rural community research initiatives, would be responsible for the coordination of community participation approaches within communities, and develop and facilitate a dynamic, multidimensional approach for the local area. This would meet objectives of the National...
Primary Health Strategic Framework\textsuperscript{[12]} for integrated community participation. Local knowledge is key to success for this position, therefore in large catchment areas, for instance Tasmania, more than one employee might be required. This person would be responsible for volunteer support, communication and social media strategy, education, capacity building and evaluation.

- Evaluation of community participation in health services should use tools to measure social benefits and health literacy, in order to collect evidence of outcomes that are relevant to rural health reform priorities\textsuperscript{[2]}, see for example Community Capital Tool: http://www.sfu.ca/cscd/community-capital-tool-launched.html

- A national innovative online knowledge sharing portal is required, to share best practice in rural community participation, to support the rural health workforce, and save time and money on approaches that are not effective or efficient. This knowledge sharing website should be interactive and use social media including blogs, videos and webinars; with a particular emphasis on how to overcome challenges and barriers. A good example of an online knowledge portal is: http://foodsecurecanada.org/resources-news

**Building Healthy Rural Communities research**

This issue brief contains research findings from the Building Healthy Rural Communities research program, currently in progress on the regional campuses of La Trobe Rural Health School, La Trobe University, Bendigo; led by a team of university researchers, service managers and six doctoral students. The research is a three year project, commenced in December 2012, which is investigating community participation in health service improvement. Findings reported in the current paper were selected from a scoping review, an international case study, and three northern Victorian community research initiatives.

**Scoping review**

A scoping literature review by Kenny et al\textsuperscript{[17]} located six studies (English, peer-reviewed) that describe effective participatory approaches to rural health service improvement; two were located in Australia; one in Tasmania\textsuperscript{[9]}, and one in Victoria\textsuperscript{[10]}, and four others were from North America. Several challenges to implementing community participation are highlighted; additionally, we note there is a shortage of rural research in this field.

**Case study**

A case study of community participation in Canadian community food programs and initiatives was conducted in October 2013-January 2014. The purpose of this case study was to investigate an exemplary case of community participation, to examine best practices in community participation in Canada and identify ‘what works’. Data were five key informant interviews with community food leaders in Toronto, Montreal and Halifax, 11 site visits.
including guided tours of food programs and community gardens, and evaluation of documents, images, videos and social media. This is the first of three case studies in an ongoing doctoral research project on international community participation in democratic, high-income countries.

**Community research initiatives**

Three community research initiatives are being conducted in partnership with rural health services. Each initiative is led by a doctoral student and involves regular community meetings and other strategies, such as a health seminar or community expo. Community participants include hospital chief executive officers, local leaders, interested citizens, health service staff, and academics from the research program. The group’s objectives are to enhance community participation with the health service, and to formalise an approach that supports effective community participation in health service planning, design, delivery and evaluation. The health services include:

- Rural Northwest Health [http://www.rnh.net.au/](http://www.rnh.net.au/)

**Limitations**

Research literature in this field is extensive and multidisciplinary, and difficult to synthesise; for example, community participation and consumer participation have different meanings\(^{[41]}\). Inconsistent terms used to describe rural (e.g. regional, remote), participation (e.g. engagement, consultation) and community (e.g. place, group of people) add to the complexity. In this issue brief, ‘rural community participation’ has been used as an umbrella term to aid communication of research findings for a broad audience. The quality of the research on rural community participation is limited by biomedical standards, consisting mainly of qualitative studies or small cohort studies which are relevant to the research topic, but do not easily lead to authoritative conclusions and recommendations for policymakers. The recommendations provided are based on the status quo of community participation policy in health services, and seek to improve current practices that are being implemented and funded across Australia.

The Canadian case study includes interviews with urban-based key informants, who were the best available experts in their field; selected for interview because they are known for developing best practice approaches to community participation in food programs and initiatives at national, provincial, and municipal levels. Two key informants were employed at a national level and coordinated community participation approaches across provinces and regions; three worked at a municipal level with some operations at a provincial level, for example policy advice or partnership development with regional food and farming industries.
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KEY WORDS centred practice, community, community participation, health reform, occupational therapy, population health.

Introduction

The purpose of this viewpoint is to challenge occupational therapists to design and implement initiatives that improve community health and wellbeing. Wilcock (2006) and Scaffa and Reitz (2013), pioneers of ‘community-based’ practice, have been pivotal in shifting occupational therapy beyond mainstream healthcare services and into non-traditional, community settings. To further develop the scope of community-based practice, we explore the possibilities of a ‘community-centred’ approach.

For many occupational therapists, the idea of community-centred practice may not be fully understood. In community development research, community-centred practice is described as working with, rather than for communities, on goals that are identified by the communities themselves (Minkler, 2012). The key values underpinning community-centred approaches parallel client-centred practice, which is intrinsic to occupational therapy philosophy (Scaffa & Reitz, 2013; Townsend, Polatajko, Craik & Davis, 2007). The community is viewed as the client and an entity for collaboration, not simply the setting in which occupational therapy is undertaken (Scaffa & Reitz, 2013). Similar to client-centred approaches commonly adopted by occupational therapists, community-centred approaches involve centralising the community in all elements of practice. To expand the current scope of practice, occupational therapists must develop evidence and practical skills for working collaboratively with communities. The article outlines emerging evidence for adopting a community-centred approach, and explains how this is a multifaceted process that encompasses both opportunities and challenges.

Defining ‘community’

To develop a comprehensive understanding of communities, occupational therapists are encouraged to consider the multiple definitions and understandings of ‘community’ within health sociology and public health. There is agreement that community is more than a place of residence. Community can be defined as a social group, which encompasses historical events, cultural traditions and inter-connected social networks or layers, and can alternatively be defined by place, meaning a spatially defined geographical location (Jewkes & Murcott, 1996). Definitions of community adopted by health services usually combine social group and place perspectives. However, their understandings are often simplistic and fail to acknowledge the inherent diversity and power interplays that occur when communities are formed (Jewkes & Murcott; MacQueen et al., 2001). MacQueen et al.’s definition of community was developed with community members as ‘a group of people with diverse characteristics who are linked by social ties, share common perspectives, and engage in joint action in geographical locations or settings’ (MacQueen et al., 2001, p. 1929). This definition is useful for practitioners because it incorporates social and geographical dimensions and highlights community heterogeneity (MacQueen et al., 2001).

Within occupational therapy, communities are understood to have multiple dimensions that impact upon opportunities for occupation, participation and health (Scaffa & Reitz, 2013; Wilcock, 2006). Likewise, principal scholars in health sociology such as Jewkes and Murcott (1996) argue that practitioners must explore the unique
dynamics of communities they work within. The community’s physical features, including the landscape, natural environment and climate, infrastructure and built environment, and geographic proximity to other places; and spiritual dimensions, such as personal or symbolic affiliations, or the presence or absence of a sense of belonging, can have wide ranging influence. In addition, the political context and the power dynamics of communities can create social divisions that prevent community participation and access to essential resources (Jewkes & Murcott; Minkler, 2012). Communities are unique socio-cultural-political spaces that comprise new options for addressing health issues, which are not generally accessible within traditional, clinical settings (Scaffa & Reitz, 2013).

**Why should occupational therapists work with communities?**

Occupational therapists traditionally provide services to individuals and groups who access health-care services. If occupational therapists were to work more broadly with communities, there is greater potential for a larger population impact. An individual’s capacity to access occupational therapy services is influenced by their personal skills, geographical and cultural factors, and in some instances, ability to navigate complex service eligibility criteria and secure financial means (Rifkin, 2009). Adopting a community-centred practice approach would reduce barriers to service access by providing care with the community, promoting engagement of hard-to-reach groups (Minkler, 2012; Scaffa & Reitz, 2013).

In Australia and the United Kingdom, policy makers call for greater community participation to address increasing health-care demand and costs. Community participation is mandated in health-care quality and safety standards in Australia (Australian Commission on Safety and Quality in Healthcare, 2011) and in the United Kingdom, through the National Health Service, and the Scottish Government’s ‘participation standard’ (Tritter, 2011). Methods used to increase service-community cooperation include consultation and deliberation techniques such as citizen juries, consumer boards, and service user co-design and co-production processes (Conklin, Morris & Nolte, 2012). Additionally, the World Health Organization leads global calls for health practitioners, health service staff and communities to work cooperatively (Rifkin, 2009). Occupational therapists should heed these policy directives and lead the design and implementation of innovative community-centred practices.

Lastly, occupational therapists are philosophically and theoretically well situated to work with communities. Values underpinning the profession of occupational therapy support a cooperative model of working with individuals, and this philosophy has potential to extend to communities (Townsend et al., 2007).

**How can occupational therapists utilise a community-centred practice approach?**

Occupational therapy encompasses many skills and capabilities that can be incorporated in a community-centred practice approach. Scaffa and Reitz (2013) encourage a community-centred occupational therapist to take on the role of ‘consultant, facilitator or mentor’, rather than the professional (p. 6). Similarly, Townsend et al. (2007) recommend utilising enablement approaches with communities, which are outlined in their Canadian Model of Client-Centred Enablement model. Using this model, the community is conceptualised as the ‘client’ and enablement skills, including advocacy, teaching, collaboration, consultation, education and evaluation, are applied to achieve community health objectives. Use of enablement strategies aims to intentionally balance the power dynamics that exist between ‘therapist’ and ‘client’ within a therapeutic interaction, which is essential for community-centred work (Townsend et al., 2007).

Taking an occupational perspective to community-centred practice would involve applying an occupational philosophy in the assessment, intervention and evaluation of community health issues (Moll, Gewurtz, Krupa & Law, 2013; Parnell & Wilding, 2010). Parnell and Wilding support this argument, and agree that the profession should ‘broaden its view and apply an occupational perspective to many of the challenges that plague contemporary life’ 2010, (p. 346). An occupational perspective could be valuable in assisting communities to identify and explore health issues, problem-solve, and propose and co-implement solutions (Scaffa & Reitz, 2013). In addition, an occupational lens could reveal solutions hidden by a narrower disciplinary focus. Emerging research in non-traditional areas of practice demonstrate how an occupational perspective can be valuable, such as work with natural disaster preparedness and post-disaster relief, and with asylum seekers and refugees (Kronenberg, Pollard & Sakellariou, 2011).

Integrating an occupational therapy perspective to planning and design of the built environment with community stakeholders can improve pedestrian safety and prevent falls, and increase mobility and access to resources (Parnell & Wilding, 2010). Moll et al. (2013) describe how occupational therapy input can be used to enhance public health initiatives, including, the design of ‘age-friendly communities’, and programs that improve access to extra-curricular activities for youth. However, few studies have examined the actual processes used for designing and implementing health programs collaboratively with communities from an occupational therapy perspective.

A philosophical framework to guide community-centred practice can be drawn from extant professional paradigmatic beliefs and trends. The occupational...
Science paradigm emphasizes the intimate link between occupational participation, population survival and health, and core occupational science concepts highlight the importance of community and belonging (Wilcock, 2006). Paradigmatic shifts away from traditional ‘mechanistic’, bio-medical practices, towards a more balanced practice philosophy that encompasses science, art, culture and wellness (Gillen & Greber, 2014, p. 39), are more conducive to a community-centred practice philosophy. Core occupational therapy values of equity, social justice and human rights, and creative and context-specific interventions (Polatajko, 2001; Scaffa & Reitz, 2013), are critical for community-centred work. (Cun-solo Willox et al., 2012; Kenny et al., 2013; MacQueen et al., 2001; Rifkin, 2009).

Challenges and barriers to community-centred practice

Challenges and barriers to community-centred practice are identified within health research. In developed affluent countries, policy centred on community-centred practice is largely driven by austerity measures and health-care budget cuts. This can influence the community’s willingness to engage with initiatives that are driven by health-care institutions (Kenny et al., 2013; Tritter, 2011). In addition, a history of unpopular service closures or sensationalised media reports about health-care problems might result in communities being suspicious or reluctant to engage. To address issues relating to community engagement, practitioners are recommended to assess community-institution dynamics and politics, historical experiences with collaboration, and levels of institutional trust (or mistrust) (Jewkes & Murcott, 1996; MacQueen et al., 2001). Additionally, community needs, expectations, and objectives must be considered (Minkler, 2012).

Generally, community-centred practice approaches to health-care are recommended over generic one-size-fits-all models. However, evidence to guide practice is limited (Kenny et al., 2013). Globally, the majority of evaluation has been conducted in developing countries with poor and under-served communities (Rifkin, 2009). Research involving developed nations is still in preliminary stages and it is not yet established if community-centred interventions are more effective than interventions developed without community input (Conklin et al., 2012; Rifkin, 2009). Cross-disciplinary partnerships within population health are needed to overcome challenges in research and evaluation, and to address knowledge gaps (Wilcock, 2006).

More specifically to occupational therapy, barriers exist within the profession that may limit transitions to community-centred practice, such as levels of public awareness of occupational therapist capabilities, restrictive service delivery and payment models, as well as inadequate public funding for population health initiatives (Gillen & Greber, 2014; Scaffa & Reitz, 2013). Generally, education for occupational therapists on community-centred practice approaches is limited, and changes to include community practices in university curriculum, for example service-learning or project placements, are relatively new (Fortune & McKinstry, 2012; Scaffa & Reitz). To transition to any non-traditional practice area, occupational therapists require skills, confidence, knowledge and evidence, systemic and political support, and backing from professional associations.

Conclusion

Occupational therapists are well situated to design and implement initiatives that improve community health and wellbeing. A community-centred practice approach should be adopted, which expands ‘community-based’ roles to enable working with, not simply within, communities. Many occupational therapists work with individuals. However, we argue that occupational therapists are philosophically, theoretically, and practically well situated to work collaboratively with communities. Occupational therapists adopting a community-centred practice approach are encouraged to take on non-traditional roles of mentor and facilitator, and to utilise fundamental participation enablement skills, including advocacy, coaching, and education. A shift from ‘mechanistic’, or bio-medical dominant interventions and roles is needed, and occupational therapists must be willing and capable of adopting practices that emphasise creativity, culture, and wellness. Community-centred practice approaches should draw on the unique capabilities of a diverse community context, which requires an understanding of the dynamic nature of communities, and influences of myriad dimensions.

Barriers within the profession must be overcome if occupational therapists are to establish a position within the population health arena. Currently, as with any non-traditional practice area, limited evidence exists within occupational therapy to guide this practice transition. There is great potential for occupational therapists to develop and research community-centred approaches that draw on existing disciplinary values, models and skills, and utilise cross-disciplinary partnerships with practitioners who are already working in this space. With increasing political impetus for health practitioners to cooperate with communities, it is timely for occupational therapists to lead initiatives, and demonstrate the value of their unique perspective. As a profession, we must build evidence for an occupational perspective of community-centred practice, and champion robust research and evaluation.

References


Objectives

• What is the meaning of ‘community’?
• Current ‘community’ and ‘community-centred practice’ definitions
• Barriers to community-centred practice
• Research methods and findings
• Implications for practice
Increasing calls for occupational therapists to work with communities...

- WFOT and many professional associations identify ‘community’ as a client of OT

- However, there is little guidance on how to shift focus from individuals to the community level

What does ‘community’ mean to you?
Defining ‘community’

- No standard definition (Rifkin, 2014)
- Different interpretations across disciplines and fields (Scaffa & Reitz, 2013)
- Place AND social group

A group of people with diverse characteristics who are linked by social ties, share common perspectives, and engage in joint action in geographical locations or settings (MacQueen et al., 2001, p. 1929)

Community-centred practice

Working with communities, not just within community settings (Hyett, et al, 2015)

Working with rather than for or on them, on goals that are identified by communities themselves (Minkler, 2012)

Community-centred interventions follow the principles of client-centred practice, where the client is the entire community (Scaffa & Reitz, 2013 pp 5-6)
What **barriers** exist that might prevent OTs from working with communities?

**Exploring ‘community’ through qualitative case studies**

- Qualitative case study methodology (Stake, 1995)
- ‘Exemplar’ cases of highly regarded community participation initiatives
  - Canadian community food security network
  - Australian rural community banking initiative
- Methods: key informant interviews, document analysis, social media analysis, fieldwork
- Limitations: small sample size, limited by time/resources, preliminary conceptual findings to inform future research
Case study 1

Community food centre and farmers market, Toronto, Canada

Case study 1: Canadian community food security network

1. Community is broader than what is immediately visible
2. Community is diverse and constantly evolving
3. Characterised by joint action and share purpose, however people participate in different ways, and have different interests
4. Communities are not always defined by fixed spatial boundaries
5. It can be unfairly assumed that communities will take on responsibility for health and social problems
Case study 2: Australian rural community banking initiative

1. People can develop connections to communities
2. Threat to community can impact well-being, because of place dependence or attachment
3. People who feel less connected to community can feel excluded
4. Community can be exploited for commercial or political gain
5. Multitude of factors influence community understandings of ‘community’ and community membership
Community as a social field

Community can be conceptualised as a social field (Kaufman, 1959; Wilkinson, 1970; Taylor et al, 2006)

- Community is diverse and constantly evolving
- Influenced by (and embedded in) historical, social, political and cultural contexts
- Fluid boundaries and changeable nature

Not a homogenous group or ‘fixed’ ‘isolated’ social environment
Community as a political tool

Community can be unfairly used as a political tool (Rose, et al 2006; Dean, 2010)

- Communities are urged to take responsibility
- Government can ‘govern through community’, and use community for social control
- To influence behaviour, or to exercise power over citizens

OTs need to understand our role/power in this and take a more critical stance

Occupation-focussed community-centred practice

Canadian Model of Client-Centred Enablement
(Townsend, Polatajko, Craik, & Davis, 2007)

- OTs can use participation enablement strategies with communities

![Figure 3: Canadian Model of Client-Centred Enablement (CMCE)](image_url)
Occupation-focussed community-centred practice

Participatory Occupational Justice Framework (Whiteford & Townsend, 2011)

- Framework encompassing 6 processes
- Guides OT to shift focus from individual problem, to unjust societal systems and structures

Occupation-focussed community-centred practice

The Kawa Model could be used with communities (Iwama, Thomson, & Macdonald, 2009)
Recommendations

To shift practice from individuals to communities, OTs are recommended to:

• Develop a conceptualisation of community
• Consider the use of the term in policy and practice
• Trial and evaluate community-centred practice approaches
• Explore opportunities for community-centred roles
• Build cross-disciplinary partnerships for practice and research

References


How can rural health services be improved through community participation?

Nerida Hyett
PhD Candidate
La Trobe Rural Health School

Deeble Summer Scholar, AHHA 2014

Issue

Rural Australian’s generally experience poorer health than urban counterparts

http://bendigokilmorerailtrail.files.wordpress.com/2012/12/heathcote.jpg
Possible solution

Community participation draws on the strengths and assets of rural communities to improve health and services provided

Rationale

• Community participation can improve health and wellbeing of participants
• Services can be improved
• Current health service models are not financially viable
• Increasing demands and expectations on health services
• Communities have a central role in health reform
• Persistent rural health/workforce issues need a new approach
Pro’s and Con’s

The evidence for community participation is not definitive, however, there are examples in Australia and overseas that demonstrate positive outcomes can result if challenges are considered and effective approaches are utilised.

Best practice community participation approaches

1. Gather local knowledge with local people
Best practice community participation approaches

2. A dynamic multi-dimensional approach is more effective than a single method

Best practice community participation approaches

3. Leveraging existing community assets and capacity
Best practice community participation approaches

4. *Paid community leaders are fundamental*

Best practice community participation approaches

5. *Use specific strategies to include marginalised community subgroups*
Best practice community participation approaches

6. *Shared decision-making improves outcomes and experience for the community*

Challenges

• Leadership fatigue

• Community over-consultation

• Sustainability of approach rather than one method
Outcomes

• Social benefits

• Capacity building

• Health literacy

Recommendations for health policy

• Community-based health services and networks e.g. Medicare Locals:
  
  o Jointly employ a local paid community leader to coordinate CP

  o Focus CP investment on building partnerships between services and leveraging existing capacity

  ▪ Prioritise proposals for tender that demonstrate effective CP approaches
Recommendations for health policy

• Funding models must be flexible for implementation of community-designed health solutions

• Create an innovative national online knowledge sharing portal

Methods

• Scoping review (Kenny, et al. 2013)

• Qualitative case study of community participation in food security programs in Canada
  • Key informant interviews, fieldwork
  • Web and document analysis, incl social media

• Three rural community research projects
  • Rural Northwest Health
  • Rochester and Elmore District Health Services
  • Heathcote Health
Thank you

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SECTION THREE:
The link between community participation and health literacy

Community participation and health literacy: What is it?

• Health Literacy – the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways, which promote and maintain good health (The World Health Organisation (WHO)).

• Health education, is central to health literacy, and influences individual lifestyle decisions, and raises awareness of the determinants of health.

• Improved health literacy encourages individual and collective actions, which may lead to a modification of the individual and social determinants.

• Based on the WHO definition health literacy requires active participation to empower community stakeholders to develop meaningful interventions to improve community health and wellbeing.
## Key points and the evidence

<table>
<thead>
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<th>Key points</th>
<th>The evidence</th>
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Community participation and health literacy: What we have learnt

i. Stakeholders can identify health literacy gaps.

ii. Researchers can help stakeholders identify what “they don’t know”.

iii. Working with community members it is possible to co-produce health literacy interventions that meet community needs.

iv. Through participation community capacity can be built to address health literacy gaps.

v. Through community participation health literacy knowledge gaps can be identified for health service to address.

vi. Community participation can assist with identifying opportunities for allied health to develop targeted interventions.

vii. It is important to target community groups to champion health literacy programs. Examples from our work include:
   a. Nursing mums with breastfeeding
   b. Sports groups with alcohol
   c. Community groups with isolation and mental health

viii. The identification of community members with lived experience of disease management and treatment, as a consumer, family member or carer supports the development of health literacy.

ix. To develop community, collective health literacy, it is important to create a community “culture” with coproduced shared health knowledge.
DEBATE

Open Access

A critical review of population health literacy assessment

Diana Guzys¹*, Amanda Kenny¹, Virginia Dickson-Swift¹ and Guinever Threlkeld²

Abstract

Background: Defining health literacy from a public health perspective places greater emphasis on the knowledge and skills required to prevent disease and for promoting health in everyday life. Addressing health literacy at the community level provides great potential for improving health knowledge, skills and behaviours resulting in better health outcomes. Yet there is a notable absence of discussion in the literature of what a health literate population looks like, or how this is best assessed.

Discussion: The emphasis in assessing health literacy has predominantly focused on the functional health literacy of individuals in clinical settings. This review examines currently available health literacy assessment tools to identify how well suited they are in addressing health literacy beyond clinical care settings and beyond the individual. Although public health literature appears to place greater emphasis on conceptualizing critical health literacy, the focus continues to remain on assessing individuals, rather than on health literacy within the context of families, communities and population groups. When a population approach is adopted, an aggregate of individual health literacy assessment is generally used. Aggregation of individual health literacy fails to capture the dynamic and often synergistic relationships within communities, and fails to reflect societal influences on health knowledge, beliefs and behaviours.

We hypothesise that a different assessment framework is required to adequately address the complexities of community health literacy. We assert that a public health approach, founded on health promotion theories provides a useful scaffold to assess the critical health literacy of population groups. It is proposed that inclusion of community members in the research process is a necessary requirement to coproduce such an appropriate assessment framework.

Summary: We contend that health literacy assessment and potential interventions need to shift to promoting the knowledge and skills essential for critical health literacy at a societal level. The challenge for researchers is to negotiate the myriad of complexities associated with each concept and component required for this task.

Keywords: Critical health literacy, Community health literacy assessment

In this critical review we explore how the development of health literacy assessment tools reflects the evolution of health literacy definitions. Improving the health literacy of individuals, organisations and communities is identified in health care reform globally as a goal associated with improved health outcomes and health service efficiency [1]. Health literacy interventions at a population level provide great potential for improving health knowledge, skills and behaviours and consequently better health outcomes of communities. However, health literacy assessment predominantly focuses on the literacy and communication skills of individuals in clinical settings. This review examines commonly used assessment tools to determine their appropriateness for assessing the critical health literacy of population groups. We demonstrate the need to develop a framework appropriate for assessing the critical health literacy of population groups, and conclude that health promotion theories and principles provide a useful scaffold for this. We acknowledge that managing the complexities of the multiple concepts in achieving this, is somewhat daunting.

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Background

Early conceptions of health literacy emphasized an individual’s ability to understand and comply with health instructions. This resulted in a focus on functional health literacy, premised on an individual having the requisite reading and numeracy skills, and interactive health literacy, relating to personal communication skills required to engage effectively with health care professionals [2]. Medical health literacy is another term which has been used to describe this, as the fundamental focus is on improving the quality of clinical interactions [3]. Nutbeam [2] further described critical health literacy, which progresses from functional and interactive health literacy. He argued for a wider range and more advanced levels of knowledge and skills that support greater autonomy and personal empowerment in health related decision making and management. Across the population critical health literacy enhances capacity to act politically to address social and economic determinants of health [2]. It has been noted, however, that this second component of Nutbeam’s description of critical health literacy, the capacity to act politically to address social and economic determinants of health, is a common omission in the literature [4,5].

Critical health literacy facilitates improved individual resilience to social and economic adversity, and contributes to community empowerment [4,5]. Zarcadoolas, Pleasant and Greer [6] propose a health literacy model which incorporates functional literacy (reading, writing, speaking and numeracy), science literacy, civic literacy and cultural literacy. This model expands upon Nutbeam’s conception of critical health literacy, providing further detail of its multiple facets. Scientific literacy relates to an understanding of science and technology, as well as how social identity influences behaviours and decision making [6]. This expanded model addresses some of the concerns expressed by Tones [7], about the necessity for the evolving conception of health literacy.

The purpose of a critical review is to present, analyse and synthesise material from a range of appropriate sources, to produce a hypothesis or a model, rather than produce an answer [8]. This method is consistent with interpretivist philosophy and constructivist orientation, as knowledge is produced through the process of considering the views of others. Compared to other forms of literature reviews, a critical review is less formally structured, and is usually narrative or chronological. It does not provide a survey of all of the available literature on a topic; rather it demonstrates extensive research with the objective of identifying significant contributions to conceptual development in a field, for critical evaluation [8]. It is only in the last year several systematic reviews of health literacy assessment tools have been published recently [9-11], along with a paper discussing the evolution of health literacy tools [12]. We therefore encourage those seeking a more detailed review the health literacy assessment tools available, to read these.

Discussion

Inconsistent conceptualisation and definition of health literacy is frequently discussed in academic literature. It has been suggested that this results from concepts having a cluster of attributes, rather than a strict set of attributes, that are subject to change as they are prioritised differently by different groups of people [5]. The most frequently cited definitions of health literacy are sourced from the American Medical Association, the Institute of Medicine and the World Health Organisation (WHO), which focus on the skills necessary for an individual to obtain, process and understand health information and services facilitating healthy decision making [4]. However, the WHO Commission on Social Determinants of Health [13] health equity report called for expansion in the scope of health literacy to include the ability to understand and communicate information related to the social determinants of health. Begoray and Kwan [14] developed an operational definition of health literacy by reviewing the shared elements of existing definitions to identify four broad health literacy skills: the degree to which people are able to access; understand; evaluate; and communicate information in order to promote and maintain health across the life-course, across a range of contexts.

A number of reviews have been undertaken in an effort to clarify the definition and conceptualization of critical health literacy in the belief that this will enable greater progress toward its achievement. Public health literature, rather than clinical literature, appears to place greater emphasis on conceptualizing critical health literacy. Yet even within public health literature, the focus of health literacy continues to primarily assess individuals, rather than consider health literacy within the context of families, communities and population groups. Sykes et al. [5] characterised critical health literacy as advanced personal skills including health knowledge, effective interaction between service providers and users, informed decision making and empowerment, including political action. An understanding the social determinants of health, critical appraisal of information and collective action, were identified by Chinn [15]. However, Sykes et al. [5] report that health professionals and policy makers believe that it is the commitment from health practitioners to provide accessible information and to
engage in shared decision making, which is required for the emergence of critical health literacy.

Over the last five years reference to action at a social and political level, and population level empowerment associated with conceptualisation of critical health literacy, have declined [5]. This conceptualisation of critical health literacy focuses on the relationship between services and individuals. The emphasis becomes an individual’s ability to navigate services, communicate effectively and confidently with a health professional, including constructively questioning or challenging them when necessary [5]. The Health Literacy Pathway Model developed by Edwards, Wood, Davies and Edwards [16] exemplifies this conception. This model describes the trajectory of an individual’s development of health literacy, as they seek, engage and act on health information in relation to their health condition [16]. Although useful in improving the health outcomes of individuals, adopting only this view of critical health literacy must be challenged, as it perpetuates an emphasis of responding to ill health, rather than acknowledging the social determinants of health and taking preventative action through promoting health.

Assessment of health literacy is recognized as an important consideration in delivering appropriately tailored effective health care and achieving better health outcomes. Increased health knowledge is thought to positively influence health behaviours and consequently this is reflected in health status. However, health literacy assessment tools continue to primarily focus on individuals and are slow in shifting shift from a medical perspective towards a societal one. It has been argued for a distinction to be made between public and individual health literacy [17].

The need to develop new tools to assess health literacy more broadly has been recognized. More recent tools have sought to address other dimensions that impact on health and health literacy [18-20]. Yet a greater focus on health literacy outside of healthcare settings is required, as this is where there is the greatest potential to impact on health behaviours to prevent or reduce ill health [4]. We contend that a distinction between how public or community health literacy and personal health literacy is assessed is necessary. We critically examine currently available health literacy assessment tools to identify how well suited they are in addressing health literacy beyond the individual and beyond clinical care settings.

The conceptualization of health literacy assessment tools is understandably consistent with the conceptualization of health literacy itself. A number of tools have been developed to assist in assessing health literacy in health care settings, which can be broadly categorized as assessing word recognition, reading comprehension and functional health literacy through informal measures. Informal methods may include observation of behavior such as forgetting eyeglasses necessary for reading information during visits; submitting incomplete forms; missing appointments, diagnostic tests or procedures; or the incorrect administration of medication or treatment advice [21].

The most commonly used tools reported in the literature are the Rapid Estimate of Adult Literacy in Medicine-Short Form (REALM-SF), which tests reading ability through word recognition and pronunciation [22]; The Test of Functional Health Literacy in Adults (TOFHLA), which requires patients to read and complete missing sections of selected passages of information to measure reading comprehension, as well as to read and apply the information on prescription labels and appointment slips to assess numeracy [23]; and The Newest Vital Sign (NVS) a quick assessment of reading comprehension and numeracy, requiring patients read an ice cream label nutritional label, then answer 6 problem-solving questions [18,21].

Discussion of the use of REALM and its short form version REALM-SF to assess health literacy in primary care settings has appeared in literature since the early 1990s. Prior to the introduction of REALM, the Wide Range Achievement Test-Revised (WRAT-R) was used to assess functional literacy skills, described as the ability to read, write and make calculations to deal with everyday situations [22,23]. Moving beyond testing word recognition and pronunciation of health related words, TOFHLA was developed in the mid 1990s, assessing reading comprehension using documents and materials found in health care settings [23]. Another health literacy assessment tool which focuses on assessing reading comprehension and numeracy skills, is the NVS, which was developed almost 10 years after TOFHLA. The key advantage claimed through the use of the NVS over TOFHLA is that it takes less time to administer [24]. Time to administer these health literacy assessments, as well as the potential to embarrass patients through the use of such assessments, lead to the development of using screening questions for the quick and unobtrusive identification of those with limited or marginal functional health literacy skills [25-27]. The use of a single question, asking the patient how confident they were in filling out medical forms, was advocated [26,27]. However, all of these health literacy assessment tools clearly focus on functional literacy assessment of individuals for clinical care, providing little assistance for assessing critical health literacy or in a population context.

Some population approaches have attempted to move beyond assessing individuals, yet the emphasis remains on functional health literacy and a medical view of health, rather than the broader social view of health and wellness. The Demographic Assessment for Health Literacy
(DAHL) is used to impute limited health literacy and estimate the association with indicators of health status [28]. Another population approach identified uses a similar model based on social demographics to predict inadequate functional health literacy [29].

More recently developed assessment tools have endeavored to adopt a broader conceptualisation of health literacy. The recognition that health outcomes of patients with diabetes were inconsistent with their functional literacy level highlighted that a person’s ability to read health information was not singularly necessary for optimal self management [30]. Ishikawa et al. [30] developed a tool they believe measures functional, communicative and critical health literacy by assessing a person’s ability to obtain, critically analyse, and use health information to positively participate in their own health care. This was presented as a self reported, four point scale questionnaire, which they felt was easy to deliver in a clinical setting. Their findings suggests that each type of health literacy may impact on health outcomes in different ways, as the skills necessary to read the information may be less important in managing diabetes than the skills of extracting, communicating, and applying information.

Another recent development in assessing health literacy is the Health Literacy Questionnaire (HLQ). The HLQ is reported as having multiple functions, including identifying the needs and capabilities of individuals, describing the health literacy of populations, and evaluating outcomes of public health and clinical interventions designed to improve health literacy [18]. The HLQ assesses nine indicators of health literacy which reflect the experience of people attempting to access, understand and using health information as well as engage with health services, reflecting perspectives sought from the general population, health care providers and policymakers. Individuals are asked to self rate their active self management of their health; social support for health; access to sufficient information to manage their health; ability to find good health information; ability to judge the quality of health information; ability to understand health information well enough to act on this; ability to navigate the healthcare system; ability to actively engage with healthcare providers; and the degree to which they feel understood and supported by healthcare providers [18].

The All Aspects of Health Literacy Scale (AAHLS) is another recently developed tool, which aims to measure functional, communicative and critical health literacy. The AAHLS is reported to identify an individual’s health literacy support needs, highlight the strengths and capabilities an individual has, provide population level information and may be used to evaluate the impact of local patient education initiatives [31]. The AAHLS is a self-reported scaled questionnaire designed to assess an individual’s ability to read health information; to write; to gather, process and appraise information; access support networks and interact successfully with health providers. The scale includes questions to assess an individual’s willingness and ability to assert individual autonomy in relation to healthcare decisions, as well as if they hold a positive belief about the contribution to the health outcomes of the broader community made by individuals.

The European Health Literacy Survey Questionnaire (HLS-EU-Q) was developed to measure and compare health literacy in populations in selected countries in Europe. The health literacy assessment tool developed by the HLS-EU Consortium is presented as being different from other tools as it is grounded in public health, and addresses the key processes of accessing, understanding, appraising and applying health related information within healthcare, disease prevention and health promotion [32]. Sorensen and colleagues argue that the key limitations of existing tools result from focusing on single or selected components of health literacy, rather than a comprehensive conceptualization of health literacy; as well as on personal attributes, rather than those of the population. The HLS-EU-Q differs from most other health literacy assessment tools, as the stated aim was to measure the health literacy of general populations, rather than specific patient groups [32]. The tool measures an individual’s response to a questionnaire consisting of 47 health literacy related items. Although a continued emphasis on healthcare and disease prevention and less on health promotion is an acknowledged limitation in the design of the tool [32].

Other attempts that focus on measuring health literacy from a public health, rather than medical perspective, are appearing in recently published literature. One study described the use of a short survey tool, which addressed the different domains of health literacy, focusing on adolescents in their daily life context of family and peers [33]. A self reported response was required to eight items that represented functional, interactive and critical health literacy. Two items relating to each of the three domains of health literacy were included, as well as two additional items relating to functional health literacy; differentiating between understanding and finding health-relevant information [33].

These developments demonstrate a response to the ongoing evolution in assessing health literacy, yet the focus remains on the health literacy of individuals or the collation of individual data. The progression of development in the health literacy tools described demonstrates acknowledgement of the complexity of health literacy as a concept, as well as the necessity to incorporate this complexity within assessment. Moving beyond individual functional health literacy competencies in medical settings,
to understand the intricacies of critical health literacy in the context of the everyday life of individuals, families and communities provides the impetus to affect great benefit in the health of individuals and populations [34]. Key deficits in current measures of health literacy as summarized by Pleasant et al. [34] include a focus on a single or narrowly defined dimension of health literacy, rather than integrating multiple dimensions; failure to consider health literacy as a public health issue; and a lack in testing or advancing an underpinning theory of health literacy. Addressing these deficits and other attributes required of proposed health literacy assessment mechanisms include the use of measures that are appropriate to the context in which they are being used, reflect more recent definitions and understanding of health literacy and prioritise social research and public health applications [34]. This is particularly relevant in relation to assessing the most challenging and frequently overlooked aspects of health literacy, being critical health literacy and the health literacy of communities or population groups.

Fundamentally public health is concerned with protecting and promoting the health of populations rather than the provision of individual care. Therefore defining health literacy from a public health perspective places greater emphasis on the knowledge and skills required to prevent disease and for promoting health in everyday life [33,35]. A public health approach recognises health literacy as an asset which can be built [34] through action at an individual, service and societal level [1,2]. Building health literacy requires more than citizens acquiring basic health knowledge. Discourse focused on health literacy from a public health perspective frequently refers to improvement in health literacy of ‘individuals and communities’ or ‘populations’ [3,34], yet there is an absence of discussion in the literature of what a health literate population looks like.

Health literacy is acknowledged as a complex multifactor concept. Assessing the impact of numerous complex variables that contribute to the development and use of this knowledge and skills is daunting. Given the complexities that influence daily life decisions which impact on health, a systematic assessment of health literacy is necessary [3]. The challenge is to move beyond a focus of functional and interactive health literacy, to focus on critical health literacy, as well as moving beyond the collection of individual assessments to describe the health literacy of groups and populations.

Health promotion provides a useful scaffold to assess the critical health literacy of population groups. McQueen and Kickbusch [36] describe health promotion as the avant-garde of public health, shifting the focus of public health away from disease to focus on the modern world challenges of creating and maintaining healthy populations. The elemental principle of empowering individuals and communities to achieve optimal health outcomes is embedded within both health literacy and health promotion, intrinsically enmeshing these concepts, leading to the call for health literacy to be more explicitly linked to health promotion theories and models [4]. Empowerment, that is the redistribution of unequal power, is central in addressing health determinants, and consequently health outcomes [37]. Perceiving health literacy as a determinant of health facilitates appropriate and customised interventions that successfully advance the public’s health [19]. Such interventions constitute health promotion activity.

Assessing the health literacy of communities or populations cannot simply or conveniently be addressed through nominating health promotion theory as guiding actions or activity. Researchers need to identify and clearly explain the framework on which health literacy assessment tools are based [14]. Adding to the complexity of this challenge is the number of theoretical foundations which contribute to health promotion, rather than one accepted fundamental grand theory [36]. Perhaps acknowledging the layers of complexity relating to health promotion theories, a public health approach, the domains of health literacy and a population perspective, will enable them to be neatly packed up like Russian nesting dolls, to facilitate the development of a suitable framework to assess the critical health literacy of communities.

The tools developed thus far to assess health literacy reflect another potential limitation, as their development has predominantly been shaped by education, communication and health care experts, with little but cosmetic input from health consumers. Genuine, collaboration with members of the general public, who have a range of literacy and health literacy levels, is required to develop an appropriate framework to assess the critical health literacy of communities. People who directly experience the barriers and benefits of health literacy are the true experts in health literacy, therefore involving the public in the research process is essential [19]. How this is best achieved in a genuine, non tokenistic manner adds a further layer of complexity to the Russian nesting doll analogy. The development of a framework to assess the health literacy of communities needs to integrate the views of community members, a focus on the critical domain of health literacy, health promotion theories, and a public health approach. The creative integration of these components should result in the coproduction of responsive, community informed, health literacy measures.

Summary

The emphasis of health literacy assessment has focused on the functional health literacy of individuals in clinical settings. Yet, addressing health literacy in the community
provides great potential for improving health knowledge, skills and behaviours resulting in better health outcomes. We have critically reviewed a number of health literacy assessment tools available internationally, and demonstrated how that they are unsuited for assessing critical health literacy at the societal level. We contend that the focus of health literacy assessment and potential intervention needs to shift to promoting the knowledge and skills essential for critical health literacy at a societal level. The need to develop a framework appropriate for assessing the critical health literacy of population groups is patently apparent. We concur with others who have an interest in this area that health promotion principles and theories provide a useful scaffold for developing the required assessment framework, particularly as possible interventions which result from such an assessment are health promotion activities. We further propose that inclusion of community members in the research process is necessary to coproduce such an assessment framework. The challenge for researchers is to negotiate the myriad of complexities associated with each concept and component of this task.

Competing interests
The authors declare that they have no competing interests.

Authors’ contributions
All authors have contributed to the intellectual development of the manuscript. DG, VDS, AK and GT were involved in the conception, interpretation and revising the manuscript critically for important intellectual content. DG was responsible for data acquisition, analysis and drafting the manuscript. All authors have read and approved the manuscript.

Author details
SECTION FOUR: Methods of community participation

Community participation and methods of participation

• A number of processes and models have been trialled internationally, and many ‘experts’ herald their own model as ‘best practice’.

• A diverse range of methods can be used to engage community members, and to facilitate or enact their participation.

• Practitioners’ should think about the different methods that can be used, and should improve their abilities to design creative and inclusive participation strategies.
## Key points and the evidence

<table>
<thead>
<tr>
<th>Key points</th>
<th>The evidence</th>
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| Methods are often distinguished by levels of power. Different typologies and models typically describe methods of community participation as a range of methods that offer low-levels or marginal participation, to methods that offer higher levels of power and control over decision-making (e.g. full citizen or community control) | • Arnstein, S. A. 1969.  
• Baum, F. 2008.  
| Methods of community participation are often distinguished by purpose and objective, including who identifies, initiates or defines processes used for participating. This might be the difference between ‘grassroots’ community participation that is defined by members of a community, and is used for empowerment compared with institutional community participation processes, which has been defined by a health service, to suit their specific purpose e.g. service efficiency. This impacts on the nature and function of the methods used, how they are perceived by the community, and expected outcomes. | • Pretty, J. N. 1995.  
• Morgan, L. 2001.  
• Rifkin, S. B. 2014.                                                                                                                                                                               |
| Methods are distinguished by processes used, for example, consultation processes that are usually uni-directional and involve seeking information or feedback from the community about a specific issue. Pretty (1995) would call this ‘passive participation’. Another example would be online community participation, which is supported through social media or forums, which using Pretty’s (1995) typology might be identified as ‘interactive participation’, which involves participation in joint decision-making, or ‘self-mobilisation’, which is participation that occurs independently of institutions. Methods are defined by the processes used to enact community participation, and what participation outcomes the specific process is able to, and aims to, achieve. Different processes have different strengths and limitations. | • International Association for Public Participation 2004.  
| Methods of community participation are influenced by place and context. In some contexts, community participation may be naturally occurring through social groups and networks, or be supported by place features, or natural/built systems and structures, like schools, sporting clubs, workplaces. Methods used should be relevant to context, which includes historical, cultural and physical contextual factors. | • Abelson, J. 2001.  
| Effective community participation methods will likely consider/include continuity of leadership, democratic processes, inclusion of disadvantaged groups, and provision of supports and resources (transport, childcare, etc) | • Kenny, A., Hyett, N., Sawtell, J., Dickson-Swift, V., Farmer, J., & O’Meara, P. 2013.  
• Kilpatrick, S., Cheers, B., Gilles, M., & Taylor, J. 2009.  
• Kilpatrick, S. 2009.  
• Rifkin, S. B. 2014.                                                                                                                      |
Methods of participation: What we have learnt

i. A range of methods are used for community participation, including social events (movie nights and themed dinners), community development projects (community gardens, social enterprise), consultative meetings or focus groups, or information sharing mechanisms (social media, newsletters, blogs, brochures).

ii. Use of multiple methods simultaneously, might more effectively enable and sustain community participation, and maximise participation opportunities for various age and cultural subgroups.

iii. People and communities choose to participate in different ways. People’s participation choices are influenced by several contextual factors, including place and geographic location, social networks and relationships, sense of community and belonging, community history and culture, past experiences with participation, and current and future expectations of how their inputs will be used (or not). It was found that people have different preferences for participating, while some people will want to take on leadership roles and participate in decision-making, others might prefer to be bystanders, and observe activities, but not become directly involved.

iv. Leadership influences community participation and types of methods used. Local leaders, with extensive social networks and capacity to communicate effectively with different stakeholders, are influential in recruiting people to participation processes, and in motivating community members to participate. Continuity of leadership can also influence participation processes and efficacy of methods used.

v. Increasingly, people are using social media to connect with their communities online. While online participation and social media might not be relevant or important to all communities, for some communities, online methods of participation provide them with improved accessibility to communities (overcoming geographical barriers), and a method of keeping up with community activities, which they could then attend in person. For example, people used social media to communicate pre and post in-person community participation events.

vi. Common methods of participating are Twitter and Facebook. Community participation leaders can also use blogs and websites to share information about their activities, to increase membership, and to share resources.

vii. Connections to rural place are important motivators of community participation. This interrelationship could be used to strengthen community participation initiatives, by identifying spaces and places that people find meaningful, and using them to build participation initiatives. One example is community gardens, which use people’s emotional and spiritual connections to nature, and enjoyment of being in natural environments, to encourage their participation in community activities and spaces. In John Aitken’s research, we used GIS and walking interviews to understand what places people find meaningful in their communities, and where they like to participate. This could be a valuable investigative and planning tool.

viii. Often community leaders find it difficult to fund and resource initiatives. One method of enhancing initiative sustainability was by building partnerships with local people, groups and organisations or businesses, and building capacity by mobilising and utilising human and material resources.

ix. Using established formal networks within a community (service clubs, sporting bodies, educational bodies) it is possible to reach almost all members of a community via their social networks. This is called ‘contagion’ theory, which recommends that the positive effects of community participation, such as improving health literacy, can ‘go viral’ by harnessing naturally occurring networks. This supports health knowledge and skills to be diffused out throughout a community. Similarly, these networks can draw in and feed up community concerns and issues.

x. Incentives may be needed to acknowledge community members time and expertise, and to reduce barriers to participation.

xi. Evidence suggests that methods of community participation cannot be applied across contexts without adaptation, place and contextual factors are important.

xii. Community participation is underpinned by comprehensive primary health care ideals, and the two go hand in hand. This means, to do community participation, service philosophies need to adopt these ideals.

xiii. Currently silos exist that prevent community participation from occurring within and between community services and groups, e.g. different groups/organisations seen to be responsible for certain areas, which limits collaboration and partnership that is required for community participation to occur and be sustained.

xiv. There is a wealth of potential is utilising social media and new technologies to expand in-person social networks, and to support existing networks, and to create new ones beyond traditional community spatial boundaries.

xv. Methods employed need to be suitable for a diverse range of community members for a whole of community approach, which extends beyond the leadership sub-group.
Gadamerian philosophical hermeneutics as a useful methodological framework for the Delphi technique

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Abstract
In this article we aim to demonstrate how Gadamerian philosophical hermeneutics may provide a sound methodological framework for researchers using the Delphi Technique (Delphi) in studies exploring health and well-being. Reporting of the use of Delphi in health and well-being research is increasing, but less attention has been given to covering its methodological underpinnings. In Delphi, a structured anonymous conversation between participants is facilitated, via an iterative survey process. Participants are specifically selected for their knowledge and experience with the topic of interest. The purpose of structuring conversation in this manner is to cultivate collective opinion and highlight areas of disagreement, using a process that minimizes the influence of group dynamics. The underlying premise is that the opinion of a collective is more useful than that of an individual. In designing our study into health literacy, Delphi aligned well with our research focus and would enable us to capture collective views. However, we were interested in the methodology that would inform our study. As researchers, we believe that methodology provides the framework and principles for a study and is integral to research integrity. In assessing the suitability of Delphi for our research purpose, we found little information about underpinning methodology. The absence of a universally recognized or consistent methodology associated with Delphi was highlighted through a scoping review we undertook to assist us in our methodological thinking. This led us to consider alternative methodologies, which might be congruent with the key principles of Delphi. We identified Gadamerian philosophical hermeneutics as a methodology that could provide a supportive framework and principles. We suggest that this methodology may be useful in health and well-being studies utilizing the Delphi method.

Key words: Health and well-being methods, dialogue, collective opinion, democratic group method

Researchers interested in harnessing expert knowledge on a broad range of health and well-being topics are increasingly using Delphi as a means of capturing collective opinion. The method has been adopted across a wide range of health, social care, and well-being studies related to policy, clinical practice, planning, and evaluation. Whilst the use of Delphi is increasing in health and well-being research, less attention has been given to the methodological underpinnings of the Delphi method. Our aim in this paper is to present Gadamerian philosophical hermeneutics as a methodological framework that others may find useful when undertaking health and well-being research using the Delphi method.

We were interested in the Delphi method (Delphi) for its usefulness for addressing research questions where diverse perspectives exist or knowledge is incomplete. Our specific interest was fuelled by our involvement in a large community-based health and well-being study. We explored Delphi as a method for facilitating anonymous conversations between participants about health literacy, as a mechanism for capturing collective views (Keeney, McKenna, & Hasson, 2011; Linstone & Turoff, 2011). However, consistent with the views of Gorman (2011), we believed that an understanding of the methodology that underpinned Delphi was fundamental in providing the framework and principles for our work, and central to research integrity. Researchers argue that there is often confusion between the terms methodology and method; however, we are clear that methodology refers to the rules, strategy, design.
principles, or frame of reference, which are influenced by the paradigm that guides the research method undertaken (McGregor & Murnane, 2010; Tracy, 2012). We completed an initial literature search to identify the underpinning methodology of Delphi but found little guidance. We postulate that this results from the manner and era in which Delphi originated. Delphi developed in a period when the scientific method of research was dominant and research was outcome driven, rather than emerging from a philosophical position. Helmer (1967), a member of the RAND Corporation credited with developing Delphi, described Delphi as a systematic method to obtain the relevant intuitive insight and judgement of experts in the absence of a proper theoretical foundation. Contemporary researchers in the health and social sciences are more aware of the pivotal role methodology plays in inductive research. Therefore, we sought to map recent thinking related to methodologies informing use of Delphi.

Using the scoping review framework of Arksey and O’Malley (2005), we sought to identify health and social science articles published between 2010 and 2014 which report Delphi as the research method. The results of the scoping activity are presented in this article to illustrate our issue of concern. A majority of researchers who select Delphi as their research method do not report, or perhaps may not consider, the methodological underpinnings of their work. This may reflect a pervasive indifference to methodology, or avoidance resulting from epistemological confusion. Admittedly, it may simply result from the lack of space provided for such discussion in journals. Yet, this omission is of little value for those who seek theoretical foundations.

Seeking to identify a philosophy that provides a methodological rationale retrospectively is problematic, yet to do so may increase the rigour and value of studies using Delphi. The scoping review assisted in identifying the views of other researchers who had similarly struggled with this problem. Our review provided a platform from which we were able to consider alternative methodologies that might be congruent with the key principles of Delphi. The cyclical process of engaging with text and reflection exemplified through hermeneutics resembled the process which is fundamental to Delphi. Another core aspect of the method is that the process seeks to challenge personal perspectives, reshaping these through consideration of the perspectives of others. Despite Gadamerian hermeneutics developing from interpretation of historical and most frequently religious texts, we believe that the philosophy of thought, or ontological process Gadamer theorizes, provides understanding of the iterative interpretive process that occurs when using Delphi. We therefore propose that Gadamerian philosophical hermeneutics could provide a suitable methodological framework for health and well-being researchers using the Delphi method. We present our argument for this, in the belief that this may be useful for others to consider.

**Background**

*The Delphi technique*

Delphi assists in pooling expert knowledge to develop a collective opinion on a specific topic. It was developed to facilitate group communication for structural modelling of weapon requirements for the military following World War II (Donohoe & Needham, 2009; Linstone & Turoff, 2011). Due to national security concerns, publication relating to early Delphi did not occur until 10 years after they took place within the RAND Corporation (Dalkey & Helmer, 1963). Helmer (1967) suggest that Delphi developed in response to the rapid change caused by advances in technology, resulting in an increased recognition for the need to plan for future possibilities or forecasting, rather than simply being reactive. Delphi was considered a systematic approach to explore the factors that influence individual judgement, and bring factors which participants may not have considered through provision of a summary of others views (Dalkey & Helmer, 1963). It was presented as an experiment, where repeated intensive questioning of individual experts occured to ensure direct confrontation between experts was avoided. Questions were designed to make the reasoning behind the participant’s perspective apparent, and how information from unknown others influenced original perspectives.

The central premise of Delphi is the generation of knowledge that results from dialogue achieved via organized interaction between knowledgeable individuals (Fletcher & Marchildon, 2014). Idea generation or brainstorming occurs through open-ended questions posed in an initial survey round (Skulmoski, Hartman, & Krahn, 2007). Traditionally, in subsequent rounds, participants are provided with a summary of the previous survey responses to consider. Participants review this, rank or indicate their level of agreement to the responses of others, and provide the reasoning for their opinion (Knott et al., 2012). Multiple survey iterations promote insightful decision-making through the anonymous re-evaluation by participants of their own view in the light of other opinions (Paraskevas & Saunders, 2012). Additional survey rounds continue until stability of responses occurs, which reflects achievement of theoretical saturation, although in some studies survey rounds cease once a predetermined level of consensus is achieved.
(Mamaqi, Miguel, & Olave, 2011; Paraskevas & Saunders, 2012). Stability of opinion is achieved when each participant has had the opportunity to consider and understand the views of others, but there are no further shifts in responses, signalling consensus and illuminating areas of difference.

Pooling of expert knowledge is one of the strengths of Delphi over research methods that focus on individual opinion, such as interviews (Snape et al., 2014). Delphi has been described as combining the collaborative effect of focus groups with the rigour of traditional surveys (McIntyre, Novak, & Cusick, 2010). Identifying the specific differences in Delphi from other group research methods assists in highlighting key methodological principles. In Delphi, participants do not interact directly with others but rely on text to share their opinions, responding to the research question in writing. The responses are collated and participants are then informed about others’ responses. Following reflection on the responses of others, participants are invited to adjust their response should they wish to. This process is repeated until stability of opinion is reached. The nominal group technique (NGT) is similar to Delphi, however, there is direct interaction between NGT group members to discuss or clarify ideas, removing the advantage of anonymous interaction provided by Delphi (Binnendijk, Gautham, Koren, & Dror, 2012). The four key components that define a process as the Delphi method are anonymity, iteration, controlled feedback, and aggregation of group response (Skulmoski et al., 2007). Anonymity is maintained throughout Delphi by reliance on written responses.

The advantage of using the Delphi method over other group research methods, such as focus groups and nominal groups, is in minimizing the influence of group dynamics on the findings (Fletcher & Marchildon, 2014). Face to face interactions have the potential for some participants to modify their responses in deference to the opinions expressed by other participants, particularly those who they may perceive as their superiors. A participant with a dominant personality may inhibit others within a group from expressing a different point of view. These possibilities are avoided through anonymous interaction, resulting in a more democratic process in which all perspectives are equally included. A further advantage of the method is that it facilitates the inclusion of geographically dispersed participants, as the process does not require participants to congregate in a single location. The time involved in undertaking the traditional Delphi method is sometimes considered its weakness.

A number of modifications to Delphi, including omission of the primary exploratory step in the process, have occurred over time. The Ranking Delphi, does not include an initial open-ended question survey round, but rather provides content often derived from the literature or other sources. A Delphi-like process is then used to rank or prioritize, using multiple survey rounds with the aim of reaching consensus, with regard to the order or level of agreement with the provided content. The “real time Delphi,” where the multiple survey rounds are compressed into a single meeting is another modification to the classical Delphi method. This potentially reduces the time available for thoughtful reflection of one’s own perceptions in light of other responses. Consideration of disagreement is valuable, as stable disagreement is recognized as being informative, highlighting differences in perspectives (Goluchowicz & Blind, 2011; Linstone & Turoff, 2011; Rowe, Wright, & McColl, 2005). The value of stable disagreement is particularly valued in what is referred to as the “policy Delphi,” where development of various options is used to inform decision-making.

The use of Delphi in health and well-being research

The use of Delphi in studies that explore questions related to health and well-being is increasing. In health and well-being policy, recent examples include the creation of activity-friendly environments for children (Aarts, Schuit, Van De Goor, & Van Oers, 2011) and access to wireless technologies for people with disabilities (Baker & Moon, 2010). Delphi has been used in studies seeking to develop practice guidelines and competencies in the area of health and well-being. The development of definitions of best practice in child protection (Ager, Stark, Akesson, & Boothby, 2010), peer support guidelines in high-risk organizations (Creamer et al., 2012), and guidelines for caregivers of people with bipolar disorder (Berk, Jorm, Kelly, Dodd, & Berk, 2011) are examples of this application. Clinical healthcare practice has been advanced through Delphi studies, including the development of practice guidelines for the management of head injuries (Undén, Ingebritsen, & Romner, 2013), professional competencies for optometrists (Myint, Edgar, Kotecha, Crabb, & Lawrenson, 2010), and identifying clinical indicators for musculoskeletal ultrasound (Klauser et al., 2012).

Delphi has proved a valuable research method in the development of resources and tools for diverse healthcare needs including a stammering information programme (Berguez, Cook, Millard, & Jarvis, 2011); the suicidal patient observation chart (Björkdahl, Nyberg, Runeson, & Ömörö, 2011); and the domains of quality of life (Pietsma, De Vries, & Van den Akker-Van Marle, 2014).

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(page number not for citation purpose)
Researchers focused on planning and evaluation in health and well-being often report using Delphi. Examples include the examination of elements of a new model of adaptive adult bereavement (Doughty, 2009) and planning education to address the needs of first responders regarding survivors’ psychosocial reactions (Drury et al., 2013). Identifying a suitable methodological underpinning for Delphi should assist in ensuring that the increasing volume of health and well-being studies using this method are well designed, and researchers rigorous in their approach.

The scoping review

Recognizing that Delphi was not a research method historically aligned to a specific methodology, we sought to understand what methodology contemporary researchers identified as a suitable supportive framework. We utilized a scoping review method to provide a rigorous and transparent approach to mapping relevant literature that would provide insight into the methodologies underpinning recent Delphi studies. Arksey and O’Malley (2005) recommend a multitarget approach for undertaking scoping reviews. Consistent with their approach, in the first stage we developed our research question, “what methodological explanation is provided in contemporary research studies for selecting Delphi as a research method?” and broad key terms to capture the broadest pool of data (Arksey & O’Malley, 2005). Drawing on a wide range of health and social science research literature, a search was undertaken in September 2014 using ProQuest, CINAHL, Expanded Academic, and Scopus databases for the second stage in the scoping process.

The practicalities of time and cost limitations required us to establish clear criteria (Hammersley, 2011). Included articles were required to be published in English between 2010 and 2014 in peer-reviewed health and social science journals. The initial search sought articles that made reference to the “Delphi technique,” “Delphi method,” or “Delphi approach” in the abstract. This initial search resulted in 3056 articles. Use of the terms theoretical perspective, philosophy, or method* anywhere within the articles was then included to further refine this search. During this stage, four articles were found to discuss Delphi as a location in Greece or ancient Greece, and two articles discussed Delphi in terms of mathematical language. As these articles did not contain information relevant to our review, they were removed from the data pool. A further 150 articles were removed as the authors did not provide any rationale for the use of Delphi. Of the remaining 149 articles, the stated justification for use of the Delphi research method related to specific aspects of the processes, predominantly the desire to achieve consensus or convergence of opinion. Several authors qualified this, saying that use of Delphi resulted specifically in the most “reliable” consensus (Schmiedel, vom Brocke, & Recker, 2013; Vakani & Sheerani, 2012; Xia & Chan, 2012). However, other researchers emphasized the benefit of identifying areas of disagreement through the use of Delphi (Snape et al., 2014; Tuominen, Tapio, Varho, Järvi, & Banister, 2014; Warth, von der Gracht, & Darkow, 2013). Other rationales provided can be broadly categorized as highlighting collaboration (Ferguson, Ireland, & Ireland, 2013; Munguatosha, Muyinda, & Lubega 2011; Nworie, 2011); structured group communication (Dikmen, Birgonul, Ozorhon, & Sapci, 2010; Keyvanfar et al., 2014; Manley & Zinser, 2012); the value of iteration and reflexivity (Ifinedo & Ifinedo, 2011; Loblaw et al., 2012; Venhorst, Zelle, Tromp, & Lauer, 2014); and greater democracy through anonymity (Chen, Wakeland, & Yu, 2012; O’Rourke et al., 2014; Venhorst et al., 2014). Only 19 articles were judged to provide some reference to a methodology, philosophy, or theoretical perspective. The PRISMA framework that guided this process is represented in Figure 1.

Table I. Results of database search.

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<tr>
<th>Data base</th>
<th>ProQuest</th>
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<tbody>
<tr>
<td>Delphi technique/Delphi method/Delphi approach (in abstract)</td>
<td>680</td>
<td>48</td>
<td>11</td>
<td>2317</td>
<td>3056</td>
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<tr>
<td>Methodology/philosophy/theoretical perspective (in text)</td>
<td>163</td>
<td>3</td>
<td>8</td>
<td>192</td>
<td>366</td>
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The use of a Boolean signifier (*), with a truncated word, enabled the search to include all terms from the same root. Therefore articles that discussed methodology would be included in the data pool by using method* as the second search term. The result of this two-stage database search is detailed in Table I.

The refined database search resulted in a more manageable 380 articles, from which 42 duplicate articles were removed. The remaining 338 articles were then read individually to determine what rationale was given by the authors for using Delphi in research. During this stage, four articles were found to discuss Delphi as a location in Greece or ancient Greece, and two articles discussed Delphi in terms of mathematical language. As these articles did not contain information relevant to our review, they were removed from the data pool. A further 150 articles were removed as the authors did not provide any rationale for the use of Delphi. Of the remaining 149 articles, the stated justification for use of the Delphi research method related to specific aspects of the processes, predominantly the desire to achieve consensus or convergence of opinion. Several authors qualified this, saying that use of Delphi resulted specifically in the most “reliable” consensus (Schmiedel, vom Brocke, & Recker, 2013; Vakani & Sheerani, 2012; Xia & Chan, 2012). However, other researchers emphasized the benefit of identifying areas of disagreement through the use of Delphi (Snape et al., 2014; Tuominen, Tapio, Varho, Järvi, & Banister, 2014; Warth, von der Gracht, & Darkow, 2013). Other rationales provided can be broadly categorized as highlighting collaboration (Ferguson, Ireland, & Ireland, 2013; Munguatosha, Muyinda, & Lubega 2011; Nworie, 2011); structured group communication (Dikmen, Birgonul, Ozorhon, & Sapci, 2010; Keyvanfar et al., 2014; Manley & Zinser, 2012); the value of iteration and reflexivity (Ifinedo & Ifinedo, 2011; Loblaw et al., 2012; Venhorst, Zelle, Tromp, & Lauer, 2014); and greater democracy through anonymity (Chen, Wakeland, & Yu, 2012; O’Rourke et al., 2014; Venhorst et al., 2014). Only 19 articles were judged to provide some reference to a methodology, philosophy, or theoretical perspective. The PRISMA framework that guided this process is represented in Figure 1.

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</table>
The final three stages of the scoping review process involved collating or charting the data, summarizing, and reporting results. Consistent with the third stage of Arksey and O’Malley scoping review framework, the author, publication year, article title, journal, research aim, and methodological statements are charted in Table II.

Interpretivism, focused on understanding the meaning of the research topic from the perspective of the participants, was the overarching epistemology given in most of the 19 articles that described some methodological principle in relation to Delphi. Reference was simply made to a qualitative research approach in six of the studies (Chan, Wey, & Chang, 2014; Daim, Laakso, Rubin, & Linturi, 2012; McNichols, 2010; Pérula et al., 2012; Santos & Gomes, 2010; Traynor, Boyle, & Janke, 2013; Van Kemenade, Hardjono, & De Vries, 2011), which is generally consistent with interpretivist epistemology and constructivist ontology (Andrews, Sullivan, & Minichello, 2004). A qualitative approach to achieve quasi-objective quantitative estimates was discussed in four studies (Brody, Byham-Gray, Touger-Decker, Passannante, & Maillet, 2012; López-Sánchez & Pulido-Fernández, 2014; Palo & Tähtinen, 2011; Tang & Wu, 2010). However, Hanekom et al. (2012) simply described Delphi as a pragmatic methodology, without further explanation. Sobalh, Ritchie, and Jones (2012) clearly stated that the Delphi study they undertook sat within the interpretivist research paradigm. They presented case studies illustrating Delphi research, stating that these cases highlight that Delphi has a “multi-paradigmatic” but consensual nature.

The authors of only five studies identified what could be considered philosophical perspectives proposed as underpinning Delphi research. LaBelle (2012), as well as Meng, Xiuwei, and Anli (2011), have used the research data generated through Delphi to generate theory. In grounded theory an iterative approach to data analysis is adopted which resonates with the iterative process of the Delphi surveys rounds that seek to clarify and consolidate the data. Paraskevas and Saunders (2012) do not provide any explanation for labelling Delphi phenomenological research, other than to say that researchers construct knowledge through the collection of multiple sets of interpretations, involving participants in the data co-creation and interpretation of the phenomenon being studied. Browne (2004), however, explains how phenomenology differs from grounded theory, as the intention is to describe the phenomena, rather than develop a theory from it. Hamilton, Coldwell-Neilson, and Craig (2014) refer to a Kantian or contributory Delphi approach, with no further explanation. Wilson (2011) incorporates Delphi in what he describes as a cyclical hermeneutical approach. Hermeneutics focuses on the interpretation of meaning (Andrews, Sullivan, & Minichello, 2004), particularly how we come to understand the meaning of text or art (Gadamer, 1996). The emphasis on a cyclical process reinforces the significance of the iterative process of the Delphi method.

Discussion

A number of variations of Delphi have developed since its inception. Critics of the Delphi method have sometimes described these as inconsistencies in the Delphi process, which may possibly result from the absence of a universally recognized methodology to guide research practice. Mitroff and Turoff (2002) argue that there is no single or best philosophical basis that underpins Delphi. However, the stance adopted in research is more than simply philosophical interest, as it influences application, and therefore results. The absence of an appropriate philosophical foundation will result in inconsistent conceptualizations, with potential for poor research practice and less convincing results (Gorman, 2011; McGregor & Murnane, 2010). The philosophical awareness of researchers strengthens the intellectual consistency and rigor of research processes and the value of findings. Reflection on the aim of the research activity is necessary to select and justify the approach adopted in any study. Attention to philosophical issues is particularly critical when several competing approaches are possible, and choice of approach should be guided by scrutiny of the underlying philosophical assumptions (Hammersley, 2011).
## Table II. Charting the scoping review results.

<table>
<thead>
<tr>
<th>Author et al.</th>
<th>Year</th>
<th>Title</th>
<th>Journal</th>
<th>Aim</th>
<th>Methodological comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brody et al.</td>
<td>2012</td>
<td>Identifying components of advanced-level clinical nutrition practice: A Delphi study</td>
<td>Journal of The Academy of Nutrition and Dietetics, 112(6), 859–869</td>
<td>The purpose of this research was to gain expert consensus on the essential characteristics and activities that define an advanced practice registered dietitian who provides clinical nutrition care to patients or clients</td>
<td>Delphi is described as “deriving quantitative estimates through qualitative approaches”</td>
</tr>
<tr>
<td>Chan, Wey, &amp; Chang</td>
<td>2014</td>
<td>Establishing disaster resilience indicators for Tan-sui river basin in Taiwan</td>
<td>Soc Indic Res 115, 387–418</td>
<td>This paper proposes an application that combines fuzzy Delphi and analytic network process techniques in order to establish a set of disaster resilience indicators for a re-developed urban area in Tan-sui River Basin (Taiwan)</td>
<td>Delphi is referred to as a reliable qualitative research method</td>
</tr>
<tr>
<td>Diam, Laalso, Rubin, &amp; Linturi</td>
<td>2012</td>
<td>The role of regulation in the mobile operator business in Finland</td>
<td>Foresight, 14(2), 154–67</td>
<td>In this study, the authors used the Delphi method for estimating the causes and effects of laws and other regulations impacting on mobile operator business in the past few decades, and consider potential effects in the years 2010–2015</td>
<td>The authors state that Delphi research may be categorized as either quantitative or qualitative study</td>
</tr>
<tr>
<td>Hamilton, Coldwell-Neilson, &amp; Craig</td>
<td>2014</td>
<td>Development of an information management knowledge transfer framework for evidence-based occupational therapy</td>
<td>VINE: The journal of information and knowledge management systems, 44(1), 59–93</td>
<td>The purpose of this paper is to present an information management knowledge transfer (IM-KT) framework which emerged from a study looking at digital literacy in the occupational therapy profession. Phase 3 of this study used the Delphi method to explore how occupational therapy could advance as a digitally literate profession refining the conceptual framework developed over phases 1 and 2</td>
<td>Phase 3 of this research is described as using a Kantian or contributory Delphi approach</td>
</tr>
<tr>
<td>Hanekom et al.</td>
<td>2012</td>
<td>Reaching consensus on the physiotherapeutic management of patients following upper abdominal surgery: A pragmatic approach to interpret equivocal evidence</td>
<td>BMC Medical Informatics and Decision Making, 12, 5</td>
<td>The aim of this paper is to develop evidence-based clinical management algorithm for the management of patients following abdominal surgery through a Delphi process of consensus</td>
<td>The Delphi is identified as a pragmatic methodology</td>
</tr>
<tr>
<td>LaBelle</td>
<td>2012</td>
<td>Constructing post-carbon institutions: Assessing European Union carbon reduction efforts through an institutional risk governance approach</td>
<td>Energy Policy 40, 390–403</td>
<td>This paper examines three different governance approaches the European Union and member states are relying on to reach a low carbon economy by 2050</td>
<td>The authors of this Delphi study state that it relies on a qualitative grounded research approach</td>
</tr>
<tr>
<td>López-Sánchez &amp; Pulido-Fernández</td>
<td>2014</td>
<td>Incorporating sustainability into tourism policy: A strategic agenda for Spain</td>
<td>European Journal of Tourism Research, 7, 57–78</td>
<td>This paper proposes a methodology for incorporating sustainability into tourism policy. Delphi analysis was initiated, with the aim of obtaining an assessment of the major errors and problems of the current Spanish tourism policy on sustainability</td>
<td>Delphi is explained to be a forecasting technique for obtaining qualitative or subjective information, which are quantified statistically, through measures such as; mean, median, and quartiles</td>
</tr>
<tr>
<td>Author</td>
<td>Year</td>
<td>Title</td>
<td>Journal</td>
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<td>Methodological comments</td>
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<tr>
<td>Mason &amp; Nair</td>
<td>2013</td>
<td>Supply side strategic flexibility capabilities in container liner shipping</td>
<td>The International Journal of Logistics Management, 24(1), 22-48</td>
<td>The purpose of this paper is to explore the extent to which supply side flexibility tactics are deployed by operators in the container liner shipping sector in 2009/2010 to restrict supply in a market which is characterized by over-supply (as well as under demand)</td>
<td>The authors describe their study as a mixed method approach, where knowledge is supplemented throughout by a qualitative Delphi-based research methodology</td>
</tr>
<tr>
<td>McNichols</td>
<td>2010</td>
<td>Optimal knowledge transfer methods: A Generation X perspective</td>
<td>Journal of Knowledge Management, 14(1), 24-37</td>
<td>This research study seeks to explore the thoughts and perspectives of Generation X aerospace engineers regarding strategies, processes, and methods to enhance the transfer of knowledge from Baby Boomers to Generation X aerospace engineers</td>
<td>Delphi is described as a qualitative research method</td>
</tr>
<tr>
<td>Meng, Xiuwei,</td>
<td>2011</td>
<td>A theoretical framework of caring in the Chinese context: A grounded theory study</td>
<td>Journal of Advanced Nursing, 67(7), 1523-1536</td>
<td>This paper reports a study that describes the components of nurse caring in the Chinese cultural context</td>
<td>The authors state that a grounded theory research design using the Delphi method were adopted in this study</td>
</tr>
<tr>
<td>&amp; Anli</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>The authors describe this as a qualitative futures study employing the Delphi method, which empirically grounds the concept with a variety of views, perceptions, and opinions</td>
</tr>
<tr>
<td>Palo &amp; Tahtinen</td>
<td>2011</td>
<td>A network perspective on business models for emerging technology-based services</td>
<td>Journal of Business &amp; Industrial Marketing, 26(5), 377-388</td>
<td>This study seeks to identify the generic elements of a business model in the field of technology-based services and uses those elements to build a networked business model</td>
<td></td>
</tr>
<tr>
<td>Paraskevas &amp;</td>
<td>2012</td>
<td>Beyond consensus: An alternative use of Delphi enquiry in hospitality research</td>
<td>International Journal of Contemporary Hospitality Management, 24(6), 907-924</td>
<td>In this paper the authors reflect on the research methodology of a project that explored organizational crisis signals detection using Policy Delphi with a criterion sample comprising 16 senior hotel executives involved in crisis management</td>
<td>Delphi is presented as phenomenological research which relies on the elicitation and subsequent analysis of expert-participant opinion from individuals who were part of the phenomenon under study and had their own unique experiences and deep understandings of the issues of concern</td>
</tr>
<tr>
<td>Saunders</td>
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<td></td>
<td></td>
<td></td>
<td>The authors describe Delphi as a qualitative study obtaining expert opinions</td>
</tr>
<tr>
<td>Pérrula et al.</td>
<td>2012</td>
<td>Is the scale for measuring motivational interviewing skills a valid and reliable instrument for measuring the primary care professionals motivational skills?: EVEM study protocol</td>
<td>BMC Family Practice, 13, 112</td>
<td>The researchers in this project try to test the hypothesis that a tool called “Assessment Scale motivational interviewing” (EVEM in Spanish) designed to assess whether the Spanish doctors have MI skills to promote in their patients behavioural changes have good psychometric properties, in terms of validity and reliability</td>
<td></td>
</tr>
<tr>
<td>Author</td>
<td>Year</td>
<td>Title</td>
<td>Journal</td>
<td>Aim</td>
<td>Methodological comments</td>
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<tr>
<td>Santos &amp; Gomes</td>
<td>2010</td>
<td>Operating room information systems adoption by Portuguese clinical users</td>
<td>WSEAS Transactions on Communications, 10(9), 626–635</td>
<td>This research aims to assess the impact of the adoption of information systems by clinical users in the operating room</td>
<td>The Delphi method is presented as a method of qualitative research that aims to obtain a qualified opinion about certain issues, from a group of selected individuals</td>
</tr>
<tr>
<td>Sobaih, Ritchie, &amp; Jones</td>
<td>2012</td>
<td>Consulting the oracle? Applications of modified Delphi technique to qualitative research in the hospitality industry</td>
<td>International Journal of Contemporary Hospitality Management, 24(6), 886–906</td>
<td>This paper aims to discuss the classical Delphi and its advantages and disadvantages in qualitative research, particularly in hospitality</td>
<td>The authors state that the articulation, interpretation and testing of the experts' belief systems is the basis of the interpretivist research paradigm underpinning the Delphi technique</td>
</tr>
<tr>
<td>Tang &amp; Wu</td>
<td>2010</td>
<td>Obtaining a picture of undergraduate education quality: A voice from inside the university</td>
<td>Higher Education, 60(3), 269–286</td>
<td>This study aims to construct ranking indicators from the perspective inside of the university and shift the ranking target from overall university quality to undergraduate education quality</td>
<td>The authors state that Delphi is a methodology by which subjective data can be transformed into quasi-objective quantitative data and to facilitate decision-making of controversial issues</td>
</tr>
<tr>
<td>Traynor, Boyle, &amp; Janke</td>
<td>2013</td>
<td>Guiding principles for student leadership development in the doctor of pharmacy program to assist administrators and faculty members in implementing or refining curricula</td>
<td>American Journal of Pharmaceutical Education, 77(10), 1–10</td>
<td>To assist administrators and faculty members in colleges and schools of pharmacy by gathering expert opinion to frame, direct, and support investments in student leadership development</td>
<td>The Delphi is described as a qualitative research technique that requests and refines the collective thoughts and opinions of a panel of experts</td>
</tr>
<tr>
<td>Van Kemenade, Hardjono, &amp; De Vries</td>
<td>2011</td>
<td>The willingness of professionals to contribute to their organization’s certification</td>
<td>International Journal of Quality &amp; Reliability Management, 28(1), 27–42</td>
<td>This paper seeks to find out which factors influence the willingness of professionals to contribute to a certification process and to understand the rationale behind this willingness</td>
<td>The Delphi is described as a qualitative research technique</td>
</tr>
<tr>
<td>Wilson</td>
<td>2011</td>
<td>New-school brand creation and creativity—Lessons from Hip Hop and the global branded generation</td>
<td>Journal of Brand Management, 19(2), 91–111</td>
<td>The stated aim of this paper is to report an Expert Delphi study which aims to present a new hip hop inspired model for brand creation; and second to offer an innovative approach to in depth qualitative studies, using “word cloud” software</td>
<td>Delphi offers a method by which a consensus of understanding can be reached in a wider context using a cyclical hermeneutical approach to qualitative opinion-based feedback</td>
</tr>
</tbody>
</table>
Hermeneutics has been interpreted in multiple ways, and the understanding or interpretation fundamental to study for all humanistic disciplines is not without contention. Several philosophies have been suggested in association with Delphi to provide a foundation which meets each researcher’s unique needs, including those represented by Locke, Leibniz, Kant, Hegel, and Singer (Mitroff & Turoff, 2002). Yet the results of our scoping review suggest that these philosophies do not meet the need of many researchers, as illustrated by the paucity of researchers who identify the methodological stance of their work. We seek to promote adoption of a framework that we consider supports the core principles of the Delphi method, to maintain research integrity.

The classic Delphi method has been described as juxtaposed between positivist and naturalistic paradigms (Hasson & Keeney, 2011). Others disagree, arguing that although analysis of results for each round may require qualitative coding or statistical summarizing (Skulmoski et al., 2007; Sobaih, Ritchie, & Jones, 2012), this process should not be perceived as transforming subjective opinion into objective data. Delphi is essentially a heuristic method, which utilizes expert opinion, experience, intuition, and tacit knowledge (Bartlett & Payne, 2013). These qualities are frequently associated with exemplary healthcare practice (Christensen & Hewitt-Taylor, 2005; Lynneham, Parkinson, & Denholm, 2008; Pretz & Folse, 2011). The research method does not result in quantitative facts, but rather the combined perspectives of experts who have knowledge of the topic and have had the opportunity to interact in ways that might be meaningful and enlightening (Cousien et al., 2014; Elkington & Lotter, 2013). The emphasis on developing understanding through the cyclical hermeneutical approach identified by Wilson (2011) through the scoping activity presents a valuable insight in the quest to identify a methodological framework for Delphi research.

Hermeneutics

Hermeneutics is the science of interpretation (Gerber & Moyle, 2004). It is the study of understanding, to decipher meaning, and hermeneutic principles are fundamental to study for all humanistic disciplines (Palmer, 1969). The understanding or interpretation of hermeneutics itself is not without contention. Hermeneutics has been interpreted in multiple ways over time, from the theory of critical explanation of historical religious texts, to systems of interpretation. Two basic schools of thought have divided hermeneutic understanding. Hermeneutics in the tradition of Dilthey and Schleiermacher is considered as providing methodological principles for objective interpretation, whereas in the tradition of Heidegger and Gadamer hermeneutics represented ontology of relativity (Palmer, 1969). Heidegger and Gadamer uphold the view that the interpretation made by a “historian” or researcher is influenced by their pre-understandings. More simply, interpretation is necessarily subjective, as interpreter influence on the interpretation is acknowledged. Heidegger associated hermeneutics with phenomenology, and emphasized self-consciousness and the primary function of words in creating understanding, or the ontology of language. Gadamer further developed this ontological concept through his efforts in establishing hermeneutics as ontology of the event of understanding (Gadamer, 1989).

Gadamer’s focus was not on processes to facilitate understanding, but rather on how understanding is shaped through the experience of exposure to text or art. Gadamer specifically noted the problematic position of healthcare in relation to the art of healing. He acknowledged the role of science, particularly in relation to medical technology and technical skill, yet argued that the art of healing comes from understanding generated through recognizing the person, not simply focusing on their body or body part. Gadamer asserted that healing is achieved through focusing on the individual and their unique situation and experience, rather than the “case” (Gadamer, 1996). The art of healthcare occurs through understanding, and similarly when understanding text and art, this occurs through engaging with a medium which causes questioning of self-understanding.

Gadamer considered understanding as a historical, dialectical, and linguistic experience. He rejected ideas of the objective subjective binary, as all human understanding is subjective (Gadamer, 1989). The concept of bracketing, as proposed by some, is discounted by Gadamer. Understanding is necessarily contextualized. Although a person may attempt to be objective, their understanding is shaped by the history of their personal knowledge and experience. Yet, new knowledge cannot emerge if the old is not challenged; therefore, an attitude of openness and interrogative communication is required. A final element of Gadamerian philosophy is that there is no final or absolute truth, when understanding is open and anticipatory. Although the Delphi research method may appear to seek consensus, it primarily seeks to facilitate the sharing of perspectives to create new shared knowledge. Therefore, we believe that...
the philosophical hermeneutics of Hans-Georg Gadamer may provide a suitable methodology to underpin this method.

**Delphi and Gadamer**

In the health and social sciences, the emphasis of contemporary Delphi research lies in gathering expert perspectives on areas of complexity where there is a lack of common understanding, and the facilitation of reflection at each stage in the process to promote mutual understanding or highlight divergence in expert opinion. Sharing perspectives via feedback of data from each survey round enables interpretation to move from the group to individual participants, and from individual participants to the group. The iterative process involved in Delphi reflects the cyclic process of Gadamer’s hermeneutic circle (Gadamer, 1989); prompting consideration of Gadamer’s work in better understanding the key processes of the Delphi method. Day and Bobeva (2005) describe Delphi as an iterative feedback method that develops insight or knowledge, which is more than the sum of the parts. Through the process of Delphi, the researcher and participants create a shared understanding of the phenomena from multiple perspectives, as each survey round is informed by those which preceded it. Gadamer (1977) proposed that proper understanding is achieved through the iterative process he described as the hermeneutic circle. The hermeneutic circle explains how understanding of what Gadamer refers to as the “whole,” is constructed through repeated consideration of its components. This is expressed in Figure 2.

![Figure 2. A Delphi Gadamerian Hermeneutic Circle, adapted from author.](image)

The hermeneutic circle depicts the process of consideration of a concept shifting between individuals and the collective, influencing the perceptions of all those involved, resulting in a shared understanding (Debesay, Nåden, & Slettebø, 2008), even when this highlights divergent views. Inherent in the process is a revision of knowledge or understanding that occurs through the process of providing feedback with each round of surveys. The role of discussion in enquiry is emphasized in Gadamerian philosophical hermeneutics (Hammersley, 2011). The process of building understanding between researcher and participants occurs in a cyclic process of interpretation, that remodels pre-existing interpretations of the phenomena being researched, co-creating meaning (Guba & Lincoln, 2005; Haverkamp & Young, 2007). The sharing of the experiences and knowledge of participants who are experts in the area of interest is a fundamental component of the Delphi method (Day & Bobeva, 2005). The development of agreement or identification of areas of disagreement, achieved through the Delphi method, demonstrates how perspectives of knowledge are shaped through interaction with others.

Researchers who work within the constructivist paradigm seek to develop an understanding of human experience through the participants’ views of the situation being studied, as reality is considered as being socially constructed and the researcher acknowledges the impact on the research of their own background and experiences (Tracy, 2012). In Gadamer’s (1977) description of philosophical hermeneutics, people bring their own cultural reference point or “traditions,” from which they seek to develop an understanding of a phenomenon. Understanding and interpretation is always influenced by one’s life’s experiences, language, culture, and history (Frankowska & Wiechula, 2011). Delphi research is typically undertaken with experts who share similar professional backgrounds. Professional groups have their own culture, developed through professional socialization, personal experiences, and beliefs, which are founded on customary assumptions about appropriate epistemological, behavioural, and normative bases of action (Laverack, 2007). Such pre-understandings or “prejudices” shape the cognitive process of developing understanding, and are inescapable (Gadamer, 1977). Being open to other perspectives and having a willingness to reconsider the prejudices or prior assumptions on which current understandings are founded is essential (Hammersley, 2011).

Gadamerian philosophy identifies a required attitude of openness to the perspectives of others, as well as a readiness to learn and accept possible differences, referred to as Bildung, as personal perspectives are
confronted and possibly altered by these different perspectives (Frankowska & Wiechula, 2011). This is addressed within the Delphi method through the structured reflexivity required of participants, when they consider the summary of feedback following each survey round. The reflexive dimension of understanding in Gadamerian philosophical hermeneutics distinguishes it from others, which focus on the “science of hermeneutics” (Linge, 1977, p. xii). The reflexive process acknowledges the “prejudices” and “traditions” that we bring with us, which cannot be “suspended” throughout the process of developing understanding, as understanding occurs through a process of mediation. Gadamer (1977) referred to this changing of perspectives as a “fusion of horizons,” which is illustrated in Figure 3.

Fusion occurs through the exchange of opinions, facilitating the expansion of one’s personal horizon through deliberately challenging understandings and the conscious integration of the horizon of the other (Gadamer, 1977, 1989; Phillips, 2007). Further strengthening the congruency between Delphi and Gadamerian hermeneutics is the argument put forward by Linstone and Turoff (2011). They maintain that Delphi is a method for structuring a group communication process, which is not aimed to produce or force consensus, but rather to facilitate collaborative learning. Therefore awareness raising and the collective and consultative process itself is equally or possibly even more important than the outcome. The Gadamerian concept referred to as the “fusion of horizon” reflects stability of opinion in Delphi, as a new understanding is reached. Stability of opinion is consistent with the concept of data saturation used in qualitative research. When no new information is emerging from the data being collected, data saturation is considered to have occurred, signifying the natural endpoint of sampling (Liamputtong & Ezzy, 2005).

We argue that Gadamerian philosophical hermeneutics provides supportive framework consistent with the aims of Delphi, as well as elaborating a rationale for clarifying the essential components of the method. Adoption of a constructivist perspective addresses many of the criticisms and perceived limitations of this method. Most of these stem from the assumption that statistical analysis of results used in Delphi implies that it is a positivist scientific enquiry, yet the recent studies identified in the scoping review and the use of Delphi across a number of health and well-being studies indicates that it is not. The explicit limitations upon transferability of the results to other contexts, needs to be acknowledged. Examining the results of the Delphi for their cogency and plausibility is considered most appropriate and useful (McIraith, Keeney, McKenna, & McLaughlin, 2010). Delphi is a research method that supports constructivist enquiry, suggesting that trustworthiness criteria used in qualitative research, of conformability, credibility, transferability, and dependability should replace the positivist criteria of objectivity, validity, and reliability (Day & Bobeva, 2005). The rigour of Delphi as a research method has been questioned in the past and this is likely to continue when methodological discussion is absent. Clarity is essential in the conduct and reporting of all research. Articulating methodology as well as method when reporting on research will positively influence research credibility. This may require additional time and space to present such arguments in publications, and require reviewers to be appropriately skilled in methodological assessment.

Conclusion

We argue that methodology remains relevant and is an essential component in conducting and reporting health and well-being research. Delphi has been demonstrated to be a versatile research method used across a range of health and well-being disciplines when the goal of research is to construct a shared opinion or understanding from a group of experts of a specific phenomenon. However, Delphi was developed at a time when methodology was not recognized as foundational to research integrity. The lack of epistemological explanation for the selection of Delphi as the appropriate method for health and well-being research is illustrated by our scoping review. This omission contributes to misconceptions, resulting in unwarranted criticisms and perceived limitations of this research method. We have tried to demonstrate how Gadamerian hermeneutics may provide a suitable methodological framework for consideration when undertaking research using this method. We believe that explicitly aligning Delphi with Gadamerian philosophy clarifies the place of Delphi in health and well-being research.

Figure 3. Gadamerian Fusion of Horizons, adapted from author.

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Santos, M., & Gomes, L. (2010). Operating room information systems adoption by portuguese clinical users. *IFIP Transactions on Communications, 9*(10), 626–635.


Methodology or method? A critical review of qualitative case study reports

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Abstract
Despite on-going debate about credibility, and reported limitations in comparison to other approaches, case study is an increasingly popular approach among qualitative researchers. We critically analysed the methodological descriptions of published case studies. Three high-impact qualitative methods journals were searched to locate case studies published in the past 5 years; 34 were selected for analysis. Articles were categorized as health and health services (n = 12), social sciences and anthropology (n = 7), or methods (n = 15) case studies. The articles were reviewed using an adapted version of established criteria to determine whether adequate methodological justification was present, and if study aims, methods, and reported findings were consistent with a qualitative case study approach. Findings were grouped into five themes outlining key methodological issues: case study methodology or method, case of something particular and case selection, contextually bound case study, researcher and case interactions and triangulation, and study design inconsistent with methodology reported. Improved reporting of case studies by qualitative researchers will advance the methodology for the benefit of researchers and practitioners.

Key words: Case studies, health research, research design, interdisciplinary research, qualitative research, literature review

Case study research is an increasingly popular approach among qualitative researchers (Thomas, 2011). Several prominent authors have contributed to methodological developments, which has increased the popularity of case study approaches across disciplines (Creswell, 2013b; Denzin & Lincoln, 2011b; Merriam, 2009; Ragin & Becker, 1992; Stake, 1995; Yin, 2009). Current qualitative case study approaches are shaped by paradigm, study design, and selection of methods, and, as a result, case studies in the published literature vary. Differences between published case studies can make it difficult for researchers to define and understand case study as a methodology.

Experienced qualitative researchers have identified case study research as a stand-alone qualitative approach (Denzin & Lincoln, 2011b). Case study research has a level of flexibility that is not readily offered by other qualitative approaches such as grounded theory or phenomenology. Case studies are designed to suit the case and research question and published case studies demonstrate wide diversity in study design. There are two popular case study approaches in qualitative research. The first, proposed by Stake (1995) and Merriam (2009), is situated in a social constructivist paradigm, whereas the second, by Yin (2012), Flyvbjerg (2011), and Eisenhardt (1989), approaches case study from a post-positivist viewpoint. Scholarship from both schools of inquiry has contributed to the popularity of case study and development of theoretical frameworks and principles that characterize the methodology.

The diversity of case studies reported in the published literature, and on-going debates about credibility and the use of case study in qualitative research practice, suggests that differences in perspectives on case study methodology may prevent researchers from developing a mutual understanding of practice and rigour. In addition, discussion about case study limitations has led some authors to query whether case study is indeed a methodology (Luck, Jackson, & Usher, 2006; Meyer, 2001; Thomas, 2010; Tight, 2010). Methodological discussion of
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Qualitative case study research is timely, and a review is required to analyse and understand how this methodology is applied in the qualitative research literature. The aims of this study were to review methodological descriptions of published qualitative case studies, to review how the case study methodological approach was applied, and to identify issues that need to be addressed by researchers, editors, and reviewers. An outline of the current definitions of case study and an overview of the issues proposed in the qualitative methodological literature are provided to set the scene for the review.

Definitions of qualitative case study research

Case study research is an investigation and analysis of a single or collective case, intended to capture the complexity of the object of study (Stake, 1995). Qualitative case study research, as described by Stake (1995), draws together “naturalistic, holistic, ethnographic, phenomenological, and biographic research methods” in a bricolage design, or in his words, “a palette of methods” (Stake, 1995, pp. xi–xii). Case study methodology maintains deep connections to core values and intentions and is “particularistic, descriptive and heuristic” (Merriam, 2009, p. 46).

As a study design, case study is defined by interest in individual cases rather than the methods of inquiry used. The selection of methods is informed by researcher and case intuition and makes use of naturally occurring sources of knowledge, such as people or observations of interactions that occur in the physical space (Stake, 1998). Thomas (2011) suggested that “analytical eclecticism” is a defining factor (p. 512). Multiple data collection and analysis methods are adopted to further develop and understand the case, shaped by context and emergent data (Stake, 1995). This qualitative approach “explores a real-life, contemporary bounded system (a case) or multiple bounded systems (cases) over time, through detailed, in-depth data collection involving multiple sources of information ... and reports a case description and case themes” (Creswell, 2013b, p. 97). Case study research has been defined by the unit of analysis, the process of study, and the outcome or end product, all essentially the case (Merriam, 2009).

The case is an object to be studied for an identified reason that is peculiar or particular. Classification of the case and case selection procedures informs development of the study design and clarifies the research question. Stake (1995) proposed three types of cases and study design frameworks. These include the intrinsic case, the instrumental case, and the collective instrumental case. The intrinsic case is used to understand the particulars of a single case, rather than what it represents. An instrumental case study provides insight on an issue or is used to refine theory. The case is selected to advance understanding of the object of interest. A collective refers to an instrumental case which is studied as multiple, nested cases, observed in unison, parallel, or sequential order. More than one case can be simultaneously studied; however, each case study is a concentrated, single inquiry, studied holistically in its own entirety (Stake, 1995, 1998).

Researchers who use case study are urged to seek out what is common and what is particular about the case. This involves careful and in-depth consideration of the nature of the case, historical background, physical setting, and other institutional and political contextual factors (Stake, 1998). An interpretive or social constructivist approach to qualitative case study research supports a transactional method of inquiry, where the researcher has a personal interaction with the case. The case is developed in a relationship between the researcher and informants, and presented to engage the reader, inviting them to join in this interaction and in case discovery (Stake, 1995). A postpositivist approach to case study involves developing a clear case study protocol with careful consideration of validity and potential bias, which might involve an exploratory or pilot phase, and ensures that all elements of the case are measured and adequately described (Yin, 2009, 2012).

Current methodological issues in qualitative case study research

The future of qualitative research will be influenced and constructed by the way research is conducted, and by what is reviewed and published in academic journals (Morse, 2011). If case study research is to further develop as a principal qualitative methodological approach, and make a valued contribution to the field of qualitative inquiry, issues related to methodological credibility must be considered. Researchers are required to demonstrate rigour through adequate descriptions of methodological foundations. Case studies published without sufficient detail for the reader to understand the study design, and without rationale for key methodological decisions, may lead to research being interpreted as lacking in quality or credibility (Hallberg, 2013; Morse, 2011).

There is a level of artistic license that is embraced by qualitative researchers and distinguishes practice, which nurtures creativity, innovation, and reflexivity (Denzin & Lincoln, 2011b; Morse, 2009). Qualitative research is “inherently multimethod” (Denzin &
Lincoln, 2011a, p. 5); however, with this creative freedom, it is important for researchers to provide adequate description for methodological justification (Meyer, 2001). This includes paradigm and theoretical perspectives that have influenced study design. Without adequate description, study design might not be understood by the reader, and can appear to be dishonest or inaccurate. Reviewers and readers might be confused by the inconsistent or inappropriate terms used to describe case study research approach and methods, and be distracted from important study findings (Sandelowski, 2000). This issue extends beyond case study research, and others have noted inconsistencies in reporting of methodology and method by qualitative researchers. Sandelowski (2000, 2010) argued for accurate identification of qualitative description as a research approach. She recommended that the selected methodology should be harmonious with the study design, and be reflected in methods and analysis techniques. Similarly, Webb and Keveryn (2000) uncovered inconsistencies in qualitative nursing research with focus group methods, recommending that methodological procedures must cite seminal authors and be applied with respect to the selected theoretical framework. Incorrect labelling using case study might stem from the flexibility in case study design and non-directional character relative to other approaches (Rosenberg & Yates, 2007). Methodological integrity is required in design of qualitative studies, including case study, to ensure study rigour and to enhance credibility of the field (Morse, 2011).

Case study has been unnecessarily devalued by comparisons with statistical methods (Eisenhardt, 1989; Flyvbjerg, 2006, 2011; Jensen & Rodgers, 2001; Piekkari, Welch, & Paavilainen, 2009; Tight, 2010; Yin, 1999). It is reputed to be the “the weak sibling” in comparison to other, more rigorous, approaches (Yin, 2009, p. xiii). Case study is not an inherently comparative approach to research. The objective is not statistical research, and the aim is not to produce outcomes that are generalizable to all populations (Thomas, 2011). Comparisons between case study and statistical research do little to advance this qualitative approach, and fail to recognize its inherent value, which can be better understood from the interpretive or social constructionist viewpoint of other authors (Merriam, 2009; Stake, 1995). Building on discussions relating to “fuzzy” (Bassey, 2001), or naturalistic generalizations (Stake, 1978), or transference of concepts and theories (Ayres, Kavanaugh, & Knafl, 2003; Morse et al., 2011) would have more relevance.

Case study research has been used as a catch-all design to justify or add weight to fundamental qualitative descriptive studies that do not fit with other traditional frameworks (Merriam, 2009). A case study has been a “convenient label for our research”—when we ‘can’t think of anything ‘better’”—in an attempt to give it [qualitative methodology] some added respectability” (Tight, 2010, p. 337). Qualitative case study research is a pliable approach (Merriam, 2009; Meyer, 2001; Stake, 1995), and has been likened to a “curious methodological limbo” (Gerring, 2004, p. 341) or “paradigmatic bridge” (Luck et al., 2006, p. 104), that is on the borderline between postpositivist and constructionist interpretations. This has resulted in inconsistency in application, which indicates that flexibility comes with limitations (Meyer, 2001), and the open nature of case study research might be off-putting to novice researchers (Thomas, 2011). The development of a well-(in)formed theoretical framework to guide a case study should improve consistency, rigour, and trust in studies published in qualitative research journals (Meyer, 2001).

Methods

Assessment of rigour

The purpose of this study was to analyse the methodological descriptions of case studies published in qualitative methods journals. To do this we needed to develop a suitable framework, which used existing, established criteria for appraising qualitative case study research rigour (Creswell, 2013b; Merriam, 2009; Stake, 1995). A number of qualitative authors have developed concepts and criteria that are used to determine whether a study is rigorous (Denzin & Lincoln, 2011; Lincoln, 1995; Sandelowski & Barroso, 2002). The criteria proposed by Stake (1995) provide a framework for readers and reviewers to make judgements regarding case study quality, and identify key characteristics essential for good methodological rigour. Although each of the factors listed in Stake’s criteria could enhance the quality of a qualitative research report, in Table I we present an adapted criteria used in this study, which integrates more recent work by Merriam (2009) and Creswell (2013b). Stake’s (1995) original criteria were separated into two categories. The first list of general criteria is “relevant for all qualitative research.” The second list, “high relevance to qualitative case study research,” was the criteria that we decided had higher relevance to case study research. This second list was the main criteria used to assess the methodological descriptions of the case studies reviewed. The complete table has been preserved so that the reader can determine how the original criteria were adapted.
Study design

The critical review method described by Grant and Booth (2009) was used, which is appropriate for the assessment of research quality, and is used for literature analysis to inform research and practice. This type of review goes beyond the mapping and description of scoping or rapid reviews, to include “analysis and conceptual innovation” (Grant & Booth, 2009, p. 93). A critical review is used to develop existing, or produce new, hypotheses or models. This is different to systematic reviews that answer clinical questions. It is used to evaluate existing research and competing ideas, to provide a “launch pad” for conceptual development and “subsequent testing” (Grant & Booth, 2009, p. 93).

Qualitative methods journals were located by a search of the 2011 ISI Journal Citation Reports in Social Science, via the database Web of Knowledge (see m.webofknowledge.com). No “qualitative research methods” category existed in the citation reports; therefore, a search of all categories was performed using the term “qualitative.” In Table II, we present the qualitative methods journals located, ranked by impact factor. The highest ranked journals were selected for searching. We acknowledge that the impact factor ranking system might not be the best measure of journal quality (Cheek, Garnham, & Quan, 2006); however, this was the most appropriate and accessible method available.

Search strategy

In March 2013, searches of the journals, Qualitative Health Research, Qualitative Research, and Qualitative Inquiry were completed to retrieve studies with “case study” in the abstract field. The search was limited to the past 5 years (1 January 2008 to 1 March 2013). The objective was to locate published qualitative case studies suitable for assessment using the adapted criterion. Viewpoints, commentaries, and other article types were excluded from review. Title and abstracts of the 45 retrieved articles were read by the first author, who identified 34 empirical case studies for review. All authors reviewed the 34 studies to confirm selection and categorization. In Table III, we present the 34 case studies grouped by journal, and categorized by research topic, including health sciences, social sciences and anthropology, and methods research. There was a discrepancy in categorization of one article on pedagogy and a new teaching method published in Qualitative Inquiry (Jorrín-Abellán, Rubia-Avi, Anguita-Martínez, 2013).
and position of the description in the article varied. Few studies provided an accurate description and rationale for using a qualitative case study approach. In the 34 case studies reviewed, three described a theoretical framework informed by Stake (1995), two by Yin (2009), and three provided a mixed framework informed by various authors, which might have included both Yin and Stake. Few studies described their case study design, or included a rationale that explained why they excluded or added further procedures, and whether this was to enhance the study design, or to better suit the research question. In 26 of the studies no reference was provided to principal case study authors. From reviewing the description of methods, few authors provided a description or justification of case study methodology that demonstrated how their study was informed by the methodological literature that exists on this approach.

The methodological descriptions of each study were reviewed using the adapted criteria, and the following issues were identified: case study methodology or method; case of something particular and

Table III. Outcomes of search of qualitative methods journals.

<table>
<thead>
<tr>
<th>Journal title</th>
<th>Date of search</th>
<th>Number of studies located</th>
<th>Number of full text studies extracted</th>
<th>Health sciences</th>
<th>Social sciences and anthropology</th>
<th>Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>Qualitative Health Research</td>
<td>4 Mar 2013</td>
<td>18</td>
<td>16</td>
<td>Barone (2010); Bronken et al. (2012); Colón-Emeric et al. (2010); Fourie and Theron (2012); Gallagher et al. (2013); Gillard et al. (2011); Hooghe et al. (2012); Jackson et al. (2012); Ledderer (2011); Mawn et al. (2010); Roscigno et al. (2012); Ryttberström et al. (2013)</td>
<td>Nil</td>
<td>Austin, Park, and Goble (2008); Broyles, Rodriguez, Price, Bayliss, and Sevick (2011); De Haene et al. (2010); Fincham et al. (2008)</td>
</tr>
<tr>
<td>Qualitative Inquiry</td>
<td>4 Mar 2013</td>
<td>16</td>
<td>11</td>
<td>Nil</td>
<td>Buzzanell and D’Enbeau (2009); D’Enbeau et al. (2010); Nagar-Ron and Motzafi-Haller (2011); Snyder-Young (2011); Yeh (2013)</td>
<td>Buckley and Waring (2013); Cunsolo Willox et al. (2013); Edwards and Weller (2012); Gratton and O’Donnell (2011); Sumson (2013)</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>45</td>
<td>34</td>
<td>12</td>
<td>7</td>
<td>15</td>
</tr>
</tbody>
</table>
case report; contextually bound case study; researcher and case interactions and triangulation; and, study design inconsistent with methodology. An outline of how the issues were developed from the critical review is provided, followed by a discussion of how these relate to the current methodological literature.

Case study methodology or method

A third of the case studies reviewed appeared to use a case report method, not case study methodology as described by principal authors (Creswell, 2013b; Merriam, 2009; Stake, 1995; Yin, 2009). Case studies were identified as a case report because of missing methodological detail and by review of the study aims and purpose. These reports presented data for small samples of no more than three people, places or phenomenon. Four studies, or “case reports” were single cases selected retrospectively from larger studies (Bronken, Kirkevold, Martinsen, & Kvigne, 2012; Coltart & Henwood, 2012; Hooghe, Neimeyer, & Rober, 2012; Roscigno et al., 2012). Case reports were not a case of something, instead were a case demonstration or an example presented in a report. These reports presented outcomes, and reported on how the case could be generalized. Descriptions focussed on the phenomena, rather than the case itself, and did not appear to study the case in its entirety.

Case reports had minimal in-text references to case study methodology, and were informed by other qualitative traditions or secondary sources (Adamson & Holloway, 2012; Buzzanell & D’Enbeau, 2009; Nagar-Ron & Motzafi-Haller, 2011). This does not suggest that case study methodology cannot be multimethod, however, methodology should be consistent in design, be clearly described (Meyer, 2001; Stake, 1995), and maintain focus on the case (Creswell, 2013b).

To demonstrate how case reports were identified, three examples are provided. The first, Yeh (2013) described their study as, “the examination of the emergence of vegetarianism in Victorian England serves as a case study to reveal the relationships between boundaries and entities” (p. 306). The findings were a historical case report, which resulted from an ethnographic study of vegetarianism. Cunsolo Willox, Harper, Edge, ‘My Word’: Storytelling and Digital Media Lab, and Rigolet Inuit Community Government (2013) used a “case study that illustrates the usage of digital storytelling within an Inuit community” (p. 130). This case study reported how digital storytelling can be used with indigenous communities as a participatory method to illuminate the benefits of this method for other studies. This “case study was conducted in the Inuit community” but did not include the Inuit community in case analysis (Cunsolo Willox et al., 2013, p. 130). Bronken et al. (2012) provided a single case report to demonstrate issues observed in a larger clinical study of aphasia and stroke, without adequate case description or analysis.

Case study of something particular and case selection

Case selection is a precursor to case analysis, which needs to be presented as a convincing argument (Merriam, 2009). Descriptions of the case were often not adequate to ascertain why the case was selected, or whether it was a particular exemplar or outlier (Thomas, 2011). In a number of case studies in the health and social science categories, it was not explicit whether the case was of something particular, or peculiar to their discipline or field (Adamson & Holloway, 2012; Bronken et al., 2012; Colón-Emeric et al., 2010; Jackson, Botelho, Welch, Joseph, & Tennstedt, 2012; Mawn et al., 2010; Snyder-Young, 2011). There were exceptions in the methods category (Table III), where cases were selected by researchers to report on a new or innovative method. The cases emerged through heuristic study, and were reported to be particular, relative to the existing methods literature (Ajodhia-Andrews & Berman, 2009; Buckley & Waring, 2013; Cunsolo Willox et al., 2013; De Haene, Grietens, & Verschueren, 2010; Gratton & O’Donnell, 2011; Sumson, 2013; Wimpenny & Savin-Baden, 2012).

Case selection processes were sometimes insufficient to understand why the case was selected from the global population of cases, or what study of this case would contribute to knowledge as compared with other possible cases (Adamson & Holloway, 2012; Bronken et al., 2012; Colón-Emeric et al., 2010; Jackson et al., 2012; Mawn et al., 2010). In two studies, local cases were selected (Barone, 2010; Fourie & Theron, 2012) because the researcher was familiar with and had access to the case. Possible limitations of a convenience sample were not acknowledged. Purposeful sampling was used to recruit participants within the case of one study, but not of the case itself (Gallagher et al., 2013). Random sampling was completed for case selection in two studies (Colón-Emic et al., 2010; Jackson et al., 2012), which has limited meaning in interpretive qualitative research.

To demonstrate how researchers provided a good justification for the selection of case study approaches, four examples are provided. The first, cases of residential care homes, were selected because of reported occurrences of mistreatment, which included residents being locked in rooms at
night (Rytterström, Unosson, & Arman, 2013). Roscigno et al. (2012) selected cases of parents who were admitted for early hospitalization in neonatal intensive care with a threatened preterm delivery before 26 weeks. Hooghe et al. (2012) used random sampling to select 20 couples that had experienced the death of a child; however, the case study was of one couple and a particular metaphor described only by them. The final example, Coltart and Henwood (2012), provided a detailed account of how they selected two cases from a sample of 46 fathers based on personal characteristics and beliefs. They described how the analysis of the two cases would contribute to their larger study on first time fathers and parenting.

**Contextually bound case study**

The limits or boundaries of the case are a defining factor of case study methodology (Merriam, 2009; Ragin & Becker, 1992; Stake, 1995; Yin, 2009). Adequate contextual description is required to understand the setting or context in which the case is revealed. In the health category, case studies were used to illustrate a clinical phenomenon or issue such as compliance and health behaviour (Colón-Emeric et al., 2010; D’Enbeau, Buzzanell, & Duckworth, 2010; Gallagher et al., 2013; Hooghe et al., 2012; Jackson et al., 2012; Roscigno et al., 2012). In these case studies, contextual boundaries, such as physical and institutional descriptions, were not sufficient to understand the case as a holistic system, for example, the general practitioner (GP) clinic in Gallagher et al. (2013), or the nursing home in Colón-Emeric et al. (2010). Similarly, in the social science and methods categories, attention was paid to some components of the case context, but not others, missing important information required to understand the case as a holistic system (Alexander, Moreira, & Kumar, 2012; Buzzanell & D’Enbeau, 2009; Nairn & Panelli, 2009; Wimpenny & Savin-Baden, 2012).

In two studies, vicarious experience or vignettes (Nairn & Panelli, 2009) and images (Jorrín-Abellán et al., 2008) were effective to support description of context, and might have been a useful addition for other case studies. Missing contextual boundaries suggests that the case might not be adequately defined. Additional information, such as the physical, institutional, political, and community context, would improve understanding of the case (Stake, 1998). In Boxes 1 and 2, we present brief synopses of two studies that were reviewed, which demonstrated a well bounded case. In Box 1, Ledderer (2011) used a qualitative case study design informed by Stake’s tradition. In Box 2, Gillard, Witt, and Watts (2011) were informed by Yin’s tradition. By providing a brief outline of the case studies in Boxes 1 and 2, we demonstrate how effective case boundaries can be constructed and reported, which may be of particular interest to prospective case study researchers.

**Researcher and case interactions and triangulation**

Researcher and case interactions and transactions are a defining feature of case study methodology (Stake, 1995). Narrative stories, vignettes, and thick description are used to provoke vicarious experience and a sense of being there with the researcher in their interaction with the case. Few of the case studies reviewed provided details of the researcher’s relationship with the case, researcher–case interactions, and how these influenced the development of the case study (Buzzanell & D’Enbeau, 2009; D’Enbeau et al., 2010; Gallagher et al., 2013; Gillard et al., 2011; Ledderer, 2011; Nagar-Ron & Motzafi-Haller, 2011). The role and position of the researcher needed to be self-examined and understood by readers, to understand how this influenced interactions.
Box 2. Article synopsis of case study research using Yin’s tradition.

Gillard et al. (2011) study of camps for adolescents living with HIV/AIDS provided a good example of Yin’s interpretive case study approach. The context of the case is bounded by the three summer camps of which the researchers had prior professional involvement. A case study protocol was developed that used multiple methods to gather information at three data collection points coinciding with three youth camps (Teen Forum, Discover Camp, and Camp Strong). Gillard and colleagues followed Yin’s (2009) principles, using a consistent data protocol that enhanced cross-case analysis. Data described the young people, the camp physical environment, camp schedule, objectives and outcomes, and the staff of three youth camps. The findings provided a detailed description of the context, with less detail of individual participants, including insight into researcher’s interpretations and methodological decisions throughout the data collection and analysis process. Findings provided the reader with a sense of “being there,” and are discovered through constant comparison of the case with the research issues; the case is the unit of analysis. There is evidence of researcher immersion in the case, and Gillard reports spending significant time in the field in a naturalistic and integrated youth mentor role.

This case study is not intended to have a significant impact on broader health policy, although does have implications for health professionals working with adolescents. Study conclusions will inform future camps for young people with chronic disease, and practitioners are able to compare similarities between this case and their own practice (for knowledge translation). No limitations of this article were reported. Limitations related to publication of this case study were that it was 20 pages long and used three tables to provide sufficient description of the camp and program components, and relationships with the research issue.

with participants, and to determine what triangulation is needed (Merriam, 2009; Stake, 1995).

Gillard et al. (2011) provided a good example of triangulation, comparing data sources in a table (p. 1513). Triangulation of sources was used to reveal as much depth as possible in the study by Nagar-Ron and Motzafi-Haller (2011), while also enhancing confirmation validity. There were several case studies that would have benefited from improved range and use of data sources, and descriptions of researcher–case interactions (Ajdshia-Andrews & Berman, 2009; Bronken et al., 2012; Fincham, Scourfield, & Langer, 2008; Fourie & Theron, 2012; Hooghe et al., 2012; Snyder-Young, 2011; Yeh, 2013).

Study design inconsistent with methodology

Good, rigorous case studies require a strong methodological justification (Meyer, 2001) and a logical and coherent argument that defines paradigm, methodological position, and selection of study methods (Denzin & Lincoln, 2011b). Methodological justification was insufficient in several of the studies reviewed (Barone, 2010; Bronken et al., 2012; Hooghe et al., 2012; Mawn et al., 2010; Roscigno et al., 2012; Yeh, 2013). This was judged by the absence, or inadequate or inconsistent reference to case study methodology in-text.

In six studies, the methodological justification provided did not relate to case study. There were common issues identified. Secondary sources were used as primary methodological references indicating that study design might not have been theoretically sound (Colón-Eméric et al., 2010; Coltart & Henwood, 2012; Roscigno et al., 2012; Snyder-Young, 2011). Authors and sources cited in methodological descriptions were inconsistent with the actual study design and practices used (Fourie & Theron, 2012; Hooghe et al., 2012; Jorrin-Abellán et al., 2008; Mawn et al., 2010; Ryttersström et al., 2013; Wimpenny & Savin-Baden, 2012). This occurred when researchers cited Stake or Yin, or both (Mawn et al., 2010; Ryttersström et al., 2013), although did not follow their paradigmatic or methodological approach. In 26 studies there were no citations for a case study methodological approach.

Discussion

The findings of this study have highlighted a number of issues for researchers. A considerable number of case studies reviewed were missing key elements that define qualitative case study methodology and the tradition cited. A significant number of studies did not provide a clear methodological description or justification relevant to case study. Case studies in health and social sciences did not provide sufficient information for the reader to understand case selection, and why this case was chosen above others. The context of the cases were not described in adequate detail to understand all relevant elements of the case context, which indicated that cases may have not been contextually bounded. There were inconsistencies between reported methodology, study design, and paradigmatic approach in case studies reviewed, which made it difficult to understand the study methodology and theoretical foundations. These issues have implications for methodological integrity and honesty when reporting study design, which are values of the qualitative research tradition and are ethical requirements (Wager & Kleinert, 2010a). Poorly described methodological descriptions may lead the reader to misinterpret or discredit study findings, which limits the impact of the study, and,
as a collective, hinders advancements in the broader qualitative research field.

The issues highlighted in our review build on current debates in the case study literature, and queries about the value of this methodology. Case study research can be situated within different paradigms or designed with an array of methods. In order to maintain the creativity and flexibility that is valued in this methodology, clearer descriptions of paradigm and theoretical position and methods should be provided so that study findings are not undervalued or discredited. Case study research is an interdisciplinary practice, which means that clear methodological descriptions might be more important for this approach than other methodologies that are predominantly driven by fewer disciplines (Creswell, 2013b).

Authors frequently omit elements of methodologies and include others to strengthen study design, and we do not propose a rigid or purist ideology in this paper. On the contrary, we encourage new ideas about using case study, together with adequate reporting, which will advance the value and practice of case study. The implications of unclear methodological descriptions in the studies reviewed were that study design appeared to be inconsistent with reported methodology, and key elements required for making judgements of rigour were missing. It was not clear whether the deviations from methodological tradition were made by researchers to strengthen the study design, or because of misinterpretations. Morse (2011) recommended that innovations and deviations from practice are best made by experienced researchers, and that a novice might be unaware of the issues involved with making these changes. To perpetuate the tradition of case study research, applications in the published literature should have consistencies with traditional methodological constructions, and deviations should be described with a rationale that is inherent in study conduct and findings. Providing methodological descriptions that demonstrate a strong theoretical foundation and coherent study design will add credibility to the study, while ensuring the intrinsic meaning of case study is maintained.

The value of this review is that it contributes to discussion of whether case study is a methodology or method. We propose possible reasons why researchers might make this misinterpretation. Researchers may interchange the terms method and methodology, and conduct research without adequate attention to epistemology and historical tradition (Carter & Little, 2007; Sandelowski, 2010). If the rich meaning that naming a qualitative methodology brings to the study is not recognized, a case study might appear to be inconsistent with the traditional approaches described by principal authors (Creswell, 2013a; Merriam, 2009; Stake, 1995; Yin, 2009). If case studies are not methodologically and theoretically situated, then they might appear to be a case report.

Case reports are promoted by university and medical journals as a method of reporting on medical or scientific cases; guidelines for case reports are publicly available on websites (http://www.hopkinsmedicine.org/institutional_review_board/guidelines_policies/guidelines/case_report.html). The various case report guidelines provide a general criteria for case reports, which describes that this form of report does not meet the criteria of research, is used for retrospective analysis of up to three clinical cases, and is primarily illustrative and for educational purposes. Case reports can be published in academic journals, but do not require approval from a human research ethics committee. Traditionally, case reports describe a single case, to explain how and what occurred in a selected setting, for example, to illustrate a new phenomenon that has emerged from a larger study. A case report is not necessarily particular or the study of a case in its entirety, and the larger study would usually be guided by a different research methodology.

This description of a case report is similar to what was provided in some studies reviewed. This form of report lacks methodological grounding and qualities of research rigour. The case report has publication value in demonstrating an example and for dissemination of knowledge (Flanagan, 1999). However, case reports have different meaning and purpose to case study, which needs to be distinguished. Findings of our review suggest that the medical understanding of a case report has been confused with qualitative case study approaches.

In this review, a number of case studies did not have methodological descriptions that included key characteristics of case study listed in the adapted criteria, and several issues have been discussed. There have been calls for improvements in publication quality of qualitative research (Morse, 2011), and for improvements in peer review of submitted manuscripts (Carter & Little, 2007; Jasper, Vaismoradi, Bondas, & Turunen, 2013). The challenging nature of editor and reviewers responsibilities are acknowledged in the literature (Hames, 2013; Wager & Kleinert, 2010b); however, review of case study methodology should be prioritized because of disputes on methodological value.

Authors using case study approaches are recommended to describe their theoretical framework and methods clearly, and to seek and follow specialist methodological advice when needed (Wager & Kleinert, 2010a). Adequate page space for case...
study description would contribute to better publications (Gillard et al., 2011). Capitalizing on the ability to publish complementary resources should be considered.

Limitations of the review

There is a level of subjectivity involved in this type of review and this should be considered when interpreting study findings. Qualitative methods journals were selected because the aims and scope of these journals are to publish studies that contribute to methodological discussion and development of qualitative research. Generalist health and social science journals were excluded that might have contained good quality case studies. Journals in business or education were also excluded, although a review of case studies in international business journals has been published elsewhere (Piekkari et al., 2009).

The criteria used to assess the quality of the case studies were a set of qualitative indicators. A numerical or ranking system might have resulted in different results. Stake's (1995) criteria have been referenced elsewhere, and was deemed the best available (Creswell, 2013b; Crowe et al., 2011). Not all qualitative studies are reported in a consistent way and some authors choose to report findings in a narrative form in comparison to a typical biomedical report style (Sandelowski & Barroso, 2002), if misinterpretations were made this may have affected the review.

Conclusion

Case study research is an increasingly popular approach among qualitative researchers, which provides methodological flexibility through the incorporation of different paradigmatic positions, study designs, and methods. However, whereas flexibility can be an advantage, a myriad of different interpretations has resulted in critics questioning the use of case study as a methodology. Using an adaptation of established criteria, we aimed to identify and assess the methodological descriptions of case studies in high impact, qualitative methods journals. Few articles were identified that applied qualitative case study approaches as described by experts in case study design. There were inconsistencies in methodology and study design, which indicated that researchers were confused whether case study was a methodology or a method. Commonly, there appeared to be confusion between case studies and case reports. Without clear understanding and application of the principles and key elements of case study methodology, there is a risk that the flexibility of the approach will result in haphazard reporting, and will limit its global application as a valuable, theoretically supported methodology that can be rigorously applied across disciplines and fields.

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Using Blogs as a Qualitative Health Research Tool: A Scoping Review

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Abstract
The global increase in and prevalence of social media is stimulating interest in the utilisation of blogs for research purposes. There is, however, a significant lack of information about the manner and scope of blog use in health research. In this scoping review, we aimed to identify how blogs are being used in health research to date and whether blogging has potential as a useful qualitative tool for data collection. Our purpose was to summarize the extent, range, and nature of research activity using blogs. In our scoping review key search terms were developed and applied to selected databases with 44 relevant studies identified. Studies were examined for the inclusion of blog use in their methods and descriptions of the manner in which they were used. While blogs were used in a variety of ways, the majority of identified studies used blogs for data collection, mostly as one method within a set of data collection methods and primarily for gathering information about experiences, perceptions, and feelings. We identified themes related to the blog's function, the health issue or topic focus, and sampling categories. Our review demonstrated that blogs have potential as a qualitative health research tool for a range of purposes, including data collection. Blogs have particular application for researchers accessing populations beyond their physical reach. Given the global commitment to research for improvements to health and health equity, this review is an essential first step to embark on future qualitative health research using blogs.

Keywords
blogs, health research, qualitative research, qualitative methods, data collection

This article reports on a scoping review of peer-reviewed literature that describes the use of blogs in health research. As the use of social media becomes commonplace, interest in the utilization of blogs for research is growing. The extent to which blogs are being used as a research tool by health researchers is, however, unclear. Our interest is in understanding how blogs are being used in health research and whether blogging has potential as a useful qualitative tool for data collection. By summarizing the extent, range, and nature of research activity using blogs, our aim is to identify what is known about the use of blogs in qualitative health research. This review is an essential first step from which to embark on future qualitative health research using blogs.

Background
New and emerging communication technologies offer a multitude of opportunities for researchers undertaking qualitative research (Rathi & Given, 2010). Qualitative research methods that have developed from new technologies include email and instant messaging interviews and on-line focus groups using Voice Over Internet Protocol (VoIP) such as Skype™ (Karpf, 2012; Redlich-Amirav & Higginbottom, 2014). Examples of recent studies that have utilised emerging web based technologies include a study exploring lifestyle factors using email interviews with five participants (Bowden & Galindo-Gonzalez, 2015), conducting instant messaging interviews on menopausal transition with 20 participants (Pearce, Thøgersen-Ntoumani, & Duda, 2014), using Skype™ to interview 15 mental health nurses about their mental health and wellbeing (Oates, 2015), and live video conferencing software to conduct interviews for triangulation of data (Glassmeyer & Dibbs, 2012). In other studies focus groups were conducted using an on-line bulletin-board style website with eighty participants on the topic of sexual decision making among gay and bisexual men.

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(DuBois et al., 2015) and an online password-protected discussion board was used with thirty-three participants with Multiple Sclerosis to document their needs and experiences in relation to health information (Synnot, Hill, Summers, & Taylor, 2014).

There is increasing interest in the use of another new technology in research, that is, social media. Lupton (2014) describes the use of social media in recruiting study participants, disseminating study findings, conducting ethnographic research and recording information within wide-ranging discourses. Recent studies that use social media in qualitative research include online forums using Twitter, for example, to capture the eating behaviours of young adults (Hingle et al., 2013) and utilising Facebook as a fieldwork site where geographers undertook collaborative story telling with participants (De Jong, 2015).

The Development of Blogs as Social Media

Within an evolving array of qualitative methods using social media there are increasing numbers of studies using Blog technology. A blog is a type of social media within the Web 2.0 platform. Having developed from the more static, one-way communication of its precursor, Web 1.0, and with similar underlying technology as a website, the distinguishing features of Web 2.0 are interactivity and constant change with an emphasis on the centrality of users (Ackland, 2013; Hamm et al., 2013; Snee, 2008). Technically, there is little difference between a static webpage and a blog, other than the way the site is used (Ackland, 2013). Blogs can be created and authored by individuals who have relatively basic Internet skills using blogging platforms such as WordPress and Blogger (Hookway, 2008).

Blogs provide a medium for incorporating various forms of content for use in different ways and purposes. They provide a "fluid" format for participating in the public sphere (Siles, 2011). A blog author "posts" a written passage or graphic on a blog, with readers leaving a comment on the same page within a space designated for this purpose (Hookway, 2008; Poore, 2014). The entries are listed in reverse chronological order and can be archived allowing researchers to map the development of a theme through the conversations surrounding it (Ackland, 2013; Harricharan & Bhopal, 2014; Hookway, 2008).

In 2015, some recent examples of blog use in research include:- a study of women’s experiences of surfing culture through a blog produced for the research in which data collected from the blog (published posts and stories) were used to supplement field notes (Olive, McCuaig, & Phillips, 2015); and a study utilising blogs for data collection and as a structured space for prompted reflections where 55 undergraduate research students recorded their thoughts and experiences about their research (Wilson, Howitt, & Higgins, 2015).

Blogging emerged in the 1990s in response to communities of Internet users who used the Internet for recording information in three different ways: online diaries, journals for personal publishing, and the weblog. The term ‘weblog’ was coined in 1997 by a computer programmer, Barger, who used the term to compile a library of frequently updated URLs (uniform resource locators) (Siles, 2011; Walker-Rettberg, 2013). Early weblog users were focused on results of online exploration: technological developments in Internet and web design, and discussion about the weblog as a website (Siles, 2011; Walker-Rettberg, 2013).

An early interface design feature was the posting of most recent updates above previous ones, creating a reverse chronological order (Siles, 2011). This feature distinguished weblogs from online diaries and personal publishing websites. In the early 2000s, diaries and personal publishing combined with blogs, leading to a marked increase in entries related to personal issues (Siles, 2011). The popularity of blogs was reflected in the drop in United States daily readership of newspapers from 52.6% of adults in 1990 to 37.5% in 2000 (Goldman, 2008). Blogs continued to evolve from a medium for passive online reading to the activity of writing, making their way into the researcher’s repertoire of research methods to explore daily life in new and interesting ways (Chenail, 2011; Goldman, 2008; Snee, 2008).

The Use of Blogs in Research

Much of the use of blogs in research has involved the collection of data through the use of web crawlers to track permalinks and blogroll links (Ackland, 2013). Permalinks are made when a blogger refers to, or comments on another blog or website, while blogroll links sit to one side of a blog page and not within a blog post. Permalinks are more useful to researchers because they reflect up-to-date reading habits of the blogger pointing out connections between bloggers (Ackland, 2013). One of the aims of blog research is to identify linkages made in a specific time period to track, for example, how an issue moves from its origin to the wider blogosphere (Ackland, 2013). There are several aspects of blogs and blogging that could be beneficial for use in research such as accessibility of mobile technology (smartphones, smart watches, tablets, and laptops) that enable populations otherwise geographically or socially removed from the researcher to be accessible anywhere, any time. There is the potential for individuals to communicate in previously inaccessible spaces (Goldman, 2008; Hookway, 2008). The majority of blogs are characterised by reflective, descriptive, interpretive and exploratory content and therefore align with common qualitative methodologies (Denzin & Lincoln, 2011). Blogs can enable participant voices to be captured and disseminated close to their vernacular intent. There is an added advantage for those wishing to be totally anonymous in their writing or responses.

Researchers have identified transparency as a potential benefit of blogging (Moravcsik, 2014; Tracy, 2010) with blogs contributing to an audit trail. They can provide clarity about
the research process and enable challenges and shifts in the study over time to be easily documented. Researchers argue that the diary style of blogs might be conducive to spontaneous and candid writing about participant experiences, and the facility for archiving entries might enable the examination of social processes over time (Hookway, 2008).

Blog entries have been described as naturalistic data in textual form, enabling the creation of substantial amounts of instant text, plus images and links without the resource intensiveness of tape recording and transcription (Hookway, 2008). Blog site statistics, offered by the blog-hosting site, enable researchers to track blogging activity over time and across geographical areas (Hookway, 2008).

Problematic aspects of blogs for research include ethical considerations around data use and anonymity, consent, privacy, authenticity, and sampling (Ackland, 2013; Rathi & Given, 2010). It has been argued that blogging can be disorientating, time-consuming and overwhelming as people learn to navigate and interact in the blogging environment (Hookway, 2008). Establishing a blog site can be time consuming and does require some level of skill. Researchers have highlighted limitations of using blogs for research when seeking to recruit participants with specific demographic or personality traits (Hookway, 2008; Rathi & Given, 2010). For instance, response rates may be low, and prolonged engagement time with participants may be difficult (Hookway, 2008; Rathi & Given, 2010). Questions have arisen around privacy of blog data and informed consent for its use in research (Ackland, 2013). It can be argued that blog posts are private content in the public domain and are therefore “fair game” (Ackland, 2013). However, the ethical issue of informed consent for use of publicly available private material remains, particularly as the division between the two domains is obscure (Ackland, 2013; Lunney, Borlagdan, McNaughton, & Ward, 2014).

Anonymity of blogging can raise issues about whether material is authentic and true as a consequence of deliberate identity manipulation and deception (Ackland, 2013). Although, as Hookway (2008) points out, these circumstances are not unique to online research and manipulating the truth can occur in other research scenarios such as surveys and face-to-face interviews or focus groups. The lack of geographic points of reference to guide researchers can lead to complications in establishing a sampling framework (Li & Walejko, 2008). A major issue in blogging research identified by Agarwal and Liu (2009) is the presence of spam blogs or “splogs” which pose a risk to the quality of blog search results. The importance of minimizing risk is emphasized, particularly the ability to filter splogs (Agarwal & Liu, 2009; Li & Walejko, 2008). Sampling issues can be compounded by access to private blogs requiring permission from the blog author, and the presence of a large number of abandoned blogs (Li & Walejko, 2008).

Internet users globally have increased 10-fold between 1999 and 2013 reaching three billion in 2014, and in early 2015, 40% of the population had access to the Internet (Internet Live Stats, 2015). When the number of Internet users globally is considered alongside the asynchronous nature of blogging, the participation potential increases, with participation being at the convenience of the research participant. Researchers argue that blogging could serve as a low-cost, global and instantaneous data collection tool for health research capturing data either at a certain point in time or across space and time (Hookway, 2008; Webb & Wang, 2013). With over two million blog posts written each day (Internet Live Stats, 2015), and the global aim of research committed to contributing to improving health and health equity (World Health Organization, 2013), we believe it is important to better understand the place of blogs in health research.

Study Design
In this study, we utilized Arksey and O’Malley’s (2005) five stage scoping review framework for its rigor and suitability for answering our research question (Daudt, Van Mossel, & Scott, 2013; Kastner et al., 2012). The five stages include identifying the research question, identifying relevant studies, study selection, charting the data and collating, and summarizing and reporting the results.

Our broad research question to maximise the scope of our mapping was: “What is known about the use of blogs in health research?” In defining health research, we used the definition of the World Health Organization’s Health Systems Research Analysis, “… the advancement of scientific knowledge and utilization of knowledge to improve health and health equity” (World Health Organization, 2014). We used the search terms “health research” AND (blog* OR weblog OR “Web 2.0”) in six databases; ProQuest Central, Ovid, Scopus, Web of Science, CINAHL, and PubMed. We were interested in peer-reviewed publications written in English and published between 2000 and 2014. The year 2000 was chosen because it was not until 1999 that user-friendly, automated blogging software became accessible (Siles, 2011). We included literature that describes the use of blogs for health research in any health discipline or topic area in any country.

The initial search resulted in 672 articles. After 96 duplicates were removed, 576 articles remained. The abstracts of the 576 articles were screened against the inclusion/exclusion criteria. Articles were removed if they did not relate to health, they described the use of blogs for purposes other than research and emphasized the Web 2.0 platform without specific reference to blog use. The full texts of 67 articles were identified and read, and a further 23 articles were excluded because their emphasis lay outside our focus criteria or the abstract had been written in English but the full text had not. A total of 44 articles were selected for review. This process is represented in the PRISMA flowchart (Fig.1). Consistent with the Arksey and O’Malley’s (2005) framework, we charted the data drawn from reviewed articles summarized in Table 1.

Findings
The final stage in Arksey and O’Malley’s (2005) framework is to collate, summarize, and report the results of the charted
literature. Themes were drawn from the reviewed studies to provide a narrative overview. Of the 44 articles that met our inclusion criteria the majority (n = 39) were published in the last five years of our search inclusion dates (2000–2014). The greatest numbers of articles were from the United States (n = 17) followed by Canada (n = 8) and Australia (n = 8). There were three (n = 3) articles from the Netherlands and the United Kingdom, and one article each from Israel, Spain, Brazil, Belgium, and Greece.

**How Blogs Were Used**

In 38 of the studies reviewed, researchers used blogs for data collection. In 11 of the included studies, data were collected from blogs in conjunction with another data source, specifically interviews (n = 3), surveys (n = 2), focus groups (n = 1), and a miscellany of sources we categorized as “Other” (n = 6). This latter category included sources such as press releases, papers and reports accessible online, websites,
## Table 1. Peer-Reviewed Articles That Report the Use of Blogs in Research.

<table>
<thead>
<tr>
<th>Author</th>
<th>Year</th>
<th>Location</th>
<th>Study Aims</th>
<th>How Are Blogs Used in the Research?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adams</td>
<td>2007</td>
<td>The Netherlands</td>
<td>Explore blogging interfaces as potential tools for disease prevention and health promotion.</td>
<td>Data collection: analysis of blog layout, content, and function; individual experiences with medical blogging.</td>
</tr>
<tr>
<td>Adams</td>
<td>2010</td>
<td>The Netherlands</td>
<td>Identify purposes for which blogging applications can be (or are being) used in relation to health.</td>
<td>Data collection: blog layout, content, and function analyzed focusing on tools for information exchange.</td>
</tr>
<tr>
<td>Beard, Wilson, Morra, and Keelan</td>
<td>2009</td>
<td>Canada</td>
<td>Survey health-related activities on Second Life—attributes and potential utility for health promotion.</td>
<td>Data collection: one of the search strategies was to search blogs for references to health related sites on Second Life.</td>
</tr>
<tr>
<td>Berger, Conway, and Beaton</td>
<td>2012</td>
<td>United States</td>
<td>Develop, implement, and evaluate a professional practice model for nursing in a large health system.</td>
<td>Data collection: discussion on blog created for nurses about their training—assess learning. Private access.</td>
</tr>
<tr>
<td>Boepple and Thompson</td>
<td>2014</td>
<td>United States</td>
<td>Examine the content found in Healthy Living blogs.</td>
<td>Data collection: a sample of 21 blogs was selected for content evaluation.</td>
</tr>
<tr>
<td>Cain and Dillon</td>
<td>2010</td>
<td>United States</td>
<td>Determine types of pharmacy blogs and discourse and impressions generated about pharmacy profession.</td>
<td>Data collection: personal views section of pharmacy-centric blogs thematically analyzed.</td>
</tr>
<tr>
<td>Caxaj and Berman</td>
<td>2010</td>
<td>Canada</td>
<td>Examine belonging and well-being among newcomer youths, foster awareness in nursing about support needs.</td>
<td>Data collection: data mining: analysis of texts from blogs.</td>
</tr>
<tr>
<td>Gillett</td>
<td>2007</td>
<td>Canada</td>
<td>Examine meanings generated about severe acute respiratory syndrome (SARS); role of sarsart.org in influencing meanings about the outbreak.</td>
<td>Data collection: transformation in function of existing blog analyzed; suggests blog utility in cultural resistance.</td>
</tr>
<tr>
<td>Graham, Rouncefield, and Satchell</td>
<td>2009</td>
<td>Australia</td>
<td>Explore how use of Nokia’s LifeBlog might work as part of an individual’s life change support program.</td>
<td>Data collection: blog used to inform development of questions for interviewing the participants—private access.</td>
</tr>
<tr>
<td>Grajales, Sheps, Ho, Novak-Lauser, and Eysenbach</td>
<td>2014</td>
<td>Canada</td>
<td>Present case studies that illustrate how, where, and why social media are used in medical and health-care sectors.</td>
<td>Data collection: data collected from award winning blogs as part of a narrative review.</td>
</tr>
<tr>
<td>Greenberg, Yaari, and Bar-Ilan</td>
<td>2013</td>
<td>Israel</td>
<td>Examine perceived credibility of blogs and medical information published in them.</td>
<td>Research object: health information blog created. Participants completed questionnaire on its credibility.</td>
</tr>
<tr>
<td>Gruzd, Black, Le, and Amos</td>
<td>2012</td>
<td>Canada</td>
<td>Investigate the relationship between biomedical literature and blogosphere discussions about diabetes.</td>
<td>Data collection: web mining—blogs analyzed for frequency of referencing biomedical literature in blogs on diabetes.</td>
</tr>
<tr>
<td>Hadgkiss et al.</td>
<td>2013</td>
<td>Australia</td>
<td>Examine health and lifestyle behaviors of people with multiple sclerosis (MS) and relationship to reported impacts.</td>
<td>Recruitment: blogs used to advertise survey, for recruitment of research participants with MS.</td>
</tr>
<tr>
<td>Hadgkiss et al.</td>
<td>2014</td>
<td>Australia</td>
<td>Explore how dietary factors are linked to health-related quality of life, disability and relapse in people with MS.</td>
<td>Recruitment: Blogs used to advertise survey, for recruitment of research participants with MS.</td>
</tr>
<tr>
<td>Hebdon et al.</td>
<td>2013</td>
<td>Australia</td>
<td>Report the protocol for a Randomized Controlled Trial aimed at testing and evaluating the TXT2BFIT program for young adults.</td>
<td>Data collection: participants were given private access to a blog on which they could post comments.</td>
</tr>
<tr>
<td>Ho</td>
<td>2011</td>
<td>Australia</td>
<td>Explore functional themes across social media relating to pregnancy.</td>
<td>Data collection: blogs identified through searches and thematically analyzed for content and function.</td>
</tr>
<tr>
<td>Hu and Sundar</td>
<td>2010</td>
<td>United States</td>
<td>Investigate effects of online health information sources on user-perceived credibility and behavioral intentions.</td>
<td>Research object: a screenshot of a blog for students to read and answer questionnaire on credibility of information.</td>
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</tbody>
</table>
Table 1. (continued)

<table>
<thead>
<tr>
<th>Author</th>
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<th>Study Aims</th>
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</thead>
<tbody>
<tr>
<td>Hughes, Joshi, and Wareham</td>
<td>2008</td>
<td>Spain</td>
<td>Establish a clear definition for Medicine 2.0 and define literature that is specific to the field.</td>
<td>Data collection: relevant blogs identified via Google searches and thematically analyzed.</td>
</tr>
<tr>
<td>Kim and Gillham</td>
<td>2013</td>
<td>Australia</td>
<td>Explore experiences and gain a better understanding of young adults affected by cancer.</td>
<td>Data collection: narratives on experience of cancer on existing blog, collected and analyzed.</td>
</tr>
<tr>
<td>Konovalov, Scotch, Post, and Brandt</td>
<td>2010</td>
<td>United States</td>
<td>Evaluate information retrieval tools to understand experiences and emotions of combat exposure of U.S. military personnel deployed during Operation Enduring Freedom and Operation Iraqi Freedom.</td>
<td>Data collection: 90 blog posts selected from military blogs; 60 blog posts were selected as a control.</td>
</tr>
<tr>
<td>Kordzadeh and Warren</td>
<td>2013</td>
<td>United States</td>
<td>Develop a typology of health 2.0 collaboration platforms and websites.</td>
<td>Data collection: information about top health related websites provided by different blogs.</td>
</tr>
<tr>
<td>Larson et al.</td>
<td>2013</td>
<td>United Kingdom</td>
<td>Develop new application of surveillance systems for early signs of vaccine issues; develop a typology of concerns.</td>
<td>Data collection: vaccine-related information collected from blogs and analyzed.</td>
</tr>
<tr>
<td>Lee, van Dolen, and Kolk</td>
<td>2013</td>
<td>The Netherlands</td>
<td>Assess food company health messages and corporate social responsibility initiatives; explore blogger reaction.</td>
<td>Data collection: blog posts coded according to opinions on initiatives announced in press releases.</td>
</tr>
<tr>
<td>Lepkowska-White and Bialkowska</td>
<td>2011</td>
<td>United States</td>
<td>Explore impact of legislation and health education on perceptions of smoking in Poland</td>
<td>Data collection: perceptions about smoking collected from one blog.</td>
</tr>
<tr>
<td>Lynch</td>
<td>2010</td>
<td>Canada</td>
<td>Describe the virtual socialization behaviors and attitudes being promoted in one community of food bloggers.</td>
<td>Data collection: behaviors and attitudes from blogs that were identified via google search and blog links.</td>
</tr>
<tr>
<td>Lynch</td>
<td>2012</td>
<td>Canada</td>
<td>Investigate discussion on food blogs that past research has identified as exhibiting characteristics of dietary restraint.</td>
<td>Data collection: from blogs that were identified via google search and blog links.</td>
</tr>
<tr>
<td>Marcus, Westra, Eastwood, and Barnes</td>
<td>2012</td>
<td>Canada</td>
<td>Analyze blogs of young adults (18–25 years of age) with mental health concerns to understand their experiences.</td>
<td>Data collection: eight blogs used for data collection to understand experience of mental health issues.</td>
</tr>
<tr>
<td>McCarroll et al.</td>
<td>2013</td>
<td>United States</td>
<td>Illustrate user characteristics of a hospital’s social media structure using analytics and user surveys.</td>
<td>Data collection: retrospective analysis of Summa Health System’s women’s health blog.</td>
</tr>
<tr>
<td>McCosker and Darcy</td>
<td>2013</td>
<td>Australia</td>
<td>Understand personal investment or labor in forming and maintaining blogs about cancer over a sustained period.</td>
<td>Data collection: personal experience posts from 24 cancer blogs.</td>
</tr>
<tr>
<td>Middleton, Bragin, and Parker</td>
<td>2014</td>
<td>United Kingdom</td>
<td>Describe use of social and traditional media, and direct invitation for recruitment to genomics study.</td>
<td>Recruitment: a purpose built blog was used for soliciting participation in a survey.</td>
</tr>
<tr>
<td>Miller and Pole</td>
<td>2010</td>
<td>United States</td>
<td>Analyze influential health blogs and bloggers to improve understanding of the health blogosphere.</td>
<td>Data collection: from 951 health blogs about characteristics of health bloggers.</td>
</tr>
<tr>
<td>Ozan-Rafferty, Johnson, Shah, and Kursun</td>
<td>2014</td>
<td>United States</td>
<td>Identify individual characteristics and experiences of health travelers to Turkey.</td>
<td>Data collection: blogs about health travel to Turkey to understand medical tourists through their own words.</td>
</tr>
</tbody>
</table>

(continued)
In addition to understanding the use of blogs in research, we found it useful to examine the function of the blogs in each of the 38 studies, researchers collected data about experiences, feelings, and perceptions of blog contributors while the remaining 17 investigated blogger behavior. The data about blogger behavior, such as self-presentation patterns, topics written by health bloggers, blog user patterns, and blogger health–related activities, were described in 16 of the studies. In two studies, blogs were used as the object being researched. In one study, the blog was purposely created for access and involved administering a questionnaire to collect data from participants related to their perceptions about the particular blog. In the other study, researchers aimed to measure the psychological effects of various online sources of health information. Screenshots of a blog and other online sources were shown to participants who then completed a questionnaire about their perceptions of the blog’s message attributes, credibility, and information completeness (Hu & Sundar, 2010).

**Blog Function**

In two studies, blogs were used as the object being researched and involved administering a questionnaire to collect data from participants related to their perceptions about the particular blog. In one of the studies, the blog was purposely created for access by research participants who were later asked to complete a questionnaire to measure their perceptions about the credibility of the blog, its author, and its message (Greenberg, Yaari, & Bar-Ilan, 2013). In the other study, researchers aimed to measure psychological effects of various online sources of health information. Screenshots of a blog and other online sources were shown to participants who then completed a questionnaire about their perceptions of the blog’s message attributes, credibility, and information completeness (Hu & Sundar, 2010).

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</thead>
<tbody>
<tr>
<td>Saiki and Cloyes</td>
<td>2014</td>
<td>United States</td>
<td>Explore self-presentation communication patterns in blog text of women living with incontinence.</td>
<td>Data collection: blog text from 19 bloggers about urinary incontinence to explore communication patterns.</td>
</tr>
<tr>
<td>Su, Howard, and Boerry</td>
<td>2011</td>
<td>Belgium</td>
<td>Explore motivations and expectations that propel individuals to purchase direct to consumer (DTC) genome-wide testing.</td>
<td>Data collection: analysis of stories of customers who purchased DTC genome-wide testing.</td>
</tr>
<tr>
<td>Valli and Cogo</td>
<td>2013</td>
<td>Brazil</td>
<td>Analyze the structure of school blogs on sexuality and their utilization by adolescents.</td>
<td>Data collection: active blogs selected—analysis of school blogs on sexuality and how they are used by adolescents.</td>
</tr>
<tr>
<td>Vozikis and Mytilinaki</td>
<td>2014</td>
<td>Greece</td>
<td>Denote increasing power of social media in health sector; propose its utility for quality improvement in health care.</td>
<td>As research object: retrospective analysis of the impact of one person’s blog on the quality of health care in Greece.</td>
</tr>
<tr>
<td>Wehbe-Alamah, Kornblau, Haderer, and Erickson</td>
<td>2012</td>
<td>United States</td>
<td>Explore the lived experiences of women with Lichen sclerosis.</td>
<td>Data collection: from three ongoing blogs for women with Lichen Sclerosis.</td>
</tr>
<tr>
<td>Weiland et al.</td>
<td>2014</td>
<td>Australia</td>
<td>Explore the association of cigarette smoking and alcohol consumption with major MS morbidity outcomes.</td>
<td>Recruitment: blogs used to recruit participants via posts about the research survey on several popular websites.</td>
</tr>
<tr>
<td>Woods</td>
<td>2013</td>
<td>United Kingdom</td>
<td>Describe and discuss how the “voice hearer” emerged as a culturally meaningful and politically charged identity.</td>
<td>Data collection: blogs were analyzed from a medical humanities perspective.</td>
</tr>
<tr>
<td>Wright and Lundy</td>
<td>2012</td>
<td>United States</td>
<td>Assess reflective thinking among graduate allied health students using a web-based collaborative blog.</td>
<td>Data collection: purpose-built blog analyzed to understand interdisciplinary international service-learning experience.</td>
</tr>
</tbody>
</table>

In all studies using blogs for recruitment to a survey ($n = 5$), blogs were not used alone but were one of a suite of social media recruitment tools. In one study (Middleton, Bragin, & Parker, 2014), a WordPress blog was designed specifically for recruiting people to a survey. Brief posts relating to the topic were written on the blog and on other websites and included links to the survey both within and alongside the text. Each blog post was advertised on LinkedIn®, Twitter®, and Facebook® where the researcher “chatted” about the blog to encourage people to link to it and then to the survey.

An online survey was distributed to subscribers of a women’s health blog in one study (McCarroll et al., 2013) and taking a different approach, another research team (Hadjkiss et al., 2013) contacted moderators of popular multiple sclerosis (MS) blogs and requested that information about a survey be posted to their websites. Two further articles, Weiland et al. (2014) and Hadgkiss et al. (2014), are derived from the Hadgkiss et al. (2013) study and relate to the same recruitment strategy.

In two studies, blogs were used as the object being researched and involved administering a questionnaire to collect data from participants related to their perceptions about the particular blog. In one of the studies, the blog was purposely created for access by research participants who were later asked to complete a questionnaire to measure their perceptions about the credibility of the blog, its author, and its message (Greenberg, Yaari, & Bar-Ilan, 2013). In the other study, researchers aimed to measure psychological effects of various online sources of health information. Screenshots of a blog and other online sources were shown to participants who then completed a questionnaire about their perceptions of the blog’s message attributes, credibility, and information completeness (Hu & Sundar, 2010).
study. Function was not specified in 20 of the 44 studies reviewed. We categorized the function of the blogs used in research within the remaining 24 studies. The blogs’ functions included provision of health information ($n = 7$), a place for support and support groups ($n = 6$), as personal health blogs ($n = 3$) and to provide education ($n = 1$). The blog function described in the remaining studies, we categorised as ‘other’.

They included a blog developed as a Virtual Journal Club for nurse education and discussion about a professional practice model for nursing (Berger, Conway, & Beaton, 2012). Pharmacy-centric blogs functioned as news, personal views, and information provision on the profession of pharmacy with the personal views blogs being analyzed to determine the impression that pharmacy websites made on the reader (Cain & Dillon, 2010). Some researchers utilized blogs whose function related to a specific topic or website. An example was the blog initiated to collect oppositional representations of the SARS (severe acute respiratory syndrome) outbreak and its social impact (Gillett, 2007) and the blog, Slashdot, which was used to investigate public perceptions regarding health literacy, within the context of discussion of proposed government regulations on acetaminophen, to guide future research in this area (MacKert, Love, Donovan-Kicken, & Uhle, 2011).

Some blogs functioned as a type of diary, that is, a place to record reflections about personal experience. Research data collected from the blogs included reflections on personal cancer experience and mental health experiences (McCosker & Darcy, 2013) and experiences of military personnel deployed to Afghanistan and Iraq (Konovalov, Scotch, Post, & Brandt, 2010). The personal blog by Amalia Klyvinou was written to document her personal malpractice experience within the Greek national health system and to show resistance (Vozikis & Mytilinaki, 2014). The associated research was a retrospective analysis of the impact of one person’s blog on the quality of health care in Greece (Vozikis & Mytilinaki, 2014).

Blogs also functioned as recruitment tools where posts were written to opportunistically direct potential research participants to a survey (Middleton et al., 2014) and as photography-based food blogs for healthy lifestyle promotion and data collection about the relationship between food and exercise (Lynch, 2012).

**Health Issue or Topic**

The health issue most represented in the studies reviewed was related to weight and healthy eating ($n = 7$) followed by emotional and mental health ($n = 4$), online health information ($n = 4$), and Web 2.0 in health ($n = 4$). Weight and healthy eating issues included unhealthy weight gain in young adults (Hebden et al., 2013), obesity and corporate social responsibility (Lee, van Dolen, & Kolk, 2013), dysfunctional eating attitudes and behaviors, or dietary restraint (Adams, 2007, 2010; Boepple & Thompson, 2014; Lynch, 2010, 2012).

Four studies focused on emotional and mental health relating to personal experience and the impact on mental health care access for young adults (Marcus, Westra, Eastwood, & Barnes, 2012), voice hearers as a meaningful identity (Woods, 2013), mental health impacts of experiences related to belonging in migrant and refugee youth (Caxaj & Berman, 2010), and experiences and emotions of combat exposure of U.S. military service members deployed during two separate Iraqi operations (Konovalov et al., 2010).

Online health information featured as the topic in four studies. These relate to understanding how people manage their personal health information in the online environment (Adams, 2007, 2010) and measuring perceptions of credibility of health information provided on blogs (Greenberg et al., 2013; Hu & Sundar, 2010).

Web 2.0 in health was the focus topic in another four studies that related more precisely to discussions about health activities on Second Life (Beard, Wilson, Morra, & Keel, 2009), use of Health 2.0 websites as health collaboration platforms (Kordzadeh & Warren, 2013) establishing a clear definition of Medicine 2.0 (Hughes, Joshi, & Wareham, 2008) and the use of social media in the medical and health-care sectors (Grajales, Sheps, Ho, Novak-Lauscher, & Eysenbach, 2014).

**Sampling Categories**

Two discernible sampling categories within our study selection were youth and women, with seven studies in each category. The studies which focused on youth, related to specific health issues, that is, sexuality (Valli & Cogo, 2013), mental health (Caxaj & Berman, 2010; Marcus et al., 2012), weight gain (Hebden et al., 2013), and cancer (Kim & Gillham, 2013). Health topics including allied health education (Wright & Lundy, 2012) and credibility of online health information (Hu & Sundar, 2010). Among the studies focusing on women, health issues discussed related to weight and healthy eating (Lynch, 2010, 2012), urinary incontinence (Saiki & Cloyes, 2014), lichen sclerosis (Wehbe-Alamah, Kornblau, Haderer, & Erickson, 2012), pregnancy (Ho, 2011), cancer (Keim-Malpass et al., 2013), and women’s health (McCarroll et al., 2013).

Country-specific sampling was used in some studies, such as smokers in Poland (Lepkowska-White & Bialkowski, 2011); people living with cancer in Australia, Canada, the United Kingdom, and the United States (McCosker & Darcy, 2013). Studies described health bloggers in the United States (Miller & Pole, 2010; Miller, Pole, & Bateman, 2011); U.S. pharmacy profession bloggers (Cain & Dillon, 2010); the Greek blogging community protesting against the Greek health system (Vozikis & Mytilinaki, 2014); people living in the Netherlands with either rare diseases or who want to lose weight (Adams, 2007, 2010); Hebrew speakers in Israel (Greenberg et al., 2013); and U.S. military service members blogging about combat experiences (Konovalov et al., 2010).

Samples in other research within the studies reviewed were targeted at topic-specific groups. The groups included people who were active in the Hearing Voices movements (Woods, 2013); people traveling to Turkey for health care
The use of blogs in qualitative health research

Our scoping review yielded 44 articles describing how blogs were used in health research. Although our search date range started at the year 2000, the 44 articles comprising our study selection were published between 2007 and 2014, suggesting that articles describing the use of blogs in health research were not published until 8 years after user-friendly, automated blogging software became accessible in 1999. Studies originated from a total of 10 countries, with the majority of studies from the United States. Most studies did not purposely create a blog for research use but used pre-existing blogs.

A common theme in the reviewed studies was the use of blogs for data collection. Rather than using blogs as a single method of collecting data, researchers are making use of blogs as one method within a suite of data collection methods and are mostly gathering information about experiences, perceptions, and feelings. A small number of studies used blogs for recruiting participants to online surveys and others used blogs as the research object, asking questions about perceived credibility of information presented in the blogs.

Some limitations of blogs were identified. The fluid and changeable nature of the “blogosphere” was recognized as a limitation that rendered the research as only a snapshot in time (Cain & Dillon, 2010; Miller & Pole, 2010; Miller et al., 2011), while sampling was seen as constrained by the impracticality of accessing large numbers of blogs and the limitations of the Google Blog search facility (Gruzd et al., 2012; Ho, 2011). Further limitations to using blogs for research were the reliance on self-reported diagnoses and information that cannot be externally validated (Keim-Malpass et al., 2013; Miller & Pole, 2010; Miller et al., 2011; Ozan-Rafferty et al., 2014), the exclusion of people without access to the Internet (Konovalov et al., 2010; Ozan-Rafferty et al., 2014), the inability to ascertain author authenticity, unreliable assessment of temporality in relation to describing experiences, and search terms retrieving irrelevant media (Konovalov et al., 2010). None of the studies commented on the usefulness of using blogs in the research.

Despite the identified limitations of researching with blogs, successful qualitative research using blogs is described in articles within our study selection. Blog characteristics align with common qualitative methodologies for gathering information about experiences, perceptions and feelings over time (Denzin & Lincoln, 2011; Hookway 2008) making blogging a useful qualitative tool for researchers (Hookway, 2008; Rathi & Given, 2010). The use of blogs as a research tool enables researchers to gain instantaneous access to distant populations (Hookway, 2008), provides research clarity and transparency with the benefit of a built-in audit trail (Moravcsik, 2014; Tracy, 2010) and circumvents the need for lengthy transcription (Hookway, 2008). For the participants, their voices can be captured and disseminated through blogs, close to their vernacular intent, with the added advantage of the choice to remain anonymous in their writing or responses.

Evolutions in qualitative methods should encourage researchers to push the boundaries by using innovative approaches that keep pace with global transformation. New communication technologies such as blogs, are a central part of contemporary global transformation, and should be considered as important in emerging qualitative research methods (Redlich-Amirav & Higginbottom, 2014). In an era characterised by new and evolving technologies, qualitative health researchers are called to capitalise on the opportunities these technologies present for local and global connection. The emergence of blogs in the broader qualitative research arena provides vast opportunities for conducting qualitative health research globally to collect richly detailed research data across a multitude of boundaries (Kenny, 2005; Redlich-Amirav & Higginbottom, 2014). Global transformation and emerging and persisting global health burdens require a research response with global capacity. In order for qualitative health research to move into this space, the knowledge and skills of researchers must progress to include blogs and other communication technologies in the design, production, management and dissemination of their research.

Conclusion

The literature examined in this scoping review suggests that the use of blogging has broadened from a social media tool to a research tool. Our review demonstrated that blogs have the potential for use as a tool for researchers in a variety of ways, including data collection, with particular application for researchers accessing populations beyond their physical reach. In health research particularly, we consider that blogs have a place within the global aim to have research making a significant contribution towards the improvement of health and health equity. The identified current repertoire of blog use in qualitative health research demonstrates its adaptive qualities and the promise that blogs hold for trialing further innovative uses for blogs in empirical qualitative health research at an international level.
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How is Community Participation Sustained in the Canadian Food Security Movement?

Case Study and Critical Analysis

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Abstract

The purpose of this study was to explore how community participation is sustained in the Canadian food movement, and to critically examine the ways in which it is sustained. Using a qualitative case study approach, data were collected via interviews, fieldwork, social media and document analysis. Case study findings illustrate how multiple methods were employed simultaneously to maximize opportunities for community participation. Sustainability was optimized by local leadership, social media platforms, and by leveraging existing capacity and building partnerships. Community participation can be sustained over the long-term using resource mobilization approaches, however, these approaches may limit grassroots legitimacy and social inclusion. Lessons learned about how community participation is sustained contribute a deeper understanding of participation for food security practitioners, policymakers, educators and researchers.

Keywords

Community participation; sustainability; food security; social movement; case study

Introduction

Community participation has become a popular platform for action on food insecurity, and in many Western countries, community food and agriculture projects are evident in many neighbourhoods (Baker, 2004; Firth, Maye, & Pearson, 2011; Litt et al., 2011; Starr, 2010). However, to address complex food security objectives (such as the United Nation’s Sustainable Development Goals), community participation must be enacted with a long term vision that encompasses sustainable actions targeting social and political change (Sachs, 2012). The myriad of challenges inherent in community participation are widely documented,
which conclude that participation processes can be difficult to sustain over the long term (Kenny, Farmer, Dickson-Swift, & Hyett, 2014; Morgan, 2001; Rifkin, 2014; Shedia-Rizkallah & Bone, 1998; Zakus & Lysack, 1998). The purpose of this study is to explore how community participation is sustained, using the Canadian food security movement as a case study, and to critically examine the ways in which community participation is sustained over the long term.

The rising popularity of community-driven food security projects is linked with increasing public understanding of socio-economic and environmental challenges, which arise from how food is produced, purchased and consumed (Starr, 2010; Wekerle, 2004). Agriculture and food (agri-food) projects have been established within communities, which aim to increase access to healthy food, via sustainable food sources. This is achieved through localized fruit and vegetable distribution centers, markets or schemes, partnered with consumer-focussed campaigns, which aim to change purchasing habits and increase awareness of the benefits of buying food from local and ethically responsible sources (Johnston & Baker, 2005; Levkoe & Wakefield, 2011; Macias, 2008; Stroink & Nelson, 2013; Sumner, Mair, & Nelson, 2010). Similarly, community agriculture projects, such as urban farms, aim to shift public perceptions of land use, and promote creative thinking about how food can be produced in industrialized, built environments (Baker, 2004; Lyson, 2014).

Researchers call for wider use of participation-based approaches within food security policy development, research, and practice. It is argued that community participation can contribute to more equitable, sustainable and innovative food systems (Blay-Palmer, Knezevic, et al., 2013). However, research is needed to develop effective methodologies, and to overcome challenges relating to practical implementation (Gliessman, 2015; Pretty et al., 2010; Putnam et al., 2014).
Drawing from research on community participation across disciplines, a range of challenges are reported that impact on sustainability. There is often inadequate funding for community participation initiatives, and difficulties with maintaining community interest and involvement over the long term (Rifkin, 2003, 2009, 2014). Problems relating to volunteer burden or fatigue can emerge in long-term initiatives (Calderwood & Davies, 2013; Henderson & Kendall, 2014). It can be difficult to maintain consistent leadership and governance (Brownill & Carpenter, 2007; Kegler, Rigler, & Honeycutt, 2010; O'Meara, Pendergast, & Robinson, 2007), and community members can grow tired of repeated, participation processes, particularly if outcomes are not achieved (Attree et al., 2011; Cornwall, 2008; Kenny et al., 2014). The challenges involved with sustaining community participation must be addressed if the agri-food sector is to effectively utilize community participation as a platform for food systems change.

To examine how community participation is sustained, we conducted a case study of the Canadian food movement, which originated in the 1970s (also described as “alternative agri-food” (Bauermeister, 2015, p. 16) or “local food” movements (Starr, 2010)) The case study is used an exemplar of long-term, sustained community participation, which provides a lens for critical enquiry into the ways in which a grassroots social movement, or ‘self-mobilized’ form of community participation, is sustained over time (Cornwall, 2008; Pretty, 1995).

In the following section, key concepts of community participation and sustainability are defined, to provide readers with insight into the viewpoint of the researchers, and to understand the theoretical frameworks that influenced research decisions.

**Conceptualizing ‘community’ and ‘community participation’**
Participation in social movements, such as the Canadian food movement, is characterized by ‘self-mobilized’ participation, a bottom-up, community-driven approach, which is most commonly observed in autonomous initiatives (external of government) (Cornwall, 2008; Pretty, 1995). It is argued that participation grows from community capacity to self-mobilize and participate in action that challenges social and political systems (Cornwall, 2008; Pretty, 1995). Communities participate in an evolving process of “conflict, confrontation, and accommodation” that aims to “influence the political process or obtain political power” (Mansuri & Rao, 2013, p. 31).

Social movements rely on the recruitment and activation of participation within communities and their networks. The efficacy of food movements is determined by their ability to mobilize citizens, and to form a cohesive collective mission and identity (Bauermeister, 2015). Authors argue that participation is identifiable as a social movement as long as it is autonomous, and is observed to communicate protest and ‘move itself’ (Fuchs, 2006). In this context, community participation should occur in “spaces people create for themselves”, and involve “people who come together because they have something in common, rather than because they represent different stakeholders or different points of view” (Cornwall, 2008, p. 275).

‘Community’ is central to food movement dialogue and collective identity. Within food security research, community is described as the people, groups and stakeholders, who are connected via their social, cultural and/or economic interests in food security, and who participate in joint action to promote, celebrate and lobby for safe, accessible, sustainable and culturally-appropriate local food (Bauermeister, 2015; Blay-Palmer, Knezevic, et al., 2013; Blay-Palmer, Landman, Knezevic, & Hayhurst, 2013; Firth et al., 2011; Sumner et al., 2010). Within agri-food movements, community is commonly described as the antithesis of modern
society, a traditional and simpler way of living with food (through growing, purchasing and consuming), which is threatened by modernity (including large-scale development and urbanism). This dichotomous view of food systems distinguishes community-based, local food producers from powerful, multi-national food corporations, and community-based food purchasing is promoted as an ethical and responsible alternative (Bauermeister, 2015; Blay-Palmer, Knezevic, et al., 2013; Sumner et al., 2010).

Within agri-food movements, the benefits of being ‘community-based’ are highly publicized, and sometimes conflated (Lyson, 2014). Community-based food security projects are reported to have various outcomes (including social, cultural, political, or health and well-being) (Obach & Tobin, 2013). Community kitchens and gardens, for example, are reported to create opportunities for improving social connections, and for improving knowledge of fruit and vegetable production, and increasing consumption of healthy food (Levkoe & Wakefield, 2011). Community food security projects are argued to foster political agency, and community participation is used to grow food justice networks and encourage activism (Levkoe, 2006).

Because of the myriad of challenges inherent in community participation, including problems with sustaining participation in the long term, the reality of enacting and sustaining community participation within food security projects is likely to be less straightforward. The complexity inherent in community participation can be visualized using Tritter and McCallum’s (2006) metaphor of a “messy mosaic” (p. 165), which describes how community participation involves a convoluted arrangement of horizontal and vertical partnerships, and multifaceted power dynamics. Ultimately, if the food movement is to achieve its objectives, community participation must be enacted in ways that achieve a re-distribution of power and
control (Arnstein, 1969; Rifkin, 2014), which requires sustained action towards changing social and political factors that underpin food insecurity and injustice.

Defining ‘sustainable’ community participation

Despite wide interest in community participation methods (Conklin, Morris, & Nolte, 2012; Mitton, Smith, Peacock, Envoy, & Abelson, 2009), fewer studies explore how participation can be sustained. Sustainability is commonly used within outcome measures to evaluate community participation initiatives, and is used to indicate program longevity (Draper, Hewitt, & Rifkin, 2010; Morgan, 2001). Defined as “long term viability”, sustainability is understood as the dynamic process of maintaining an initiative (Shediac-Rizkallah & Bone, 1998, p. 87). Early studies proposed that sustainable community participation involves maintaining an initiative with partial or complete community control, which could include integrating or institutionalising participation methods within a larger system (Shediac-Rizkallah & Bone, 1998; Zakus & Lysack, 1998). To understand how community participation is sustained, researchers recommend examining the intensity and longevity of participation methods (Morgan, 2001), and community relationships and communication mechanisms (Quick & Feldman, 2011).

Community participation needs to be sustained for a certain period, to ensure scarce resources are invested effectively and the full range of outcomes realised (Head, 2011; Rifkin, 2009; Shediac-Rizkallah & Bone, 1998). Employing participation methods that are not sustainable increases risk of early dissolution, which may reinforce community mistrust of institutions and prevent people from engaging in initiatives (Shediac-Rizkallah & Bone, 1998). However, sustaining participation for ‘participations sake’ is inappropriate (Draper et al., 2010; Morgan, 2001). Shediac-Rizkallah and Bone (1998) argued that not all community
participation initiatives should be sustained indefinitely, and in some cases continuation is ineffective.

To address issues of sustainability, we explore how community participation is sustained in the Canadian food movement, and critically examine the ways in which community participation has been sustained over time.

**Methods**

**Study design**

A qualitative case study design was used that incorporated Stake’s (1995) instrumental case study approach. The phenomenon of interest, ‘community participation’, was explored via case study of the ‘Canadian food security movement’. This particular case was selected because of the extended length of time participation had been sustained. Ethics approval from [name to be added following review] University Faculty of Health Sciences Human Research Ethics Committee was obtained for the study described.

**Data collection**

A range of data sources were purposively sampled to provide an in-depth description of the case from multiple perspectives, and to enhance data triangulation (Hyett, Kenny, & Dickson-Swift, 2014; Merriam, 2009; Stake, 1995). The data sources included interviews, fieldwork observations, public documents, and social media.

**Interviews**

Internet searches were conducted to locate people responsible for community participation in Canadian food security programs. Two interviewees were recruited by email invitation, who then recommended key people from their networks. Further potential
participants were approached by email and three agreed to participate. Five interviews were conducted in October 2013; including, three in Toronto, Ontario (pop 2,615,060), one in Montreal, Quebec (pop 1,649,519), and one in Halifax, Nova Scotia (pop 390,096) (Statistics Canada, 2012). Participants were all employed in paid positions, two in national level organisations, and three at a municipal level. Participants were selected as key informants, because of their leadership positions and capacity to describe methods and strategies employed within programs.

The interviews were conducted in-person at the informants’ place of employment. They all provided informed written consent to have interviews audio-recorded and transcribed verbatim. Interviews were conducted by two researchers (author 1 and author 2) using a semi-structured question guide, and lasted approximately 60 minutes.

Fieldwork observations

Fieldwork observations were recorded over two weeks in October 2013, including seven field site visits in Toronto, two in Montreal and two in Halifax. Observations of interviewee work sites, community gardens and markets, and three guided tours of community food hubs led by program leaders (not interviewed) were recorded via photographs and written field notes.

Public documents

Public documents of seven organisations were collected during fieldwork in October 2013 and via online sources until December 2013. The thirty-four documents included in the data analysis were program annual reports, evaluation reports, policy submissions and reports, research papers written by interviewees, program manuals, and information handouts.

Social media
Online strategies were used to support community participation, and to explore this, social media data were collected and analysed. The social media data of seven organisations were collected, which was publicly available online. Online social media data sources (N=94) included Twitter (n=9), Facebook (n=9), YouTube and Vimeo (n=6), blogs (n=22), and webpages (n=48). Data were collected between July and December 2013, which involved extracting and storing social media data using the NVivo 10 application and NCapture plugin (QSR International, 2014).

Data analysis

The data coding process was assisted by the computer software application NVivo 10 (QSR International, 2014). All data sources were coded using techniques common to case study approaches, including descriptive, in vivo, and process coding methods (Saldaña, 2013). Codes were grouped into categories, which were analysed to develop themes (Saldaña, 2013). The themes relating to how community participation is sustained were: use of multiple methods, good leaders are fundamental, online participation via social media, and leveraging outcomes: “Is there a way we can seed it or spark it”.

Findings

Case background

The Canadian food security movement is a civil society movement that began in the 1970s. Over 5000 Canadians have participated in food programs and initiatives for over three decades (Peoples Food Commission, 1980; Peoples Food Policy Project, 2011), and there are an increasing number of food programs in major cities (Baker, 2004; Blay-Palmer, Landman, et al., 2013; MacRae & Donahue, 2013; Stroink & Nelson, 2013). Food security, defined as ‘access to adequate amounts of safe, nutritious, culturally appropriate food produced in an
environmentally sustainable way and provided in a manner that promotes human dignity’ (Levkoe, 2006, p. 91), is the goal of the movement. Beginning in the 1970s with grassroots activism in rural communities, citizen-led groups were formed to take action on food insecurity issues affecting their livelihood (Peoples Food Commission, 1980). Citizen-led action is key to achievements of the movement, including the Peoples Food Policy Project (2011), which utilized a ‘kitchen table talk’ method to consult with over 3000 Canadians. Community submissions were used to develop seven shared principles and ten discussion papers that underpin ongoing national food systems work (see http://foodsecurecanada.org/policy-advocacy/resetting-table). The Canadian food movement is a unique case that demonstrates how participation has been sustained, which continues to deliver positive health and social outcomes for communities (Engler-Stringer & Berenbaum, 2007; Johnston & Baker, 2005; Levkoe & Wakefield, 2011; Wakefield, Fleming, Klassen, & Skinner, 2013; Wakefield, Yeudall, Taron, Reynolds, & Skinner, 2007).

**Key themes**

**Use of multiple methods**

Multiple methods are employed simultaneously to enable and sustain community participation. Methods, listed in Table 1, include social events, such as movie nights and themed dinners, and public green spaces and urban agriculture projects, including car park and roof top gardens. By utilising several methods simultaneously, programs maximize participation opportunities for various age and cultural subgroups. Key informants explained that community participation is sustained as a result of the combination of multiple methods employed.
Table 1. List of methods used for community participation

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<th>List of community participation methods</th>
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<tr>
<td>Newsletter</td>
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<td>List serve</td>
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<td>Website</td>
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<td>Wall calendar</td>
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<td>Household canvassing/door knocking</td>
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<td>Postal survey</td>
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<td>Online written or photographic submissions</td>
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<tr>
<td>Twitter feed</td>
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<td>Facebook page</td>
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<td>Food skills workshop</td>
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<td>Social events, e.g. volunteer night</td>
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<tr>
<td>Community food hub, e.g. food market, garden, kitchen, distribution centre</td>
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<tr>
<td>Urban agriculture projects, e.g. bee-keeping, composting</td>
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<tr>
<td>Social enterprise, e.g. bike shop, meals on wheels, café</td>
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<td>Story-making workshops</td>
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<td>Students placements or internships</td>
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<td>Online learning portal, open access resources</td>
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<td>School-based food education and healthy food access programs</td>
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<td>Citizen blogs</td>
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<td>Community meetings for policy making, priority setting and strategic planning, e.g. kitchen table talks</td>
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<tr>
<td>Community working groups for food, environment and farming issues</td>
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<td>Peer advocacy service</td>
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Methods used to promote participation of specific community subgroups include school-based healthy eating and gardening projects in Toronto and Halifax. These involve children, teachers and parents, and include breakfast programs, edible gardens, food education and cultural activities, and cafeteria healthy meals programs. In a Montreal community food hub, social events are held for young adults and elderly people to encourage intergenerational interaction. Informants provided several other examples of this, such as vocational training programs with adolescents, cooking skills workshops with families, and multicultural community gardens and urban farms with new migrant populations. Using multiple methods
sustains community participation by improving attendance numbers, and reducing over-
reliance on one particular sub-group.

The multiple method strategy for community participation was described by
informants as dynamic and changeable to suit the local context. Methods used have multiple
purposes, described by a key informant (KI3) in Toronto:

It may only be 30 people that actually garden, but then 150 people participate in their
photo competition, and then another 1000 come to their once a year party, but then the
rest of them love looking down on the garden

The methods used are frequently adapted in response to current policy problems, media
interest, and the availability and source of funding. Citizens with innovative ideas are
involved in creating new methods, for example a bee-keeping collective within a Montreal
program, and a composting demonstration project in Toronto. Key informant (KI3) described
the dynamic nature of community participation:

Often food is used as a way to, you know you start a garden and all of a sudden you
can do energy efficiency projects, you know people are sort of together, working, and
know each other, and working on these other initiatives, as residents

The informants described a multiple method strategy that supported community participation
in all organisation activities, operations, and governance. This strategy is embedded in the
local context and aligned with the national food security vision and agenda. All of these
elements contribute to sustainability of community participation in the food movement.

*Good leaders are fundamental*

Food leaders, known as “commissioners”, “animators” or “champions”, have a
fundamental role in the coordination and implementation of food movement initiatives. There
were several characteristics used by informants that describe how food leaders are used
strategically for sustaining community participation. Informant (KI1) describes food leaders
as “people who worked at organisations like The Stop, and Santropol Roulant, and community health centres, who were really anchored in a community, and a place, and already had legitimacy and leadership and all that stuff established…” Food leaders were characterised as “visionary people with big ideas”, who were “dedicated” and “instrumental” (KI1). Key people who are able to (KI1) “popularise the notion of food sovereignty” and support community participation in food security initiatives.

Food leaders are employed or volunteer in community food programs, and are people that have respected food, health and farming leadership roles in their communities (K14). Another key informant (KI3) described the “food animator” role in a current food and garden initiative that is run in partnership with a social housing organisation:

This work does need to be animated right? In Toronto Community Housing we have a resident, we call them animators, you know resident leaders as well as staff whose job it is to do some of that hard work, convening meetings, putting up posters, providing resources and navigating. Frankly, the system, you know it’s not easy to start a community garden.

The role and responsibilities of food leaders have had to evolve to be sustainable. In addition to original responsibilities of creating awareness, building interest and momentum, and organising community events (KI1), current community food animator roles described (KI2 and KI3) include community capacity building and sourcing food production resources and infrastructure. One informant (KI5) noted that food leaders need to be politically savvy, and all key informants identified that grant writing and policy submission skills, and skills to liaise with philanthropic funders, are valued.

Food leaders are selected for their public profile and personal skills. Described by an informant (KI2), food leaders in Halifax programs are people who are good “networkers”, “connectors and resourcers”, “people who are working on the ground, in community food programs, that know what the needs of the community are to some degree”. A key informant
(KI1) indicated that leaders are thought to “represent the diversity in the food movement”. She described effective leaders as “facilitators and staff who are sensitive and skilled at drawing people into the process”, who are able to support “other people to see their work as contributing to this food systems perspective” (KI1). Situated in community food programs, effective leaders are able to make horizontal and vertical linkages between local people and the national identity of the food movement.

Informants argued that food leaders support community participation initiatives with their local knowledge and influence. Food leaders are people who already have leadership roles in their respective communities, are ‘insiders’, and this is used to maximize participation and outcomes. One key informant (KI3) explained how this approach “values the work that is happening on the ground – that is already happening in communities by existing leaders”. Food leaders are selected to support linkages across neighbourhoods, communities and regions, which provides a strong foundation for sustaining the national movement.

**Online participation via social media**

Social media is used to engage with the public, and at a national level, to communicate across Canada’s vast regions and provinces. The importance of a dynamic web platform and social media presence was argued by three key informants (KI1, KI4, KI5), and social media data analyses revealed similarities in how online methods are used.

Social media are primarily used to provide information to members. Online mediums including webpages, blogs, Facebook and Twitter, are used to increase organisational membership, attract sponsors, advertise employment or internships, and to promote community food activities. Social media are used to provide a real time mechanism of celebrating achievements and awards, and acknowledging efforts of volunteers. Social media
promotes organisational ideas and values, and indicates policy endorsements or alliances. Current participation opportunities are advertised online, including a Google map of community gardens in Halifax, and tweets about an upcoming cooking workshop in Montreal.

Analysis of Twitter feeds and Facebook wall posts revealed how organisations use micro-blogging to share short messages about healthy food, food security, and related policy issues. Twitter and Facebook are used pre, post and during community activities to increase participation, and appeared to link various participation methods. Social media use and online community participation, is used to complement in-person methods. Community food hubs in Toronto, for example, use Twitter and Facebook posts to encourage people to share photos of what they purchased at the healthy food market, and what they cooked with their good-food-box delivery.

There are various mechanisms for community participation via online mediums. Community members participate by reading information, clicking hyperlinks or observing photos and videos, and interact with the information by adding comments. This allows community members to share information with their own wider social networks via Facebook ‘like’ or Twitter ‘retweet’ functions. The number of Twitter followers for each program ranged from 562 to 10,691, with a mean average of 4472 followers across nine Twitter accounts. Facebook users ‘like’ a program’s page to be a member, and can ‘rate’ the organisation by using a five-star system and provide written feedback. For example, on one organisation’s Facebook page a user had rated them five stars and commented “What is it but one of a handful of great organisations paying it forward to future generations”, and three other Facebook users ‘liked’ this comment. Facebook pages have less members than Twitter,
with page ‘likes’ ranging from 351 to 5018, with a mean average of 2279 across nine Facebook accounts.

The images provided in Figure 1 and 2 demonstrate how Facebook is used to stimulate conversations about food. Facebook posts with the most amount of ‘likes’ were photos; examples of two photos with a high number of ‘likes’ are provided. The picture in Figure 1, received 1,207 ‘likes’ and was ‘shared’ by 1,999 Facebook users. Users wrote comments such as “We need A LOT more "Farmacists"!” and “Terrific. Best advice. You are what you eat and absorb. Eat veggies”. Most comments were made in good humour, and commented on the satire of healthy food, medication and health. Other users stated their personal opinion or made comments in direct response to other users. The picture in Figure 2, was of fruit and vegetables from a terrace garden linked to a food organisation, the picture was liked by 70 users and was shared in 18 instances. One user commented “It's amazing how wonderful the food you grow right in your own backyard/frontyard looks. Keep growing more and more”.

**Figure 1 Example of Facebook “Farmacy” comic wall post**

*Fig 1. Comic posted on Facebook by a food security organisation that depicts a ‘Farmacy’ Images posted on Facebook and are transferrable under Intellectual Property law (see [https://www.facebook.com/legal/terms](https://www.facebook.com/legal/terms)). The owner of Figure 1 has given permission for this*
comic to be used ‘responsibly’ (see http://www.bizarrocomics.com), and this comic has been posted on several other websites by different internet users.

**Figure 2 Example of Facebook fruit and vegetable image wall post**

![Image of fruits and vegetables purchased by a Facebook user from a food security organisation. Images posted on Facebook and are transferrable under Intellectual Property law (see https://www.facebook.com/legal/terms).](image)

Social media is used to create a positive public profile. This profile includes the organisation name, location, vision, values, objectives, current activities and intra-organisational links. The content displayed on the organisations website and social media profiles demonstrates what food-related polices they endorse, and some have clear links to members of parliament or political parties who advocate for food system policies. Participation via social media provided an online dimension of participation used to sustain the Movement.

*Leveraging outcomes: “Is there a way we can seed it or spark it”*

Leveraging is a method reported by key informants (K2, K3, K4, K5), which is used to expand community capacity and support program sustainability. Key informants explained, in the current fiscal context, funding for food security programs and initiatives is inconsistent,
and often comes from philanthropic donors or short term government grants. They argued there is a need for programs to utilize existing resources and maximize outcomes to be sustainable. This involves leveraging existing resources rather than building new initiatives. One key informant (KI3) explained “we [municipal food council initiative] don't have the capacity to start fresh, but to add something to the work that is happening”.

In an annual report of a Toronto-based food organisation, leveraging is described as “transformational”, and “[leveraging] ensures that each dollar we invest in our programs multiplies, impacting the greatest number of people”. Three key informants described how leveraging is used to increase the scale of food program activities, increasing opportunities for communities to participate (K2, K3 and K5). There were similarities identified in the analyses in how food program leaders utilize leveraging as a strategy for sustaining community participation, which are grouped into a four stage process outlined in Table 2.

Table 2. Four step leveraging approach

<table>
<thead>
<tr>
<th>Stage</th>
<th>Description</th>
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<tr>
<td>1. Assessing community readiness</td>
<td>• Food security needs to be a community-owned priority</td>
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<td></td>
<td>• Involves “feeling out” (KI5) community readiness and interest, capacity and resources</td>
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<td>• KI2: [we] went around the province and did a tour, to see where there is need and where we could infuse those resources, so we have hired somebody in [regional place] because there was a real readiness there and people were already working on food issues</td>
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<td></td>
<td>• Locating a community, “a place where there is already energy that we can build on” (KI2)</td>
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<td></td>
<td>• Access to local partners, funding and resources</td>
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<tr>
<td>2. Partnership development</td>
<td>• Finding suitable partners and forming effective partnerships</td>
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<td></td>
<td>• KI2: “we work through neighbourhood organisations, with people who understand those neighbours”</td>
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</table>
| 3. Resource investment | • KI3: “we always work with community partners and also engage local community leaders to make sure that those projects are a success”
• Partnerships include non-food related programs including a community health centres, social housing commissions, and schools and educational facilities

| 4. Support for participation sustainability | • Strategic investment of human, material and financial resources in skill and infrastructure development projects
• Securing existing community resources minimizes expenditures, e.g. vacant land or buildings, and human resources, including business owners, volunteers, students and interns, and community leaders
• Resource investment at a local level is important, to “increase local capacity” (KI5), and support “local communities so that they can organize themselves, and you know, hire coordinators to do this work, and it builds capacity at that local level” (KI3)
• Skill sharing is an integral investment in human resources, via “mentoring communities” and “sharing resources freely in an open source approach” (annual report)

|  | • Food leaders maintained a level of support for leveraged community projects
• High staff turnover in partner organisations influenced their ability to sustain an autonomous project (KI2)
• Sustainability is supported through funding, human resources and skills (KI2 and KI5).

KI2: [our main challenge is] supporting the program staff at one of the organisations that we work at, to increase their capacity, so that they can be the ones that keep supporting that, not always us, one of our biggest challenges, is all of the organisations we work with have a lot of turnover, they are really high intensity community development jobs and I think people burn out, people move on

Discussion
The findings of this case study provide new insights into how community participation is sustained. In analysing the case study, four strategies were extrapolated that were identified as key to sustaining community participation in the Canadian food movement. The findings of this study, similar to other studies of social movements, can be used to increase understanding of the different ways in which ‘self-mobilized’ forms of community participation are sustained over the long term, and how methods and strategies are changed over time to sustain community interest and involvement (Barnes & Coelho, 2009; Passy & Giugni, 2001; Starr, 2010; Wallerstein, Mendes, Minkler, & Akerman, 2011).

To critically examine the ways in which community participation was sustained in the Canadian food movement, theories drawn from the social movement literature are useful. Brown and Zavestoski (2004) define social movements as collective action for the purpose of social change that uses formal and informal networks to challenge “political power, professional authority, and personal and collective identity” (p. 679). The classification of the Canadian food movement as a social movement is debated (Starr, 2010), however, descriptions of the food movement provided by participants’ align with Brown and Zavestoski (2004) and others (Bauermeister, 2015; Levkoe, 2006; Lyson, 2014; Starr, 2010; Wekerle, 2004) who have classified the Canadian food movement as a social movement. The purpose of this discussion is not to debate classification of the food movement, this is done elsewhere (Starr, 2010), but to use principal theory from the social movement literature to discuss the case study findings.

Within the Canadian food movement, communities participated in similar ways to what has been observed in other social movements in affluent, Western societies (McCarthy & Zald, 2001). In this case study, the participants described how community participation was facilitated using organized practices that were guided by well-formed objectives. Like other modern social movements, historically, the participants described how deprivation and
protest were key elements of community activation. However, in order to sustain long-term community participation, the participants argued that rather than working in opposition to government, there is increasing need to partner with governments and decision-makers, and leverage outcomes for social and political change. The views of the participants’ are comparable to existing research, which highlights that organisational capacity building, resource acquisition, and partnership development are important elements of sustainable participation initiatives (Edwards & Gillham, 2013; Jenkins, 1983; McCarthy & Zald, 2001).

Sociological theories developed from research on social movements, primarily Resource Mobilization Theory (RMT), can be used to understand why the strategies employed within the case study might have contributed to sustainability (McCarthy & Zald, 2001). Using a resource mobilization theoretical lens, it could be argued that community participation within the food movement was sustained because strategies used were effective for activating communities, and for mobilising and deploying the required resources (Edwards & Gillham, 2013; Jenkins, 1983; McCarthy & Zald, 2001). Resource Mobilization Theory was developed within the context of large-scale social movements with centralized participation strategies (McCarthy & Zald, 2001), which closely aligns with descriptions of the Canadian food movement within the case study.

Adopting a resource mobilization theoretical lens, it can be argued that community participation within the food movement was influenced by the presence or absence of resources (Jenkins, 1983). The Canadian food leaders in our study recommended that several types of resources are needed to sustain participation (Edwards & Gillham, 2013; Edwards & McCarthy, 2004). These include human resources, such as moral, social or cultural capital, and physical objects that include organisational assets or monetary resources (Edwards & Gillham, 2013). Within the case study, the participants argued that resource acquisition was key to sustaining community participation. The participants identified community leaders and
online social media platforms as valuable resources, and described how the absence of resources, primarily stable funding, was overcome by utilising volunteers, local assets, and by building capacity through leveraging strategies.

It is argued that participation within modern social movements is largely determined by rational choice and perceived costs and benefits of participating (Canel, 1997; Edwards & McCarthy, 2004; McCarthy & Zald, 2001). Elements of current Canadian food security programs described within the case can be used to illustrate this argument. In the food movement, the strategies described by participants may have assisted decision-making by incentivising community participation and removing potential barriers, for example by offering travel reimbursements and honorariums for volunteers. The participants developed the multiple methods strategy to provide a range of choices and options to suit a variety of participation preferences. Descriptions were provided of the increasing use of online participation options via social media to increase accessibility. Using resource mobilization theory, it is argued that incentives must be sufficient to influence individual and collective decision-making, and to overcome personal barriers or competing commitments (Edwards & McCarthy, 2004; Jenkins, 1983). This appears to be evident within current Canadian food security programs and may have contributed to sustainability.

Within the case study, the participants described how historical experiences with food insecurity were important for initiating the food movement and defining movement vision and objectives. However, resource accessibility, such as through community leaders, online platforms and leveraging strategies, were identified as key to sustaining current programs. Bosco (2001) argues that one drawback of participation strategies informed by resource mobilization theory, is that historical and cultural dimensions are not considered. McCarthy and Zald (2001) agree, and emphasize the importance of understanding the real life context of participation when forming strategies, including competing life commitments and the
availability of social support (McCarthy & Zald, 2001, p. 536). Authors argue that even when participation is the rational answer, actions are not automatic and participation does not always occur (McCarthy & Zald, 2001).

Generally, the purpose of many Western social movements is to empower disenfranchised populations, however, affluent community members are often required for sustainability (Edwards & Gillham, 2013; Edwards & McCarthy, 2004). This was evident in Canada, where recruitment of affluent community members was observed in participation methods such as farmers markets, and through philanthropic partnerships developed through leveraging strategies. Social media were used to promote a positive public profile and to co-opt additional supporters, and skilled and well-connected leaders were identified as important for increasing movement membership. Resource mobilization theorists agree that personal grievances and experiences of disadvantage are important for initiating participation, however, a wide range of monetary and social resources are needed for large-scale participation initiatives to be sustained (Canel, 1997; Edwards & Gillham, 2013; Jenkins, 1983).

Limitations of resource mobilization approaches must be considered when translating the strategies used within the food movement to other contexts. Researchers have advised that strategies which require harnessing collective control over resources are not always easy to implement (Edwards & McCarthy, 2004; Jenkins, 1983). For example, employing leaders who are skilled in resource mobilization might have enhanced food movement sustainability, but participation could have been perceived as less legitimate by the Canadian communities (Edwards & McCarthy, 2004; Jenkins, 1983). Edwards and McCarthy (2004) suggest resource mobilization is simpler for privileged groups, and consequently, if the food leaders focussed solely on resource mobilization, unintended negative consequences such as social exclusion might result (Edwards & McCarthy, 2004; Jenkins, 1983). However, communities
may benefit from food movement outcomes, specifically food security policy outcomes, which might be sufficient justification (McCarthy & Zald, 2001). Researchers recommend that social exclusion might be avoided if entrepreneurial and political leadership qualities are balanced with community social and cultural interests, and if a democratic methodology is maintained (Bosco, 2001; Canel, 1997), which are factors that could be integrated within strategies described in this case.

Limitations of the study

This is a small case study that contributes preliminary conceptual findings that will provide a foundation for further empirical research. The data were collected from a small number of informants, and their views might be influenced by the nature of their employment positions. Some interview questions required participants to recall historical events. To increase trustworthiness of the subjective and retrospective nature of the interviews, an historical document analysis was used to triangulate responses. Generalizations drawn from qualitative case study findings are limited and contextual factors need to be considered for knowledge translation (Stake, 1995). During fieldwork, data collected were from best available and accessible sources at the time of travel, inclusion of informants from other provinces might have provided different perspectives.

Conclusion

Methods and strategies used to sustain community participation over the long term may improve investment of scarce resources and overall viability of initiatives. Community participation can be sustained by using a dynamic combination of multiple methods, which utilize local leaders, leverage outcomes from strategic partnerships, and use social media to complement in-person methods. Our study highlights participation methods that can be used to overcome issues and challenges related to sustaining long-term participation, for example,
by increasing and maintaining community interest, and improving accessibility via online participation platforms.

It is likely that no single participation method can be sustained indefinitely. Methods must be responsive to the needs of the community and align with human and financial resources. Approaches to community participation that draw on resource acquisition and mobilization approaches can sustain participation within initiatives. However, by focusing on sustainability, participation may lack legitimacy with communities, and conflict with efforts to promote social inclusion. Sustained community participation is critical for addressing food security issues at the community-level, and for consolidating long-term social and political actions on global food systems change. Lessons learned about sustaining community participation in the Canadian food movement contribute a deeper understanding of approaches to community participation for food security practitioners, policymakers, educators, researchers.

References


SECTION FIVE:  
Leadership and governance

What is the role of leadership and governance in community participation

• Community participation is mandated for Australian health services and requires strong leadership and explicit governance approaches.
• Governments are unclear about how community participation will actually be achieved (see section two challenges).
• There are few documented models of governance to guide community participation processes.
• The capacity and knowledge base of CEOs and Boards of Management about current community participation directions is largely unknown.
• Community participation can challenge the boundaries that are required by governance processes, particularly if it is not clearly understood.
• Governance issues can become problematic where organisations utilise a “top down” approach that contrasts with the “bottom up” community participation process.
• Within small communities, many organisations exist, with different governance arrangements. Bringing these together can be challenging.
**Key points and the evidence**

<table>
<thead>
<tr>
<th>Key points</th>
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<tr>
<td>There are some who critique the recent ‘discovery’ of community participation by health policy makers, and reflect on Foucauldian theories of govermentality, to question whether this ‘discovery’ is simply absolving responsibilities from government to the governed.</td>
<td>• (Titter, 2009).</td>
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<td>Some question the purpose of participation agendas in Western democracies, where political structures are designed for those in power to be elected as the ‘voice’ of the people.</td>
<td>• (Forster &amp; Gabe, 2008; Head, 2011).</td>
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<td>The Australian Commission on Safety and Quality in Health Care mandates a role of governance for health services in Standard 1 that “outlines the broad criteria to achieve the creation of an integrated governance system to maintain and improve the reliability and quality of patient care, and improve patient outcomes.”</td>
<td>• (ACSQHC, 2012, p. 3).</td>
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<td>Membership of the Australian Institute of Company Directors (AICD) is not compulsory for health service board members and other organisations provide governance training. However, the legislative requirements for managing and overseeing a health service are significant and the capacity of board members is an important factor in the successful management of community health services. Health services are recommended to use community organisations and consultants to build governance capacity for staff in senior management and clinical situations.</td>
<td>• (ACSQHC, 2012; Bismark, Biggar, Crock, Morris, &amp; Studdert, 2014; Duffy et al., 2013; Newman et al., 2011).</td>
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<td>Clinical governance sits alongside corporate governance with more of a focus on maintaining and improving patient care within the system. It has been defined as: “A system through which organisations are accountable for continuously improving the quality of their services and safeguarding high standards of care. This is achieved by creating an environment in which there is transparent responsibility and accountability for maintaining standards and by allowing excellence in clinical care to flourish.” Clinical governance is a key indicator in health service performance. Good clinical governance requires capacity building and leadership within health services to ensure quality outcomes.</td>
<td>• (ACSQHC, 2012, p. 8). • (Knight, Kenny, &amp; Endacott, 2015).</td>
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<tr>
<td>Involving community members in coproducing new services requires empowerment and capacity for community participants. In addition, it also requires capacity within the organisation to implement recommendations and develop coproduced services. Community participation can challenge the boundaries that are required by governance processes, particularly if it is not clearly understood or there is a breakdown in trust between participants and the sponsoring organisation.</td>
<td>• (Eversole, 2010). • (O’Meara, Pendergast, &amp; Robinson, 2007).</td>
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Key points and the evidence (cont.)

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<th>Key points</th>
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<tr>
<td>Governance issues can become problematic where organisations utilise a “top down” approach which contrasts with the “bottom up” community participation process. Community stakeholders can feel a loss of ownership over the project and its outcomes. These challenges are outlined by O’Meara and colleagues (2007, p. 164): “Governance issues are one of the more vital ingredients in the mix of influencers for community building projects, and must be prioritised for action in a skilled, structured and timely manner. It is vital for all parties at the onset of a project that they clearly understand the shape and character of the balance of power and responsibilities between the community, councils and paid project facilitators.” Governance training and board capacity building are important factors in ensuring good governance practice.</td>
<td>(Eversole, 2011; Farmer, Currie, Kenny, &amp; Munoz, 2015; Lehmann &amp; Gilson, 2014; Loeffler, Power, Bovaird, &amp; Hine-Hughes, 2013; O’Meara et al., 2007)</td>
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<tr>
<td>Health services are obliged to engage with consumers and build community capacity if required. Options for involving consumers in the governance of health service organisations include: • involving consumers as representatives on the board or existing committees • creating or reviewing an existing consumer advisory committee; these can be ongoing or for specific topics • using less formal mechanisms, such as a ‘critical friends’ group • seeking feedback on governance issues by speaking with consumers in waiting rooms, carrying out informal surveys or speaking with local consumer advocacy and community groups.</td>
<td>(ACSQHC, 2012)</td>
</tr>
<tr>
<td>In rural health, there are challenges when policy and service delivery may be managed by different organisations. In Victoria, local government will develop the health and wellbeing policy. Community health and wellbeing programs are also delivered by the local health service. This can lead to governance problems and consumers are confused about the role of regional organisations delivering services and community members. Imposed funding models may also create “silos” delivery of health services rather than integrated care. This can be further complicated where agencies act as gatekeepers towards community members wishing to access services and department knowledge and resources. This mixing of governance roles highlights one of the deficiencies of health service delivery in rural Australia particularly when organisations may not have formal consultation processes and may even compete for project implementation and delivery within the community.</td>
<td>(Altpeter, Schneider, &amp; Whitelaw, 2014; Eversole, 2010; Farmer et al., 2015; Kenny, Farmer, Dickson-Swift, &amp; Hyett, 2014; Nimegeer, Farmer, Munoz, &amp; Currie, 2015)</td>
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Community participation: What we have learnt about leadership and governance

i. Community participation directives could be viewed as a tool of Government to ensure that communities take responsibility for their own health and wellbeing.

ii. Community participation should be embedded into all processes and activities of a health service, and this must be led from the top ie CEO and Board of Management level.

iii. The role of the facilitator in community participation cannot be underestimated, and the way in which each student approached their project had a major impact on outcomes.

iv. Health services must think about governance models from the commencement of community participation initiatives.

v. Community participation can only be sustainable with a commitment to financial support and with champions and drivers.

vi. There may be a disconnect between health services understanding of community participation and what the community expects.

vii. Community members may be highly cynical of health services attempts to engage and much time will be needed to build trust.

viii. There may be strong demarcations between existing community groups that will create challenges for participatory exercises.

ix. Past episodes of protest within a community might have resulted in long standing sensitivities that need to be worked through.

x. There is a risk that health services/Boards view community participation as a tick box activity simply designed to meet quality and safety standards.

xi. Community participation can only be embedded in a service when there is a commitment to sharing power and involving community members in real decision including financial ones.

xii. There is a risk that the community will grasp the opportunity to enthusiastically embrace initiatives that may not necessarily meet the aims and directions of the service.

xiii. Health service representatives may be concerned about being held accountable for, and feeling obliged to fund and support emerging initiatives because these initiatives arose from community participation instigated by the health service.

xiv. In some communities in this project, a governance process was developed to formally evaluate all community participation initiatives against developed criteria, before implementation commenced. Criteria included cost, evidence of effectiveness, and identification of an appropriate lead partner agency.
The role of governance in community participation: John Aitken

A key challenge for health care providers is to ensure that health service users are actively involved in the planning, delivery and evaluation of the services offered. Community participation approaches supported by effective and evidence-based governance models are vital for the success of any community participation strategy.

As part of a framework for developing governance processes in community partnership policy the Australian Commission on Safety and Quality in Health Care provides the following definition of governance:

“Governance: the set of relationships and responsibilities established by a health service organisation between its executive, workforce and stakeholders including consumers. Governance incorporates the set of processes, customs, policy directives, laws, and conventions affecting the way an organisation is directed, administered, or controlled. Governance arrangements provide the structure through which the objectives (clinical, social, fiscal, legal, and human resources) of the organisation are set, and the means by which the objectives are to be achieved. They also specify the mechanisms for monitoring performance. Effective governance provides a clear statement of individual accountabilities within the organisation to help in aligning the roles, interests and actions of different participants in the organisation in order to achieve the organisation’s objectives. In these Standards, governance includes both corporate and clinical governance” (ACSQHC, 2012, p. 5).

The role of the Board in Corporate Governance

Health service boards have to address governance issues at a number of levels. Whilst clinical governance and corporate governance have some overlap they also serve different functions within a health system. Board governance guidelines are provided by the Australian Institute of Company Directors (AICD). These guiding principles provide Boards with a framework to ensure that duties are carried out in a manner which is compliant with legislation, identifies strategic goals and delivers services that meet community expectations.

1. The Board plays a key role in approving the vision, purpose and strategies of the organisation. It is accountable to the organisation’s members as a whole and must act in the best interests of the organisation.
2. The Board sets the cultural and ethical tone for the organisation.
3. All directors should exercise independent judgment and provide independent oversight of management.
4. Taking into consideration the scale and nature of the organisation’s activities, the board should comprise an appropriate number of directors who have a relevant and diverse range of skills, expertise, experience and background and who are able to effectively understand the issues arising in the organisation’s business. Where practicable, the chairman of the board should be independent, with the role of the chairman being separate from the role of the CEO.
5. The Board should have an appropriate system of risk oversight and internal controls put in place.
6. Directors should act diligently on an appropriately informed basis and have access to accurate, relevant and timely information.

7. The Board would normally delegate certain functions to management. Where it does so, there should be a clear statement and understanding as to the functions that have been delegated.

8. The Board is responsible for the appointment of the CEO and the continuing evaluation of his or her performance.

9. The Board should ensure that the organisation communicates with members and other stakeholders in a regular and timely manner, to the extent that the Board thinks is in the best interests of the organisation, so that they have sufficient information to make appropriately informed decisions regarding the organisation.

10. The Board’s performance (including the performance of its chair, the individual directors and, where appropriate, the board’s sub-committees), needs to be regularly assessed and appropriate actions taken to address any issues identified.

Membership of the Australian Institute of Company Directors (AICD) is not compulsory for health service board members and other organisations provide governance training. However, as outlined below the legislative requirements for managing and overseeing a health service are significant and the capacity of board members is an important factor in the successful management of community health services (Bismark, Biggar, Crock, Morris, & Studdert, 2014; Duffy et al., 2013; Newman et al., 2011).

Corporate Governance procedures ensure that the service operates within the boundaries defined by various legislated procedures specific to health services. The following section outlines some of the key legislative documents pertaining to Victorian health services:

**Administrated by the Minister for Health**

- Abortion Law Reform Act 2008 (jointly administered with the Minister for Women)
- Anglican Welfare Agency Act 1997
- Assisted Reproductive Treatment Act 2008
  - Assisted Reproductive Treatment Regulations 2009
- Cancer Act 1958
  - Cancer (BreastScreen Victoria Registry) Regulations 2003
  - Cancer (Reporting) Regulations 2012
- Cemeteries and Crematoria Act 2003
  - Cemeteries and Crematoria Regulations 2015
- Crown Land (Reserves) Act 1978 (provisions relating to specific Crown land)
- Drugs, Poisons and Controlled Substances Act 1981 (jointly and severally administered with the Ministers for Mental Health and Agriculture)
  - Drugs, Poisons and Controlled Substances Regulations 2006
- Drugs, Poisons and Controlled Substances (Precursor Supply) Regulations 2010
- Epworth Foundation Act 1980
- Food Act 1984
  - Food (Forms and Registration) Regulations 2005
- Gene Technology Act 2001
  - Gene Technology Regulations 2011
- Health (Commonwealth State Funding Arrangements) Act 2012
- Health (Fluoridation) Act 1973
- Health Practitioner Regulation National Law (Victoria) Act 2009
  - Health Practitioner Regulation National Law Regulation 2010
- Health Practitioners (Special Events Exemption) Act 1999
- Health Records Act 2001
  - Health Records Regulations 2012
- Health Services Act 1988 (jointly and severally administered with the Minister for Housing, Disability and Ageing)
  - Health Services (Private Hospitals and Day Procedure Centres) Regulations 2013
- Health Services (Conciliation and Review) Act 1987
- Howard Florey Institute of Experimental Physiology and Medicine (Repeal) Act 2007
- Human Tissue Act 1982
  - Human Tissue Regulations 2006
- Improving Cancer Outcomes Act 2014
- Land Act 1958 (provisions relating to specific land)
  - Land Regulations 2006
- Lord Mayor’s Charitable Fund Act 1996
- Medical Research Institutes Repeal Act 2008
- Medical Treatment Act 1988
- Non-Emergency Patient Transport Act 2003
  - Non-Emergency Patient Transport Regulations 2005
- Pharmacy Regulation Act 2010
- Prohibition on Human Cloning for Reproduction Act 2008
- Public Health and Wellbeing Act 2008
  - Public Health and Wellbeing Regulations 2009
- Radiation Act 2005
  - Radiation Regulations 2007
- Research Involving Human Embryos Act 2008
- Royal Melbourne Hospital (Redevelopment) Act 1992 (except section administered by the Minister for Education)
- Safe Drinking Water Act 2003
  - Safe Drinking Water Regulations 2015
- Therapeutic Goods (Victoria) Act 2010
- Tobacco Act 1987
  - Tobacco Regulations 2007
  - Tobacco (Victoria Health Promotion Foundation) Regulation 2011

**Administered by the Minister for Mental Health**

- Carers Recognition Act 2012 (jointly and severally administered with the Minister for Housing, Disability and Ageing and the Minister for Families and Children)
- Crimes (Mental Impairment and Unfitness to be Tried) Act 1997 (jointly administered with the Attorney-General, the Minister for Families and Children and the Minister for Housing, Disability and Ageing)
  - Crimes (Mental Impairment and Unfitness to be Tried) Regulations 2009
- Drugs, Poisons and Controlled Substances Act 1981 (jointly and severally administered with the Minister for Health and the Minister for Agriculture)
  - Drugs, Poisons and Controlled Substances (Drugs of Dependence - Synthetic Cannabinoids) Regulations 2014
  - Drugs, Poisons and Controlled Substances (Confiscation) Regulations 2014
  - Drugs, Poisons and Controlled Substances (Precursor Chemicals) Regulations 2007
  - Drugs, Poisons and Controlled Substances (Volatile Substances) Regulations 2014
- Mental Health Act 2014
  - Mental Health Regulations 2014
  - Mental Health Tribunal Rules 2014
- Severe Substance Dependence Treatment Act 2010 (except sections administered by the Attorney-General)
Other relevant Acts and Regulations

- Audit Act 1994
- Charter of Human Rights and Responsibilities Act 2006
- Coroners Act 2008
- Crimes Act 1958
- Financial Management Act 1994
- Freedom of Information Act 1982
- Guardianship and Administration Act 1986
- Information Privacy Act 2000
- Interpretation of Legislation Act 1984
- Occupational Health and Safety Act 2004
- Ombudsman Act 1973
- Privacy and Data Protection Act 2014
- Public Administration Act 2004
- Public Records Act 1973
- Sentencing Act 1991
- Subordinate Legislation Act 1994
- Protected Disclosure Act 2012

NB: A comprehensive list of these can be found at: https://www2.health.vic.gov.au/about/legislation/overview

Clinical governance

Clinical governance sits alongside corporate governance with more of a focus on maintaining and improving patient care with the system. It has been defined as:

“A system through which organisations are accountable for continuously improving the quality of their services and safeguarding high standards of care. This is achieved by creating an environment in which there is transparent responsibility and accountability for maintaining standards and by allowing excellence in clinical care to flourish.”

(ACSQHC, 2012, p. 8).
Clinical governance is a key indicator in health service performance. Clinical governance impacts capacity building and leadership within health services contributing to quality outcomes (Knight, Kenny, & Endacott, 2015).

The following list is an outline of the required elements of a robust clinical governance system;

- Priorities and strategic direction are set and communicated clearly.
- Planning and resource allocation supports achievement of goals.
- Culture is positive and supports patient safety and quality improvement initiatives.
- Legislative requirements are complied with.
- Organisational and committee structures, systems and processes are in place.
- Measure performance and monitor quality and safety systems within the service.
- Report, review and respond to performance to support continuous improvement of quality and safety within the service.
- Roles and responsibilities are clearly defined and understood by all participants in the system.
- Continuity of care processes ensure that there is continuity across service boundaries. (Dept of Human Services, 2009, p. 5)

The Australian Commission on Quality and Safety in Health Care provide an outline of the key considerations.

1. **Governance and quality improvement systems**
   - There are integrated systems of governance to actively manage patient safety and quality risks.

2. **Clinical practice**
   - Care provided by the clinical workforce is guided by current best practice.

3. **Performance and skills management**
   - Managers and the clinical workforce have the right qualifications, skills and approach to provide safe, high-quality health care.

4. **Incident and complaints management**
   - Patient safety and quality incidents are recognised, reported and analysed, and this information is used to improve safety systems.

5. **Patient rights and engagement**
   - Patient rights are respected and their engagement in their care is supported. (ACSQHC, 2012, p. 14)

Clearly, good governance is key priority, however, to create shared governance as part of the participatory process requires community members to have the capacity and agency to participate in governance processes (Eversole, 2011; Farmer & Kilpatrick, 2009; Head, 2007; Kilpatrick, Auckland, Johns, & Whelan, 2008; O'Meara, Pendergast, & Robinson, 2007).

**Challenges to good governance and community participation**

Involving community members in coproducing new services requires empowerment and capacity for community participants, in addition it also requires capacity within the organisation to implement recommendations and develop the coproduced services (Eversole, 2010). Community participation can challenge the boundaries that are required by governance processes, particularly if it is not
clearly understood or there is a breakdown in trust between participants and the sponsoring organisation (O’Meara et al., 2007).

Governance has been highlighted as an essential component of community capacity building. Governance issues can significantly impact the success of a project. A recent example of the importance of strong governance mechanisms and leadership is outlined in an Aboriginal health project in the Kimberley, in Western Australia. A community participation model was used to change the local health service from a focus on acute care to a prevention focussed health service. Governance was a key enabler for the project and important in its success.

“Strong community and health leadership were required to overcome the barriers and resistance to organisational change. The formal Partnership agreement provided the necessary structural changes and governance framework by clearly outlining roles and responsibilities” (Reeve et al., 2015, p. 414)

Community leadership is important as it contributes to the success and sustainability of community health projects, providing ‘community ownership’ of outcomes and interventions (Nimegeer, Farmer, Munoz, & Currie, 2015; Reeve et al., 2015).

Governance issues can also become problematic where organisations utilise a “top down” approach which contrasts with the “bottom up” community participation process. Community stakeholders can feel a loss of ownership over the project and its outcomes (Farmer, Currie, Kenny, & Munoz, 2015; O’Meara et al., 2007). These challenges are outlined by O’Meara and colleagues (2007, p. 164)

“Governance issues are one of the more vital ingredients in the mix of influencers for community building projects, and must be prioritised for action in a skilled, structured and timely manner. It is vital for all parties at the onset of a project that they clearly understand the shape and character of the balance of power and responsibilities between the community, councils and paid project facilitators.”

Lack of governance will impact on project outcomes where stakeholders feel confused about which organisations they can engage with, particularly when projects are not progressing as expected (Farmer et al., 2015). In rural health, there are challenges when policy and service delivery may be managed by different organisations. In Victoria, local government will develop the health and wellbeing policy and by the local health service this can lead to governance problems and consumers are confused about the role of both regional organisations delivering services community members. Imposed funding models may also create “silo” delivery of health services rather than integrated care (Altpeter, Schneider, & Whitelaw, 2014; Farmer et al., 2015). This can be further complicated where agencies act as gatekeepers towards community members wishing to access services and department knowledge and resources (Nimegeer et al., 2015). This mixing of governance roles highlights one of the deficiencies of health service delivery in rural Australia particularly when organisations may not have formal consultation processes and may even compete for project implementation and delivery within the community (Eversole, 2010; Kenny, Farmer, Dickson-Swift, & Hyett, 2014).

Governance issues also feature in the Victorian Auditor General’s Report (Auditor-General, 2012) on community participation which identifies a lack of capacity within health services and VicHealth to deliver community participation outcomes. Similarly, in Scotland there is a policy of community
participation with stakeholder roles defined but no governance framework recommended to ensure proper process is followed (Farmer et al., 2015). One could argue that health bureaucracies outsource these empowerment processes, but are not fully committed to full participation themselves. Government departments may prefer the steady hand of bureaucracy as Eversole (2011, p. 68) highlights:

“Tensions between hierarchical institutions and networked and participatory governance approaches are perhaps most marked in contexts such as Australia and the UK where there are strong bureaucratic government institutions that struggle, structurally and culturally, to accommodate more participatory ways of governing.”

The Victorian Auditor General’s Report “Consumer Participation in the Health System” outlines the key challenges that the Victorian Health Department has in implementing its own policy:

“The Department should monitor health service and departmental compliance with consumer participation requirements and their efforts to measure impact more closely to determine policy effectiveness. The Department has not yet assessed its own performance against the policy or undertaken a comprehensive evaluation of the impact of ‘Doing it with us not for us’. Inadequate monitoring now makes this task more challenging.” (Auditor-General, 2012, p. 42)

Governance should therefore be seen as extending through the bureaucracy, the health service and education institution; through the facilitator to all stakeholders in the research project. Governance frameworks should provide for community leadership with clear lines of communication ensuring stakeholder rights are respected and supported, and that meaningful feedback can be provided on project outcomes.

An example of a Governance Model for Community Participation in a Rural Health Service.

Once an agreed project is identified by health service and the University a process of examination against Improvement Guide Standard 2: Partnering with Consumers (ACSQHC, 2012) should be undertaken to ensure it meets the guidelines for community participation.

The Board of the Health Service would then need to minute the project at a Board meeting, acknowledging the proposed project meets the guidelines for partnering with consumers. The CEO would then allocate staff and resources to the project. An initial budget for the project should be allocated.

The University project leader would be required to prepare a budget, allocate staff and University resources and initiate an ethics application.

Pending the outcome of the ethics application a steering committee can be formed and facilitators appointed. Protocols for the project can be derived from the ethics application.

The steering committee can draw up joint terms of reference for the project which will be the basis of the governance structure.

The governance committee should comprise:

- Health service CEO or direct report nominee
- University Project leader or direct report nominee
- Health Service Board member
- Facilitator
- 3-4 Community members

After ethics approval the Board should formally approve the project and draft terms of reference with university participants.

The facilitator can begin the project and identify community stakeholders. Strategies such as advertising and snowballing (Rogers, 2013) should be used to identify other potential stakeholders.

The facilitator would then organise meetings distribute ethics statements, obtain informed consent, explain the governance structure and begin the project.

The steering group should continue to oversight the project until the community participants are ready to form a governance group.

Once the governance committee is formed it should nominate a chairperson and ratify the project terms of reference. The governance committee should hold regular meetings and review the projects progress against objectives to ensure outcomes meet project goals. Governance group members would then report back to the participation group, the Board of the health service and the university project team.
This following flowchart outlines the key aspects of this governance process:

1. **Does the project meet ACSQHC Standard 2?**
   
2. **Health Service Board**
   - Signs off
   - CEO allocates staff and resources

3. **University project leader**
   - Allocates staff and resources
   - Ethics application submitted

4. **Joint steering committee formed**
   - Project terms of reference drafted
   - Facilitator appointed

5. **University Ethics Approved**

6. **Health Service Board approves Project**

7. **Facilitator starts project governed by steering committee.**

8. **Community Stakeholders recruited to project**
   - Governance committee formed
The messiness of community participation utilising action research frameworks is well documented (Cook, 2009; Kenny et al., 2014). Governance committees should be aware, both of potential problems; and also the opportunities that stakeholder participation and coproduction provide in producing better community health interventions (Bovaird, 2007; Kidd, Kenny, & McKinstry, 2015; Ottmann, Laragy, Allen, & Feldman, 2011).

Ultimately the governance committee will determine when the project is finished. The facilitator should prepare a report detailing project outcomes for all stakeholders. The Board should review the outcomes and determine whether they fit into the health service strategic plan, or identify new areas for future research. The University project team will report the outcomes to their ethics committee. The project will be completed, outcomes reviewed by the governance committee, future recommendations may be made and then the governance committee will be disbanded.

Bibliography and further reading


Building leadership in Australian healthcare: The case of RNH

John Aitken

The importance of governance, management and leadership in developing a sustainable rural health service is highlighted in a number of studies (Farmer & Kilpatrick, 2009; Madsen & O’Mullan, 2014; Tham, Humphreys, Kinsman, Buykx, Asaid, Tuohy & Riley, 2010). Building staff leadership and management skills is a priority for the RNH leadership team. Leadership development has also extended to board members who have continued to focus on developing skills and capacity building and have attended governance training offered in the Grampians region by the Building Board Capacity working group (RNH Annual Report, 2014)

Health literacy therefore became a key determinant for successful outcomes in this project. The CEO of RNH, Catherine Morley wanted a process that was evidence based that community members could utilise, that health service staff could implement; and that engaged with the community in a replicable process. A key goal for the project was to have a sustainable process that could be continually adapted to improve community health literacy.

The project group consisted of 14 representatives from La Trobe University and La Trobe Rural Health School developed the following ten parameters as keys for success:

1. A successful community engagement model.
2. A strategy of the health that worked with and not for the community.
3. Case studies that demonstrated successful community engagement and participation.
4. Research that was evidence based, sustainable and replicable.
5. Creating a sense of urgency about prioritising community participation.
6. Community own their own health and the health service several ways – encourage community to take ownership.
7. Connection dialogue and shared understanding. Ongoing fluid conversation – underpinning this some type of sustainable process that can continue. Figure out a way that this process can be continued beyond the project.
8. See multiple models coming out of the 3 communities participating in the larger project; namely, Warracknabeal, Rochester and Heathcote.
9. A successful governance process being implemented for the project
10. All community stakeholders participate in the project, including youth and young families which had been difficult to engage with in previous community discussions.

While each community that participated in the project is different there were some common goals. These were to develop community participation, identify knowledge gaps, coproduce interventions and determine outcomes.

The other parameter identified as essential by the RNH CEO, Catherine Morley was leadership. In 2012, the Australian Federal government had established to help workforce Australia to implement leadership programs within health services and the broader health community. Prof Jane Farmer was also interested in leadership and had spoken about it at the Victorian Healthcare Association
Improving the health of communities through participation

(VHA) Conference in 2012. Jane saw leadership as being complementary to the processes of community participation and engagement and was interested in the leadership goals that health workforce Australia had identified in its guidelines. These guidelines included in the following statements:

“Leadership for a people focussed health system that is equitable, effective and sustainable.

• ‘People focussed’ aligns with evidence that the best healthcare has the person at its centre and workplace satisfaction leads to better clinical and consumer outcomes.

• ‘Health system’ includes all the organisations and people whose primary purpose is to improve health.

• ‘Equitable’ reflects evidence that health inequalities exist within populations, and hospitals and health care services can be sources of inequality for patients, clients and workers.

• ‘Effective’ means the best possible clinical, consumer, quality and team outcomes.

• ‘Sustainable’ focuses on meeting the health care needs of both current and future generations”

(Health Workforce Australia [2013]:
Health LEADS Australia: the Australian Health Leadership Framework, 2013)

The challenge was to develop a framework that helps evaluate health services performance, role and impact on community health and well-being; an evaluation process has been proposed, that includes indicators for health service performance, sustainability and quality of treatment goals and outcomes (R. Tham et al., 2010; Rachel Tham, Humphreys, Kinsman, Buykx, Asaid, & Tuohey, 2011). Community engagement strategies lead to co-production and community co-designed health services (Bovaird & Loeffler, 2013; Boyle, Harris, Foundation, Technology, & Science, 2009; Fenwick, 2012; Munoz, 2013; Munoz, Farmer, Warburton, & Hall, 2014; Amy Nimegeer et al., 2011; Ramirez, 1999; Roberts, Nimegeer, Farmer, & Heaney, 2014)

In order to develop successful interventions to address community health needs, leadership from the health service would be required. In addition, skills in coproduction where the health service helps to facilitate interventions designed by community participants would also be necessary. Coproduction and participatory development can be seen as a key drivers for successful outcomes and interventions as co-produced interventions have a higher success rate than those imposed in a top down process by health bureaucracies and government policy government policy (Eversole, 2010; Ottmann, Laragy, Allen, & Feldman, 2011).
SECTION SIX:
Engaging community members

Community participation: Engaging community members

- Although the term ‘engagement’ is frequently used interchangeably with ‘participation’, a fundamental difference is the inferred development of a collaborative relationship associated with the concept of engagement.
- O’Mara-Eves, Brunton, McDaid, Oliver, Kavanagh et al. (2013) describe engagement as an umbrella term, that depicts a continuum of approaches or ways of interaction to involve community members in decision-making.
- Approaches emphasise a shift from consultation towards community development, participation and empowerment.
- Empowerment is recognised as the ideal model of community participation.
- The quality of community participation should be considered in terms of who initiated the engagement (public service organisations or communities); the degree to which people were engaged (consulted, in collaborative partnerships or in control); and whether it is individuals or organised community members who are engaged.
### Key points and the evidence

<table>
<thead>
<tr>
<th>Key points</th>
<th>The evidence</th>
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| Engagement indicates an ongoing and active relationship, which builds social capital through increasing the skills and connections among local people. Engagement develops two types of social capital in particular, ‘bonding’ social capital which connects people more closely to their immediate social groups and social support networks; and ‘bridging’ social capital develops social connections between wider groups which facilitates access to other resources. | • Curtis, A., Ross, H., Marshall, G. R., et. al. (2014).  
| It takes considerable time (at least several months) to build trust and confidence for effective engagement with community members. | • Head, B. W. (2007).  
| Capacity building is crucial for engaging meaningfully, as individuals and groups have very different starting points in terms of the knowledge and experience. | • Head, B. W. (2007).  
| Effective engagement requires transparency about the purpose of engagement and the level of decision-making participants have. | • Curtis, A., Ross, H., Marshall, et. al. (2014). |
| It is important to be inclusive, and empower less advantaged people to participate | • Curtis, A., Ross, H., Marshall, G. R., Baldwin, C., Cavaye, J. et. al. (2014). |
| Engagement builds human and social capital through inclusive group processes fostering social learning and encourages positive social norms. Discussion processes should enable participants to see other perspectives and enable participants to act together more effectively. | • Curtis, A., Ross, H., Marshall, G. R., Baldwin, C., Cavaye, J. et. al. (2014). |
Engaging community members: What we have learnt about the process

i. The ideal of including everyone is flawed, for example our election processes where all over 18 are given the opportunity to vote for the government. Not all people have an opinion or agree with the possible options and therefore the result is the ‘donkey’ vote.

ii. There is little chance that everyone will be content with all outcomes, but at least they got to ‘have their say’.

iii. Those that want to participate, or want to represent those who are unable to participate, will opt in if they believe that their effort will impact on the outcome.

iv. People participate in different ways. Some people are happy to attend structured meetings and formal process, others prefer to engage in less demanding ways.

v. We need to provide an engagement space that is welcoming to all and be prepared to work with community members to find the most appropriate ways of engagement.

vi. Be proactive and prepared to go out to places where community members naturally meet to capitalise on engagement.

vii. Be prepared to listen to community members, especially those that are often absent from our engagement processes – this means seeking out those people and making time to hear what they have to say.

viii. There is no “one size fits all” model of engagement. The best way is through trial and error remembering that every community is different.

ix. Do your homework – learn about the history and the context of the community you are working with. This will be important for the success of any engagement process.
Title:

Why do Rural People Participate in Community Initiatives? A Case Study of an Australian Community Bank

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ABSTRACT

Background

Health policy emphasises the importance of working collaboratively with rural communities. However, major knowledge gaps limit policy translation at the community-level. Rural places have fewer services and higher need for community participation, which is often used to fill service gaps and leverage outcomes from rural community assets. The aim of this study was to increase understanding of rural community participation, by exploring why rural people participate in community initiatives.

Methods

A qualitative case study was conducted of a highly regarded Australian rural community bank, located in North-west Victoria (pop <6,000). Data were key informant interviews (n=6), historical documents, media reports, and webpages (n=30), and fieldwork observations, which were analysed for descriptive themes and conceptual findings.

Results

Themes of the ten per centers, benefit to community, and taking control describe how community participation was driven by emotional connections to place. Conceptual findings indicate a place-based participation framework that draws on place theories would increase understanding of rural community participation.

Conclusions

Study findings reveal how rural community participation is influenced by interrelationships between people, place and community. Knowledge of motivations and drivers of rural
community participation will inform the development and implementation of innovative public health initiatives.

**Keywords**

Community participation, rural health, place attachment, health policy, case study

**BACKGROUND**

Internationally, health policy emphasises the importance of working collaboratively with communities when implementing health improvement programs and initiatives [1-4]. Much of this policy is underpinned by The Ottawa Charter [5] and the World Health Organization primary healthcare reform agenda [6, 7], where community participation is promoted as a key strategy for population health and wellbeing.

In Western countries, policy is enacted through governments requiring health organisations to seek out and utilise various community participation strategies [2, 8]. Whilst these requirements are in theory directed at improving health outcomes, researchers argue there are major knowledge gaps concerning community participation that limits the translation of policy to the community or health service level [3, 4, 9]. Practitioners and community leaders report difficulties with mobilising communities to take action on health issues [10-12]. Engaging a wide range of community members can be challenging, and it is difficult to sustain community motivation and interest for the duration of initiatives [10].

Rural places have fewer services and higher need for community participation, which is often used to fill service gaps and leverage outcomes from rural community assets [13].
Across rural Australia, the Community Bank initiative, uses a model of community participation that is unlike approaches used in the health service sector. Rural community participation is used to leverage local assets and resources to establish a community-owned banking business [14]. The community-owned business operates as a conduit between the private Australian company, Bendigo Bank, and the community. Australian rural community banks operate in the ‘Third Sector’ as a type of co-operative, hybrid social enterprise (dual purpose business, 50 per cent of profits are reinvested for social, environmental and community good [15, 16]).

Internationally, the community banking initiative is identified as an exemplary model of rural community participation [14, 17]. In Australia, over 100 rural communities participating in the national initiative [18]. Compared to existing services, community banking is argued to be user-centred, which offers a greater voice to consumers and personalised services tailored to grassroots community needs [14, 19]. Despite the availability of alternative, competitive banking products and services available online, the appeal of community banking is reported to be unwavering [20].

Our interest in the community banking sector focuses on the success of these initiatives in mobilising communities to participate. Through the exploration of motivators and drivers for community participation in the rural community banking sector, our purpose was to identify useful learnings on why people participate in community banking. Given the challenges of facilitating participation with rural health initiatives, we were keen to examine a case study drawn from the successful community banking sector, to identify key factors that might assist with the translation of participation policies within the health service context [3, 4, 9].

**Defining community participation**
There are numerous definitions and understandings of community participation within the health literature. Community participation can be defined as both a process, and objective or an end result [4]. When used as a process, community participation is understood as the joint action people take, within their shared locality or setting, to pursue common interests and needs [21]. Authors describe community participation as an evolving process [1] that emerges as a vague mosaic [22], occurring differently across contexts as a “reflection of the context in which it takes place over time” [1]. Generally, key features of community participation processes include leadership, capacity building, resource mobilisation, and governance [1]. Outcomes of community participation are usually concerned with issues of power and control, which have proved difficult to quantify and measure [1, 3, 4].

**Community participation in the rural context**

In the rural context, researchers describe significant practical challenges with community participation [23]. Small communities, with a history of health service closures, can be difficult to mobilise for health service participation because of entrenched institutional mistrust [24, 25]. Bureaucracies and power differentials can create divisions between institutions and community members, which prevents meaningful co-operation required for long term planning and development projects [26]. Conflicting interests between participants and groups are more pronounced in small rural populations [23]. Few rural places have economies of scale, and many essential community services are reliant on volunteers [27]. Geographical characteristics of rural places can be obstacles, including population size and distribution, relative distance to health amenities, and the physical landscape [1, 28-30].

Research in rural settings is crucial to develop a comprehensive understanding of their unique contextual challenges [23, 28, 31]. While increasing numbers of researchers attempt to measure outcomes of community participation in rural health settings [32, 33], fewer
studies explore the critical step of why rural community members participate. It is unclear why rural people participate with particular initiatives, but choose not to participate with others [23, 28], and a number of challenges are unresolved [4, 23]. Further conceptual exploration is required to critically examine why rural communities participate and how barriers are overcome.

**Aim**

The aim of this study was to explore *why* a community participated with the rural community banking initiative, and to understand contextual drivers and motivations. Using a qualitative case study approach, we hypothesized that learning’s from the community banking sector might be transferable to address knowledge gaps in enacting participation within a rural health context [4, 24, 28, 34].

**METHODS**

**Situating the researchers**

As practitioners and researchers in the health sector, we are acutely aware of the challenges encountered by health professionals undertaking community participation initiatives. While none of the researchers participate with community banking, where we live, in rural Victoria, Australia, community banking is a popular form of participation. In selecting an existing, successful case of community banking, we aimed to understand why people and communities become involved, through investigating the context of community participation and the experiences of community banking leaders. Selecting a local case study provided us with unique insight into the case study context [35], including lived experience of the natural disasters and major economic challenges that have impacted our region.

**Study design**
The qualitative case study design incorporated Stake’s [35] instrumental case study approach, which was used to investigate the phenomena of interest – community participation. This study design is effective for gathering rich descriptive data, and allows for selection of data sources and analysis methods that are most suited for understanding the case [36-38]. Drawing from naturalistic case study principles, this particular case was studied with minimum intervention, by gathering perspectives on the case from existing sources of data that were available in the bounded context (place and time) [39]. Ethics approval from La Trobe University, Human Research Ethics Committee (approval number FHEC13/170) was obtained for the procedures described.

Case selection

In using Stake’s qualitative case study tradition we selected a case that exemplified strong community participation, which was bounded by rural (community) context [35]. An established community bank was purposively selected in consultation with the Bendigo Bank national office that oversees the initiative. The Eylestown (pseudonym) community bank is located in a rural town of Victoria, Australia, with a population of approximately 1,000 people. This particular community bank was identified as an exemplary initiative, which has been sustained for 10 years, has increased its scale of operations and scope of community grants and sponsorships.

Data collection

Multiple data sources were sampled, to collect sufficient contextual data, to develop a holistic case study and to enhance data triangulation [35, 37]. Sources included in-person interviews with key informants, field notes and researcher reflections, and data from documents and webpages.

Interviews
The community bank chairperson identified potential participants associated with the community bank, who were invited to participate in the study via email. Six people provided written consent and participated in a face to face interview during July 2014. Interviews were semi-structured and included open-ended questions regarding their motivations and aspirations, and experiences with, and perspectives on community participation with the bank, for example ‘why do you participate with the community bank?’ and ‘what do you hope to achieve?’ Interviews were held at the participant’s home or at the community bank site, ranged from 45-90 minutes, were audio-recorded and transcribed verbatim. Table 1 describes the sample of participants, which is provided to increase understanding of the actors in the case study [35]. Field observations and interviewer reflections were recorded during visits to the town to support researcher immersion in the case and understanding of case context [39].

Table I Description of participants

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Gender</th>
<th>Age (&lt;50 or &gt;50)</th>
<th>Employment status</th>
<th>Past or Current involvement</th>
<th>Time served</th>
</tr>
</thead>
<tbody>
<tr>
<td>Geoff</td>
<td>Male</td>
<td>&gt;50</td>
<td>Retired</td>
<td>Past</td>
<td>&gt;5 years</td>
</tr>
<tr>
<td>Michael</td>
<td>Male</td>
<td>&gt;50</td>
<td>Semi-retired</td>
<td>Current</td>
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</tr>
<tr>
<td>John</td>
<td>Male</td>
<td>&gt;50</td>
<td>Retired</td>
<td>Past</td>
<td>&gt;5 years</td>
</tr>
<tr>
<td>Steve</td>
<td>Male</td>
<td>&lt;50</td>
<td>Employed full time</td>
<td>Current</td>
<td>&lt;5 years</td>
</tr>
<tr>
<td>Jack</td>
<td>Male</td>
<td>&gt;50</td>
<td>Employed part time</td>
<td>Current</td>
<td>&gt;5 years</td>
</tr>
<tr>
<td>Bob</td>
<td>Male</td>
<td>&lt;50</td>
<td>Employed full time</td>
<td>Current</td>
<td>&gt;5 years</td>
</tr>
</tbody>
</table>
Documents and webpages

Consistent with case study approaches, data in the form of documents and webpages (N=30) were obtained in addition to interviews to gain an in-depth understanding of the case study context [37]. Media releases and newspaper articles were provided of the community bank launch (n=6) and the first public meeting (n=2). The webpages of the community bank and the local Shire were reviewed and pages that contained information on community participation and that described the community context (social, political, physical aspects) (n=10) were included using the NVivo 10 NCapture application [40]. The community bank steering committee plan and business establishment plan (n=2), and annual chairpersons reports (n=10) were included, which provided additional information on why the community established the bank, and how people came to be involved with the initiative.

Data analysis

Data coding was completed using NVivo 10 qualitative data management software [40]. All data sources were thematically analysed using coding techniques common to qualitative case study approaches, including descriptive, in vivo, emotion and value coding methods [41]. Codes were grouped into categories, which were analysed to develop themes [41]. The themes that describe the community members reasons for participating with the community bank include: the ten per centers, benefit to community, and taking control. Thematic descriptions are supported by verbatim narrative for readers to compare the participants’ experiences of participation with their own. This process, known as naturalistic generalization, aims to assist the reader to be an active participant in the construction of new knowledge [35].

RESULTS
Case background

A group of local residents established the Eylestown community bank during 2002-2003, local residents own the bank and it is operated by a board of directors. Since establishment, the community banking business has grown to include three additional bank outlets, which serves a district of approximately 6,000 people. All profits are shared equally between the Bendigo Bank corporation and Eylestown, a strategy aimed at boosting small rural town survival and sustainability [42].

Community participation in the establishment phase included consultation meetings, a business feasibility study, marketing through local media, and promotional activities. Participation with the Eylestown community bank has endured many difficult periods, including drought, floods and the global financial crisis. Overall, Eylestown has operated the community bank for approximately 10 years and distributed $1 million in profits into the community through various sponsorships and grants. The scope of sponsorship has increased to include a major infrastructure project to support sport and leisure participation, and tourism. A wide range of community groups, including schools and sports clubs, have received small grants to purchase essential equipment or to upgrade their facilities.

The study participants, past and current board directors and one staff member, volunteer their time to the bank, and four participants have been involved for its duration (10 years). The study participants, all male, mainly semi-retired or retired business owners, farmers and school teachers, commented that it was difficult to engage female board members, and none had been appointed long term. A future strategy to increase youth participation was identified, for increasing the range of community views, and for ensuring board succession.

Themes
The descriptive themes: the “ten per centers”, benefit to community and taking control reflected the study participants’ reasons for participating in the community bank. Thematic descriptions are supported by verbatim narrative for readers to compare the participants’ experiences of participation with their own. This process, known as naturalistic generalization [38, 43], aims to assist the reader to be an active participant in the construction of new knowledge [35].

**The “ten per centers”**

The “ten per centers” was the name given to the highly committed people involved with the Eylestown community bank. Descriptions of this group were provided by all interviewees and in the chairperson’s reports and media releases. The ten per centers are community-minded people with an extensive history of participation. For example, the participants were involved beyond the community bank with farmer organisations, football club management, country fire brigades, and hospital and sports club fundraising. The ten per centers were described as people who are known to participate with various initiatives, and who are frequently approached for their leadership, support, and for access to their networks.

Participation with Eylestown community bank was described as enjoyable, interesting, and rewarding. Steve states that he enjoyed being on the board, “I quite enjoy the work… I don't feel it's onerous or anything like that, I don't mind doing that, it's enjoyable”. The participants’ described their hopes for making an impact through their participation, and the enjoyment that they received from the company of the people involved, and the opportunity to learn from others and to share knowledge and skills. Geoff explained how a diverse range of perspectives were valued, and that this helped to define board member roles and ensure representation of a variety of community views.
John believed that the percentage of people who participate, the ten per cent, is fairly static, and he relates this to over 50 years of experience with a range of community initiatives. He stated, “I think in any community, there are 10% of people that make things happen, 40% who watch things happen, and 50% of people say ‘what’s happened?’” John reflected on his experiences as bank chairperson,

You are always trying to get more people involved, but I think that little formula is pretty right. You’ve got a certain number of people that will lead, and you’ve got a certain number who will join in and support you, and you’ve got a certain number who don’t want to be involved.

In this quote, John describes feeling unsure of whether promotion and marketing strategies actually change the percentage of people who participate. To support his claim, John described the differences between the people who chose to participate with the bank, and those who opted out or opposed it:

Well when you think about it, it’s only a small community, go back to our committee of 10, there is a small hard core group that are quite determined to promote it, and below that a section of the community that will support it in name, and they are our shareholders and account holders, and beyond that are the group that are either too lazy to change or don’t even entertain the thought, and the far end are the radicals that are totally opposed.

All participants agreed that despite their ongoing efforts to involve the broader community, they do not expect everyone to participate. However, this confused and disappointed them. John explained:
Oh I tended to ignore them after a while, you never get 100 per cent. Some of my board members in those days, they’d get a bad comment from somebody, because you’re asking people for money, eventually, and I’d say well look we’ve never get a 100 per cent and some people won’t like you, they won’t like me, I don’t know why, so you’ll never get a 100 per cent of people supporting you. But no, I just tried to ignore them.

Participants described that ten per centers are people who are not deterred by hard work or responsibility, characterising their board director role by self-sacrifice and selflessness. Michael described his position on the board as a “labour of love”, and stated that he was prepared to accept personal responsibility if the community bank failed. The participants provided several anecdotes of key people who were involved in establishing the community bank, which demonstrate the value of ten per centers. For example, the participants provided stories of farmers who moved their business to the community bank, despite tough financial times caused by drought, transfer fees, and less competitive products. A participant recalled how a local businessman owned a local bank agency outlet, and sold this agency to the bank at a low price, which provided essential start-up capital and improved bank feasibility. Another recalled how a local servicemen’s group provided the land to a local builder to build the bank, which is leased on a long term agreement at less than market price. Although they were only a small percentage of the community overall, the participants identified the ten per centers as instrumental to the community bank establishment and long term success.

_Benefit to community_
Participants agreed that their central motivation to participate is their belief that the bank will benefit the community. John explained, “It’s a method of pouring money back in the community that the big banks don’t do.” Their motivations draw from success stories shared by other banks, and Bob explains that this is especially important in a rural context, “small country towns are the real success stories”. Success stories and possibilities are prominent in promotional materials produced by the Bendigo Bank, rural word-of-mouth, and the media. Participants described the success of community banks by the number of franchises, the amount of money raised, and number of grants and sponsorships distributed. John explained: “Once you get involved, and once you start finding out what can be achieved, well then you get enthusiastic and you want to push it along and make it happen”. It is accepted that not all rural community banks are immediately successful, but the ones that have been successful inspire hope and belief in the concept and its potential.

The goal shared by the participants was to create a community-controlled revenue stream to invest in community groups and assets. It is their opinion that investment in community assets would attract newcomers and retain residents, and enhance community sustainability. Michael said sponsorship provides important opportunities for new residents to integrate and mix with existing residents. Bank sponsorship of infrastructure projects is expected to attract young people to return home after completing university studies (Michael and Steve). Additionally, grants provided to leisure and sporting groups enable elderly residents to remain active and well (Bob and John). Participants strongly believed that investment in their community would slow the population decline and enhance town liveability.

Participants argued that community members who banked with them shared their belief in the concept. Jack explained: “Oh, I think people can see that the benefits that have accrued in the last ten years, the amount of money that’s come into the community, is
probably up to about 1.2 million now, in ten years, which is amazing.” Jack described how community bank grants and sponsorships are channelled into programs that target community needs, “…there's been particular focus to some of the major sponsorships towards the youth, so it's trying to support the clubs in continuing to promote their sports to young people, so that's certainly getting young kids healthy, [which] has a health aspect to it.” Additionally, sponsorships are provided to arts projects and sporting clubs, Bob explained that the bank provides support for community groups, which “…might still exist anyway, but are able to function better”. They believed distributing sponsorships and grants strengthened the community’s belief in the concept and reinforced motivations to support their community banking business. Their belief in the benefit to community outweighs fears, risks and challenges. Reflecting on his ability to maintain his motivation, Bob stated “you’d never do it unless you really believed in it”.

**Taking control**

The participants described how the events of drought, bank and business closures, and population decline, prompted rural residents to come together and find a solution to their concerns. Geoff described how bank closures spurred him to take action:

Basically what happened was the banks went through a period of closing down country branches, and at one stage we had four, we had four major banks represented in town and one by one they gradually closed down. The last one to go was the Big Bank

a. The others had put in agencies or else had shifted their account holders to a different town. The Big Bank was the last one to close down and so happens, my daughter was working at the Big Bank … the town was quite upset, not only are you losing population, you are losing workers
The bank closures caused an emotional response in the community, and action to establish the community bank was fuelled by “anti-big bank sentiment” (Jack) and concerns about the future of their town. John explained:

The two other banks closed, and everyone got a bit depressed, you know ‘the town is finished’ ‘what’s going to happen to [the town]?’ And then we started to promote the idea of bringing in a community bank. So that created a bit of interest in people’s eye, people were saying well that something’s that might happen.

Establishing a community bank was seen as an opportunity to create a new future for their town, which capitalised on the community’s antagonism towards the big banks (Michael). Participants recalled that during the period of bank closures, residents were vocal about their concerns regarding Eyestown’s future. Michael explained how the bank closures affected him personally:

We banked with Australia Bank, my grandfather and father, we had banked with Australia Bank for years and years and years. And we got this letter in the mail, directing our account to [nearby town located approximately 60 kilometres away]. And it was really, we had like a hundred years of banking with them and we got a letter telling us, you know, that our banking would be located in [other town]. No thank you very much, no courtesy phone call to ask where we would like to do our banking, and yeah I was pretty insulted by that. I just thought that was astonishing.

The participants’ shared concerns about the sustainability of their small community, which held a tradition of being a prosperous and proud town. Michael explained, “Well I’m born
and bred here, never been anywhere else”, and two participants have lived on family farms locally for three generations (Michael and Steve). Building a successful community bank was hoped to rejuvenate town pride and community spirit. John explained:

Ohh well it’s just another pride I suppose, you need to do something, and we’ve got a nice facility, and it’s just like anything in the town, you want to see your town improving, you want something significant, and you don’t want to see your little town disintegrating.

The participants described how the physical presence of the community bank emerged as a symbol of hope. The participants retold the story of how the community bank was built. The community were surprised by the rare sight of building construction on a heritage main street, and were excited by the opening of a new business during a 10-year drought. The local newspaper associated the community bank opening with new life and growth. The headlines read “Cutting the cord”, with a picture of the local doctor cutting the ceremonial ribbon at the bank opening. The doctor stated “Today we celebrate a birth in Eylestown. It has been over 12 months since a baby was delivered at the Eylestown Hospital, but today we are celebrating the birth of a new business in the town”. John described:

Yeah nothing much happens in these sort of towns, but this was a vacant block, we had to go and negotiate with the Servicemen’s Club to buy the land, and negotiate with the builder to build it … We had a bit of fun, because it was a tin fence that was there before, and we kid ourselves our bit, and said to the builder, we will just cut a hole in the fence, an inspection hole, [indicates this is for people to peek through, laughing] it was like we were building a skyscraper in a big city

The “presence of a viable community bank” (Bob) was important to renew faith in community wellbeing and sustainability. Michael contends the bank closures were “more
than just losing a bank”, but were visible evidence of their town decline, which impacted on community spirit. The participants agreed that building the community bank was a timely, community-driven solution that was effective in solving their collective problem.

**DISCUSSION**

**Rural community participation**

The findings provide a unique insight into why communities participate in a rural context. In the context of community banking, participants included volunteer board directors, shareholders and account holders, who Cutcher [14] describes as ‘co-producers’, meaning they are active participants in the consumption and production of products and services. Community bank leaders can be understood as ‘local champions’ [23], who are capable and confident operating a not-for-profit company within a legal business franchise agreement. The community bank leaders were deeply embedded within their understanding of ‘community’, which allowed them to activate and mobilize social networks integral to bank establishment and sustainability [44].

Health policy-makers and executives have expressed interest in co-operative or co-production models in the healthcare sector [45, 46], which are similar to community banking. However, there are risks in employing co-operative models in rural communities [47]. Volunteer labour may be exploited for commercial gain, for example, Bendigo Bank is entitled to 50 per cent of profits from the community-run business. A high burden of responsibility is placed on local leadership, for example, the ten per centers.

The community bank leaders who participated in the study were all male, and mainly middle-aged, retired or semi-retired, business owners, farmers and school teachers. This sample reflects the demographic profile of community bank board directors at a national
level. Nationally, the majority of board members are male and middle aged, and 32% identify themselves as small business owners [14]. Cutcher [14] argues that small business owners are the population group with the most to lose from dissolution of rural banking services, which underpins their participation.

The focus of our discussion will be on examining the thematic findings to build theory on why rural people participate in community initiatives. Improved understanding of the motivators and drivers for community participation is needed to overcome the myriad of challenges involved with enacting community participation within a rural health context [4, 24, 28, 34, 48].

**Community and place attachment**

In this Australian study, rural people participated in community banking because of the value they placed in community sustainability and wellbeing. The rural community was important to the participants, and the findings illustrate how emotional connections and attachments to place drive community participation.

Manzo and Perkins [49] explore the relationship between place attachment and community participation, and argue that cross-disciplinary health and place research is needed to understand complex issues with community participation. Adopting this novel analytic lens of place and community attachment theories, we explore why place attachment has an influence, which will increase understanding of the reasons why people participate with community initiatives, and provide new insights to researchers. Whilst this case study is of community banking, the findings illuminate the participants’ rural community participation experience, which has broader implications for health and social science research.
Universally, people are known to form emotional attachments to geographical locations they perceive as meaningful or significant, through their everyday experiences with places [50]. In our study, the participants’ emotional connections with Eylestown, was formed and developed through their experiences with family and friends, community work and local employment. Attachment to places are thought to strengthen over time [50], which is evident in the participants’ long standing connections to the community, which for some, was fostered over many generations. The participants described how their emotional connections to Eylestown strongly influenced their participation with community banking, and they expressed desires to protect and preserve the community for themselves and for their family and friends.

In our study, the connection between participation with community banking and place attachment was illustrated by the participants’ reflections on place identity and place dependence. Williams and colleagues [51] contend that places become intertwined with peoples’ identities, and over time, people become dependent on places to sustain their livelihood and wellbeing. Participants, who worked on farms and in local schools and businesses, were cognizant of several threats to Eylestown. Population decline, loss of business and local employment, and relocation of families and elderly residents away from Eylestown, directly impacted on the participants and their capacity to sustain employment and be financially secure. Threats to Eylestown were perceived as having a major impact on participants’ sense of wellbeing [51]. Because of the value they placed on being an Eylestown community member, they were willing to take action on threats to preserve this important part of their identity.

The links between emotional connections with community and community participation can be explored through the lens of community attachment theory. In previous studies, authors have identified that high community attachment contributes to participation,
for example community members participated in pro-environmental action on unwanted industrial and residential developments to protect the natural landscape and valued place features they believed distinguished their community from others [49, 52, 53]. In our study, participation in community banking was driven by a similar desire to protect community and to maintain valued place characteristics and resources, such as sporting and leisure facilities and heritage buildings.

Within the Eylestown community, the participants’ feelings of belonging and sense of community demonstrate a strong community attachment [52]. Feelings of belonging arise through the development of social bonds, and in our study this was evident through participants’ neighbourhood relations, shared history, culture and traditions, mutual concerns and interests, and perceptions of trust and cohesion [49, 54]. In a rural context, strong feelings of belonging are known to increase community participation and are associated with community resilience [55]. The participants’ expressed positive perceptions of community, which is thought to improve community identity, community capacity and empowerment [56, 57]. Ponzetti [58] argued that sense of community is a major influence in why people value and choose to live in rural places, despite challenging environmental conditions, which was evident in Eylestown where participants’ experienced severe drought and floods.

Community attachments are thought to serve several functions. In Eylestown, the participants’ community attachments were useful in creating social networks, which other authors have argued are important for community safety [52]. In our study, the decline of the community and threats to banking services and financial security disrupted community attachment and prompted varied responses, including grief and loss, apathy or ambivalence [54, 59]. While participants’ appeared to have positive community attachments that were conducive to community participation in times of threat, other community members did not
participate. It is argued that people can feel oppressed or restricted by place attachment, which results in non-participation or opposition [59].

Disruptions to place and community attachments reveal previously hidden or subconscious place meanings and values, which inspired the participants to commit to and participate in community planning and development [49, 52]. Mihaylov and Perkins [52] Model of Community Place Attachment Leading to Collective Action, Adaptation, or Acceptance in Response to Environmental Disruption, can be used to understand why some community members participated with the community bank, and others chose not to. By applying Mihaylov and Perkins [52] model to our work, participants’ responses to threat can be understood as fear for community safety, and the actions of the ten per centers as protective and adaptive.

In Eylestown, only a small percentage of community members volunteered to protect their community from threat. Manzo and Perkins [49] state that “Certainly, there are cases where people do not identify with their neighborhood, where they do not feel attached or have a sense of community, and where they do not participate in community improvement or planning efforts” [49]. For the 90 per cent of community members who were not highly involved with the community bank, their participation avoidance could reflect an acceptance of how things are, a lower desire or need to protect the community, or high confidence in the community leaders (the ten per centers) [52]. A low level of place attachment could result from the increasingly transient nature of rural communities in Western countries [60, 61]. Place attachment in rural populations is likely to be influenced by seasonal and contractual nature of major industries, commonly agriculture and mining, and the influx of retirees, ‘tree-changers’ and second home owners, and the new arrival of low-income families who move to rural areas to secure affordable housing [62-64].
Another drawback of using place and community attachment theories to inform community participation initiatives, is that community members with no or lower attachments are likely to be excluded [59]. In establishing the Eylestown community bank, strategies that called on place attachment to mobilise community participation divided the community. This supports Manzo’s [59] contention that place attachment is not always inclusive or functional. However, using place attachment and drawing upon community vision and values was effective in activating ten per cent of the community, which was sufficient to meet and exceed the community banks financial objectives.

Definitional problems associated with ‘community’ make it difficult to apply community attachment theories in all contexts [52]. The concept of community has been heavily criticised, and practitioners are yet to reach a common understanding [52, 65-67]. It is generally agreed that community is not a simple notion, being both spatiality and socially constructed, and the meaning of community varies across contexts [8], and for members and non-members [65]. The only consensus reached across studies is that communities involve people [65], are more than a shared locality, and are inseparable from context or place [1, 8, 65, 68], which is reflected in the participants’ vision of Eylestown.

The German philosopher Ferdinand Tonnies [69] defined community, Gemeinshaft, as dichotomous with modern society, or Gesellschaft. In communities, he proposed, people live traditional and harmonious, communal ways, and bond over shared social mores, seeking help from each other, independent of the State [69]. Tonnies [69] suggested that in rural places, like Eylestown, this characterisation of community is more pronounced, stating “all praise of rural life has pointed out that the Gemeinshaft among people is stronger there and more alive; it is the lasting and genuine form of living together” [69]. Critics have deconstructed this romanticised characterisation of community [23, 68], which reveals that modern understandings of rural communities may be better aligned with Tonnies [69].
definition of *Gesellschaft*. Tonnies [69] contends societies are places where people are driven by rationalised individualism and self-interest, where individuals act inter-dependently, governed by a capitalist market and State law. In our study, the participants’ experiences of rural community banking illustrates that Gemeinshaft is important for motivating community participation, however, *Gesellschaft* is required for meeting the communities financial objectives and for ensuring initiative sustainability [20].

The commodification of Gemeinshaft within community banking initiatives was examined by Cutcher [14], who suggests romanticised views of community have been cleverly integrated into marketing and branding. She proposes that the perceived demise of Gemeinshaft in rural places has increased participation with community banking initiatives, and contributed to the brands appeal [14]. The use of nostalgia and the past, as a lens for critiquing the present, is used as a key emotional driver [70]. Participation with community banking is driven by nostalgia for the traditional sense of community, which is underpinned by a sense of loss and fear of modernization, and desire for moral certainty and traditional simplicity [70]. Within Eylestown, the community bank appeared to benefit from this juncture, drawing motivations to participate from both backward-looking romanticism of traditional customer service and loyalty, and progressive forward thinking of producing a sustainable revenue stream for town sustainability [20].

Within the health context, exploitation of Gemeinshaft for organisational and political purposes is not a new phenomenon [68]. A community is often narrowly defined as an entity or object, a ‘thing’ that is controlled or harnessed, or a target group identified for a specific purpose or problem [65]. Criticised as politically persuasive, community is used as a label or brand, which never seems to be used unfavourably, and is employed to conjure nice images of imagined people and places [65, 68]. A Gemeinshaft view positions ‘community’ for commodification, which is exemplified through community banking and health policy in
Australia and the UK. We have highlighted that rural communities contain diverse attitudes towards participation, which may limit translation of health policy that relies on communities adopting Tonnies traditional views [69].

In the absence or inaccuracy of ‘community’ [68], the development of a place-based participation framework, drawn from place theories, could offer an alternate theoretical framework for participation that can be used to inform health policy initiatives. Place-based participation may be a more accurate definition, which avoids misleading people, or using idealistic visions of ‘community’ to co-opt or exploit residents’ time and energy. However, Eylestown residents may have been less willing or motivated to participate if the community ideology was not used. Health policy makers are recommended to consider the potential harmful consequences of using an unrealistic or unattainable ‘community’ vision to motivate participation and build initiatives, which could include institutional mistrust, exclusion and social divisions [10, 23]. In our study, we have highlighted how the vision of Gemeinshaft was at the crux of why people participated with community banking, which was sufficient to motivate the ten per cent and achieve objectives of town sustainability. Not all Eylestown residents were motivated by traditional community ideals, nostalgia or romanticised visions of social togetherness, however, non-participation did not deter the ten per centers from achieving community objectives for the benefit of others.

**Study limitations**

This is a small case study that contributes preliminary theoretical and conceptual findings that will provide a foundation for further empirical research. This case study had a small sample size of interviewees, however, repetition of interview content across participants indicated data saturation, and data triangulation was used to confer interview content and to understand study context [35]. The themes relate personal accounts of motives
and drivers recalled by the participants, who were a sample of highly involved, community-minded males who regularly participate with local development initiatives.

Using qualitative case study, our findings cannot be generalized to other populations [35, 37]. It was not our intention to represent the breadth or diversity inherent in rural community participation, which has been reported by several authors [46, 48, 71, 72]. The gender profile, for example, of participation in community banking initiatives differs to rural participation more broadly, which is generally even [71], or has slightly higher rates of female participation [73]. The middle-age dominance of participants in community banking, however, does exemplify the ‘greying’ nature of rural communities, and the ageing profile of rural places in Western countries [13, 72].

The themes do not account for the experiences of community members who were less involved, or did not participate, and we recommend further study of non-participation and community exclusion, to understand the influence of place attachment on community participation in its entirety.

CONCLUSIONS

In a rural context, participant motivations for community banking strongly related to desires for community sustainability and wellbeing, and were driven by emotional connections to place. The case study exemplified the perspectives of community-minded people who were highly involved with community groups and initiatives, and found participation to be enjoyable and rewarding. Participation stemmed from vision of community and community values and was motivated by threat to place identity and livelihood. Using community place attachment theory to conceptualise the person-place-community relationship is useful for understanding reasons why people participate in community initiatives. The findings emphasise that while a small percentage of community
members choose to become highly involved in community planning and development efforts, others who demonstrate lower or no attachment to places may avoid participating, or might be excluded.

Further exploration of the links between community participation and place could be achieved through a longitudinal study design and use of place attachment measurement tools. Research findings would be valuable for designing health and wellness programs that are better suited to residents’ placed-based motivations and needs. Limitations of place-based approaches must be considered, and the problems that emerge when defining ‘community’, or when community is commodified or exploited for political or commercial gain. Ongoing challenges with community participation indicate that a new place-based participation framework could be explored, which draws on place theories to understand participation. Overall, further understanding of the connections between people, places and communities is needed.

ABBREVIATIONS

UK: United Kingdom

COMPETING INTERESTS

The authors declare that they have no competing interests.

AUTHOR CONTRIBUTIONS

All authors made a substantive contribution to the conception and design of the research. NH collected the data and completed preliminary data analyses. All authors analysed and confirmed case study findings, and contributed to the preparation of the manuscript, including drafting and revisions.

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\(^a\) Bank name removed to protect anonymity

\(^b\) Bank name removed to protect anonymity
Review Article

Scoping review of the exclusion and inclusion of rural newcomers in community participation

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Abstract

Few studies have considered the impact of rural migration on rural community engagement. The objective of this research was to undertake a scoping review about the inclusion and exclusion of newcomers in rural community participation to inform design of inclusive participation processes. The scoping review used the six stages of Arksey and O’Malley’s methodological framework. Narrative analysis of the articles was structured using three themes of inclusion and exclusion derived from the literature: interpersonal, socio-cultural norms, and structural and organisational processes. Inclusion and exclusion at the interpersonal level is intricate and often represents broader social rules and tensions that newcomers must navigate in order to become involved. Social norms, such as fear of outsiders and difference, can exclude newcomers from participating in a rural community. Newcomer’s awareness of these issues means they are mindful of how they contribute and give respect to the social position of existing residents. Despite this, resistance to change is experienced by newcomers when contributing in organisational contexts. Formal participation processes can harness the practice and value of rural hospitality that newcomers experience as inclusionary. Deliberately designing group processes and operational norms for inclusion can reduce tensions when change occurs and prevent group loss due to exclusionary practices.

KEY WORDS: community development, immigration, rural issues, scoping review, social planning.

Introduction

Few studies have considered the impact of rural migration on rural community engagement. Developing inclusive strategies for integrating newcomers in the rural community will be central to rural health services better representing and responding to the changing health needs of communities.

Frequently, community participation research fails to fully represent the complex nature of communities, human interaction, and relationships between individuals and systems. Instead researchers regularly question the effectiveness of participation, the problems with principles of participation and practical barriers to individuals participating. Oversimplifying the complexities of participation in health decision making potentially reduces the exercise to a tick box approach to fulfil state-imposed requirements rather than a genuine response to community needs. This approach has been critiqued for failing to challenge the structures that continue to create disadvantage and thus poor health. The fallout from this has been a tendency for health services to focus on quantitative representation rather than on the quality of participation.

Using an inclusion and exclusion lens enhances the effectiveness of the processes of participation, therefore creating more meaningful outcomes from participation. An inclusive framework focuses on the way we work and the structures within a community, rather than on the inability of the community to engage, to achieve quality in participation and more meaningful outcomes. It is these conditions that contribute to health promoting conditions of participation in rural health care.

The benefits of strong social ties and support networks for health have been long recognised as part of the movement and action of social determinants of health. Marmot and Wilkinson’s study of socioeconomic circumstances and well-being across the globe concluded that social inclusion has a protective effect on health, encouraging healthier behaviour patterns and creating feelings of happiness. Communities also benefit

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from social inclusion through improved social capital, improved education, reduced poverty, better housing, increased reciprocity and reduced drug use.12–14 These benefits enable community capacity to adapt to changing situations.

Newcomers to rural areas are diverse in identity and can bring with them resources beneficial for the sustainability and health of rural communities. ‘Newcomers’ refers to those people who move within Australia from one region to another, particularly reflecting a recent in-migration trend characterised by amenity expectations related to housing affordability, lifestyle choices and employment.15 Newcomers often have a slightly higher average educational level, are more open minded than long-term residents, have a different range of skills and social networks, contribute to local economy and have energy to contribute to sustaining rural vitality.16–20 In Plowman’s21 study of innovative rural communities, he found that more innovative communities have higher proportions of newcomers. Nevertheless, rural communities are not always welcoming, reflecting the animosity towards urban encroachment and rural dilution.22,23 Resulting tensions act to exclude newcomers from participating in community activities, potentially limiting community change for health.

There is opportunity to design processes of participation to promote inclusion of the diversity present in rural communities. Designing processes to improve skills, supporting openness to new ways of knowing and forming new linkages within rural communities are some of the areas suggested by researcher practitioners.9,24 Understanding existing processes of inclusion and exclusion of newcomers provides some insight into designing participation processes for inclusion. To do this, a scoping review was undertaken to determine what research has been published about the inclusion and exclusion of newcomers in rural community participation to inform design of inclusive participation processes.

Methods

This review used Arksey and O’Malley’s25 methodological framework for scoping studies. To develop a sufficiently broad research question and to aid decision making early in the review, we followed Levac, Colquhoun and O’Brien’s26 advice to combine the question with the purpose of the study. Based on existing knowledge of the community participation in the healthcare literature,27 the research team broadened the search beyond health care. An initial search of key terms and Boolean phrases (Table 1) returned 486 article citations, from which 57 duplicates were removed and a screen of titles and abstracts was conducted based on the inclusion criteria (Table 2). Based on this screening, 12 articles were found to be relevant for full-text assessment from which five articles were selected based on relevance. Although one article combined a mix of metropolitan and regional settings, it was included because of the use of the term ‘regional’. One article28 was added following a search of the references of the 12 full-text articles and another added from our own collections.29 The flow of article selection is represented in Figure 1 using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram, recommended for transparent and complete reporting of review phases.

Consistent with Arksey and O’Malley’s framework, summaries of each article and documented data related to referencing, setting/location, research question(s) or aim, research design, findings and conclusions, and recommendations for further research were made (Table 3). To aid in the final stage, further analysis involved importing the final seven articles into qualitative analysis software. The articles were coded based on a combination of themes derived from the articles and the purpose of the review. We agreed on these themes based on a shared understanding that inclusion and exclusion is both

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TABLE 2: Search terms and Boolean phrases

<table>
<thead>
<tr>
<th>Key word</th>
<th>Boolean search phrases – combined using AND</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inclusion and exclusion</td>
<td>(exclu* OR inclu* OR integrat* OR marginal*)</td>
</tr>
<tr>
<td>Newcomer</td>
<td>('new comer*' OR newcomer* OR outsider* OR 'out sider*' OR incomer* OR 'city settler*' OR settler* OR in-migration OR immigration OR transient* OR commuter* OR 'tree changer*' OR non-resident* OR nonresident* OR non-local* OR returnee*)</td>
</tr>
<tr>
<td>Community participation</td>
<td>('decision making' OR 'local action' OR 'community participation' OR 'citizen participation' OR 'community engagement' OR 'public participation' OR 'consumer participation')</td>
</tr>
<tr>
<td>Rural</td>
<td>(rural* OR region* OR remote* OR 'small town*' OR countryside).</td>
</tr>
</tbody>
</table>

FIGURE 1: Scoping process flow diagram. Developed using the PRISMA diagram. Close-up of the flow diagram showing the scoping process, highlighting the reasons for exclusion and inclusion. It includes details such as conference details, international immigration, and the focus on rural communities.

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### TABLE 3: Summary information of articles reviewed

<table>
<thead>
<tr>
<th>Author</th>
<th>Year</th>
<th>Journal and Location</th>
<th>Country/Location</th>
<th>Research Question/Aim</th>
<th>Research Design</th>
<th>Findings/Conclusions</th>
<th>Recommendations for Further Research</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ngo, M. and Brklacich, M.</td>
<td>2013</td>
<td><em>Agriculture and Human Values</em></td>
<td>Southern Ontario, Canada</td>
<td>This paper explores how new farmers struggle via their day-to-day lives to create their sense of place (identity and sense of community)</td>
<td>Sense of place framework, living and working with farmers, 20 hours semi-structured interviews, observations and participatory photography (210 photographs) with 9 newcomer farmers.</td>
<td>Challenges fitting in – not considered a ‘real farmer’, maintaining links to an urban community, navigating social landscapes of farming and community identity, social dimensions of industrial farming community and local food production farming; mixed experiences – individual circumstances meant being a new farmer ‘was an uneven, differentiated process’; defining expectations – expectations of acceptance, of community</td>
<td>Developing strategies for local food movement farmers to enhance connectivity and opportunities for networking as well as learning exchanges for different needs. Interactions across rural spheres and perceptions of newcomers entering agricultural professions and communities warrant further study.</td>
</tr>
<tr>
<td>Foster, N. and Marshall, J.</td>
<td>2002</td>
<td><em>The Canadian Geographer</em></td>
<td>Grand Manan, Canada</td>
<td>To understand the meanings and significance of migration for Grand Manan and for the migrant Newfoundlanders</td>
<td>35 ethnographic interviews, 20 impromptu conversations, interviews with organisation and school staff, and field observations. (Exact numbers of newcomers and existing residents not known.)</td>
<td>Resentment and resistance of ‘locals’ to new residents has defined social relationships. Particularly through symbolism of housing, travelling for work, competition for jobs and poor attendance of children at schools. It was in the schools where exclusion of newcomers was obvious, specifically children experiencing bullying and racist interactions. Exclusion may be impacted by the characteristics of experience of migration of the ‘receiving community’. Families feeling like they are ‘between belonging’.</td>
<td>Newcomers are clear of their experiences; however, existing residents are not aware of this experience. No specific recommendations were made.</td>
</tr>
<tr>
<td>Lee-Ack, E.</td>
<td>2008</td>
<td><em>Australian Journal on Volunteering</em></td>
<td>South-West Victoria, Australia</td>
<td>Research specifically looked for the impact, if any, on the volunteer sector caused by business and service closures or changes in rural towns.</td>
<td>Unclear, seems interview data were collected from a mix of newcomers, long-term residents and volunteer organisations.</td>
<td>Tendency for groups to blame outsiders (sometimes hostile towards groups) for non-volunteering rather than assessing their own capacity to provide flexible access to different ways of participating. Recognition of a ‘veneer of friendliness’ when actually it is very difficult for newcomers to engage. Important for all people to acknowledge the past.</td>
<td>Need for socially inclusive practices in recruitment and retention of new volunteers, and raising ‘awareness of benefits of inclusion and perils of exclusion’. Greater emphasis on rural and regional communities being inclusive.</td>
</tr>
<tr>
<td>Kilpatrick, S., John, S., Vitartas, P. and Homisan, M.</td>
<td>2011</td>
<td><em>Journal of Rural Studies</em></td>
<td>Inland NSW, coast Qld, inland SA, central Tas, central Vic., remote WA, Australia and Southern Alberta, Canada</td>
<td>The paper asks how can rural communities capture maximum benefit from professional and other highly skilled workers in the context of an increasingly mobile and transitory workforce?</td>
<td>7 case study sites, individual interviews with mobile skilled workers (89) and key informants (28).</td>
<td>The relationship between integration and retention of mobile skilled workers needs to be better understood. Recruitment and retention research is not enough – the whole integration process needs to be understood, beyond financial incentives towards social support and job satisfaction.</td>
<td></td>
</tr>
<tr>
<td>Author(s)</td>
<td>Year</td>
<td>Journal</td>
<td>Location</td>
<td>Research Details</td>
<td>Findings/Implications</td>
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<td></td>
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<tr>
<td>Paull, M. and Redmond, J.</td>
<td>2011</td>
<td><em>Third Sector Review</em></td>
<td>Western Australia, regional and metropolitan</td>
<td>This paper explores some evidence relating to 'purple circles' and offers ideas from organisational behaviour and human resource management literature that might help organisations to respond more appropriately to succession. Workshops and focus groups, number and exact detail not reported.</td>
<td>Psychological and social barriers to getting into new settings. For example, experience of long-term involvement may lead to use of exclusive language, assumptions and unspoken premises that limit access to information of newcomers, as well as creating anxiety. Realistic expectations, flexibility in approach and responding positively to ideas aid in welcoming newcomers. Declining communities have significantly higher rates of participation in group civic involvement and community involvement, while people in growing communities are more likely to be socially active in public spaces. The longer the residence the higher the rates of informal social and community involvement. Particularised trustees tend to concentrate their efforts on people who belong to the community with which they identify, shying away from wide-ranging civic engagement and are more likely to see the world in terms of “we” and “they”. This was most salient in the comments of respondents who were “newcomers” or “outsiders”. “generalised trusters” bring individuals into contact with people different from themselves’. Problems posed for further research: whether awareness-raising alone is sufficient to ameliorate effects of the ‘purple circle’; exploring behaviours of those ‘insiders’ and the perceptions of newcomers about their influence, deliberate exclusion and succession outcomes of organisations where awareness of the ‘purple circle’ has been raised. Consider ways in which to support older people to continue to do what they are already doing, particularly in declining communities.</td>
<td></td>
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<tr>
<td>Davis, S., Crothers, N., Grant, J., Young, S. and Smith, K.</td>
<td>2012</td>
<td><em>Journal of Rural Studies</em></td>
<td>North-West and East Victoria, Australia</td>
<td>Does social and civic engagement differ across declining, stable and growing rural communities? To develop a better understanding of productive ageing in different types of communities. Anonymous self-complete postal questionnaire, across 20 rural towns, long-term residents and newcomers (tree-changers) over 50 years of age, 3925 included in analysis. Descriptive analysis. Numbers of newcomers, long-term residents, and born and bred residents not reported.</td>
<td>Does social and civic engagement differ across declining, stable and growing rural communities? To develop a better understanding of productive ageing in different types of communities. Anonymous self-complete postal questionnaire, across 20 rural towns, long-term residents and newcomers (tree-changers) over 50 years of age, 3925 included in analysis. Descriptive analysis. Numbers of newcomers, long-term residents, and born and bred residents not reported.</td>
<td></td>
<td></td>
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<tr>
<td>De Rijke, K.</td>
<td>2012</td>
<td><em>Oceania</em></td>
<td>Mary River, QLD, Australia</td>
<td>The paper aims to make an ethnographic contribution to the study of environmental disputes, and the symbolic politics of unusual alliances in peri-urban areas of settler-descendant societies such as Australia. Anthropological fieldwork, open and semi-structured interviews with committee members, activists and others, participant observation. Mix of newcomers and long-term residents, born and bred residents. Exact numbers not reported.</td>
<td>Anthropological fieldwork, open and semi-structured interviews with committee members, activists and others, participant observation. Mix of newcomers and long-term residents, born and bred residents. Exact numbers not reported.</td>
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created and experienced by and between individuals, within immediate and broad contexts.31

Results

Narrative of the findings was structured using three themes: interpersonal, socio-cultural norms and structural processes of inclusion and exclusion. With the exception of one study,29 the articles drew on qualitative methods using one or multiple methods of data collection. Five articles16,28,32–34 specifically sought and reported on the voice of the newcomer. Much of the research with newcomers is conducted within a context of workforce change and life cycle.

The term ‘newcomer’ is not consistently defined. When referring to ‘newcomers’, authors use words such as ‘exurbanites’ and ‘displaced urbanites’,28 the ‘innovative creative class’, ‘idealists’16 and ‘lifestylers’.35 Yet newcomers themselves seem not to identify with such terms, particularly as these indicate something undesirable or conjure impressions of disparity. Instead newcomers maintain a more synonymous persona to rural living, being clear that they are ‘not opting out of society’,28 but rather taking an opportunity to facilitate something more meaningful.28,29,34 The literature shows that newcomers desire to be involved in their community in multiple ways, yet their perceived identity can act to impede or enable this.

Interpersonal

Identity related to time residing in a rural community, sense of identity and sense of community were found to impact on the inclusion of newcomers. Kilpatrick and colleagues16 development of integration stages indicates that it can require up to and beyond 3 years for a mobile worker to be integrated into a community. It is common for newcomers who have had periods of residence of 10–20 years to identify as being ‘new’ to the area29,32 and report the experience of ‘feeling like a newcomer’.14 This experience is comparable with feeling like being a local for ‘two nanoseconds’35 compared with those families born and bred in the district for generations.29,34,35 In Davis and colleagues29 study, older newcomers were aware of the need to belong to the group who are born and bred as they ‘will always support others who are local born and bred’. Despite this, it is probable that the longer someone lives in a community, the more likely it is they share common histories and will be included in community activity.

Disparaging and hostile verbal interactions go some way to deterring newcomers from participating in community activities. Words such as ‘stupid’, ‘not a true farmer’, ‘feral’, ‘newfies’ and ‘upstart’ were given as examples of terms used to describe newcomers.28,32–34 Together with broader community resistance to the newcomers, these interactions were significant barriers to newcomers creating social networks. Feelings associated with such direct exclusion were not explored fully in any of the studies. However, feelings of betrayal were identified.28,32 Such interaction indicates that existing residents have little affiliation with the circumstances of newcomers, potentially overshadowing more inclusive interactions.

Casual social actions serve as crucial components of newcomers’ inclusion in community participation activities. As one newcomer described, the experience of walking into a group where everyone is talking in separate groups creates ‘the feeling of being an outsider’.34 Instead, having someone who welcomes and introduces the newcomer acts as a bridge to a broader social network.16,32 Such interaction will only be effective if the newcomer is prepared to integrate themselves into the community.16 On occasion, newcomers ‘needed to be assertive or in some cases, confrontational’ to be included in community activities.16

Socio-cultural norms

Fear of outsiders and the perceived differences they represent in rural communities is a prominent theme. Lee-Ack33 reports struggles with diversity among existing older rural resident volunteers, who state ‘I don’t think we’re really ready for those kind of people’. Older newcomers in Davis and colleagues29 study identified these same intolerant attitudes held by existing older residents. Such attitudes are likely to prevent newcomers from wanting to identify with incompatible values,32 preventing inclusive community involvement.

The role of trust in newcomers being accepted was discussed explicitly in one article,29 although the theme is inherent across others. Notably, those residents with high bonding trust tend to focus their attention to those they perceive as belonging. Longer-term newcomers are aware of these strong rural bonds and the lack of trust of newcomers. While there is frustration with this, newcomers explain that overall ‘folks hearts are in the right place and everyone is very friendly’.29

Moral authority is given to existing residents by newcomers when involving themselves in community participation activities. De Rijke’s32 account of community activism explores how newcomer community leaders navigated local politics of belonging. Acceptance of the activities of this group relied heavily on the ways in which long-term residents were accorded authority in matters of local stability. Additionally, the horse was used as a symbol of shared meaning to engage with both long-term rural primary production and with urban newcomers’ horse-riding endeavours. These actions
strengthened existing residents’ confidence in the newcomers and tolerance of differences.

Structures and organisational process

Processes of succession planning and involving new group members might be more of a tick-box exercise rather than a genuine desire to engage with new people. Despite social and political desirability to involve specific population groups, some people or groups are unwilling to allow others to make decisions or take on tasks. These people or groups are referred to as the ‘old guard’ or the ‘purple circle’. These are often ‘longer-term members who try to influence new decision makers or who try to keep things the same as they have always been’.

Newcomers to these groups experience power plays, withholding of information, being told ‘I don’t want to work with them’, ideas being dismissed without consideration, setting up others for failure, decisions being made outside of meetings and becoming a bystander. While the ‘old guard’ is competent and socially well connected, resistance to change and unwillingness to try different approaches inevitably limits what community participation can achieve.

There are many aspects of historical knowledge that existing members take for granted, leading them to use exclusive language and make assumptions. Long-serving members have organisational memory and tacit knowledge that newcomers lack. Overcoming this requires agreed-upon ‘rules of engagement’ such as well-structured meetings, agendas, action plans and skill-based working groups as a method for consciously creating cohesion between newcomers and long-term residents. This approach is useful for co-producing knowledge and building capacity of newcomers for when older people are unable to participate. Intentionally designing group processes and operational norms for inclusion can reduce tension when change occurs and prevent group loss due to exclusionary practices.

Deliberate community strategies to enhance inclusion of newcomers are limited in the literature but are essential for retaining newcomers. Communities and employers can be proactive in matching a newcomer to community leadership and participation roles based on knowing the newcomer’s skills and expertise. This can be expanded into ‘meet and greet’ programs run by a local council or employer groups to welcome newcomers and support their involvement in community activities. Such a program can be incorporated into broader employee volunteer support policy and activities. Communities and groups can overcome financial barriers to participation for newcomers by finding alternative methods, such as barter or service exchange. These actions assist newcomers to form more meaningful ties to the community.

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Discussion

Inclusion and exclusion at the interpersonal level is intricate and often represents broader social rules and tensions that newcomers must navigate in order to become involved. Social norms, such as fear of outsiders and difference, can exclude newcomers from participating in a rural community. Newcomer’s awareness of these issues means they are mindful of how they contribute and give respect to the social position of existing residents. Despite this, resistance to change is experienced by newcomers when contributing in organisational contexts.

Whole communities have a responsibility to promote the acceptance and welcoming of newcomers. Rural sporting clubs and religious organisations are well known for their engagement strategies as a standard part of their operation to connect with newcomers. Places of employment, schools, interest groups and community groups can incorporate these strategies. Welcoming and outreach activities that are approached with friendliness, trust, invitation, open-mindedness, resourcefulness, information sharing, skill development and willingness to develop shared history with newcomers promote feelings of belonging and inclusion. Community groups can aim for a mixture of the ‘old guard’ and newcomers for the purpose of sustainability, continuation, reducing prejudice and generating fresh ideas. Informal actions of home visits, providing local produce or watching out for the kids also have benefits for inclusion. Drawing on local knowledge and familiar social practices has the potential to establish greater meaning from participation and new kinds of working relationships. Facilitators of participation processes have a key role in this, requiring skills in exploring multiple ways of knowing, discovering shared understandings, reflecting on options rather than insisting on own preferences and making decisions based on these. Like existing residents, who are able to introduce newcomers to new social networks and orient them to local social practices, inherent to facilitating in an inclusive manner is experience and familiarity with the local rural setting. This is in contrast to the often very unfamiliar ‘rules of engagement’ formal services engage with.

Fitting in to a new community requires balancing sensitivity to existing relationships and histories with personal values and needs. Those people who dismiss existing relationships are likely to experience exclusion. This can be helped by supporting new people to become aware of the role and value of these histories. In the same way that participation activities can embrace welcoming attitudes, newcomers seeking involvement and belonging are aided with individual dispositions of friendliness, trust, open-mindedness and willingness to learn.
Designing community participation activities, beyond the interpersonal level, that are inclusive requires greater depth of understanding. Quick and Feldman critique a range of participation strategies for inclusion, based on case-series mapping, concluding that an inclusion lens informs participation theory and practice. However, as this work is American based, similar assessments need to take into account rural diversity in the Australian context. Similarly, any study will need to encompass the individual, social and organisational levels of rural community. Anticipated benefits of designing for inclusive participation might go some way to mitigate the exclusion of those with less financial and social resources.

Limitations of this study

This review used rigorous and transparent methods suitable to the nature of the study. The use of reference manager software ensured articles and citations were accounted for during the process and assisted with the research teams’ decision-making processes. The overall research quality was not assessed; however, the articles collected were useful for summarising existing published literature to inform the design and research of inclusive rural participation processes.

Conclusion

Rural newcomers provide an insight into the potential for designing community participation processes for inclusion. The effort required to achieve this can be reduced if whole communities invest in their people, through demonstrating a willingness to listen to new voices. Formal participation processes can harness the practice and value of rural hospitality that newcomers experience as inclusionary. Deliberately designing group processes and operational norms for inclusion can reduce tensions when community change occurs and prevent group loss due to exclusionary practices. Exploring the socio-cultural processes within rural communities and mechanisms for supporting inclusion will provide a more complete picture to inform meaningful and authentic participation processes.

Acknowledgement

Thank you to Jill Stokes, Health Sciences Faculty Librarian, La Trobe University, for her recommendations for database searching and in construction of the Boolean phrases.

References


22 Smailes PJ. From rural dilution to multifunctional countryside: some pointers to the future from South Australia. Australian Geographer 2002; 33: 79–95.


SECTION SEVEN:
The ethical implication of community participation

Community participation and ethical implications

• Assumptions are made about communities being homogeneous collectivities with shared culture and identity.
• Some communities are over-consulted leading to consultation fatigue.
• Exclusion of willing participants can occur when special accommodations are not taken into account for individuals or groups with extra needs.
• Community participation in service planning could raise false hopes and waste people’s time if identified services cannot be delivered.
• Exclusion of willing participants can result from selecting community members to fit a “type” of community member.
• Confidentiality of participating in groups or forums cannot be assured once individuals leave that space.
### Key points and the evidence

<table>
<thead>
<tr>
<th>Key points</th>
<th>The evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Confidentiality and privacy are challenged. Disclosing incriminating</td>
<td>• Banks et al, 2013&lt;br&gt;• Lofman, Pelkonen &amp; Pietilae, 2004&lt;br&gt;• Shore, 2006&lt;br&gt;• Teti, Murray, Johnson &amp; Binson, 2012&lt;br&gt;• Mitchell &amp; Baker, 2005&lt;br&gt;• Williams et al, 2010</td>
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<tr>
<td>behavior and illness experiences, particularly in small communities</td>
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<td>impact on community relationships and put people at risk.</td>
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<td>This contradicts the foundational assumption that community participation</td>
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<tr>
<td>empowers the community.</td>
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<td>for community-identified issues are not necessarily deliverable;</td>
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<tr>
<td>expectations and possibilities need clarification at the onset to avoid</td>
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<tr>
<td>setting false expectations.</td>
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<tr>
<td>Sensitive health topics might probe personal and collective memories of</td>
<td>• Brabeck et al, 2015&lt;br&gt;• Greene, 2013&lt;br&gt;• Lundy &amp; McGovern, 2006</td>
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<tr>
<td>communities (eg historic trauma, cultural conflict).</td>
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</tr>
<tr>
<td>Participation is about giving people a voice, however, making the</td>
<td>• Teti et al, 2012&lt;br&gt;• Vishalache &amp; Cornforth, 2013&lt;br&gt;• Cahill, 2007</td>
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<tr>
<td>invisible visible (minority viewpoints, disclosing certain activities)</td>
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<td>might result in conflict or stigmatisation.</td>
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<tr>
<td>Participants can be burdened with stress arising from lack of knowledge,</td>
<td>• Logie, James, Tharao &amp; Loutfy, 2012&lt;br&gt;• Mistry et al, 2015</td>
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<tr>
<td>experience and competence to fulfil partnering role.</td>
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</tr>
<tr>
<td>Participation of culturally diverse communities requires cultural</td>
<td>• Bromley et al, 2015&lt;br&gt;• Di Stefano et al, 2013&lt;br&gt;• Flicker and Worthington, 2012</td>
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<tr>
<td>responsiveness, such as culturally appropriate method of participation</td>
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<td>and selection of discussion topics that take into account cultural</td>
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<tr>
<td>taboos.</td>
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<tr>
<td>Entrenched power disparities between practitioners and community members</td>
<td>• Banks et al, 2013&lt;br&gt;• Walsh et al, 2008&lt;br&gt;• Brabeck et al, 2015</td>
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<tr>
<td>may be culturally entrenched and difficult to shift and can lead to</td>
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<tr>
<td>manipulation of community opinions about their needs.</td>
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<tr>
<td>Communities can be divisive leading to the interests of less powerful</td>
<td>• Eversole, 2003&lt;br&gt;• Mulligan, 2015</td>
</tr>
<tr>
<td>and less vocal members to be overlooked.</td>
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</tbody>
</table>
Community participation: What we have learnt about the ethical implications

i. Ethical issues can arise when power disparities, cultural norms and, community and institutional expectations are not acknowledged and addressed.

ii. There are inherent ethical issues associated with any top down process.

iii. Funding priorities can impact on ethically sound participatory processes.

iv. Political priorities can impact on ethically sound participatory processes.

v. The priorities of a health service many not necessarily align with community priorities.

vi. Service/governance driven outcome agendas may be in conflict with participation ethos and in this sense – ethical issues.

vii. There is a risk that participation is used to align community priorities with institutional priorities.

viii. There are potential power differentials associated with academic involvement in community participation.

ix. The notion of insider/outsider tensions can impact on community participation processes.

x. Political nature of some topics could divide community – ramifications for those who chose to participate/not participate.

xi. Those who are already engaged ‘the ten percenters’ are likely to continue to be involved in participation activities and have the majority voice in community issues.

xii. In rural communities there is often a small pool of community members and stakeholders to draw from. This can lead to decision-making continuing to be influenced by only the dominant voices.

xiii. Capacity building within a community is essential to empower genuine bottom up activity. However, if limitations or boundaries are imposed on this, then it is not an ethical approach.

xiv. Community participation activities may become divisive if processes are not transparent, are dominated by strong personalities or a limited agenda, where equal opportunity to express difference of opinion or priorities is not provided.

xv. There is a need for on going conversation around service and governance issues prior to participation programs being introduced – greater clarity in agendas
Ethical challenges in community based participatory research: A scoping review
Elena Wilson, Amanda Kenny, Virginia Dickson-Swift

Abstract

Ethical challenges in community-based participatory research are of increasing interest to researchers working with communities. However, it is not known how widespread these challenges are nor how extensively the topic has been explored. Using Arksey and O’Malley’s scoping review method we mapped studies where authors identified ethical challenges in community based participatory research. Findings indicate that ethical challenges are reported widely and that researchers continue to raise questions about ethics associated with this method. Our purpose in this article is to enable researchers to better understand ethical challenges when making decisions and preparations for research with communities.

Keywords

Ethics, community based participatory research, CBPR
Article

In this article we report the findings of a scoping review of peer-reviewed literature on ethical challenges in community-based participatory research (CBPR). There are ethical challenges with this method, but it is not known how extensively the topic of ethics in CBPR has been explored. Our purpose is to map the extent, range and nature of research activity on ethics in CBPR and use this as a basis to discuss challenges. As Australian researchers, engaged in research on rural healthcare planning (Kenny et al., 2013), the work of Banks et al. (2013) and Minkler (2004) provided a basis to consider ethics in CBPR. We believe that ethical considerations are integral to CBPR and mapping the evidence base of studies on ethical challenges is important for research, health policy and practice.

Background

Community-based participatory research was developed from Lewin’s utilitarian problem solving and the emancipatory style of Freire (Minkler & Wallerstein, 2008). From the 1960s, the use of CBPR grew exponentially, addressing knowledge to support a fairer society (Minkler & Wallerstein, 2008). Researchers using CBPR draw on critical social theory (Stanton, 2014; Wallerstein & Duran, 2008) often underpinned by the work of Habermas: utilitarian problem solving, normative social and cultural values, and emancipatory understanding (Minkler & Wallerstein, 2008). It is informed by feminism, post-structuralism and post-colonialism (Minkler & Wallerstein, 2008),
which focus on social justice and challenge objectivity (Denzin & Lincoln, 2011; Israel, Eng, Schulz, & Parker, 2013; Minkler & Wallerstein, 2008).

CBPR aims for useful outcomes for participants (Banks et al., 2013) based on ethics, and community empowerment (Blumenthal, 2011; Boser, 2007; Minkler, 2004), operationalized through reciprocal knowledge transfer and community co-researchers (Wallerstein & Duran, 2008). Guiding principles for CBPR, include shared conceptions of community, community capacity building, social equality, and power sharing. Processes are cyclical, iterative and projects are unique requiring principles to be flexible (Israel, 2005; Israel et al., 2013).

Method

Using the scoping review processes of Arksey & O’Malley (2005), we followed a systematic, transparent and replicable process (Grant & Booth, 2009) that contributed to methodological rigor and reliability (Arksey & O’Malley, 2005; Davis, Drey, & Gould, 2009; Rumrill, Fitzgerald, & Merchant, 2010). We developed the research question: What studies exist that explore the ethical challenges in community-based participatory research? to capture an extensive range of literature (Arksey & O’Malley, 2005).

Identifying relevant studies
A preliminary search of databases yielded few studies prior to 2003, so our inclusion period was 2003-15. The full inclusion and exclusion criteria is outlined in Table 1.

INSERT TABLE 1

The following search terms were developed with support from an expert librarian: (“CBPR” OR “community based participatory research” OR “action research” OR “co-production” OR “collaborative research” OR “community-engaged research”). Terms were combined with [AND (“ethic*” OR “moral principles” OR “integrity”)]. A search of the Cochrane library failed to locate any systematic reviews on the topic. The following databases were searched: CINAHL, Medline, ProQuest Central, Wiley Online, Project Muse, Scopus, Web of Science, JStor, SAGE Journals Online, Informit Complete and Expanded Academic.

Study selection

Our initial search yielded 5,116 articles. After title and abstract screening 4,975 articles were removed as they did not meet inclusion criteria. Full text of 141 articles were read, with 90 articles excluded as their focus lay elsewhere, such as the functions of Human Research Ethics Committees (HRECs) and frameworks, principles and conceptualisations of CBPR. Articles that met all inclusion criteria numbered 51. In Figure 1 the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analyses) process is outlined.
Charting the data

The charting stage involved “applying a common analytical framework” (Arksey & O’Malley, 2005, p. 26) and we included: author, year of publication, study location by country, population/sample characteristics, study aims, methods and ethical issues. This is summarised in Table 2.

Collating and summarizing

The fifty-one studies spanned fifteen countries: USA (n=20), Canada (n=10), UK (n=5), Australia (n=3), USA and Canada (n=1), USA and Guatemala (n=1), and one in each of Malaysia, Jamaica, Denmark, Finland, Burkina Faso, Iran, Ireland, South America, Kenya and Greenland. A greater number of studies were published in the years 2012 (n=8) and 2013 (n=12) compared to other years within our search dates. Data collection methods were mainly case studies (n=22) and interviews (n=13). Methods used in the remaining studies included focus groups, literature analysis, document analysis, reflection, and vignettes. Some were combined with critical reviews, observation, online discussion, journals, and surveys.

Discussion

We identified statements about ethical challenges in the articles and categorised them into five broad themes: Protection of Participants (Anonymity, confidentiality and
privacy, Informed consent processes, and Risk versus benefit); Insiders and Outsiders (Culture and Community Research Workers); Partnership, Collaboration and Power; Validity and Research Integrity; and The CBPR Researcher and Ethics Review.

Protection of participants

Protecting participants was noted as a priority for ethics review bodies (Shore, 2007) and CBPR was described as an ethical practice (Mikesell, Bromley, & Khodyakov, 2013). Authors, however, challenged the assumption that CBPR is inherently ethical, citing neglect of ethical considerations could pose challenges for the protection of participants (Mikesell et al., 2013). It was questioned whether CBPR is always in participants’ best interest or whether it could inadvertently put people at risk (Brabeck, Lykes, Sibley, & Kene, 2015; Mikesell et al., 2013). The need to balance transparency with protecting vulnerable communities (Morgan, Cuskelly, & Moni, 2014) was identified so vulnerable, marginalized participants are supported if telling ‘unwelcome truths’ (Vishalache & Cornforth, 2013). An example was provided of working with illegal migrants and the implications of participation should the research be examined by authorities (Brabeck et al., 2015).

Others argued that the duty to protect participants can undermine autonomy and authority of people with disabilities, despite a desire to treat participants as equal partners (Morgan et al., 2014). Researchers suggest that standardised conceptualisations
of disability and vulnerability can involve people in processes that compromise the integrity of CBPR and the dignity of individuals (Gustafson & Brunger, 2014).

**Anonymity, confidentiality and privacy.** In some studies ethical challenges were raised in relation to anonymity, confidentiality and privacy (Banks et al., 2013; Lofman, Pelkonen, & Pietilae, 2004; Shore, 2006). Participant anonymity is described as contradictory to the foundational assumptions of participants as co-researchers (Banks et al., 2013; Brabeck et al., 2015). Disclosing incriminating behaviour and illness experiences (Teti, Murray, Johnson, & Binson, 2012), particularly in small communities was described as problematic, where privacy and confidentiality may impact on community relationships (Mitchell & Baker, 2005; Williams et al., 2010). Issues were raised about ownership of data, research findings and outcomes (Banks et al., 2013; Blake, 2007).

Examples of privacy and confidentiality challenges were described: the duality of the community research worker role (Bromley, Mikesell, Jones, & Khodyakov, 2015; DePalma, 2013; Greene, 2013), multiple roles held by participants (Goduscheit, Bergenholtz, Jørgensen, & Rasmussen, 2008; Mitchell & Baker, 2005), and the dual role of clinicians when patients were participants in a study (Bastida, Tseng, McKeever, & Jack, 2010; Davison et al., 2013). Researchers described being conflicted between confidentiality and anonymity of participants and openness due to the close research relationships characteristic of CBPR (Brugge & Cole, 2003).
Informed consent processes. Challenges of informed consent in our reviewed studies related to existing relationships between participants (Anderson, 2013; Blake, 2007; Boser, 2006; Shore, 2007) creating biased recruitment processes that can threaten data integrity (Lofman et al., 2004). Roles can be unclear in CBPR, challenging decisions about whose consent should be sought and for what purpose (DePalma, 2013; Mikesell et al., 2013; Vishalache & Cornforth, 2013). Gaining consent was described as challenging in culturally diverse communities, where culturally appropriate consent processes are needed (Baydala et al., 2013). Consent gained only at the beginning of a study was described as problematic as CBPR often requires flexibility (Lofman et al., 2004; Mikesell et al., 2013; Vishalache & Cornforth, 2013).

Risk versus benefit. Authors described the obligation to produce benefits and improvements for community identified issues (Brugge & Cole, 2003; Kuriloff, Andrus, & Ravitch, 2011; Walsh, Hewson, Shier, & Morales, 2008). Tensions between research benefit and potential harm were identified (Goduscheit et al., 2008; Lofman et al., 2004). Communities might be burdened by participation in CBPR, despite potentially benefitting from the research (Bromley et al., 2015).

Tensions arose in research on sensitive topics that probed personal and collective memories of communities such as historic trauma, and political conflict (Brabec et al., 2015; Greene, 2013; Lundy & McGovern, 2006a). Vulnerable or marginalised research participants exhibited suspicious and fearful responses based on
past traumatic experiences (Campbell-Page & Shaw-Ridley, 2013; Chabot, Shoveller, Spencer, & Johnson, 2012; Tee & Lathlean, 2004). Authors described ethical issues in situations where participants may be expressing minority viewpoints or disclosing activity that might result in prosecution or stigmatisation (Teti et al., 2012; Vishalache & Cornforth, 2013). A lack of clarity regarding decision making about whether a safe space is needed, who decides and defines this, and whether a safe space is capable of being safe for all at the same time (DePalma, 2013) were highlighted.

Caution was raised by authors about political ramifications of making the invisible visible, the potential for conflict between communities or groups and the need for tangible recognition of participation (Cahill, 2007; Cordner, Ciplet, Brown, & Morello-Frosch, 2012; Kuriloff et al., 2011; Rink, Montgomery-Andersen, Koch, Mulvad, & Gesink, 2013). In some communities there was division over issues (Minkler, 2005) contributing to waning community interest and engagement (Bainbridge et al., 2013).

Insiders and outsiders

Researchers identified insider-outsider tensions from: conflicting beliefs, expectations, and assumptions between academic and community partners (Mikesell et al., 2013), differences in research scheduling and priorities, community perceptions that researcher benefits outweigh those to the community (Minkler, 2004, 2005; Schaffer,
and resistance to outsider researchers particularly after historical trauma (Lundy & McGovern, 2006; Minkler, 2004; Schaffer, 2009).

Boundaries between researchers and participants were described in one study, as fluid and not always obvious (Carter, Banks, Armstrong, Kindon, & Burkett, 2013). Authors stated that ‘outsider’ researchers attempting to gain credibility and cooperation from ‘insiders’ can result in role ambiguity and ethical conflicts associated with different roles (Goduscheit et al., 2008; Lofman et al., 2004).

Community research workers. Bromley et al. (2015) explain that ethical issues arise when the role of the participant moves beyond provision of data to the community research worker role (Bromley et al., 2015). Community research workers might experience inclusion and exclusion as partnerships evolve over time and norms and agreements are reviewed (Banks et al., 2013; Shore, 2006). They may feel powerless to refuse requests made by researchers (Brabeck et al., 2015; Hunt, Gogognon, & Ridde, 2014).

Misconduct of community research workers, is reported and involves: exceeding the boundaries of their job description by intervening to help participants (True, Alexander, & Richman, 2011), breaching protocols for confidentiality and consent, and fabrication or falsification of data (Richman, Alexander, & True, 2012; True et al., 2011). Paid community research workers in one study were approached by community members to gain favour, while some were accused of gaining financial profit from
Improving the health of communities through participation. Paid community research workers have to take extra care in their behaviour (Mistry, Berardi, Bignante, & Tschirhart, 2015).

Community research workers will not always have the competence, knowledge or experience to fulfil partnership expectations and can be burdened with stress created by this situation (Logie, James, Tharao, & Loutfy, 2012; Mistry et al., 2015). Tasks may not be easier to fulfil because community research workers are in their own community (Mistry et al., 2015). The emotional impact and the importance of providing appropriate emotional support (Logie et al., 2012), are described with subtleties of community interactions and interpersonal relations important when recruiting local community members to contribute to research (Castleden, Morgan, & Lamb, 2012).

**Culture.** Authors described cultural misunderstanding when outsider researchers do not share the same culture or race as community partners (Minkler, 2004; Schaffer, 2009). Perceptions and expectations can differ (Bainbridge et al., 2013), leading to cultural misunderstandings between research and community protocols such as those relating to informed consent with First Nations communities (Baydala et al., 2013; Jamshidi et al., 2014).

Researching in culturally diverse communities requires consideration of participants’ fears of gossip, culturally appropriate methods of collecting data, and selection of research topics that take into account cultural taboos (Bromley et al., 2015; DiStefano et al., 2013; Flicker & Worthington, 2012; Shore, 2006). Gender and
seniority cultural norms can conflict with research objectives, such as with young female facilitators (Mistry et al., 2015). Researchers from two reviewed studies, described female deference to male participants in group discussions, with younger participants reluctant to disagree with older males (Puffer, Pian, Sikkema, Ogwang-Odhiambo, & Broverman, 2013; Vishalache & Cornforth, 2013). Equity and respect can be a challenging to manage in these situations (Vishalache & Cornforth, 2013). This can be exacerbated if the influence of traditional community leaders benefits certain groups in their community (Hunt et al., 2014). Recognition of the unique complexities of research with indigenous populations resulted in calls for recognition as a distinct form of research (Castleden et al., 2012; Flicker & Worthington, 2012).

*Partnership, collaboration and power*

Subversion of power is assumed in CBPR (Gustafson & Brunger, 2014), yet power disparities are discussed by authors who question how power is established, shared and controlled (Banks et al., 2013; Brugge & Cole, 2003; Hunt et al., 2014; Kuriloff et al., 2011). Power differences between academic researchers and community members can lead to resource disparities in research partnerships (Hunt et al., 2014; Puffer et al., 2013) leading to research exploitation (Banks et al., 2013; Brabeck et al., 2015; Lofman et al., 2004; Lundy & McGovern, 2006; Minkler, 2005), coercion and racism (Mikesell et al., 2013; Minkler, 2005). Conflict can arise from timelines and
expectations which may be academic, or funder driven, rather than reflecting community need (Banks et al., 2013; Walsh et al., 2008).

Brabeck et al. (2015) suggest power differentials can lead to altruistic action, which may seem beneficial on the surface, but can present an ethical dilemma. It may be unethical not to use researcher resources and privilege to address community injustice, yet it may be equally unethical for researchers to unintentionally raise false hope (Brabeck et al., 2015).

The concept of community representation was discussed by authors in relation to who represents, and should speak for the community (Mikesell et al., 2013; Minkler, 2004). Community research workers might be expected to represent both academia and the community in which they live (Mistry et al., 2015). Mitchell and Baker (2005) described the dilemma for researchers when considering who has the right to give consent for the community and whether it is ethical to suppress autonomy and rights for the good of the community. Dissemination of confronting information, and dealing with unflattering data or data that reinforces stereotypes (Brabeck et al., 2015; Brugge & Cole, 2003; Cordner et al., 2012; Mikesell et al., 2013; Minkler, 2004; Schaffer, 2009) can be ethically challenging, when balancing a duty to make all findings public (Minkler, 2004). Williams et al. (2010) caution researchers when negative results are disseminated within communities. Authors discuss methods to use for distribution, co-authorship, publicity, and control over archived data (Banks et al., 2013; Gustafson &
Ownership of participants’ stories can be unclear and raises issues of who owns the story (Brabeck et al., 2015; Morgan et al., 2014).

Post research impact was identified as an ethical issue in two reviewed studies, with disadvantaged communities losing resources and relationships at project end (Jamshidi et al., 2014; Puffer et al., 2013). Community research workers remaining in the community at project end can have long-term emotional harms, if they are viewed differently by the community as a result of their involvement (Greene, 2013; Mistry et al., 2015). Research targeting disadvantaged communities, can increase levels of labelling, discrimination and stigmatization (Walsh et al., 2008).

Validity and research integrity

Within the articles mapped, concerns were raised about balancing valid scientific knowledge and the needs of the community (DiStefano et al., 2013; Goduscheit et al., 2008). The integrity of the CBPR approach can be compromised when attempting to involve all equitably in the research process (Schaffer, 2009), or when study aims result in different expectations over time (Bromley et al., 2015).

Working with universities can cause unresolved tensions, such as university delays in remuneration for paid workers (Bainbridge et al., 2013). Validity of study data can be undermined when; coercion or unfair treatment arises from personally close partnership relationships (Bromley et al., 2015), research partners may push to alter data to avoid unflattering conclusions (Bromley et al., 2015), pressure to meet
recruitment goals, or when assisting a research participant results in research misconduct (True et al., 2011). Validity of research results could be compromised if protocol are not adhered to and researchers respond with less rigorous procedures to avoid jeopardizing their relationship with the community (Anderson, 2013; DiStefano et al., 2013).

The CBPR researcher and ethics review

In the reviewed studies the importance of a researcher reflexive approach, through engagement in ongoing evaluation and critical self-reflection was noted (Banks et al., 2013; Campbell-Page & Shaw-Ridley, 2013; Shore, 2006). Examples were given of work with vulnerable populations where researchers need personal awareness and skill to work through sensitive relational and group dynamics (Castleden et al., 2012; Chenhall, Senior, & Belton, 2011; Cordner et al., 2012; Tee & Lathlean, 2004). Ongoing evaluation and self-reflection is crucial due to the emergent nature of social relationships at a community level (Boser, 2006; Castleden et al., 2012; Chenhall et al., 2011; Walsh et al., 2008).

Responsibilities of the researcher include consideration of the potential for negative impacts of their research (Cahill, 2007), including social and economic effects and community level stigmatization (Walsh et al., 2008; Williams et al., 2010) or unexpected influences on policy (Rink et al., 2013). The high level of skill and responsibility required by researchers conducting CBPR requires both CBPR and ethics
training (Banks et al., 2013; Bastida et al., 2010). The vulnerability of researchers is identified with the need for debriefing among peers (Carter et al., 2013). CBPR projects may be difficult when researchers struggle with research content which parallels their own life circumstances (Carter et al., 2013).

**The ethics review process.** The divergence between ethics review processes and the emergent nature of CBPR was regarded as problematic by authors (Campbell-Page & Shaw-Ridley, 2013; Lofman et al., 2004; Shore, 2007). Some described a disconnect between ethics committees and the experience of CBPR researchers attributed to the traditional biomedical orientation of ethics guidelines that differs from some core values of CBPR (Shore, 2007). Inadequacy of the review process for recognizing the realities of participatory research (Chenhall et al., 2011) can obstruct the researcher from fulfilling the ethical responsibilities of the role (Blake, 2007; Davison et al., 2013; Shore, 2007). Unintentional harm to the community could arise (Flicker, Travers, Guta, McDonald, & Meagher, 2007) when researchers struggle with applying biomedical framing of ethics review because it views participants as individuals and disregards the collective framing of CBPR in which participants are considered both as individuals and as a community (Davison et al., 2013; Deeds et al., 2008; Flicker et al., 2007).

Although ethics review processes are considered foundational, they are often not sufficient for CBPR (Williams et al., 2010) and can be more complex when multiple ethics committees are involved (Rink et al., 2013). CBPR researchers are encouraged to
write about their experiences of obtaining ethics approval, to inform the knowledge base for new CBPR researchers (Campbell-Page & Shaw-Ridley, 2013; Chabot et al., 2012; Puffer et al., 2013; Shore, 2006).

**Identified recommendations for further research**

Further recommendation for research were included in many studies reviewed, including: further exploration of forms of power relationships and knowledge co-production (Cordner et al., 2012), using broader samples to ascertain representativeness of other CBPR researchers (Shore, 2006), and further exploration of ethical challenges by extending participation to stakeholders such as communities and ethics committees (Anderson, 2013; Brugge & Cole, 2003; Shore, 2006). Authors suggest further research focused on specific population groups that may have unique ethical challenges, the conceptualization of community relating to individual and collective identities (Bromley et al., 2015), the experiences of community research workers (True et al., 2011), the protection of community rights and how they are monitored over time, who consents for a community, and when does a community become the subject of ethical consideration (Deeds et al., 2008), perspectives of ethics committee members and administrators, comparing review processes of university ethics committees with tribal review boards, and investigating the processes for establishing ethics committees and selecting their members (Anderson, 2013; Shore, 2007). Authors suggest research that explores the extent to which young people understand their rights as research participants in the
institutional context (Chabot et al., 2012) and adaptations of research methodologies for vulnerable populations (Nepal, Banerjee, Slentz, Perry, & Scott, 2010; Rink et al., 2013). Researchers working in HIV are called to disseminate their methods for risk mitigation (Puffer et al., 2013), including further research on sustainability and post CBPR impacts of projects occurring in low and middle income settings (Davison et al., 2013).

Conclusion

From this scoping review we conclude that authors continue to raise questions about the ethical conduct of CBPR. The identified key ethical challenges for CBPR researchers relate to: the protection of participants (anonymity, confidentiality and privacy, informed consent processes, and risk versus benefit); insiders and outsiders (culture and community research workers); partnership, collaboration and power; validity and research integrity; and the CBPR researcher and the ethics review process. While several issues are raised for future investigation and clarification, it is vital that data be gathered internationally about the ethical aspect of the CBPR research journey for the benefit of researchers new to this field. For those undertaking or planning CBPR, we believe this review informs researchers and collaborators of the challenges identified across a range of projects and alerts them to ethical issues commonly experienced so that informed consideration and preparation can occur prior to approaching communities. Further research in this area is needed.
References


Flicker, S., Travers, R., Guta, A., McDonald, S., & Meagher, A. (2007). Ethical dilemmas in community-based participatory research: recommendations for


Empirical Research on Human Research Ethics, 8(2), 119-128. doi: http://dx.doi.org/10.1525/jer.2013.8.2.119


Table 1. Inclusion and exclusion criteria applied to studies located by the search

<table>
<thead>
<tr>
<th>Criterion</th>
<th>Inclusion</th>
<th>Exclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time period</td>
<td>January 2003 to May 2015</td>
<td>Studies outside these dates</td>
</tr>
<tr>
<td>Language</td>
<td>Articles published in English</td>
<td>Not published in English</td>
</tr>
<tr>
<td>Type of article</td>
<td>Original research in peer reviewed journal</td>
<td>Grey literature, unpublished</td>
</tr>
<tr>
<td>Study focus</td>
<td>Exploration of ethical challenges in CBPR</td>
<td>Studies outside this focus area.</td>
</tr>
<tr>
<td>Literature focus</td>
<td>Provides empirical evidence of ethical implications CBPR and a clearly stated research method</td>
<td>No empirical evidence of ethical implications and no clearly stated research method.</td>
</tr>
<tr>
<td>Population</td>
<td>Any population.</td>
<td>No population</td>
</tr>
</tbody>
</table>
Table 2. Summary of articles included in study selection

<table>
<thead>
<tr>
<th>Author/Year</th>
<th>Study Location</th>
<th>Population/sample</th>
<th>Aims of the study</th>
<th>Method</th>
<th>Participant protection</th>
<th>Insiders and Outsiders</th>
<th>Partnership, Collaboration and Power</th>
<th>Validity and Research Integrity</th>
<th>CBPR Researchers and Ethics Review</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anderson, E., 2013</td>
<td>Chicago area, USA</td>
<td>11 academic and 13 community partners</td>
<td>Explore views on challenges to protection of participants and research integrity.</td>
<td>Focus group</td>
<td>*</td>
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<tr>
<td>Bainbridge, R. et al., 2013</td>
<td>Australia</td>
<td>Aboriginal community living in remote Australia</td>
<td>Engage with opportunities &amp; challenges of achieving effective, meaningful CBPR.</td>
<td>Observation, document analysis</td>
<td>*</td>
<td>*</td>
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<tr>
<td>Authors</td>
<td>Country</td>
<td>Participants/Context</td>
<td>Methods/Findings</td>
<td>Study Type</td>
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<tr>
<td>Banks, S. et al., 2013</td>
<td>UK</td>
<td>Academic/community partners</td>
<td>Explore practice and ethical challenges of CBPR projects.</td>
<td>Case studies, focus group</td>
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<tr>
<td>Bastida, E. et al., 2010</td>
<td>Texas, USA</td>
<td>Residents, community advocates, agency staff</td>
<td>Discuss ethical issues in CBPR : using Beyond Sabor Project as a case example</td>
<td>Case study</td>
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<tr>
<td>Baydala, L.T. et al., 2012</td>
<td>Canada</td>
<td>6 university and community researchers</td>
<td>Present lessons learned: cultural basis of consent involving First Nations Elders</td>
<td>Focus groups</td>
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<tr>
<td>Blake, M., 2007</td>
<td>UK</td>
<td>50 women</td>
<td>Examine difference: PAR &amp; ethics review</td>
<td>Case study</td>
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<tr>
<td>Boser, S., 2006</td>
<td>USA</td>
<td>n/a</td>
<td>Outline ethical implications of participatory research partnerships.</td>
<td>Literature analysis</td>
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<tr>
<td>Bromley, E. et al., 2015</td>
<td>US</td>
<td>29 investigators</td>
<td>Describe ethical priorities and challenges</td>
<td>Interviews</td>
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<tr>
<td>Brugge, D and Kole, A., 2003</td>
<td>Boston, USA</td>
<td>12 key informants</td>
<td>Explore CBPR in low income populations</td>
<td>Interviews</td>
<td></td>
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<tr>
<td>Cahill, C., 2007</td>
<td>USA</td>
<td>undocumented students</td>
<td>Explore participatory ethics &amp; relational praxis</td>
<td>Case study;</td>
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<tr>
<td>Campbell-Page,R and Shaw-Ridley, M., 2013</td>
<td>Canada</td>
<td>Undocumented immigrants: Toronto</td>
<td>Be transparent about &amp; understand/resolve ethical issues faced by research team</td>
<td>Case study</td>
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<tr>
<td>Carter, K et al., 2013</td>
<td>UK</td>
<td>Community researchers</td>
<td>Indicate community researcher challenges</td>
<td>Case study.</td>
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<tr>
<td>Authors</td>
<td>Country</td>
<td>Participants/Context</td>
<td>Research Focus</td>
<td>Methods</td>
<td>Notes</td>
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<td>Castleden, H. et al., 2012</td>
<td>Canada</td>
<td>15 researchers with Indigenous partners</td>
<td>Examine views on CBPR partnerships: Indigenous partners</td>
<td>Telephone interviews</td>
<td>*</td>
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<tr>
<td>Chabot, C. et al., 2012</td>
<td>Canada</td>
<td>Youth, community decision makers</td>
<td>Describe challenges: youth &amp; multiple ethical standards</td>
<td>Case study: interviews</td>
<td>*</td>
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<tr>
<td>Chenhall, R et al., 2011</td>
<td>Australia</td>
<td>Indigenous Australians</td>
<td>Develop &quot;ethics in practice&quot; perspective.</td>
<td>3 case studies</td>
<td>*</td>
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<tr>
<td>Cordner, A. et al., 2012</td>
<td>USA</td>
<td>Various communities</td>
<td>Identify ethical concerns common in community-engaged research</td>
<td>3 case studies</td>
<td>*</td>
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<tr>
<td>Davison, C. et al., 2013</td>
<td>Caribbean</td>
<td>3 leadership hubs</td>
<td>Study nurse involvement: HIV/ AIDS policy</td>
<td>Focus groups</td>
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<tr>
<td>Deeds, B. et al., 2008</td>
<td>USA</td>
<td>Ethics committees</td>
<td>Identify concerns in CBPR ethics review</td>
<td>Text analysis</td>
<td>*</td>
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<tr>
<td>DePalma, R., 2010</td>
<td>UK</td>
<td>Primary education sites &amp; universities</td>
<td>Explore issues of safety &amp; ethics participatory action research</td>
<td>Observation, online forum</td>
<td>*</td>
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<tr>
<td>Di Stefano, A. et al., 2013</td>
<td>U.S.A.</td>
<td>Pacific Islanders in US, researchers</td>
<td>Describe ethical issues from the study.</td>
<td>Case study.</td>
<td>*</td>
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<tr>
<td>Flicker, S. et al., 2007</td>
<td>USA &amp; Canada</td>
<td>IRBs and REBs</td>
<td>Compare CBPR experience/review forms</td>
<td>Content analysis</td>
<td>*</td>
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<tr>
<td>Flicker, S. et al., 2012</td>
<td>Canada</td>
<td>REB stakeholders: different institutions</td>
<td>Explore views on public health research with Aboriginal populations</td>
<td>Interviews</td>
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<tr>
<td>Goduscheit, R. et al., 2008</td>
<td>Denmark</td>
<td>Inter - organisational Network participants</td>
<td>Explore ethical challenges of action research funded by participating company</td>
<td>Case study, interviews</td>
<td>*</td>
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<tr>
<td>Name</td>
<td>Location</td>
<td>Participants</td>
<td>Methods</td>
<td>Findings</td>
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<td>Greene, S., 2013</td>
<td>Canada</td>
<td>2 peer research assistants</td>
<td>Explore ethical tensions: community based researchers &amp; peer research assistants</td>
<td>Vignettes/story telling</td>
<td></td>
<td></td>
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<tr>
<td>Gustafson, D. and Brunger, F., 2014</td>
<td>Canada</td>
<td>1 researcher</td>
<td>Reflect: tensions in a feminist PAR study</td>
<td>Critical reflection</td>
<td></td>
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<tr>
<td>Hunt, M. et al., 2014</td>
<td>Burkina Faso</td>
<td>39 stakeholders</td>
<td>Examine ethical issues in action research</td>
<td>Interviews</td>
<td></td>
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<tr>
<td>Jamshidi, E. et al., 2014</td>
<td>Iran</td>
<td>Partner organisations, academic/community</td>
<td>Explore principles &amp; potential ethical issues in CBPR</td>
<td>Interviews</td>
<td></td>
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<tr>
<td>Kuriloff, P. et al., 2011</td>
<td>USA</td>
<td>Schools</td>
<td>Overview ethical challenges in PAR study</td>
<td>Case study</td>
<td></td>
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<tr>
<td>Lofman, P. et al., 2004</td>
<td>Finland</td>
<td>Orthopaedic patients</td>
<td>Describe &amp; discuss ethical issues in PAR</td>
<td>Case Study</td>
<td></td>
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<tr>
<td>Logie, C. et al., 2012</td>
<td>Canada</td>
<td>Women living with HIV/AIDS</td>
<td>Discuss ethical challenges experienced by peer research assistants in a CBPR study</td>
<td>Case study</td>
<td></td>
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<td>Lundy, P. &amp; McGovern, M., 2006</td>
<td>Ireland</td>
<td>Local residents of Ardoyne, North Belfast</td>
<td>Explore role of action research &amp; ethical dilemmas: violently divided societies</td>
<td>Case study</td>
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<tr>
<td>Mikesell, L. et al., 2013</td>
<td>US</td>
<td>n/a</td>
<td>Identify ethical challenges in CBPR</td>
<td>Literature Review</td>
<td></td>
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<tr>
<td>Minkler, M., 2004</td>
<td>US</td>
<td>Various</td>
<td>Explore key ethical challenges</td>
<td>Case studies</td>
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<td>Minkler, M., 2005</td>
<td>US</td>
<td>Various</td>
<td>Illustrate ethical challenges of CBPR</td>
<td>Case Studies</td>
<td></td>
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<tr>
<td>Mistry, J. et al., 2015</td>
<td>South America</td>
<td>Project community team members</td>
<td>Analyse ethical dilemmas: local CBPR teams</td>
<td>Case example</td>
<td></td>
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<td>Mitchell, L.M. &amp; Baker, E., 2005</td>
<td>Canada</td>
<td>Aboriginal &amp; Native American communities</td>
<td>Discuss challenges of conducting ethical research with these communities</td>
<td>Reflection</td>
<td>*</td>
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<td>Morgan, M. et al., 2014</td>
<td>Australia</td>
<td>Adults with intellectual disability</td>
<td>Identify ethical issues/tensions between participatory research ideology and reality</td>
<td>Reflection</td>
<td>*</td>
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<tr>
<td>Nepal, V. et al., 2010</td>
<td>US</td>
<td>Linguistically isolated</td>
<td>Discuss challenges of conducting CBPR.</td>
<td>Not stated</td>
<td>*</td>
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<tr>
<td>Puffer, E.S. et al., 2013</td>
<td>Kenya</td>
<td>n/a</td>
<td>Discuss ethical challenges of CBPR for HIV intervention</td>
<td>Case example</td>
<td>*</td>
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<tr>
<td>Richman, K. et al., 2012</td>
<td>USA</td>
<td>Community research workers</td>
<td>Explore facilitators and barriers to responsible conduct of research</td>
<td>Interviews</td>
<td>*</td>
<td>*</td>
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<tr>
<td>Rink, E., 2013</td>
<td>Greenland</td>
<td>Inuulluataarmeq study communities</td>
<td>Present challenges and lessons learned on 4 year CBPR project</td>
<td>Case Study.</td>
<td>*</td>
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<tr>
<td>Schaffer, M.A., 2009</td>
<td>n/a</td>
<td>n/a</td>
<td>Identify common CBPR ethical problems.</td>
<td>Literature review</td>
<td>*</td>
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<tr>
<td>Shore, N., 2006</td>
<td>USA</td>
<td>10 CBPR researchers</td>
<td>Explore CBPR researcher perceptions of ethical issues and Belmont Report</td>
<td>Interviews.</td>
<td>*</td>
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<td>Shore, N., 2007</td>
<td>USA</td>
<td>CBPR researchers</td>
<td>Explore experience with IRB process.</td>
<td>Interviews.</td>
<td>*</td>
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<tr>
<td>Tee, S.R. and Lathlean, J.A., 2004</td>
<td>UK</td>
<td>n/a</td>
<td>Consider how ethical issues in research with vulnerable people can be addressed.</td>
<td>Reflection and literature review.</td>
<td>*</td>
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<td>Teti, M. et al. 2012</td>
<td>US</td>
<td>21 women living with HIV Aids</td>
<td>Discuss lessons learned and ethical challenges of photo-voice.</td>
<td>group meetings, interviews</td>
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<td>Study</td>
<td>Country</td>
<td>Participants</td>
<td>Activity Description</td>
<td>Method</td>
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<tr>
<td>True, G. et al. 2011</td>
<td>US</td>
<td>Research workers</td>
<td>Understand ethical challenges of research personnel misbehaviour</td>
<td>Interviews</td>
<td></td>
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<tr>
<td>Vishalach, B. and Cornforth, S., 2013</td>
<td>Malaysia</td>
<td>22 students aged 16-17 yrs in Malaysia.</td>
<td>Show response to use of working agreement to create safe discussion spaces</td>
<td>PAR &amp; reflection</td>
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<tr>
<td>Walsh, C.A. et al., 2008</td>
<td>Calgary, Alberta, Canada</td>
<td>11 youth program participants</td>
<td>To summarise ethical processes, dilemmas and potential for post research harm.</td>
<td>Case study</td>
<td></td>
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<tr>
<td>Williams, R.L. et al., 2010</td>
<td>New Mexico, US</td>
<td>Primary Care patients</td>
<td>Gather data on methods for community research to inform ethical discussions</td>
<td>Focus groups</td>
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</table>
Figure 1: PRISMA representation of literature screening

Records identified - database searching (duplicates removed)  
\( n = 5,115 \)

Records screened - 1st level screening (Titles)  
\( n = 5,116 \)

Inclusion criteria not met (theoretical, editorials, focus not on ethical challenges, etc.)  
Records excluded  
\( n = 4,366 \)

Records screened - 2nd level screening (Abstracts)  
\( n = 750 \)

Collaborative learning, book reviews, and frameworks, etc.  
Records excluded  
\( n = 609 \)

Full text articles assessed for eligibility  
\( n = 141 \)

Focus on review boards, ethical frameworks/principles/policies, volunteering, etc.  
Records excluded  
\( n = 90 \)

Eligible full text articles  
\( n = 51 \)
A NEWSLETTER OF THE CANADIAN RURAL HEALTH RESEARCH SOCIETY
SPECIAL EDITION | AUGUST 2015

14th Conference of the Canadian Rural Health Research Society

September 20th - 22nd, 2015 Edmonton, Alberta
http://crhrs-scrsr.usask.ca/edmonton2015/

Join us in September for the 14th Conference of the Canadian Rural Health Research Society: Better Health for Rural Canadians: from Evidence to Practice. We will be joined by our conference partner, the Canadian Association for Rural and Remote Nursing (CARRN). http://www.carrn.com/index.htm

Please distribute this notice to your colleagues, trainees, and others who may be interested.

Canadian Rural Health Research Society
Secretariat Office
E-mail: crhrs-scrsr@usask.ca
http://crhrs-scrsr.usask.ca

IN THIS ISSUE

- Remembering Dr. Patricia Martens
- Reflections on Rural Methods
- Ethical Implications of CBPR
- Statistical Applications for Rural Areas
- Upcoming Conferences of Interest
- Member Updates, Publications, Reports, and Resources

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Saskatoon, SK S7N 2Z4
http://crhrs-scrsr.usask.ca/

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Fax: (306) 966-8799
E-mail: CRHRS-SCRSR@usask.ca

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In Remembrance:  
Dr. Pat Martens 1952-2015

Dr. Patricia (Pat) Martins (née Weber) 1952-2015  
Director of the Manitoba Centre for Health Policy (2004-2014)  
Member of the Order of Canada (2013)  
Fellow, Royal Society of Canada (2013)  
Fellow, Canadian Academy of Health Sciences

On behalf of the Board and the entire membership of the Canadian Rural Health Research Society, I want to express our profound grief at the passing of Dr. Patricia Martens. Dr. Martens was a pioneer in health services and policy research and a key figure in the development of rural health research in this country. Her innovative work and her scintillating personality inspired a generation of colleagues and students across the country to do more and to do better. She could hold a large audience spellbound with a presentation that was at once stunningly informative and surprisingly funny and then finish by getting the entire group up for five minutes of aerobics. One of her greatest and most enduring contributions not only to rural health research but to health services and policy research more broadly was her inventive approach to getting researchers and policy makers to work together in the interest of enhanced health services and improved health for individuals, communities and regions. We will all miss her very much.

Dr. Stephen Bornstein, Chair, CRHRS  
Professor and Director for the Centre of Applied Health Research  
Memorial University of Newfoundland


In her own words: Dr. Marten on Asbestos and Mesothelioma (CAUT) | [http://bit.ly/1F8C0Bu](http://bit.ly/1F8C0Bu)

Reflections on Rural Health Research

In this edition of Rural Links, we feature two explorations of methods that might offer specific advantage or challenges for rural research. In the first reflection on the qualitative method of community-based participatory research (CBPR), Elena Wilson, Amanda Kenny and Virginia Dickson-Swift at La Trobe University (Australia) explore the ethical complications of doing research in rural communities. In spite of their empowerment approach, community members challenged them on their approach. The research team has chosen to explore and reflect on the expectations of communities, research environments and ethics boards. They invite other researchers to participate in this reflection on experiences of CBPR in rural areas through a blog post. In a second piece, Sidney Shapiro of Laurentian University shares a data processing work-around that takes advantage of new technologies to rapidly sift through large amounts of data. This may hold promise for working with rural communities, when large amounts of data are necessary to capture diverse small communities. These reflections raise the question of whether rural research does or does not require unique methodological approaches; and secondarily, whether rural contexts provide important insights and adaptations that can enhance existing research approaches. We welcome your comments in response to these articles, and we will publish “letters to the editor” in our next edition of Rural Links.

Silvia Vilches  
Rotating Editor
## Methods I: Ethical implications of Community-Based Participatory Research (CBPR)

Despite recognition of CBPR as an equitable, empowering research approach, recruitment difficulties and ethical challenges were experienced in a partnership project between the La Trobe Rural Health School (Australia) and 3 rural health services in 3 different communities. We focus on our experiences in one small rural township, population 3,000, in a bush-land setting approximately 150 kilometers inland from the south-eastern coastline of Australia.

Despite our best intentions and following CBPR principles carefully, we had difficulties in reconciling the formal ethical standards for recruitment with the expectations of potential participants and the research partner. We decided to formally investigate the challenges of using a CBPR approach for achieving community participation, focusing on one rural community in particular.

The recruitment protocol was problematic in two ways. First, our formally approved research recruitment plan included community information sessions to develop credibility and trust, yet the expectation of the health service partner was to have us ‘in’ the community actively developing relationships to attract participation. Second, the formal recruitment paperwork and process required by our ethics committee conflicted with a more social process of informing and gaining consent better suited to this community.

We were not the only organisation interested in this community. The high level of disadvantage, aging population, and above average rates of obesity and chronic disease meant that several other consultations and research projects were taking place at the same time we were scheduled to commence recruitment. The health service partner became concerned about over-consultation burdening the community and requested that we delay recruitment by 3 months.

As ‘outsiders’ we needed to find a way ‘in’ to the community, sometimes walking a fine line between the formally approved processes and the informal relationship building necessary to gain community trust to build interest in the project. What we did not expect was the high level of distrust community members had towards us as university researchers. In fact, as time went on, we discovered that active negative gate-keeping had taken place which limited the reach of our recruitment drive. This sense of distrust seemed to also be present between community member agencies, with over seventy community groups working in silos, often for similar goals, yet making no attempts to work together. Trying to work with a fragmented community added a layer of complexity to our recruitment attempts.

We were perplexed by our situation. Applying what is seemingly an equitable and empowering approach turned out to be fraught with difficulties. We wondered if other researchers using CBPR had the same issues. To identify the ethical challenges experienced by CBPR researchers at an international level we conducted a scoping review. We also created a blog [http://www.cbprethics.wordpress.com](http://www.cbprethics.wordpress.com) as a data collection site and invited researchers to write on the blog about the ethical issues they experienced at key stages of their CBPR process. (This blog is still active at time of publication).

The ethical challenges discussed to date on the research blog focus on informed consent processes and research rigour. Other researchers also see the formal informed consent process as intimidating and a barrier to engagement and discussed the need to explore how to best provide a consent process that is meaningful for communities. Compromised research rigour is a concern and researchers highlight the need to negotiate community cultural expectations with ethics approved processes, and conflicting interests between research partners and community members. Other challenges discussed by researchers can be read at [http://www.cbprethics.wordpress.com](http://www.cbprethics.wordpress.com).

The ethical challenges discussed on the blog to date are similar to those identified in our scoping review literature, suggesting some consistency in the types of issues encountered. Despite the challenges encountered in CBPR, it is a well-intentioned approach that we still see as important for working with rural communities. It led to successful community collaborations across our rural partnership project overall, but we agree with Minkler (2008), who recommends greater attention be paid to ethical considerations.

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- **Virginia Dickson-Swift** (PhD), Senior Researcher, La Trobe Rural Health School, College of Science, Health and Engineering, La Trobe University, Australia

I was recently involved in a quantitative study that involved a comprehensive chart review, in Sudbury, Ontario, Canada, studying prescription drugs. With my research partner, Kirk Unger, we studied the charts of four hundred patients for an entire calendar and gathered various types of data, such as demographic data, prescriptions written by type and month, dosages, and many other pieces of data. Following our successful ethics application, we worked up a pilot to see what type of data we would be collecting and what the best method to do so would be. We quickly realized that we were looking at manual entry of approximately 1.4 million records. For an unfunded project with a few part time volunteers, limited resources, a need to ensure confidentiality, and a number of time constraints, data entry from the charts into SPSS alone would take longer than we had available.

Gathering data that captures rural or remote populations, particularly in a study that is looking at collecting and entering large amounts of data, may encounter similar human factor limitations. In this project, we decided to work completely off-line, avoiding issues of security involved in storing data on the internet. It seemed that the majority of data that would need to be entered would be very simple and repetitive (most patients were not prescribed most medications in any given month, for example). We looked for various solutions to speed the entry of the data while ensuring accuracy.

We ended up using a method that met all the challenges we faced, and allowed for rapid and secure data entry. Using a standalone desktop computer, not connected to the internet, we installed WAMP Server¹, a program that includes Apache, PHP and MySQL, allowing the computer to operate as a webserver. We then installed a local copy of LimeSurvey². The database and all associated files were stored in an encrypted TrueCrypt folder. It is important to note that TrueCrypt is now no longer secure and has been replaced with Microsoft BitLocker³ among other alternatives. Using these programs together allow us to log into the computer with a password, unlock the encrypted drive, start the local webserver, and run a local version of our survey software, all without sharing data on the internet.

We used simple forms to collect our data, such as text entry fields for nominal data, radio buttons and Likert scales for ordinal and ratio data. Once the data was collected using simple forms (such as one survey form per chart), we could simply click a button to export the collected results into SPSS. A nice feature of this setup was being able to see rough ratios and analysis in real time as the data was saved in LimeSurvey. While this may seem complicated, it is simply a matter of installing the above three programs, there is almost no configuration needed, and little to no technical knowledge required.

Using these programs in concert provide a stable, reliable, secure, and easy to use solution, particularly when faced with the challenge of entering large amounts of data.

Sidney Shapiro
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Laurentian University
sx_shapiro@laurentian.ca

Conferences of Interest

Grey Matters Conference:
Health and Aging and Dementia in Alberta
www.greymatters2015.com
Alberta Seniors is pleased to be co-hosting the 2015 Grey Matters Conference with the Town of Drumheller on September 29 - 30, 2015. The Grey Matters Conference is a two-day event that offers provincial service providers opportunities to network, gain knowledge and increase awareness of issues, supports and services for seniors. Topics include:

- Creating age-friendly communities
- Innovative programs and services for seniors
- Creativity and lifelong learning
- Networks, partnerships and interagency collaborations that work
- Enhancing seniors’ health and wellness

Abstract submissions are now closed. Sponsorship opportunities are available!

Rural Resources:

Gateway Rural Health Research Institute: http://www.gatewayresearch.ca/

The Office of Rural Health and Primary Care: http://www.health.state.mn.us/divs/orhpc/

Canadian Journal of Rural Medicine: https://mail.google.com/mail/u/0/#inbox/14e87d4475c09225

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¹ http://www.wampserver.com/
² https://www.limesurvey.org/en/
Building Community Resilience: Innovation, Culture, and Governance in Place
Call for Presentations, Registration Open


The Building Community Resilience Conference will bring together community leaders, voluntary organizations, governments, businesses, and researchers to highlight people, organizations, and communities who are doing innovative things based on good governance, economic development, environmental considerations, and culture. These activities are critical to creating and sustaining healthy and resilient communities.

Conference organizers welcome submissions from community organizations, community leaders, non-profit organizations, government, students, researchers, and businesses to share information on the topic of building resilient communities or regions. The conference will examine opportunities for sustainable living that are more likely to emerge from small and peripheral communities – rural, coastal or island. The deadline for the call for presentations and stories was April 15. Further details can be found at [http://pei2015.crrf.ca/](http://pei2015.crrf.ca/).

The conference will be co-hosted by the Canadian Rural Revitalization Foundation, Institute of Island Studies at the University of Prince Edward Island, and the North Atlantic Forum. Conference registration is now open.

Research Reports & Publications

Team Workshop Report
Network for Canadian Oral Health and Research

The final report for the NCOHR team-building workshop. It has been also submitted to the library and archives Canada and Quebec.

Fourth workshop theme: Challenges in conducting research, implementation of effective interventions, and knowledge transfer in rural and remote, Indigenous, poor and immigrant populations.

- Addressing inequality, including rural/urban and Indigenous/non-Indigenous
- Using oral health and primary health as bridges to increase health literacy and address risks such as high sugar diets
- Advocate for important oral health supports, such as fluoridation
- Promote the work of interdisciplinary teams so as to facilitate effective communication, research and knowledge translation

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Informing Rural Primary Care Workforce Policy: What Does the Evidence Tell Us?
[http://bit.ly/1yQg8mO](http://bit.ly/1yQg8mO)

Evenson, MA. University of North Dakota Center for Rural Health Research and Policy.

This literature review profiles 51 publications constituting the body of evidence - based research produced by the federally - funded Rural Health Research Centers (RHRCs) from 2000 to 2010 which is relevant to the rural primary care workforce. The review includes the following sub - sections : Supply and Demand; Recruitment and Retention; Training Pipeline and Education; Lifestyle and Compensation; Nurse Practitioners, Physician Assistants, & International Medical Graduates; and New Directions for
Primary Care. Although this review reaffirms a general claim that has been made for at least the last decade and earlier – rural primary care workforce shortages not only exist but continue to worsen, as they result from complex, multifaceted issues which necessitate solutions that are equally complex – it also underscores larger issues driving research: Supply and demand research has emphasized the need for uniform, rural-specific primary care workforce data. Evidence continues to indicate that targeted, rural-focused recruitment initiatives as well as state and Federal-level policies which provide financial incentives are effective ways to recruit and retain primary care providers in rural areas. RHRC research publications focusing on training pipeline and education topics are largely in agreement about the demographics of medical students and primary care providers who are more likely to practice and stay in rural areas as well as the factors which influence these decisions. There has been an increasing push to streamline primary care, particularly in rural areas where communities are more commonly required to “do more with less,” and in recent years RHRC research has articulated and analyzed new, alternative models for primary care. 2010 saw the passage of the most comprehensive Federal health reform legislation in decades, and RHRC researchers have examined the implications this legislation may have on the rural primary care workforce.

Publications


Appointments, Awards, Honours, Promotions

Grants award
Clinician Scientist - Phase 2 "Fostering Oral Health through Interdisciplinary Research: Intervention, Access and Impact," Canadian Institutes of Health Research (CIHR). Elham Emami, DDS, MSc, PhD, Professeure agrégée, Faculté de médecine dentaire, École de santé publique, Département de médecine sociale et preventive, Université de Montréal.

Editorial Position
Dr. Elham Emami, DDS, MSc, PhD. Appointed Associate Editor of Trials Journal

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Increasing focus in Australia and internationally on community participation in health policy

Community participation
- is a democratic right
- is incorporated into legislative and policy framework that governs health services
  - Victorian health services Act 1988
  - Victorian health priorities framework
  - Charter of Healthcare Rights

Principle mechanisms for achieving objectives of broader frameworks in Victoria
Improving the health of communities through participation

Developing locally responsive rural health services.

2012 VAGO – Victorian DoH Community Participation Policy audit
2012 ACSQH – Report: NSQHS Standards implementation issues for small rurals
2014 ACSQH – Report: Survey 338 health service employees re NSQHS Std 2

What they found

OVERALL
- Implementing community participation policy is challenging
  - Cultural change
  - Lack of staff training, understanding - various interpretations

RURAL
- Executive leadership - Task for DON or Quality Manager
- Confidentiality
- Lack of resources
- HOW to achieve cultural change required for community participation
  HOW to enact Community Participation
How they responded

VAGO – 5 recommendations for health services

Formal government response to recommendations:

“primarily a matter for the health services and their boards to address” (Clark, R. MP, June 2014)

ACSQH NSQHS Std 2 surveys concluded:-

*Community participation is challenging
*No agreed ‘best practice’ approach

(standards – including Std 2 - currently being revised)

LACK OF DIRECTION: HOW TO ENACT MEANINGFUL COMMUNITY PARTICIPATION (Kenny et al., 2013)

Case study: Rural health services and the task of community participation at the local community level

Aim: Explore how a rural health service in Victoria enacts community participation at the local community level

Methods:

Key informant interview
16 In-depth Interviews
– 6 management, 7 staff, 3 stakeholders

Document analysis
– health service documentation


Interviews were guided by questions such as:

- Could you please describe what you understand by community participation?
- Is community participation part of the operation of your health service?
- Could you please provide some examples of how community participation occurs in the health service?
- What methods of community participation are utilised in the health service?
- What are the barriers to/supports for implementing community participation in the health service?
- Is community participation part of your role? If so, how do you include community participation in your role? What are the challenges/enablers?
- If you have been directly involved in enacting community participation what were the outcomes?
- How important do you think it is to encourage the community to participate in health service delivery, design of services and decision making?

Preliminary findings

- Conceptualising participation in different ways
- Someone else’s responsibility
- Clinical excellence is priority
- Barriers to enactment – funding, resources, time, training, staff and community culture
- Reliance on one group to achieve community participation
- Cultural transformation
- Disconnect between policy and practice
Australian policy:

Divergence between policy ideal and reality of enacting community participation

Policy assumption: people want to participate, health services are resourced

Lack of guidance for engaging rural populations - esp. disadvantaged and marginalised

Our findings

highlight the difficulties faced by rural health services, to meaningfully engage with disadvantaged rural populations.

problematize the community participation policy directive

For further information please contact:

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Bibliography

Australian Commission on Safety and Quality in Health Care (ACSQHC) (September 2011), National Safety and Quality Health Service Standards, ACSQHC, Sydney.


We wish to acknowledge Heathcote Health, Victoria, Australia who funded the scholarship for this project.
Concluding Comments

The research program reflected a strong partnership between La Trobe Rural Health School, Rural Northwest Health, Rochester and Elmore District Health Service and Heathcote Health. The partnership resulted in a program of work focused on community participation, and practical outcomes have been achieved for the services, the PhD students attached to the program and the researchers from the La Trobe Rural Health School. Without the commitment of the services to fund this unique program, it would never have happened.

We want to warmly thank Dr Kaye Knight for the fantastic work that she did on this program. Kaye was a terrific resource for the students as they established their projects, and was central in getting everyone organized. Thanks to Dr Amy Nimegeer, who inspired everyone to strive for greatness. We would be totally remiss if we did not acknowledge the creativity of Clare Bullen. Clare has unending patience and takes our scrappy pages and turns them into polished documents. This report would not have come together without Clare’s fantastic help.

All students approach PhDs in different ways, every PhD is different and every student will achieve different outcomes. Our purpose in completing a program of work was to maximise the outcomes for everyone involved by leveraging the funding to complete work across three services and cross cutting projects that explored different aspects of community participation. Through this program we have produced a major piece of work. The advantage of the approach taken enables all services to gain benefits from each project as the learnings are shared. Structuring our report in this way enables us to add information to this folder as more outcomes are achieved. This type of research often produces outcomes well beyond the lifespan of a project and funding. We look forward to celebrating more successes as they are achieved.
References


Improving the health of communities through participation


