

The benefits of community participation in rural health service development: where is the evidence?

Robyn Preston¹, Hilary Waugh¹, Judy Taylor², Sarah Larkins¹

¹James Cook University, ²Spencer Gulf Rural Health School UniSA/University of Adelaide

Introduction

The term 'community participation' is commonly understood as the collective involvement of local people in assessing their needs and organising strategies to meet those needs.¹ The importance of community participation in rural health service development is uncontested. The rural health policy framework Healthy Horizons Outlook² includes the principle, 'participation by individuals, communities and special groups in determining their health priorities should be pursued as a basis for successful programs and services to maintain and improve their health'. The document also states that 'social capability and the physical capacity to plan and implement local programs are required for communities to improve and maintain their health'.^{2 (p7)}

This is not an isolated pronouncement. The origins of the concept of community participation in rural health lie in its application by international organisations, such as the World Health Organization,³ in developing countries in an attempt to improve health, social and economic conditions. In Australia, government agencies at the national and state level⁴ have maintained an interest in community participation because of the perceived benefits. Community participation in rural health service development has been argued to result in more accessible, relevant, and acceptable services.^{5, 6} In addition it is often implied that community participation will result in higher community satisfaction with health services, and indeed better health outcomes, yet evidence to support this assertion is limited.⁷

Rural and remote Australian communities support community participation and sometimes demand it. There is a long tradition of community contributions to all kinds of health services including hospitals, general practice services and preventative health programs.⁸⁻¹⁰ Community participation, in helping develop these services and programs, is often premised on the assumption that the health of the community, its vitality, and sustainability is threatened if health services and programs are unavailable or inappropriate.⁶ However, this type of community participation, if it is largely driven by community members, may fall outside the radar of the health system¹¹ and is rarely reported in the academic literature. Our motivation is to review the evidence to determine whether community participation does make a difference to health outcomes.

Clearly, there are quite different perspectives on what community participation is, how it should occur, and whether it should be top-down or bottom-up.¹² In spite of the popularity of the concept in policy frameworks and in practice, there is no equivalent commitment to measuring the outcomes of community participation as an intervention, or analysing the processes of community participation in order to improve them. For example, in reporting progress against the Healthy Horizons framework, no attempt is made to measure levels or types of community participation even though the framework clearly articulates benefits of it. The document claims that 'forums [have been] established in the Australian states and territories so that health departments can build partnerships with communities and key stakeholders to identify and address community health problems, disseminate information and support the advocacy role of communities and health professionals'.⁵ However, we know that the existence of these forums does not necessarily equate with broad-based and vigorous participation.¹³

The reluctance by policy makers to analyse and measure community participation arises in part because governments are primarily interested in measuring outcomes in relation to health system components they control. Secondly, because of its illusive and multi-layered nature it is difficult to design good quality trials to measure the effectiveness of community participation as an intervention (separate from other interventions), but this lack of evidence does not necessarily equate to a lack of outcomes.⁷ Finally, there are definitional disputes about what constitutes 'community participation.' Terms such as 'community involvement', 'community development', and 'community mobilisation' could all describe collective involvement of local people in assessing health needs and implementing programs. More recently, the terms 'community capacity building' and 'community engagement' have gained popularity and both of these processes involve community participation.

In order to strengthen the knowledge-base about the benefits of community participation we undertook a review of the literature. The aim was to synthesise the evidence for outcomes from community participation in rural health service development. Our work builds on that of Andrews et al¹⁴ who conducted a literature review about the use of community health workers in research; Rifkin et al¹² who undertook a review of participatory approaches to health planning and promotion; Rosato et al¹⁵ who examined community participation in maternal, newborn, and child health, and the World Health Organization's review of the evidence on the effectiveness of empowerment to improve health.¹⁶ It adds to Kilpatrick's⁷ review of community engagement in health development.

Methodology

Working definitions

Community participation

We defined 'community participation' as people from a community of place¹⁷ or of interest¹⁸ participating together in advisory groups, fundraising, attending consultations, planning, or in other activities.

Rural health service development

We defined 'rural health service development' to include activities such as planning for, creating access to, implementing, and evaluating health services. It also includes creating access to and operationalisation of all types of community-based health programs including health promotion, health planning, priority setting and community capacity building.

Outcomes of community participation

We defined outcomes of community participation as all those aspects positive, neutral, and negative, which are reported and demonstrated to show that community participation was a key component.

Review process

Literature search

A search of international and Australian peer reviewed published literature, in particular, empirical studies about community participation and rural health service development was undertaken (Appendix 1). 'Community participation' was chosen as the key search term because of its habitual usage in international and national rural health service development literature. However, because terms can be used interchangeably we also searched for 'community involvement' and 'community engagement'.

Databases including the Cochrane Collaboration, PubMed, CINAHL and INFORMIT were searched for publications in English published between 1997 and 2008. This search yielded 309 publications. In addition, the National Rural Health Alliance conference proceedings, public forums and concurrent papers CD (1995-2007) yielded 186 documents and the on-line Journal of Rural and Remote Health (<http://www.rrh.org.au>) yielded 140 documents. The 'Communication Initiative Network' website (<http://www.comminit.com>) was searched and four relevant documents were identified. Two relevant documents were identified from The World Health Organization website (<http://www.who.int>). Australian Policy on-line (www.apo.org.au) revealed no relevant documents. The Australian Aboriginal and Torres Strait Islander Health Worker Journal provided three documents. Forty-five relevant articles and reports already known to the authors were included in the review.

The authors ran duplicate searches and cross-checked each other's review results to ensure methodological rigour. In total 689 papers formed the basis of a data review to identify publications that were relevant to ascertain the benefits of community participation in rural health service development.

Data review

The 689 publications were reviewed by at least two of the authors for eligibility using the following inclusion criteria.

- Rural: activities were undertaken predominately outside of capital cities.
- Community participation took place.
- Community participation was directed towards rural health service development.
- Outcomes (positive, neutral, or negative) were demonstrated and reported.

This step resulted in 161 papers being accepted for further analysis. These papers were entered into EndNote.

Data synthesis

The authors conducted further analysis to reach agreement and ensure that the final results included only papers that met all of the inclusion criteria. This resulted in 37 publications being synthesised using the following categories.

- Country/contextual factors
- Who initiated community participation
- Community participation process
- Type of health service development
- Conceptual approach to community participation: contributions, instrumental, empowerment or developmental⁶ (Table 1)
- Level of evidence: The NHMRC levels of evidence were used as a framework against which to assess the strength of the evidence for the effectiveness of community participation on outcomes.^{19 (p.8)} We added the category of level 5 evidence from the Cochrane Collaboration.
- Outcomes (positive, neutral or negative): reported and demonstrated.

We have used a typology to define, illustrate, and clarify the different conceptual approaches to community participation (Table 1).⁶ This typology consists of four approaches; the contributions, instrumental, empowerment, and developmental. In this evolving categorisation, these various conceptual approaches to community participation often overlap and are difficult to distinguish in practice.

Table 1 Four conceptual approaches to community participation⁶ (p88)

<p>The contributions approach</p> <p>The contributions approach considers participation primarily as voluntary contributions, to a project, such as time, resources, or community-based knowledge. Professional developers, usually external to the community, lead participation and make the decisions about how the contributions will be used.</p>
<p>The instrumental approach</p> <p>The instrumental approach defines health and wellbeing as an end result, rather than as a process, with community participation as an intervention supporting other public health or primary health care interventions, health planning, or service development. Participation is usually led by professionals and the important components of the interventions or programs are predetermined according to local and national priorities.</p>
<p>The community empowerment approach</p> <p>The community empowerment approach seeks to empower and support communities, individuals, and groups to take greater control over issues that affect their health and wellbeing. It includes the notions of personal development, consciousness-raising, and social action.</p>
<p>The developmental approach</p> <p>The developmental approach conceptualises health and social care development as an interactive, evolutionary process, embedded in a community of place or interest. Local people, in partnership with professionals, have a role in decision-making and in achieving the outcomes they consider are important. The developmental approach is underpinned by principles of social justice.</p>

A number of publications which were not included in the final results remained relevant to the research question and have been referenced in this document where appropriate.

Results

The results of the data synthesis are presented in Appendix 2.

This paper provides a broad synthesis of outcomes associated with community participation in rural health service development. It is intended as an introductory step on the journey towards exploring some of the contexts and processes that might facilitate the trialling and measurement of community participation as an independent strategy or intervention towards improving the health of people in regional and remote areas.

From our review we have evidence that community participation can result in beneficial health outcomes and increased uptake of services. Fourteen (38%) of the studies presented in Appendix 2 reported improved health outcomes associated with community participation providing evidence at level 4 or above. In some cases the health improvements were profound. For example, Mandahar et al²⁰ using an empowerment and developmental approach to community participation reported significant improvement in birth outcomes in a poor rural population using a participatory intervention with women's groups.

We also have evidence that community participation can result in other outcomes that may be related to achieving health improvements. Outcomes such as better access to health services,^{11, 21-25} more

relevant and culturally appropriate services,^{11, 26-29} or just maintaining a service in the face of a threat to remove it³⁰ have been achieved through community participation. Sixty-five per cent (n=24) of studies reported in Appendix 2 achieved this type of outcome from community participation. However, the level of evidence presented in these studies is at the lower end of the evidence scale, often in the form of a single descriptive case study, or a satisfaction survey.

A further important finding is that the studies demonstrated a spread of approaches to community participation. Twelve studies (32%), primarily in developing countries, used a contributions approach.^{23-25, 28, 31-38} Ten studies (27%) used an instrumental approach using community participation as an intervention.^{21, 27, 29, 39-45} Four studies (11%) used an empowerment^{22, 26, 46, 47} approach and eleven (30%) used a developmental approach where community participation was conceived of as an evolutionary process with community members achieving community initiated goals as well as those of health systems.^{9, 10, 20, 30, 48-54}

When analysing studies we have reported on the **overall** outcomes resulting from community participation as an intervention or an approach. We have not reported on **the role of** community participation in **creating** these outcomes. We found too few studies reporting exclusively on the specific role of community participation, independent of other elements of the program, to provide us with a broad platform of knowledge about our research question.

Discussion

We note that although community participation is a complex and multi-level process it is nonetheless able to be measured and even trialled as a health intervention impacting on health outcomes. What might assist in building better knowledge about community participation is better designed studies where the role of community participation is reported upon independently of other aspects of the intervention or program. Randomised controlled trials which provide a higher level of evidence about community participation are costly, rare, and require a historical build up with the community. Health improvements are not gained and demonstrated without an extended timeframe, sound methodology, adequate and sustained resources, and strong relationships. The community's experience in Yalata demonstrates that it takes many years of sustained community action to change health policy.¹⁰ However, we consider that the considerable improvements that can be made to health through community participation justify increased resources to support and analyse it.

In addition, we acknowledge that writing about community participation sometimes describes what governments, health systems and organisations intend to occur rather than what does actually occur. The use of terms does not necessarily categorise discrete or different processes. Rather than the terms it is the processes involved that are important to analyse in an attempt to elucidate their effectiveness in different contexts.

From the analysis of these papers it is impossible to align a particular conceptual approach to community participation with the achievement of particular types of health and health related outcomes. However, we consider it of the utmost importance for policy makers and practitioners to be aware of the approach they use. The contributions approach, which draws on voluntary contributions from community members, must have built in safeguards to ensure sustainability. The developmental and empowerment approaches require a long timeframe (up to ten years) to demonstrate health and health related outcomes. So the approach must be explicit and related to the task, timeframe, the community concerned, and the available resources.

It is clear from our review that this is not always the case. There are numbers of reports of projects that aim to build community capacity for health promotion that have a very short timeframe. Evaluations of these projects and programs have claimed outcomes such as increased 'social capital' and 'empowerment' without quantifying them even though there are tools to measure these.³⁵ Results are often based on questionnaires asking about participation and implying that because people came together and enjoyed an activity then social capital was raised. The authors had to scrutinise activities and not rely on language to determine what was actually occurring. This is not to say that community participation did not happen or social capital was not built but the report did not clearly demonstrate how this occurred.

The other point arising about the conceptual approaches is that they are not discrete. For example, in some studies local people are recruited into health systems as employees and they act as 'boundary crossers' where they draw on their community connections to create links between health systems and communities.^{11, 21, 24-26, 28, 31-33} This could be seen as both an instrumental and contributions approach to community participation. In addition, the developmental and empowerment approaches usually overlap.

Finally, allocating a 'conceptual approach' (as per Table 1 above) may well depend on from whose perspective we are categorising it. For example a health service may be seeking ideas through a process of consultation (contributions approach), when a community is seeking to steer and own a program (empowerment approach). These conceptual approaches to participation may also change or develop over time.

It is important to note that the wealth of information at the community level about community participation may not have been captured in this review. Community initiated developmental projects, which often demonstrate sound outcomes, are unlikely to be reported in the peer reviewed literature. Academics, non-government development agencies, and government departments are more likely to publish about projects that they have funded and have a stake in. Therefore, community perspectives on community participation are rarely captured. It would be worthwhile to investigate how communities have viewed and valued their own participation in many of the programs reported here.

Additionally, it is disappointing that weight is not given to reporting upon how community participation processes are related to achieving health outcomes. Often studies reported improved health outcomes and extensive participation but the connection between the two were not clearly described and quantified.

Study limitations

This literature search was not exhaustive and was limited by time and resources. A thorough search may have used all possible terms to capture articles about community participation such as 'community involvement', 'community capacity building', 'community engagement', 'community initiated', 'community-based', 'community driven', 'community developed', 'community directed' or 'community controlled'. Community engagement is a more recent term and is usually used by governments or health systems rather than communities in describing aspects of policy implementation or consultations. Because we were interested in actions by communities in addition to those by governments and health systems we chose to focus on 'community participation' rather than community engagement. Unpublished reports and PhD theses were not included in this review.

There were problems with both the methodology and the reporting of the studies that made it difficult to determine whether or not the paper met our criteria for inclusion. These problems included a lack of

specificity about the intended outcomes of community participation compared with those that occurred, limited use of comparison or control groups, and a lack of clarity about the specific benefits of the community participation aspect of the intervention.

Conclusions

While there is some evidence to establish the benefits of community participation in producing health and health-related outcomes; only a few good quality higher level studies have been conducted. Few, if any, studies have definitively demonstrated that community participation provides better health outcomes than no community participation in the same circumstances. However, further attention to the analysis and reporting of the community participation aspect of primary health care and public health interventions is warranted, as absence of evidence of an effect is not the same as absence of an effect. Improved analysis of community participation could be achieved by comparative studies, longitudinal studies as well as randomised controlled trials.

Achieving further clarity about the benefits of community participation requires tools to measure and analyse it as a collective phenomenon. To date there has been less interest in this than in measuring more tangible outcomes of public health and primary health care interventions.

Finally, we would stress the value of genuine community/health sector partnerships to develop health services for rural communities. Using a developmental approach will enable communities to work in partnership with health systems to employ resources to the health issues that are of most concern to communities. However, governments, practitioners, and health systems must recognise and accept that community health development requires a long term and consistent investment, with health system reform processes and restructures managed so that they do not impact negatively on the processes. If this can be achieved then improved community health can be expected.

This review has provided new information from a novel synthesis of the literature about the benefits of community participation for health outcomes in the rural and remote context. However, it highlights the areas in which the existing evidence is lacking, and raises a number of issues for future exploration and clarification.

Presenters

Robyn Preston is a Lecturer at the School of Medicine and Dentistry, James Cook University, Townsville.

Hilary Waugh is a research assistant at the School of Medicine and Dentistry, James Cook University, Cairns.

References

- [1] Zakus J, Lysack C. Revisiting community participation. *Health Policy and Planning*. 1998;13 (1):1-12.
- [2] National Rural Health Alliance. Health Horizons 1999 -2003: A framework for improving the health of rural, regional and remote Australians. . A joint development of the National Rural Health Policy Forum and the National Rural Health Alliance for the Australian Health Ministers' Conference. Canberra: National Rural Health Policy Forum and the National Rural Health Alliance; 2000. Available from: <http://nrha.ruralhealth.org.au/publications/?IntContId=43&IntCatId=6>. Accessed: [on line accessed 20 November 2008].
- [3] World Health Organization, . Community involvement in health development: challenging health services, Report of a WHO Study Group, Geneva: WHO 1991.

- [4] Government of South Australia. . Draft strategy for planning South Australia's health services. Adelaide; 2008 [on line accessed 20 November 2008]. Available from: <http://www.publications.health.sa.gov.au/spp/76/>:
- [5] National Rural Health Alliance. Healthy Horizons, Progress against the Healthy Horizons framework for improving the health of rural and remote Australians, Report to the Australian Health Ministers Advisory Council. Canberra; 2002. Available from: http://nrha.ruralhealth.org.au/cms/uploads/publications/hh_2002_06b.pdf [on line accessed 20 November 2008].
- [6] Taylor J, Wilkinson D, Cheers B. Working with Communities in Health and Human Services: Oxford University Press 2008.
- [7] Kilpatrick S. Multi-level rural community engagement in health. *Australian Journal of Rural Health*. 2009;17:39-44.
- [8] Collins Y. The more things change, the more they stay the same: health care in regional Victoria. In: Bourke L, Lockie S, eds. *Rurality bites: the social and environmental transformation of rural Australia*. Sydney: Pluto Press 2001:103-17.
- [9] Taylor J, Wilkinson D, Cheers B. Community participation in organising rural general practice: is it sustainable? *Australian Journal of Rural Health*. 2006;14:144-7.
- [10] Brady M, Byrne J, Henderson G. 'Which bloke would stand up for Yalata?' The struggle of an Aboriginal community to control the availability of alcohol. In: *Australian Institute of Aboriginal and Torres Strait Islander Studies*, ed. 2003.
- [11] Kilpatrick S, Cheers B, Gilles M, Taylor J. Boundary crossers, communities, and health: Exploring the role of rural health professionals. *Health and Place*. 2009;15:284-90.
- [12] Rifkin S, Lewando-Hundt G, Draper A. Participatory approaches in health promotion and health planning: a literature review. Health Development Agency, London. 2000.
- [13] Frankish C, Kwan B, Ratner P, Higgins J, Larsen C. Challenges of citizen participation in regional health authorities. *Social Science and Medicine*. 2002;54:1471-80.
- [14] Andrews JO, Felton G, Wewers ME, Heath J. Use of community health workers in research with ethnic minority women (Structured abstract). *Journal of Nursing Scholarship*. 2004;36(4):358-65.
- [15] Rosato M, Laverack G, Howard Grabman L, Tripathy P, Nair N, Mwansambo C, et al. Alma-Ata: Rebirth and Revision 5. Community participation: lessons for maternal, newborn, and child health. *Lancet*. 2008;372:962-71.
- [16] World Health Organization, Wallerstein N. What is the evidence on effectiveness of empowerment to improve health? 2006 2006:1-37.
- [17] Cheers B, Luloff AE. Rural Community Development. In: Bourke L, Lockie S, eds. *Rurality Bites, the Social and Environmental Transformation of Rural Australia*. Sydney: Pluto Press 2001:129-42.
- [18] Guterbock TM. Community of interest: Its definition, measurement, and assessment. *Sociological Practice Review*. 1999;1(2):88-104.
- [19] National Health and Medical Research Council. How to Use the Evidence: assessment and application of scientific evidence. Canberra: National Health and Medical Research Council 2000. Available from: http://www.nhmrc.gov.au/publications/synopses/_files/cp69.pdf
- [20] Manandhar DS, Osrin D, Shrestha BP, Mesko N, Morrison J, Tumbahangphe KM, et al. Effect of a participatory intervention with women's groups on birth outcomes in Nepal: cluster-randomised controlled trial. *Lancet*. 2004;364.
- [21] Bedelu M, Ford N, Hilderbrand K, Reuter H. Implementing antiretroviral therapy in rural communities: the lusikisiki model of decentralized HIV/AIDS care. *J Infect Dis*. 2007 Dec 1;196 Supplement 3:S464-8.
- [22] Braun KL, Tsark JU, Santos L, Aitaoto N, Chong C. Building Native Hawaiian capacity in cancer research and programming. A legacy of 'Imi Hale. *Cancer*. 2006 Oct 15;107(8 Suppl):2082-90.
- [23] Jacobs B, Price N. Improving access for the poorest to public sector health services: insights from Kirivong Operational Health District in Cambodia. *Health Policy Plan*. 2006 Jan;21(1):27-39.
- [24] Sirivong A, Silphong B, Simphaly N, Phayasane T, Bonouvong V, Schelp FP. Advantages of trained TBA and the perception of females and their experiences with reproductive health in two districts of the Luangprabang Province, Lao PDR. *Southeast Asian J Trop Med Public Health*. 2003 Dec;34(4):919-28.
- [25] Adatu F, Odeke R, Mugenyi M, Gargioni G, McCray E, Schneider E, et al. Implementation of the DOTS strategy for tuberculosis control in rural Kiboga District, Uganda, offering patients the option of treatment supervision in the community, 1998-1999. *Int J Tuberc Lung Dis*. 2003 Sep;7(9 Suppl 1):S63-71.
- [26] George M, Masotti P, MacLeod S, Van Bibber M, Loock C, Fleming M, et al. Bridging the research gap: aboriginal and academic collaboration in FASD prevention. The Healthy Communities, Mothers and Children Project. *Alaska Medicine (13th International Congress on Circumpolar Health, Novosibirsk, Russia, June 12-16, 2006)*. 2007;49(2 Suppl):139-41
- [27] Hodgson M. Planning with rural communities: to hit and not miss. 7th National Rural Health Conference. Hobart 2003.
- [28] Kironde S, Kahirimbanyi M. Community participation in primary health care (PHC) programmes: lessons from tuberculosis treatment delivery in South Africa. *Afr Health Sci*. 2002 Apr;2(1):16-23.
- [29] Wilson M. Local health planning to meet the needs of communities. 6th National Rural Health Conference. Canberra ACT 2001.

- [30] O'Meara P, T H. Saving Helimed: The power of community action in country Victoria. 7th National Rural Health conference. Hobart, Tas 2003.
- [31] Bang AT, Bang RA, Baitule SB, Reddy MH, Deshmukh MD. Effect of home-based neonatal care and management of sepsis on neonatal mortality: field trial in rural India. *The Lancet*. 1999;354(9194):1955-61.
- [32] Baqui AH, El-Arifeen S, Darmstadt GL, Ahmed S, Williams EK, Seraji HR, et al. Effect of community-based newborn-care intervention package implemented through two service-delivery strategies in Sylhet district, Bangladesh: a cluster-randomised controlled trial. *The Lancet*. 2008;371(9628):1936-44.
- [33] Bhutta ZA, Memon ZA, Soofi S, Salat MS, Cousens S, Martinez J. Implementing community-based perinatal care: results from a pilot study in rural Pakistan. *Bull World Health Organ*. 2008 Jun;86(6):452-9.
- [34] Bradley M, . Building partnerships with the community for health promotion. National Rural Public Health Forum 1997.
- [35] Hill K. Royal Flying Doctor Service Field days: supporting access to primary health care for people living in remote north Queensland utilising a capacity building approach. 9th National Rural health Conference. Albury NSW 2007
- [36] Kidane G, Morrow RH. Teaching mothers to provide home treatment of malaria in Tigray, Ethiopia: a randomised trial. *The Lancet*. 2000;356(9229):550-5.
- [37] Ndiaye SM, Quick L, Sanda O, Niandou S. The value of community participation in disease surveillance: a case study from Niger. *Health Promot Int*. 2003 Jun;18(2):89-98.
- [38] Sare D, Kirby D. Road Trauma Reduction and Injury prevention participation in Rural Communities. 5th National Rural Health Conference. Adelaide, SA 1999
- [39] Abelson J, Forest PG, Eyles J, Casebeer A, Martin E, Mackean G. Examining the role of context in the implementation of a deliberative public participation experiment: Results from a Canadian comparative study. *Social Science & Medicine*. 2007;64(10):2115-28.
- [40] Fleming M-L, Higgins H, Owen N, Clavarino A, Brown W, Lloyd J, et al. Community capacity building for health promotion: Lessons from a regional Australian initiative. *Australian Journal of Primary Health*. 2007;13(3):22-8.
- [41] Goodrow B, Scherzer G, Florence J. An application of multidisciplinary education to a campus-community partnership to reduce motor vehicle accidents. *Educ Health (Abingdon)*. 2004 Jul;17(2):152-62.
- [42] Hancock L, Sanson-Fisher R, Perkins J, McClintock A, Howley P, Gibberd R. Effect of a community action program on adult quit smoking rates in rural Australian towns: the CART project. *Prev Med*. 2001 Feb;32(2):118-27.
- [43] Lobo R, Brown G, Edwards J. Developing locally relevant outreach programs for same sex attracted youth in regional areas. *Health Promot J Aust*. 2007 Aug;18(2):109-12.
- [44] Loos C, O'Hara L, Dingle M. Issues in local community participation, experiences of the Kolan Injury prevention Program. National Rural Public Health Forum 1997.
- [45] Parker E, Meiklejohn B, Patterson C, Edwards K, Preece C, Shuter P, et al. Our games our health: a cultural asset for promoting health in Indigenous communities. *Health Promot J Aust*. 2006 Aug;17(2):103-8.
- [46] Fitzpatrick J, Ako W. Empowering the initiation of a prevention strategy to combat malaria in Papua New Guinea. *Rural and Remote Health*. 2006;7(693).
- [47] Nikniaz A, Alizadeh M. Community participation in environmental health: Eastern Azerbaijan Healthy Villages project. *East Mediterranean Health J*. 2007 Jan-Feb;13(1):186-92.
- [48] Eyre R, Gauld R. Community participation in a rural community health trust: the case of Lawrence, New Zealand. *Health Promot Int*. 2003 Sep;18(3):189-97.
- [49] Field P, McLay A, Grundy J. Laramba family wellness model: Integration, sustainability and transferability. 6th National Rural Health Conference. Canberra, ACT 2001.
- [50] Kenny P. Aboriginal youth development: a community based program in far west NSW. 5th National Rural Health Conference. Adelaide, SA 1999.
- [51] Kilpatrick S. Community engagement and working with government. Inaugural Rural and Remote Health Scientific Symposium. Brisbane, QLD 2008.
- [52] Peddle DN, Turray R, AIM Staff, The women and men of Port Loko District, St. Joseph' Vocational School. Participatory action research evaluation: Amazonian initiative movement improve the lives of women through livelihood options and reduce female genital mutilation in Port Loko district. Mid term report: American Refugee Committee (ARC); 2007. Available from: <http://www.care2share.wikispaces.net/space/showimage/mid-term+report+on+FGM--final.pdf>.
- [53] Rowley KG, Daniel M, Skinner K, Skinner M, White GA, O'Dea K. Effectiveness of a community-directed 'healthy lifestyle' program in a remote Australian aboriginal community. *Aust N Z J Public Health*. 2000 Apr;24(2):136-44.
- [54] Warchivker I, Hayter A. An evaluation of a nutrition program in a remote community in central Australia. 6th National Rural Health Conference. Canberra, ACT 2001.

Appendices

Appendix 1 Literature sources and search strategies

We searched these literature sources	We used these search terms and strategies
Cochrane Collaboration PubMed/MEDLINE CINAHL INFORMIT Web of Science/Web of Knowledge	We searched for each of these groups of terms: (1) ("community participation" OR "community involvement" OR "community engagement") (2) ("health" OR "health service*" OR "health sector") (3) (evidence OR outcome*) (4) (accept* OR access* OR appropriate*) (5) (rural OR remote OR regional OR Aboriginal OR Indigenous OR "Torres Strait Islander") Then we combined the groups of results to capture only those publications containing ALL of the desired search terms: (6) (1) AND (2) AND (3) AND (4) AND (5)
National Rural Health Alliance conference proceedings, public forums and concurrent papers CD 1995-2007	We searched 'key terms' using the term: 'community participation'
Online Journal: Rural and Remote Health	We searched 'key words' using the term: 'community'
Communication Initiative Network website	We searched the site using the terms: 'community participation' and 'health' 'community engagement' and 'health' 'community involvement' and 'health'
Australian Aboriginal and Torres Strait Islander Health Worker Journal	We hand searched for articles meeting the criteria.
World Health Organization Website	We searched the site using the terms: 'community participation' and 'health' 'community engagement' and 'health' 'community involvement' and 'health'
Australian Policy On-line Website	We searched the site using the terms: 'community participation' and 'health' 'community engagement' and 'health' 'community involvement' and 'health'

Appendix 2 Data synthesis of eligible papers

	Doc ref number Author and date Country/ contextual factors	Initiator	Community participation process	Type of rural health service development	Conceptual approach to participation (see Table 1)	NHMRC Level of evidence incl. Level 5 Cochrane collaboration	Reported and demonstrated outcomes
1	000006 Abelson et al 2007 ³⁹ Provincial CANADA	Four Canadian Universities	Deliberative public consultation process	Health planning: allocation of resources	Instrumental	Level 5	Enhancement of decision- making processes in some settings
2	000048 Adatu et al 2003 ²⁵ Central UGANDA	National TB and leprosy program. TB DOTS (Directly Observed Treatment Strategy)	Community health aides mobilised to monitor TB amongst patients in the community	Operationalising community-based primary health care program	Contributions	Level 4	Enhanced access to TB treatment leading to increased number of treated cases
3	000128 Bang et al ³¹ 2000 Gadchiroli District INDIA	SEARCH (Society for Education, Action, and Research in Community Health)	Village health workers received training in neonatal care, health education and supervision	Operationalisation of home-based neonatal care	Contributions	Level 3.2	Reduction in neonatal, stillbirth and newborn mortality rates
4	000127 Baqui et al 2008 ³² BANGLA-DESH	United States Agency for International Development and Saving Newborn Lives Programme, Save the Children (US)	Community health workers (female) provided antenatal and postnatal in-home care	Operationalising in- home neonatal preventative and curative care	Contributions	Level 3.1	Reduction in neonatal mortality

	Doc ref number Author and date Country/ contextual factors	Initiator	Community participation process	Type of rural health service development	Conceptual approach to participation (see Table 1)	NHMRC Level of evidence incl. Level 5 Cochrane collaboration	Reported and demonstrated outcomes
5	000059 Bedelu et al 2007 ²¹ Lusikisiki: Rural SOUTH AFRICA	Medicins Sans Frontiers (MSF)	Nurses and health workers giving drugs, counselling locally with community support as opposed to centralised hospital dispensing	Operationalising community-based HIV clinical program	Instrumental	Level 3.3	More people receiving treatment
6	000129 Bhutta et al 2008 ³³ The Hala and Matiari Sub- Districts PAKISTAN	Department of Paediatrics and Child Health, Aga Khan University, Karachi, Pakistan.	Lay Health Workers and Traditional Birth Attendants trained in perinatal care	Operationalisation of community-based perinatal care through establishment of local community health committees, community outreach and education	Contributions	Level 3.2	Reduced still-birth and neonatal mortality rates
7	000147 Bradley 1997 ³⁴ Busselton WA AUSTRALIA	Vasse Health Service in collaboration with the surfing community in Margaret River	Partnership to attract funding, access to local networks for health professionals. Community people on health promotion committees	Health promotion to reduce surfing injuries	Contributions	Level 5	Higher local awareness of community developed surfing code of ethics
8	000100 Brady et al 2003 ¹⁰ Yalata Aboriginal community, SA AUSTRALIA	Yalata Aboriginal community	Community lobbying government with the intent to control the availability of alcohol locally.	Community controlled health priority setting, prevention and capacity building	Developmental	Level 4	Local change in alcohol legislation

	Doc ref number Author and date Country/ contextual factors	Initiator	Community participation process	Type of rural health service development	Conceptual approach to participation (see Table 1)	NHMRC Level of evidence incl. Level 5 Cochrane collaboration	Reported and demonstrated outcomes
9	000083 Braun et al 2006 ²² Hawaii, USA	Center to Reduce Cancer Health Disparities	Community engagement with Native Hawaiians :training, technical assistance, resources to reduce cancer disparities	Health planning, developing culturally appropriate education, primary and secondary prevention and research	Empowerment	Level 5	Enhanced access to cancer information and screening services in some locations
10	000111 Eyre & Gauld 2003 ⁴⁸ Lawrence, NEW ZEALAND	Rural community of Lawrence, NZ.	Community Trust involvement in needs assessment, resource input and community governance	Health service planning, governance, and resourcing of local health services	Developmental	Level 5	Developed community health trust to provide health services and evaluated the process
11	000148 Field et al 2001 ⁴⁹ Aboriginal Community NT AUSTRALIA	National Heart Foundation	Community involvement in needs assessment, planning, resource allocation, service delivery and evaluation	Implementation of primary health care model and programs initially to address diabetes	Developmental	Level 5	Changed nutrition patterns Improved primary prevention through council, CDEP, school & store. Community directed intersectoral action plans and programs. Community management of some initiatives
12	000103 Fitzpatrick & Ako 2006 ⁴⁶ Highlands PAPUA NEW GUINEA	Erima Empowerment Research Project in PNG	Kewapi language group took responsibility for the acquisition, distribution and effective use of 400 WHO approved bed nets in the village.	Primary prevention	Empowerment	Level 3.3	Improved health and eliminated mortality from malaria

	Doc ref number Author and date Country/ contextual factors	Initiator	Community participation process	Type of rural health service development	Conceptual approach to participation (see Table 1)	NHMRC Level of evidence incl. Level 5 Cochrane collaboration	Reported and demonstrated outcomes
13	000099 Fleming et al 2007 ⁴⁰ Remote Community QLD AUSTRALIA	Queensland Health, Queensland Universities, Not-for profit Organisations.	Community involvement to identify needs, prioritising funding for health promotion initiatives, and establishing Health Promotion Committee	Health planning and promotion	Instrumental	Level 5	Increased numbers of community participants in planning groups and programs
14	000080 George et al 2007 ²⁶ 4 Aboriginal Communities Alaska USA	Canadian Institutes of Health Research -Institute of Aboriginal Peoples' Health (Universities)	Local women and Health Workers involved in designing culturally appropriate foetal alcohol spectrum disorder prevention programs	Health promotion, prevention, health planning	Empowerment	Level 5	Design of four culturally appropriate community interventions
15	000090 Goodrow et al 2004 ⁴¹ Rural Appalachia USA	Community Partnership Program, East Tennessee State University	Partnership between university and local community; enquiry-based learning model to identify and plan strategies	Operationalisation of primary prevention to improve road safety	Instrumental	Level 4	Reduction in road fatalities
16	000051 Hancock et al 2001 ⁴² 20 rural towns AUSTRALIA	University of Newcastle (NSW) and Cancer Council NSW	Local community action groups formed to initiate and to monitor intervention	Operationalisation of primary prevention to reduce smoking	Instrumental	Level 3.1	Smoking rates reduced

	Doc ref number Author and date Country/ contextual factors	Initiator	Community participation process	Type of rural health service development	Conceptual approach to participation (see Table 1)	NHMRC Level of evidence incl. Level 5 Cochrane collaboration	Reported and demonstrated outcomes
17	000149 Hill 2007 ³⁵ Rural QLD AUSTRALIA	Royal Flying Doctor Service	Voluntary coordinator provides local liaison and staff and communities work together to schedule field day and topics	Health promotion with clinic	Contributions	Level 5	Enhanced community connectedness and capacity for health through partnership networks, problem solving, and knowledge transfer Increased sense of community and increased leadership potential
18	000150 Hodgson 2003 ²⁷ Yorke Peninsula SA AUSTRALIA	Wakefield Health Service	Consultation Working advisory committee established 7 Community forums Community survey (500 responses) Service provider consultations	Local rural health planning	Instrumental	Level 5	Refocusing health service towards community needs Expansion of health services to meet community needs Consolidation of providers into more flexible teams Strongly locally supported health plans Unintended consequence— emergence of local leadership
19	000089 Jacobs & Price 2006 ²³ Kirivong District, Takeo Province CAMBODIA	The Swiss Red Cross	Local community people identified other poorest locals for financial support to access health services	Improving access for poorest community members to health services	Contributions	Level 3.2	Improved access to health services for poorest community members

	Doc ref number Author and date Country/ contextual factors	Initiator	Community participation process	Type of rural health service development	Conceptual approach to participation (see Table 1)	NHMRC Level of evidence incl. Level 5 Cochrane collaboration	Reported and demonstrated outcomes
20	000151 Kenny 1999 ⁵⁰ Far West Aboriginal Health Service NSW AUSTRALIA	Far West Aboriginal Health Service NSW government	Community and health provider Youth Working Groups. Communities involved in developing, running, and evaluating programs	Operationalising youth development strategy	Developmental	Level 5	Working Groups have put in place a broad range of projects, employing the resources of many stakeholders relevant to the well being of young people.
21	000125 Kidane & Morrow 2000 ³⁶ Tigray Province ETHIOPIA	John Hopkins University, Baltimore USA	Self-formed community groups selected a mother coordinator (MC) trained to refer sick children. In the intervention MCs were trained to recognise symptoms of and treat malaria.	Screening, primary prevention, health promotion and treatment	Contributions	Level 2	Major reduction of under 5 mortality
22	000117 Kilpatrick 2009 ¹¹ Rural and Remote AUSTRALIA	Rural communities and Universities/ Centres for Rural Health	Individual community members who are also health professionals act as 'boundary crossers' to activate community-based projects to improve health and wellbeing	Developing community-based health services, general practices, and community market.	Developmental	Level 5	Development of health services in rural communities that may not otherwise have been there
23	000141 Kironde & Kahirimbanyi 2002 ²⁸ Rural SOUTH AFRICA	District Health Service, Northern Cape Province	Lay volunteers involved in supervision of TB treatment Directly Observed Treatment	TB treatment, surveillance, and referral	Contributions	Level 5	No difference in treatment outcomes for new patients supervised from the community compared to other treatment modes. Community-based treatment superior to self- administered therapy for re- treatment patients.

	Doc ref number Author and date Country/ contextual factors	Initiator	Community participation process	Type of rural health service development	Conceptual approach to participation (see Table 1)	NHMRC Level of evidence incl. Level 5 Cochrane collaboration	Reported and demonstrated outcomes
24	000058 Lobo et al 2007 ⁴³ WA AUSTRALIA	Western Australia Centre for Health Promotion Research, Curtin University	70 people trained in issues for Same Sex Attracted Youth (SSAY)	Health promotion including capacity building	Instrumental	Level 4	Improved awareness in community about issues. Improved knowledge and confidence about issues amongst the target group
25	000152 Loos et al 2007 ⁴³ The Wide Bay /Burnett Region QLD AUSTRALIA	Queensland University of Technology (QUT) Health Promotion Council of QLD	QUT conducted interviews and workshops with local stakeholders. Small number of community members recruited for advisory committee.	Injury prevention program including training and promotion	Instrumental	Level 5	Injury surveillance thought to be onerous by organisations. Community not mobilised as injury prevention was not high on agenda. Subsidised first training for 200 people resulted in 29 take-ups
26	000020 Manandhar et al 2004 ²⁰ NEPAL	International Perinatal Care Unit, University College London.	PAR facilitation with local women to identify issues and developed local strategies to address them	Primary prevention and perinatal care	Developmental	Level 2	Reduction in neo-natal and maternal mortality.
27	000142 Ndiaye et al 2003 ³⁷ NIGER	National Immunisation Program Centre for Disease Control and Prevention US	Community sponsored health promotion campaigns and surveillance	Disease surveillance	Contributions	Level 5	Increased community surveillance. Voluntary participation unsustainable
28	000067 Nikniaz & Alizadeh 2007 ⁴⁷ Azerbaijan IRAN	The East Azerbaijan provincial health centre based on WHO healthy villages program	Men's and women's health committees, staff training, training for community, collaboration between organisations	Primary prevention	Empowerment	Level 4	Reduced parasites and parasitic diseases. Increase in sanitary toilets and safe water.

	Doc ref number Author and date Country/ contextual factors	Initiator	Community participation process	Type of rural health service development	Conceptual approach to participation (see Table 1)	NHMRC Level of evidence incl. Level 5 Cochrane collaboration	Reported and demonstrated outcomes
29	000153 O'Meara & Houge 2003 ³⁰ Rural Gippsland VIC AUSTRALIA	Gippsland community Helimed auxiliary	Political action and information provision to stop closure of HELIMED service	Provision of emergency transfer to urban hospitals by helicopter	Developmental	Level 5	Service continued
30	000064 Parker et al 2006 ⁴⁵ Cherbourg and Stradbroke Island QLD AUSTRALIA	Queensland University of Technology (QUT) and communities	Community forums to monitor project—the introduction of traditional games	Health promotion including capacity building	Instrumental	Level 5	Process evaluation indicated satisfaction with games. Games included in activities of a range of community organisations.
31	000027 Peddle et al 2007 ⁵² Port Loko District SIERRA LEONE	Amazonian Women's Initiative (NGO)	Establishing, monitoring, resourcing and evaluating community action groups to prevent Female Genital Mutilation (FGM)	Health promotion, education, capacity building, in women's reproductive health	Developmental	Level 5	Changes in knowledge, skills and attitudes. Formalised agreements between action group and FGM practitioners not to practice
32	000139 Rowley et al 2000 ⁵³ Kimberley Region North WA AUSTRALIA	Community initiated with Monash University (VIC) partners	Community identified lifestyle health problems and directed strategies to address them including food availability.	Primary prevention, health promotion and operationalisation of clinical programs in partnership	Developmental	Level 5	Improved dietary intake and physical activity. Reduced fasting insulin levels, with protection from increased plasma glucose and triglycerides for high risk group. After 6yrs program run entirely by community members.

	Doc ref number Author and date Country/ contextual factors	Initiator	Community participation process	Type of rural health service development	Conceptual approach to participation (see Table 1)	NHMRC Level of evidence incl. Level 5 Cochrane collaboration	Reported and demonstrated outcomes
33	000154 Sare & Kirby 1999 ³⁸ Millicent Community SA AUSTRALIA	South East of South Australia Division of GP Inc.	Public meeting Widely representative voluntary committee Local Council financial contributions	Operationalisation of injury prevention strategies	Contributions	Level 5	Reduction in road injury patterns predicted fatalities.
34	000053 Sirivong et al 2003 ²⁴ Luangprabang Province LAOS	Provincial Health Department, Luangprabang, Lao	Community-based Traditional Birth Attendants' (TBA) trained	Creating access to antenatal postnatal and child health services	Contributions	Level 4	50% of women used trained TBA. Increased use of antenatal care. Increased immunisation and feeding of colostrum
35	000116 Taylor et al 2006 ⁹ Rural SA AUSTRALIA	Rural communities	Community members through hospital boards recruited GPs, fund raised, & provided governance for practice	Participation in the development of general practice services	Developmental	Level 5	High levels of community participation in developing general practice services but participation unsustainable.
36	000155 Warchivker et al 2001 ⁵⁴ Remote NT AUSTRALIA	Pintubi Homeland Health Service, Ngintaka Women's Centre, the community store, the Centre for Remote Health	Community members developed the structure of the program. Researchers in consultation developed a revised form of individual growth monitoring.	Childhood nutrition and growth program development and operationalisation.	Developmental	Level 3.3	Significant improvement in the growth status and the prevalence of malnutrition. Except for 0–4 months, lower incidence of diarrhoea.

	Doc ref number Author and date Country/ contextual factors	Initiator	Community participation process	Type of rural health service development	Conceptual approach to participation (see Table 1)	NHMRC Level of evidence incl. Level 5 Cochrane collaboration	Reported and demonstrated outcomes
37	000156 Wilson 2001 ²⁹ Rural NSW AUSTRALIA	Mid Western Area Health Service	Consultation committees/ planning teams to identify local priority issues	Local rural community health planning	Instrumental	Level 5	6 out of 16 sites have plans. Extra funding, significant structural and clinical practice change, increased community participation, and a shift in service provision to include marginalised target groups. Interagency planning group