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Community participation for rural healthcare design: description and critique of a method

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Abstract

This paper outlines a community participation process that was developed to engage rural community stakeholders in designing new health services. The paper explains what led up to the process and provides critique around applying the process for other health services and in other communities. Internationally, community participation is widely invoked, but it is only broadly explained in the literature, other than reviews of outcomes or descriptions of problems. This paper provides an actual process, derived from iterative research, that others could use, but explains caveats in the method and its application. From developing this method of community participation for service design, we conclude that rather than being a benign and inherently 'good thing', community participation is a process into which health services managers and communities should enter cautiously. Stronger parameters around desirable outcomes and awareness of potential pitfalls in the process are important to address. Keywords: community participation, outcomes, primary healthcare, rural health, service delivery models, service design social capital, but the nuances of actually doing it are seldom unpicked.

What this paper adds

- Describes how an actual process for a particular outcome was delivered in rural places.
- Highlights the advantages and disadvantages of a particular method of community participation.
- Reflects on more generalisable issues about implementing community participation processes, particularly in a rural place.

Introduction

The purpose of this paper is to present a method for undertaking rural community participation to design health services, to overview how it was derived and to critique it. Writing about community participation tends to consist of abstractions saying how good or important it is, reviews of outcomes or papers highlighting difficulties. Here, we present a 'real' community participation method and scrutinise its benefits and challenges, thus presenting a process that others could apply, alongside knowledge of the caveats they should consider. The paper draws on data and reflections from a project 'Remote Service Futures' (Nimegeer et al. 2010), to design a rural community engagement project for designing health services, that took place in Scotland, 2008–2010.

Consumer and community participation in service design and production are advocated in health policy internationally (NHS Scotland 2006, Australian Government Department of Health and Ageing 2011). Aligned with Needham's (2011) concept of a 'policy storyline', public participation is 'compelling, emotionally resonant, but also multi-interpretable'. Community participation encompasses applications of citizen input ranging from passive provision of information about local peoples' opinions (Coulter 2010, pp. 12–14) to involving people in service design and to co-production of services (Horne et al. 2013). By one definition, community participation is the active

'collective involvement of local people in assessing their needs and organising strategies to meet those needs' (Preston et al. 2014 from Zakus and Lysack 1998, pp. 8–9) and co-production as service delivery 'in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours' (Boyle & Harris 2009, p. 5). Co-production brings in service planning and production aspects to community participation and fits with current neoliberal government ideologies (e.g. the Big Society in the United Kingdom) which call on individuals and communities to do more for themselves (Stott 2010). Recent 'austerity' agendas have seen even greater impetus for active service production by citizens in communities (Public Services Commission 2011).

There is an assumption in the way health policy describes community participation that it will be health service-driven. By implication, this suggests that community participation is primarily beneficial for health service organisations, perhaps because it helps to design health services that meet community needs (Ridley & Jones 2002, pp. 67–70). Health services' leadership of community participation also suggests that, at least initially, they will be the dominant power in relationships with citizens. Alford (2009) distinguishes community participation from consumer involvement, noting that consumers are concerned with their individual consumption experiences. A community, conversely, represents the 'collective we', having wider concerns about 'civilised society, economic and technological development, social equity and reduced transaction costs' (Alford 2009, pp. 40–41).

Community participation might be viewed as particularly relevant for rural places (Kenny et al. 2013). Rural service provision is an acknowledged 'wicked' issue (Humphreys et al. 2009). Services are costly to provide because populations are smaller and providing access to specialised services, close to rural residents, lacks economies of scale (OECD 2006, pp. 30–31). It has also become increasingly hard to incentivise health professionals to work in rural areas (Buykx et al. 2010). Research shows rural places have high social capital which should make citizens amenable to participation in designing appropriate services that meet local needs and are sustainable (Woolvin & Rutherford 2013). Contemporary political ideology suggests that people in rural areas need to build on their assets to develop unique place-based solutions, moving from endogenous subsidisation to local governance which builds community capacity (OECD 2010). Alford (2009, pp. 47–48) notes that individuals need to perceive benefits if they are to participate and in rural areas, there is evidence that citizens will engage in activities around service change due to concerns about impacts on community sustainability (Kearns & Joseph 1997).

Rural health managers would be justified, therefore, in viewing community participation as a tool to help sustain local services by building co-productive partnerships between services and citizens to design and provide what is needed locally (Kilpatrick 2009). Managers might see it as a way to gain community support for services and to get new ideas (Naccarella et al. 2006). Embedded in communities as they are, rural health practitioners and local managers might feel obliged to embrace community participation as contributing to community capacity-building and sustainability. In some countries, all health services must implement public participation as it is expressly stated in government standards (e.g. ACSQH 2012). Given the ambiguous policy storyline nature of community participation, it is unsurprising that health services employees are confused about how to do it and which outcomes to expect.

Rationale for community participation

Recently, discourse about participation in national standards and guidelines has moved from discussing consumer involvement, feeding into individual healthcare decisions and giving feedback on services to – in addition – engaging citizens collectively as partners in community participation (Scottish Health Council 2010a, ACSQH 2012). The community turn is suggested as stemming from political ideas about making citizens consider costs and regulating demand, and generating greater civic society (Head 2007). Participation implies citizens' and managers' active involvement, appropriate governance and decision-making structures, and understanding of how to create and sustain partnerships. Contemporary health service leadership competency frameworks confirm that practitioners should be able to engage and enable communities including involving citizens in 'decision-making, health policy, education and training, and healthcare redesign' (Health Workforce Australia 2013, p. 12).

[Figure 1: Arnstein's Ladder – adapted from Arnstein (1969)]

The classic theoretical frame for analysing community participation is Arnstein's (1969) Ladder (adapted in Figure 1). It delineates varyingly powerful roles for citizens with different participation types. Participation affords a space where different knowledge bases about a community issue can come together (Healey, 2009). Renn et al. (1993) provide a tested model of how to engage citizens. They deployed participatory decision-making to benefit from '...multi-actor, multivalue, multi-interest' perspectives, seeking to combine knowledge based on 'commonsense and personal experience', 'technical expertise' and 'social interests and advocacy'. The premise is that revealing and sharing different knowledge will lead to better informed perspectives on challenges and might help to solve problems. Acknowledging different perspectives is pertinent in rural healthcare because its organisation requires contextual, personal knowledge of citizens based on intense reciprocal relationships to work with a system-based, centralising, rational management paradigm. Providing rural services exemplifies Giddens's (1990, p. 88) contrast between relational 'trust in persons' and 'facework commitments' (rural people) versus transactional 'trust in systems' and 'faceless commitments' (health services organisation) (Farmer 2007). Based on previous study findings, Table 1 categorises stakeholder groups in rural health community participation, proposing their perspectives and knowledge.

[Table 1: Types of knowledge and motivations in rural community participation]

In categorising, the table inevitably neglects the diversity and complexity within each stakeholder grouping. Alford (2009, p. 23) highlights that individuals often have multiple roles; for example, local practitioners are also citizens and perhaps service consumers and policy makers. Alford (2009) notes, too, that what stakeholders want or receive in public services is rarely completely explicit. For example, he argues that service managers primarily want citizen compliance within a situation of rationing due to a constrained budget (Alford 2009, p. 42). In rural places, citizens may want local services due to their symbolic association with community sustainability (Prior et al. 2010).

Recent literature reviews summarise community participation outcomes from individual and collective perspectives. Community outcomes include social capital, partnership working and empowerment (Milton et al. 2011). Individual outcomes include perceived physical and psychosocial health and social outcomes (Attree et al. 2011). Negative impacts arose if community participation

was poorly conducted, including tokenistic consultation or if information generated did not affect decision-making (Attree et al. 2011). Specific to rural places, community participation outcomes were greater awareness of health services, learning new skills and strengthened relationships (Kenny et al. 2013). Peculiarly, as community participation processes are portrayed as service initiated, the outcomes for service management appear under-researched.

Methods

Between 2008 and 2010, university-based researchers and health services managers collaborated on a partnership project to develop a community participation process specifically for designing health services in small rural communities distant from service centres. The impetus was the desire to involve local stakeholders in reconfiguring service provision. Contemporary rural health policy suggests that traditional models of locally resident, single-handed general medical practitioners (GPs) and nurses are unsustainable (NHS Scotland 2007a) and, instead, that more services should be provided by outreach teams operating from a central hub. Previous attempts to discuss service reconfiguration had led to stressful confrontations between health service managers and community members.

The health authority partner was influenced in its desire for a method of community engagement by policy on involving consumers and communities (e.g. NHS Scotland 2007b). Managers wanted a process that was relatively cheap and feasible to conduct, where citizens and managers could exchange knowledge and ideas. The community participation process had to produce the output of a local service design that was capable of implementation (i.e. complied with legislation and regulation requirements). As the project focus was to develop a customised participation process, rather than to produce actual service change at the time, community members were informed that outcomes of their involvement (service designs) would not necessarily be implemented unless all stakeholders were keen to progress them. The project was approved as a service improvement initiative by the NHS Highland Ethics Committee.

Study design

Broadly, a community-based participatory action research (CBPAR) framework was used (Minkler 2005). Our interpretation of CBPAR was to engage all actors in decision-making as intelligent contributors, but with diverse types of knowledge, perspectives and experience. Employing the iterative cycling of action, reflection and adaptation associated with action research allowed us to start with a prototype process, and then to trial and refine the process as we implemented it, in a step by step fashion, in the community settings. University researchers also acted as facilitators of community workshops. Community participants included local citizens, health and social care workers, services managers and local politicians, sometimes with overlapping roles. Based on the initial reading, a prototype four-stage community workshop design was devised that incorporated key topics stakeholders should consider and an asset, rather than a problem-based perspective, was taken. Key influences were Arnstein's (1969) Ladder (see Figure 1) which gave an easily assimilated, reflective framework to engage communities with our broad aim of engaging them. We asked that we see the process as one of 'partnership'. Renn et al.'s (1993) participation process stages were influential: (i) identify concerns (and we added, assets); (ii) consider options and their impacts; and

(iii) elicit preferences. With four communities involved, each stage of work with one community informed the next stage of work with that community and the relevant stage of work with other communities. This allowed maximum 'learning' by the end of the project. At each stage, data pertinent to service design and evaluating the process were collected, but data collection had to respond to what the community found 'normal' and acceptable.

Sample

Participant communities were remote from service centres (50-minute drive to the nearest community health centre for two mainland communities and up to 3 hours distant from a regional hospital for two island communities). Local health services had traditionally been provided by one or two generalist resident practitioners (a GP and/or a community nurse). In Scottish Government (2012) area classification terms, the communities included in the project were 'very remote rural', with populations of 200–450 people. Our conceptualisation is of 'communities of place' (Delanty 2003, p. 55) with clear physical parameters – being two islands and two peninsula communities. All had a recent history of protest and/ or resistance around proposed health service changes.

Each of the four workshops was individually advertised in communities via local noticeboards, newsletters, newspapers and community web pages. We contacted local health and social care practitioners, and invited them to attend and to 'spread the word'. Overall, the minimum number of people who attended a workshop was 3, while the maximum was 30. (The range of participant numbers for communities was as follows: (i) 3–30; (ii) 5–30; (iii) 8–28; (iv) 6–15. As we were concerned to maximise inclusion, we also conducted a total of 39 interviews across the four communities.) Interviewees were either self-identified or suggested by local health or social care practitioners, following an initial discussion and informal consent process with interviewee.

Data collection

During the series of community workshops, participants' comments about service design process were collected via flipcharts, notes and post-it notes, with overall themes identified and verified at the end of the workshop. Briefings were distributed to the wider community via community council reports, newsletters and newspapers, with people asked to comment. Workshops were not recorded as we found community participants wanted as 'normal' a discussion process as possible. A key aspect of workshops was to be highly adaptive to the groups' expressed requirements about data collection methods; for example, on three occasions, workshop participants objected to using post-it notes and flipcharts, and just wanted to talk. At end of the workshop, participants were asked to complete a short 'satisfaction' questionnaire. Two researchers (of A.N., J.F. and M.C.) attended each workshop. We received consent to record 13 interviews and notes were taken of others, with two researchers present at each. All data were collected within 17 months, with 6– 12 weeks between individual community's workshops.

Analysis

Adaptation of the theme and conduct of individual workshops was based on experiences of previous workshops, verbal comments during workshops and written comments on satisfaction

questionnaires. Interview data were mainly used to inform the issues around health service design that was the topic focus of the community participation process.

Findings

By the end of the project, we had evolved a method of community participation for health service design; features of the four key stages are described below. We are also able to provide a critique of the opportunities and challenges afforded by the model. These were raised in the process of designing and implementing the participation process.

A method for rural community participation in health service design

Entry and introduction

Individual discussions were held with community 'gatekeepers', including health professionals, community and local councillors and informal local leaders. Without their support, it would be difficult to 'enter' the community to talk about health and services. This was a negotiated and imprecise phase. In the course of discussion, we might identify other local leaders that we should contact. The initial group was identified through discussion with local health managers, practitioners and some web-searching to identify those appearing as key local figures. Shortly after contacting the community gatekeepers, a meeting was held in the community hall with advertising using posters, local newspapers and newsletters, websites or emailing lists and word of mouth through the gatekeepers.

For each community, it was most helpful to establish a core group that we asked to participate in the whole process. From trying different methods within the project, we found a successful way to establish this group by asking local services, organisations, clubs and associations to provide a 'representative'. The existence of a group was also advertised locally and interested volunteers were invited to get in touch and participate. Through this process of obtaining (i) representatives from existing institutions and (ii) self-nominating volunteers, we ensured a core ongoing group. The relevance of an ongoing group was that participants accrued information over time, thus building their knowledge. Participants developed trust, relationships and confidence. This is a pragmatic way of forming a community participation group.

Community members were asked if they would participate in a process to design local health services that met their priorities and informed that the output would be hypothetical and there was no onus to change. Local health practitioners and managers were also invited to participate to share their knowledge and perspectives.

Community health

Following Renn et al.'s (1993) first stage – identify concerns – one and sometimes two, group meetings identified what community members viewed as local health problems and how their perceptions compared with evidence from available data. A key idea was to discuss health and social issues rather than workers and roles. Initially, in all participant communities, local people raised a need for doctors and nurses. Our response, as facilitators, was to ask them to focus on health and social priorities.

Once community views of health issues had been recorded, some routinely collected data depicting local health and social status were provided to workshop participants. For all four communities, we showed data from Scottish Neighbourhood statistics (see <http://www.sns.gov.uk/>) showing age and disadvantage rates, compared with other parts of Scotland. Data on the most common conditions seen at the local general practice were also summarised. Other data covered after-hours and emergency service contacts. All data were anonymised at the community or local area level.

Participants then discussed similarities and differences between their perceptions of local health and social issues, and issues highlighted by 'formal' quantitative data. Common health challenges shown in data were conditions associated with smoking, obesity, high blood pressure and mental health. This caused participants to suggest that perhaps communities could take collective action to prevent some of these problems. Citizens tended to overestimate the number of local emergency and after-hours call-outs. Presenting data showing actual call-outs gave people an objective perspective of the need for high levels of emergency access. The endpoint of this stage was to identify priority local health and social issues that future services should address.

Service solutions

Given the issues raised at Stage 2, a meeting, showcase and drop-in was held to present what other rural communities have done to address health challenges. In attendance and giving short presentations were representatives of services and initiatives that had tackled health problems in other rural communities, for example, tele-health and tele-care, volunteer first responder schemes, extended and generic health practitioner roles and transport schemes. The showcase allowed participants to ask questions, meet service providers and to discuss issues in non-confrontational, non-public settings. Community members expressed satisfaction with meeting diverse service providers and learning about service delivery options. Several service providers had not previously visited the remote communities and they discovered geographical or communication constraints. Service providers met each other and discussed opportunities for working together.

Design

To obtain a new service design, we devised an exercise that drew on previous discussions. The Remote Service Futures 'game' (Nimegeer et al. 2011) had the following steps.

1. Agree local health priorities: for example, common priorities were identifying and dealing with medical/health emergencies, anticipating health and care problems of older people, improving local health and well-being, and supporting young families.
2. Identify 10 key competencies to address agreed health priorities: a large set of competencies of different health and social care provider roles, including community-based volunteers, were provided as card-strips, built from the standard position descriptions of health and related workers. Participants could add competencies if they were not provided.
3. Build the 10 competencies into a local health service design: participants were provided with cards that described the scope of practice, in competencies, for different 'standard' existing health or other community workers and volunteers. Importantly, the cards were not labelled 'doctor', 'nurse', 'paramedic', rather they were simply Worker A, B, C, etc. Participants were asked to align the competencies they had chosen at Step 2) with the cards to see if one or more worker types

existed that met selected competencies. If not, they could design a new role and/or identify other ways to provide the competencies.

Participants were given an estimated current budget for providing community health services. On the cards describing worker roles, the 'cost' of having this role was also provided. Participants were asked to keep within the current budget. Through this process, participants from two communities designed new local health services. Participants of one community elected to retain their current (single-handed GP) service. For the final community, only three participants presented for the final session, a group size we considered too small to carry out the design exercise (Farmer & Nimegeer 2014).

Critique of the community participation process

Through an adaptive, refining process, the project produced a community participation process that united multiple types of knowledge in decision-making, involved relatively few visits to communities and no expensive resources other than staff time and travel. For all of the communities, stakeholders came together to consider local health issues and contemporary service delivery options. The process is now acknowledged as one model of good practice by the Scottish Health Council (2010b). (The extent to which the process is being implemented by the health authority that partnered in its design will only be ascertained in 2014–2015 with a follow-up evaluation that has already been approved.)

In developing the Remote Service Futures participation process, issues were raised that maybe important for those embarking on community participation. Throughout the research, having resident health professionals remained a key desire of citizens in comparison with a peripatetic team approach favoured by managers. If the new designs suggested by two communities actually were to be implemented, service managers would have to accept a local approach and apply time to negotiate the cross-service working and development of new roles that would be required. Participation is classically portrayed as a multi-stakeholder process to reach consensus, but considerable will would be required to implement a new model if it misaligns with established practice or policy direction. Service agencies may lack the resources to negotiate this process, especially if models are different for each community. One design involved combining paramedic and nursing roles which raises the issue of governance as one agency might have to take responsibility for driving change if multiple agencies are required to work together to make changes happen.

In the two communities that did not design an innovative service model, either insufficient citizens presented to make a new service design or the service design replicated the original. There is little guidance for health services about what to do in such impasse situations if the key outcome needed is changed service delivery. The key principle for consideration here is the extent to which health services want to give communities a free rein to choose. They may wish to constrain the range of choices from the start, for example here by stating that a key principle is outreach teams, rather than locally resident practitioners. Our findings suggest that, at the very least, it is important for a health service to identify and acknowledge potential process outcomes before commencing.

The project showed some evidence that health literacy and health system literacy might be outcomes of community participation. As our concern was to produce a participation process that

produced designs, we had not implemented before- and after data collection that would definitively tell us about 'added value' or process impacts of community participation such as health literacy changes. Community members began to comment at later workshops that they had developed an understanding of what services existed, how they linked together, who to contact and how, in what circumstances. They expressed that, by meeting service providers and managers, they felt more able to engage in constructive dialogue about services. There were also comments about the value of knowing about service costs. Learning extended beyond citizens to managers who commented that they had learnt system competency through discussions with other service providers and understood more about the challenges of community members, for example, infrastructural constraints like poor roads and mobile phone coverage.

Given this, there could be greater appreciation of the health system literacy outcomes arising from multi-stakeholder community participation rather than focusing on service plans produced. We suggest that those using community participation start to devise a package of process measures that show community participation effects, and that health literacy and health system literacy might be a useful place to start as health literacy improvements would be perceived as beneficial outcomes by all stakeholders.

Attracting community members to take part was challenging. Only small proportions of citizens in each community participated in public meetings (the highest number that attended a workshop in any community was 30). Inclusion of only small numbers is raised as a problem for community participation (Shortall 2008), and there is an implicit expectation that nothing less than universal inclusion provides sufficient views. Much has been made of evidence that powerful minorities dominate rural community participation (e.g. Shucksmith 2000), but even 'gold standard' methods have found that only those with time on their hands and a reason to participate will do so (Renn et al. 1993, Alford 2009, p. 188). In situations where services are not at obvious immediate risk, service providers may have to be more accepting that only a proportion will participate. More research is needed, however, to understand why some people participate, in what circumstances, with what impacts and what incentives work best to entice people to formally contribute.

Conclusion

Community participation is an example of a contemporary policy storyline – it sounds inherently worthy, but it is fuzzy and challenging in its enactment. Here, we described a process specially developed for multistakeholder community participation to design rural healthcare services. We suggest the process is reproducible and relatively cheap, and highlight some risks and opportunities with the method as it currently stands.

A service design was produced by/for three of four study communities, but the two innovative approaches would be difficult to implement as misaligned with policy direction to outreach services. Leadership and governance would be required if plans were to be carried through to implementation. Two communities reached impasse. It is difficult to suggest what actions a health authority should take next to stimulate change. The lesson is that health services should be wary of the outcomes of community participation and perhaps constrain possible options to those they could actually support to fruition. Health system literacy appears as a beneficial outcome, suggesting community participation might affect individuals' and communities' health and services knowledge. Measurement of health literacy outcomes and in particular, better knowledge about navigating the

healthcare system maybe something that should be built into evaluation of the effects of community participation. A process for inclusion that appeals at least to more, if not all possible, participants remains a holy grail. More research is needed to explore the idea that only selective voices are heard in community participation and what that means for health services in terms of the information they find about community members and their involvement in decision-making.

On the basis of our experiences, we propose that community participation for designing services has potentially quite measurable impacts and is do-able, but aspects require further consideration and clarification. Our process was short, sharp and aimed at decision-making and perhaps this is only appropriate in certain situations. Some communities may require longer processes with more opportunities for information exchange and relationship building before embarking on joint planning. Indeed it may be risky for health services to ask communities to make decisions as it is difficult to identify next steps if communities do not engage or their decisions are unacceptable. Our experiences have made us think that rather than a benign and cosy process, community participation is a delicate and potentially dangerous process for managers and citizens to engage in. Thus, it is important that methods, their likely outcomes and modes of operation become more codified if community participation is to move from a fuzzy policy storyline to a robust approach embedded within local health system development.

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Conflict of interest

There are no conflicts of interest.

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