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Stakeholder involvement in primary health care research

Report and recommendations

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Part 1. Background

1.1 INTRODUCTION

Australia has not progressed in engaging consumers in research to the same level as other countries such as the UK. The National Health and Medical Research Council (NHMRC) and Consumers' Health Forum (CHF) introduced a Statement on Consumer and Community Participation in Health and Medical Research in 2002 (2), but little in terms of follow up and implementation has occurred. Some universities (e.g., University of Western Australia (UWA)) and peak bodies (e.g., Cancer Council) have established processes for involving consumers in research but these efforts have not spread far beyond their own organisations.

APHCRI, in leading capacity building in primary health care research, should also lead in establishing consumer involvement as an integral part of primary health care research in Australia. APHCRI's instructions to applicants for Stream and Centre of Excellence funding refer to the importance of consumers as research beneficiaries, but also as a stakeholder in knowledge translation and dissemination. The Research Advisory Board (RAB) includes community consumer input through consumer members and policy advisers through the relationship between APHCRI and the Department of Health and Ageing (DoHA). Researchers and practitioners are represented through the research and knowledge translation process, using tools such as the APHCRI website, publication and round tables. However the role of the community consumer in APHCRI's work and the role of APHCRI in relation to these consumers have not been defined. The RAB approved the need to develop a stronger consumer voice in the APHCRI network. This report addresses work carried out over the past year and recommends a way forward for the network.

1.2 LITERATURE REVIEW RATIONALE

APHCRI's recent stock-take of primary health care research (3) found that the 'target users' of research were infrequently engaged in research funded through the Primary Health Care Research, Evaluation and Development (PHCRED) strategy. Approximately 12% of projects had an advisory board to guide the research process but only 2-4% engaged consumers, users or policy makers, or had a formalised collaborative process built into the research process.

In developing APHCRI's role for engaging consumers in primary health care research and in the translation of research knowledge into policy, a number of preliminary questions must be explored, including what is involved, best practice, models and resources available and evidence of the benefits and negatives. Initial research was carried out to explore these questions and identify resources and models of consumer involvement in health research.

1.3 APPROACH

The authors identified resources through:

Web search

A web search of relevant consumer and research sites known to the researchers within Australia and internationally was conducted. Examples included NHMRC, Health Issues Centre, WA Health Consumers Advisory Council, Consumers Health Forum (in Australia); National Institute of Health (USA); Canadian Institute of Health Research; Medical Research Council,

National Institute of Health Research and National Health Service (in UK). Links on each of these websites were followed.

Expert views

Considerable information was gained from phone interviews through references, referrals and notes from interviewees. Interviewees represented WA Health Consumers Advisory Council, Victorian Health Issues Centre, APHCRI, School of Population Health UWA and Telethon Institute of Child Health Research, Centre for Health Communication and Participation, Cochrane Consumer and Communication Group, La Trobe University, Victoria and the WHO Patient Safety initiative.

Brief literature search

The initial step was to conduct a search using Google Scholar. Search commenced with terms ‘consumer engagement in primary health care research’ and ‘consumer involvement in research on primary health care’. These produced only a handful of useful results. As illustrated in Table 1, it was discovered that the multiplicity of terms used in this field combined with the huge range of material meant that even a reasonable preliminary literature search based on conventional methods would exhaust the time available for this initial scoping activity.

‘Snowballing’

Further material was accessed through reference lists of articles, bibliographies and reports found and the links to resources provided on known websites.

Table 1. Core search terms

Consumer	User	Public	Patient	Citizen	Lay	Client	Community
Involvement	Engagement	Participation	Empowerment	Partner/ship	Action	Consult	Collaboration
Research	Clinical Trial	Service/Program development	Randomised Control Trial / RCT				

Research focused on accessing material in accessing material from Australia, UK, USA, and Canada.

1.4 RESULTS

A large amount of material was found. There were a number of useful and key consumer resource sites and organisations which focused on or included consumer engagement in research in their brief. Significant ones were INVOLVE and James Lind Alliance (UK); School of Population Health, UWA and Consumers Health Forum (Australia). Others include the Victorian Health Issues Centre (HIC) and various Cancer Councils in Australia; Canadian Institute for Health Research (CIHR); Cochrane Consumer Collaboration (international) and the LEAD Project (US). In addition, there was a range of consumer involvement material within specific health care target groups, most notably in mental health, cancer and Indigenous health (in Australia and internationally).

Access to policy statements and guidelines came from a variety of sources: Medical Research Council (UK); NHMRC (Australia); CIHR (Canada); NIH (US). There were also many 'how to' best practice models and guidelines. A number of extensive and comprehensive recent bibliographies are available. Several INVOLVE bibliographies were done between 2005 and 2009 (drawn from their data base or their published articles or reports). These contain at least 200 references. In Australia, in 2009 the HIC published results of a literature search for the Victorian Cancer Council.

Primary health care services research (as compared to, for example, clinical research) would appear to lend itself more readily to community and consumer involvement. This is due to the qualitative and/or program development and evaluation nature of much research in this field, and the potential for partnerships with communities or groups within which such research is carried out. However, this preliminary exploration found very little focused specifically on primary health. It was not identifiable as a discrete sub topic. To pinpoint research focused exclusively on this aspect, a more detailed review of the general literature would be necessary. Much of the research listed in bibliographies does in fact have a primary health care focus but is not identified as such in keywords.

Statements, policies and guidelines

The NHMRC & CHF 'Statement on Consumer and Community Participation in Health and Medical Research' (2) set the standard for consumer involvement in Australia. With the vision 'Consumers and researchers working in partnerships based on understanding, respect and shared commitment to research that will improve the health of humankind' (p.v.) the Statement envisages consumers and researchers working in collaboration, drawing on each other's knowledge to shape decisions about research priorities, specific research questions and design of research projects.

Similar statements have been published by the Medical Research Council, the National Health Services (NHS) and the National Institute of Health Research (NIHR) in the UK; the Canadian Institute of Health Research (CIHR), and the National Institute of Health Research (NIH) in US. Many of these statements are lengthy and hard to summarise briefly. They generally contain key values and principles which guide consumer involvement policy and processes, plus the various components of research processes in which consumers should be engaged. Principles include an appreciation that consumer involvement will add value to the research program or project; commitment to openness and mutual trust and respect; active and engaged involvement by consumers and researchers alike; recognition of the need for support to consumers and researchers to effectively engage; plus an understanding that policies and processes must be sufficiently flexible to accommodate particular organisational situations as well as those of consumers.

There are many guidelines and 'how to do it' models for organisations to follow. Anne McKenzie and Bec Hanley's "Green Book"(4) is a popular resource in Australia and is now supplemented by their fact sheets and other resources on the new Involving People in Research website (www.involvingpeopleinresearch.org.au). In 2006 INVOLVE (UK) published a series of Guidelines to 'help commissioners, researchers and the public to think about public involvement in research commissioning' (www.invo.org.uk). The Wellcome Trust commissioned TwoCan Associates to produce "Getting it Right Guidelines" for staff working in health charities to help them effectively engage with research (5).

Levels and types of involvement

The different 'levels' of consumer involvement that can occur within an organisation or research have been characterised in the literature as a continuum from low to high. This is sometimes expressed as a 'ladder', or 'hierarchy', of participation (6). The 'ladder' provides a useful summary of different points at which consumers can become engaged

in the research process, as well as providing 'signposts' to organisations in determining their consumer involvement policy objectives. It should also be noted that organisations may choose to engage with consumers at different levels in different research projects, or at different stages of the research process. Diagrammatically the hierarchy can be represented as follows:

The Ladder of Participation

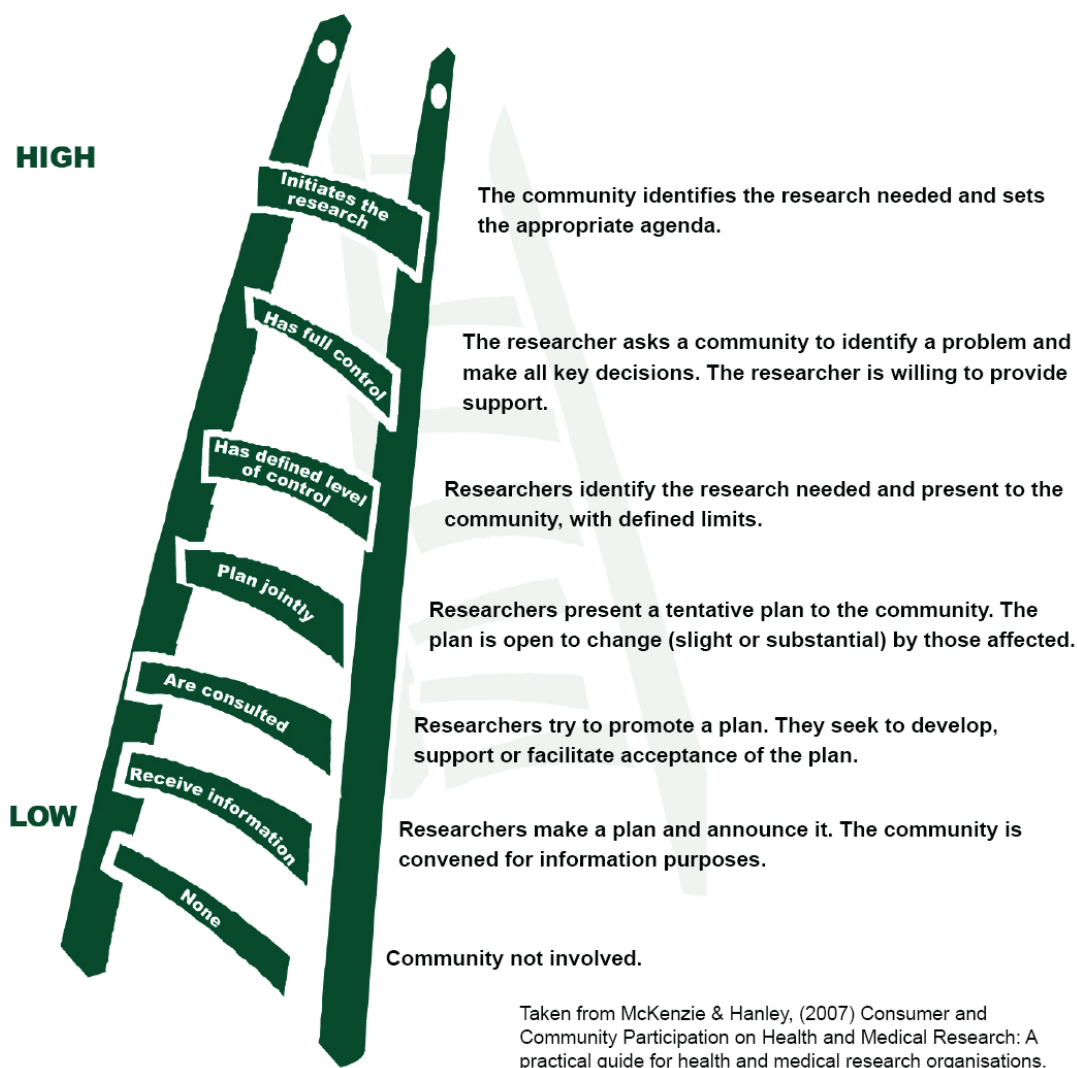


Figure 1. Ladder of participation (reproduced with permission)

Progression up this 'ladder' can be interpreted as one of increasing empowerment of consumers within the research process. At or near the top of the ladder is an area of research known as 'participatory action research' where the research is community controlled, or the collaboration is an equal partnership. Such research involves community action, training of community leaders and building in sustainability after the research is completed to the benefit of the community. This work is often done with disadvantaged groups or communities.

Components of research process

Processes in which consumers can be involved encompass the full scope of the research enterprise. A comprehensive consumer involvement strategy will include all of them. They include:

- a. Governance within a funding organisation:
 - Membership of governance bodies, advisory bodies etc
 - Selection and prioritising of research agenda
 - Development of grant application policies and guidelines
 - Grant application assessment.
- b. Within the research activity:
 - Research design (selection of research questions etc.)
 - Engagement of participants
 - Data collection (interviews; survey design etc.)
 - Analysis of results
 - Dissemination of results.

Examples can be found within the literature of consumers ‘adding value’ to all aspects of a research project (e.g., Tuffrey-Wijne & Butler’s discussion of involving people with learning disabilities (7); Staley’s report on involvement in NHS research (8)). Consumer involvement is of particular value when it occurs early in the research development process, at the design stage. Consumers also especially enhance recruitment of research participants, improve survey design, and can play a key role in dissemination of results and their translation into useful community action, programs or policy development (4, 6).

Further useful information on involvement in research processes is contained in the NHMRC guide “Keeping research on track: A guide for Aboriginal and Torres Strait Islander peoples about health research ethics”(9). The guide suggests there are eight steps in the research journey: establishing relationships, conceptualisation, development and approval, data collection, analysis, report writing, dissemination and learning from our experience. Questions and responsibilities for both the researchers and the Aboriginal and Torres Strait Islander community members are outlined for consideration at each stage of the process to help “keep the research on track.” This model is similar to the one proposed in Part 4 of this report and together with the checklist suggested in the Statement (2) would provide a strong framework upon which to build the APHCRI policy and guidelines for consumer involvement.

Elements of best practice

There are a number of resources and articles which identify and evaluate the elements of good consumer involvement, and what makes the difference between success and failure (e.g.,2, 4, 10, 11-13). According to these resources, critical factors in ‘best practice’ and the keys to a successful implementation of a consumer involvement policy include:

- Commitment from senior levels of the organisation/research team;
- Consumer involvement as a coherent and stated policy priority;
- An overall strategic planned approach and objectives with key milestones: even though only a small portion of it may be actually implemented at a time, it is important for everyone to have a shared vision of where they are going;
- Transparency and open communication: taking the time to develop a shared understanding, recognising that organisational adoption of consumer involvement in research usually requires a culture change within the organisation;
- Detailed guidelines as to what is expected of all participants;

- Sufficient and dedicated resources: effective consumer involvement takes time and commitment, which is difficult for already bare bones funded research organisations;
- Development of a network of consumers engaged with the organisation; and
- Dedicated training and support for both consumers and researchers.

Traps to avoid include:

- Merely producing a policy statement without any follow up;
- Limiting consumer involvement to token consumer membership of an advisory group;
- Bringing consumers in too late to a project;
- Undertaking isolated one-off initiatives without the context of a comprehensive, practical, strategic overview or action plan;
- Inadequately resourcing the activity, particularly in relation to recruiting and supporting consumer participants; and
- Not recognising or allowing for the 'culture change' aspect of consumer involvement within the research community.

Evaluation studies: the impact of consumer involvement

There is an increasing amount of literature presenting assessments and analyses of the impact of consumer involvement on the research endeavour. Results were generally positive as to the benefits of consumer involvement although they also identified challenges and difficulties. Note, however, that the methodology for the evaluations was based mostly on anecdotal accounts drawn from participants (researchers and consumers) in interviews or surveys rather than rigorous comparative or outcome-based methods. One exception is a recently published randomised controlled trial of the effect of consumer involvement in the design of a clinical trial patient information sheet that demonstrated greater understanding of the information on the sheet with consumer input (14).

Two interesting assessments of consumer involvement, both in the UK, are worth noting. Ward and colleagues (15) found that despite policy directives to involve consumers in research in Australia and UK, there is evidence of significant disparity between policy and practice. The article reports on a UK qualitative study of researchers about their perceptions and experiences of consumer involvement in research. There was a consensus on the value of consumer involvement in research, but a dissonance between this and the 'on the ground' extent and impact of actual engagement due to cultural differences between the research environment and consumer expectations and experiences. Also in the UK, in 2009 the Clinical Research Collaboration published a series of critical assessments of its 'PPI' (Patient and Public Involvement) program (e.g., 13, 16). 'Lessons Learned' contains a useful summary of the ingredients for effectively progressing consumer involvement (13).

Benefits of consumer involvement are that they enhance 'relevance, credibility, dissemination and transferability' within the research enterprise (15, 17). Added value from consumer involvement was evident for research that was qualitative, involved public health and/or community program research and for clinical research (8).

Problems identified include initial difficulties for researchers in understanding how consumers can contribute; also for consumers in understanding the complexities of the research approach; availability of time and resources on both sides in restricted resource environments; and problems of tokenism and a 'know/do' gap limiting the real impact of consumer involvement (15, 18).

The importance of training and support for consumers and researchers

Every published account of programs to engage consumers in research emphasises the importance of providing training and support to consumers as well as researchers as an adjunct to consumer involvement but separate from the actual research project (e.g., 2, 11, 12, 17). Support is usually provided in the form of training workshops and seminars. There are several programs in Australia which offer this training and support, notably the WA based workshops run by School of Population Health at UWA and courses offered by Cancer Councils in Victoria and in NSW. Formal training can be supplemented by web based knowledge hubs and the creation of 'community of interest' or networks of researchers and consumers reinforced by newsletters, 'tweeting' etc.

In the UK the TRUE research was commissioned by INVOLVE to explore the provision of training to support the active involvement in research of the public and users of NHS, public health and social care services (19). The project reviewed 26 training programs and listed what each involved. It summarised guidelines for 'doing training' and the essential elements of useful training. What came through strongly from the findings was "the enormous value of the training initiatives to participants' personal development and confidence, (which) ...spurred them on to continue with their interest in research and to want to contribute further". (19, p110)

Involvement of specific target groups

While organisations such as INVOLVE and James Lind in the UK, CIHR in Canada and UWA School of Population Health in Australia focus on supporting consumer participation in health research generally, there is a wide range of resources focused on consumer involvement in research involving particular groups of patients or communities. This may be because of specific health conditions or their membership of identifiable population groups. Cancer and mental health consumer groups exist in Australia and elsewhere which have considerably supportive and developed programs of consumer involvement in relevant research. Other consumer groups with less developed support for consumer involvement include those for stroke, patient safety, heart disease, asthma, arthritis and learning disabilities. Target population groups are generally identified defined by their status: ethnicity, age, socioeconomic position etc. A lot of their consumer involvement material falls into the category of participatory action research. Key models in this area in Australia are in the areas of Aboriginal health (e.g., 20).

1.5 KEY IMPLICATIONS

Key implications to be drawn from the material found can be briefly summarised as follows:

- There is a large range of material on consumer involvement but little material found was directly identified as consumer involvement in 'primary health';
- The nature of research in primary health care lends itself to consumer involvement;
- There are a few key organisations (e.g., INVOLVE in the UK; Involving People in Research at UWA) which provide guidelines for best practice and support literature to enable easy access to the resources needed to develop effective policies and practices for consumer involvement;
- Training for both researchers and consumers is important;
- Some evaluations of benefits and negative consequences of consumer involvement in health research exist that conclude that consumer involvement is of beneficial rather than negative impact on the research endeavour.

An opportunity thus exists for APHCRI to lead consumer involvement in Australian primary health care research by establishing a clear and relevant policy and framework that includes ongoing evaluation, and facilitating access to resources and training for health services researchers and consumers.

1.6 BEGINNING THE CYCLE

One of the recommendations in “The Green Book”(4) for organisations developing a policy of consumer involvement is to take a planning cycle approach to implementation. The first step in the cycle is to establish “Where are we now?” Between September 2010 and July 2011, APCHRI carried out a number of activities which established the current extent and nature of consumer involvement in APHCRI research, piloted training workshops and identified and refined an existing model of involvement that is well-suited to the nature of primary health care research.

Part 2 of this report describes an audit of APHCRI research, including a scoping of APHCRI final reports for description of involvement and a short research project involving interviews with Chief Investigators on previously funded APHCRI projects. Part 3 briefly describes training offered to current APHCRI researchers as part of the Stream workshops and the two in-depth workshops facilitated by Anne McKenzie and Bec Hanley. Part 4 outlines the flexible model of involvement proposed as part of APHCRI’s strategic framework for consumer involvement and Part 5 concludes the report with recommendations for the next steps for the development of APHCRI’s vision, framework and objectives for consumer involvement as an organisation.

Part 2. Audit of involvement in APHCRI research

2.1 SCOPING OF APHCRI REPORTS

In preparation for conducting a more detailed and formal audit, a catalogue and brief analysis of APHCRI research was assembled from reports available on the APHCRI website. However, the format of reports and lack of explicit guidelines for both including consumers and reporting on their involvement made it difficult to determine from the brief analysis the extent of involvement in most projects. Many projects included the views of other “research consumers” including health practitioners and policy advisers, so a broader stakeholder approach was adopted when scoping the reports. Table 1 presents the breakdown of the research reports analysed in the initial scoping for the audit.

Table 1. Brief analysis of existing APHCRI research

Type of research	Number of projects	Number with involvement of any stakeholders	Number with explicit involvement of consumers	Unclear
Funded projects				
Reviews (systematic, narrative, rapid)	36	23	17	6
Interventions or evaluations	13	8	3	5
Qualitative or descriptive	3	2	1	1
APHCRI ANU research (completed, report available)				
Reviews	3	3	2	1
Evaluations	3	2	1	1
Other	3	1	1	

APHCRI funded research

The majority of past APHCRI funded projects were reviews: systematic, narrative or rapid reviews. A large number (around 64%) of these reviews included some form of reference group or informant process in their methods that could be interpreted as involvement in the broadest sense. Many reports outlined how the reference group contributed to the research process but there were also quite a number where although a reference or advisory group was mentioned, their role was unclear. In most cases it was also hard to determine the makeup of reference groups but it seemed few included consumers or their representatives.

A similar proportion of intervention and evaluation projects also reported some form of stakeholder involvement. This included two studies that adopted a participatory action research model for at least one stage of their research. The Aboriginal health project MAHPET specifically included local community representatives in the local research groups to advise on the research processes, including cultural sensitivity and the implications and implementation of findings. However, as for the reviews there were many reports that mentioned some form of involvement but the extent and role of the stakeholders involved was not clear.

Of the three qualitative or descriptive studies examined, two mentioned stakeholder involvement but the nature of the involvement was explicitly described in only one of the reports.

APHCRI ANU research

Reports were available for only a limited number of APHCRI ANU projects as many are ongoing. As for APHCRI funded research, there was ample evidence of stakeholder involvement at a broad level but the exact role of others included in the research process was in many cases unclear in the reports.

Most participation in APHCRI ANU research was again in the form of a reference group consulted for the formulation of reviews and the synthesising of results for the reports. However, there were also some examples of possible collaboration with staff in practices and Divisions.

Summary

As noted in the recent “Stocktake of Primary Health Care Research in Australia” (3), few primary health care projects to date have engaged consumers (as service users) formally in the research process. However, if a broader stance on involvement is adopted, including other stakeholders such as practitioners and policymakers, existing APHCRI research does demonstrate a significant foundation on which to build a framework for active participation.

A reasonable percentage of projects included an advisory or reference group but often the role of these informants was unclear. Most commonly, researchers reported engaging policy advisers to inform the final drafting of policy options for the APHCRI reporting process. Although close ties with policymakers as a stakeholder group is a key part of APHCRI research it is important to consider the part other stakeholders such as consumers and practitioners can also play in the research process and how this may best be flexibly managed at all stages of research and for projects with different aims and methods.

2.2 INTERVIEWS WITH CHIEF INVESTIGATORS

Approval was gained from the ANU Human Research Ethics Committee to conduct a small study with APHCRI Network investigators to explore their experiences with the active involvement of non-researchers in their APHCRI projects. The study consisted of two parts:

1. Individual telephone interviews with Chief Investigators as key informants
2. An online survey open to anyone involved in an APHCRI funded project, including but not limited to Chief Investigators, other investigators and stakeholders

Method

For Part One of the study, based on the scoping of the reports 11 Chief Investigators (CIs) were purposively sampled to represent Stream projects that had clear evidence of involvement, clear evidence of no involvement and cases where involvement could not be determined. Individual invitation letters were sent to the 11 CIs, of whom seven consented to participate and five were interviewed. This included two with clear involvement reported, two for whom it was not clear from their reports if involvement occurred and one who had not involved stakeholders. The participants were individually interviewed by telephone, with interviews lasting between 25 and 60 minutes. A structured interview protocol was used that was based on the short audit tool used throughout the UWA School of Population Health and Telethon Institute for Child Health. Interviewees were asked about involvement in two stages: first about the involvement of consumers specifically and secondly about the involvement of other stakeholders. If consumers and other stakeholders were involved in the

project(s) conducted for APHCRI, a series of questions exploring the benefits, challenges and processes of involvement followed. If there had not been involvement, questions explored whether the interviewee thought consumers and other stakeholders should have been involved in running the project and how they may have been involved. All interviewees were also asked about existing policies and procedures for involvement at their organisations and the potential role of APHCRI in facilitating better involvement in primary health care research.

To supplement the information gained from the interviews with Chief Investigators, a notice was sent via the PHCRIS e-bulletin inviting anyone involved in an APHCRI funded project to complete an online survey about consumer and other stakeholder involvement. This resulted in one further Chief Investigator who indicated their project had included stakeholders but not consumers, and one response from a project Research Officer who indicated their project involved both consumers and other stakeholders. The online survey asked the same questions as the interview protocol and used skip logic to direct participants to the appropriate follow-on questions according to their responses about whether involvement had occurred.

Results

The researchers were overall extremely positive about the value and importance of conducting research with the active involvement of stakeholders. Six of the seven participants indicated that their organisation had a commitment or a stated policy on active involvement of stakeholders in research and all described how they are working on building stakeholders including consumers into the higher level decision-making around the research program. For example:

...there's a commitment to involve consumers and community organisations as much as possible in our research... and that includes in the sort of design and development and so on...And that's reflected in our various advisory committees for our research centre as a whole... [I2]

Participants were also interested in any policy for stakeholder participation taking account of who the most appropriate people were to be including.

I suppose the point that I have been making is that you have to ask the question it seems to me, is: whose voice is needed in this discussion? [I1]

Most participants reported that there were few formal processes for training stakeholders who were involved in conducting their research although some mentioned terms of reference for steering committees. It was generally felt that most of the stakeholders involved had a fair understanding of their role but it was acknowledged that some problems encountered (see challenges below) could be overcome by orientation and training for stakeholders taking an active role in conducting research.

The majority of participants also reported that there was no formal evaluation of the involvement part of the research process. One participant mentioned that a new process at his research organisation is to ask a member of a steering committee to give a short report at the end of meetings to ensure all members have had opportunity to contribute and are actively contributing as a means of monitoring involvement and addressing problems as they occur. However, nobody reported examining the outcomes of involvement.

Benefits

The main benefits of involving both consumers and other stakeholders fell into three related domains: relevance of the research, reality checking methods and findings, and the effects of having people passionate about a topic involved.

Most participants felt that one of the greatest benefits of involving consumers and other stakeholders in the research process was ensuring that the research being conducted was relevant to the community and services in which it was being conducted. Some felt that it added a sense of community approval but primarily the feeling was that involvement, particularly in the early stages of a project, ensured that the research focused on priorities that mattered to stakeholders. This led some participants to describe the benefits involvement has had for their research program more broadly, stating that they felt that the active involvement of stakeholders has helped to frame their research. As one participant put it:

Oh it's absolutely essential. I mean it's not just part of a, a bit of a benefit, I don't think we could remotely do it but we've just found time and time again how... how wrong we can get it...[12]

Participants also described how stakeholder involvement had helped “reality check” their research. Researchers felt that the input on choosing tools, implementing interventions and working with findings was invaluable and extremely productive. One further commented that stakeholder involvement had kept their research in touch with the real world:

...research that barrels along purely believing that it's uncompromised is actually research that has lost its footing in the real world. And therefore... it's not compromise so much ... just reality checking the whole way through. [14]

The final major theme concerned the effects of having people who were passionate and engaged with a topic on the research process. Just as researchers had found that stakeholder involvement helped with the applicability outcomes already mentioned, they also found that engaged stakeholders as a part of the research team could really drive the process.

But then when you get someone who comes along and really has the passion of the field, and you know, wants to make a difference, and, and it keeps you on your toes, that's really good.[13]

Challenges

The challenges that participants reported for involving stakeholders fell into four main areas: problems finding appropriate stakeholders, funding for involvement, ensuring effective involvement and avoiding tokenism, and managing tensions.

A very common theme in discussions about both consumers and other stakeholders was how to find appropriate people to involve. Many participants described unsatisfactory experiences with “professionalised” consumers from general health consumer organisations, although they also had good experiences with representatives who were strongly engaged with the topic. Amongst the broader stakeholders, government representatives were seen as particularly problematic for sustained involvement.

...linkage between the researchers and the policy makers from the stage of developing the research questions through to implementation sounds a nice theory, but it absolutely fell flat in terms of... they didn't come or they were too junior, or they changed, there were different people... [15]

Participants were also very concerned about the lack of specific funding to facilitate stakeholder involvement, especially at the stage of proposal development. There was recognition that people deserve remuneration for their input to a project but this is not commonly a budget line in funding applications and there is no provision for engaging people to work on possible new areas. This also led to discussion on how to manage relationships with stakeholders in the context of the tiny success rate and lengthy application process for grants.

How to get them involved when you haven't got any money to pay them before you get project funding can be difficult. If they have this thing that they have to be paid, even if you haven't got, you know, the likelihood of being funded might be 20 percent. How do you engage them then? That can be a bit tricky. [13]

There were many references to the challenges of ensuring effective involvement and avoiding tokenism. Researchers were concerned about wasting the time of people who had committed to being involved in processes such as reference groups but who struggled to provide input. However, they were also concerned that involvement could take the research off track or that the input offered would be too generic, contrasting with the passionate consumer described under benefits.

...it would probably span what I've, you know, said from the, the not that productive, professional person who comes along to meetings and you pay them and it's all fairly sterile in a way. Versus the other one where you've got this person who's just making a huge contribution, and enhancing the whole way everything's done. Yeah. And so it's about the two way-ness of it. I think...It, it's better if it's, if it's mutually beneficial, and, the person's engaged, passionate, shares that interest. [13]

The final area of challenge related to managing tensions when involving stakeholders in the research process. This included tensions between stakeholder groups with existing power relationships, such as the inclusion of doctors on a project about nurses, and tensions over changes that stakeholder groups wanted to make to the research process that were not possible or appropriate.

... the members of the steering committee felt that they should be really deciding the detail of the research methods and so on, and that created a little bit of a problem for us, it got a bit out of control, at one point we had to kind of have a bit of a discussion with them about that because you know, there was... there were things that were negotiable and there were things that weren't...For example you know they wanted to change the wording in a questionnaire that was based on a validated instrument.[12]

Potential solutions that APHCRI could address

The final question asked was whether participants had suggestions for steps APHCRI could take to help facilitate stakeholder involvement in APHCRI Network research. The majority of participants responded that as a research funder, APHCRI could take a lead role in providing funding for stakeholder involvement. This included suggestions for a specific budget line within funding Streams and Centres of Excellence for involvement activities and the possibility of developing very small seed funding grants to encourage collaborative development of proposals for larger grant rounds. Participants also felt that providing or facilitating access to training and resources for researchers on effective involvement techniques and other stakeholders on research methods and rigour were possible areas where APHCRI could establish a role. Some researchers felt APHCRI may be in a position to help develop relationships with stakeholder groups such as consumer organisations but others felt this may be more effective if done at the level of the individual research organisations throughout the Network. One stakeholder group where APHCRI has a role, already mentioned as a challenge to engage, was government stakeholders.

I think historically the most important thing that APHCRI has done, particularly with some of the systematic reviews has been to try and encourage engagement of the Commonwealth department with these projects, and I think that still is very important and very difficult I might add. [12]

Finally, the suggestion was raised that APHCRI develop an evaluation framework for both the Network researchers and the Research Advisory Board to assess the success of involvement both in terms of the experiences of all stakeholders and the outcomes of the research. However, it was noted that such a framework would need first need to identify what constitutes success.

2.3 CONCLUSION

The results of this small audit of APHCRI funded research support the findings of the literature review of consumer involvement more generally as discussed in Part 1. Primary health care researchers support the active involvement of stakeholders in research to maximise relevance and applicability but sometimes struggle with enabling effective engagement. They see the potential role of APHCRI as a source of training, facilitator of relationships with stakeholder groups and especially to provide leadership on designated funding for involvement activities. Recommendations for how these suggestions could be implemented in the APHCRI Network are discussed in Part 5.

Part 3. Training workshops with primary health care researchers

3.1 COMMISSIONED TRAINING WORKSHOPS

Two training workshops for researchers were conducted in the week of 11-15 April, facilitated by Anne McKenzie and Bec Hanley, the authors of the 'Green Book'. The workshops were attended by a total of 30 people: 13 invited from the APHCRI network and 17 participants from other organisations who paid to attend. The participants represented universities and research institutes from five states (ACT, NSW, Vic, Qld, WA), health service providers, government and the Healthcare Consumers Association of the ACT (HCCA).

The core material consisted of practical tools, methods and exercises to encourage workshop participants to think critically about consumer involvement in research, delivered by the facilitators. This was supplemented by case study presentations on a researcher's perspective (Dr Michelle Banfield, APHCRI Research Fellow), consumer's perspective (Adele Stevens, HCCA), ethics (Prof Mandy Thomas, Pro Vice Chancellor (Research) and Chair of Human Research Ethics Committee, ANU) and resources available through consumer organisations (Deborah Smith, Consumers' Health Forum). One of the participants, an Indigenous researcher, presented information on her research in the second workshop. The workshop format was highly flexible, allowing significant opportunity for discussion amongst participants, questions and clarification for the facilitators and workshopping of real life issues.

3.2 EVALUATION

The feedback received from participants was extremely positive both during the workshops and in subsequent communication. People enjoyed the dynamic facilitators and varied program and continue to report that they have had a "paradigm shift" in the way they think about their research. Participants are promoting the workshops to their colleagues and encouraging APHCRI to run further workshops in the future. APHCRI Network members who were unable to attend the April workshops due to other commitments have also indicated interest in future workshops. The facilitators have indicated interest in an ongoing collaboration with APHCRI.

3.3 STREAM WORKSHOPS

In addition to the formal training provided through the facilitated workshops, researchers in the 2011 Interdisciplinary Research Stream have received brief training and support for implementation of the proposed flexible model of stakeholder involvement (see part 4). In December 2010, researchers from this Stream were introduced to the principles of consumer involvement in research and briefed on the proposed flexible model. Research groups participated in an exercise designed to encourage thought on who they may involve in their research, the stages of research at which people may be involved, and the level or degree of involvement that might be appropriate. As the researchers already had well-developed research plans by this time, it was not expected that significant modifications to incorporate involvement would be made before the research commenced. However, it was extremely encouraging to hear reports from the research groups at the progress workshop in May 2011 that the researchers had continued to consider stakeholder involvement in their research proposals since the December introduction, and had made efforts to modify their research protocols to include some level of involvement and/or consumer perspectives.

Part 4. Proposed model of involvement

4.1 RATIONALE

As outlined in Parts 1 and 2 of this report, primary health care research is well suited to consumer and community involvement in the research process and there are a number of stakeholder groups who have an interest in being included. In line with APHCRI's strategic goals concerning the uptake of evidence and the development of strategic partnerships, many of these groups are already often included in reference groups and steering committees on projects throughout the APHCRI Network. The majority of projects throughout the APHCRI Network have had consultation with various primary health care professionals and policy advisers to some degree but it has not been as common to include consumers in these processes and as discussed in section 2.2, researchers have not felt confident facilitating the participation of consumers who were involved. It is clear that an approach to a framework for involvement in APHCRI research therefore needs to support ongoing contributions from practice and policy stakeholders whilst also developing the role of consumers as equal contributors. This will seat consumer involvement within the existing strategic framework of APHCRI and establish consumers' right to an equal "seat at the table".

4.2 MODEL

Dr Elspeth MacDonald has developed a flexible model of involvement for practice-based research networks that was designed to facilitate involvement of various stakeholders in a health research project. She is very enthusiastic about its adaptation for primary health care research and use in the APHCRI Network.

The model has three dimensions which when combined, form an easy to use matrix that allows researchers to plan the involvement of stakeholders at the initiation of the project. The model is designed to break planning into manageable pieces and move away from black and white thinking such as "involve or not".

The three dimensions are:

- The stakeholders to involve;
- The stages of the research at which they will be involved; and
- The level of involvement for each stakeholder group at each stage.

Stakeholders

The variety of stakeholders with an interest in actively participating in primary health care research has variably been conceptualised as a puzzle with interlinking pieces or a wheel in the style of a pie graph (Figure 2), both requiring all pieces (stakeholders) to be included to make a whole. The proposed model encourages researchers to think about which groups may wish to play an active role in a research project when they are formulating ideas and ideally develop those ideas in conjunction with the stakeholders. So, for example, if developing a proposal to look at the development of chronic



Figure 2. The stakeholder wheel (reproduced with permission from (1))

disease management plans and team care arrangements in order to inform policy developments in this area, relevant stakeholders might include GPs, practice nurses, practice managers, allied health professionals, policy advisers and decision makers, and consumers. The latter may include trained representatives from organisations such as Healthcare Consumers Association but it may also include consumers without formal training but who have personal experience with the issue under investigation. By considering and consulting with stakeholders *early* in the process, a solid basis for relevant research with greater likelihood of uptake is established.

Stages of research



Figure 3. The research cycle (adapted from (2))

The second dimension of the model follows what the NHMRC term the “quality improvement cycle” for research (2). As illustrated in Figure 3, the cycle identifies the broad stages of the research process, all of which offer specific opportunities for stakeholder involvement. The stages are not exhaustive or necessarily mutually exclusive, but they offer a guide to the research process which may be more useful than thinking of a project as a whole entity. The NHMRC offer some suggestions on putting involvement into practice at each stage and the responsibilities or questions that researchers and other stakeholders may wish to address (2, 9, 12). Anne McKenzie has further developed extensive materials targeting specific strategies for each of these research stages, offering practical tools and ideas to guide planning (see (4) and www.involvingpeopleinresearch.org.au).

Level of involvement

The final dimension of the proposed model is the level of involvement of each stakeholder group. As described in Part 1, the involvement literature often describes involvement as a ladder from low to high or along a continuum. As illustrated in Figure 4, the current model draws on the idea of a continuum, with the addition of markers indicating the amount of involvement. The markers can be easily transferred to the planning matrix as discussed in the next section.

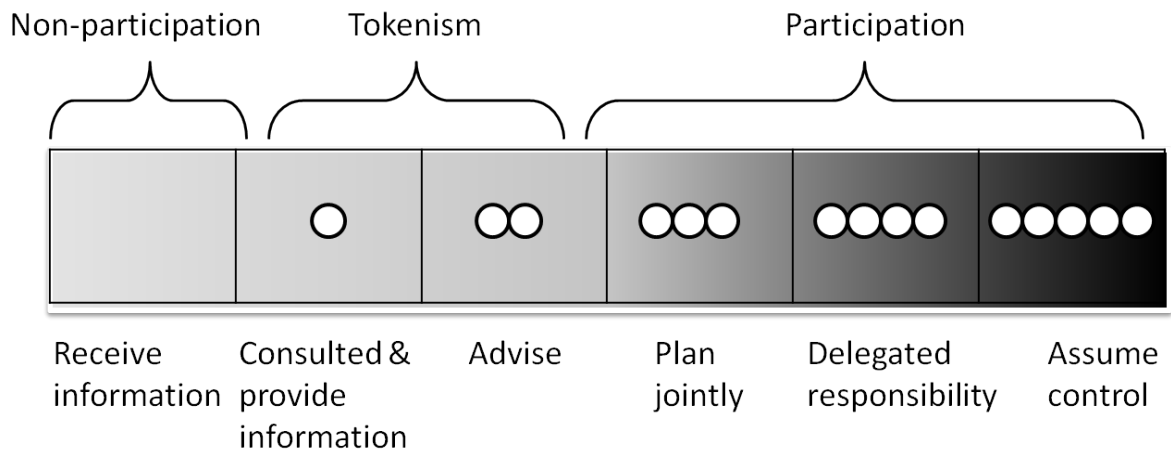


Figure 4. Continuum of involvement

The original model as developed by Dr MacDonald includes stars as markers as illustrated, but these may be misinterpreted as value judgments (e.g., five stars are better than four stars) when in fact the markers simply illustrate the increasing amount of involvement. Feedback from attendees at the Consumers Reforming Health Conference, at which the proposed model was presented, agreed that a different marker such as a dot may help dispel this.

The model matrix

When the first two dimensions of the proposed model are combined, they form a blank table matrix into which research planners can insert the level of involvement markers to complete the plan of involvement in their project (Figure 5).

		Stakeholders			
Stages					
	Deciding what to research				
	Deciding how to do it				
	Doing it				
	Letting people know the results				
	Knowing what to do next				

Figure 5. Stakeholder involvement matrix

An example

Figure 6 represents a fictitious example of how a completed plan for a project with a service focus may look. In this example, there is joint planning between all stakeholder groups when

deciding what to research. This might include asking stakeholders to identify practice and/or policy problems consistent with a Stream theme and assist in developing the proposal.

Researchers have greater responsibility for deciding on methods and carrying out the project in this plan, with some consultation and advice from stakeholders. If a project is methodologically complex, it may not be practical to have a greater degree of involvement of non-researchers at these stages of research, but it is still important to seek advice on issues such as data collection methods that are sensitive to participants and the acceptability of information sheets. A recent study on clinical trial information sheets in the UK found that 66% of participants showed understanding of all aspects of the trial when provided with an information sheet revised by consumers, compared with only 15% of participants given the original sheet (14).

Consumers and practitioners have more responsibility when the research findings are disseminated in the example plan. This is a key way to effect broad dissemination of results for translation into effective practice. Stakeholders could help collate the study findings in a format that is accessible to other professionals or consumers and facilitate actions such as distribution to networks and presentations to stakeholder groups.

Completing the cycle (and beginning a new cycle) with decisions on the next steps such as implementation plans and further research is again a joint planning process. This stage is particularly amenable to actions such as roundtable discussions and interactive workshops. However, care must be taken to ensure that power imbalances and tensions are skillfully managed by including more than one representative of disempowered groups like consumers and possibly the use of a professional facilitator.

	Consumers	Practitioners	Policy advisers	Researchers
Deciding what to do	○○○	○○○	○○○	○○○
Deciding how to do it	○○	○○	○○	○○○○
Doing it	○○	○○	○○	○○○○
Letting people know the results	○○○○	○○○○	○○○	○○○
Knowing what to do	○○○	○○○	○○○	○○○

Figure 6. Example stakeholder involvement plan

A key feature of the proposed model is flexibility. Researchers are not constrained by applying one level of involvement to their entire project or to all the involved stakeholders. Further, we suggest the APHCRI policy allow the plan to be modifiable throughout the course of the research if necessary. For example, if consumers showed particular interest in data collection and capacity existed to train them, it would be possible to update the above plan to reflect delegated responsibility for consumers in carrying out the research.

Finally, the proposed model is designed to encourage researchers to think about their own capabilities in managing the involvement process and design a project that maximizes the opportunity of all to succeed. As discussed in Section 2.2, researchers strongly support stakeholder involvement in research but many feel they do not have sufficient experience and skills to undertake higher level involvement such as employing a consumer researcher. The proposed model allows these researchers to start with involvement in specific parts of their research and build on their successes in a continual cycle of improvement and extension.

Part 5. Conclusion and recommendations

It is clear from the work conducted for this project that primary health care researchers are both ready and willing to increase consumer involvement in their research and that a solid base of broader stakeholder involvement already exists, on which we can build. Further, there is extensive literature around the ways to increase consumer involvement and a number of groups around the world working on frameworks for practical application of the knowledge.

Notable in Australia is the work of Anne McKenzie and colleagues at the University of Western Australia and Telethon Institute for Child Health. Anne's training workshop for researchers has now been delivered to over 200 researchers throughout Australia and she has recently launched a website, www.involvingpeopleinresearch.org.au that is designed to be a central resource hub for tools and information on active involvement of consumers in research. Anne has expressed keen interest in incorporating the flexible stakeholder model proposed in this report into her training and resources. We have also had preliminary discussions about the possibility of ongoing collaboration between APHCRI and the Involving People in Research group to develop minimum standards for involvement, develop and deliver training and develop evaluation materials both for grant assessment and evaluation of the progress and success of involvement in funded projects.

5.1 RECOMMENDATIONS

Policies and documentation

- Develop a clear policy and minimum standards for consumer involvement in APHCRI Network research, within the framework of broader stakeholder involvement. Anne McKenzie has already offered the policy developed for UWA/Telethon as a basis and has minimum standards under development that she would like to finalise collaboratively. Given the scope and flexibility of the proposed model some level of involvement should be expected on all research.
- Produce guidelines on the proposed model of involvement, to be used in conjunction with the minimum standards when applying for funding.
- Develop evaluation guidelines for the RAB and ERC to assess proposed involvement in grant applications. Wright et al (21) have published appraisal guidelines that could be adapted for use in the APHCRI context. The weight that stakeholder involvement carries as a part of overall assessment should also be decided.
- Draft reporting guidelines for the process and outcomes of involvement in funded research. These could be based on the application evaluation guidelines along with measures of stakeholder experiences.
- Develop a strategic plan for implementation of the policy and standards.

All of the policy documentation should be finalised in collaboration with APHCRI stakeholder groups, including the RAB, primary health care researchers, practice and policy stakeholders and consumer representatives. Some consultation on the feasibility and acceptability of the model has already occurred through a presentation at the Consumers Reforming Health conference. This conference was attended by health practitioners, researchers, consumers and policy representatives and the feedback was extremely positive. Further feedback could be gained by inviting email comment on draft electronic documents and by convening one or more discussion groups. Documentation

should also be reviewed on a semi-annual basis at the conclusion of funding rounds in a constant quality improvement cycle.

Training

- Ongoing access to training for researchers is strongly recommended. A primary issue impeding effective involvement at present is a lack of confidence about how to do it, but researchers who have already attended training have found it overwhelmingly positive and very useful. Anne McKenzie runs training in Western Australia on a semi-regular basis as a part of the UWA summer school program. A possible approach may be for APHCRI to support one or two representatives of new research teams (CRE and Stream) to attend these workshops. Alternatively we could consider commissioning further workshops to be conducted on the East coast and the development of in-house training.
- Access to training on research methods for non-researchers would also be beneficial. A number of consumer organisations run this type of training so it may be feasible to simply assemble a list of available programs to which researchers can direct interested stakeholders. However, programs run through organisations such as the Cancer Council may have a focus on methods such as clinical trials and may not address research methods most commonly used in primary health care and health services research. A future consideration could be the development of a short in-house orientation program specific to primary health care and health services research.

Funding

- Consideration should be given to the inclusion of a specific budget item within funding applications for stakeholder involvement activities. For example, the 2011 Stream Funding Expression of Interest form asked applicants to identify engagement with consumers; this could be followed up in the full applications with space to provide specific costing on the identified activities and reporting on expenditure.
- Future strategic planning could also explore a competitive seed funding process that provides very small grants for the specific purpose of engaging stakeholders in the development of proposals for larger grants.

Resources

- It was originally proposed that APHCRI develop an online resource hub for involvement in research. Whilst it will still be necessary to develop a repository of the policy, standards and guidelines, the work of providing practical tools and links to external resources is already being conducted by the Involving People in Research group. The process of establishing reciprocal links between the APHCRI website and www.involvingpeopleinresearch.org.au has already been initiated.

Links and collaborations

- Ongoing collaboration with the Involving People in Research group to share resources, develop and deliver training and form a national alliance committed to consumer involvement in research would rapidly progress APHCRI's role and standing in the consumer involvement community.
- Some links with organisations such as Consumers' Health Forum and the Healthcare Consumers Association of the ACT have already been established. It may be within APHCRI's scope to initiate contact with all of the state-based consumer organisations as a first step, but researchers should be encouraged to develop their own ongoing relationships with contacts in these groups.

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