"Unique and essential": a review of the role of consumer representatives in health decision-making

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Consumers Health Forum of Australia

CONTENTS

"Consumer representatives have a unique and essential role. Without consumer representatives there is often no-one on a committee whose job it is to represent a non-medical and in many cases a broader perspective."

Cindy Schultz-Ferguson, CHF Consumer Representative

KEY FINDINGS

The role of consumer representatives within the Australian health system has evolved significantly over the past two decades to become integral to the development, implementation and evaluation of health policies, programs and services. As the role of consumer representatives has grown, so too has the importance of developing a robust research base to inform the way in which consumer representation is used to add maximum value to the quality, efficiency and equity of our health system.

This report reviews key recent research into the contribution of consumer representatives to health decision-making and identifies the main emerging themes from these studies. Drawing on a literature review and other data sources, including 'grey' literature (such as policy papers) and interviews with experienced consumer representatives, the report makes six key findings (see below). It also identifies the main recent developments in the role of consumer representatives in the health systems of the UK, Canada and New Zealand and outlines some key features of each country's approach.

Overall, the literature review found an emerging consensus around the importance of consumer and community engagement in health care and the value added by consumer representatives to health decision-making. This was consistent across countries, sectors of the health system studied and the level at which consumer engagement occurred. Findings were also similar in literature from the range of different disciplines involved in this area, including sociology, anthropology, public policy and health services management. While there are still research gaps and unanswered questions identified in the literature, these were not, in general, considered significant enough to undermine the evidence base for consumer representation and participation in health care.

The six experienced consumer representatives interviewed for this project provided an overall endorsement of the importance of their roles and reinforced many of the findings of the literature review. They provided a number of examples of how they had improved the outcomes of policies, programs and services through their role on health-related committees and boards. These examples included improving the targeting of a program, influencing the long-term governance arrangements of an organisation and increasing the effectiveness of consumer-targeted information campaigns.

The review of international developments in the area of consumer engagement also reflected the growing support for consumer representation and found that a number of countries had developed high level policy commitments to increasing consumer engagement throughout the health system. These were being supported through funding, research, resource development and infrastructure

support with a focus on improving both the value and the outcomes of health care and ensuring that health policy and funding decisions reflect consumer values and priorities.

In drawing together the main findings across the range of data sources used, the report identifies the following key themes:

- **Consumer representatives add demonstrated value to health decision-making:** there is widespread evidence from a range of sources that consumer participation in health decision-making adds value at all levels. This includes improving the targeting of initiatives, the efficiency of resource use and the quality of care provided by a health service or program.

- **Multiple levels of consumer engagement are needed**: consumer representation should not occur in isolation but should be seen as a continuum from individual patient input into clinical decisions to consumer representation at the Board or organising committee level.

- **Consumers need to be represented at the highest level of governance:** For consumer input to have the broadest reaching impact on decision-making, consumers should be included at the highest level of organizational structure that is feasible.

- **Matching consumer representatives to suitable roles is essential:** this includes finding the most appropriate representative for each role and ensuring there is diversity of representation to reflect the broad range of consumer views.

- **Adequate resources are needed to support consumer representatives in their roles:** to maximise the contribution of consumer representatives it is important that they be seen and treated as people with expert skills and knowledge, in the same way that other committee members are professionals in their areas of expertise. It is also crucial that adequate resources are provided to consumer organisations in order to recruit, train and support consumer representatives.

- **Evaluating and monitoring of consumer representation is important:** consumer representation needs to be evaluated on an ongoing basis to ensure it is meeting the needs of consumers and the community.

ABOUT THIS REPORT

The Consumers Health Forum of Australia (CHF) is the national peak body representing the interests of Australian healthcare consumers. CHF works to achieve safe, quality, timely healthcare for all Australians, supported by accessible health information and systems.

The research project was undertaken by independent researcher and health policy consultant, Jennifer Doggett. The project comprised three components: a review of recent (post 2010) research and other relevant documents on this issue; an examination of international developments in consumer engagement, with a focus on the UK and the USA; and interviews with six experienced consumer representatives documenting their experiences as members of a broad range of health-related committees and organisational boards.

This report builds on a 2010 review, *An analysis of the contribution of health consumer representatives to medical decisions and outcomes*, which can be accessed at: https://www.chf.org.au/pdfs/rep/rep-research_report-an_analysis_of_the_contribution_of_health_consumer_representatives.pdf

PROJECT OVERVIEW

AIM

The aim of this project was to review and assess the evidence that demonstrates the contributions and outcomes of consumer representation on health and medical Boards/Committees, in particular to document the impact of consumer representatives' contribution to health policies, programs and services.

SCOPE

Australian and international literature, international examples and direct consumer experience.

REPORT STRUCTURE

The Report provides an outline of the methodology for the project, followed by a summary of the major areas of research in this area. It identifies and discusses key themes emerging from each of the data sources used and concludes with a summary of key findings across all three sources. After the conclusion is an annotated bibliography of the literature reviewed for the project. Details of the methodology used in the preparation of the report are provided at Appendix A and a list of key policy documents reviewed is at Appendix B. Case studies are provided throughout the report as examples of the contribution made by consumer representatives to improving policies, programs and services within the health sector.

CASE STUDY

Changing organisational cultures and practices over the long term – Jan Donovan

I was on the Board of the National Prescribing Service (NPS) in its early days and one of my main areas of focus was to promote greater consumer engagement around medicines. One factors that has helped achieve this was that the Board supported a resolution that every NPS project had to have a consumer arm. As a result of that resolution, there are now consumer representatives embedded in every program and two consumers on the NPS board. I believe that this is one important factor contributing to the success of the NPS in increasing the quality use of medicines in the Australian community.

"Consumer input isn't just about providing anecdotal evidence – consumer representatives base their positions on the best available research, consultations with consumers and their expert knowledge of community values and preferences."

Christine Walker, CHF Consumer Representative

CASE STUDY

Improving the quality and targeting of health information and education – Melissa Cadzow

I have been on a number of committees as a consumer representative where I have played a direct role in changing both the content and language of information and education materials in order to make them more relevant and engaging to their target audiences. For example, I provided feedback on language and images used in a resource targeting parents of new babies to ensure that the resource reflected much more closely the experience of this target group.

SUMMARY OF RESEARCH FINDINGS

"Consumers representatives can be a true partner in designing better health services and improving the outcomes of ongoing projects. These are not token roles but are serious partners at the table."
Melissa Cadzow CHF, Consumer Representative

There is a substantial body of research supporting the importance of consumer involvement in health decision-making and a growing literature focussing specifically on the role of consumer representatives.

Overall, research in this area has found that consumer engagement adds value to the health system in a number of ways, including improving the quality of care, the efficiency of resource use and the level of community support for the program or service.

The key areas documented by the research in which consumer representatives influenced health policy and program decisions in order to achieve more effective policy and program design and implementation included:

- identifying consumer issues that needed to be addressed in policy and program design;
- improving the design and targeting of health communication strategies;
- influencing the content of medical education and training programs;
- balancing the interests of industry sectors through presenting the consumer perspective on health program resources and materials;
- increasing the effectiveness of existing programs through improving access and targeting strategies;
- influencing reporting requirements to ensure a consumer perspective is included and available to influence government decision making;
- raising the profile of existing programs with key bodies to gain their support and endorsement;
- advocating for health literacy strategies to empower consumers;
- influencing the content of key government health policies such as the National Medicines Policy;
- contributing to a cultural shift to broader views on consumer participation in health policy and program development;
- influencing governance arrangements to ensure ongoing consumer input throughout an organisation;
- changing the rhetoric and terminology of health policies and communications to reflect consumer experience; and,
- achieving improvements in transparency of committee decision making processes.

In the past five years there has been increase in both the volume and diversity of research conducted on consumer input into health decision-making. This increase in research activity has occurred in a number of countries with the most notable being in countries undergoing significant health reforms, including the UK and the USA. The majority of this research confirms the findings of previous studies in this area and strengthens the evidence base for the benefits of consumer engagement in health.

Key findings of recent literature include the impact consumer and community representatives have had in improving health care in the following areas:

Improving existing services: there are a number of studies showing that consumer input has led to improvements in the delivery of health services, including through improving the design of new buildings, the location of existing services and transport and parking arrangements.[1] There is also good evidence that consumer input has resulted in the creation of additional services to meet consumer needs.

A number of studies also demonstrate the role consumer representatives have played in improving the organisation of existing services, to increase access and efficiency[2], for example by improving booking arrangements and appointment systems.[3]

Creating new services: Consumer input appears to be particularly important in influencing the development of new services in the primary care sector. One UK study found that over a quarter (28%) of primary care groups in the UK reported that consumer involvement had led to new services being provided to the community, for example an advice service for teenagers on sexual health and contraception and an integrated evening care service[4].

Communication and culture: Improved dialogue between health professionals and patients was documented by a number of studies, including both at the individual patient-doctor level and at a broader consumer-management level.[5] For example, one case study reported on the involvement of consumers in the development of standards for health professionals breaking bad news to patients.

There are also some examples in the literature of how consumer representatives supported better communication between patients and other patients, for example, through establishing peer support groups.[6]

Information provision: Another important area in which consumers had substantial input was around information development and dissemination, including producing public and patient information, raising awareness of chronic conditions and the development of training sessions for both service users and health professionals[7]. A number of studies described the role of consumer representatives in producing public information on issues such as mental health, cancer and stroke.[8]

Professional attitudes: There is some evidence that consumer involvement in health care has led to a change in health professionals' attitudes, values and beliefs about the value of consumer involvement, although this was not a uniform finding[9].

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[1] McEvoy 2013
[2] McEvoy 2011
[3] Mockford 2011
[4] Mockford 2011
[5] Broerse 2010
[6] Kamphuis 2012
[7] Tong 2012
[8] Tong 2012
[9] Martin 2008

The expansion of the number of research disciplines involved in working on consumer engagement issues is evidence of its increased profile and relevance, within both the public policy and academic spheres. It also signals a maturing of the research culture in this area which has enabled it to benefit from the cross-fertilisation of different approaches and research methodologies of these disciplines.

Overall, the increase in the volume and diversity of research on consumer representatives has strengthened the evidence base for the benefits of consumer representation by confirming the findings of previous research while also addressing some research gaps, particularly through providing explanations for 'how' and 'why' consumer representatives have a positive impact on health decision-making.

An increase the range of disciplines engaged in research in this area since 2010 was also apparent from the review. For example, there were a number of sociological and anthropological studies of how health systems and health care organisations operate in relation to consumer engagement. One of these studies[10] reports an ethnographic study of a genetics policy network which draws on a repertoire of cultural, relational and cognitive resources to understand how the sociological concreteness of citizenship may be embodied and exercised through public involvement theory and practice in health care. Drawing from different social science disciplines, another study[11] demonstrated how disputes over representativeness relate not just to a struggle for power according to contrasting group interests, but also to a substantive divergence in understanding of the nature of representativeness in the context of state-orchestrated efforts to increase public participation.

The literature review also identified an increase over the past five years in the number of review articles and meta-analyses which provide an overview of the research findings in this area.[12] Case studies on specific organisations and programs have also become more common forms of research than in 2010, particularly in the countries (identified above) undergoing significant health reforms. The role of consumers in providing input into medical and health care research and the development of clinical guidelines was a key focus of a number of these review articles. One review article found that both researchers and consumers saw consumer and community participation as making an important contribution to the research outcomes in particular:

> "…by enhancing scientific and ethical standards, providing legitimacy and authority, and increasing the project's credibility and participation. They saw it was fundamental to the research process and acknowledged consumer and community representatives for their excellent contribution. Consumer and community representatives were able to directly influence decisions about the research. They thought that consumer and community participation had significant influence on the success of project outputs and outcomes." (Payne et al 2011)

A key finding from meta-analyses conducted in this area is that the main barrier to building a more solid evidence base for consumer representation is the lack of standardised terms and practices in

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[10] Lehous et al 2012
[11] Martin 2008
[12] For example, Domecq 2014

this area. These analyses found that as definitions of consumer representatives and the way in which they operate differ across organisations, sectors and countries, it can be difficult to make meaningful comparisons or to assess the relative effectiveness of the engagement mechanisms employed. One study found that

> *"a key limitation of the patient and public involvement (PPI) evidence base is the poor quality of reporting impact. Few studies define PPI, there is little theoretical underpinning or conceptualization reported, there is an absence of robust measurement of impact and descriptive evidence lacked detail".* (Mockford et al 2012)

Conklin et al supported this finding stating that: *"…empirical evidence of the outcomes of public involvement activities in health care remains underdeveloped. The concept and the indicators used to examine and determine outcomes remain poorly specified and inconsistent, as does the reporting of the evidence".* (Conklin et al 2012)

Sarrami-Foroushan et al also argue that there are also gaps in the data being collected on the details of consumer and community (CCE) engagement. They state that:

> *"… although there is a significant body of research on CCE, the development of the field is hindered by a lack of evidence relating to specific elements of CCE. Strategies for CCE vary in terms of their aim and type of proposed activity, as do the methods and tools which have been developed to support them. The success of CCE is dependent on both the approach taken and contextual factors, including structural facilitators such as governmental support, as well as barriers such as costs, organisational culture and population-specific limitations."* (Sarrami-Foroushan et al 2014)

Therefore, despite the significant expansion and progression of research into this area, there are still identified gaps in the literature and some methodological issues that need to be resolved to improve the relevance and utility of future research. In particular, it is important that the terms and categories of consumer representation are formalised so that there is agreement within the research community on the definition of their roles and outcomes. The role of consumer representatives in evaluations and reviews is also an area identified in the literature as requiring additional research.

CASE STUDY

Balancing the interests of industry and protecting consumers – Henry Ko

One role I had was in assessing resources produced by pharmaceutical companies for consumers. As advertising prescription medicines directly to consumers is banned in Australia, it was very important that the resources be clearly identified as information and not marketing materials. With a consumer focus in my role on the committee, I was able to assess how the materials would be perceived by consumers and often picked up on subtle messages and nuances that were missed by other members but which may have resulted in them

having a promotional impact on consumers. My input ensured that consumers could receive the benefit of these resources, such as a low GI cookbook, without being subjected to prohibited advertising messages.

"Consumer input is critical to dealing with some of the 'wicked problems' and emerging challenges facing our health system, such as dealing with growing antibiotic resistance and knowing when to stop administering care."

Jan Donovan, CHF Consumer Representative

At both the research and policy level, consumer engagement in health has progressed significantly since 2010. This reflects a growing recognition by health services and health planners that consumer engagement helps health programs and services achieve their aims and these practices are supported by a growing body of research which provides information about optimum engagement strategies.

AUSTRALIA

Consumer engagement within the health sector has progressed since 2010 in Australia as well as internationally. In Australia, the main development at the national level has been the development of a national standard for consumer engagement throughout the health sector by the Australian Council of Quality and Safety in Health Care (ACQSHC).

Standard 2 of the National Safety and Quality Health Service Standards requires the involvement of consumers in the organisational and strategic processes that guide the planning, design and evaluation of health services.

The Standard states that the actions identified build on *'emerging evidence of the benefits partnering with consumers can bring to health services. For example, involving consumers in service planning, delivery, monitoring and evaluation is more likely to result in services that are more accessible and appropriate for consumers.'*[13]

The Standard does not mandate any specific form of consumer engagement and in promoting the Standard ACSQHC states that *"there is no single approach to partnering with consumers. How healthcare organisations choose to establish and maintain their partnerships needs to reflect the organisation's context, the purpose of the partnership, the desired outcomes and the environment in which the partnership is occurring."* However, it does outline the main goals, underlying principles and suggests strategies to support greater consumer engagement across the health sector.

In addition to the national Standard, there have also been developments in this area at the State/Territory level. For example, in NSW the Clinical Excellence Commission (CEC) has established the *Partnering with Patients* program[14] to foster the inclusion of patients and family as care team members to promote safety and quality. This Program aims to recognise the importance of

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[13] ACSQHC 2011
[14] http://www.cec.health.nsw.gov.au/programs/partnering-with-patients

improving quality of care by responding to the needs and preferences of patients while equally engaging staff in creating supportive environments for all.

In South Australia, the *Guide for Engaging with Consumers and the Community*[15] was developed through collaboration between key stakeholders including the SA Safety and Quality in Health Care, Consumer and Community Advisory Committee (CACAC) and external consumer organisations. This Guide is being used by SA Health staff to strengthen and improve the practice of consumer and community engagement across the organisation. A series of tools were also developed to assist staff who are planning, managing or implementing consumer and community quality improvement projects, programs or activities. The tools are based on current best practice consumer participation methodology toolkits and resource guides.

THE UNITED KINGDOM (UK)

Under successive governments, the UK has been increasing its focus on consumer engagement within the health sector. However, this policy goal has recently become more prominent due to the recent inquiry into safety breaches at a National Health Service (NHS) trust which resulted in a number of patient deaths.

The Francis Inquiry report[16] was published in 2013 and examined the causes of the failings in care at Mid Staffordshire NHS Foundation Trust between 2005-2009. The report makes 290 recommendations to increase the safety and quality of health care, including the need for greater patient and public scrutiny of the health system.

The UK Government responded to the recommendations of the Francis Inquiry in Hard Truths: the journey to putting patients first which includes recommendations for improving patient involvement in their care. This report states *'patients want it, and the evidence shows that when they are involved, decisions are better, health and health outcomes improve, and resources are allocated more efficiently.'*

The King's Fund has produced a number of resources to support the move towards a more consumer-focussed health system, including an assessment[17] of the Government's progress towards this goal which found that NHS England's programme of work on transforming participation provides a first step but which also identified the following crucial steps that needed to be undertaken by national health bodies:

- develop a model of professional education and training based on working with users and citizens
- provide staff and patients with access to high-quality tools for structuring and recording care-planning and shared decision-making
- measure involvement and hold organisations to account

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[15] http://www.sahealth.sa.gov.au/wps/wcm/connect/f8d1d0004e454788aa0caf8ba24f3db9/Guideline_Engaging+with+Consumers+and+Community_Aug2013.pdf?MOD=AJPERES&CACHEID=f8d1d0004e454788aa0caf8ba24f3db9

[16] http://www.midstaffspublicinquiry.com/report

[17] http://www.kingsfund.org.uk/publications/people-control-their-own-health-and-care

- enable local organisations to focus on patients not politicians, with a national approach to reform that supports organisations to lead change locally.

The King's Fund has also produced a toolkit to support Patient and Family-Centred Care (PFCC) which aims to improve health care quality through increasing consumer engagement and input.

The Royal College of General Practitioners is also playing an important role in progressing this policy agenda through its own inquiry into patient-centred care. The Report of the inquiry strongly endorsed the need for patient experience to be put at the centre of primary health care and also highlighted the importance of consumer representation at all levels of the health system:

> *We are very supportive of the growing numbers of patient leaders who are able to bring a strong patient perspective into the heart of heath and care decision-making, and commend those places that have begun to operate in this way. However, we believe that in order to embed the patient voice consistently across the NHS, there is a pressing need to encourage and equip patients to take up more leadership and governance roles – including through the provision of leadership development opportunities.[18]*

NEW ZEALAND

The Health Quality & Safety Commission was established under the *New Zealand Public Health & Disability Amendment Act 2010* to ensure all New Zealanders receive the best health and disability care within our available resources.

The Commission has developed a Framework[19] for consumer engagement to provide overarching guidance and a principled approach to involving consumers as partners in health and disability policy, planning and services.

The Framework has a theme for each year supported by three concurrent workstreams. It is designed to be implemented over four years by the Commission and the health and disability sector. Themes for each year are: Leadership and awareness raising of the Partners in Care framework; collaboration; innovation; and evaluation. The three concurrent workstreams are: increase health literacy; improve consumer participation; leadership capability for providers and consumers.[1]

The emphasis for the Commission in the first year is to position itself within the sector as a key organisation for consumer engagement in relation to health quality and safety. This will also be the time when the framework is socialised across the sector, and for networks and collaborations to be established (e.g. with the Ministry of Health, Health and Disability Commission, public and private health providers and consumer groups).

In the second and third years the Commission will focus on forming and/or strengthening partnerships to empower and facilitate sector leaders (providers and consumers) to set their own agendas for implementation in future years. This enables best practice to support consumers to do it for themselves.

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[18] http://www.rcgp.org.uk/policy/rcgp-policy-areas/~/media/Files/Policy/A-Z-policy/RCGP-Inquiry-into-Patient-Centred-Care-in-the-21st-Century.ashx
[19] http://www.hqsc.govt.nz/assets/Consumer-Engagement/Publications/Post-Feedback-Update-of-PIC-Framework-July-2012.pdf

The introduction of the Affordable Care Act (ACA) – known informally as "Obamacare" – in the USA has resulted in the creation of new health funding and delivery models, including accountable care organizations (ACOs) and integrated care systems for people eligible for the government-funded insurance programs Medicare (people over 65 or under 65 with a disability) and Medicaid (people on low incomes).

The new delivery models and payment systems created through the ACA are required to engage with consumers, although the way in which this engagement occurs varies across the country. There is no current standard regarding best practices for involving consumers in health care delivery organizations, meaning that organisations and services can interpret consumer engagement in different ways.

Many of the target groups for these programs are communities which previously had not has access to health insurance, including people on low incomes and people with disabilities. In some cases the organisations involved in establishing new models of care under the ACA have not had previous experience in engaging these populations.

This has resulted in a focus on models of consumer engagement, with an increase in research and policy development on consumer engagement as an important component of the success of new health care delivery models.

CASE STUDY

Challenging assumptions and enabling the better use of data - Christine Walker

Consumer representatives have been particularly important in challenging false beliefs among health professionals about data collection. One committee I was on involved looking at data collection in primary health care. Some of the GPs on the committee put forward the argument that the data collection being proposed would violate individual privacy and not be supported by consumers. However, I was able to counteract these views and explain that in my experience and in my own research I have evidence that consumers fully support the collection of data because they see it as contributing to improving quality of care. Consumers do understand that data can be used to improve service delivery. This enabled the project to go ahead.

CONSUMER INTERVIEWS SUMMARY

The six experienced consumer representatives interviewed for this project provided an overall endorsement of the importance of their roles and reinforced many of the findings of the research identified in the literature review. They provided a number of examples of how they had improved the outcomes of policies, programs and services through their role on health-related committees and boards. These examples included improving the targeting of a program, influencing the long-term governance arrangements of an organisation and increasing the effectiveness of consumer-targeted information campaigns.

The interviewees identified the value of consumer representatives as stemming from consumers' unique perspective on the health system, as both the users and the ultimate funders of all forms of health care. Their experience as consumer representatives highlighted the important role of consumers on committees as the only ones without a vested interest or with other allegiances and responsibilities. As the only members whose sole focus is on consumers, consumer representatives are able to raise issues and present points of view that are not influenced by other interests.

The interviewees also stated that their role was often to provide a non-medical perspective on issues and that without them there would be no-one on the committee able to present this point of view. In their experience, the non-consumer members of a committee typically come from a similar professional background so the consumer representative is often the only one able to challenge the views being presented. The interviewees described one important aspect of their role as raising issues which all members thought were important but which others did not feel comfortable raising themselves, due to their relationship with the organisation involved.

As well as contributing to specific policies and programs, the interviewees felt that it was very important that the consumer voice also be heard at the strategic level of organisations and governments. In particular the inclusion of consumer representatives on organisational boards and high level strategic committees was identified as essential in order to ensure that a consumer focus was embedded at all levels of the health system.

The interviewees identified a number of 'best practice' examples of consumer engagement in Australia and also some barriers to maximising consumer input and areas in which consumer engagement could be increased within the Australian health system. These are discussed in more detail, below.

Putting issues on the agenda - Alison Marcus

One experience that I had was on the original Quality use of Medicines working group of the National Prescribing Service. The issue of excess or out-of-date medicines in the community was not even on the group's radar. However, through my experience and my consumer networks I knew that unwanted medicines were a key issue for consumers and a potential risk to the community if used or disposed of inappropriately. Once I raised this issue it was on the group's agenda and ultimately this led to the Return of Unwanted Medicines (RUM) project.

"Having more than one consumer representative on a committee is important so that the consumers don't feel outnumbered by the other members."

Henry Ko, CHF Consumer Representative

KEY THEMES

"It is essential that the consumer voice is heard at the strategic as well as the operational level of the health system. Everyone else may be a consumer but they also wear other hats. The consumer representative is the only person whose sole focus is on consumers and they are able to say things that they others can't."

Melissa Cadzow, CHF Consumer Representative

There were six key themes that emerged from the literature review, the consumer interviews and the examination of recent international developments in consumer engagement. These are discussed in more detail below.

CONSUMER REPRESENTATIVES ADD DEMONSTRATED VALUE TO HEALTH DECISION-MAKING

There is widespread evidence that consumer representation adds value to health decision making at all levels. The consumer representatives interviewed could all report instances where they had clear influence over a committee decision or process which resulted in a better outcome for a health program or service. These included decisions which improved the targeting of initiatives, the efficiency of resource use and the quality of care provided. This finding was reflected in the literature which included a number of studies describing how consumer participation contributed to better decision making in health. For example, Payne et al[20] found there was consensus among researchers that consumer and community participation contributed to project outputs and outcomes by enhancing scientific and ethical standards, providing legitimacy and authority, and increasing the project's credibility and participation. They concluded that consumer participation was fundamental to the research process and that consumer and community representatives had significant influence on the success of project outputs and outcomes.

THE NEED FOR MULTIPLE LEVELS OF CONSUMER ENGAGEMENT

Consumer representatives on committees and boards are one important form of consumer engagement but there are a number of others identified by the interviewees and discussed in the literature, including community surveys, focus group meetings, feedback and evaluation forms and newsletters. There is some research which supports the need for each form of consumer engagement to be seen as part of a continuum of engagement, from individual patient input into clinical decisions to consumer representation at the Board or organising committee level. It is important that when looking at the input of consumer representatives on committees that they should not be seen in isolation but within the context of any other consumer engagement strategies undertaken by the relevant organisation or service.

The different engagement mechanisms are identified in the literature as having specific strengths and weaknesses and the importance of using the most appropriate mechanism for each function is discussed in some studies. A number of case studies reported identify the multiple ways in which specific organisations engage with consumers and argue that by using multiple methods to engage consumers the opportunity for consumer participation increases and the benefits of consumer input

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[20] Payne 2011

are maximised.   Some researchers also argued that without more research in this area, consumer engagement may lose value and become tokenistic:

> "……patient engagement in healthcare research is likely feasible in many settings. However, this engagement comes at a cost and can become tokenistic. Research dedicated to identifying the best methods to achieve engagement is lacking and clearly needed" (Prutsky et al 2014)

REPRESENTATION AT THE HIGHEST LEVEL OF GOVERNANCE

The governance structure outlines the way in which an organization is controlled and the levels at which decisions are made. For consumer input to have the broadest reaching impact on decision-making, consumers should be included at the highest level of organizational structure that is feasible.

A number of the consumer representatives interviewed for this project stressed the importance of consumer input into 'high level' decision making so that the overall direction and policy context of the organisation or program reflected consumer interests. They also identified the lack of support at high levels of governance as a barrier to their roles. In some cases interviewees reported feeling as though their contribution was tokenistic as there was no real commitment to change previous plans or agendas at the strategic decision-making level. A number of examples were provided of when consumer input had been undermined or neutralised due to unsupportive executives or Boards. For example, one interviewee reported that when a Board did not support the recommendations of a consumer advisory committee it sacked all of the members and replaced them with new people. Conversely, one interviewee reported that she knew that a committee she was on was well-regarded by the senior management of the organisation when the CEO attended every meeting.

The inclusion of consumers within all levels of governance was identified by interviewees as insulating the organisation or service from the negative impact of politically-driven changes. This view is also supported by international trends towards increasing consumer involvement in strategic decision-making. For example, in the USA under the Affordable Care Act, having a consumer-majority board of directors is a governance requirement for community health centers.

IDENTIFYING THE RIGHT CONSUMER REPRESENTATIVE FOR EACH ROLE

The importance of selecting the most appropriate consumers for positions on boards and committees was a key theme identified by interviewees and addressed in recent policy changes internationally. The need for a structured and transparent recruitment process was raised by some of the consumer representatives interviewed who described their roles in different committees as, in some cases, requiring or benefitting from specific experience and knowledge.

International practice in this area, in particular in the USA, reflects the importance of consumer input processes reflecting the diversity of consumer views as much as possible. This diversity includes demographic factors such as representation across gender, race and ethnicity, and

socioeconomic factors as well as non-demographic factors such as representation of different geographic regions served, different medical diagnoses, or different services used.

The importance of diversity in consumer representation was highlighted by one consumer representative interviewed who stated that one of the most important enablers for health care committees was to include a mix of people as members, with at least two consumers. In her experience the most effective groups are those where the consumer representatives can support each other and share the role of advocating for consumers. In particular she stressed that the inclusion of consumers from different backgrounds can add more variety and depth to the contribution made by the representatives.

Another interviewee stressed the importance of a structured recruitment process to ensure that an appropriate representative was selected. She reported that in her experience "Some groups seem to think that talking to any consumer is the same as having an experienced consumer representative on the board." This means that sometimes organisations don't go through a structured process to select appropriate consumer members and therefore don't get the optimum input from them.

Both the interviewees and the research review identified some specific population groups that were currently under-represented in consumer engagement processes in the health sector. These included: people from culturally and linguistically diverse backgrounds; Indigenous Australians; fathers and grandparents (specifically in relation to family services); people from rural and remote areas; people with rare diseases; and young people.

ADEQUATE AND DEDICATED RESOURCES

The need for adequate resources to support effective consumer engagement is a key theme emerging from research, international examples and consumer interviews. All forms of consumer engagement require organisational commitment, support and a level of resourcing in order to be effective. This can include direct remuneration for consumer representatives, organisational resources (such as meeting rooms and transport services), staff time (to provide administrative support), among others.   Resources were also important in relation to the training and support provided to consumer representatives to enable them to carry out their role.

The interviewees felt that to maximise the contribution of consumer representatives it was important that they be seen and treated as people with specific, valuable expertise and skills, in the same way that other committee members are professionals in their areas of expertise. The perception of consumer representatives as volunteers was identified by interviewees as damaging to their credibility and as undermining their value to the overall work of the committee.

THE IMPORTANCE OF EVALUATION AND MONITORING

The importance of evaluating and monitoring consumer engagement in health systems is an emerging theme in the literature in this area. As consumer engagement has become more established within health organisations and attracts more resources, there is a growing awareness of the importance of evaluating its impact. For example, one study found consensus among panelists surveyed that it is feasible to evaluate the impact of public involvement on some research processes,

outcomes and on key stakeholders. The value of public involvement and the importance of evaluating its impact were endorsed. (Barber et al 2012)

This emerging area of research focusses on relating consumer engagement to the organisational mission and evaluating the role of consumers in the process by which this mission is achieved. Evaluations which connect consumer engagement mechanisms to the goals of the organisation or service are becoming more important in providing an evidence base for the contribution made by consumer representatives and others. These typically include both process and outcome-related goals, such as the numbers of consumers participating in consultation process and the changes that result from consumer input.

Independent evaluation is also suggested as one way of obtaining an external perspective on an organization's engagement processes. Other mechanisms suggested are to require organisations to submit reports to relevant entities such as purchasers and regulators on their consumer engagement goals, processes, and outcomes.

This is an under-researched area overall and one in which there is no agreed methodology or mechanism for measuring the contribution made by consumers to a specific policy, program or service. In researching this issue, Hilder and Farjou found that while *'numerous drivers encourage, support and - in some instances - mandate consumer, carer and community participation within Australian health services. Some of these are more effective than others. Similarly, many factors influence the willingness of health services to monitor and evaluate their performance and quality of care. Whilst both are highly valued elements to improving health outcomes and providing quality health care, they are usually considered separately.* (Hilder and Farjou 2013)

One suggestion made by an interviewee was to adopt the 'Balanced Scorecard' approach used in other sectors, such as manufacturing and service industries. This model integrates consumer engagement into the overall goals of the organisation so that it is assessed along with other goals, such as productivity and environmental impact.

Improving targeting of programs – Cindy Schultz-Ferguson

I was on a committee looking to introduce a program called Supportive Care, targeted at people with cancer to assess their need for non-medical support services as well as their medical treatment. The program involved an assessment by trained nurses/social workers to determine their needs. The take-up of the program was very low and well below the 50% target. The Committee was trying to work out why the take-up was so low and what strategies they could use to increase the take up. I suggested that they move away from a nurse/social worker-referral model and allow consumers and carers to refer themselves, via low cost, simple strategies, such as putting up a posters/flyers in the relevant waiting rooms.

CONCLUSION

The past five years has seen significant growth in research into the role of consumer representatives in health decision-making. In general, this research has confirmed the findings of previous studies that consumer and community engagement adds significant value at all levels of the health system. The increased number of case studies in the literature that have been conducted have added important detail to our knowledge of the ways in which consumer representatives benefit health decision-making. There are also a number of key review articles which bring together a range of studies and clearly indicate that consumer representation adds demonstrated value at both the organisational and strategic levels.

In particular, the literature review and consumer representative interviews have found that consumer representation is important across the spectrum of the health system but in particular needs to occur at the highest level of governance. Multiple forms of engagement were also highlighted as an important strategy to maximise value, as were the need for adequate resourcing and support for consumer representatives and their member organisations.

The robust evidence base now available supports an ongoing and strengthened role for consumer representation throughout the Australian health system. By building on the findings of the literature review and learning from recent international developments in this area, we can ensure that consumer representation occurs at all levels of health decision-making and delivers maximum value to the Australian community.

CAN THE IMPACT OF PUBLIC INVOLVEMENT ON RESEARCH BE EVALUATED? A MIXED METHODS STUDY

Rosemary Barber, Jonathan D Boote, Glenys D Parry, Cindy L Cooper, Philippa Yeeles and Sarah Cook

Health Expectations 15(3) 2012

This paper investigates whether it is feasible to evaluate the impact of public involvement on health and social research. Based on a two-round Delphi study, consensus was reached that it is feasible to evaluate the impact of public involvement on 5 of 16 impact issues: identifying and prioritizing research topics, disseminating research findings and on key stakeholders. Qualitative analysis revealed the complexities of evaluating a process that is subjective and socially constructed. While many panelists believed that it is morally right to involve the public in research, they also considered that it is appropriate to evaluate the impact of public involvement. This study found consensus among panelists that it is feasible to evaluate the impact of public involvement on some research processes, outcomes and on key stakeholders. The value of public involvement and the importance of evaluating its impact were endorsed.

PATIENT AND PUBLIC INVOLVEMENT IN CLINICAL GUIDELINES: INTERNATIONAL EXPERIENCES AND FUTURE PERSPECTIVES

Antoine Boivin, Kay Currie, Béatrice Fervers, Javier Gracia, Marian James, Catherine Marshall, Carol Sakala, Sylvia Sanger, Judi Strid, Victoria Thomas, Trudy van der Weijden, Richard Grol, Jako Burgers on behalf of G-I-N PUBLIC

Quality and Safety in Health Care. 19(5) 2010

Clinical practice guidelines (CPG) are important tools for improving patient care. Patient and public involvement is recognised as an essential component of CPG development and implementation. This paper reports on an attempt to develop an international practice and research agenda on patient and public involvement in CPG. It concludes that greater international collaboration and research are needed to strengthen existing knowledge, development and evaluation of patient and public involvement in CPG.

ELICITING ETHICAL AND SOCIAL VALUES IN HEALTH TECHNOLOGY ASSESSMENT: A PARTICIPATORY APPROACH

Yvonne Bombard, Julia Abelson, Dorina Simeonov, Francois-Pierre Gauvin

Social Science & Medicine, Volume 73, Issue 1, July 2011

This study aimed to elicit a set of ethical and social values from citizens that could be used to guide Ontario's HTA evidentiary review and appraisal process. A secondary objective was to explore the feasibility of using participatory approaches to elicit these values. After establishing a 14-person Citizens' Reference Panel on Health Technologies was established to provide input to the Ontario Health Technology Advisory Committee in developing its recommendations, a mixed methods approach was used where informed, deliberative discussions were combined with pre- and post-questionnaires, which assessed the relative importance of various ethical and social values as well as their stability over time. Over the course of five meetings, panel members progressed toward the identification of a set of core values – UNIVERSAL ACCESS, CHOICE and QUALITY CARE. These values were consistently prioritized as the core values that should be considered in the evaluation of health technologies and ensuing recommendations. Sustained and deliberative methods, like a citizens' panel, offer a promising approach for eliciting ethical and social values into HTA.

INVOLVING BURN SURVIVORS IN AGENDA SETTING ON BURN RESEARCH: AN ADDED VALUE?

Jacqueline E.W. Broerse, Marjolein B.M. Zweekhorst, Annemiek J.M.L. van Rensen, Monique J.M. de Haan

Burns, Volume 36, Issue 2, March 2010

The role of burn survivors in burn research is usually restricted to being objects of study and beneficiaries of research results, while decision-making on research is traditionally the domain of a small group of experts, mainly scientists. In this article we compare the research priorities of burn survivors and professionals and investigate to what extent it is possible to come to a joint research agenda. Considerable overlap was observed between the research priorities of burn survivors and professionals, particularly with respect to biomedical and clinical research on wound healing and scar management. However, differences were also observed, e.g. treatment of itching and oedema on scars and donor places. The model proved useful in eliciting research priorities from both professionals and burn survivors, and in stimulating a meaningful dialogue between these groups. The involvement of burn survivors identified burn research areas that are currently not the focus of research in The Netherlands.

RESIDENTS' PERCEPTIONS OF EFFECTIVE COMMUNITY REPRESENTATION IN LOCAL HEALTH DECISION-MAKING

Phillip Chung, Colleen M. Grogan , Jennifer E. Mosley

Social Science and Medicine 74(10) 2012

This research found three primary characteristics were identified as contributing to successful consumer input: 1) outcomes 2) expertise, and 3) active communication. These characteristics did not operate in isolation but together communicated the trust and commitment that respondents found fundamental to representation. In exploring this essential yet often neglected question, the authors sought to build an empirical foundation to more fully examine the precursors to effective community health representation. These data provide important clues as to how to build an

inclusive process that expands rather than constrains the pool of community-based representatives.

WHAT IS THE EVIDENCE BASE FOR PUBLIC INVOLVEMENT IN HEALTH-CARE POLICY?: RESULTS OF A SYSTEMATIC SCOPING REVIEW

Annalijn Conklin, Zoë Morris and Ellen Nolte

Health Expectations 2012

This paper aimed to review the peer-reviewed empirical evidence on outcomes of public involvement in health-care policy. It found that sound empirical evidence of the outcomes of public involvement activities in health care remains underdeveloped. The concept and the indicators used to examine and determine outcomes remain poorly specified and inconsistent, as does the reporting of the evidence. There was some evidence for the developmental role of public involvement, such as enhancing awareness, understanding and competencies among lay participants. Evidence for instrumental benefits of public involvement initiatives was less well documented. However, focus on outcomes risks missing the normative argument that involving the public in the health-care policy process may be seen to be of intrinsic value

PARTICIPATION OF THE PUBLIC IN THE GOVERNANCE OF HEALTHCARE

Toni Dedeu

http://pub.bsalut.net/cgi/viewcontent.cgi?article=1004&context=jhiic

This review compares recent policy commitments by governments in the UK and Spain to increase public participation in healthcare governance. It shows that definitions of public involvement and participation are endless, as they are permanently being renegotiated as people continue to engage in necessary local discussions. Public voices should not be underestimated as each one has value. These include a wide range of participants, including citizens in voluntary organisations, institutional representatives, and healthcare services staff among others, as they are all patients and carers as well. Furthermore, although public involvement is not community development, strong community voices are invaluable to public involvement work.

PATIENT ENGAGEMENT IN RESEARCH: A SYSTEMATIC REVIEW.

Domecq JP, Prutsky G, Elraiyah T, Wang Z, Nabhan M, Shippee N, Brito JP, Boehmer K, Hasan R, Firwana B, Erwin P, Eton D, Sloan J, Montori V, Asi N, Dabrh AM, Murad MH.

BMC Health Services Research 2014

This systematic review aimed to answer 4 key questions: what are the best ways to identify patient representatives? How to engage them in designing and conducting research? What are the observed benefits of patient engagement? What are the harms and barriers of patient engagement? It found that in general, engagement was feasible in most settings and most commonly done in the beginning of research (agenda setting and protocol development) and less commonly during the execution and

translation of research. Overall, the review concluded that patient engagement in healthcare research is likely feasible in many settings. However, this engagement comes at a cost and can become tokenistic. The study concludes that research dedicated to identifying the best methods to achieve engagement is lacking and clearly needed.

"IT ALL DEPENDS": CONCEPTUALIZING PUBLIC INVOLVEMENT IN THE CONTEXT OF HEALTH TECHNOLOGY ASSESSMENT AGENCIES

Francois-Pierre Gauvin, Julia Abelson, Mita Giacomini, John Eyles, John N. Lavis

Social Science & Medicine, 70(10) 2010

This article investigates how public involvement is conceptualized in the HTA agency environment. Using qualitative concept analysis methods, the researchers find that HTA agencies' role as bridges or boundary organizations situated at the frontier of research and policymaking causes the agencies to struggle with the idea of public involvement. The HTA community is concerned with conceptualizing public involvement in such a way as to meet scientific and methodological standards without neglecting its responsibilities to healthcare policymakers. The paper offers a conceptual tool for analyzing the nature of public involvement across agencies, characterizing different domains, levels of involvement, and types of publics

SHARING THE PIE WITH CONSUMERS: A TOOL TO SUPPORT CONSUMER PARTICIPATION AND COLLABORATION IN EVALUATIONS

Hider, Kim; Farjou, Dina

Health Issues, Issue 110 (Summer 2013)

This paper investigates the way in which consumers can engage in health program and service evaluations. It addresses the numerous drivers that encourage, support and - in some instances - mandate consumer, carer and community participation within Australian health services and concludes that some of these are more effective than others. The authors argue that similarly, many factors influence the willingness of health services to monitor and evaluate their performance and quality of care. They conclude that whilst both are highly valued elements to improving health outcomes and providing quality health care, they are usually considered separately and argue for a more unified approach to conducting evaluations.

FACTS AND FIGURES ABOUT PATIENT ASSOCIATIONS IN THE NETHERLANDS BETWEEN 2007 AND 2009: REVIEW OF THEIR ACTIVITIES AND AIMS

Helen Kamphuis, Karin Hekkert, Marie-Christine van Dongen, Tijn Kool

Health Policy, Volume 107, Issues 2–3, 2012

This article describes the development of a monitor of Dutch Patient Associations in 2005 and 2006 and the most important outcomes and trends for 2007, 2008 and 2009. The authors analyze individual Dutch patient associations focusing on empowerment and advocacy for their own members. They find that different types of associations pursue different goals to provide a 'voice' for their members. There are many small organizations and a few big ones. Advocacy remains important although the motives differ between patient associations. Overall, Dutch patient organizations reported activities they are expected to perform. They try to reduce information asymmetry by informing patients better through several media. They also provide peer support groups to their members. They reach the general public through their social media activities. Their primary focus is providing services to their members.

THE UNBEARABLE LIGHTNESS OF CITIZENS WITHIN PUBLIC DELIBERATION PROCESSES

P. Lehoux, G. Daudelin, J. Abelson

Social Science & Medicine, 74 (12) 2012

This essay thus seeks to shed light on the ways in which individuals define what "being" a citizen means for them and choose to embody or not such a role. Inspired by a four-year ethnographic study of a Canadian science/policy network in genetics, which integrated citizens into its operation, this paper provides four biographical sketches that portray the complexity and richness of what these individuals were "made of." The authors reflect on how they sought to make sense of their participation in the network by drawing on a repertoire of cultural, relational and cognitive resources and on their lived experience. The discussion suggests that the quest for the "ordinary" citizen is misleading. Instead, acknowledging the sociological concreteness of citizenship and understanding how it may be embodied and exercised should be a key focus in public involvement theory and practice in health care

REPRESENTATIVENESS, LEGITIMACY AND POWER IN PUBLIC INVOLVEMENT IN HEALTH-SERVICE MANAGEMENT

Graham P. Martin

Social Science & Medicine, 67(11) 2008

This paper examines this negotiation of representative legitimacy between staff and involved health service users by drawing on a qualitative study of service-user involvement in pilot cancer-genetics services recently introduced in England, using interviews, participant observation and documentary analysis. In contrast to the findings of much of the literature, health professionals identified some degree of representative legitimacy in the contributions made by users. However, the ways in which staff and users constructed representativeness diverged significantly. The author seeks to show how disputes over representativeness relate not just to a struggle for power according to contrasting group interests, but also to a substantive divergence in understanding of the nature of representativeness in the context of state-orchestrated efforts to increase public participation. This divergence might suggest problems with the enactment of such aspirations in practice; alternatively,

however, contestation of representative legitimacy might be understood as reflecting ambiguities in policy-level objectives for participation, which secure implementation by accommodating the divergent constructions of those charged with putting initiatives into practice.

COMMUNITY PARTICIPATION IN PRIMARY CARE IN IRELAND: THE NEED FOR IMPLEMENTATION RESEARCH

Rachel McEvoy and Anne MacFarlane

Primary Health Care Research and Development 14(2) 2013

This paper provides an overview of community participation in primary care, establishing the policy context in which a recent 'Joint Initiative on Community Participation in Primary Health Care' was developed in Ireland. This Initiative was designed to support the involvement of disadvantaged communities and groups in the development of primary health care services at local level. An independent formative evaluation of the Joint Initiative took place between September 2009 and April 2010. The paper presents a summary of key findings from this evaluation paying particular attention to the issue of sustaining community participation in newly developed Primary Care Teams (PCTs) in the current and changing economic climate, an issue considered crucial if the documented positive impacts of the Joint Initiative are to be maintained and the potential for health gains in the longer term are to be realised.

THE IMPACT OF PATIENT AND PUBLIC INVOLVEMENT ON UK NHS HEALTH CARE: A SYSTEMATIC REVIEW

Carole Mockford , Sophie Staniszewska , Frances Griffiths , Sandra Herron-Marx

International Journal for Quality in Health Care 24(1) 2012

The aims of this study were to identify the impact of patient and public involvement (PPI) on UK National Health Service (NHS) healthcare services and to identify the economic cost. It also examined how PPI is being defined, theorized and conceptualized, and how the impact of PPI is captured or measured. The review indicates that PPI has a range of impacts on healthcare services. However, key limitation of the PPI evidence base is the poor quality of reporting impact. Few studies define PPI, there is little theoretical underpinning or conceptualization reported, there is an absence of robust measurement of impact and descriptive evidence lacked detail. The study concluded that there is a need for significant development of the PPI evidence base particularly around guidance for the reporting of user activity and impact. The evidence base needs to be significantly strengthened to ensure the full impact of involving service users in NHS healthcare services is fully understood.

COLLABORATING WITH CONSUMER AND COMMUNITY REPRESENTATIVES IN HEALTH AND MEDICAL RESEARCH IN AUSTRALIA: RESULTS FROM AN EVALUATION

Janet M Payne, Heather A D'Antoine, Kathryn E France, Anne E McKenzie, Nadine Henley, Anne E Bartu, Elizabeth J Elliott and Carol Bower

This paper reports on a questionnaire on consumer engagement completed by both research and consumer and community representatives completed a questionnaire. The questionnaire found that most consumer and community representatives agreed that the process and context measures of their participation had been achieved. Researchers thought consumer and community participation contributed to project outputs and outcomes by enhancing scientific and ethical standards, providing legitimacy and authority, and increasing the project's credibility and participation. They saw it was fundamental to the research process and acknowledged consumer and community representatives for their excellent contribution. Consumer and community representatives were able to directly influence decisions about the research. They thought that consumer and community participation had significant influence on the success of project outputs and outcomes.

KEY CONCEPTS IN CONSUMER AND COMMUNITY ENGAGEMENT: A SCOPING META-REVIEW.

Sarrami-Foroushani P Travaglia J, Debono D, Braithwaite J.

This scoping meta-review aims to identify key consumer and community engagement (CCE) in health care concepts and examine terminology used to describe them. 59 systematic reviews met the selection criteria and were included in the final analysis. The analysis identified nine different concepts related to CCE: shared decision making, self-management, CCE in health care systems, community-based health promotion, providing access to health care, rehabilitation, participation in research, collaboration in research design and conduct, and peer support. The identified concepts differ from each other in many aspects including the aim of the activity, the role of consumers and the type of professionals' involvement. Each concept was described by a range of terms, with some terms shared by different concepts. In addition, two overlapping concepts of patient-centeredness and patient empowerment were recognised. This study describes CCE-related key concepts and provides new insight into their relationship with different CCE-related terms. Identification of key CCE-related concepts and terms will be useful to focus future studies and initiatives and enhance production of CCE-related evidence.

IMPLEMENTING STRATEGIES IN CONSUMER AND COMMUNITY ENGAGEMENT IN HEALTH CARE: RESULTS OF A LARGE-SCALE, SCOPING META-REVIEW.

Sarrami-Foroushani P, Travaglia J, Debono D, Braithwaite J.

Despite the long history of consumer and community engagement (CCE) research and practice, there is no consensus on the best strategies for CCE. In this paper, the authors identify various dimensions of CCE-related strategies and offer a practical model to assist policy-makers, practitioners and researchers. Identified reviews show that although there is a significant body of research on CCE, the development of the field is hindered by a lack of evidence relating to specific elements of CCE.

They also indicate a diverse and growing enterprise, drawing on a wide range of disciplinary, political and philosophical perspectives and a mix of definitions, targets, approaches, strategies and mechanisms. CCE interventions and strategies aim to involve consumers, community members and the public in general, as well as specific sub-groups, including children and people from culturally and linguistically diverse backgrounds. Strategies for CCE vary in terms of their aim and type of proposed activity, as do the methods and tools which have been developed to support them. Methods and tools include shared decision making, use of decision aids, consumer representation, application of electronic and internet-based facilities, and peer support. The success of CCE is dependent on both the approach taken and contextual factors, including structural facilitators such as governmental support, as well as barriers such as costs, organisational culture and population-specific limitations.

CITIZEN PARTICIPATION AND DISCONTENT IN THREE SOUTHERN EUROPEAN HEALTH SYSTEMS

Mauro Serapioni and Ana Raquel Matos

The health systems of the countries considered in this analysis – Italy, Portugal and Spain – underwent reforms that brought citizen participation to the forefront of the health system. Through national laws or health plans, each of these countries has recognised the need to promote participation in order to 'give a voice' to citizens in the health sector. Accordingly, a range of significant activities have been implemented in the region, although they have been developed unequally within national territories, at different paces and involving the mobilisation of different actors. This article focuses on the most relevant experiences of citizen participation designed and implemented in the three selected countries, describing their key features and potential, as well as the main critical issues and contradictions that have emerged over time. Particular emphasis is given to the impact of the current financial crisis on Southern European national health systems, especially in terms of participatory methods, the way in which citizen participation is progressing and civil society's reaction to these important changes

THE USE OF CITIZENS' JURIES IN HEALTH POLICY DECISION-MAKING: A SYSTEMATIC REVIEW

Jackie Street, Katherine Duszynski, Stephanie Krawczyk, Annette Braunack-Mayer

This study used Medline (PubMED), CINAHL and Scopus databases to identify deliberative inclusive methods, particularly citizens' juries and their adaptations, deployed in health research. Identified studies were evaluated focussing on principles associated with deliberative democracy: inclusivity, deliberation and active citizenship. The review demonstrated that the citizens' jury model has been extensively adapted. Inclusivity has been operationalised with sampling strategies that aim to recruit representative juries, although these efforts have produced mixed results. Deliberation has been supported through use of steering committees and facilitators to promote fair interaction between jurors. Many juries were shorter duration than originally recommended, limiting opportunity for

constructive dialogue. With respect to citizenship, few juries' rulings were considered by decision-making bodies thereby limiting transfer into policy and practice.

CONSUMER INVOLVEMENT IN TOPIC AND OUTCOME SELECTION IN THE DEVELOPMENT OF CLINICAL PRACTICE GUIDELINES

Allison Tong, Pamela Lopez-Vargas, Martin Howell, Richard Phoon, David Johnson,, Denise Campbell, Rowan G Walker, and Jonathan C Craig

This study aims to describe a targeted approach for involving consumers actively in guideline development, by focusing on topic and outcome selection, and to discuss the impact on content and structure of the final guideline. The participants actively engaged in the workshop discussions and articulated topics and outcomes they perceived should be included in clinical guidelines. Four main changes to guideline-related outputs were observed. A new guideline subtopic was introduced, guidelines were consumer-endorsed, guideline recommendations and suggestions for clinical care were augmented with consumer-focused issues, and plain English guidelines were developed. The study's conclusions were that consumer workshops in parallel and feeding into guideline development can be a feasible and effective approach for active consumer contribution. This process can inform the development of both consumer-focused guidelines for clinicians and specific versions for consumers.

EUROPEAN LEAGUE AGAINST RHEUMATISM RECOMMENDATIONS FOR THE INCLUSION OF PATIENT REPRESENTATIVES IN SCIENTIFIC PROJECTS

M P T de Wit, S E Berlo, G J Aanerud, D Aletaha, J W Bijlsma, L Croucher, J A P Da Silva, B Glüsing, L Gossec, S Hewlett, M Jongkees, D Magnusson, M Scholte-Voshaar, P Richards, C Ziegler, T A Abma

This article describes the development of recommendations to enable successful inclusion of the patient perspective in European League Against Rheumatism (EULAR)-funded scientific research projects. The project resulted in a definition of patient research partner and agreement on a set of eight recommendations for their involvement in research projects. These recommendations provide practical guidance for organising patient participation, capturing (1) the role of patient research partners, (2) phase of involvement, (3) the recommended number, (4) recruitment, (5) selection, (6) support, (7) training and (8) acknowledgement. The article concludes that collaboration between patients and professionals in research is relatively new. Trials or effectiveness studies are not yet available. Nevertheless, it is possible to define recommendations for the inclusion of patients in research following a solid expert opinion based consensus process.

LITERATURE REVIEW

The literature review aimed to identify and analyse relevant research published since 2010, with a preference given to papers that met the following criteria:

- Australian research
- Peer reviewed research
- Recent research
- Review articles and meta-analyses.

Databases/online libraries searched were:

Australian theses
Australasian Digital Theses

http://www.caul.edu.au/caul-programs/australasian-digital-theses/finding-theses

Closing the Gap Clearinghouse
Indigenous health
www.aihw.gov.au/closingthegap/

Cochrane Library
Specifically:
- Cochrane Database of Systematic Reviews
- DARE (Database of Abstracts of Reviews of Effects)
- Methodology Register

http://www.thecochranelibrary.com/view/0/index.html

DART-Europe
European research theses

http://www.dart-europe.eu/basic-search.php

Grey Literature Report
Grey literature publications in public health and links to the full-text.

http://www.nyam.org/library/pages/grey_literature_report

Health Evidence Network
HEN (produced by WHO) lists their Evidence reports which are syntheses of the best available evidence in response to policy-makers' questions.

http://www.euro.who.int/en/what-we-do/data-and-evidence/health-evidence-network-hen

MEDLINE/PUBMED

The U.S. National Library of Medicine's (NLM) bibliographic database covering the fields of medicine, nursing, dentistry, veterinary medicine, the health care system, and the preclinical sciences.
http://www.ncbi.nlm.nih.gov/pubmed

Networked Digital Library of Theses & Dissertations
Dissertations and theses from hundreds of universities worldwide.

http://www.ndltd.org/

NHS Evidence in Health and Social Care
NHS Evidence is managed by the National Institute for Health and Clinical Excellence (NICE). It provides an excellent source of quality and evidence-based materials.

http://www.evidence.nhs.uk/

Oxford University Press Journals
Search across over 150 full-text journals including a number from health sciences and medicine.
http://services.oxfordjournals.org/search.dtl

PLOS Medicine

PLOS Medicine provides an open-access venue for peer-reviewed advances in medicine and health care. http://journals.plos.org/plosmedicine/

Science Direct

A full-text scientific database offering journal articles and book chapters from nearly 2,500 journals and 26,000 books. http://www.sciencedirect.com/

WHOLIS
World Health Organisation Library database, WHOLIS, indexes all WHO publications from 1948 onwards and articles from WHO-produced journals and technical documents from 1985 to the present.

http://dosei.who.int/uhtbin/cgisirsi/Wed+Nov+22+03:11:10+MET+2006/0/49

Wiley Online Library

Wiley Online Library provides access to journal content in a variety of disciplines in both the hard and social sciences. The service provides full- text access to over 4 million articles across 1900 journals as well as searchable contents listings, abstracts and related Web sites.
http://onlinelibrary.wiley.com/cochranelibrary/search/

Boolean searches were conducted of these databases using the following key words:

- Citizen involvement/participation
- Consumer advisory committees
- Consumer involvement/participation

- Consumer representatives
- Health research
- Health policy
- Health reform
- Health boards
- Health-care decision making
- Health authorities
- Methodology
- Priority setting
- Regional health authorities
- Regional health planning

Due to time and resource constraints, the literature review was limited to material available electronically without cost (other than ongoing subscriptions to databases, where applicable).

INTERNATIONAL EXAMPLES

International examples of recent developments in consumer engagement were identified through the research component of the project as well as through discussions with CHF staff and the consumer experts interviewed.   Key policy documents from the main countries identified, the UK, New Zealand and the USA, were reviewed along with relevant research on the implementation of consumer engagement strategies in these countries.

CONSUMER INTERVIEWS

Semi-structured interviews were conducted with six consumer representatives about their experiences representing consumers on health-related organisations and boards. The consumers interviewed were:

- Melissa Cadzow
- Jan Donovan
- Henry Ko
- Alison Marcus
- Cindy Schultz-Ferguson
- Christine Walker

CHF CONSUMER REPRESENTATIVES PROGRAM

The six interviewees are participants in the CHF Consumer Representatives Program, which sources consumer representatives for around 200 national health-related committees and working groups across the health sector.

The aims of the Consumer Representatives Program are:

- to provide a means of optimising the participation of consumer and community groups in national policy, planning and service decisions which affect the health of consumers; and
- to promote the rights of all consumers to be involved in health policy, planning and service decisions.

The CHF Consumer Representatives Program nominates and supports consumer representatives for national health-related committees. This includes:

- nominating consumer representatives who can promote consumer views to national health committees;
- providing advice and assistance to CHF-nominated consumer representatives;
- encouraging CHF-nominated consumer representatives to provide regular reports to health consumer organisations on the work of the committees on which they sit;
- providing resources and workshop opportunities for CHF consumer representatives (subject to funding limitations); and
- identifying committees that should have consumer representatives, so the representation can be encouraged.

APPENDIX B – KEY POLICY DOCUMENTS REVIEWED

AUSTRALIA

National Safety and Quality Health Service Standard 2: Partnering with Consumers

The Australian Commission on Safety and Quality in Health Care

http://www.safetyandquality.gov.au/our-work/patient-and-consumer-centred-care/national-safety-and-quality-health-service-standard-2-partnering-with-consumers/

Partnering with Patients program

NSW Clinical Excellence Commission

http://www.cec.health.nsw.gov.au/programs/partnering-with-patients

Guide for Engaging with Consumers and the Community

A practical toolkit to assist health care services to implement a Framework for Active Partnership with Consumers and the Community 2013

http://www.sahealth.sa.gov.au/wps/wcm/connect/f8d1d0004e454788aa0caf8ba24f3db9/Guideline_Engaging+with+Consumers+and+Community_Aug2013.pdf?MOD=AJPERES&CACHEID=f8d1d0004e454788aa0caf8ba24f3db9

NEW ZEALAND

Partners in Care Framework – updated post feedback July 2012

http://www.hqsc.govt.nz/assets/Consumer-Engagement/Publications/Post-Feedback-Update-of-PIC-Framework-July-2012.pdf

UK

An inquiry into patient centred care in the 21st century

Report of an independent inquiry commissioned by the Royal College of General Practitioners

November 2014

http://www.rcgp.org.uk/policy/rcgp-policy-areas/~/media/Files/Policy/A-Z-policy/RCGP-Inquiry-into-Patient-Centred-Care-in-the-21st-Century.ashx

Equity and excellence: Liberating the NHS

Presented to Parliament by the Secretary of State for Health by Command of Her Majesty

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213823/dh_117794.pdf

People in control of their own health and care: the state of involvement

Catherine Foot, Helen Gilburt, Phoebe Dunn, Joni Jabbal, Becky Seale, Joanna Goodrich, David Buck, Jeremy Taylor

The King's Fund

http://www.kingsfund.org.uk/publications/people-control-their-own-health-and-care

Hard Truths: The Journey to Putting Patients First

Volume One of the Government Response to the Mid Staffordshire

NHS Foundation Trust Public Inquiry

January 2014

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/270368/34658_Cm_8777_Vol_1_accessible.pdf

USA

Key Features of the Affordable Care Act

US Department of Health and Human Services

http://www.hhs.gov/healthcare/facts/timeline/index.html

US Department of Health and Human Services

Strategic Plan

Strategic Goal 1: Strengthen Health Care

http://www.hhs.gov/strategic-plan/goal1.html