

Consumer engagement critical to success in an Australian research project: reflections from those involved

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Abstract. This paper describes the people, activities and methods of consumer engagement in a complex research project, and reflects on the influence this had on the research and people involved, and enablers and challenges of engagement. The 2.5-year Integrating and Deriving Evidence Experiences and Preferences (IN-DEEP) study was conducted to develop online consumer summaries of multiple sclerosis (MS) treatment evidence in partnership with a three-member consumer advisory group. Engagement methods included 6-monthly face-to-face meetings and email contact. Advisory group members were active in planning, conduct and dissemination and translational phases of the research. Engaging consumers in this way improved the quality of the research process and outputs by: being more responsive to, and reflective of, the experiences of Australians with MS; expanding the research reach and depth; and improving the researchers' capacity to manage study challenges. Advisory group members found contributing their expertise to MS research satisfying and empowering, whereas researchers gained confidence in the research direction. Managing the unpredictability of MS was a substantive challenge; the key enabler was the 'brokering role' of the researcher based at an MS organisation. Meaningfully engaging consumers with a range of skills, experiences and networks can make important and unforeseen contributions to research success.

Additional keywords: consumer participation, multiple sclerosis, online health information, patient and public involvement, research involvement.

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Introduction

The rationale for active participation of patients, carers and members of the public ('consumers') in their care and in shaping health services and systems more broadly is well-established (Sarrami-Foroushani *et al.* 2014b). Similarly, consumer involvement in preparatory, execution and translational phases of health research (Shippee *et al.* 2015) is increasingly expected by consumers, researchers and funders (Canadian Institutes of Health Research 2014; National Health and Medical Research Council and Consumers Health Forum of Australia 2016;

National Institute for Health Research, see <http://www.nets.nihr.ac.uk/ppi>, accessed 8 February 2018). Consumers have an increasingly accepted right to engagement in health research (INVOLVE 2012) and this may lead to improved research quality and relevance (Brett *et al.* 2014a, 2014b), and ultimately better health outcomes.

Guidance supporting meaningful collaboration between researchers and consumers exists (INVOLVE 2012; IAP2 Australasia 2015), but wide variation in reported approaches and experiences (Sarrami-Foroushani *et al.* 2014a) leads to

What is known about the topic?

- Consumer engagement in research is increasingly expected and desired by consumers, researchers and research funders, but limited reporting hinders replication of good practice, shared learnings or building expertise.

What does this paper add?

- This description highlights how engaging consumers with skills, expertise and networks in research can contribute to success in a range of important and unforeseen ways.

uncertainty about best practices (Shippee *et al.* 2015; Ocloo and Matthews 2016). Researchers are criticised for predominantly engaging consumers in development activities, or favouring consultation only, rather than in core decisions and activities throughout the research cycle (Lawn 2016; Ocloo and Matthews 2016). Variations in terminology and conceptualisations (Shippee *et al.* 2015), contested definitions of ‘consumer’ (Maguire and Britten 2017) and limited practice reporting (Staniszewska *et al.* 2011; Boote *et al.* 2015) compound uncertainties. Recent reports focused on quantifying consumer engagement effects in research (Brett *et al.* 2014a, 2014b), but limited descriptions of actual processes hinder replication, shared learning and expertise building (Staniszewska *et al.* 2011).

In Australia, the National Health and Medical Research Council expects funding proposals to include consumer engagement plans, and outlines a partnership approach in their revised joint statement with Consumers Health Forum of Australia (National Health and Medical Research Council and Consumers Health Forum of Australia 2016). However, meaningful consumer engagement, including strategic influence over decisions, by Australian researchers (Lawn 2016), research organisations (Saunders and Girgis 2010) and funders (Nasser *et al.* 2017; Saunders and Girgis 2010) remains inconsistent. Evidence of consumer engagement benefitting Australian organisations and researchers could motivate improvement (Lawn 2016; Saunders and Girgis 2010).

We therefore aimed to describe the people, activities and methods of consumer engagement in a complex Australian health research project, and to reflect on the influence this had on the research and people involved, and the enablers and challenges of engagement. We write from researcher and consumer perspectives. Our reporting is informed by relevant frameworks and guidelines (Concannon *et al.* 2014; Staniszewska *et al.* 2017).

Context*The IN-DEEP study*

The Integrating and Deriving Evidence Experiences and Preferences (IN-DEEP) study was a 2.5-year mixed-methods study involving researchers, consumers and non-government organisation staff, conducted in parallel in Australia and Italy. Here we describe the Australian experience only. The IN-DEEP study built upon a qualitative inquiry into multiple sclerosis (MS) treatment information-seeking by people affected by MS

(meaning people with MS and their families or carers) to inform online consumer summaries of MS treatment evidence from Cochrane Reviews (Hill *et al.* 2012; Synnot *et al.* 2016, 2018). The study involved three formal research stages with >100 participants affected by MS: (1) focus groups and an online forum; (2) face-to-face review panels and online pilot testing of early website materials; and (3) online website evaluation survey (Table 1). The funding application was developed with MS Australia clinical and leadership staff, but without formal consumer input. This application included formation of a consumer advisory group before project commencement.

Engagement aim, conceptualisation and definitions

The aim of engaging consumers was to improve the relevance of the IN-DEEP study’s outputs to Australians with MS. The researchers envisaged this would include provision of strategic advice about key study aspects. In reality, we worked as partners throughout the research.

We use ‘consumers’ to include people with lived experience of a health condition or service, and their supporters, carers, advocates, representatives, including organisational representatives; for example, people from patient or consumer groups (National Health and Medical Research Council and Consumers Health Forum of Australia 2016). The researchers view engagement as a ‘bi-directional relationship between stakeholders and researchers resulting in informed decision-making about selection, conduct, and use of the research’ (Concannon *et al.* 2012, p. 986). Implicit in this approach were principles of co-production, including respect and equality, recognising people as knowledgeable assets, seeking mutually beneficial relationships and blurring boundaries between ‘professionals’ and ‘stakeholders’ to enable shared control and responsibility (Heaton *et al.* 2016).

People involved*Recruitment of the advisory group*

The researchers sought to include people affected by MS (both genders, different MS types) having some familiarity with research and connection with the broader MS community. M. P. Summers a research team-member who worked at MS Australia (a national advocacy and support organisation for Australians with MS), provided recruitment advice, drawing on his networks. After discussion, an information specialist working in a state-based MS organisation who spoke daily with people affected by MS about their information needs was also invited. Four consumers were approached by M. P. Summers (all accepted the invitation), with this number felt sufficient for meaningful interaction while still providing opportunity for all to contribute. Researchers emailed study information, and offered further explanation in a follow-up phone call about the investigators and their history, the type of input sought and expected time commitment.

Description of advisory group members and researchers

The advisory group included three women (C. L. Cherry, R. Stuckey and C. A. Milne); two with MS and one information specialist. One man with MS attended an early meeting but was unable to continue. The women with MS had different disease

Table 1. Detailed consumer advisory group member engagement activities and methods of engagement, mapped against research stages and phases
IN-DEEP, Integrating and Deriving Evidence Experiences and Preferences; MS, multiple sclerosis

IN-DEEP Study Stage (number of participants)	Research phase	Advisory group activities	Methods of engagement used
1. Focus groups and online forum to explore MS treatment information-seeking (<i>n</i> = 60 people affected by MS)	Planning	Input into focus group questions and structure	Face-to-face meeting, where proposed focus group approach was presented and feedback sought.
	Conduct	Suggested networks for recruitment	Suggestions sought over email, with request to forward on the e-invitation to others.
	Dissemination and translation	Provided advice on implications of findings for Stages 2 and 3	Face-to-face meeting using facilitated discussion (each person individually invited to provide reflections and advice). Provisional focus group results (thematic analysis) were emailed 1 week in advance.
2. Face-to-face review panels followed by online pilot testing, reviewing templates for online summaries of Cochrane Reviews of MS treatments (<i>n</i> = 25 people affected by MS, health professionals and MS Australia staff)	Planning	Prioritised which reviews to include on website	Emailled list of potential reviews, along with proposed criteria for selecting reviews. Invited to comment on appropriateness of proposed criteria, and nominate up to 10 reviews for the website.
	Conduct	Reviewed and revised early website testing materials	Face-to-face meeting, using facilitated discussion to seek feedback and revisions from each person individually, followed by group discussion. Provisional website structure and materials were circulated 1 week in advance over email.
	Dissemination and translation	Reviewed and edited website documents after review panels with participants	Face-to-face meeting, in which the results of the review panels and a list of proposed changes were presented to the group, followed by facilitated discussion. All documents were circulated 1 week in advance over email. Additional <i>ad hoc</i> input sought over email, for advice about how best to report or describe specific aspects of the website material.
	Planning	Reviewed evaluation questions	Draft questions provided over email, and feedback invited.
3. Online website evaluation survey (<i>n</i> = 58 people affected by MS and health professionals)	Conduct	Suggested networks for recruitment	Suggestions sought over email, with request to forward on e-invitation to others.
	Dissemination and translation	Spoke at website launch	One advisory group member (C. L. Cherry) spoke about her experiences of being involved in the study at the launch held at the MS Australia offices.
		Disseminated website to networks Co-authored journal article Discussed ideas for future research	Emailled promotional materials and invited to forward on to networks, including by social media. Emailled an early outline and pre-final drafts of manuscripts for comment and contribution. Face-to-face meeting, free discussion of ideas for possible future research projects that could be developed into funding proposals.

types, and had lived with MS for >10 years. Both had healthcare and academic backgrounds. One was currently active on the state-based MS organisation community advisory board; a role including monthly meetings with people with MS of different genders, educational backgrounds and disability levels, involvement in online and face-to-face peer support groups, and management of a Facebook page used by >2000 people affected by MS. The other consumer has represented people with MS for over 30 years; including 12 years as a consumer member of the Victorian MS Board, active involvement in projects working with people with MS to improve service provision, and in projects developing participative mechanisms specifically designed to give consumers with MS a voice. The information specialist was employed at MS Limited (MSL; a combined entity of several state-based MS organisations). She was involved in the public information line and co-authored research briefings for clinical staff and publications for consumers.

S. J. Hill led the research team with a co-investigator at MS Australia (M. P. Summers) and research officer (A. J. Synnot). Both S. J. Hill and M. P. Summers have extensive experience working with consumers in research, advocacy and service roles.

How we worked together

The advisory group and researchers met face-to-face as one of the first activities. Meetings occurred at Melbourne MSL offices, which were accessible to members. The advisory group's role was discussed upfront and agreed to be providing advice on key aspects of MS, MS treatment information-seeking, and on living, or caring for, people with MS. Over time, the advisory group's contribution expanded organically, and members contributed to all stages of the IN-DEEP study's planning, conduct, dissemination and translation (Table 1). Below is a summary of engagement methods used and advisory member activities.

Methods of engagement

Face-to-face meetings (interstate member joining by phone) were held approximately 6-monthly (Table 1). Timing of meetings was not pre-specified, but corresponded to key study decision points needing formal input. Additional *ad hoc* email input and discussions occurred between meetings. Before meetings, advisory group members were sent an agenda, including areas needing feedback, and written materials to facilitate preparation. We used an informal small group discussion structure, with researchers ensuring each person had opportunities to provide reflections and advice. Decisions made were recorded and reported back to advisory group and research team members in Australia and Italy.

Advisory group activities

Advisory group members were involved in planning phases of each study stage, including helping shape questions for focus group participants and prioritising Cochrane Review topics for the website (Table 1). They were also involved in conduct of the research; for example, suggesting networks for participant recruitment, commenting on provisional data analysis and reviewing planned website materials. During dissemination and translation phases, advisory group members helped interpret how results should be incorporated into subsequent IN-DEEP

study stages, or potential future projects, and participated in dissemination activities, including speaking at the website launch and co-authoring journal articles.

How advisory group members influenced the research

The IN-DEEP study's consumer advisory group improved the quality of research conduct and outputs in several ways. First, study conduct was more responsive to, and reflective of, the needs and experiences of Australians with MS. For example, based on advisory group members' recommendation, in stage 1 we held separate focus groups for newly diagnosed people, those living with MS for longer and family members, to account for potential participant sensitivities. We used 'family members' instead of 'carers' in project materials (as people, including partners of those with MS, may not identify as 'carers') and held meetings at local MS organisations based on advice about optimal physical accessibility. Thus, the researchers were 'primed' to potential participant needs and able to engage more sensitively throughout. This also flowed into research outputs. Asking advisory members to prioritise Cochrane Review topics for the website based on their likely use or interest to Australians ensured topics were relevant to an Australian audience. Their advice about framing and wording of Cochrane Review results enabled more sensitive interpretations and explanations of evidence. An example is amending wording describing interferon side-effects. The original wording, 'The potential side effects of Interferons are mild and treatable' was described as inaccurate and potentially alienating for some people with MS. After discussion, this was changed to, 'most interferon side effects are mild and can often be relieved with symptomatic treatments, without the need to stop taking them.'

Second, consumer advisory group engagement expanded research reach and depth. By suggesting networks, groups and individuals to approach for recruitment, collaboration or promotion, we reached otherwise inaccessible (to us) people with MS. In addition, advisory group members could 'fill in the gaps' with groups under-represented in focus group sampling. For example, the researchers did not seek to recruit participants whose first language was not English, but could draw indirectly upon their experiences from C. A. Milne's involvement with a phone service this group uses. All advisory group members could draw on experiences supporting or working with people with greater MS-related disability. Further, by discussing results of each study stage, researchers deepened their understanding and interpretation of data. For example, after reviewing focus group thematic analyses, advisory group members noted findings resonated with their experiences or those of people they knew (adding credibility) and offered some explanations for emerging themes.

Finally, advisory group members and researchers together had enhanced capacity to mitigate or address situations or issues arising during the study. The controversy associated with treatment for 'Chronic Cerebro Spinal Venous Insufficiency' (CCSVI) (Friedemann and Wattjes 2014) arose during the study. The academic backgrounds of advisory members with MS meant they understood the limitations of emerging research on CCSVI and could advise on how researchers might approach this issue, including responding to any study participants' questions about

why the IN-DEEP study's resulting website could not include treatments for CCSVI. In addition, the advisory group provided substantial input into wording used to clearly communicate scientific concepts, including randomisation and confidence intervals and suggested wording to explain why Cochrane Reviews rarely offer definitive conclusions.

Benefits of working together

For advisory group members, the key benefit was making a valued contribution to research that would assist the MS community, drawing upon their personal experiences or years of talking to people with MS. For example, C. L. Cherry felt the researchers had a genuine desire to produce something of benefit to the MS community, and that aiming to produce a resource that was practical and useful but also evidence-based was a great achievement. C. A. Milne was delighted this research was even happening and found the opportunity to be involved was 'just amazing'. Having spent years talking to people with MS and their families about research and treatment options and working with people one-to-one, she was pleased to have an opportunity to share the knowledge and wisdom she gained from those myriad conversations. R. Stuckey felt it was particularly important she could share the experiences of people who would not have the confidence or opportunity to participate in research themselves.

Advisory group members also felt valued, empowered and satisfied. R. Stuckey found it empowering to draw on often difficult previous personal experiences, challenges and disappointments to provide useful, constructive input to others. She found combining personal experience and professional expertise to inform and enrich the work very satisfying. C. L. Cherry felt her research background was respected (and used, where appropriate), and networks she had access to through MS Advisory Council involvement were also respected and appropriately used. Seemingly small things, such as involvement by advisory group members in the website launch and presentation, made involvement seem valued and not token.

For researchers, the collaboration gave them increased confidence in the need for, and approach taken, when dealing with a challenging study that had some sensitivities. For example, providing Cochrane reviews directly to people affected by MS remained somewhat controversial throughout the research, with debate regarding potential confusion for people reading about systematic review evidence uncertainty compared with the seemingly conclusive single-trial-based treatment information. The researchers were sometimes concerned their idealism to share research-based treatment information was a 'researcher aim' and not necessarily relevant for people facing decision-making dilemmas in the 'real world'. Regular discussions with advisory group members provided a more balanced perspective and helped confirm researchers' view that aiming to share evidence was beneficial, even if it did not meet all of peoples' needs.

Challenges of engagement

For both researchers and advisory group members, the primary challenge was that MS is a chronic, disabling, unpredictable condition. This directly affected the group, with one member unable to continue past the first meeting. Subsequently, careful attention was paid by researchers to the physical needs of and

demands on members, including selecting meeting venues with adequate air conditioning (people with MS often experience heat sensitivity) and easy parking and access.

Enablers of engagement

A critical enabler was the brokering or boundary-spanning role played by M. P. Summers. The term 'knowledge broker' is more commonly used in evidence to policy and practice literature, meaning someone who can 'facilitate transactions and the flow of information between people or groups separated or hindered by some gap or barrier' (Long *et al.* 2013, p. 1). Such barriers can be geographical, organisational, cultural or related to a lack of trust or common understanding. Knowledge brokers are often individuals with experience of or familiarity with the perspective of the groups or individuals they are trying to bring together, who can mitigate conflict and engender trust and collaboration (Long *et al.* 2013). M. P. Summers' understanding of both research and MS 'worlds' and his MS community connections were integral to selection of advisory group members who could contribute to a complex, multi-component study. Additionally, his commitment to consumer engagement in research lent organisational support and facilitated fruitful working relationships between researchers and the advisory group, given he was known to, and trusted by, all three advisory group members before the project commenced.

An additional enabler was that the research budget included out-of-pocket expenses and meeting catering. Advisory group members perceived a final celebratory dinner and collaboration on publications as demonstrations their input was valued.

Discussion

We describe how Australian consumers and researchers collaborated on a range of activities, and in diverse ways, throughout a complex research project. What was conceived as consultation, quickly evolved into co-production (Heaton *et al.* 2016). Consumer engagement improved the quality of research process and outputs, and brought important and unanticipated benefits to advisory group members and researchers alike.

Many of the benefits we describe, for the research and those involved, are consistent with previous reports. For example, Brett *et al.* (2014a) found engaging consumers can improve the appropriateness and wording of research instruments, assist with recruitment, help researchers gain a deeper understanding of the issues under investigation, ensure emerging themes and trends are interpreted from the consumer perspective, fill in knowledge gaps and ground final reports or other dissemination in user experience. Similarly, the most commonly cited benefits of engagement for consumers are feeling listened to, empowered and valued and being able to give something back and make a meaningful contribution to research (Brett *et al.* 2014b). Finally, our primary benefit for researchers (gaining confidence in the research direction) is what Dudley *et al.* (2015) refer to as a 'diffuse impact' of consumers and researchers working as a team on a research study.

Our findings diverge from published reports in two areas: we had a greater capacity to mitigate project challenges by engaging consumers and we describe so few challenges of the engagement itself. Commonly cited engagement challenges include frustrations about the time involved (for consumers and

researchers), insufficient training in consumer engagement (for researchers), unclear roles and expectations (for consumers) and difficulty finding the right people (for researchers) (Buck *et al.* 2014; Domecq *et al.* 2014; Forsythe *et al.* 2016; Shen *et al.* 2017). Our capacity to solve strategic challenges may reflect the researcher and health professional backgrounds of two consumer advisory members. This may also explain the low number of engagement-related challenges encountered, given many commonly cited negative effects of consumer engagement are underpinned by misunderstandings, mismatched expectations or tensions between academic and consumer perspectives (Brett *et al.* 2014b). Additionally, the context in which engagement takes place, in which consumers feel valued and in an equal partnership with researchers (as in this study), is an important mediating factor for positive effects (Brett *et al.* 2014b; Dudley *et al.* 2015).

Given critiques and current gaps in the literature, strengths of this work include that we outline our conceptualisation, definitions and purpose of engagement (Staniszewska *et al.* 2017), describe engagement across much of the research cycle (Concannon *et al.* 2014), including the underreported stages of data analysis (Shippee *et al.* 2015) and interpretation (Concannon *et al.* 2014), and focus on processes used to elicit and integrate consumer and researcher expertise and knowledge (Edelman and Barron 2016). Sufficient detail about engagement context and approach is important to replicate practice and assess the transferability of approaches used to different settings (Staley *et al.* 2014).

The nature of 'representativeness' in consumer engagement, and who can legitimately represent diverse or 'voiceless' individuals and groups, is contested (Maguire and Britten 2017). As such, the purposive selection of highly research- and health-literate consumers as advisory group members could be perceived as a shortcoming (Ocloo and Matthews 2016). Yet, critical to the benefits realised in this study were advisory group members' ability to engage meaningfully and advocate effectively (Cancer Australia and Cancer Voices Australia 2011) for people affected by MS. They achieved this by contributing personal experiences, drawing upon experiences of others (Cancer Australia and Cancer Voices Australia 2011) and using their professional skills (Maguire and Britten 2017). Further, a more diverse range of 'lay' perspectives were included in the IN-DEEP study through participation of 100 people affected by MS across study stages.

The knowledge brokering or boundary spanning (Long *et al.* 2013) role of one researcher was an important enabler of engagement. Equally important were the consumers themselves; three people with the requisite skills, experiences, commitment and networks (Cancer Australia and Cancer Voices Australia 2011) to contribute meaningfully. We contend that the people affected by MS in the group also acted as knowledge brokers. With their professional experience in health care and academia, they could understand both MS and research 'worlds' and act as conduits (Maguire and Britten 2017) or 'interpreters' of information and ideas.

Conflicts of interest

The authors declare that they have no conflicts of interest.

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