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ORIGINAL PRACTICE DEVELOPMENT AND RESEARCH PAPER

An innovative toolkit: increasing the role and value of patient and public involvement in the dissemination of research findings

Elaine McNichol* and Paul Grimshaw

*Corresponding author: University of Leeds, UK
Email: e.mcnichol@leeds.ac.uk

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Abstract

Background: Evidence of patient and public involvement (PPI) in health research dissemination is weak and the development of mechanisms to assist the adoption and diffusion of PPI outcomes into research findings, patient experience and clinical practice is at an early stage.

Aim: This paper seeks directly to address this weakness by increasing researchers' awareness and understanding of the potential value of PPI in dissemination and identifying practical strategies that could improve the quality and impact of PPI by connecting the process with the wider innovation literature on adoption and diffusion.

The toolkit: Guidance for these strategies is provided in the form of a toolkit that elevates the importance of PPI in dissemination of research and blends it with good practice in diffusion of innovations. It highlights how planning for PPI and dissemination at each stage of the research cycle facilitates the diffusion of research findings, while generating a culture of knowledge exchange with important stakeholders.

Conclusions: Establishing and improving PPI dissemination in the research process has similarities with introducing any new innovation into a social context. Therefore, understanding and integrating insights from the literature on adoption and diffusion and linking them to PPI and the research cycle provides a different frame of reference for developing our approach in healthcare. Here we connect PPI to the adoption literature and suggest that a strong focus on the social nature of innovation will increase the reach and impact of research dissemination. This challenges the traditional research culture and suggests a need for a more open and continuous web of PPI relationships that are characterised by well balanced, timely contact and consist of appropriate and flexible interactions, planned into the whole research cycle.

Implications for practice: This paper highlights the value of taking a structured approach to PPI and the importance of investing time in developing productive PPI relationships at the beginning of a project. Similarly, dissemination should be planned for and undertaken at key points and in different ways throughout the process in order to maximise its potential impact. The key implications are the value of:

- Widening the scope of PPI dissemination into the whole research cycle
- Opening up routes to improved research impact through better quality patient involvement
- Challenging the stereotypical relationship between researcher and patient
- Introducing innovation adoption concepts into PPI dissemination

Keywords: Patient and public involvement, dissemination of research, innovation, adoption, relationships, toolkit

Introduction: contextual basis and theoretical underpinning

The aim of this paper is to establish a toolkit using an evidence base of what is known to be good practice from the literature on adoption and diffusion of innovations, and apply this to patient and public involvement (PPI) in research dissemination. The idea is to demonstrate the value of connecting knowledge from the literature to increase the effective use of PPI in dissemination. This is done by first presenting a short review of current research on PPI in research and specifically in dissemination. We then introduce innovation concepts from the management literature and apply this creatively to the PPI experience and healthcare research literature to help build a toolkit for the PPI research cycle.

The current literature on PPI focuses on a number of key areas:

- The general merits of the role of PPI in research
- The question 'what is the impact of PPI on UK NHS healthcare?' (Mockford et al., 2012), the bias in the healthcare literature towards a qualitative discussion of this question and a general lack of robust supporting evidence (Boote et al., 2012)
- The need for more work to understand the value and impact of PPI on the nature and quality of research

There is relatively little discussion about the role of PPI in the dissemination part of the research cycle. Given the growing need to improve the impact of research in general, it is important that researchers have a range of contextually useful tools for the process of exchanging important research outputs. Here we seek to provide a toolkit developed through experience of PPI in research, which draws on innovation adoption concepts and connects them specifically to PPI in dissemination throughout the whole research cycle as opposed to at a single stage labelled 'dissemination'. Such a toolkit has the potential to give researchers and the users of research greater confidence in the quality of their dissemination strategies and therefore in the potential impact of their findings on all relevant stakeholders.

PPI research background

Public involvement in research is supported by three key pillars: knowledge, rights and quality (Boote et al., 2002). The knowledge and experience of patients can improve research – patients have a right to be involved in any health intervention that may affect them, and user/patient involvement can improve the quality and impact of healthcare (INVOLVE, 2014). Here, we focus on developing mechanisms to address the second of those points. There has been growing evidence for some time that PPI is changing service provision (Crawford et al., 2002; Barello et al., 2012), affecting research aims and methods (Staniszewska et al., 2007) and enhancing research and research question formation (Brett et al., 2010; Boote et al., 2012). PPI should also provide research that is more refined for users and, in theory, result in better utility. However, reviews of the evidence on PPI interventions fail to indicate a sustained increase in quality of healthcare outcomes (Brett et al., 2010; Staniszewska et al., 2011a; Shippee et al., 2013). Crawford et al. (2002) suggest that this lack of evidence may be in part due to the ethical imperative of introducing PPI as a way of engaging service users rather than driving healthcare improvements. A more critical viewpoint may be that PPI can be perceived as a way of legitimising administrative and policy decisions rather than handing power to patients (Crawford et al., 2002). Researchers may also have contributed to the lack of empirical evidence by tending to seek PPI on mainly qualitative projects, even though it is equally pertinent to quantitative research (Boote et al., 2012). The nature and degree of PPI should be determined by the needs of the project and can vary from occasional consultation at different stages of the research cycle (INVOLVE, 2014) through to having a co-investigator or lead investigator who is actively involved in data collection and analysis.

There is currently little in the way of economic evidence of the impact of PPI (Mockford et al., 2012) and the quality of reporting its impact is low (Mockford et al., 2012; Staniszewska et al., 2011a). This could be due to a number of factors:

- There is often a time-lag between intervention and any outcomes (Crawford et al., 2002)
- The impact of lay people can become entangled with that of professionals (Iliffe et al., 2011)

- PPI lacks conceptual clarity (Staniszewska et al., 2011a; Mockford et al., 2012)
- Research studies and mechanisms are not being designed to collect useful data on user impact (Rutter et al., 2004; Stewart et al., 2011)

Further, Staniszewska et al. (2011a) report high variability in the reporting of impact and little rigour or formality in its evaluation. A lack of focus on negative impact is also reported (Brett et al., 2010; Staniszewska et al., 2011a). The measurement of impact is influenced by the perspective of the researchers and the audience so the search for rigorous quantitative assessment is complex and elusive (Staniszewska et al., 2011b; Barber et al., 2012). The main focus of reporting of PPI is its impact on question identification (Boote et al., 2012) and not on routine practice (Boote et al., 2010). It may be that impact is undermined by a lack of awareness or attention to the practical aspects of establishing good quality PPI in research. These practicalities include ensuring there are sufficient resources for the range of expenses incurred through PPI activity and that adequate allowance is made in the project timeline for proper communication and involvement. The importance of researcher knowledge and skill for maximising the value and impact of PPI in research is recognised (Brett et al., 2010; Mockford et al., 2012) and has been addressed by INVOLVE (2014) through the publication of a set of documents. INVOLVE provides reports and guides for researchers to assist the understanding, development and delivery of PPI, as well as briefing notes and vignettes based on PPI case studies and narratives, and guidance to help evaluate impact. Much of this work is pragmatic and based on user experience, rather than being driven by theories that explicitly examine how the process of dissemination might be informed throughout the research cycle.

Boote et al. (2011) report that PPI can suffer due to time constraints set by stakeholders and the extra funding required to engage with patients. Evidence of impact on practice remains weak. For example, the main suggestion to emerge from a systematic review of the delivery and evaluation of mental health services (Simpson and House 2002) was that users can be engaged as active researchers or trainers of mental health professionals without detriment to service delivery. This is a rather narrow observation and a missed opportunity to assess whether user involvement added any value. Brett et al. (2010) suggest important impacts for researchers include improved research questions, suggestions for proposals and research gaps, improved cultural equivalence and better informed understanding of context. For engaged communities, the outcomes are better links and communication, which may promote the acceptance of interventions and provide growing support for research in sensitive areas. For example, the relationships PPI can introduce may be particularly helpful in refining research in fields such as neurodegenerative disease (Iliffe et al., 2011). Recruitment of peers by users is a particularly effective outcome of PPI (Staley, 2009). General success factors focus on: understanding and managing the stages of involvement, gauging the level of involvement, chosen research outcome methods (Boote et al., 2002) and careful management of communication and interaction, particularly in relation to minimising disparity of power and control between professionals and lay people (Boote et al., 2002; Staniszewska et al., 2011a). Daykin et al. (2007) report the need for structure and resources to enable partnership working, an understanding of politics and discourse to help establish user empowerment and avoid professionals dominating the agenda and outcomes, and management and understanding of the culture of the organisation and its relationships with users. In relation to the potential value of PPI in the dissemination and impact of research findings, Staley (2009, p 94) suggests that PPI ‘also helps to strengthen the power and persuasiveness of the results, making it more likely that other people will take action’.

Making links from PPI to innovation

As outlined above, there is a consensus around the difficulty of understanding and improving the impact of PPI on research and ultimately on practice or behaviour change. A number of ways forward have been suggested for improving PPI in dissemination, but concepts from elsewhere may help show how new technologies can be promulgated. If the perspective of Simpson and House (2003) is adopted, PPI can be conceptualised in the same way as other innovations. The method here was to consider

PPI in research dissemination as an innovation, and then to develop a toolkit by combining researcher, practitioner, patient, carer and public experience with feedback from PPI in a number of projects (leg ulcers, chronic pain and reflux) and from a university based PPI group with an established model of innovation. The toolkit would have a specific focus on dissemination and impact as an ongoing activity throughout each stage of the research cycle. The model illustrates how the research cycle can be considered in the light of PPI and innovation concepts, with a particular emphasis on dissemination – creating a PPI embedded approach to research dissemination.

Using Rogers' (2005) attributes to connect to PPI

Introducing innovation in healthcare is a complex and difficult process. Part of this difficulty arises from the existing organisational arrangement of healthcare settings as well as the problems of introducing disruptive innovations in general. These problems may be exacerbated in such settings, where the needs of the patient may be remote from the decision making process over adoption and diffusion of innovations (Hwang and Christensen, 2008). Though this may not be fully overcome there is potential in the PPI setting to establish patients as a source of improved innovation or research dissemination. Rogers' (1962; 1983; 2003) model of innovation is an established perspective based on the examination of more than 4,000 innovation studies (Abrahamson, 1991). The theory has been developed and used in healthcare as a way of examining the diffusion of innovation in a range of settings, such as telecare (Peeters et al., 2012), electronic innovations in primary care trusts (Carljford et al., 2010), telemedicine (Al-Qirim, 2007), health reforms (Rifat et al., 2007) and elderly support programmes (Bradley et al., 2004). Considered most often in the spread of technical innovations, there is an opportunity to apply Rogers' model (2003) to the dissemination of a new approach or philosophy of working, such as PPI. (Simpson and House, 2003). Rogers' model includes a number of important aspects; a major part of the theory concerns the diffusion of innovation throughout human populations via individual adoption. One of Rogers' insights was that all forms of innovation, from clothing to new products and management ideas, are disseminated through social groups at different rates ('early adopters' or 'laggards') and there are aspects of the innovation itself that will affect take-up. Rogers (2003) suggested a range of innovation attributes and surrounding social relations that determine the likelihood of adoption by individuals:

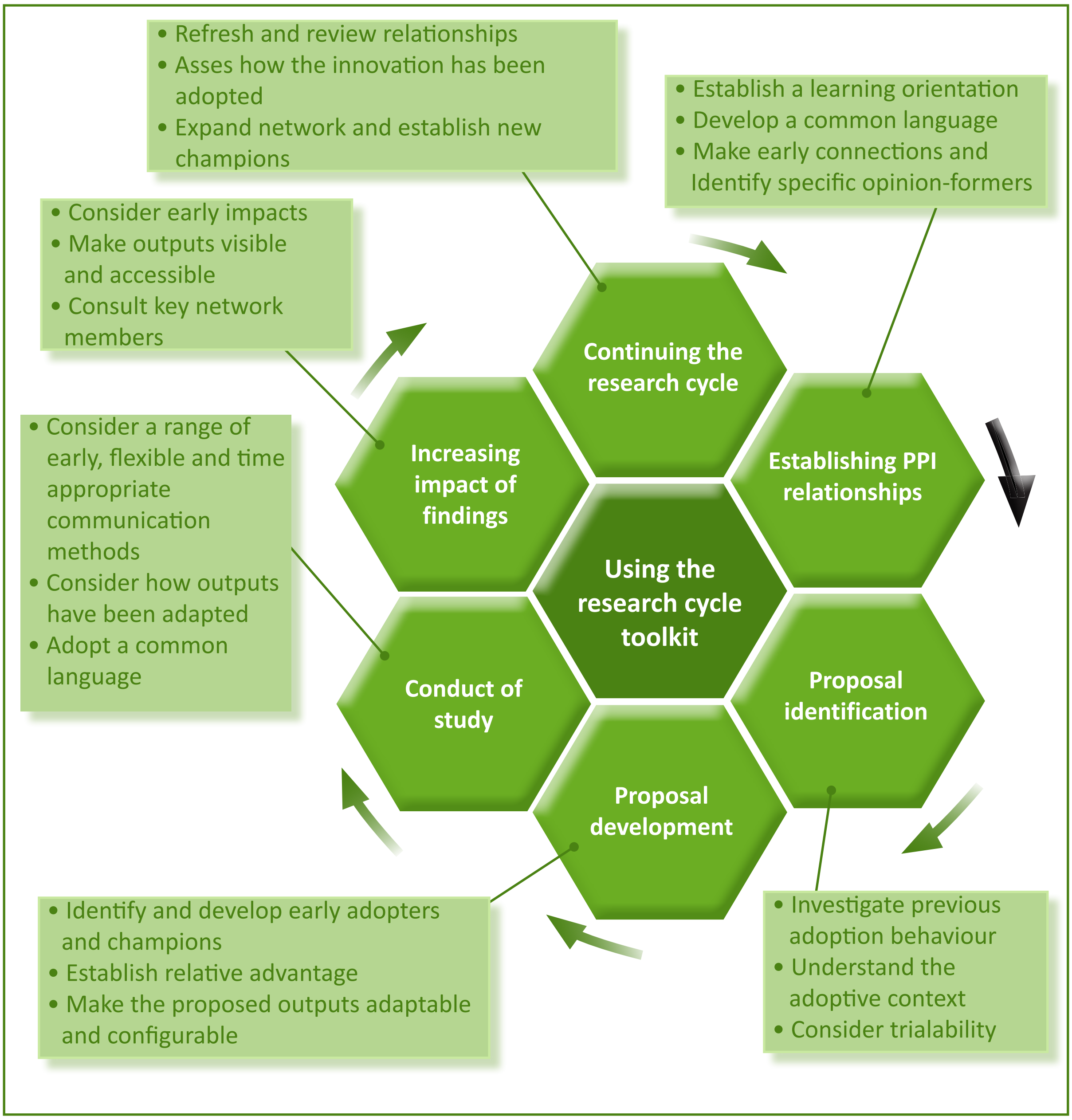
1. *Relative advantage.* Is the proposed innovation better than what exists? Subfactors of relative advantage include: lower cost; time/effort saved; decreased discomfort; and some reward or social status enhancement
2. *Compatibility*. Does the innovation fit with the current values, social norms and behaviours of the social group (intended audience). The more novel an innovation or intervention, the greater the risk of it not being acceptable to or fitting the needs of the audience. Adoption of novel ideas is affected by the ideas that precede them and by the prevailing culture
3. *Complexity*. Is the innovation easy to understand and use? How complex is it likely to be for this audience? What has failed or succeeded before? Is the innovation as simple as it could be?
4. *Trialability*. Can the innovation be tried before making the decision to adopt? Successful innovations will adapt as they spread (Rogers, 1995; Van de Ven, 1999). Trialability is more important early on in the cycle – later adopters are more likely to use evidence of peer adoption as a proxy for trailing the innovation themselves.
5. *Observability*. Are the results visible and easy to measure for the user? This has particular resonance for non-technical innovations, as the active use of the intervention may not be readily visible to other non-adopting members of the social system. So a key issue in facilitating and fast-tracking the adoption of health and social care research findings into practice is to make them 'attractive' by making them easy to see, understand and try out.

Rogers (2003) also identifies the importance of understanding the social system around the intended users of an innovation. This includes knowing who the opinion-formers and change agents are and the link they provide between the innovation and target users. They often have a high degree of knowledge in the area, which, combined with their influence through social networks with the intended users, can help build the desire or need for the innovation thus creating the conditions for knowledge exchange, a wish to try or observe the innovation in use and then potentially to adopt it.

A toolkit for PPI in dissemination throughout the research cycle

The next section connects the above innovation attributes with the stages of a research cycle (note that the research process will vary depending on the ontological/epistemological approaches adopted by the research team). The toolkit below represents a basic process that could be adapted, depending on the style of enquiry. INVOLVE and the Canadian Institute for Health Research have both published guidance on PPI in research and in their publications they identify dissemination as one of a number of discrete phases of the cycle. This toolkit places dissemination as a constant theme that, to be effective, needs to runs throughout the research cycle and be considered at all stages (see Figure 1).

Figure 1: How the toolkit facilitates PPI in dissemination



The toolkit set out below draws on the principles of innovation dissemination that are inherent in Rogers' (2005) ideas on diffusion and related theory, and combine this with issues raised in the PPI dissemination literature and the practitioner experience of the lead author. We have established the toolkit to provide researchers with a checklist of useful questions to consider at different stages of the research cycle. Important elements at each stage of the cycle highlighted in Figure 1 are explored more fully below.

The constant thread through this toolkit is the potential for a greater level of PPI in dissemination, in order to increase the reach and impact of the learning from a study or service development. Its aim is to prompt the research team to think about how increased PPI might be achieved, be it researchers, individuals engaged through PPI or practitioners implementing the findings. There is an important first step of establishing PPI relationships in advance of beginning a piece of work to support the principle that PPI in research as well as dissemination is underpinned by good working relationships built on trust and mutual respect.

Why?

An important first question is 'why are you looking to establish a PPI relationship – for what purpose?' (INVOLVE, 2014). The response will in part reflect your beliefs and values about the merits of greater PPI in research, which in turn will influence your approach. Is it because you think it is a good idea and will enhance the quality of the research and its impact on health and social care practice? Or is it because the funding body requires it and you need to find a partner. Maybe you have previously engaged in PPI activity at a consultation level but the current project requires a more proactive and advanced level of PPI. Depending on your response, this toolkit will be a prompt to think more robustly about the role of PPI not just in research but specifically in dissemination throughout the research cycle; alternatively, the toolkit's questions may challenge your perception of how and when the involvement of patients and the public can provide a valuable addition to your approach to dissemination and help maximise the reach and impact of study findings.

The toolkit

Establishing PPI relationships

'People will participate in ways that have meaning and value to them and through which they believe they can have an impact' (Brodie et al., 2011). This stage focuses on developing nascent relationships with the groups that your work is looking to influence; in effect it is about investing time in getting to know each other. Long term knowledge exchange is more likely to occur when the motivation to work together has a learning orientation focused on the acquisition of new skills and/or knowledge, rather than on achieving specific goals (Swift et al., 2010). Oliver et al. suggest language differences can be an alienating factor in PPI. They propose this is manifest through the use of technical jargon – specialist and medical, and also managerial and administrative. It is probably not feasible to tailor and translate all interactions but glossaries and having ready access to people who can clarify terms may help (Oliver et al, 2001). The development of appropriate dissemination is predicated on the understanding and development of relationships and networks that facilitate the sharing and exchange of experience, understanding and information. This in turn underpins the adoption of innovations and interventions into practice. The nature of relationships is central to knowledge exchange, as it is a fundamentally social process (Blau, 1964). This is reflected in three important areas:

- The quality of the relationship
- The network structure, or who you connect with and how
- The existence of a shared or common purpose that underpins the relationships and network

Creating these relationships early will help researchers understand what is important to the group that they are interested in working with and enable them to develop, discuss and test out their ideas as they emerge. It is important to connect with patient groups and the public *before* putting forward a proposal or securing funding. This fosters trust that the researcher is making contact because they want to understand the patient and public experience and innovate in that area. This reduces the risk of 'tokenism' (Wyatt et al., 2008), which can occur when researchers may have to communicate because they have secured funding and need a patient group to work with. It also enhances the relevance and quality of proposals that are submitted and increases the likelihood of securing future funding. Connecting to opinion formers and individuals who can help you to reach the target audience at this stage should be seen as essential. The following questions are informed primarily by consultation with those involved in PPI activity, who reported what helped or hindered the development of a good working relationship with the professionals, and supported by the innovation literature.

Questions

- How are you connecting to and networking with appropriate patients, patient groups, and practitioners?
    - Are you going to them?
    - What methods of communication are you using – face to face, written, internet, or social media?
    - Are you listening?
    - Do you know what is important to them? List the issues
    - How are your ideas addressing their needs?
    - Are you being clear about what you are bringing to the relationship and what you are looking for?
    - Is the relationship built on mutual respect? Identify supporting evidence
    - Have you identified change agents? Those are the people who will recognise the opportunity and identify the best approach to make the change happen. Are they empathetic to the target audience? Are they well connected to the target group? Do they have credibility with the target group? Are they connected to opinion leaders, the individuals whose ideas and behaviours influence others?
    - How are you going to acknowledge or reward involvement?
        - Financially, via money or vouchers to individuals or a donation to a patient group?
        - By providing training, access to resources or attendance at conferences?
        - Discuss and agree this with individuals or patient groups before undertaking any work

Proposal identification

The sharing of knowledge through the establishment of PPI relationships and networks at an early stage makes it more likely that the research proposal that will be compatible with the needs, desires and motivations of the intended audience. The development of a partnership approach with a high degree of empathy with the user is important in order to understand what knowledge might be useful. Investing time in developing relationships will promote the establishment of a shared understanding of what issues are important and then which of those would be best to take forward in order to meet the needs of all parties (Rogers, 2003). It is important in this context to ensure that the rationale for deciding to progress a particular issue, as well as its anticipated benefits, are articulated in a clear, jargon free manner. This will involve appreciating previous efforts to address the same or a similar issue and what factors helped or hindered. Identifying and discussing 'local' knowledge and internal systems and processes is also essential.

People may have well disguised existing ideas that may prevent a new idea been adopted (Rogers, 2003). These may not be immediately obvious to the researcher. For example, people may already have a simple solution or have previously rejected a similar idea or innovation. The earlier such factors are understood, the greater the likelihood of successful sharing and adoption of knowledge at the end. Knowledge exchange in this respect is vital; its value is clearly demonstrated by the National Cancer Research Institute's support for the establishment of a consumer liaison group to foster the development of lay/professional partnerships whose purpose is to influence the field of cancer research (National Cancer Research Institute, 2102). Such early engagement and responsiveness to patient concerns brings a stronger connection between the research and patient groups and the public. People feel valued and become more committed to the process and the outcome of the work being disseminated and adopted into practice.

Questions

- How was the idea identified?
    - One meeting, a series of meetings, a focus group, a report?
    - Who else from the wider community has had the opportunity to comment?
    - How have you engaged? Letter, meeting, website, social media?
    - How have you made it easy for the patient groups to engage?

- Are you confident that the 'idea' addresses issues of concern to the PPI group(s)?

- Has the proposal been developed with the PPI groups?
    - Have you evidence of how it has developed/changed as a result of their input?
    - Who will benefit and how? Be specific

- Has the area been looked at previously?
    - If yes, what learning can be used to help inform this proposal?

Proposal development

Improved dissemination in the longer term requires active involvement and buy-in from key PPI stakeholders at an early stage so that they become 'idea champions'. This helps to facilitate the on-going exchange of knowledge and understanding as the proposal is developed, helping to maintain a common purpose and a shared language and understanding that will strengthen the quality of the final proposal. It is important to be clear about the purpose of the research, as that will help inform who else you engage with and how. The following are some broad headings; the proposal may be addressing one or more of these areas, or variations of them.

Is the proposal designed to:

- Generate insight and understanding about a particular healthcare or social care issue?
- Amend an existing service in some way or establish a new one?
- Develop a new technology to be used by healthcare and/or social care professionals?
- Develop a new technology to be used by patients, carers, public?
- Develop a care pathway/introduce a new intervention?

A key consideration at this stage is the relative advantage of the proposal – what added value might it bring, to whom and for what purpose? Do these advantages address issues that are of concern or interest to patient groups? If so, then these issues may work as 'attractors' by creating wider attention and thus improving engagement of potential change agents or champions, who in turn can connect with early adopters of new ideas. A challenge with longitudinal public health research, with a focus on preventive innovations, is that it can be harder to promote adoption and diffusion among social groups if the reward or main intervention 'pay-off' will come in the long term. Robust PPI can help clinicians and researchers identify shorter term messages that can be built into a clear communication and involvement strategy. Formative results can be usefully communicated to encourage the development of a feedback loop into the longer term conduct of the study. This can help to keep the study on track and fit for purpose while generating interest in and an appetite for the longer term findings. Patient, carer or public involvement at this stage helps to establish informed advocates who will communicate their knowledge and views (Graham et al., 2012).

Relative advantage needs to be considered in terms of:

- 'Impact' and the metrics that will be required to demonstrate impact
- 'Impact' for whom?
- The message. What are the different messages and how will they be shared and disseminated, to whom and at what stages?

Questions

- How clear is your proposal?
- How are you making it easy for the public and patient groups to get involved in the development of this proposal? Be specific
- How can you demonstrate the relative advantages to help engage individuals and groups?
- What language and examples are being used to demonstrate this? Are they appropriate for different audiences?
- What methods of communication are you using and are they appropriate for different groups? Patient groups are not homogenous, so language and examples will need to be tailored accordingly
- Do you know who your innovators and early adopters are in relation to the intended outcomes of the proposal?

Conduct of study

There is a range of ways in which PPI can be embedded in a study and it is important to agree how you will do this in advance of securing funding, as it will have an influence on study resources and costs. Some examples include:

- Frequency – being clear about how often PPI will be sought, with an emphasis on the desire for continuous engagement throughout the process
- Advisory, for giving feedback on the proposal, lay summaries and the content of patient information leaflets
- Feedback on preliminary findings
- Membership of the research steering group team
- Active participation as a core part of the research team (co-production)

Active involvement in research could include study recruitment, data collection and analysis, writing up reports and dissemination of findings, as well as contributing to reports, conferences and publications, and through more diverse community networks that may not be available to the professionals.
Consider using change agents to identify problems at this stage.

Dissemination during the conduct phase of a study allows time for information and learning from the study to be shared so that it reaches a greater number of people beyond the research team and creates the opportunity for dialogue and the scope for feedback and adaptation before the final product, practice interventions, service changes and outcomes are developed.

Questions

- How are you making it easy for people to:
  - Know about the project?
  - Get involved?

- How are you ensuring that the people who get involved have the appropriate skills and experience?
  - Role specification?
  - Interview?

- How are you supporting people who do get involved?
  - Appropriate training and development?
  - Support and supervision?

- What are the ongoing messages about this work that you would like people to be disseminating?
- Is there a feedback loop for people to offer their thoughts and observations on what you are disseminating?
- How do you respond to feedback? When appropriate, is it incorporated into the work you are doing?

Increasing the impact of findings

The purpose of good quality dissemination is to increase impact. As stated before, this starts with establishing robust relationships and networks before a proposal is developed. Dissemination needs to be planned for as a constant theme throughout the study, as opposed to an activity that happens for a short period as the study comes to a close. It is an ongoing process and should happen at appropriate intervals to maintain awareness and maximise the potential of engaging new followers and, consequently, adopters of the study outputs. When people are making decisions about whether to adopt new knowledge and change their behaviour, the nature and detail of the information they need and will find persuasive will differ depending where they are in the process of adoption and how information is communicated (Rogers and Schoemaker, 1971). Therefore, dissemination requires a communication strategy that organises the sharing of key information in different ways at different times in order first to attract the attention of the different stakeholders and then engage them with the key messages. This can be done by varying the level of complexity and timing of dissemination. Patients and the public bring with them a diverse range of skills and networks, which means they are ideally placed to talk about a proposed study and then about interim and final findings in different ways and in different places to different audiences.

PPI in dissemination can occur in numerous ways and to many audiences. A patient’s ability to influence not just other patients and the public but healthcare professionals (Graham et al., 2012), through the added value that their lived experience brings, is powerful. It can help explain why a piece of work is being undertaken and then bring the findings to life by describing their impact on that patient’s health and wellbeing and on their experience of healthcare and social care services.

Examples of PPI in dissemination

- Telling a story about the experience of a particular issue in either a written or digital form, or on a conference stage (the experience could be about a specific health condition, a service or about involvement as a member of the study team)
- Co-authoring a paper for publication, or writing part or all of a report
- Teaching and giving seminars
- Attending meetings with commissioners, providers, managers and practitioners
- Through social media, such as the Patients Like Me website or blogs such as Derek Stuart’s Making a Difference

Questions

- How could you involve patients and the public more in the dissemination of your findings?
- Do you need to offer any training or mentorship to support them in dissemination activity?
- Do you know the skills and networks of your PPI representatives?
- Are you making best use of the skills and networks of your PPI representatives?
- Is your research now better known and understood among opinion-formers?
- Are you using change agents to reinforce your key messages?
- What are the messages that you want to be disseminated to the different audiences?
- How clear are the messages – are they easily understood? Do they address in a succinct way the current advantages of your intervention? Can it be adapted and easily tried out?
- Are your messages needs driven?

Continuing the research cycle

Dissemination that has an impact on outputs – which may be a new product, service change or good practice guidelines being adopted and diffused into practice – is an ongoing process and a shared responsibility.

All members of the research team should focus on their circle of influence and disseminate through publications, conferences and social media as appropriate, knowing that if they make the innovation sufficiently attractive then some of those in their circle of influence will do likewise, ensuring that the information and learning reaches a greater number of people, generating interest and increasing the likelihood of adoption into practice. Importantly, those innovations that succeed best are adaptable and configurable by the target audience; think contextually configurable guidelines rather than rules. Once relationships are formed they can be used to help with development and dissemination of future research topics. Sharing of network information with colleagues and enabling them to connect with each other could also make their work more impactful and efficient. There are challenges in maintaining networks, but the benefits can be substantial.

Next steps for the toolkit

The process of dissemination has begun through the PPI input into the development and use of this toolkit. This will be continued through a range of traditional and innovative dissemination strategies aimed at engaging researchers, clinical practitioners and PPI groups locally, nationally and internationally, and by facilitating a conversation with those who use the toolkit to assess how it has been adopted or adapted in practice. These conversations will strengthen the relationship with key stakeholders and inform further development and dissemination of the toolkit.

Discussion

We have drawn on some of the literature around the adoption and diffusion of innovations to offer a different viewpoint and highlight strategies that could be useful. In this instance the focus is on PPI in dissemination; however, many of the strategies could be adapted to apply to different stakeholders. This is illustrated by the following points, which highlight some important general considerations for the adoption and diffusion of research findings:

- How easy is it to understand the relative advantages of the study findings?
- Do you know and understand the local knowledge context?
- Do you know the key opinion-formers?
- Have you identified and harnessed your champions?
- How easy is it to use or implement the service, product, protocol, guidelines and findings?
- Does that ease of use or implementation vary between the public and patient groups, and the different professional groups?
- Do you have a variable and flexible communication strategy targeted towards the main audience?
- Can the innovation be tried or tested before making the decision to adopt?
- Can the intervention be adapted to its local context?
- How readily can an adopter of the innovation convey the advantages to other potential users?.For example, do you have a social space where people can upload and share positive experiences?

Implications for practice

Embedding PPI in the dissemination of research findings to help increase their adoption and diffusion requires teams and organisations to establish a culture that recognises:

- The potential value that greater PPI in dissemination can bring
- The importance of establishing productive and reciprocal partnerships as part of everyday working
- That dissemination and PPI involvement are ongoing activities and should happen in different ways and at different levels throughout the life of a research study and, where possible, continue once a study is completed to maximise the reach and impact of the findings

Establishing this culture raises some interesting points for practice:

- The need for clinicians and researchers to invest time up front in establishing relationships with patients and the public. This time needs to be resourced by the host institution so it occurs on a regular, ongoing basis in advance of seeking funding
- The value of achieving a balance between maintaining professional standards and being flexible and open to new and diverse approaches to dissemination

- Dissemination planning should occur at the beginning and throughout a study rather than at the end of a study when researchers are working to secure the next tranche of funding
- The importance of relaxing the power and control that professionals currently have over what is disseminated, how, when, by whom and to whom?
- Greater PPI in the dissemination process will inevitably lead to more open access and the potential for people to do other things with the insights, findings and innovations that emerge. This is congruent with the innovation literature, which supports this process of adaptation as being crucial to the process of successful adoption and diffusion
- The need for clinicians and researchers to be more open to a diverse range of dissemination methods that will increase access to their work and therefore knowledge of their findings, and in turn increase the capacity for adoption and diffusion into practice
- The need to work with patients and the public to 'translate' the work that they are engaged with, using language and messages that are more easily understood by a lay audience
- The need to manage the tension between widening access to research and the Research Excellence Framework incentives for publication in a four-star academic journal. While the latter is important from a quality standard perspective, it may reduce the scope for a wider interpretation of impact by restricting the audience

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Elaine McNichol (PhD, MSc Health Professional Education, RMN), Academic Lead for Service User and Carers, School of Healthcare, University of Leeds, England.
Paul Grimshaw (PhD, BSc), Research Fellow, Centre for Technology, Innovation and Entrepreneurship (C-TIE), University of Leeds, England.