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Patient and Public Involvement and Engagement for PhD Students

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ABSTRACT

This paper aims to provide useful advice regarding the development of skills for patient and public involvement and engagement (PPIE) in research. The authors of this paper comprise experienced PhD supervisors and trainers, researchers leading PPIE activities including in the National Institute for Health and Social Care Research (NIHR) Nottingham Biomedical Research Centre (BRC), and experts in the conduct of PPIE. The paper arose from discussions in preparation for a programme of PPIE training for PhD students in the University of Nottingham, UK. We offer this advice on the basis that it is likely to be of use to others undertaking research training such as undergraduates or research associates moving into health-related research areas. Although the PPIE team of the NIHR Nottingham Biomedical Research Centre prepared this paper, we hope that it is of value across the whole spectrum of health research, not solely to experimental medicine and is of relevance to research more widely than that supported by the UK's NIHR.

The first section introduces PPIE, explains what it is and what it is not, and why it is important. The second section provides specific advice.

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INTRODUCTION

What is PPIE?

We use terminology as advised by INVOLVE [1, 2] a body established in 1996 and now supported by the National Institute for Health Research (NIHR) to support active public involvement in NHS, public health and social care research.

- Patient and public “involvement” in research is when members of the public are actively involved in the conduct of research projects and organisations. Examples of public involvement in research are as joint grant holders or co-applicants on a research project; involvement in identifying research priorities; as members of a project advisory or steering group; commenting and developing patient information leaflets or other research materials; undertaking interviews with research participants; or user and/or carer researchers carrying out the research.
- Patient and public “engagement” is when researchers share and disseminate information with those groups and individuals. Engagement can take place at science festivals open to the public with debates and discussions on research. Other opportunities include open days at research centres where staff invite the public to find out about research. The use of media such as television programmes, newspapers and social media can raise awareness. Researchers can disseminate their findings to research participants, to colleagues or members of the public.
- Research “participation” refers to when people take part in a research study. Examples of participation include people recruited to a clinical trial, or other research study, completing a questionnaire, or participating in a focus group as part of a research study. Researchers unfamiliar with PPIE can confuse participation with involvement and engagement, mistakenly believing that if patients or members of the public are participants in a study that this constitutes involvement or engagement. This mistake is even more common in some qualitative research studies where qualitative research interviews (which require research ethics committee and other regulatory approvals) may be confused with PPIE consultation exercises (which do not require research regulatory approvals).

Whilst involvement, engagement and participation are different concepts, the processes involved often overlap. For example, engagement with the public or patient groups may lead to greater recruitment to studies (participation) and create opportunities for patients and the public to shape the research (involvement). The term “patient” here does not merely imply individuals with certain

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conditions, but includes formal and informal carers, support networks, families, and informal and formal advocates. Patients and public involvement activities merge with wider involvement of other stakeholders such as care providers in the health and social care sectors.

The importance of PPIE

Professor Dame Sally Davies, in her prior position as Chief Medical Officer in the UK, neatly summarised the justification for PPIE in health research: “No matter how complicated the research, or how brilliant the researcher, patients and the public always offer unique, invaluable insights. Their advice when designing, implementing and evaluating research invariably makes studies more effective, more credible and often more cost efficient as well.” [3] One of the multiple reasons for this sentiment is that clinical research can fail to recruit the necessary types and numbers of patients needed, due to inadequate understanding of the barriers to engagement and participation. Another point is that greater involvement of patients and the public in the research process may lead to greater trust in the scientific process and hence better adoption of advice stemming from the research findings. Hypothetically, it is possible that PPIE will not improve some research projects. However, our experience is that this is uncommon. There is growing appreciation that PPIE in research is not simply a part of sensible research practice, but an ethical and moral imperative. Public bodies are the main funders of research and the knowledge gained is ultimately intended for patients and the public. As such, patients and the public have a right to be involved in the generation of this knowledge, and for researchers to share it with them: the “democratisation” of research [4]. The UK’s NHS already has a statutory duty for patient and public involvement and engagement, and this includes research involving NHS facilities, staff and patients. Research funding from the NIHR and an increasing number of other research bodies is conditional upon robust plans for patient and public involvement, plans for the dissemination of the eventual findings, and their route to impact. Research impact is any effect of research such as a change or benefit to the economy, society, culture, public policy or services, health, environment or quality of life, beyond academia. Research impact is achieved through “knowledge exchange” between researchers and “research knowledge users” which include patients, the public, alongside the businesses and services who also serve the public. Such is the current view of PPIE that, at the time of writing, the NHS Health Research Agency (HRA) is undertaking a consultation exercise regarding whether public involvement in clinical trials should be a requirement in legislation [5].

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Much of health-related research involves health and social care users, their facilities and/or staff, where NHS research governance arrangements (including the need for PPIE) apply. These arrangements are different from, and often more complex than, those that apply to research using volunteers recruited under different governance arrangements, such as when approved by a university research ethics committee. Many legal and financial governance processes are involved when planning and conducting research in NHS facilities to ensure that costs and resources used to support research are not be at the expense of clinical services. These research governance processes overlap with clinical governance processes, where there are often extensive PPIE organisations and networks. Good PPIE training will assist PhD students in making best use of clinical and research networks and consultation processes that already exist.

Patient and public involvement in research can be at any or all of the stages of the research cycle [2] as summarised below.

Identifying and prioritising research topics and questions. User groups or public consultations help to do this. The James Lind Alliance [6] is an example of an organisation dedicated solely to this activity, and its outputs guide research funders in how they should allocate research funding.

Design of research studies and development of the grant proposal. Whilst the research questions define many aspects of research study design, patients and the public can have a vital role in ensuring that the patient or public-facing aspects of it are feasible, acceptable and understandable. Often one or more interested members of the public join the research study group, sometimes as co-applicants.

Undertaking the research. Patients and the public can assist in public-facing aspects of the research such as optimising recruitment or providing feedback during the course of a study. Certain patients and members of the public involved in research develop considerable research skills in their own right and can contribute more directly to specific forms of research, such as by conducting interviews.

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Analysing and interpreting. This can include the assurance that researchers present emerging results in a way that is believable, understandable and logical to the non-researcher.

Dissemination. Multiple potential stakeholders or groups of people could use the knowledge gained from research studies. However, patients and the public are obviously key in health research.

Patients and the public can help to ensure that outputs from research are understandable, and then transfer this knowledge to potential users through individual and group networks.

Implementation. Patient and public bodies that have been engaged in the generation of research knowledge are in a better position to help put that knowledge into practice.

Monitoring and evaluation. Just as professional researchers reflect on what they have learned in order to define their next steps, patients and public partners in the research process can also reflect on the impact (or lack of it) in the same way.

Health research varies in its scope and methods such that it is inappropriate to assume PPIE will improve all research projects in all the domains above. It is usual practice to consider which of these domains are likely to be of value for each research study and to design a bespoke PPIE plan accordingly.

PPIE in early translational research / experimental medicine research

The role and value of PPIE is easiest to appreciate when considering *applied health research* when the participants are patients demonstrating specific symptoms from conditions such as stroke or asthma, and when PPIE colleagues can employ their lived experience of these conditions to the process. Early translational research, also called experimental medicine research, occurs at an earlier stage in the research pipeline. This occurs when new researchers apply biological or technical knowledge (such as obtained by discovery research using cell and animal research, or the development of new materials or devices) in human volunteers and then patients. Researchers often use the phrase “from bench to bedside” to describe its scope. Translational research may not apply to single clinical conditions or directly to clinical problems (e.g., research into inflammation), or may be methodological (e.g., developments in diagnostic imaging). In such research, it may be unclear

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what the ultimate use of the knowledge will be, and this can make it challenging to identify the most appropriate PPIE partners. In highly technical translational research, it is less apparent that PPIE will necessarily improve the quality of the core science [6]. However, in each circumstance, PPIE could (at the very least) help in the process of exploring the subsequent value of the research output and hence facilitate better routes to subsequent translation. Without care and expertise in PPIE, potential PPIE partners could find the process either intimidating or off-putting. Researchers compound this problem if they do not arrange the time or resources to support the necessary PPIE activities.

PPIE for PhD students

If it is accepted that PPIE is an essential part of health-related research, it follows that health-related researchers should be trained in this essential area, just as they should be trained in other essential aspects of research (research ethics, data handling, critical analysis, evidence synthesis, and so on). Examiners expect that PhD theses are at a level comparable to peer-reviewed research publications. In the same way that journal reviewers and editors increasingly require evidence of patient and public contributions to published material, both internal and external PhD examiners will expect the same: PPIE is not an optional extra.

ADVICE

We advise that all PhD students in health-related research, including early translational research, should receive high quality training in patient and public involvement and engagement in research (PPIE). We recognise that some PhD students, such as those without clinical backgrounds or those who have predominantly worked in laboratories, may be unfamiliar with dealing with patients and the public and are potentially daunted by the prospect. Supervisors should sympathetically support their students throughout their PPIE training. Our advice is as below.

Introduce students to PPIE early

It is a responsibility of the PhD managerial system to explain, justify and remind supervisors and their students of the need for PPIE training. It is important to introduce the topic early so that the PhD student achieves the maximum experience and benefit, and that students and their supervisors can address any concerns from the outset. Students should be encouraged to embed the time

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required for PPIE activities into their research management plan. Students and their supervisors should negotiate timely access to suitable public or patient groups.

Supervisors should provide their students with materials, such as this document, and access to the resources they are likely to need. There are easily accessible national resources [listed in 2]. We assume that each University will also have local PPIE resources. For example, in our institution, the post-graduate faculty of the university has already collated lists of relevant external websites, the contact details of local PPIE groups and supports a PPIE group. Universities usually have close links with local hospitals, which themselves may have extensive PPIE organisations and resources – covering patients and public involvement and engagement in research but also in service delivery. For example, in our institution, the local hospital has an extensive PPIE strategy and resources such as a virtual “Research Lounge” specifically designed to encourage conversations with patients and the public [8]

Deliver introductory courses in PPIE

Although PhD training is largely about learning to become a researcher through conducting research, oftentimes, PhD development requires students to undertake taught courses. From our experience, we advise that a course lasting two half-days, built mainly around discussions between students and experienced PPIE colleagues (both research staff and members of the public with experience) is beneficial. Part 1 can outline the principles of patient and public involvement in the conduct of every part of the research cycle. The collaborative nature of PPIE can be illustrated by reference to the UK’s NIHR six national standards for public involvement in research (inclusive opportunities, working together, support and learning, communications, impact, and governance) [9] and PPIE colleagues describing their roles in specific research studies. Part 2 can cover how lay assessors contribute to research governance such as in research ethics committees or the award of research grants. A course designed in this way encourages students to think about how they will develop PPIE plans for their research. It can be helpful for experienced PPIE staff to offer further informal and individualised discussions with students to advise or help steer them towards the support and resources they require.

PhD supervisors should expect their students to provide plans for potential PPIE input into their projects and include discussion and advice about this as part of the PhD supervision. If supervisors

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feel unable to do this, they should consult the local and national resources and seek support. Experts in PPIE should be in hand to offer such support.

Supervisors should include PPIE expertise within PhD support, advisory, reference or steering groups

Research studies usually have in place groups to support and provide advice. Some are small and bespoke to a specific study, whilst others are large and generic for a broad swathe of research studies. Supervisors will introduce PhD students to these groups or develop new ones if required. It is important that PPIE representation is included within these groups.

Supervisors should put specific PPIE support in place

PPIE contribution to a small specific study advisory group may be sufficient, but individual students and commonly groups of students should have access to specific PPIE support. This could be a “PPIE panel” (a group of experienced PPIE colleagues offering periodic seminars to a small group of students) or a “PPIE buddy” (a student and an experienced PPIE colleague are partnered in the expectation of an on-going relationship), or both. PPIE colleagues could potentially be part of the formal PhD supervisory team.

With institutional support, students and supervisors must ensure that PPIE is integral to the research

By this, we emphasise that PPIE activities should not be separate from the research, or outsourced. Students should experience PPIE as an integral part of the research process. This is not to imply that all supervisors should develop unique or bespoke PPIE systems or processes. Indeed, they should aim to engage local PPIE expertise, just as they might engage local statistical skills or laboratory facilities into a research study. This highlights that universities should provide PPIE resources just as they provide statistical skills and laboratory facilities. It is accepted that relatively expensive PPIE (such as to hire an external facility, or travel and accommodation costs that are beyond a typical PhD budget) might prove difficult to provide but, since PPIE is an essential aspect of research training, adequate funds must be available to cover reasonable costs.

Final and interim or annual PhD assessments should include a section on PPIE activities

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Final and interim or annual PhD assessments should include specific mention of the researcher's PPIE training, a description of the specific patient or public involvement in the research, and a reflection of its value to the quality of the research.

PhD students should be encouraged to develop their lay communication skills

PhD students need to develop communication skills to clearly and accurately convey scientific concepts to a non-specialised audience, and to present such research to public communities. This might include a brief or summary, a blog, social media posts, the preparation of a short video, or a magazine article, and participation in public engagement events. Patients and public involvement in these presentations should be encouraged.

CONCLUSION

Here we have highlighted the salience of embedding PPIE training as a necessary component of research and researcher development. We hope that this paper will inform best practice for all stakeholders, providing a clear structure for the design of PPIE training.

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