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Zoë A. Sheppard, Sarah Williams, Richard Lawson and Kim Appleby

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# Patient and public involvement and engagement: Practice case study with reflections and learnings from a small rural district general hospital

Zoë A. Sheppard\* – *Dorset County Hospital NHS Foundation Trust, UK*  
Sarah Williams – *Dorset County Hospital NHS Foundation Trust, UK*  
Richard Lawson – *Dorset County Hospital NHS Foundation Trust, UK*  
Kim Appleby – *Clinical Research Network Wessex, National Institute for Health Research, UK*

## Abstract

The notion of patient and public involvement and engagement (PPIE) in research has been around for some time, and it is considered essential to ensure high-quality relevant research that is shared and that will make a difference. This case study of practice aims to share the PPIE practice from Dorset County Hospital NHS Foundation Trust, a small rural district general hospital. It describes the process of recruiting patients and members of the public as research volunteers, as well as the plethora of engagement and involvement activities with which they have been involved to date. This is followed by a reflection on the process and an overview of plans for the future, highlighting key challenges as well as learnings. A dedicated role to support/oversee PPIE activities is recommended to coordinate large groups of research volunteers, as well as to monitor the important impact of their input, which is considerable. Increasing diversity and access to under-served groups, and embedding the research volunteer role within the wider clinical research team, are also highlighted as fundamental challenges, as well as opportunities to make the most from this valuable resource. The case study of practice puts forward a recommendation to all research departments to embed PPIE in all of the work that they do.

**Keywords:** public, involvement, engagement, health, research

### Key messages

- Patient and public involvement and engagement (PPIE) in research is essential, and it should be embedded into all departments conducting research.
- A dedicated role to coordinate and monitor the impact of PPIE activities is recommended, including ensuring that under-served groups are reached.
- PPIE should be continually monitored and reflected upon to ensure that it is meaningful and making a difference.

## Background

The concept of patient and public involvement and engagement (PPIE) has been around for some time. In 2009, Professor Dame Sally Davies, the then Director General of Research and Development at the Department of Health, said: 'no matter how

complicated the research, or how brilliant the researcher, patients and the public always offer unique, invaluable insights' (Staley, 2009: 4). In contrast to being *participants* in research studies, *involvement* refers to patients and/or members of the public being involved in the design or the delivery of the research itself, whereas *engagement* refers to their input into raising awareness of research (NIHR INVOLVE, n.d.).

The established concept is that participants should be *partners* in research, that is, that the research is done *with* the participant and not *to* them (Liabo et al., 2018). The experience of the patient co-author of this paper when he was involved in a trial was that he did not ever receive the results. This made him feel that he was not a partner in the study, but that he was experimented on – here the research was done to him, not *with* him. However, the experience made him keen to ensure that research participants are given the results, and that these findings are not hidden in, what are to the public, obscure medical journals, despite a move towards publications that are openly accessible to all.

However, the importance of PPIE has been well-established *throughout* the research cycle – not only the sharing of findings, but also in establishing the relevance of the research question and informing the research design (NIHR Research Design Service, n.d.). For this reason, PPIE is now an essential requirement in funding applications, and it should not be considered a 'tick the box exercise' (Andrews et al., 2015). Furthermore, PPIE means that research is more likely to make a difference, which is important for evidence-based practice and, increasingly, for the assessment of research within academia through impact case studies (REF, 2019).

Ten ways in which people could get involved or engage with research have been highlighted (NIHR, 2019). These include helping with publicity events, and providing the patient perspective on research studies and design, as well as involvement in staff training and recruitment. Indeed, there has been a move to embed PPIE in research *delivery*. This article presents a case study of the development of a PPIE initiative in a small rural district general hospital in Dorset in order to share practice.

## Setting

Dorset County Hospital NHS Foundation Trust is a small rural district general hospital serving the population of West Dorset (approximately a quarter of a million people), as well as providing kidney services for the whole of the county and for South Somerset – the hospital's profile can be found on their website (NHS, 2019a). The research department was established in 2001 with an original focus on cancer research. The department has since grown, and it now has research studies in most clinical areas, given the importance of offering patients access to research as per the National Health Service (NHS) Constitution (DHSC, 2021) and Long Term Plan (NHS, 2019b). While the hospital tends to be a site for national studies, it has aspirations towards growing its own research. Again, more information about the department is available on their website (Dorset County Hospital NHS Foundation Trust, 2021).

## Process

To the best of the authors' knowledge, there had been no PPIE activities at Dorset County Hospital NHS Foundation Trust prior to 2017. However, collaborating with patients and public was identified as a key strategic aim in the overall growth plan for research at the hospital. Seeing this both as a need and an opportunity, the research team sought advice from the National Institute for Health Research Clinical Research Network Wessex (one of the 15 research delivery networks located on the

south coast) who put them in touch with Portsmouth Hospitals University NHS Trust, where well-established work was already taking place. Following this advice, the team collaboratively worked up a role description with support from the hospital's Volunteer Coordinator, and advertised for expressions of interest at the hospital open day in October 2017. The duties included helping raise awareness of research, assisting with guiding the direction of the research strategy, representing the patient perspective, and helping with the design of research projects. Further to this, a press release was put out through the local radio station, Wessex FM, and a local newspaper, the *Dorset Echo* (Cook, 2017), to which there was a significant response.

One of the Lead Research Nurses (a co-author of this paper) conducted individual telephone interviews with those who expressed interest in the research volunteer role to establish their suitability and interests. Human Resources (HR) then carried out mandatory checks and administrative tasks ahead of a hospital induction including the issuing of volunteer agreements, identification badges and parking permits. A departmental induction meeting was convened in February 2018 for the research volunteers, known at Dorset County Hospital NHS Foundation Trust as Patient Research Ambassadors (PRAs), to find out more about the role and, importantly, to meet each other, although one of the research volunteers observed that individuals had different agendas. This individual was 'impressed by [the] considered and measured approach on initial recruitment'. While they found that the induction process was 'broader than expected', they questioned the relevance of some of the training modules. However, they thought that there was a need for training in the research process and methods, as well as in the research volunteer role and scope – there was a difficult balance with the former, given the need for the *patient* perspective, and the fear of patients becoming too 'expert' to provide this.

The time at the departmental induction meeting was used to obtain the research volunteers' input into the research strategy to be developed, and this was followed by further regular 'get-togethers'. During the COVID-19 pandemic, regular and more frequent 'get-togethers' have been organized virtually, largely by one of the research volunteers. These have held the group together, and they have provided opportunities for training, sharing experiences, and discovering new areas with which the research volunteers can assist. The 'get-togethers' are also exploring ideas of how to engage with under-served groups using the research volunteers' unique life skills and specialist knowledge.

Due to the lack of PPIE training available at the start of the programme, a bespoke training course was organized for the research volunteers, research staff and clinicians, facilitated by the Centre for Public Engagement at St George's, University of London. This also provided an opportunity for the research volunteers to meet members of the research team, and for the role to be introduced to wider clinical staff. Where previously it was not widely known among the research team and among clinicians that this research role now existed, having protected time such as the training day provided a timely and appropriate opportunity for the research volunteers to introduce themselves and the role. This led on to initial connections being formed, and allowed opportunities and ideas for both engagement and involvement activities to surface.

## Activities

Since the first departmental induction session, the research volunteers have been involved in a plethora of engagement and involvement activities (summarized in Table 1). With regard to engagement, they have raised awareness of research via display stands both at the hospital and externally in a local supermarket. At the latter event, it

**Table 1: Summary of engagement and involvement activities by research volunteers at Dorset County Hospital NHS Foundation Trust 2018–20**

| Engagement activities                                                                                                                                                                                          | Involvement activities                                                                                                                                             |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Stands to raise awareness of research, for example, International Clinical Trials Day, health awareness dates, hospital open day, hospital annual general meeting, monthly staff inductions, local supermarket | Strategy development and Trust Board presence                                                                                                                      |
| Trust membership event                                                                                                                                                                                         | Representation at Research Strategy Committee and on Sponsorship Committee                                                                                         |
| Online profiles and press releases, as well as article in a parish magazine                                                                                                                                    | Team meetings, team training (for example, mentoring, skills and shadowing), Health Literacy Champion, input into student placements and staff recruitment process |
| Presentation to Patient Participation Group in general medical practice                                                                                                                                        | Involvement in existing and new research projects including user-led                                                                                               |
| Hosted Building Research Partnerships event                                                                                                                                                                    | Digital Discovery Day                                                                                                                                              |
| Presented to local university                                                                                                                                                                                  | Input into Clinical Research Network Wessex activities, for example, listening exercise, Participant in Research Experience Survey, priority setting               |

was clear that, while the local hospital had an excellent reputation, there was a lack of awareness that it delivered research. It is hoped that raising such awareness will in time increase participation in research studies.

The research volunteers also attended and shared their experiences during a presentation to the Trust membership. Furthermore, they have shared their stories with a wider reach through the local media (*Dorset Echo*, 2018) and by providing online profiles. A particularly active research volunteer (co-author of this paper) has also presented to his Patient Participation Group at his local general medical practice, as well as to the local university, and at a public engagement event called Building Research Partnerships. Indeed, a small group of research volunteers were on the organizing committee for the Building Research Partnerships event considering appropriate venues and content for the day.

With regard to involvement activities, as noted above, the research volunteers had input into the departmental strategy, and one attended the Trust Board meeting to present it to the Board. This was key for the Head of Research: 'As there had been no real such involvement previously, it was a priority when I joined the organization, and it was a necessity for me that the research strategy was co-produced with patients as well as staff.'

Another research volunteer provided the patient perspective at Research Strategy Committee meetings, which focused on reviewing proposals for small internal research funding. He also reviewed studies to decide whether the hospital can sponsor/take responsibility for them. The research volunteers are therefore very much part of the research team – they attend team meetings and team training days, assist with student placements, and are involved in the staff recruitment process, demonstrating collaboration with the staff. The Lead Research Nurse co-author explains:

In my experience, I was very much focused on the patient as a trial participant, in some ways doing to the patient, rather than with the patient. The process really opened my eyes to how we can collaborate with patients and the public to embrace their voice, perspective and embed them as part of our team – in my experience, this should absolutely be an

aim at the outset of any plan to form a volunteer group within the NHS setting.

The research volunteers have utilized their skills and experience. For example, one research volunteer provided patient mentoring to a member of staff, and another has run training sessions in presentation skills. Several others have shadowed staff members to get more of a feel for the work of the department, although one of the research volunteers commented that *everyone* needed to do this. Another research volunteer has actively been involved in the delivery of two research studies, and others have had input into the design of research, including nationally. One of the research nurses explained about a research volunteer's contribution to study delivery: 'From the outset, we discussed what she would like to gain from her experience, and how she felt she could help us as a team. She felt she would feel the most comfortable in a patient-facing/companion role.' Sadly, there was 'not enough scope within the role to keep her occupied or challenged', which was 'frustrating for us all'. This demonstrates the need to identify appropriate activities for the research volunteers that match both their aspirations and skill sets, as well as the needs of the service.

Two research volunteers were successful in obtaining small £500 grants in PPIE from the Clinical Research Network Wessex – one to hold a Digital Discovery Day to bring together key stakeholders to facilitate ideas in the area of digital health, and the other bringing PPIE networks across Wessex together for a further PPIE training session to build confidence in the role among the research volunteers. The research volunteer who led the Digital Discovery Day explained that they became a research volunteer:

... to repay a debt of gratitude to the NHS for extended treatment at Dorset County Hospital ... leveraging my experience in delivering products and services for many public companies, I was able to facilitate a digital discovery workshop with health practitioners, clinicians and patients.

As well as having input locally into the research agenda, the research volunteers have been involved regionally across Wessex by feeding into a 'listening exercise', the design of the Participant in Research Experience Survey, and important priority-setting work for the region.

Furthermore, the research volunteers are getting involved in hospital-wide work which indirectly raises awareness of research. There is representation on the hospital's Patient and Public Engagement Action Group, known as Your Voice. The patients' point of view is represented in terms of patients' experience of the hospital, also linking this with health research. The patient co-author, a retired teacher who taught basic skills, has become the department's Health Literacy Champion. In this function, he is helping to make participant information about research easy to read, and he often refers the research team to the Simplified Measure of Gobbledygook (SMOG) index (Readability Test Tool, n.d.). The patient co-author of this paper commented: 'I have no medical training, which I think is important when it comes to representing the patient and the public in research.'

## Reflections

There has been a large range of research volunteer activity since the first meeting in February 2018. One of the data managers within the research department commented that 'it was very pleasing to see ... a diverse group of characters, abilities, skills and

interests ... which had potential to provide an amazing resource for our research teams'. The majority of the activity to date has been engagement, but involvement is likely to increase as the co-produced research strategy is implemented through research led by the hospital. It is perhaps easier to find opportunities for research volunteers to be involved with engagement activities, particularly in a smaller trust which has previously had a focus on being a site for national research studies. Saying this, the contributions and enhancements that the research volunteers have given to the involvement activities have been invaluable in raising the profile of the 'patient voice' and perspective in the research design process. Groups of research volunteers have usefully been able to be quickly and easily brought together to provide input into research ideas and design for funding applications, among other things. Other longer-term input has been acknowledged by clinicians in differing roles and with varying research experience, demonstrating the value and contribution of the research volunteers, as these three quotations from different individuals show:

The Patient Research Ambassadors (PRAs) have shown a real interest in my PhD project; some have proactively made links between my work and other local services, which has really helped with the dissemination of my ideas. Otherwise, a select number of PRAs have willingly and repeatedly volunteered their time to read protocols, suggest topics for inclusion and critique questionnaires.

Patient and public involvement has been a great addition to the study during the initial research period, and when amendments needed to be made in response to the COVID-19 outbreak. Members of the public were able to express their views on the importance of the study, the design, recruitment methods and results dissemination. Their valued opinions and suggestions meant that we can improve the study and consider new ideas that are more relevant to potential participants.

The Keratoacanthoma/Skin Cancer Research work has benefited from involvement of our Patient Research Ambassador at all stages of the project. She has helped us to focus the research questions on what is important for patients, in particular highlighting our local experience at Dorset County Hospital, in which we have demonstrated that deferring surgery for suspected keratoacanthomas can lead to potentially avoiding surgery for some patients, as well as the importance of good communication and decision making, which needs to be tailored to each individual patient ... We hope that our Research Ambassador will remain involved as we plan towards a multicentre study.

The research volunteer role is a new and evolving one at the hospital. An advantage is that they can contribute depending on their availability, interests and skill sets. This means that they can get involved as little or as much as they can or want, either virtually or actively, bringing flexibility. This is demonstrated by a quotation from the patient co-author:

I have found that being a research volunteer is both interesting and rewarding. I have found that when I need to, I can step away from the role, and do as much or as little as I like, so it is not an onerous commitment. I have enjoyed all the tasks I have completed so far, and would like to be further involved.

However, it also means that some research volunteers may struggle to identify how to input without a regular structured programme of activities, and so perhaps have more 'marginal' input when their contribution needs to feel 'meaningful'. Strategies to address this have included further training (for example, 'elevator pitches' to prepare a summary of the role, and creation of slide sets to reuse when making presentations), sharing ideas, and shadowing clinical research delivery staff and other research volunteers to build confidence.

The initiative has been set up through a lot of time and hard work, but with relatively few dedicated resources attached. The Lead Research Nurse co-author obtained a £10,000 Transitional Award from Health Education England which had a specific focus on PPIE, and the research volunteer recruitment initiative became part of this work programme. A dedicated research communications, involvement and engagement manager is recommended to coordinate such an extensive programme of activities. Such a role could develop a communications and PPIE strategy, and provide more support to the less confident research volunteers to keep them engaged and motivated in areas of their personal interest. A data manager had the following observations demonstrating the need for such a role:

For anyone looking to engage PRAs, early consideration of a paid or voluntary administrator role from the start would, I feel, very much help the process. Tasks could include liaising with the hospital's HR department regarding advertising, setting up and following through the application process; promotion of the PRA role within the department and throughout the hospital; pro-actively scouting for activities and events that would benefit from PRA engagement; setting up a discussion/chat group on social media for the PRA group; liaising with the PRA group and keeping them engaged; facilitating discussions with researchers and the PRA group (providing administrative service, room booking, invitations, organising refreshments, managing a budget for the events, etc.).

One of the research volunteers thought that greater external input might also have assisted in establishing the 'contribution and value' of the research volunteers. However, with a lack of resources, and in the true nature of involvement, a couple of the more active research volunteers are stepping up and taking a lead in keeping the momentum going.

One of the key reflections, as well as challenges, has been how the research volunteers have become integrated and embedded into the existing research team. When the research volunteer group was formed, a small number of staff were instrumental in coordinating the group, and had regular communications with them. The eventual aim for the group was that the research volunteers would become an integral part of the research team, and would work alongside the clinical research delivery staff. However, initially team members' understanding of the role, and how the research volunteers could contribute to 'everyday life' within the team, was uncertain to some. For example, doubts about patient confidentiality were dispelled when the research team understood that the research volunteers were subject to the same rules of confidentiality as professional staff, and similarly had to regularly complete training in information governance.

The integration challenge was overcome partly with time, and through inviting team members to actively get involved with research volunteer events such as the 'get-togethers' and through the shadowing initiative. Regular visits by the patient co-author

to the team office increased the visibility of the role, and individuals spending time with this research volunteer was clearly very beneficial in increasing understanding and embedding the role as a fundamental aspect of the team. Indeed, one of the research nurses provided the following observation about the individual: ‘an enthusiastic and motivated member of the team, who is really keen to champion the role of the PRA, and engage with the public to encourage participation in research’.

Despite the challenges faced, the initiative has been hugely successful, and it has been formally recognized through winning the Clinical Research Network Wessex Excellence in PPIE award 2018, and a Trust Going the Extra Mile award 2018 (in the volunteer category), while the patient co-author won a Hospital Hero award in February 2020. Furthermore, the initiative was praised during an interview with the Care Quality Commission in August 2018.

## Plans for the future

While great strides have been made, there is still much work to do. As noted above, as the research strategy is implemented, there are likely to be increased involvement activities and user-led research projects, given that some are already in development. Indeed, one of the research ideas from one of the research volunteers has been taken forward in a funding application. It is hoped that the research volunteers will become more embedded within the team by reviewing the research portfolio, providing input into participant recruitment methods, and assessing which studies to take on. Indeed, they participated in assessing which studies should restart during the COVID-19 pandemic.

Engagement activities are likely to continue to be the mainstay of the research volunteer role, and such activities could also be used as opportunities to fundraise to support research led by the hospital. The patient co-author is organizing an awareness day calendar with a rota, so that awareness of research in the hospital can be linked with relevant health awareness days. This will provide more regular activities with which less proactive members of the research volunteer group can engage. He is also targeting specific public groups where it is felt that raising awareness of health research would have impact – the Women’s Institute, for example.

Raising awareness of opportunities to support and participate in research among teenagers is also considered worthwhile, so plans are in place to hold an interactive engagement event for sixth formers at a local school centred on a film called *People are Messy* (Theatre of Debate, n.d.). The film, which was produced by the Theatre of Debate, was developed in partnership with the Oxford Biomedical Research Centre and the National Institute for Health Research, supported by the Wellcome Trust. It is a dramatization of the benefits of research, and is specifically aimed at older teenagers. Plans are also in hand to raise awareness of research through the hospital’s young volunteer scheme at a local college where the patient co-author of this paper taught. As with many engagement plans, both these young person initiatives have had to be put on hold due to the COVID-19 pandemic.

While this case study of practice attempts to summarize the work to date, it is also important that a better system is set up to monitor the input of the research volunteers in order to measure their impact – that is, to evidence whether the initiative is ‘making a difference’. Anecdotally, the impact is already felt to be considerable by some, and this paper goes some way towards highlighting this, although the impact of the initiative is intended to be the subject of a separate paper. Indeed, as the research volunteers become more embedded with the work of the department, it is felt that

their impact and value will be increasingly seen. As an example, the patient co-author of this paper was involved in the consideration of taking on an orthopaedic research study at the hospital. His input in reviewing the participant information sheet was thought to be so valuable that he was invited to attend the site initiation visit, and he has subsequently been asked to provide advice for the study nationally. He has also been asked to take part in a James Lind Alliance prioritization exercise about foot and ankle surgery. It is hoped that such experiences will inspire other members of staff to engage with the research volunteers, which will in turn make them feel valued.

It will be exciting to see how the research volunteer role evolves. For example, the hospital is collaborating with the local university to explore how to better consider under-served groups and 'democratize' PPIE, in line with the important INCLUDE guidance (NIHR, n.d.). By sharing practice and reflections, it is hoped that this paper will inspire other research departments to do something similar and make PPIE part of their department. Indeed, this is already happening with research staff at Portsmouth and Dorset County, sharing best practice with other local hospitals. While there is already great work being done throughout the country, more is needed, and it is hoped that this case study of practice reaches a wider audience with a recommendation to make PPIE the 'norm' throughout the entire research cycle, including within research departments, rather than being tokenistic or even non-existent.

## Conclusion

Many engagement and involvement activities have already been carried out by the research volunteers, and the initiative has won several awards. However, the initiative continues to evolve, particularly in light of the COVID-19 pandemic, and it has not been without its challenges. Most notable has been the lack of resources attached to the initiative, specifically a dedicated individual to coordinate and embed individuals within the clinical research team, as well as to monitor the impact. Moving forward, it is hoped that more can be done to monitor and report on the impact of the PPIE, as well as to increase diversity and access to under-served groups. Despite the challenges, it is recommended that all research departments incorporate PPIE into their everyday business, so that PPIE is truly embedded throughout the entire research process.

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## Notes on the contributors

**Zoë A. Sheppard** is Head of Research for the Research and Innovation Department at Dorset County Hospital.

**Sarah Williams** is Lead Research Nurse for the Research and Innovation Department at Dorset County Hospital.

**Richard Lawson** is a Patient Research Ambassador for the Research and Innovation Department at Dorset County Hospital.

**Kim Appleby** is Communications and Engagement Manager for Clinical Research Network Wessex, National Institute for Health Research.

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