Strengthening public and patient involvement and engagement in research

By really listening to the opinions of patients and public members, researchers are able to ensure a collaborative learning approach where everyone involved feels the benefit of this unique relationship.

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Read time: 8 Mins

This article discusses the ongoing responsibilities of researchers to lead good patient and public involvement and engagement, the need for diversity and inclusion, and the potential this holds to address not just inequality of transfusion care but also inequity.
Patient and public involvement and engagement (PPIE) is an expanding focus for researchers, funders, patients and the public. The extent to which patient and public perspectives are integrated into research varies widely, despite its clear benefits. Although quality interactions build trust between researchers, clinicians and patients, the failure to seek and value input and feedback can leave interactions being tokenistic as opposed to impactful.

Our work within the Blood and Transplant Research Unit (BTRU) in Data Driven Transfusion Practice is a collaborative research project that involves patients and public members as a key part of the research team. The overall aim of the BTRU is to accelerate the development of data-driven methods to optimise blood use and integrate them within routine practice to improve patient outcomes (see The future of data in transfusion medicine).

The voices of patient and public members have already added considerable value to our research efforts. As an example, our panel members were troubled by rates of unnecessary blood use in patients and potential inefficiencies and wastage in the blood supply chain. The importance of equity was strongly expressed; variation in capabilities should be addressed and our findings must be disseminated to all hospitals nationally.

We shared the use of electronic systems to collect and feed back data on blood use to clinicians and supported and prompted them to deliver evidence-based transfusion practice. In our discussions, we drew parallels with companies that have well established processes for monitoring stock levels and ensuring timely and precise delivery of orders to visualise well-functioning processes for blood use in the future.

HANIF AHMED, BTRU PANEL MEMBER

> **“ PPI members are new in the research field; they need time to understand but not to be treated as ignorant. Each member has their ethnic diversities, which may have some influence on how they look at things.**

Custodians in a digital age

Recent advances in machine learning and data analysis mean we are fast approaching an era of learning health systems built on the use of routinely collected healthcare data. The increasing ability to harmonise these vast swathes of data and probe even complex free text notes offers the unique opportunity to both visualise and utilise this information to improve clinical practice.

Despite the considerable challenges of creating safe data storage facilities, collating data, analysing findings and implementing clinical change, there is an additional feature which must be considered – custodianship. The data contained in these large databases are the result of huge clinical effort. Funded by the NHS and ultimately the taxpayers of the UK, some estimates state that the time spent by clinical staff inputting data is nearly 50% of their working day, which represents a huge economic spend.

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Ultimately, though, this data represents the deeply personal and often life-changing stories of individuals across the country. Our Patient and Public Panel members speak passionately about their own experiences and feel a real sense of ownership over the data. Although much work has gone into explaining the consent opt-out model to the wider public, we found that the ground level knowledge is still sporadic and the trust remains fragile. Many of our Patient and Public Panel members were surprised to know their data could be accessed without direct consent and many voiced concerns around how they believe large data might be sold to companies.

As researchers, we must be sure to listen to these concerns and discuss how they can be addressed. The effects of mass consent withdrawal should not be underestimated as we move forward. The need to communicate effectively with all patient groups across the UK could not be more important if we wish to continue to realise the benefits that big data has enabled.

Resourcing and training are key

One of the more important aspects to ensure we are conducting good PPIE is ensuring that the resources and training are in place to mediate this activity as a specific part of the research programme. Strategic planning, dedicated budgets and time are all essential, but the presence of specific support staff and quality training delivered not just by PPIE staff but also in collaboration with patient and public members goes a long way to ensuring success.

The presence of someone with specific responsibility for PPIE allows a personal and dynamic relationship to be built with patient and public members and has proved key in our unit. It is important to recognise that trust takes time to develop; it is the consistency and care taken by these important members of the research team that makes all the difference to the long-term involvement and development of patient and public members.

Representation as a driver of equality

Alongside resources, we must ensure that diverse contributions are valued and that unrepresented communities within medical research are given the opportunity to express their opinions. We hope our Patient and Public Panel is a good example of this, with 84% of participants from ethnic minority backgrounds with a good mix of gender and age representation and a wide range of transfusion-related health backgrounds.

We have also been lucky enough to have active involvement from the leaders of third sector organisations including the South Asian Health Action, Sickle Cell Society and the African Caribbean Leukaemia Trust, which has been a huge help to drive a more diverse group of participants.

GLORIA TOLUWALOPE, BTRU PANEL MEMBER

> **“ I got involved in the BTRU because I wanted to learn more about what goes on behind the scenes in terms of how the research is done, how patient data is processed, and give my opinions based on the experiences I have had so it can be done better for others.**

As well as asking for involvement in our research efforts, we have also collaborated to meet the needs of patient and public members, facilitated discussions with NHS Blood and Transplant staff and conducted outreach work. A recent discussion held with 20 women of the Islington Bangladeshi Association explored questions about anaemia, diet, blood transfusion and donation. This session highlighted the need to focus on a related topic of personal interest, where people can take small steps towards research engagement and involvement.

Equality and equity

The presence of a diverse Patient and Public Panel has brought a wide range of contributions and questions themed around equality and equity in healthcare, which seem to illicit the deepest interest. We have been asked how factors like a patient's geographical location, ethnicity or socioeconomic status will affect their access to treatment and their outcomes. Panel members speaking from personal experience are quick to describe differences in care and approaches that support the variable audit findings that we are all well aware of.

As examples, for many years, it has been recognised that patients from ethnic minority and disadvantaged backgrounds may not receive equal healthcare, which can result in different patient outcomes. The MBRRACE-UK Perinatal Mortality Surveillance report 2019 showed that Black pregnant women are 5-times more likely and Asian women twice as likely to die during pregnancy and childbirth than White women. Daily reported experiences within the healthcare system have indicated that women from ethnic minority groups feel 'unwelcome and poorly cared for', while young Black men are 6-times more likely than young White men to be sectioned for compulsory treatment under the Mental Health Act (Bradford District Care Trust).

Relation to transfusion medicine

Inequalities and inequities have been less explored in transfusion medicine. However, differences in transfusion rates and the Hb levels at which transfusions are given have been shown to differ depending on ethnicity; more work is needed to clarify these differences and their consequences.

It is also known that patients with transfusion-dependent anaemias, such as sickle cell disorder, who have multiple complex alloantibodies are sometimes unable to receive enough appropriately matched blood. This reflects, in part, the challenges of having a sufficiently large and diverse pool of blood donors. Inadequate matching of blood may increase the risks of complications and adverse reactions to transfusions.

Clinical trials may often be largely conducted in White patients and may not have the power to highlight risks unique to other less frequently involved participant sub-populations. These findings are of great interest to our patient and public members; there was a strong appetite to have this explored and addressed within our research. Ensuring that research questions not only address the original objectives but can be expanded to meet the other questions raised by patient and public members has brought about a sense of collective ambition.

Overall, we have found that, by really listening to the opinions and motivations of patient and public members, researchers are able to ensure a collaborative learning approach where everyone involved feels the benefit of this unique relationship. We believe equality of healthcare will be informed by the understanding, involvement and ultimately trust of public and patient members. The effective implementation of PPIE is a critical and also extremely rewarding part of the research process.

To end, we leave you with the advice we received from Eddie Carr, an experienced patient and public member involved in healthcare research.

> **“ I became involved in the BTRU research programme because I felt that I wanted to use my lived experience as an NHS patient to help shape and steer health research for the benefit of all. Being of Black African ethnicity, I endeavour to provide representation from a diverse perspective and promote inclusivity in pursuit of helping to reduce health inequalities. I would like all clinical staff and researchers to know and appreciate the positive and valuable benefits that patient and public interaction can bring. Progress best occurs when a voice is not just heard but is listened to and engaged. PPIE seeks to provide that important communication forum.**

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