

Example - Showcasing good practice for public involvement in research

Keith Wilson, Patient Ambassador at the Liverpool Heart and Chest Hospital



People and place

[Liverpool Heart and Chest Hospital](#) provides heart and chest services for the North West of England, performing 80,000 outpatient appointments and 13,000 inpatient procedures each year. The hospital has a strong [research](#) ethos, carrying out research at both local and international levels. It aims to be a national leader in the involvement of patients and families in research. The [Service User Research Endeavour \(SURE\) Group](#) was established in 2004 and in 2014, Head of Research, Dr Margarita Perez Casal, oversaw the appointment of a full time Research Patient Ambassador post. Part-funded by the [Lord Leverhulme Charitable Trust](#), the role is carried out by Keith Wilson, a former cardiac patient.

What they are doing

The Research Patient Ambassador role was created to bring patient perspectives to the heart of the research team. The post is accountable to the Non-Executive Director for Research and works closely with the research team on an everyday basis. “My role is solely to protect the interests of research participants,” explains Keith. “Anything which involves a person in research, I am involved.”

Keith’s remit is wide and linked directly to the delivery of the Trust’s research strategy. He is involved in the design, running and evaluation of research projects and in applications for research funding. He is responsible for building links with other public involvement initiatives nationally and for organising service user advisory panel activities for research within the Trust. He is the first point of enquiry for researchers and other Trust staff on service user and patient involvement issues.

Keith also chairs the SURE Group. Members are current and previous patients of the hospital. They receive training to fulfil their role and hold an Honorary Contract with

the hospital Trust. They work with the Trust's Research and Innovation Committee to help define, implement and monitor the Trust's Research and Development policies and actively support user-led research projects, reviewing all research applications and accompanying materials for appropriateness and accessibility. "People on the ward who ask about research are made aware of the fact that the documentation has been through a patient group," says Keith. "We aim to make research open, transparent and easier to understand and participate in."

The difference it is making

Keith believes that the development of his role and that of the SURE Group as resources for the Trust's clinicians and researchers has enhanced their understanding of the benefits of public involvement, and the needs of patients as research participants. "I look from a patient point of view. I have experience of the fear and anxiety that a patient experiences. A clinician or scientist has their own perspective, but mine's different – it's personal, I can appreciate what it is like to participate in a research project. It's important to remember that research is about patients, not clinicians." As a result, Keith reports significant increases in numbers of patients recruited to trials at the Trust, and greater retention of participants. "If people look at the documentation and understand it, they're more likely to take part and stick with it."

Keith has also noticed a change in the way researchers approach patient involvement and participation. "I know it's working when the clinicians and researchers come to me at the start of their research project for me to give an opinion and see what the SURE Group thinks. It's not a case of 'This is what we've done', it's 'This is what we're thinking of doing, what do you think?'" Keith notes that it is not unusual for researchers to consult him before approaching the Ethics Committees.

Keith feels that the Trust's commitment to public involvement has created a culture shift which will be fully embedded within a generation. "Teaching staff now invite me to talk about the importance of patient involvement to the junior nursing staff, as part of their research module. To those students, patient involvement is the norm."

Why it works

At Liverpool Heart and Chest Hospital, patient involvement has the support of senior leaders. Keith suggests that this not only sets an example to the whole organisation, it also ensures the notion of patient involvement is integrated, sustained and not reliant on any one particular individual.

On a practical level, as well as creating a full time professional post for involvement, the SURE Group has been given a proper infrastructure to make sure it can deliver on its aims, including secretarial support, a dedicated contact number and learning and development opportunities. As Keith describes: "Anything we need – such as training for an aspect of a research project – they will provide us with someone to give us the detail."

Importantly, this is not tokenism: the Group has investment and genuine influence. If Keith and the SURE group feel that patient information for a research project is not accessible to patients, unless changes are made, the Trust does not proceed with

that project. “If the patient group doesn’t agree with any part of the research”, Keith explains, “and if it can’t be sorted out, the research does not go through. There is total commitment to this and it makes everyone feel valued.” The Trust has empowered patients to speak out and make a contribution to research in what could otherwise be an intimidating environment. “It’s important for me to question things”, says Keith, “to ask, to say what I don’t understand, when things don’t make sense to me.”

Commitment is a key theme, both from the Trust, which has made a full time financial commitment, and also the patients who are involved. Keith has worked hard to promote the credibility and value of patient involvement. “I know everyone in this Trust. I have regular contact with the Chief Executive, the clinicians, the senior house officers and the junior doctors.”

Finally, for Keith, a major strength of the initiative is collaboration: “I don’t work alone: I’m the product of other people’s involvement and the work they’ve done to enable me to contribute.” There is no ‘them and us’ between the research team and the patients. Patient involvement is an important, integrated and valued part of the system.

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