

IN Bulletin 7 – Shared Research

Welcome to the seventh issue of our IN: Bulletin.

This bulletin focuses on shared research where those who have been supported by a social care scheme interview others. Shared Lives Peer Researchers Rachel Turner and Paul Vickery and Principal Investigator Nadia Brookes explain.

Sophie Ainsworth



I stumbled into the world of research and healthcare, following a diagnosis of Lupus in 2014, when I was 14 years old. Since then I have become a passionate advocate for patient voice in healthcare, particularly for children and young people, who are often overlooked.

Following my diagnosis, I became a participant in research studies, both as a patient and being on advisory groups. I have sat on the advisory group for the TRECA Study, which develops multimedia interventions for patient information sheets. I have also worked closely with the Alder Hey Clinical Research Facility and Lupus UK on a variety of projects and have been an NIHR Patient Research Ambassador for two years.

Most of my work nowadays focuses on RAIISE, a charity I founded two years ago which stands for Raising Awareness of invisible Illnesses in Schools and Education. It is dedicated to supporting students who are living with 'invisible' illnesses to ensure they are given the support they need in

school by equipping teachers with resources and information to do so.

Jane Taylor



I have spent most of my working life in higher education and now work part time for the Open University. My interest in patient and user involvement comes from my own experience as both patient and carer. I was diagnosed with rheumatoid arthritis aged 26 and antiphospholipid syndrome and osteoporosis in my 30s. Over the intervening years I developed a couple of other long term conditions for good measure! As well as my own experience I support a sibling with schizophrenia and diabetes and a daughter with a number of health conditions.

I am currently Chair of Arthritis Research UK's Patient Insight Partner group and have worked with the charity in a voluntary capacity for 8 years bringing patient insight to various research activities including review and evaluation of funding applications and training of researchers in using PPI.

I also chair the European Patient Insight Group for APPROACH, a 5 year IMI-funded project on osteoarthritis involving 25 European partners and one USA partner – advising on clinical trial design, ethical issues and patient communication.

I am a member of a Maternal and Foetal Health Advisory group at St. Mary's Hospital, Manchester and a Member of an Expert Advisory Group for the Taskforce on Multiple Conditions.

I am passionate about ensuring that all patient and carer

voices are represented and are part of the whole research cycle from shaping research questions to ensuring findings get widely disseminated.

Cheryl Gowar



I am particularly concerned with people being able to take an active role in the management of their long-term conditions, and with the appropriate treatment and support infrastructure being in place to allow for that.

My main concern is to challenge inequality in health and care provision. My career started in academic research but I moved into the health and social care sector in 2011 when I started working for RADAR (the Royal Association for Disability Rights), now Disability Rights UK.

Currently, I am the Policy and Campaigns Manager at NAT (National AIDS Trust). There I have led on projects involving access to good healthcare for people from Black, Asian, and minority ethnic (BAME) communities, trans people, and people being held in immigration detention.

Public Information Pack (PIP)

Booklet 2: Getting started

2018. How to get actively involved in NHS, public health and social care research – Getting started.

The Public Information pack (PIP) is made up of four booklets and is for members of the public who are interested in getting involved in NHS, public health and social care research. The booklets have been produced by INVOLVE with support and advice from members of the public to help us ensure we cover the kind of information people need when first getting involved in research.

The other three booklets in the series are:

[PIP 1: A quick guide](#)

[PIP 3: Finding out more](#)

[PIP 4: Jargon buster](#)

No. of pages: 31

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Ngawai Moss



I was recruited into a large clinical trial in 2011 and have been involved in a broad range of Patient and Public Involvement work ever since.

My area of interest is Women's Health where I am an active member of Katie's Team (an Advisory Group hosted at QMUL). With their support I have been active in most areas of the research lifecycle and also [co-authored a paper](#) about involving pregnant women, mothers and members of the public to improve the quality of women's health research. In 2017 I also became part of the 'Women and Families Involvement Group' within the National Maternity and Perinatal Audit.

Having a young family and elderly relatives I have used a broad range of health and care services which also informs my perspective and motivates me further to use my business skillset to increase the impact and reach of the INVOLVE Advisory Group's work.

I am also a member of the British Standards Institute (BSI) Knowledge Management Systems Committee and love anything chocolate!

Ruth Richardson



I have held senior management roles in the voluntary, community and social enterprise (VCSE) sector since 2010 and am currently Deputy Chief Executive of a community interest company delivering talking therapies in the South West. In this role I lead on partnership work and patient involvement, and am passionate about ensuring the voice of the end user is represented in all aspects of healthcare – from research, planning and design through to evaluation and sharing learning. In a previous role I recruited and supported a team of older people to become commissioners of voluntary sector services and also community researchers, evaluating the effectiveness of interventions to tackle isolation and loneliness in later life. I became involved with Involve in order to support the vision of world-class public engagement in research, and to share my own experiences of service user involvement.