

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.

Angela King



I spent over a decade in the health related voluntary sector as a volunteer (including Trustee) and employee (including Chief Executive), before stepping into a variety of Patient and Public Involvement roles, mostly within the National Institute for Health Research (NIHR), where I continue to act as a lay reviewer.

I was an INVOLVE Advisory Group Member from 2010-2013, and have been a lay member of a number of national advisory

bodies, steering groups and committees (including the organising committee of an international scientific conference and the REF2014). I have presented at conferences, run workshops, written articles and designed and delivered training for researchers and patients.

I have worked as an independent consultant in patient involvement/engagement for several years, is a member of the Health Foundation's College of Assessors, Trustee of Pharmacy Research UK, member of the NIHR Dissemination Centre's College of Raters, a lay reviewer for the BMJ and a member of the Healthcare Quality Improvement Partnership's Service User Network.

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.

Janet Tonge



My background is in improvement work in the NHS and local government where I've worked extensively with public groups and people affected by various health conditions in order to help commissioners and clinicians understand how well services are working and what needs to

change.

Most recently I led a programme to improve cancer services in Manchester which had the principle

of co-production with people affected by cancer at its heart.

I am a supporter of older parents one of whom has multiple conditions. This has given me more

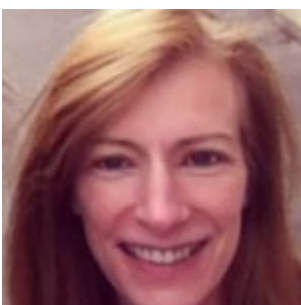
experience than I would like of navigating health services especially those related to cardio vascular

disease and neurological conditions. I also have experience of musculoskeletal services myself.

My research interests are focussed on lung cancer and in particular developing information and tools

to help people make up their minds about whether to be screened or not.

Joyce Fox



My background is in education – secondary, FE

and HE – and in the management and delivery of training.

I have lived with a long-term condition for over 20 years, and have provided hands-on care, support and advocacy for relatives with co-morbid conditions. My experiences have given me considerable learning and insight, and a passion to find ways to co-produce to ‘make a difference’ and contribute to change that will deliver long-term widespread benefits to patients, professionals and healthcare provision in general.

I am particularly interested in the area of self-management for people with long term conditions and hidden disabilities – both in raising public and professionals’ awareness, and in supporting and developing its practice through the timely provision of appropriate resources and support.

I am involved in co-production at local, regional and national level, and am keen to contribute to, and ensure there is, meaningful and effective public involvement at all stages of service delivery and research. I have participated in a variety of research studies, and I am currently a member of a number of advisory groups and a research partner. I am particularly interested in the areas of Learning and Development, and Community and Partnerships.

Eleni Chambers



I've worked in research since the late 90's in

different contexts, including whilst working for user-led organisations and as a survivor researcher in University departments. My interest in involvement originates from activism in service delivery settings.

Currently I am also a trustee for the National Survivor User Network, a member of Shaping Our Lives National User Group and a member of the PPI Reference Group for NETSCC within the NIHR, as well as being active in my local area. I have a particular interest in involving communities who are marginalised and/or not usually involved and am currently doing a PhD in involvement in Palliative Care research.

David Chandler



I have diverse experience, having been involved in the voluntary sector since 1993. I have held the posts of coordinator of the Skin Care Campaign at the National Eczema Society, general manager at Teaching Aids at Low Cost, an international healthcare training and education NGO and Chief Executive of the Psoriasis Support Trust. I also co-founded, and jointly managed the Psoriatic Arthropathy Alliance (a charity) with my wife Julie, following my own diagnosis with psoriatic arthritis.

During this time, I have been a patient advocate, and given presentations on the patient perspective in Europe and the US, written and published articles, developed awareness campaigns and been involved in the development of both quantitative and qualitative research.

I am currently Chief Executive of PAPAA – The Psoriasis and

Psoriatic Arthritis Alliance a UK patient charity. Prior to moving into healthcare advocacy, I worked in commercial business. I am also involved in a number of committees and agencies (including NICE and the MHRA) as a patient or lay member, combining my own personal experience of having both psoriasis and psoriatic arthritis with that of those the charity represents. I have a keen interest in social inclusion, equality issues and like to champion the ordinary person's views, by encouraging individuals to engage and have a voice.

Laura Young



I have recently joined INVOLVE, and my role is to provide support and assistance to the Office Co-Ordinator & Director's PA and to the Website and Information Technology Officer. My background lies in design, and I have already brought my skills to INVOLVE by refreshing and rebranding existing publications, creating infographics and providing assistance when it comes to the editing and updating of the INVOLVE website. I have many exciting projects that I am looking forward to getting actively involved in. I have previously worked in the banking sector, the design industry and also in lettings.

Kate Sonpal



Working with the public has always been important to me.

After several years as a nurse I became the Patient and Public Involvement Officer at the Southampton NIHR Clinical Research Facility, Biomedical Research Centre, and Biomedical Research Unit. As part of this role I established core public involvement groups for both adults and children, as well as a young adults group in collaboration with the South Central Research Design Service. Outreach work allowed me to help researchers facilitate condition specific groups, as well as reach out to the local community and ensure that opportunities for involvement were offered to a diverse range of people.

I ensured that education on public involvement was a priority, both to the public and the research community. I am passionate about the involvement of people in research, especially children and young people.

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