Guidance on co-producing a research project

Co-producing a research project is an approach in which researchers, practitioners and the public work together, sharing power and responsibility from the start to the end of the project, including the generation of knowledge.

This guidance is a first step in moving toward clarity about what we mean by co-producing a research project. It explains the key principles and features of co-producing a research project and suggests ways to realise the principles and key features. Finally, the guidance outlines some of the key challenges that will need addressing, in further work, to aid those intending to take the co-producing research route.

Pages: 20

Cicely Saunders Institute

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.

Cambridgeshire and Peterborough NHS Foundation Trust

What you need to know about payment

An introductory guide for members of the public who are considering active involvement in NHS, public health or social care research.

20 pages

Please note that benefits guidance and tax legislation been subject to considerable change/reinterpretation since 2019. Any INVOLVE documents referring to the payment of involvement fees may now be out of date and are pending a review during 2020. INVOLVE's guidance should not be substituted for professional advice, and INVOLVE accepts no liability for decisions or actions taken as a result of its guidance. You are always recommended to take your own tax, finance or legal advice.

Barts Health NHS Trust