

# Patient and Public Involvement (PPI) Event

12 March 2024

## EVENT GUIDE



09:30 - 10:00 Registration and Refreshments

10:00 - 10:25 Welcome

A virtual message from Professor Dame Anna Dominiczak,  
Chief Scientist (Health) Scottish Government

Reducing health inequalities by conducting locally-relevant research  
Bea Dawkins, Public Involvement and Engagement Specialist, NIHR Health  
Determinants Research Collaboration (HDRC) Aberdeen

10:25 - 11:25 Workshop 1:

1A  
Pre-Clinical Research

1B  
Working with  
Underserved Groups

1C  
Improving Clinical  
Trials with PPI

11:30 - 12:30 Workshop 2:

2A  
Working with  
Underserved Groups

2B  
Aging, Caregiving,  
Cognitive Impairment

2C  
Impact and Evaluation



12:30 - 13:30 Lunch/Networking

13:30 - 14:30 Workshop 3:

3A  
CSO Early Career  
Researchers

3B  
Rewards and Finances

3C  
PPI in Data Science



14:30 - 14:50 Break

14:50 - 15:30 Workshop 4:

4A  
Working with People with  
Additional Needs

4B  
Working with Children  
and Young People

4C  
Support for PPI

15:30 - 16:00 Feedback, PPI Awards and Future Direction

Programme is correct at time of printing but may be subject to change.

## Workshop 1 Overview 10:25 - 11:25

### Workshop 1A: Pre -Clinical Research Chaired by: Julie Simpson | Learning Studio 1

- 10.25 - 10.40 Introducing PPI to the next generation of cancer researchers.  
Professor Valerie Speirs, Professor of Molecular Oncology, University of Aberdeen
- 10:40 - 10:55 Establishing a menstrual bleeding disorders PPI group  
Dr Marianne Watters, Clinical Research Fellow, University of Edinburgh
- 10:55 - 11:10 Experiences from the CRUK RadNet Glasgow PPI Group  
Dr Aileen Duffton, Lead Research Radiographer, NHS Greater Glasgow and Clyde; and Linda Galbraith, PPI Lead, RadNet Glasgow
- 11:10 - 11:25 PPI in basic science research in diabetes  
Dr Anna Barnett, NHS Research Scotland Diabetes Network Manager, University of Dundee; and Jennifer Watson, PPI contributor

### Workshop 1B: Working with Underserved Groups Chaired by: Carol Porteous | Auditorium

- 10.25 - 10.40 Co-producing research with people with living/lived experience of substance use  
Aileen O'Gorman, Professor of Substance Use and Social Policy, University of the West of Scotland; and Wez Steele, Senior Training and Development Officer, Scottish Drugs Forum
- 10:40 - 10:55 Consortium Against Pain Inequality (CAPE) - engaging and involving adults with lived experiences in research on the impact of adverse childhood experience on chronic pain  
Maureen O'Reilly and Debs Smith, CAPE Chronic Pain Advisory Group members
- 10:55 - 11:10 'We're vaccine curious not vaccine hesitant': working with community organisations to produce evidence-informed recommendations about increasing COVID vaccine uptake among ethnic minority groups.  
Professor Shaun Treweek, Professor of Health Services Research, University of Aberdeen
- 11:10 - 11:25 Barriers and Facilitators to ethical co-production with Autistic individuals with lived/living experience of eating disorders  
Dr Fiona Duffy, Consultant Clinical Psychologist/Senior Lecturer, Edinburgh University; and Becky Choat, Scottish WomensAutism Network

### Workshop 1C: Improving Clinical Trials with PPI Chaired by: Sarah Kennedy | Learning Studio 2

- 10.25 - 10.40 Patient and Public Involvement in Decentralised Clinical Trials  
Dr Amy Rogers, Clinical Lecturer, University of Dundee, Ken Tait, member of the Trials@Home Project Patient Expert Panel
- 10:40 - 10:55 MND-SMART - PPIE Group  
Judith Newton, Motor Neuron Disease Nurse Consultant for Scotland, University of Edinburgh
- 10:55 - 11:10 Public and Patient Involvement in a trial of remotely-delivered weight management for people with long covid and excess weight  
Dr Tracy Ibbotson, PPIE lead, University of Glasgow; and Chris White, Long Covid Scotland
- 11:10 - 11:25 Empowering patient involvement in cancer clinical trials  
Andrea Harkin, Operations Director, Glasgow Oncology Clinical Trials Unit; and Elspeth Banks, PPI Oversight Group Chair, Glasgow Oncology Clinical Trial Unit

## Workshop 2 Overview 11:30 - 12:30

### Workshop 2A: Working with Underserved Groups Chaired by: Sarah Kennedy | Learning Studio 2

- 11:30 - 11:45 PPI to guide an inclusive, viable approach to PhD study design exploring: Barriers to healthcare service access in socioeconomically deprived people living with Long COVID in Scotland  
Heather Potter, Robert Gordon University PhD Student, School of Nursing and Midwifery, Robert Gordon University
- 11:45 - 12:00 Working with underserved groups in physical activity for health academic research in Scotland - drawing on global experience.  
Deirdre Harrington, Senior Lecturer, University of Strathclyde
- 12:00 - 12:15 How can care for mental health patients be optimised  
Dr Jane Grassie, Emergency Medicine Consultant, Victoria Hospital Kirkcaldy, NHS Fife
- 12:15 - 12:30 Experience of engaging with people from minority ethnic communities and lived experience of chemotherapy  
Rubina Zafar, PAINSTORM and SenseCheQ Patient Partner, in conversation with Judith Fisher, University of Dundee

### Workshop 2B: Aging, Caregiving, Cognitive Impairment Chaired by: Julie Simpson | Learning Studio 1

- 11:30 - 11:45 Creation of 'Partners in Research' and 'Research in Care Homes (RICH) Voices'  
Dr Rosie Ashworth, Patient and Public Involvement Lead, NRS Neuroprogressive and Dementia Network, and David Ross, public contributor
- 11:45 - 12:00 Embedding public involvement in Palliative Care PhD research in Fife  
Dr Sarah Bowers, Clinical PhD Fellow, University of St Andrews; and Neil McNair, public contributor
- 12:00 - 12:15 IncludeAge: Working with older people with learning disabilities to encourage and support their active involvement in a research project.  
Dr Joe Tai, Postdoctoral Research Associate, University of Dundee; and Heather Blair, Lived Experience Expert, Advocating Together
- 12:15 - 12:30 CareFit app - aiming to improve physical activity awareness and accessibility for informal carers  
Kieran Egan, Senior Research Fellow, University of Strathclyde

### Workshop 2C: Impact and Evaluation Chaired by: Carol Porteous | Auditorium

- 11:30 - 11:45 Evaluating and Recording PPI Impact within the Usher Respiratory Team  
Anna Crawford, Patient and Public Involvement and Engagement Officer, University of Edinburgh; and Lynn Laidlaw, EAVEII PPI Group, Usher Institute, University of Edinburgh
- 11:45 - 12:00 A Research Funder's Perspective  
Sarah Thomas, Research Manager, Make 2nds Count
- 12:00 - 12:15 Ensuring SPECTRUM research is grounded in public views.  
Becky Howell, Research Assistant, University of Stirling; and Laura Santi, Alcohol and Food Discussion Group
- 12:15 - 12:30 How can we evidence the impacts of public involvement in policy-engaged population health research? Insights from participatory evaluation of a multisector sexual health research collaboration (CONUNDRUM)  
Dr. Ruth Lewis, Lecturer, School of Health and Wellbeing, University of Glasgow

## Workshop 3 Overview 13:30 - 14:30

### Workshop 3A: CSO Early Career Researchers Chaired by: Julie Simpson | Learning Studio 1

This session will focus on the latest round of CSO Fellows, their projects and their PPI plans going forward.

- Dr Hamed Badmos, Postdoctoral Research Associate (Therapeutic Science Research), University of Glasgow
- Dr Stephanie Allan, Research Associate (Mental Health and Wellbeing), University of Glasgow
- Dr Rebecca Graham, Postdoctoral Research Fellow, University of Edinburgh
- Dr Joseph Symonds, Senior Clinical Research Fellow (Mental Health & Wellbeing), University of Glasgow

### Workshop 3B: Rewards and Finances Chaired by: Sarah Kennedy | Learning Studio 2

13:30 - 13:45 Health Services Research Unit's Journey Towards More Equitable Collaboration with Public Research Partners  
Dr Magdalena Rzewuska Díaz, Advanced Research Fellow, Patient and Public Involvement and Engagement Lead; and Peter Flockhart, public research partner

13:45 - 14:00 Involving Universal Credit claimants in research  
Dr Marcia Gibson, Research Associate, MRC/CSO Social and Public Health Sciences Unit, School of Health and Wellbeing, University of Glasgow

14:00 - 14:15 PPI Rewards, finances and acknowledgment at the Asthma UK Centre for Applied Research Patient and Public Involvement Platform.  
Laura Gonzalez Rienda, Asthma UK Centre for Applied Research Patient and Public Involvement Platform Research and Operations Assistant, Usher Institute, University of Edinburgh

14:15 - 14:30 The importance of navigating PPI activities with partner organisations and participants on their drug use recovery journey: more is not always better  
Dr Camila Biazus Dalcin, Lecturer, School of Health Sciences, University of Dundee

### Workshop 3C: PPI in Data Science Chaired by: Carol Porteous | Auditorium

13:30 - 13:45 "My Data": a PPI project to understand the perceptions of administrative data usage for research of people who used drugs.  
Louise Marryat, Baxter Fellow and Public Engagement Lead, University of Dundee

13:45 - 14:00 Scotland Talks Data: Reflections on Recruitment and Working in Partnership  
Harriet Baird, Engagement Lead, Scottish Centre for Administrative Data Research, University of Edinburgh and Katie Oldfield, Public Engagement Manager, Research Data Scotland

14:00 - 14:15 Dedicated funding, people and time: the game changers for PPIE in health data research  
Sharon Gordon, ACHDS Programme Co-ordinator, University of Aberdeen

14:15 - 14:30 Searching for the sweet spot between accuracy and clarity  
Kirsteen Campbell, Communications and Engagement Officer, University of Edinburgh and Mhairi Docherty, public contributor

## Workshop 4 Overview 14:50 - 15:30

### Workshop 4A: Working with People with Additional Needs Chaired by: Julie Simpson | Learning Studio 1

14:50 - 15:00 Research for Everyone: making complex health research easier to understand  
Fiona Barlow, Impact and Communications Officer, Scottish Learning Disabilities Observatory at the University of Glasgow; Aaron Hume, public contributor

15:00 - 15:10 An inclusive approach to patient and public involvement (PPI)  
Dr Chris McParland, Postdoctoral Research Associate (Nursing) - University of Glasgow

15:10 - 15:20 Lessons learned from a PPIE project with underserved groups: What matters to you? Exploring Equitable Access to Healthcare with Black, Asian, and Global Ethnic Majority Women (GEM) in Aberdeen  
Leila Neshat Mokadem, Senior Lecturer (Pharmacy), University Equality Champion, PhD candidate (PPIE), Robert Gordon University

### Workshop 4B: Working with Children and Young People Chaired by: Sarah Kennedy | Learning Studio 2

14:50 - 15:00 Children and Young People, Parents and Patients as Active Partners in Clinical Trial Design and Health Technology Development- What Difference Does it Make?  
Dr Pamela Dicks, Network Manager and PPI Lead, NHS NRS Children's Network; and member the Young Persons Advisory Group (YPAG)

15:00 - 15:10 Loneliness in a Digital World - meaningfully involving young people in shaping health research  
Sarah Robertson, Youth Engagement Lead, Generation Scotland/University of Edinburgh; and Eva Drummond, public contributor

15:10 - 15:20 What factors influence young people's involvement in policymaking and service improvement? A systems perspective.  
Carolyn Blake, Research Associate, University of Glasgow

### Workshop 4C: Support for PPI Chaired by: Carol Porteous | Auditorium

14:50 - 15:00 Creative approaches to reimagining Patient and Public Involvement (PPI) in cancer research  
Gaston Welisch, Research Associate, Glasgow School of Art

15:00 - 15:10 Values and value in patient and public involvement: moving beyond methods  
Dr Rosemary Hollick, Senior Clinical Lecturer and Honorary Consultant Rheumatologist, University of Aberdeen; and Lynn Laidlaw, public contributor

15:10 - 15:20 Developing a flexible approach to Involvement meeting the needs of patients, carers, health providers, academics and the whole research community  
Chris White, Network Peer Involvement Worker, NRS Mental Health Network