

New Developments in Public Involvement in Research

“Building the evidence base for public involvement in health services research”

A conference organised by the PenCLAHRC
Patient and Public Involvement Team

13-15 November 2013, Exeter



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Detailed abstract and presenter information can be found in the Abstract Booklet

Patient and Public Involvement in PenCLAHRC

The PenCLAHRC Public involvement Team aims to embed meaningful patient and public involvement throughout all PenCLAHRC activities. Delivering this requires the team to develop effective methods for the engagement of members of the public, both in helping to set the research agenda and in shaping specific projects. Key to this has been the setting up of a dedicated public involvement group within PenCLAHRC - the Peninsula Public Involvement Group (PenPIG). PenPIG is a group of patients and carers who volunteer their valuable time to make sure PenCLAHRC's research is relevant to the needs of the public. The members have many roles including; helping to recruit new staff, acting as co-applicants on projects, advising on research projects, presenting at conferences, training new medical students and contributing to the running of PenCLAHRC.



Introduction



Professor Nicky Britten

**PenCLAHRC Lead for Patient and Public Involvement
Professor of Applied Health Care Research**

Dear Delegate,

On behalf of the conference organising team, I would like to extend a very warm welcome to you! I do hope that you enjoy the conference, learn more about the many interesting projects being presented, make new connections as well as seeing old friends, and maybe even get to see a little of the historic city of Exeter. We were inspired to organise this conference because there is now such a diversity of research projects enriched by public involvement, offering the opportunity to share learning and build up an evidence base. Public involvement can take many forms – there is no ‘one size fits all’ – and we can all learn from the experiences of others. Through doing so, we can all deepen our understanding of public involvement, and help to shape the growing research literature on this topic. We hope that the conference will provide a safe space in which to discuss the successes and failures of public involvement, and its associated rewards and challenges. Conference delegates are drawn from several ‘constituencies’ and we hope that this will lead to fruitful and enjoyable discussions as the conference progresses. The programme includes inspiring headline speakers, a range of workshops, papers about individual research projects, many meal breaks, and even the Devon based humorous poet Matt Harvey, host of Radio 4’s Wondermentalist programme. Whether or not you are making a presentation or running a workshop, we hope that the conference will make a positive and lasting contribution to your own research or to your understanding of public involvement.



Professor Stuart Logan

**Director of PenCLAHRC and Institute of Health Research
Cerebra Professor of Paediatric Epidemiology**

One of the most far reaching developments during my research career is the increasing recognition that proper engagement with the public can have a profound impact on research. This development has been driven largely by ethical considerations – the public pay for research through taxes and donations and the data we collect belong to the participants, so they deserve to have some control of what is done – and because researchers have realised that engagement increases the likelihood of successful delivery of projects.

For me personally, equally important has been the recognition that those who use services are the final decision makers and that, if researchers address the questions that matter to service users in a way that answers their information needs, it substantially increases the likelihood of the findings having an impact. The increasingly closer working between our research groups and members of the public has also fundamentally changed how I experience the process of doing research. For me these opportunities, in particular having input from families with disabled children, has completely transformed the questions I am interested in, how I think about research design and how we approach dissemination and implementation.

I am delighted that we have been able to host this conference in Exeter as part of our collective attempt to decide how best we can facilitate engagement and how we can assess its impact.



Keynote Speakers



Sir Iain Chalmers

A founder of the Cochrane Collaboration and coordinator of the James Lind Initiative

Iain Chalmers practised as a clinician for seven years in the UK and the Gaza Strip, before becoming a full time health services researcher. Between 1978 and 1992 he was founding director of the National Perinatal Epidemiology Unit. Between 1992 and 2002, he was founding director of the UK Cochrane Centre, which convened the meeting at which the Cochrane Collaboration was inaugurated. Since 2003, he has coordinated the James Lind Initiative to promote public and professional acknowledgement of the need to address uncertainties about the effects of treatments. He is coordinating editor of The James Lind Library and Testing Treatments Interactive. He was knighted in 2000 for services to health care.



Professor Jennie Popay

Professor of Sociology and Public Health at Lancaster University

Jennie Popay is Professor of Sociology and Public Health in the Faculty of Health and Medicine at Lancaster University. She leads a programme of research on the social determinants of health inequalities including evaluations of complex area based interventions addressing these determinants. She seeks to involve the public in all her research and has first-hand experience of the rewards and challenges this entails. She has recently completed a Medical Research Council funded study producing guidance on assessing the impact of public and patient involvement in health research.



Derek Stewart OBE

Associate Director for Patient and Public Involvement at the National Institute for Health Research for the Clinical Research Network

Derek was treated successfully for cancer of the larynx in 1995 and has since become involved in numerous aspects of patient involvement at local, network and national levels. As the founder Chair of the Consumer Liaison Group, Derek assisted with the development of patient participation in the establishment and work of the National Cancer Research Network and Institute. From 2001 until 2006 Derek was Chair of Gedling Primary Care Trust in Nottinghamshire, England gaining 3 stars on inspection. This contribution to health services, in particular cancer, led to Derek being awarded an OBE in the Queen's Birthday Honours list 2006. Currently Derek is the Associate Director for Patient & Public Involvement at the National Institute for Health Research for the Clinical Research Network (NIHR CRN). The Network covers Diabetes, Mental Health, Dementias, Stroke, Cancer, Medicines for Children as well as a Primary Care and Comprehensive studies in research.



Meet the Conference Team



Professor Nicky Britten
PenCLAHRC Lead for PPI



Dr Andy Gibson
Research Fellow in PPI



Dr Jo Welsman
Associate Research
Fellow in PPI



Kade Beeson
Public Involvement
Coordinator



Dawn Sambells
PenCLAHRC Research
Information and
Communication Officer



Linda Dumchen
PA to Third Gap



Cath Williams
PenCLAHRC Administrator



Jim Harris
PenPIG* member



Stephanie Jibson
PenPIG* member



Lynn Tatnell
PenPIG* member

*Peninsula Public
Involvement Group



Delegate Information

Venue

Refreshments	Regular tea and coffee breaks are scheduled into the programme and will be served in Drakes Bar and the Hartington room. Additional drinks can be purchased from the Cocktail Bar or Drakes Bar. A buffet lunch will be served each day in the Cavendish Suite. If you have any specific dietary requirements, please let a member of the conference organising team know (if you haven't already).
Coats/Valuables	The hotel is providing coat racks, which will be located next to the main stairwell on the ground floor. However please note that these will not be supervised. We therefore recommend that you keep valuables on your person where possible, as we cannot accept responsibility for any loss or theft.
Fire Exit	Should the fire alarm sound, please make your way to the nearest fire exit (as signposted) and congregate outside.
Getting Around	A floor plan of the venue is located at the back of this booklet for your convenience. Please let a member of the conference organising team know if you require any assistance.
Exeter Information	Your delegate pack contains a brief guide to local restaurants and an Exeter City Centre street map. Further advice can be obtained from the hotel reception. Local taxi numbers are: Gemini 01392 666666 and 1st Call Exeter 01392 444333.

On the Day

Contact/Queries	The front desk is located in the main foyer/lounge and will be staffed at all times during the conference. Please let us know if you have any queries/need help in any way.
Emergencies	In case of emergency, please immediately alert a member of the conference team or hotel staff. You can also call Andy Gibson on 07941 344653 or Jo Welsman on 07707 167793.
Photography	A photographer will be present on each day to capture the event. If you do not wish to have your photo taken, please alert a member of the conference organising team as soon as possible, or let the photographer know.
Wi-Fi	The hotel offers free Wi-Fi to all delegates/guests. To log-in select 'Access free Wi-Fi' (no password is required).



Follow us on Twitter

PenCLAHRC: [@PenCLAHRC](#)
Patient and Public Involvement team: [@PenCLAHRC_PPI](#)
Sir Iain Chalmers: [@iainchalmersTTi](#)
Professor Jennie Popay: [@Popay100](#)
Derek Stewart OBE: [@DerekCStewart](#)

We will be covering the conference on Twitter using the hashtag [#piexeter2013](#)
Please can we ask that you tweet responsibly and respect the confidentiality of others.



Wednesday 13 November

11:00	Registration and Tea/Coffee		
12:00	Lunch , Cavendish Suite		
13:00 13:30	Welcome/Housekeeping – Nicky Britten Opening Address – Stuart Logan Keynote Speech – Sir Iain Chalmers: Ways in which patients and the public can help to reduce waste in research , Devonshire Ballroom (Chair: Stuart Logan)		
14:00	Plenary, Devonshire Ballroom (Chair: Stuart Logan) Building the Evidence Base: Verbal Presentations Patricia Wilson et al: Patient & Public Involvement in Research: What Works Best, Under What Circumstances and Why? The RAPPORT study. 14:30 David Evans et al: Public involvement in research – assessing impact through a realist evaluation. 15:00 Louise Locock et al: Experiences of patient and public involvement in medical research – a Healthtalkonline study.		
15:30	Tea/Coffee		
16:00	Parallel sessions		
	Option A: Derby (Chair: Maryrose Tarpey) New Approaches: Verbal Presentations Sarah Hamilton et al: Putting lived experience at the centre of the PEOPLE study: A collaborative model of research into personalisation for people with severe mental illness. 16:30 Kate Fuller et al: Getting research to the people: collaborating to provide meaningful evidence. 17:00 Sarah Denford et al: A patient and public involvement group mock decision making panel for the approval of the drug liraglutide.	Option B: Devonshire Ballroom (Chair: Jo Welsman) Exploring Experiences: verbal presentations Sarah Dean et al: Patient and Public Involvement (PPI) in Research: Academic Suicide or Success? An example from a Stroke Rehabilitation project called ReTrain. Hayley Reed et al: Collaborating with young people through a research advisory group. Tina Cook et al: Accessing and assessing the impact and legacy of participatory health research.	Option C: Burlington Exploring Experiences: Workshop Emma Lomax et al: Discovering the Golden Rules of PPI in Research Delivery
ALL DAY	Interactive Room, Chatsworth: An opportunity to explore physical models and other hands on activities, such as websites (Matthew Hurley et al and Kath Maguire et al) Posters will be available to view throughout the conference and are located on the ground floor		
17:30	Close		



Thursday 14 November, am

08:30	Registration, Tea/Coffee		
09:00	Keynote – Jennie Popay: Why involve the public in health research: democracy, legitimacy or efficiency? Devonshire Ballroom (Chair: Nicky Britten)		
09:30	Plenary, Devonshire Ballroom (Chair: Nicky Britten) Assessing Impact: Verbal Presentations Jonathan Boote et al: Public involvement in an NIHR-funded programme grant: a longitudinal, qualitative evaluation of impact and experiences.		
10:00	Sophie Staniszewska et al: The GRIPP 2 checklist: Enhancing the quality and transparency of patient and public involvement reporting.		
10:30	Tea/Coffee		
11:00	Parallel sessions		
11:30	<p>Option A: Devonshire Ballroom (Chair: Sophie Staniszewska) Training and Support: Verbal Presentations Chris Morris et al: Involving families in childhood disability research: building a partnership.</p> <p>Paula Wray et al: Peer Researcher Accredited Training Course – an adaptive training module for service users and carers, providing the tools for individuals to become partners in research.</p>	<p>Option B: Derby Exploring Experiences: Workshop Jo Welsman et al: So who will you listen to? Public participant perspectives on aspects of equality, diversity and representation.</p>	<p>Option C: Burlington New Approaches: Workshop Emma Law et al: The Participation Chain for People with dementia and their carers.</p>
12:00	Lucy Simons et al: Learning at the heart of public involvement in research.		
12:30	Lunch, Cavendish Suite		



Thursday 14 November, pm

13:30	Parallel sessions		
	<p>Option A: Devonshire Ballroom (Chair: Chris Morris) New Approaches: Verbal Presentations</p> <p>Liz Goodwin et al: People with multiple sclerosis and health economists: working together to build a better research base for making decisions about the funding of treatments for MS.</p>	<p>Option B: Derby Training and Support: Workshop</p> <p>Francine Jury et al: Engaging researchers in Patient and Public Involvement.</p>	<p>Option C: Burlington Exploring Experiences: Workshop</p> <p>Faith Harris-Golesworthy et al: A PPI Journey: an exploration of the meaning of involvement in applied health research in PenCLAHRC.</p>
14:00	<p>Michael Taylor et al: Using virtual worlds for patient and public engagement.</p>		
14:30	<p>Kristin Liabo et al: Young people's impact on a systematic review.</p>		
15:00	Tea/Coffee		
15:30	Parallel sessions		
	<p>Option A: Devonshire Ballroom (Chair: David Evans) Building the Evidence Base: Verbal Presentations</p> <p>Katherine Cowan et al: What is the relationship between the research agenda of currently funded diabetes research and that of people with diabetes and carers?</p>	<p>Option B: Derby Working with Young People: Workshop</p> <p>Chris Morris et al: Involving young people in health services research: sharing evidence, ideas and experience and identifying opportunities for the future.</p>	<p>Option C: Burlington Training and Support: Workshop</p> <p>Eileen McDonach et al: The European Patient Ambassador Programme (EPAP): Patient and carer involvement in the development and evaluation of a new online training programme.</p>
16:00	<p>Kath Maguire et al: Public and Patient Involvement in Theory and in Practice.</p>		
16:30	<p>Daniel Spiers et al: Mystery Shopper 2012 - an insight into Trust research awareness.</p>		
ALL DAY	<p>Interactive Room, Chatsworth: An opportunity to explore physical models and other hands on activities, such as websites (Matthew Hurley et al and Kath Maguire et al) Posters will be available to view throughout the conference and are located on the ground floor</p>		
17:00	Close		
19:00	Conference Dinner, Cavendish Suite		



Friday 15 November

08:30	Registration, Tea/Coffee		
09:00	Parallel sessions		
	<p>Option A: Devonshire Ballroom (Chair Andy Gibson) Assessing the Impact: Verbal Presentations Rosie Davies et al: Bridging the gap between good practice principles and research study realities.</p>	<p>Option B: Derby Exploring Experiences: Workshop PenPIG and Rebecca Whear et al: One size does not fit all – The many faces of PPI in PenCLAHRC</p>	<p>Option C: Burlington Building the Evidence Base: Workshop Gemma Unwin et al: Involving minority ethnic groups in health research: generating recommendations from an international systematic narrative review</p>
09:30	<p>Cath Quinn et al: Can people with lived experience of a mental health condition contribute to analysis and what does everyone gain?</p>		
10:00	<p>Jonathan Boote et al: Supporting public involvement in research design and grant development: a case study of a public involvement award scheme managed by an NIHR Research Design Service</p>		
10:30	Tea/Coffee		
11:00	<p>Plenary, Devonshire Ballroom (Chair Nicky Britten) Exploring Experiences: Verbal Presentations Val Shilling et al: Evaluating formalised peer support for parents of disabled children: experiences of involving stakeholders in carrying out a programme evaluation</p>		
11:30	<p>Jill Thompson et al: Spaces for change? Critical reflection on the impacts of PPI to those involved.</p>		
12:00	<p>Keynote Speech, Derek Stewart: Tomorrow's patient: How might public involvement prepare for the future? (Chair Kath Maguire) Closing remarks</p>		
12:45	Close and light lunch, Cavendish Suite		

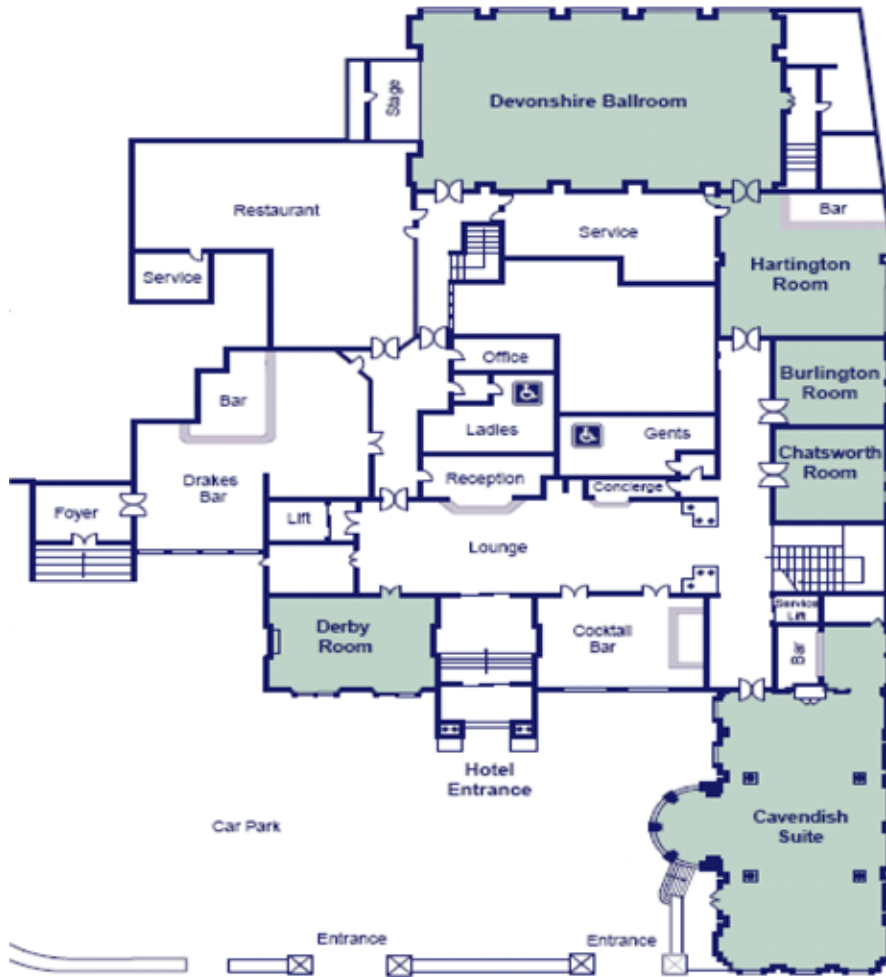
Key

	Building the Evidence Base		Assessing the Impact
	Training and Support		Exploring Experiences
	New Approaches		
	Working with Young People		



Map of Venue

Ground Floor



First Floor

