

‘International Perspectives on Evaluation of Patient & Public Involvement in Research’

Thursday 15th & Friday 16th November 2018

Lindisfarne Room, Hadrian Building, King's Road.
Newcastle University

Conference Programme

Visit the conference website for further information:

<https://research.ncl.ac.uk/napcr/eventskeydates/evaluatingppiinresearch/>

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Welcome

To the Inaugural Conference on International Perspectives on Evaluation of PPI in Research

We are delighted to welcome our plenary speakers: Simon Denegri (NIHR), Antoine Boivin (CEPPP) and Kirstin Carman (PCORI), who will give the open plenary showcasing international examples of approaches to PPI in research; Mogens Hørdér (Denmark), Thilo Kroll (Ireland), Dave Green (UK) and Núria Radó-Trilla (Spain), who will present international perspectives on the evaluation and impacts of PPI; and Laura Forsythe (PCORI), who will deliver our closing plenary entitled 'The Patient-Centred Outcomes Research Institute (PCORI) Evaluation Journey'.

We are also excited to welcome panel members, Sophie Staniszewska, Louise Locock, Nicky Britten, Patricia Wilson, Kristina Staley, Andrew Gibson, Natalie Edelman, Duncan Barron and Tina Coldham who will participate in our facilitated debate entitled 'Exploration of key questions on evaluation of PPI in research'. We are also indebted to Sally Crowe, who has been instrumental in helping us to prepare this debate.

We are particularly pleased to welcome our international delegates and those visiting Newcastle for the first time.

Patient and Public Involvement (PPI) – also referred to as 'Patient and Public Engagement' and 'Citizen Engagement' by international colleagues - is the practice or process of patients, members of the public and researchers working together to prioritise, plan, conduct and disseminate research. PPI is growing in momentum but questions remain about how it should or could be evaluated. This inaugural conference will provide an international platform to critically explore and reflect on the issue of evaluation of patient and public involvement in research.

We would like to thank everyone who is presenting work, chairing a session or contributing in some other way to the organisation of this event. We welcome any comments or suggestions you may have on the format or organisation of the conference – please do complete the online evaluation after the event. We hope that you enjoy all aspects of this inaugural conference.

Follow us on Twitter **@intppieval** and spread the word with **#intppieval18**

Welcome to our beautiful city and University campus.

This conference is generously and enthusiastically supported by our University and Faculty of Medical Sciences Engagement teams, and our sponsors, the Institute of Health & Society, School of Primary Care Research, and NENC Clinical Research Network.

KEY INFORMATION

Chairing

We are extremely grateful to all those who have agreed to co-chair a session at the conference. If you have agreed to chair but are not able to make the session for any reason, please let us know at the registration desk so we can make alternative arrangements. In the unlikely circumstances that you find yourself in a session without a chair, we'd be very grateful if someone from the audience could volunteer to watch the time and if necessary field questions to allow the presenters to focus on their papers.

Cloakroom and Luggage Storage

Cloakroom and luggage storage are available on the following days:

Thursday, 15th November 10:00 – 18:00

Friday, 16th November 08:00 – 17:30

Please note luggage cannot be stored overnight, and if not collected before closing time they may not be available until the following day. The facility is located within the main conference venue.

Conference Dinner

For those delegates already pre-booked to attend, the conference dinner will take place in The Courtyard Restaurant, on campus, on Thursday 15th November, at 6:30pm for 7pm. There will be no 'tickets' for dinner but your name badge will be stickered to indicate that you have booked a place.

Interactive in-conference voting

During the conference you will have the opportunity to participate in an on-line vote using the Ombea Response system. You will not be able to register in advance, but you may find it helpful to bookmark the site on your laptop or mobile device. This can be found here <http://ra.ombea.com/>

Internet Facilities

Wireless Guest Service

Delegates who have an ac.uk email address will be able to connect to eduroam.

All other delegates can use the free cloud WiFi network WiFi Guest to access the Internet using their own computer. The service is provided free of charge, is simple to use and requires no configuration changes to the visitor's computer. You will need to create an account to use the service, unless you already have an account for The Cloud.

Creating An Account

Here are the steps to get connected:

- From your device connect to the network WiFi Guest
- On The Cloud landing page locate the box Get online at Newcastle University and click Go
- Scroll down to select Create Account
- Enter your details and the account will be created.

The device will then be connected to WiFi Guest.

How to use the service

Connect your device to the open wireless network WiFi Guest and open a web browser. You will be automatically redirected to the The Cloud login page where you should enter your account details. After connecting the first time your device should remember your credentials for next time.

Meals and refreshments

For all delegates, refreshments will be available on arrival at the conference venue on Thursday 15th November, 14:00 – 15:00hrs

Lunch is provided on Friday 16th November from 12:00 – 13:00

The conference dinner will be held on Thursday 15th November (see details above)

Tea and coffee will be served:

Thursday, 15th November, 16:50 – 17:15

Friday, 16th November, 08:00 – 08:45

10:20 – 10:45

14:45 – 15:15

Delegates please note that the information provided on campus about allergens in any item of food on menus relates to the ingredient(s) in that specific product. However, those ingredients are sourced from, and our food is produced in, an environment where other allergens may be present. We will provide separate plates for those with allergies.

Meeting Rooms

All parallel paper sessions will take place in a number of rooms within the Lindisfarne Suite. No other buildings on campus will be used for presentations. All plenary sessions and the facilitated debate will take place in the Lindisfarne Room.

Messages

There will be a message board close to the conference registration desk where delegates can leave messages for each other.

Photography during the conference

Photographs will be taken at the conference and may be used in promotional materials or publications. If you do not wish to be photographed, please advise the photographer or a member of the conference team.

Posters

Posters can be viewed in the Lindisfarne Room from 14:00 – 15:00, Thursday 15th November and thereafter during any of the refreshment breaks. Please do not forget to vote for the best poster. Voting slips can be found in your delegate packs and we invite you to vote for one poster identified as 'professional' contributor and one identified as 'patient and public contributor'. Categories will be identified by colour coded sticker. Completed slips should be placed in the 'Voting Box' at the registration desk. The winners will be announced in the closing plenary on Friday 16th November.

PowerPoint

All meeting rooms will be equipped with a screen, PowerPoint and PC or laptop. Presenters should have submitted their presentations in advance but we recommend that you also have a copy on USB memory stick. Presenters should access the rooms before their session starts or during lunchtimes to check the facilities. Please note, we **DO NOT** supply Mac converter leads.

Programme Changes

We will try to avoid programme changes, but some are unavoidable due to last minute withdrawals. Any programme changes will be displayed on the message board by the reception desk, along with any general messages and announcements.

Registration

Conference registration will open at 10:00am Thursday, 15th November in the Lindisfarne Room.

Please note, delegates should wear their conference badges at all times while on campus as they may be refused access to conference sessions, refreshments and meals if a badge is not visible.

Delegates may be asked to present their badge at any time.

Special Needs and Assistance

We would be glad to hear from any delegates who would like assistance during the course of the conference. If this is the case for you, please let us know at the registration desk. Portable hearing loops are fitted as standard within the conference venue. Assistance will be on hand for those who need to use the lift or the wheelchair access to the Lindisfarne Room.

Twitter and Other Social Media

We encourage delegates to tweet about the conference using **#intppieval18** but please do not share photographs of individuals or of slides without requesting permission from the individual and/or author(s) first.

Workshops

Workshop capacity is limited by room size or at presenter's request. Delegates can sign up for workshops at the registration desk and should do so as soon as possible to avoid disappointment.

The sign-up sheets will only have space for the maximum number of attendees and will be removed as soon as the places are filled. Please **do not** add your name outside the attendance register spaces allocated as you will not be admitted to the workshop space.

CONFERENCE PROGRAMME

Thursday 15 th Nov: Day 1					
10.00am – 3.00pm Registration & Poster assembly in Lindisfarne room (posters to be up by 2.00pm)					
12.30-1.30pm	Pre-Conference Workshops <ul style="list-style-type: none">See conference Abstract Booklet and website for content and sign-up details				
<i>Breakout Room</i>	Alnwick	Bamburgh	Dunstanburgh	Ford	
Workshop Leads	Workshop Nicky Wilson	Workshop A. Lawrence-Jones	Workshop Markella Boudioni	Workshop Lindsay Muscroft	
	<i>Patient and Public Involvement: one way to democratise research</i>	<i>What is a PPI Café and how can I set one up?</i>	<i>Organisational support for PPI in Research</i>	<i>Patient involvement in course development – token gesture or the future of med ed? How do we evaluate?</i>	
2.00 – 3.00pm	Welcome reception Main room (Lindisfarne) Light refreshments will be provided <ul style="list-style-type: none">Poster viewing & Soapbox presentations (2)				
3.00 – 3.10pm	Conference opening: Dr Lynne Corner & Dr Susan Hrisos				
3.10 – 3.20pm	BMJ Publication Policy for reporting PPI in research <ul style="list-style-type: none">Tessa Richards, Senior Editor Patient Partnerships, BMJ				
3.20 – 4.20pm	Opening plenary				
Plenary 1	International examples of approaches to PPI in research <ul style="list-style-type: none">Simon Denegri, National Director for patients, carers and the public, National Institute for Health Research (NIHR), UKAntoine Boivin, Co-director of the Centre of Excellence on Partnership with Patients and the Public (CEPPP), CanadaKristin Carman, Director of Patient & Public Engagement, Patient-Centered Outcomes Research Institute (PCORI), USA				
4.20 – 4.50pm	Panel Discussion. Chair: Professor Richard Thomson, Co-chair: Mr Dave Green				
4.50 – 5.15pm	Comfort Break with refreshments. Poster viewing & Soapbox presentation (1)				
5.15 - 6.30pm	Parallel Sessions (6) Themed Presentations				
Lindisfarne	Alnwick	Bamburgh	Dunstanburgh	Ford	Etal
Evaluation & Impact of PPI	Children & Young People	PPI Models & Methods	PPI Models & Methods	Evaluation & Impact of PPI	Building Capacity
6.30pm	Close of Day 1				
7.00pm	Conference Dinner at The Courtyard, Old Library, Newcastle University The dinner venue is within 10mins walking distance of the conference venue, and is wheelchair accessible. Information on alternative local places to eat will be provided in your delegate pack.				

Friday 16 th Nov: Day 2 (Full Day)					
8.00 – 8.45am	Registration with refreshments, poster viewing and networking				
8.50 – 9.00am	Welcome: Professor Richard Thomson				
9.00 -10.00 Plenary 2	International perspectives on evaluation and impacts of PPI <ul style="list-style-type: none"> Mogens Hørder (Denmark) ‘Learning from Implementation of PPI in Denmark - and where to go next?’ Thilo Kroll (Ireland) ‘PPI Ignite project’ Dave Green (UK) PPI Research Partner ‘UK PPI perspective on evaluation’ Núria Radó-Trilla (Spain) ‘PPI in the Catalan biomedical research context’ 				
10.00 – 10.20	20min Panel Discussion. Chair: Dr Audrey L’Espérance; Co-chair: PPI Partner				
10.20- 10.45	Comfort Break with refreshments. Poster viewing & Soapbox presentation (1)				
10.45- 12.00pm	Parallel sessions (6) Breakout room				
Lindisfarne	Alnwick	Bamburgh	Dunstanburgh	Ford	Etal
Themed Presentations Policy, Ethics and Life Sciences Team	Themed Presentations	Workshop Kristina Staley Kristin Liabo	Themed Presentations	Themed Presentations	Themed Presentations
Situated Methods for Effective Participation	Evaluation & Impact	Evidence or experience? Different ways of knowing whether involvement makes a difference	Evaluation & Impact	Innovation in PPI	Reflections on Involvement
12.00 – 1.00pm	Buffet Lunch with Poster viewing & Soapbox presentations (2)				
1.00-1.15pm	Introduction to the facilitated debate: Dr Susan Hrisos & Dr Lynne Stobbart				
1.15-2.45pm Plenary 3	Facilitated debate: Exploration of key questions on evaluation of PPI in research <ul style="list-style-type: none"> Debate panel members: Sophie Staniszewska, Louise Locock, Nicky Britten, Patricia Wilson, Kristina Staley, Andrew Gibson, Natalie Edelman, Duncan Barron and Tina Coldham. Debate facilitator: Sally Crowe. 				
2.45- 3.15pm	Comfort Break with refreshments.				
3.15- 4.20pm	Alnwick	Bamburgh	Dunstanburgh	Ford	Etal
Parallel Workshops	Sophie Staniszewska Measuring patient and public involvement: Principles, approaches and challenges	Patricia Wilson Elspeth Mathie Helping PPI reach full impact - Normalisation Process Theory in user-friendly language!	Andy Gibson Jo Welsman Co-producing evaluation to evaluate co-production: a workshop	Teresa Finlay Lisa Hinton From frameworks to frameworking to support PPI in research	Rosie Davies Jo White Michele Kok Developing a practical approach to evaluating public involvement in research
4.30- 4.50pm Closing plenary	‘The Patient-Centered Outcomes Research Institute (PCORI) Evaluation Journey’ <ul style="list-style-type: none"> Laura Forsythe. Staff Director, Evaluation and Analysis, (PCORI), USA 				
4.50-5.15pm	Lynne Corner Reflections, Poster prizes, Next steps, Thank you, and Close				

Invited Speakers



Simon Denegri OBE is National Director for Patients, Carers and the Public in Research at the National Institute for Health Research (NIHR). He was Chair of INVOLVE – the national advisory group for the promotion and support of public involvement in research funded by NIHR – from 2011 until 2017. He was Chief Executive of the Association of Medical Research Charities (AMRC) from 2006 until 2011 and, prior to this, Director of Corporate Communications at the Royal College of Physicians from 2003. He also worked in corporate communications for Procter & Gamble in the United States from 1997 to 2000. He writes and speaks extensively about community and public involvement in health and social care and blogs at <http://simon.denegri.com/> He also writes poetry which he publishes at <http://otherwiseknownasdotcom.wordpress.com/> He was awarded the OBE in the Queen's Birthday Honours 2018.



Antoine Boivin, MD PhD holds the Canada Research Chair in Patient and Public Partnership. He completed his MSc and PhD training in the United Kingdom and the Netherlands, with a focus on patient and public involvement in quality improvement. He founded the Guideline International Network Patient and Public Involvement Working Group, and is the co-founder, with a patient, of the Center of Excellence for Partnership with Patients and the Public, as well as the Quebec SPOR SUPPORT Unit strategy for patient and public partnership in research. Dr Boivin published the first randomized trial of patient involvement in priority-setting, which received a distinguished paper award by the North American Primary Care Research Group and was selected among the top 5 research articles published by the Milbank Quarterly in 2014. He currently acts as professor and founding director of the Partnership Lab at University of Montreal Hospital Research Center, along with his part-time clinical practice in community-based family medicine.



Kristin L. Carman, MA, PhD, is the Director of Public and Patient Engagement at the Patient-Centered Outcomes Research Institute. In this position, she is responsible for leading and directing PCORI's overall efforts to see that patients and other healthcare stakeholders are fully involved in and guide all aspects of PCORI's work. Carman joins PCORI from the American Institutes for Research, where she served as Vice President and Director of the Center for Patient and Consumer Engagement, and a Co-Director of the Health Policy and Research Group, a team of more than 70 health-services research professionals. In that role, she helped conduct research on issues of public importance in healthcare quality, access, and financing; comparative effectiveness; patient and family engagement; health systems improvement; public deliberation; and health-related communications. She also led groundbreaking engagement projects funded by the Agency for Healthcare Research and Quality (AHRQ). Kristin has spearheaded consumer engagement research projects funded through AHRQ and the Robert Wood Johnson Foundation including a randomized clinical trial on deliberative juries and cognitive testing of the translation of complex scientific information and concepts for the public and patients.



Laura Forsythe, PhD, MPH, is the Director for the Evaluation and Analysis department at the Patient-Centered Outcomes Research Institute (PCORI). She is responsible for evaluating PCORI's engagement activities and overseeing externally funded projects. Laura is experienced in conducting research on facilitating adjustment to chronic illness. Her work has examined how psychological factors, the social context, and interventions affect pain, mood, and functioning among chronic pain populations. Most recently, Laura was a Cancer Prevention Fellow at the National Cancer Institute. Her work there focused on the development of a more effective approach to caring for cancer survivors through the study of survivor, provider, and healthcare system influences on health and well-being after cancer.



Mogens Hørder, Professor, DMSc, is based in the Department of Public Health, University of Southern Denmark. Mogens does research in Public Health. One of his current projects is ["The Patient as Partner in Danish Health Research"](#).



Thilo Kroll, Associate Dean for Research, has been at University College Dublin, Health Sciences Centre Since 1992. He has been conducting research into the social dimensions of health and well-being with a particular emphasis on public health perspectives on disability and health topics. He has also carried out social and health-related research in various health systems and care environments in the United States, the United Kingdom, Germany and Scandinavia. Thilo's background in psychology has led to a variety of interdisciplinary research studies combining quantitative and qualitative research methods with a particular emphasis on inclusive research designs for otherwise marginalised groups. His research interests and passion are focused on systems-related topics in global public health and inclusion. His work ranges from the individual to health and population level service systems.



Dave Green, Patient & Public Research Partner. As a member of the public, Dave has been involved in healthcare research at the Institute of Health & Society, Newcastle University for the last 10 years. He is also a panel member on the UK's National Institute of Health Research (NIHR) researcher led board for Health Services & Delivery Research (HS&DR). He also reads a lot!



Núria Radó-Trilla, holds a PhD in Biomedicine from Pompeu Fabra University (Barcelona) and MSc in Science Communication from Imperial College London. She is currently a researcher at the Agency for Health Quality and Assessment of Catalonia (AQuAS). Núria's work in AQuAS focuses on assessment and she is responsible for the Engagement pillar of the Health Research and Innovation Assessment System of Catalonia (SARIS).

Invited Debate Panellists



Sophie Staniszewska leads the Patient and Public Involvement (PPI) and Patient Experiences Programme at the RCN Research Institute, Warwick Medical School, University of Warwick. Previously, Sophie was Director of Research at the National Centre for Involvement and Director of Graduate Studies in the School of Health and Social Studies. She is a member of the National Quality Board Patient Experiences Sub-group, and recently completed a scoping study for NICE which developed the Warwick Patient Experiences Framework that informed the NICE Patient Experiences Guidance. Sophie also led a systematic review of the impact of patient and public involvement on health and social care research, funded by the UKCRC, and is currently working with EQUATOR to develop international guidance to enhance quality in PPI reporting.



Louise Locock, Professor, based in the Health Services Research Unit (HSRU) at the University of Aberdeen. Louise joined the HSRU in 2017, following 14 years in the Health Experiences Research Group, Nuffield Department of Primary Care Health Sciences, University of Oxford, where she was Director of Applied Research. She is a qualitative social science researcher interested in personal experience of health and illness; patient-centred quality improvement and co-design; and patient and family involvement in research and care. A recent focus of her work is on how to better use different patient experience data to improve care.



Nicky Britten, Professor, leads the Third Gap research group within the Institute of Health Research at University of Exeter Medical School. Nicky is a medical sociologist with particular interests in lay views of prescribed and non-prescribed treatments, patient-doctor communication about prescribing, the management of multiple medications in chronic illness, the synthesis of qualitative research, and user involvement in research. She is also a member of the Executive of [PenCLAHRC](#) with particular responsibilities for patient and public involvement, person-centred care, and the internal evaluation. Before coming to Exeter, Professor Britten worked at the London School of Economics, Bristol University, the United Medical and Dental Schools of Guy's and St Thomas's Hospitals, and King's College London.



Patricia Wilson, Professor of Primary and Community Care based in the Centre for Health Services Studies (CHSS), Kent University. Before joining CHSS Patricia was a Reader in Patient Experience in the Centre for Research in Primary and Community Care at the University of Hertfordshire. Patricia's interest in involving people in their care at self-management level extends to the field of patient and public involvement (PPI) within NHS structures and health research. She has a national and international PPI profile and was part of a group working to establish more regionally focused and synergistic PPI by bringing together component parts of the research infrastructure – CLAHRCs, AHSN, RDS and the research networks. Patricia sits on the NIHR INVOLVE advisory board, Self-Management UK advisory panel, and the Editorial Board of Research Involvement and Engagement journal.



Kristina Staley is an experienced analyst, researcher and writer. She has a background in biomedical science, gaining her PhD from Cambridge University, and working as a post-doctoral fellow in the USA. She moved into health and science policy working at the King's Fund and Sussex University's Science Policy Research Unit, to involve the public in health policy debates. Working as an adviser at the London Science Museum provided Kristina with considerable experience in making research accessible to the public. She has worked in a wide range of voluntary and statutory sectors organisations, including NICE, the Health Research Authority, INVOLVE, Parkinson's UK, and The Mental Health Research Network, to evaluate and develop policy and practice. She is the author of INVOLVE's seminal report: 'Exploring Impact: Public involvement in NHS, public health and social care research'.



Andy Gibson is Associate Professor in Patient and Public Involvement (PPI) at the University of the West England (UWE), where he leads the UWE PPI team based in the Department of Health and Social Sciences. Andy has a social sciences background, and his research interests focus on public involvement in health research. He is the academic lead for People in Health West of England (www.phwe.org.uk). He developed a framework for conceptualising PPI, that also has practical utility in the evaluation and planning of PPI. He was also part of the MRC funded team that developed the Public Involvement Impact Assessment Framework (PiiAF).



Tina Coldham, is current Chair of NIHR [INVOLVE](#). Tina was a mental health service user for 17 years, and says she is still a practicing depressive! She started involvement as a user activist through a local successful campaigning user group and setting up self-help groups. Recently Tina stood down as Chair of the National Survivor User Network. She is currently on the Board of the Social Care Institute for Excellence and is chairing their Co-Production Network. Her interest in public research developed early as a survivor researcher, to help build evidence of what she and others knew mattered in mental health. Tina's continued research passion is to share and learn across the sector.



Natalie Edelman, PhD, is a mixed methods researcher. Her interests include the interface between sexual and mental health, community delivery of sexual health interventions, problematic drug use, public involvement in research, researching disenfranchised populations and evaluation of complex interventions. She is a Fellow of the Royal Statistical Society and was a research adviser for the NIHR Research Design Service South East from 2006 to 2013, where she was Public Involvement Lead and later Continuing Professional Development Lead. Natalie leads the School of Health Sciences' Special Interest Group in Quantitative Methods and Statistics, and the NIHR Fellows Network-South East, and is Public Involvement Expert Lead for the Health Protection Research Unit hosted by University College London.



Duncan Barron works to promote meaningful user involvement with research teams and encourages patient and public involvement (PPI) at the earliest stages of their research. He has experience of supporting and training members of the public in their involvement roles. Duncan currently works part-time as PPI Regional Operational Lead for the NIHR Research Design Service in the South East where he is based at the University of Brighton, and part-time as joint PPI Lead at the Centre for Public Engagement at Kingston University & St George's University London.

Panel Debate Facilitator



Sally Crowe specialises in patient and public involvement in research, research priority setting, health outcomes development and health technology. She facilitates health related events that include the public, and also supports development projects and evaluation.

Guest Contributors



Dr Tessa Richards is a senior editor at *The BMJ* and leads the BMJs patient partnership initiative. She worked as a general physician, rheumatologist and a GP before joining the BMJ editorial staff. Here she has led the journals GP, Education and Analysis sections, and established the Over-diagnosis series (part of the BMJs Too Much Medicine campaign), and one on High Integrity Health. She is a member of the Royal College of Physicians, a BMJ columnist and writes regularly on patient perspectives. She lives with stage IV cancer and two long term conditions, and is a carer for close family members with rheumatoid arthritis, dementia, and blindness.



Audrey L'Espérance is strategic advisor and research associate with the Centre of Excellence on Partnership with Patients and the Public. Audrey has a PhD in political science from the University of Ottawa and completed a two-year postdoctoral fellowship at the University of Toronto. She was visiting scholar at the Centre for the Study of Bioscience, Biomedicine, Biotechnology and Society at the London School of Economics and Political Science in the UK in 2011. Her work focuses on public policies and practices related to assisted reproduction, experiential knowledge, and policy-making processes. She has expertise in program evaluation, public policy analysis and project management in academic and public-health settings.



Conference Organising Committee

Susan Hrisos, PhD, Senior Research Associate, Institute of Health & Society.

Lynne Stobbart, PhD, Senior Research Associate, Institute of Health & Society.

Joanne Lally, PhD, Senior Research Associate, Institute of Health & Society.

Anu Vaittinen, PhD, Research Associate, Institute of Health & Society.

Rose Watson, Research Assistant, Institute of Health & Society.

Rachel Stocker, PhD, Research Associate, Institute of Health & Society.

Melissa Girling, NIHR Research Fellow, Institute of Health & Society.

Beth Bareham, Postgraduate Research Student, Institute of Health & Society.

Nadege Uwamahoro, Postgraduate Research Student, Institute of Health & Society.

Dave Green, Patient & Public Involvement Research Partner, Institute of Health & Society.

Irene Soulsby, Patient & Public Involvement Research Partner, Institute of Health & Society.

Janet Longbottom, Patient & Public Involvement Research Partner, Institute of Health & Society.

Richard Thomson, Professor of Epidemiology & Public Health, Institute of Health & Society.

Lynne Corner, Director of Engagement, Faculty of Medical Sciences, Newcastle University.

The Conference Stars!

Terry Lisle, Senior Research Administrator, Institute of Health & Society

Christine Pearson, Research Administrator, Institute of Health & Society

Anita Tibbs, Research Administrator, Institute of Health & Society

Ann Payne, (former) Research Administrator, Institute of Health & Society

ORAL PRESENTATIONS

Using our training to highlight the value of patient and public involvement (PPI) in research.

Helen Atkinson, Eleanor Lockhart

Faculty of Medical Sciences, Newcastle University

NIHR Newcastle BRC

Background

Writing a good plain English summary and communicating scientific research to a lay audience are essential skills for researchers, and we wanted to create an opportunity for our NIHR Newcastle Biomedical Research Centre (BRC) PhD trainees to further develop their expertise. Our aim was to create an interactive learning environment and involve both the trainees and public in a workshop.

Materials and methods

In March 2018, ten Biomedical PhD trainees from the BRC took part in an interactive workshop in partnership with nine [VOICE](#) public volunteers. We asked the trainees to discuss their research with the aim of improving their skills in communicating scientific research to a lay audience.

We created mixed groups consisting of trainees and public. Each trainee then presented and received individual feedback from the public on how to make their plain English summaries more accessible. Using the feedback from the workshop, the trainees recorded a concise summary video of their research. We then launched a competition through [VOICE](#) to reach a wider audience and asked VOICE members to vote.

Results

The winner of the competition was announced at a public event by BRC Director Professor Avan Sayer. One of the trainees, Ramtin, highlights the impact of PPI on his research:

“The feedback and recommendations from VOICE members helped me a few months later to prepare a talk for the Three Minute Thesis competition (3MT). I successfully won the second prize both at the Newcastle University competition and the North East Regional Competition, which was attended by five universities.”

Conclusions

We learnt the importance of introducing bespoke PPI training at an early stage for PhD students and have a further multi-disciplinary training event planned in October 2018. A video was created to encourage the public to take part in future PPI opportunities.

Partners not participants: critical reflections of the experiences and impact of PPI in mental health

Rebecca Baines, John Donovan

Collaboration for the Advancement of Medical Education Research and Assessment (CAMERA), University of Plymouth

² *Volunteer mental health patient research partner, Plymouth*

Background

The active involvement of patients and the public throughout the research process is widely encouraged. However, limited research critically examines the impact of such involvement particularly in a mental health setting. As a result, we share and reflect on a two year journey involving two researchers (a 'traditional' academic researcher and volunteer mental health patient research partner) and charity organisations working together to achieve a common goal – improve the quality of organisational responses to patient feedback in an online environment.

Methods

Using a series of images, reflective logs and transcribed audio-recordings we present the convoluted, yet successful, journey from a patient-initiated idea through to a peer-reviewed publication.

Results

A number of traditional measures of 'success' were achieved including peer-reviewed publications, webinars, blogs and conference attendance. However, unanticipated, and perhaps more valued personal measures of success and impact were also achieved including enhanced physical and mental wellbeing, improved confidence and self-worth, patient empowerment and research ownership. Critical reflection of existing practises and processes reveal a number of barriers enforced by traditional approaches that jeopardise the value and potential impact of PPI in research.

Conclusions

Although at times challenging, PPI throughout the research process is achievable, valuable and meaningful. Opportunities and barriers will present themselves when working together in research, but in an exciting, innovative and often transformative way. We raise a number of important questions that must be considered when defining, designing and evaluating measures of success in PPI research. As in our research approach, this presentation and its content has been co-produced from the outset.

What are the essential and desirable principles of effective PPI? A systematic review and modified Delphi methodology

Rebecca Baines

Collaboration for the Advancement of Medical Education Research and Assessment (CAMERA), University of Plymouth

Background

There is international interest in the active involvement of patients and the public. However, consensus on how best to optimise its application is currently unavailable. This research therefore

sought to identify, and assess, the underlying principles of effective patient and public involvement (PPI).

Methods

Four-phase methodology: (i) extensive review of published and grey literature in healthcare, research, education and regulation across medicine, dentistry and nursing; (ii) inductive thematic analysis of review findings; (iii) development of best practise principles; and (iv) consensus testing of identified principles using a modified Delphi methodology.

Results

Twelve systematic reviews and 88 grey literature publications were reviewed leading to the unique identification of 13 principles. Essential consensus (>75% agreement) was obtained for nine principles reviewed. Working in equal partnership and sharing information achieved the highest consensus rates: 16/17 essential 94.1%; 1/17 desirable 5.8%. The four remaining principles were categorised as desirable by expert respondents. No principles were considered irrelevant. No alternative principles were suggested.

Conclusions

This study's innovative approach advances existing knowledge by providing previously unavailable guidance about PPI best practice. Research findings hold important theoretical and practical implications for those looking to work together effectively. Expert respondents suggest essential principles must be achieved to optimise PPI best practise. Desirable principles should also be aspired to wherever possible to advance PPI practise.

Enabling the Voices of Children and Young People to Impact Health & Social Care Research: Reflections from the Young Person's Advisory Group

Duncan S Barron, Victoria Hamer, Kate Sonpal, Ian Brownbill

Research Design Service (RDS) SE & Kingston University

Background

To date patient and public involvement (PPI) in health and social care (H&SC) research has been dominated by the involvement of adults with less attention paid to hearing from children and young people (C&YP). There is therefore a need for more inclusive C&YP-centred models as their voices are 'less frequently heard'

We will highlight the evolution of the Young People's Advisory Group (YPAG) for Kent, Surrey & Sussex (KSS) which was launched in 2017. Parallel Parents and Carers (PaC) meetings also provide input to new research ideas.

Materials and methods

Current membership stands at 25 C&YP (8 -18yrs) and 12 PaC. The journey to securing funding and recruitment and co-facilitation methods will be highlighted. The importance of the YPAG Planning Committee (which includes numerous partners, as well as INVOLVE and parents) on the YPAG's successes and impacts will be discussed. Suggestions to meet multi-agency procedural challenges for working with C&YP will be proffered.

Results

The YPAG is sought after by paediatric H&SC researchers, and popular with C&YP and PaC. Five YPAG meetings have been held to date and nine research studies have been presented and discussed. The group has helped co-design research Plain English Summaries (PES), publicity materials, and 'Top Tips' for researchers; a C&YP-designed poster is in development. Examples will be presented. YPAG KSS is now affiliated to the Generation R YPAG Alliance.

Conclusions

C&YP remain an under-heard group in H&SC research. Empowering them to co-facilitate/co-produce the YPAG has been valuable for encouraging their ideas regarding the design and conduct of new research. They evaluate that they are being listened to, and that meetings are rewarding and confidence building. Ways to assess the impact of the YPAG and PaC on research from several perspectives (C&YP, PaC, researchers) are in development with GenerationR and require piloting.

PPI contributions to evidence synthesis: a case study of a PPI panel for a network meta-analysis project

Fiona R Beyer, Sandy Harvey

Institute of Health and Society, Newcastle University

Background

Patient and public involvement (PPI) is essential in health research, but rare in systematic reviews (SRs). We invited a PPI panel to contribute to a SR investigating interventions for hazardous and harmful alcohol consumption. This work built on published SRs, and we explored contributions the panel could make when the question and inclusion criteria were pre-determined.

Materials and methods

We convened a PPI panel from Voice, which aims to capture the public's experience, ideas, opinions and expectations about research. We sent a lay summary of the project in advance for information and comment. At the panel, the first author briefly introduced the project, and led a discussion for one hour using the following questions: (i) is there anything you do not understand? (ii) what concerns do you have about this project, is anything missing? (iii) what do you consider priority outcomes? Subsequently the first author met with two of the panel for an in-depth review.

Results

Sixteen panel members contributed to a vibrant discussion, raising methodological issues such as sources of heterogeneity in the populations and interventions. They also highlighted priority outcomes such as binge drinking, health outcomes, and changes in understanding or knowledge about drinking. The panel members in the follow-up meeting, despite extensive experience with Voice, had not previously participated in SR PPI. They reflected on ways to engage with, optimise involvement of, and acknowledge PPI members in research. They also discussed the purpose of PPI in research in general and SRs in particular.

Conclusions

The PPI panel were enthusiastic and provided useful insights into sources of heterogeneity and priority outcomes in a complex SR, which impacted on the outcomes and discussion points for the

SR. In the follow-up meeting, the panel members provided insight about PPI contribution to both this project and SRs in general.

Development and evaluation of patient research partner involvement in a multi-disciplinary European translational research project

Marie Falahee, Rebecca Birch, Gwenda Simons, Heidi Wähämaa, Catherine M. McGrath, Eva C. Johansson, Diana Skingle, Kerin Bayliss, Bella Starling, Danielle M. Gerlag, Christopher D. Buckley, Rebecca J. Stack, Karim Raza

Institute of Inflammation & Ageing, College of Medical & Dental Sciences, University of Birmingham

Background

Patient and public involvement (PPI) enhances research quality and is central to contemporary health policy. The value of PPI is recognised in rheumatology research, though there are limited examples of PPI in laboratory/translational science. The EU FP7 funded 'EuroTEAM' (Towards Early biomarkers in Arthritis Management) project developed biomarker-based approaches to predict the future development of rheumatoid arthritis and incorporated both translational and psychosocial research with public involvement.

Objectives

To describe the development of PPI in EuroTEAM, assess the impact of PPI from the perspectives of researchers and patient research partners (PRPs), and formulate recommendations for PPI in future projects.

Materials and methods

Two mixed-methods surveys (one for PRPs and one for researchers) were developed to assess the impact of PPI on specific work packages and on the project overall. All researchers and PRPs were invited to complete a survey towards the end of the project. PRPs contributed to the development of the surveys, and the interpretation and reporting of the results.

Results

There was consensus about the positive impact of PPI on the research and on the experiences of those involved. Researchers described adapting their practice in future projects to facilitate PPI. Spin-off projects and ongoing collaborations between PRPs and researchers reflected the value of PPI to participants. PPI was integrated more frequently in psychosocial research, though examples of PPI in laboratory/translational science were also described. PRPs asked for more opportunities to contribute meaningfully and for more extensive feedback on their contributions.

Conclusions

The findings were used to formulate recommendations for the effective involvement of patients in future projects, including specific training requirements for PRPs and researchers, the identification of PRP focused tasks/deliverables at the project planning stage, and supporting access to involvement for all PRPs. The multidisciplinary approach, incorporating basic science and psychosocial research, facilitated patient involvement overall.

Impactful, but limited: qualitative study of patient and public involvement in research to select what outcomes to measure in clinical trials

Lucy Brading, Azmina Verjee, Heather J. Bagley, Paula R. Williamson, Kerry Woolfall and Bridget Young

Institute of Psychology Health and Society/North West Hub for Trials Methodology Research, University of Liverpool

Background

Outcomes like pain or survival are used in trials to measure if a treatment is effective. The chosen outcomes must be relevant to both patients and health professionals. Increasingly, researchers are conducting 'core outcome set' (COS) studies with patients and professionals for particular health conditions to agree what key outcomes should be measured in every trial of treatments for that condition.

To ensure the patient voice is reflected in a COS study, PPI partners need to be involved. We explored the experiences and perspectives of PPI partners and researchers to inform guidelines to enhance PPI in future COS studies.

Methods

Semi-structured, qualitative interviews with 14 PPI partners involved in 12 COS studies and year-long ethnography with a purposive sample of four COS studies, including observations and interviews with 17 PPI partners and 16 researchers/professionals. Analysis of field notes and interview transcripts was informed by thematic analysis.

Results

Most PPI partners and researchers described PPI involvement in COS as impactful but limited to feeding back on study documentation. Many PPI partners described a 'steep learning curve' to understand COS studies and most researchers found explaining COS challenging. However, no PPI partners received formal training in COS - rather researchers and PPI partners were united in focussing on the need to select partners who already possessed 'the right' experience and skills for the role. Many PPI partners contributed to COS studies as both participants and research partners, although none described this as problematic. Those PPI partners who choose not to participate believed their partnership role would colour their responses as participants.

Conclusions

COS studies bring important opportunities and distinctive challenges for PPI. These findings provide insights to inform guidelines with the aim of enhancing PPI and the inclusion of the patient voice in COS studies.

“What I’ve liked is the flexibility”. Developing inclusive approaches to young people’s involvement in research

Louca-Mai Brady

Kingston and St George’s Joint Faculty of Health, Social Care and Education

Background

The United Nations Convention on the Rights of the Child established international recognition that all children have a right to have a say in decisions that affect them. But the voices of young people deemed to be most ‘vulnerable’ are often absent from the public involvement literature.

The Youth Social Behaviour and Network Therapy (Y-SBNT) study was a randomised controlled trial which looked at an intervention currently used in adult alcohol services in the UK to see whether it could be adapted for young people. This presentation outlines the learning from an evaluation of young people’s involvement in the study. It also draws on recent work by the presenter including the involvement of young people affected by adverse childhood experiences in a systematic review.

Methods

The initial plan for Y-SBNT was to form an advisory group of young people with lived experience of using substance misuse services. When this proved problematic the study developed alternative approaches in collaboration with researchers and young people. Input from 17 young people informed all stages of the research. Public involvement in the study was evaluated as part of the presenter’s PhD research on young people’s involvement.

Results

We found that involvement of young people needed to be dynamic and flexible, with sensitivity to their personal experiences and circumstances. The project identified a need to reflect critically on the extent to which rhetorics of public involvement give rise to effective and meaningful involvement for young people.

Conclusions

This presentation will outline the model which emerged from the Y-SBNT study and the presenter’s other work in the field. It will explore whether traditional models of public involvement can potentially exclude some of the young people most likely to use health services and discuss the potential for flexible and young people-centred approaches to involvement.

Evaluation of a strategy for patient and public involvement in palliative care and rehabilitation research

Lisa J Brighton, Simon N Etkind, Halle Johnson, Peihan Yu, Adejoke Oluyase, Emeka Chukwusa, Margaret Ogden, Sylvia Bailey, Pam Smith, Susanne de Wolf-Linder, Jonathan Koffman, Catherine J Evans

Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation, King’s College London, UK

Background

Patient and public involvement (PPI) can improve the quality, relevance, and impact of research. We aimed to evaluate PPI at a palliative care and rehabilitation research institute in London, UK,

exploring PPI members' and researchers' experiences of the processes and outcomes of involvement, to optimise our practice.

Materials and methods

Involvement was evaluated against our Institute's PPI strategy (developed through previous stakeholder consultation) and national guidance. We conducted a survey of studies during 2017/18 to describe PPI activity, then undertook focus groups to explore PPI members' and researchers' experiences. PPI member and researcher focus groups were conducted separately, using convenience sampling, and semi-structured topic guides co-designed by researchers and PPI members. Focus group transcripts were analysed thematically in collaboration with PPI members, paying attention to divergent views, with double-coding to ensure rigour.

Results

Of 28 recent research projects, 25 incorporated PPI. Four focus groups have been conducted with PPI members and researchers (n=24; 75% female; 54% with 3+ years of PPI experience). PPI members felt the process was 'educational' and 'collaborative', and researchers felt it increased the relevance of their work and offered a 'grounding' perspective. Both agreed that PPI increased research relevance and aided wider, effective dissemination. Participants felt involvement was happening earlier and becoming more integrated throughout the research cycle. However, conducting PPI during data collection and analysis (particularly in highly quantitative projects) was challenging. A 'one-size-fits-all' approach was not felt to suit the diversity of research projects. All suggested more could be done to develop a flexible and diverse PPI network, by 'reaching out' to rather than 'bringing in' experiences.

Conclusions

PPI is included in almost all projects, with varying levels of integration. Flexibly tailoring PPI methods to individual project aims and designs is essential to meaningful collaboration. Future research should identify ways to facilitate this.

The Patient Perspective: Reflections on our experiences of being involved in research

Jane Clark, Olivia Fulton, Lynn Laidlaw, Allison Worth

University of Edinburgh Clinical Research Facility Patient Advisory Group

Background

The University of Edinburgh Clinical Research Facility Patient Advisory Group was set up in 2013 to provide support, advice and training to clinical researchers to enable them to involve patients and the public in meaningful ways. The group has acquired considerable experience in a range of activities including: reviewing research grants; advising on study methods; addressing complex ethical dilemmas; working on lay summaries and patient information sheets; developing a range of methods to train researchers and students in good PPI practice; helping other research teams set up their own PPI groups; conference presentations; public engagement. Working in PPI in Scotland presents particular challenges due to the lack of funding and infrastructure support. We will reflect on what a committed group of people can achieve despite these constraints.

Aim

To draw on our experience of involvement to encourage the audience to reflect on their own PPI practice

Our presentation

Three members of the Patient Advisory group will reflect on our experiences of being involved, including:

- our motivation – why we want to be involved
- what we've achieved
- making the most of what patients can offer
- working with children and young people
- working with postgraduate students
- the importance of good communication and feedback
- reducing waste and costs in clinical research through effective patient and public involvement
- our recommendations for researchers on successful involvement
- evaluation: what matters to us

Conclusions

We hope our presentation will encourage debate, reflection and provide patient and public perspectives on the key factors needed for the evaluation of patient and public involvement in research.

Going the extra mile along a road less travelled

Vivien Coates, Mary Austin, Toni McAloon

School of Nursing, Ulster University.

Background

The Going the Extra Mile report highlights a vision for the future in which public and patient involvement (PPI) is so embedded in the research culture that it is the norm. It is recognised that the public/patients have a right to be involved in publicly funded research with the potential to impact on personal health or available health services.

Materials and methods

We employed an experience based co-design approach using focus groups in which the experiences of patients with elevated BMI's and clinicians informed an intervention to enhance obesity management. Two people with elevated BMI's were core members of the research team. One PPI member (MA) with extensive facilitation expertise was to conduct the patient focus groups, as has been recommended, to enable involvement to go beyond advising to actually doing the research (<http://www.invo.org.uk>).

Results

The PPI input was important but it also caused a major problem as after receiving a favourable ethical opinion we waited four months before research governance approval was granted for the study to proceed. Governance concerns were raised about a lay person conducting research and included requests that MA submitted her CV, completed the full on-line GCP training, Research Integrity Training and provide her own professional indemnity. This delay had a serious effect upon research completion and meant there was only time to conduct one patient focus group.

Conclusions

People with elevated BMI's played an active role in steering the project and eventually in data collection and designing the intervention. This study led to changes in the insurance offered by the sponsors but needs further thought if PPI is to be implemented fully in a timely way. If PPI representatives are to play an active role in data gathering and analysis the governance processes to enable them access to do so require further consideration.

Creating a Virtual Patient Advisory Group using social media and traditional telephone and email platforms.

David Coyle

NIHR Devices for Dignity Med Tech Co-operative

Background

Recruitment of fully representative patient members for a Patient Advisory Group is often very challenging because certain sections of the patient population find that geographic location, work commitments, poor health or mobility prevents them from participating.

We will share our experience and learning of operating a "Virtual" Patient Advisory Group (PAG) involving the use of social media platforms and traditional telephone and email platforms rather than face-to-face meetings in a large national research trial.

Materials and methods

We will explain our choice of social media and online platforms and how we supported patient volunteers to operate in a virtual work setting. How successful virtual working has been in terms of achieving the Patient Advisory Group Remit and Objectives. We will also share examples of the work completed by the PAG group without ever meeting face to face. Finally, we will share our experience of the benefits and challenges of implementing this method of working.

Results

The research trial will not be finished until end 2019 so it is too early to fully evaluate the results. We will describe the benefits of virtual working and the potential of accessing the patient voice in real time. We will also describe the challenges we have faced and how we overcame them.

Conclusions

Early indications suggest this way of working can help achieve greater patient reach particularly young patients and patients who are still working and encourages a wider geographic representation of patients. Virtual working also appears to be a very efficient and cost effective way of working.

Patient and public involvement as a complex intervention: assessing impact on recruitment to clinical trials using two different approaches

Joanna C Crocker, Ignacio Ricci Cabello, Adwoa Parker, Chrysanthi Papoutsis, Alan Chant, David Evans, Louise Locock, Sian Rees

Nuffield Department of Primary Care Health Sciences, University of Oxford

Background

In recent years there have been calls to assess the impact of patient and public involvement (PPI) in health research: sceptics demand 'proof' that PPI is beneficial to research, while many advocates of PPI, although convinced of its intrinsic value, support some form of impact assessment to help inform PPI practice and funding decisions. We sought to evaluate the impact of PPI on one outcome essential to the success of clinical trials: participant recruitment. In doing so, we positioned PPI as a complex intervention.

Materials and methods

We conducted a systematic literature review to assess the impact of PPI on recruitment to clinical trials, using two different approaches to evaluating complex interventions: meta-analysis (to quantitatively estimate the effect of PPI on recruitment rates) and realist analysis (to gain a deeper understanding of the mechanisms which trigger these effects). The meta-analysis is complete and the realist analysis is currently underway.

Results

Twenty-five studies were included in our review. The meta-analysis revealed that on average, PPI interventions significantly improved recruitment to clinical trials relative to no PPI or non-PPI interventions, especially if at least one PPI contributor had lived experience of the condition under study. The realist analysis is building a detailed theory of how, when and why PPI produces these effects (or not) in different contexts. We will present the findings from our two analytic approaches and discuss the strengths and limitations of each in contributing evidence around PPI impact.

Conclusions

The findings of our meta-analysis provide some proof of the benefits of PPI for trialists and funders considering whether it is worth doing. The findings of the realist analysis could further guide trialists in deciding what sort of PPI to undertake in their particular context, if one of the aims of PPI is to improve recruitment.

The Impact and Opportunities for a Patient Research Ambassador

Anne Devrell, Teresa Melody

University Hospitals Birmingham NHS Foundation Trust

Background

Embedding effective Patient Research Ambassadors (PRA) within an NHS organisation is challenging. In my view, the essence of patient and public involvements happens when a whole range of opportunities arise to be an active and valued participant in the research process.

Objectives

My experiences of a NHS research group have demonstrated that we as lay people do provide important and necessary perspectives that clinicians cannot ignore! Our input into all activities and requirements for patients, looking at the process and expectations from their point of view is obvious. But we can, and do, add value to other elements of the research cycle.

For my part, I have been a co-author for two studies and a member of the TMG and TOC for a feasibility study.

From these experiences I have become a Lay Member for my LCRN Partnership Board and a Peer Performance Review member; the latter where, as Chair of the WM PRA Forum, I am expected to challenge the decisions taken by senior NIHR staff around studies that are not on track to meet their stated target.

In addition, I co-produce and deliver training and development opportunities with my local PPIE and PRA team through the Building Research Partnerships programme (BRP).

Results

Experiences as a PRA have definitely 'grown' me in a completely new environment, using my professional and personal skills to good effect and adding value to the studies I have been involved in. I know, from feedback, that my input into the BRP has developed the programme in a way that wouldn't have happened without lay perspectives.

Conclusion

PPIE in research is here to stay! I am committed to building capacity for PRAs and the public so that they can experience the valued and valuable opportunities that being a partner in research offers.

Involving young people with past mental health difficulties as co-researchers: reflections on conducting interviews and data analysis in qualitative mental health research

Dr Lindsay H. Dewa, Jack Jaques, Caroline Kalorkoti, Anna Lawrence-Jones

Imperial College London

Background

There is little evidence in how meaningful young people with past mental health difficulties find undertaking research. Our study, exploring the feasibility and acceptability of technologies in detecting deteriorating mental health, also reflects on the process and value of working with young co-researchers, from researcher and lay-perspectives.

Materials and methods

We set up an advisory group where roles were assigned based on preferences, across the research process (design, management, data collection, analysis, dissemination). Three young people attended a two-day training event on conducting interviews and thematic analysis, to become co-researchers. The lead researcher supported them, shadowed interviews and provided feedback. Co-researchers each coded three transcripts that the researcher had also coded, enabling us to assess the value of patient involvement in analysis. The group met to produce a coding framework.

Results

During analysis discussions, there were clear instances where the co-researchers noticed different codes to the researcher that were informed by their respective relevant first-hand experiences. They explained the study using language familiar to a person with a mental health condition and it was clear participants felt comfortable exploring topics with a person who had similar experiences to themselves. However, co-researchers found it difficult to avoid leading questions and represent the “objective researcher role”. Key factors ensured the partnership worked well, including: building good working relationships; creating a safe space for open discussions; being in regular contact; and, involving co-researchers in decision making. In interviews, co-researchers easily built rapport with participants.

Conclusions

Young co-researchers with past mental health difficulties are suitably placed to conduct interviews with peers and code transcripts, with appropriate training and support. Findings show co-researchers give added value to the data, and in turn, they enjoyed the process, gained valuable experience and confidence in themselves. Learnings will inform good practice guidance in involving young people with mental health difficulties in undertaking research.

The ethical, governance and management implications of involving service users and carers as co-applicants, project team members and co-researchers in health research.

Anne-Laure Donskoy, Dr Virginia Minogue, Dr Mary Cooke

University of Manchester and Service User and Carer Working Group, NHS RD Forum

Background

Public and Patient Involvement (PPI) in health service research has evolved through the last 30 years. As involvement has developed so have the roles and responsibilities of service users and carers (SUC). This includes acting as co-applicants in research funding applications, being co-researchers, and project team members. Whilst salaried professionals may fully understand their roles and responsibilities within a research study, it is less clear if PPI representatives are aware and understand the full implications of taking on these roles. Becoming a co-applicant or an equal member of a team implies shared responsibilities, yet many SUC are volunteers and do not have the supportive mechanism of an employment contract. Anecdotal evidence collected by a group of service users and carers suggested that there was a lack of understanding on the part of PPI representatives, and professional researchers, of the legal and governance implications of service users and carers as co-applicants, co-researchers and project team members. This led to a review of current practice aimed at identifying the challenges and issues experienced.

Materials and methods

To undertake the review, the NHS RD Forum Service User and Carer Working Group undertook a literature review, ongoing data collection based on their experiences of PPI in research, two workshops, and a consultation exercise across the RD Forum, to identify the issues from the perspective of SUC and research managers. The review focused on awareness of responsibilities,

communication and support, understanding of the contractual and legal governance issues and responsibilities of involving SUC. It also identified areas of effective involvement and good practice.

Results

The review, data collection and consultation exercise led to collaborative working with Involve and the Health Research Agency in order to raise awareness, promote good practice and effective co-production in research. Guidelines for research managers, researchers, SUC are currently being produced.

Conclusions

The contractual and legal governance issues and responsibilities that are specific to SUC co-applicants, project team members, and co-researchers are not fully understood by SUC, researchers, research managers or sponsors.

Co-production workshop on patient involvement in undergraduate medical education

Helen Finnamore, Adedoyin Alao, Hugh Alberti, David Kennedy, Bryan Burford, Susan Hrisos, Roger Barton, Gillian Vance

Newcastle University

Background

Patients presenting to general practice (GP) with real-time illnesses provide valuable learning opportunities for medical students. These ‘real-time’ patients, who may not have prior experience of medical student education, contrast with expert patients who tend to be briefed about their educational role. As undergraduate curricula evolve to incorporate more teaching in primary care, educators will increasingly need to draw on these real-time patients. However, the educational role of this group of patients has rarely been studied.

As part of a study to enhance real-time patient involvement in medical education, we conducted a co-production workshop to discuss ways to address barriers identified in the study.

Materials and methods

A half-day workshop was held with 39 participants including students, GPs and patients. This included small group discussions, co-facilitated by researchers and patients, which considered practical solutions to selected barriers. Discussions were audio-recorded and summarised on flip charts, to be analysed using thematic analysis.

Results

Initial findings have identified patient empowerment, practice processes and normalisation of teaching in GP Practices as key solutions to real-time patient involvement.

Patient *empowerment* was critical to involvement: patients felt they have much to offer students, but need ‘permission’ to educate.

Patients take a ‘journey’ through undergraduate medical education, which could be eased by attention to *practice processes*. They need clear, relevant and visible information materials, but, crucially, also an ‘invitation’ to start the journey.

Normalising the presence of medical students in GP Practices, as is the case in teaching hospitals helps the patients to feel better prepared to take part in the teaching process.

Conclusions

Real-time patients need to feel empowered to educate students. Their role may be supported by practical information materials, but practice culture should be challenged so that active patient involvement becomes the rule, rather than an exception. Further work to implement findings in this curriculum will be explored.

How to foster PPI with those excluded from public involvement itself?

Dr Mary Galvin, Dr Clíona Ni Cheallaigh

The Centre for Practice & Healthcare Innovation, Trinity College Dublin

Background

While there is encouragement of public involvement in the development of health interventions and healthcare issues, PPI seeks to go a step further with this involvement “with recognition of the need to engage citizens not only in providing feedback on health-care delivery or interventions, but in processes whereby decisions are made...” (Baxter, Clowes, Muir et al., 2016). But what happens to those citizens who find themselves socially excluded from their healthcare needs? One such group is our homeless population.

This presentation, drawing upon previous research on health seeking behaviours of homeless individuals (Ní Cheallaigh, Cullivan, Sears, et al., 2017), will challenge PPI to go further in how it seeks to understand *involvement*. We argue that a way of achieving this is through applying experience-centred design (ECD), which gives “...people the chance to have a richer life, to include people who otherwise feel excluded, and to ensure that everybody has a chance to have their say. Especially those who often feel voiceless” (McCarthy and Wright, 2010).

Methods

Examples of ECD methodologies will be presented that naturally align with fostering PPI. The methods presented will attempt to equip researchers with a way to support a fluid dialogical research process, ensuring PPI across *all* health research contexts and not solely those of the socially included. These methods will respond to experience either in the form of digital health interventions or more service based responses.

Findings & Discussion

What we hope this presentation achieves is an entry point into a dialogue around how we ensure PPI, as well as responsive design of healthcare, within the homeless research context. While the presentation takes a positional stance, it seeks to provoke thought and reflection within the PPI community upon how we can achieve PPI with groups that are excluded from public involvement itself.

Using Patient and Public Involvement (PPI) to increase the impact of meaningful patient research and understanding of the burden of multi-morbidity illness on the lifeworld of children, young people and their families

Julie Guest, Eileen Kaner, Karen Heslop, Andrew Gennery, Roderick Skinner

Institute of Health and Society, Newcastle University

Background

The study aims to explore the lived experience of children, young people and their families, faced with the further burden of complex novel invasive treatments that have uncertainties and outcomes that may be life threatening. This study puts young patients and families at the heart of the project to enable in-depth exploration through interview based fieldwork and thematic analysis to provide insight into their perspectives about hospital treatment for serious health conditions in early life.

Materials and methods

Two PPI consultations were undertaken with the 'Young Persons Advisory Group (YPAG)', initiating discussion around the methodological and ethical considerations of the study design, followed by a second discussion around the semi-structured interview questions. However, within this dynamic it became apparent that the group had little complex health care experience.

To strengthen and frame the scope of the study views from expert children, young people and parents who had experience of complex life limiting condition were also sought.

Results

The PPI consultations with YPAG highlighted the importance of developing informed interview topic guides and appropriate methodological choices. However, engagement with previously treated patients and their families has been integral to giving validity to the patient information sheets, consent forms and interview topic guides.

Conclusions

The PPI consultation journey for this study has helped to shape the focus of the study and was based on an ethical and acceptability standpoint from both YPAG and an expert patient group. This has ensured that these are appropriate and will support recruitment to the study.

What are the most patient-centred outcomes for prehospital trauma trials? A patient involvement exercise

James M Hancox, Emma Toman, Samantha J Brace-McDonnell, David N Naumann

NIHR Surgical Reconstruction and Microbiology Research Centre, Queen Elizabeth Hospital, Birmingham, UK.

Background

Outcome measures are used in clinical trials to determine efficacy of interventions. These are chosen by study investigators during research planning, based on the most appropriate factors affected by the trial. It is important for the chosen outcome measures to be relevant to the well-being of

patients so that clinical research might lead to meaningful improvements in care. We aimed to determine which outcome measures in prehospital major trauma trials are most patient-centred.

Materials and methods

A Patient and Public Involvement (PPI) group consisting of trauma survivors and their relatives was invited to discuss trauma research outcome measures. Common themes were extracted from studies identified in a systematic search of the published literature. This search was conducted using Medline, Embase, clinicaltrials.gov, Web of Science and Google Scholar. The PPI group ranked the categories of outcomes in order of most importance (first individually; then as a group), and agreed some consensus statements regarding the outcome measures reported in the medical literature.

Results

There were 27 studies identified in our systematic search of the literature, including 9,537 patients. Outcome measures were divided into nine categories: quality of life (QoL); length of stay; mortality/survival; physiological parameters fluid/blood product requirements; complications; health economics; safety and feasibility; and intervention success. Of these, mortality/survival was the most common reported category. The PPI group agreed that the most important category was QoL, and that mortality/survival should only be reported if concurrently reported with longer term QoL. Length of stay and health economics were not considered important.

Conclusions

Outcome measures in prehospital clinical trials in major trauma are heterogeneous, inconsistent, and not necessarily patient-centred. Trauma survivors considered quality of life and mortality most important when combined. Consensus is required for consistent, patient-centred, outcome measures in order to investigate interventions of meaningful impact to patients.

The Sharebank – a cross-organisational model for sustainable learning and development for patient and public involvement in research

Adele Horobin, Colleen Ewart, Raksha Pandya-Wood, Michael Prior, Andy Wragg

National Institute for Health Research (NIHR) Nottingham Biomedical Research Centre

Background

The National Institute for Health Research (NIHR) 'Going the Extra Mile' report recommends there should be more support for patient and public involvement (PPI) and that local organisations should work together to improve that support. Evaluating how to do this will guide local collaboration. We have developed a cross-organisational model, from the 'grass roots', to fulfil these recommendations. This is of strategic importance to NIHR and evaluation is ongoing.

Materials and methods

The Sharebank is a free (no fee) learning and development network for PPI in health and social care research. It brings organisations together to create a programme of resources and training based on reciprocity, where each organisation contributes in return for accessing other's offerings. Through this, experience and knowledge is pooled and researchers, PPI leads and public will be better equipped to do effective PPI.

The Sharebank was conceived in the East Midlands and launched as a pilot in 2015 with events in Nottingham and Lincoln. Since then, membership has expanded and is now delivering activities for 2018/19. Public and staff representatives steer the Sharebank together. Evaluation is ongoing.

Results

The pilot was enthusiastically received, with a clear demand for training (70 participants, including public and researchers). Organisations are also willing to join, and contribute to, the Sharebank. The collaborative nature of developing a training programme has allowed us to identify what members would like support with and what support they can offer.

Conclusions

The Sharebank provides a low cost opportunity for public and staff from local organisations to come together and shape PPI support and training around local needs. The next step will be in translating this model to other regions, which may have differing levels of existing cross-organisational collaboration. This is being supported through a part-time secondment of the Sharebank model founder (Horobin) to INVOLVE.

Patient and public involvement in palliative and end of life care research

Professor Bridget M Johnston; Dr Lisa Kidd

University of Glasgow

Background

The evidence base for patient and public involvement in health research and within palliative and end-of-life care is expanding. Moderate evidence has shown that involvement can result in more relevant, readable and understandable patient information for research studies. As well as, increased knowledge, skills, confidence, personal support, and emotional and practical demands of members.

The team have recently set up a patient and public involvement (PPI) group at University of Glasgow. Our aim is to meaningfully involve, using novel and creative methods, group members from diverse backgrounds in our palliative and end of life care research.

We have recently been selected as one of 10 NIHR test bed national standards for public involvement in research <https://sites.google.com/nihr.ac.uk/pi-standards/test-beds/test-bed-projects>

This paper will draw our achievements and present novel ways of working with people at the end of life.

Materials and methods

Thematic analysis of group participation and key priorities for research benchmarked against the NIHR test bed standards

Results

We will present results from a workshop (**standard 3**) conducted with support from Glasgow School of Art using creative and inclusive methods to co create research ideas with people and their informal carers facing life limiting illnesses. Themes matched against the standards include:

- Experiences of care Standard 1, Standard 2

- Participants have identified difficulties experienced in their stories of care and the need for more emotional and practical support.
- Priority areas for end of life care research Standard 2 identified by our group.
- Different ways members are involved in our research
- Ways we communicate with our group (Standard 4)

Conclusions (Standards 5 and 6)

The importance of patient and public involvement are strongly endorsed by our group we will present ways we are achieving the NIHR test bed standards and plans for future work and engagement.

“Faithful Judgements”: exploring direct and indirect knowledge of assisted reproductive technologies

Jackie Leach Scully

Policy, Ethics and Life Science Research Centre (PEALS), Newcastle University

Healthcare research that tries to incorporate public and patient perspectives always needs to keep in mind that there is a diversity of publics and interest groups, some of which are more easily accessible than others. The views of more marginalised social groups can easily be lost from sight. In addition, the knowledge and opinions of those who have direct experience of a medical condition or healthcare intervention may be markedly different from the more abstract views of those without such experience, but both have value as contributions to PPI-led research. This presentation will describe a two-year ESRC-funded study that examined how members of Christian and Muslim faith groups evaluate and experience assisted reproductive technologies. We used qualitative semi-structured interviews with participants who self-identified as ‘religious’ and whose fertility issues meant they had been confronted with deciding whether or not to use assisted reproductive technologies. This was complemented by dialogue groups, in which faith group members were given vignettes involving reproductive and genetic healthcare issues and asked to discuss the ethics of using a range of reproductive and genetic healthcare technologies. Taken together, the data revealed significant but previously unrecognised barriers to patients’ attempts to gather information, and also indicated some concerns shared across the faith groups about the acceptance of faith group membership in the public sphere in general and the clinical setting in particular.

PPI Planning & Evaluation Tool (PPI PET)

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Background

No simple tool exists to evaluate the impact of PPI. Consequently, the evidence-base for the impact of PPI both on research and the researchers and public involved is poor. Planning and assessment of impact is often challenging for busy researchers.

Materials and methods

We developed the PPI Planning and Evaluation Tool (PET) following a scoping exercise of existing tools. It was developed to meet the following objectives:

- (1) To produce a better evidence-base for the impact of PPI on both research and people (researchers and public);
- (2) To map and analyse patterns in PPI activity conducted across Imperial College London to allow for comparison and mutual learning across PPI projects;
- (3) To find a balance between a tool that is not overly burdensome for completion by researchers, while also developing a critical understanding of the “impact” of the PPI activity;
- (4) A flexible tool that could be applied to a wide range of PPI projects, producing a bespoke plan and tailoring impact measures to suit each project.

Results

The PET brings together planning and evaluation, so that researchers can assess their activity against their personal objectives. It was co-designed with researchers and the public and transferred to an online form to make completion easier for researchers (with a downloadable PPI Plan). The PET follows four simple planning stages (WHEN > WHY > WHO > HOW), followed by an “IMPACT” stage to be completed after PPI activity has been completed. Initial results from pilots run across several Imperial research centres will be presented.

Conclusions

The PET aims to ensure PPI impact is considered at the planning stage and then analysed once the PPI project is completed, in a researcher-friendly way. When used across several cases, the PET aims to highlight the specific elements of PPI approaches that establish impact.

Readiness to embark on patient-researcher partnership within the CNTRP: patients research partners' and research professionals' views

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Background

Patients have unique expertise in the diseases they deal with. In recent years, the importance of involving patients in research has been increasingly recognized. The Canadian National Transplant Research Program (CNTRP) has started, since 2014, to engage with patients. The Patient-Researcher Partnership (PRP) Platform was launched in August 2016 and started to integrate patient as project co-leaders and research partners. The objective of this study was to assess the PRP activities.

Methods

From April 2017, research professionals (RPs) and patients were invited to complete a series of questionnaires (0-6-12 months) developed from the PCORI netENACT and We-ENACT surveys. We present here the results of the baseline questionnaire

Results

Eight patients and 13 (RPs) filled the baseline questionnaire. Fifty percent of patients felt prepared and knowledgeable about PRP whereas 61.5% of RPs did not feel prepared and reported having none or little knowledge about PRP. For patients, professional and previous medical experiences help them to engage in PRP but medical jargon, lack of knowledge in research methods, finding their place in the research team and lack of clear expectations were viewed as hurdles to PRP. RPs mentioned their professional interactions with patients in clinical settings and research as facilitators to PRPs but research infrastructure, lack of training on how to partner with patients and absence of clear goals and objectives were challenging their PRPs. For both patients (75.0%) and RPs (61.5%), the CNTRP was highly supportive of PRP activities.

Conclusion

Patients felt more ready to embark in PRP and more knowledgeable on PRP than RPs. Although CNTRP is viewed as highly supportive of PRP, they are facing challenges with their PRP activities. Future questionnaires will provide useful information on how to develop and sustain a meaningful PRP within a research network.

Reflections on evaluation of PPI in research on frailty in rural Tanzania

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Institute of Health and Society, Newcastle University

Background

Patient and public involvement (PPI) in global health research is increasingly recognised as invaluable for impactful research. It is now an essential component of most international research ethics and funding applications. Yet little research has been conducted evaluating PPI when researching cross-culturally. We will present findings and reflections on the evaluation of data dissemination activities as UK researchers investigating frailty in older people living in Hai district, rural Tanzania.

Materials and methods

Priority areas for data dissemination were chosen based on our results and on the World Health Organization's guidelines on Integrated Care for Older People (ICOPE). Dissemination activities will be conducted primarily by workshops, and evaluation will be conducted by feedback questionnaires and through small group discussions. These activities will be targeted at different groups including; community healthcare workers, older people, community and church leaders, and local NGOs.

Results

These data will be available by the conference dates. We will report on our patients and public's evaluation of our data dissemination activities, and will reflect on the particular challenges and facilitators to this evaluation. We hypothesise that in this setting, the engagement of prior international research teams with PPI activities will have a large influence on current perspectives of PPI. Additionally, we anticipate evaluation will be challenging due to high levels of illiteracy among older people.

Conclusions

It could be argued, that PPI in our research context is extremely important in order to redress some of the power imbalance inherent in the northern-southern hemisphere, researcher-researched relationship. In the context of global health, which seeks to address health inequity within and between countries, PPI may be the key to empowering the most disenfranchised of groups, such as frail older people. Reflecting on lessons learnt during fieldwork will be key to improving researcher practice and optimising the potential of PPI.

Co-designing new tools for collecting, analysing and presenting patient feedback in NHS services: working in partnership with patients and carers

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Background

The way we collect and use feedback is important because of concern that vulnerable patients and carers may be excluded because of the limited ways it is done. In this study, we worked together as a team of researchers and PPI partners to co-produce new tools for the collection, analysis and presentation of patient feedback in the NHS. We focused on services for people with musculoskeletal conditions and services for people with severe mental health problems. Our PPI group represented a range of relevant experiences in specialist services, and we also worked with two Patient and Participation Groups (PPGs) which are groups set up to enable public participation in primary care.

Materials and methods

We will sketch out how our co-production process worked in practice by using illustrations of how the PPI work added value and shaped the design and delivery of the new tools tested.

We also experienced some major challenges during the project, and here we discuss how we managed these, and the lessons learned with implications for the practice and evaluation of PPI.

Results

We worked together to co-develop visual interview props and key questions to prompt discussion within the qualitative research around possible tools for capturing feedback on experiences of health services. PPI contributors also gave peer support when new tools were tested out in the different services settings. They also had a lead role in co-designing an animated film to communicate the findings of the study, as well as co-delivering a public dissemination workshop. Most of the PPI contributors within the sub-groups focused on specific conditions (musculoskeletal and mental health) had previous experience of doing PPI for research. However, the PPG groups did not have this experience, but had experience of working with health professionals to inform services. Using examples, we will talk about the experiences of tailoring varied strands of the PPI work, and matching specific roles to enable appropriate participation. We also talk about some experiences of how we managed to work together and create a supportive environment when unforeseen challenges emerged (e.g. dealing with illness, bereavement, conflicting viewpoints).

Conclusions

Our experiences of developing multiple components of PPI work for this complex study across multiple health services, demonstrates the importance of tailoring PPI to suit different settings, and to best suit individual strengths and capacity. It also shows the value of bringing diverse experiences together, and a shared approach to managing challenging situations.

Coding PPI: classifying and evaluating actions to achieve impact

Chris Macdonald

Arthritis Research UK

Background

Arthritis Research UK is dedicated to ensuring that everything we do is driven and shaped by the needs and insights of people with arthritis. We extend these principles and expectations to our research community; a commitment to PPI is required of our researchers and proposed PPI activity is assessed during our award making process. Building on this strong commitment, we have recently taken steps to classify and evaluate PPI activity across our entire awards portfolio (300+ grants).

Materials and methods

Inspired by the Health Research Classification System, we have developed a coding system that assigns a numerical value describing the PPI activity for each of our research awards. This allows us to ascertain the nature of interaction that the researchers have with people with arthritis and is also an indicator of how meaningful that interaction is.

Results

Observing these quantified patient and public interactions as a whole has begun to shed new light on to the PPI activities of our research community. Clear themes have been highlighted through our analysis. Our data have allowed us to recognise areas of outstanding success; it has also highlighted where more can be achieved. To address these challenges and enhance/support best practice we have now created a planned series of interventions based on our evaluation activities that will maximise the integration of patient insight in our funded research.

Conclusions

We have developed a novel simple coding tool that allows the assessment of PPI for a large number of awards, highlighting both success and areas for future development.

Reflections and Experiences of a Lay Co-Researcher in a Renal Research Study

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Background

There is limited reporting of patient and public involvement (PPI) within research studies, particularly in renal research [1,2] and just a few accounts of the co-researcher role from the perspective of lay research team members [3]. When designing the PIPPIN project (Patients as Partners to Improve Long Term Conditions Services), we wanted to bring an alternative viewpoint to the study and recruited a first-time lay co-researcher to the research team as an equal partner, to carry out some of the research activities alongside or independent of the academic researchers.

Materials and methods

The aim of this presentation is to share the co-researcher's reflections and experiences of her involvement in this renal research study. A retrospective, reflective approach was taken using data available as part of the day-to-day research activity. Electronic correspondence and documents such as meeting notes, minutes, interview analysis and comments on documents were also examined.

Results

From our experience of working together, we offer a broad definition of the role of a lay co-researcher. The co-researcher has identified a number of key themes from her reflections; the differences in time and responsibility between being a co-researcher and an Advisory Group member; how the role evolved and involvement activities could match the co-researchers strengths (and the need for flexibility); the need for training and support; the time commitment. It is recommended that a co-researcher is involved from the very beginning of a study.

Conclusions

The reflections and experiences of lay co-researchers have been largely under-represented in the literature. In our study, the role of co-researcher was seen to be rewarding but demanding, requiring a large time commitment. It is hoped that the learning from sharing this experience will encourage others to undertake this role, and encourage researchers to consider how to best support lay co-researchers.

How do we know if our contributions to researchers make a difference?

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Background

Health research that involves the public, patients, carers and people with lived experience (Patient and Public Involvement (PPI) contributors) can have substantial and varied 'impact'; these include

impact on the person who contributes, on the researcher, on the research project and on the community (1). However, because PPI contributors' comments are not always acknowledged, many do not know if their contributions have any impact. They are left not knowing if their contributions made any difference to the research, if any changes have been made and if they could have done anything differently (2).

Materials and methods

The idea for a research study to improve feedback was driven by PPI contributors from six PPI groups in the East of England. Their views and experience, alongside PPI leads and researchers were sought and analysed. We also co-designed PPI feedback processes and Guidance for Researchers which have been implemented and evaluated using surveys, interviews and audits.

Results

We found that roughly one fifth of PPI contributors never received feedback (for which a number of definitions emerged). One significant aspect of the feedback process between researchers and PPI contributors (and documenting impact) was a route for important learning and development for all parties.

Conclusions

Providing PPI contributors with feedback and concentrating on reciprocal relationships, not only enables researchers to capture impact but in addition, feedback/'impact' comments facilitate learning and development for all those involved. The rationale for capturing impact from a user-led perspective rather than being driven by academia or reporting requirements is an important shift in emphasis. By discussing expectations in advance and emphasising the importance of feedback as a means of learning and development, the meaning of impact can be further explored from the perspective of the PPI contributor.

Making spaces and participation places

Pauline McCormack

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During the development of new biomedical systems assumptions are often made that the science will map directly onto the real world in a predictable and linear fashion. History suggests this is rarely the case, and there are frequent discrepancies between promised benefits and actual experience. These disjunctures can result in promised benefits not being delivered, leading to a lack of trust and consensus amongst the actors involved, which is disruptive to the implementation and acceptance of the new system. Patient/user inclusion in the design, operation and governance of such systems can help to avoid this. Taking the example of RD-Connect - an integrated platform connecting databases, registries, biobanks and clinical bioinformatics for rare disease research, this paper will outline how the RD-Connect platform has included the experiential knowledge of patients in the construction of the platform.

Using the notion of communities of practice, which encourage collective learning through shared endeavour, we created spaces and activities to enable meaningful, on-going dialogue between patients/advocates and researchers/scientists/clinicians. The identification and documentation of key procedural and ethical barriers was followed by deliberative, decision making workshops on key

topics. In parallel, patient groups undertook capacity building exercises, contributed to the gathering of evidence around patient expectations for the RD-Connect platform, and took part in project governance. This has resulted in the recognition of shared values and goals and high levels of trust and confidence between researchers and patients resulting in the creation of a system whose operation is deeply informed by patients' concerns and expectations.

Engagement and secondary research: the ECOUTER approach

Joel Minion, Madeleine Murtagh

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The volume and types of biomedical data available digitally (e.g. medical records, full sequence genotyping) is increasing rapidly. With its growth comes the capacity to support innovative and highly valuable secondary research. But analysis of extant data takes place at arm's length to – and typically without the awareness of – those individuals from whom the data have been collected. This detachment makes engaging with participants quite challenging, particularly if researchers are to ensure that their use of such data is transparent, fair and commensurate with citizen expectations. ECOUTER (Employing CONceptUal schema for policy and Translation Engagement in Research) is an engagement methodology that helps bridge this gap by bringing engagement to the stakeholder rather than the reverse. The approach begins with a central question (e.g. *what issues are central to using personal medical information for health research?*), from which participants build a mind map of contributions and links to other resources. The results are analysed by social scientists to develop a conceptual schema, which is then fed back to participants and refined before final recommendations are made. An ECOUTER exercise can be conducted either online over time and at geographical distance, or in person at a single event. This paper considers what ECOUTER offers beyond current approaches to engagement work as well as some of the key limitations encountered to date. Examples are provided based on several ECOUTER exercises past and pending on the topic of secondary research and biomedical data.

Ethical Issues with Community-Based Participatory Partnerships for Public and Patient Involvement in Health Research

Dr Virginia Minogue, Dr Jon Salsberg

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Background

One of the essential differences between community-based participatory research (CBPR) and more general Public & Patient Involvement (PPI) as it is currently defined, is the impact of involvement on the participants' community.

The PPI Ignite programme led by the University of Limerick is focused on the development of partnerships with community service and advocacy organisations to enhance PPI in research. This is based on evidence that shifting ownership of the knowledge creation and mobilisation processes from academics to community participants increases its impact. It also repositions the power of decision making and increases the potential of change being sustained.

This presentation will outline the ethical implications of CBPR and the importance of partnership agreements between researchers and community participants.

Materials and methods

The University of Limerick has developed a PPI Ignite training programme for community research partners, which includes exploration of the ethical and governance issues in CBPR and the development of partnership agreements. This training has also been delivered to researchers, academics and funders who may be considering partnering with the community.

The training focused on the collective rights of the community, principles of good ethical practice, data ownership and IP, the challenges of ethical review for community partners, and developing partnership agreements.

Results

The training built capacity and competence to enable research partners to identify a range of ethical and governance issues to be considered in developing good partnership agreements.

Conclusions

The collective rights of the community have to be properly considered in CBPR and indeed in meaningful public and patient involvement. Effective partnership agreements facilitate shared decision making and the shift in ownership of knowledge from academic researchers to community partners.

Evaluating PPI in research into medical education – a reflection on the difficulties faced

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Background

Just as patient involvement in research is more likely to produce results that can be used to improve health and social care(1), it can be hypothesised that patient involvement in medical education will more likely produce doctors that today's patients require. However, there is little published research on patient involvement in medical education. Without robust evaluation of PPI in this area, how can we be sure the patient's contribution is positive?

We report a recent experience of obtaining ethical approval to evaluate effectiveness and feasibility of a new learning activity for the curriculum, designed and developed by patients.

Materials and methods

Patients proposed that to increase the patient voice within the curriculum, students could accompany patients travelling to and from a hospital appointment, observing it purely from the patient's perspective, experiencing transportation difficulties, and delays, all whilst discussing the impact of their condition(s), and their opinions about the doctor's communication during their appointment.

With the help of these patients, a pilot study protocol was devised to test effectiveness and feasibility of this learning activity. Approval was required from an NHS research & ethics committee due to the inclusion of NHS patients, despite them receiving no intervention.

Results

The ethical approval process has caused considerable delay to this project. Barriers faced have been:

- Individual - time needed to complete the lengthy/repetitive application, and lack of personal prior experience,
- Departmental - teaching schedule commitments and lack of experience of other faculty members (NHS REC approval is not needed for much educational research),
- Institutional - a full university sponsorship committee review (meeting infrequently) was needed before submitting
- National - several part of the IRAS form are less relevant to medical education, and infrequency of available local REC meetings.

Conclusions

The current ethical approval process is less suited to medical education research and could potentially put educators off conducting research to robustly evaluate the contribution of patients to their courses, leading to unanswered questions regarding impact of patient involvement in medical education.

Impact assessment methodology for Patient and Public Involvement (PPI), a systematic review

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Background

The development of a workable patient and public involvement (PPI) impact assessment methodology is important to the National Institute for Health Research (NIHR) who have prioritised it in the development of its PPI work. Though efforts are underway within the PPI community to establish a consensus on effective impact assessment methodology, it is timely to first step back and examine the evidence base that currently exists on impact and assessment of PPI.

Various reports have been published examining PPI impact and/or methods, but these sources are largely developed without any consistent, PPI evaluation methodology. The aim of our work has therefore been to systematically review the literature available in the field, to identify the range of different PPI impact assessment methods that have previously been developed and/or used in practice and to use that evidence base to inform the development of a typology for PPI impact assessment methods.

Materials and methods

We undertook a systematic review to identify relevant reports of published PPI impact assessments or assessment methods or frameworks. We appraised the quality of the reporting on PPI impact assessments using recognised PPI reporting and critical appraisal tools and are now working to develop a typology of PPI impact assessment methods.

Results

Our presentation will report in the findings of the systematic review, including:

- An overview of PPI impact assessment methods that have been developed or applied in practice.
- Identification of PPI impact assessment methods that have developed but (to date), not reported as used in practice?
- Identification of strengths and weaknesses of various methods

Conclusions

The findings of the systematic review have informed the development of a feasibility workshop with researchers, PPI leads, public contributors and NIHR representatives to develop a workable impact assessment methodology to be piloted within NIHR HPRUs prior to rolling out across the wider PPI community.

What mechanisms and resources need to be included to evaluate the reciprocal involvement of seldom heard groups in health and social care research? A collaborative rapid realist review of the literature

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Background

Public and patient involvement is increasingly embedded as a core activity in research funding calls and best practice guidelines. However, there is recognition of the challenges that prevail to achieve genuine and equitable forms of engagement. Our objective was to identify the mechanisms and resources that enable the reciprocal involvement of seldom heard groups in health and social care research.

Materials and methods

A rapid realist review of the literature that included: (i) a systematic search of CINAHL, PsycINFO, PubMed and Open Grey (2007-2017); (ii) documents provided by expert panel members of relevant journals and grey literature. Six reference panels were undertaken with homeless, women's, transgender, disability, and traveller and Roma organisations to capture local insights. Data were extracted into a theory-based grid, linking context to behaviour change policy categories.

Results

From the review, 20 documents were identified and combined with the reference panel summaries. The expert panel reached consensus about 33 programme theories. These relate to environmental and social planning (7); service provision (6); guidelines (4); fiscal measures (6); communication and marketing (4); and regulation and legislation (6).

Conclusions

While there is growing evidence of the merits of undertaking PPI this rarely extends to the meaningful involvement of seldom heard groups. The 33 programme theories agreed by the expert panel points to a variety of mechanisms and resources that need to be considered. Many of the programme theories identified point to the need for a radical shift in current practice to enable the reciprocal involvement of seldom heard groups.

Working together and caring for carers: The Research User Group (RUG) in the Organising Support for Carers of Stroke Survivors (OSCARSS) study

Emma Patchwood, Kelly Burke, Kate Woodward-Nutt, Audrey Bowen

University of Manchester, UK

Background

OSCARSS is a pragmatic cluster randomised controlled trial, including 35 clusters across England and Northern Ireland. OSCARSS explores clinical and cost-effectiveness of a professionally-delivered intervention to support caregivers of stroke survivors.

A Research User Group (RUG), of caregivers, was established in 2015 to collaborate and input into study design, delivery, management and dissemination.

Methods

Members were primarily identified through a UK stroke support service. The RUG meet regularly and are represented on the Trial Management Group. Initial meetings established group rules, understanding of the research aims; building trust and rapport. Agenda and accessible documents are sent in advance of meetings, to help members prepare and contribute. Members are reimbursed for time and expenses.

Results

Over 2.5 years, the group has developed into a committed, cohesive team, able to confidently exchange views and experiences with researchers. Particular achievements of the RUG include:

- co-developing the carer support intervention;
- designing accessible study materials;
- choosing meaningful outcome measures;
- refining administrative processes and eligibility criteria utilising existing networks to maximise recruitment and retention;
- training staff;
- engaging in social media, conference presentations and workshops to promote the project.

OSCARSS is ongoing with final outcomes expected autumn 2018 and results publicised spring 2019.

Conclusions

The RUG has developed a unique and important role in OSCARSS and members have personally gained from their involvement as proactive collaborators. The ongoing relationship increases trust that carer voices will be heard and allows members to voice different and sometimes opposing views, before coming to agreement as a group. Disadvantages might include a lack of fresh ideas due to fairly fixed membership. Overall, we believe the RUG collaboration has benefitted OSCARSS and presents learning opportunities for other professionals wishing to meaningfully involve service users in their work. RUG will continue to support analysis and dissemination of OSCARSS to September 2019.

Exploring the potential of PPIE in Singapore: the perspective of local researchers

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Background

Singapore is developing strategies to become a world-class research hub, bridging the gap between basic scientific research and clinical applications. It is recognised that globally 80% of the research is not being implemented. To enhance research impact requires patient and public involvement (PPI) at all stages of the research process.

Materials and methods

Twenty semi-structured, qualitative interviews exploring the views of scientists and clinical scientists on the potential for PPI in Singapore.

Results

Researchers perceived that in a Singaporean context PPI will be challenged by low health literacy in some communities, lay people's unquestioning trust of health professionals ('patients just don't speak up about what they need'), and communication challenges (four official languages and numerous dialects). Factors that may facilitate PPI include social support structures, and easy access (confined geography, cheap efficient transport). Researchers see the potential of PPI as a positive way to increase impact and implementation of evidence and promoting health promotion ('a patient's voice is generally more powerful than a physician's opinion'). Conversely, there is a lack of understanding of the rationale for PPI ('the role [of PPI] should be to make life easier for researchers') and potential vulnerability ('they feel like a laboratory rat', 'they are the subjects'). A quadruple jeopardy (old age, education, ethnicity and citizenship) as well an underlying ageist discourse ('It's actually the older people that might be lower educated people that would only use their mother tongue') was highlighted.

Conclusions

To adopt meaningful PPI and facilitate patient engagement in Singapore requires researchers to develop inclusive strategies that emphasise intra-cultural respect and communication, as well as to put practical steps in place around accessible information. Funders should consider making PPI mandatory and provide resources and training in the operationalisation of PPI.

Patient involvement in *ex-ante* evaluation of a research programme

Núria Radó-Trilla, Paula Adam

Several international initiatives, such as the National Standards for Public Involvement in Research (UK), suggest involving patients in evaluation processes can bring value to the process and promote better outcomes in terms of relevance and credibility. This is mainly because patient's involvement can enrich the perspectives of the assessment process and thus eventually lead to better impact on health. As in many other similar contexts, experience in patient engagement in research in Catalonia is incipient. Most of the efforts have been engaging patients in fundraising (La Marató de TV3 is the

best example). However, the 2016-20 Strategic Plan for Health Sciences (PERIS) for the first time puts the patient at the centre of the strategy. The associated research public funding programme has developed since then different actions to promote translational research, based on traditional funding schemes approach. Being aware of the difficulties to promote effective patient engagement, the Agency of Health Quality and Assessment of Catalonia (AQuAS) organised a series of discussion groups to identify recommended steps for patient engagement. One of the recommendations was to include patients in the *ex-ante* evaluation process of two different calls from the research programme PERIS. With the objective to help ensure that the funding priorities are aligned with patient needs, patient engagement will be in the assessment of one specific item of the proposals, that is, “how oriented to patient needs the proposals are”. To the best of our knowledge, this is the first time that patients are invited to participate in an assessment panel. First time for AQuAS, first time for the Government, first time for the researchers and first time for the patients. Managing this change is complex. From AQuAS we are following the strategy of starting modest, develop guidance materials both for researchers and patients, and use champion’s materials as a basis. The outcomes of this experimental trial will be jointly discussed to identify ways of improvement and lessons learnt for next edition of the funding programme.

Conversations with Experts by Experience: Taking Lived Experience into Research and Scientific Education

Sarah Rae, Iliana Rokkou, Phil Alsop, Lesley Cousins, Hisham Ziauddeen

NIHR Collaboration for Leadership in Applied Health Research & Care (CLAHRC) East of England (Lay PPI Advisor to the Board)

Background

Mental health research attracts a large number of enthusiastic research scientists. Many of these researchers do not come from a clinical background and often have to work from second-hand accounts of the mental symptoms and illnesses they study. The CEbE programme was set up to give such researchers the opportunity to learn first-hand about the illnesses they study, and have their researched informed by teachers who are experts by experience (EbE).

Materials and methods

Each CEbE session is a group conversation between 5-8 EbE teachers and 8-10 researchers, facilitated by an EbE and a psychiatrist. Sessions are conducted on first name terms and any question can be asked, people can choose to answer or not. The key rules are: maintain respect and confidentiality, anyone is free to leave (and return to) the session at any point without having to explain. The programme is run twice a year during the University’s Michaelmas and Lent terms. It is funded by CPFT and secured a Small Project grant (£2000) from RCPsych in 2016. Feedback is collected after each session and is used to inform and improve the programme.

Results

From November 2014 to the present, we have run 26 sessions, beginning with psychosis, mood disorders and anxiety and expanding to PTSD, OCD and eating disorders. This year we will be piloting sessions on borderline personality and autism spectrum disorders. Feedback has been very positive

from both researchers and teachers with many teachers returning several times (these data will be presented). The first research study inspired by the programme is currently under ethics review.

Conclusions

The CEbE programme is a unique PPI initiative that takes lived experience into scientific education where it is much needed. It was developed with EbEs and places them in a central role as teachers.

The role of patient organisations in supporting PPI: evaluation of the Parkinson's UK Research Involvement Award model

Natasha Ratcliffe, Christine Proctor

Parkinson's UK

Background

The Parkinson's UK PPI pilot conducted in 2015 revealed that patient organisations have a key role to play in supporting researchers and people affected by health conditions to work together. In 2017, Parkinson's UK launched the Research Involvement Award, through which researchers receive hands-on support to develop PPI activities to meet the specific needs of their research. Here, we reflect on the Research Involvement Award model and explore the impact involvement has had on researchers, their research and PPI contributors.

Materials and methods

Three Research Involvement Awards were selected as case studies for evaluation. Research teams were asked to complete a detailed evaluation survey about their experience, including the impact involvement had on their research and themselves as a researcher. PPI contributors were asked to share their experience of involvement, including how they felt they had shaped the research.

Results

Involvement led to tangible changes to the way research was done, including a complete revision of the study methodology in one project. The support and guidance received through the award helped researchers develop a better understanding of PPI and methods of involvement, which they can apply to future working. For PPI contributors, key impacts included an increased sense of empowerment and increased confidence in working with researchers. The evaluation also revealed important learnings for ways to strengthen the award model in the future.

Conclusions

PPI had tangible impacts on the research, research teams and PPI contributors. The hands-on support and facilitation provided through the Research Involvement Award helped to promote good practice in involvement and maximise the impact of involvement. This kind of support from patient organisations provides a solid platform for researchers and PPI contributors to build on for future working.

Using arts-based methods to explore recruitment and engagement with multi-generational Black Asian and Minority Ethnic (BAME) communities into health research

Andrew Willis, Manbinder S Sidhu, Polly Wright, Nicola Mackintosh, Manish Pareek, Kamlesh Khunti

Centre for BME Health, Diabetes Research Centre, University of Leicester Background

Black, Asian and Minority Ethnic (BAME) groups are at greater risk of developing co-morbidities and more likely to report poor health outcomes compared to the White British population. However, they are less likely to participate in health-related research.

Our aim was to investigate how BAME communities' interpretations towards co-morbidities influence decisions to participate in research and create a training package for researchers to facilitate diversity in involvement

Materials and methods

Members from BAME communities were invited to attend a single workshop to share experiences (if any) of participating in health research. We utilised an arts based method of creating "corporate" characters to understand biographical and social-environmental implications towards research participation.

We developed three character monologues which were performed by professional actors for a training seminar using a theatre forum approach. Researchers watched performances, asked questions to actors in character, and reflected on their own practices to engage BAME communities.

Results

Seventeen members from Indian Gujarati and Pakistani Muslim communities attended one of two workshops. Eight researchers attended the training seminar.

Members of BAME communities felt current methods of engagement were suited to retired, knowledgeable individuals, prepared to make lifestyle changes, with access to wider supportive social networks. Those less likely to engage were younger people, isolated, with significant family/work responsibilities, and poor relationships with health care professionals.

Our character monologues covered the following themes: stereotyping, stigma, communication with health professionals and researchers, and reaching out to target populations.

Feedback from researchers stated the training seminar and method used were highly relevant and useful to their research, led to a better understanding of the reasons behind BAME (non) participation, and provided critical discussion for increasing diversity of involvement.

Conclusions

Arts based approaches can enable new understandings of barriers and facilitators towards engagement in research, and inform training to reach and retain BAME individuals within health research.

Supporting researchers to develop their PPI activities through a bursary funding scheme.

Fiona E Strachan, Corrienne McCulloch, Fiona Denison, Lorraine Adamson, David Hope, Lucy Marshall, Alice Harper, Nicola Rea, Stacey Stewart, Eleanor Whitaker, Allison Worth

Edinburgh Critical Care Research Group, NHS Lothian

Background

In order to support researchers to actively involve patients and the public in their research, we launched a bursary scheme to support involvement that could not otherwise be costed, for example prior to grant application.

The strategic aim in setting up the fund was to develop and promote good research by:

- developing PPI so it is practised widely across our organisation and becomes embedded in the research process
- ensuring PPI is conducted well and is a good experience for both the public and researcher
- raising the profile of PPI among the research community and the public

Materials and methods

Bursary funds for the scheme were provided from a central R&D budget and applications invited from the local research community. Applications were reviewed by our volunteer advisory group, facilitated by the Patient and Public Involvement Advisor. The maximum amount that could be awarded per project was £500.

Results

In the two years since the bursary launch, eight projects have been supported and £4000 funding awarded in total. Clinical areas supported include Reproductive Health, Cardiology, Dementia, Psychology and Critical Care. Activities supported include establishing an active advisory group within a specialty, hosting workshops and face to face events. Each of the teams supported have been able to progress their patient and public involvement activities in a much more focussed way and this has increased the reach of engagement across the organisation. Groups have been involved in review of grant applications and study documents and in consultations on approaches in research and developments in clinical care.

Conclusions

The support offered through a local bursary scheme has led to an increase in patient and public engagement in our research community and allowed research teams to involve patients at all stages in the research process.

Patient and Public Involvement Training: meeting the needs of a growing and diverse population

Jo Taylor, Christine Smith, Ilyas Akhtar, Amanda Edmondson, Alison Morris, Christine Rhodes, Catherine Richardson, Janet Hargreaves

Department of Health Sciences at the University of York, and National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care, Yorkshire and Humber (CLAHRC YH)

Background

As the role of Patient and Public Involvement (PPI) contributors expands to all stages of the research cycle, there is increasing demand for training that meets the needs of this diverse population. This presentation will discuss the development and evaluation of a bespoke training package for PPI contributors. Key challenges to its successful implementation will also be considered.

Materials and methods

Embracing elements of participatory research, the training package was developed in cycles, incorporating feedback from PPI contributors at each stage to increase acceptability. The training was then independently evaluated using process evaluation methods to examine engagement and explore PPI knowledge and confidence with 13 participants who received the training. Findings were used to refine the package, and the training continues to evolve informed by on-going evaluation and wider PPI developments.

Results

The development and evaluation of the training spanned two years and involved input from NHS and academic partners and more than 20 PPI contributors. Designed as a single day, the training evolved into two short days to increase acceptability. Each day comprises taught content on PPI across the research cycle, and group activities using research case studies to develop PPI skills and demonstrate how PPI can influence the research process and outcomes.

The evaluation validated the training package; uptake and engagement among participants were high and they reported increased understanding and confidence. Challenges associated with meeting the needs of a diverse population, whose expectations and knowledge varied considerably, were identified. Having skilled facilitators with expertise in research and PPI was highlighted as a key ingredient to its success.

Conclusions

Dedicated training for PPI contributors leads to increased confidence and knowledge about the importance of PPI. The research community should lead in this development to ensure PPI contributors are empowered to become true partners in the research process.

Using mixed-methods approaches to evaluate the impact of patient and public involvement in commissioning of biomedical and early translational health research

Doreen Tembo; Alice Hawliczek

Patient and Public Involvement and External Review, NIHR Evaluation, Trials and Studies Coordinating Centre

Background

The National Institute for Health Research (NIHR) and Medical Research Council Efficacy and Mechanism Evaluation (EME) programme funds studies that tend to be biomedical and in the early phase of the health research translation pathway. The NIHR integrates Patient and Public Involvement (PPI) in its research and research management processes. One of these processes is the reviewing of pre-commissioning materials called research briefs. Anecdotal evidence suggested that public reviewers and staff involved questioned whether PPI at this early stage for the EME Programme was useful. Furthermore, there is limited evidence around the role and impact of PPI in this field.

Materials and methods

We determined to carry out a mixed-methods evaluation to explore best practices and the impact of PPI within this context. We used a quasi-experimental design and a questionnaire to assess the impact of public reviews on prioritisation decisions. We also collected qualitative data through semi-structured telephone interviews. We utilised an interpretive thematic approach to analyse the data. Public contributors were involved in proposal design, study instrument design and data analysis in this study.

Results and next steps

Four main themes arose from the data. These included the 1) extent and type of influence public members have on decision-making; 2) different levels of perceived benefits of PPI 3) challenges of PPI 4) enablers of PPI. We make recommendations for the EME programme and other NIHR programmes to enable PPI in the early stages of commissioning. We ask the challenging question: 'should PPI be carried out if it does not add value to the process?' The findings present valuable insight to researchers and funders who are grappling with PPI in commissioning and in early translation research. We reflect on the limitations and challenges of carrying out evaluations on business processes especially during a period of organisational change.

Measuring outcomes and impact of patient engagement (involvement); a scoping review

Lidewij Eva Vat

Athena Institute, Vrije Universiteit Amsterdam

Background

There is increasing consensus that engaging (involving*) patients in medicines development is important. The Patients Active in Research and Dialogues for an Improved Generation of Medicines

(PARADIGM) consortium aims to advance meaningful patient engagement (PE) for improved health outcomes.

This presentation will give an introduction to PARADIGM and summarise results of our scoping review into methods for evaluation of PE. Our focus is on outcomes and impact per stakeholder group at three key decision-making points in medicine development. The review will inform the development of metrics for monitoring and evaluation to support PE and increase the 'return on engagement' for all stakeholders, part of the wider PARADIGM project.

Materials and methods

Using Arksey and O'Malley's (2005) scoping review methodology we focused on key databases, then extended with grey literature searching and snowballing. The search resulted in 1500 citations, of which 155 were selected on title/abstract screening, followed by a full-text review.

Results

The review will be complete by the end of September and we will present updated results at the conference. Preliminary results suggest benefits for

- research (e.g. increased recruitment and retention, better adherence to protocols)
- regulation processes (e.g. better quality of assessment)
- people and organizations involved (e.g. increased knowledge, satisfaction, decreased costs).

Preliminary conclusions

There is a need for consensus-based monitoring and evaluation frameworks. Some indicators for measuring PE impact are proposed but evidence for how to evaluate the impact of PE for each stakeholder group is scarce.

* Use of the term "engaging/e/ment" in the context of European health services, research and development equates to the INVOLVE definition of patient and public involvement (PPI) (www.invo.org.uk).

Mainstreaming Public Involvement – testing an innovative approach to evaluation

Fiona Ward, Ana Porroche-Escudero

Lancaster University

Background

NIHR established regional Collaborations for Leadership in Applied Health Research and Care (CLAHRCs) to strengthen partnership working for evidence based health and care. CLAHRC North West Coast aimed to place Public Involvement (PI) at the heart of governance and all research and related activities. This paper presents findings from an internal evaluation of CLAHRC NWC, which examined progress towards this ambitious objective.

Design and methods

The study adopted a theoretical framework that combined conceptual elements from gender mainstreaming (Moser and Moser, 2005) and the Involvement Cube (Gibson et al, 2012). The evaluation team included six academics and two Public Advisers plus a sub-group of six from the Public Advisers Panel. Data include: interviews (n=37) and nine focus groups (n=47) with CLAHRC

university-based staff and Partners from NHS, local authorities and third-sector organisations; two workshops and peer-to-peer interviews with Public Advisers (n=47); on-line surveys for Advisers, Interns, PhD students (n=32); and analysis of policy documents and routine data.

Results

The findings highlight the importance of creating a culture of PI and, on an ongoing basis, promoting an understanding about good practice in how to involve members of the public. Establishing structures and processes that achieve accountability to and inclusion of the public in governance and research activities was vital to embedding PI, as was distributing accountability across Partners for integrating and monitoring PI opportunities. Public Advisors were more likely to feel valued and projects be seen as relevant to them when they were involved early in the process.

Conclusions

Aligning dimensions of the Involvement Cube (voice, ways of being involved, public/organisational concerns and conservation/change) with the key phases of mainstreaming (adopting the terminology, creating institutional structures and implementation) provided a more nuanced picture of embedding PI in a large collaboration, in terms of the timing, extent and quality of involvement.

Ideological, Pragmatic and Tokenistic: Patient participation within a collaborative

Oli Williams, Shona Agarwal, Graham Martin

University of Leicester and NIHR CLAHRC East Midlands

Background

Our research team conducted a qualitative evaluation of the patient and public involvement (PPI) strategy of a large, multi-site, multi-disciplinary collaborative applied health research organisation in England. Despite a mandate to conduct local patient-centred research and a single, coherent PPI strategy, the meaningfulness of PPI practice varied markedly across the organisation.

Materials and methods

Our research question was: to what extent are the structures and activities within the organisation conducive to conducting meaningful, constructive and fair PPI? We observed and analysed the structures, processes and mechanisms pursued by the organisation to foster influence for PPI, and we considered the evidence for their impact on the organisation's focus, activities and outputs. Methods included document analysis, semi-structured interviews and ethnographic case studies.

Results

Across the organisation research teams interpreted the purpose and worth of PPI in different ways. Involvement strategies were typically defined by three traits: (1) ideology – PPI in research was considered a democratic right; (2) pragmatism – patients/publics were seen as 'end-users' whose involvement would improve the applicability of research evidence; (3) tokenism – PPI was viewed as an obligation but of limited use to generating high-quality research evidence. These differences were often attributed to the personal preferences and beliefs of particular researchers. However, our analysis highlights (i) tensions between organisational directives to conduct 'world class' research and conducting meaningful PPI and (ii) the vast majority of researchers did value PPI but achieving

the ‘gold standard’ of co-production was not always methodology desirable or achievable due to organisational prioritisation of ‘world class’ research.

Conclusions

Improving PPI within multi-disciplinary, applied health research organisations relies upon (i) organisational change (ii) promoting tailored practice rather than prescriptive ‘gold standards’ (iii) (re)focusing on modifying inhibitory structures rather than correcting individual recalcitrance. We propose an original ‘Meaningful PPI Spectrum’ resource which could facilitate this process.

Arts practice and ethics

Simon Woods

Policy, Ethics and Life Science Research Centre (PEALS), Newcastle University

The Policy Ethics and Life Sciences Research Centre (PEALS) has worked on bioethical debates about the use of human embryos in medical science for several years. Public engagement is a necessary component of these debates. Medical science uses the embryo in more and less controversial ways, for assisted reproduction techniques to enable a woman with fertility problems to have a child. This technique has moved from the sensation of the first test-tube baby to a routine clinical service. Similarly, embryo use in stem-cell science is openly discussed and public debate encouraged. However, the use of embryos in the more fundamental science of human developmental biology is rarely publicly discussed. This talk considers the creative practice methods involved in collaborations between PEALS, scientists, artists and publics. Local writer Lisa Matthews led the first project, funded by the North East England Stem Cell Institute. ‘Stemistry’ employed creative writing methods to improve the quality of dialogue between stem-cell researchers and wider publics. ‘Stemistry’ used writing workshops, performances and a pop-up poetry lab in a public space. The second project, supported by a small grant from NICAP (Newcastle University Institute for Creative Arts Practice) and EngageFMS, involved composer and musical director Mark Carroll, who used methods of musical composition with children from three local schools to creatively explore the development of human embryos. Children were invited to submit short melodies based upon the Carnegie stages of embryo development in which all the vital organs and limbs of the embryo are formed. Mark used selected melodies to build a unique composition mapping out the development of an embryo in real, musical time with final composition performed in March 2018. These projects are examples of how it is possible to engage with scientists and publics, working across the disciplinary boundaries of science, social science and the arts and humanities.

ELEVATE: evaluation of the impact of Patient and Public Involvement in the Asthma UK Centre for Applied Research

Allison Worth, Olivia Fulton, Gill Highet

The University of Edinburgh

Background

The Asthma UK Centre for Applied Research (AUKCAR), a collaboration of 17 UK universities, aims to improve the lives of people affected by asthma. Patient and Public Involvement (PPI) has been

embedded in the Centre's work from the start, with dedicated staff working in partnership with lay volunteers to support researchers to plan and deliver meaningful involvement. In 2018, we conducted an evaluation of the impact of PPI on AUKCAR research, researchers and lay volunteers.

Materials and methods

The study and study materials were co-designed by staff and lay volunteers. We conducted a documentary analysis of AUKCAR materials, including meeting minutes and support requested from the PPI group. The views of researchers and lay volunteers on their experiences of PPI and its impact on them and their work were gathered through questionnaires and qualitative interviews.

Results

Forty researchers and lay volunteers completed questionnaires and 24 took part in interviews. The impacts of involvement on AUKCAR research included: keeping the patient voice at the front of research; making research more relevant/ applied; improving study methods and information; helping set the research agenda.

Researchers and lay volunteers identified profound personal impact from their collaboration, including: increased confidence; better communication skills; increased asthma knowledge; interesting range of opportunities.

Facilitators to meaningful involvement were identified as: the qualities and skills of staff and lay volunteers; supportive, nurturing relationships; underpinning values of equality and appreciation. Challenges remain in the geographical dispersion of the partner universities and lay volunteers; inadequate resources; not all researchers embrace PPI. Areas for improvement were identified: more face-to-face contact; more consistent provision of feedback to lay volunteers on the impact of their involvement; online skills training for lay volunteers and researchers.

Conclusions

This co-produced evaluation captured specific impacts, including both examples of best practice in PPI and areas for development.

POSTERS

Towards authenticity: a public participation viewpoint of involvement in the design, delivery and reporting of the evaluation of a health research awareness training package for Patient and Public Involvement participants.

Ilyas Akhtar, Amanda Edmondson, Janet Hargreaves, Alison Morris, Christine Rhodes, Catherine Richardson, Christine Smith, Jo Taylor

Public Partnership Group at the University of Huddersfield

Background

To develop the scope and impact of public involvement in health research, the National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care, Yorkshire and Humber, developed a bespoke training package for the public. The University of Huddersfield's Public Partnership Group were invited to host the training and undertake a co-collaborative independent evaluation.

This poster will present the evaluation from the public participation viewpoint.

Materials and methods

The evaluation followed Process Evaluation Methodology and embraced elements of participatory research, such that the participants in the training and public members of the team were co-collaborators with a robust, significant and visible share in the process. This is evidenced by their roles in undertaking the majority of data gathering [surveys, non-participant observation, interviews] and analysis, engaging in all reflective discussions and leading on producing the report.

A University ethics panel approved the evaluation.

Public involvement consisted of the 13 participants who received the training, and three of the six members of the evaluation team.

Results

The evaluation confirmed the value of the training and highlighted the difficulties of pitching a training event to such a diverse and heterogenic group. Very skilful facilitation was needed to maintain pace, whilst engaging people with different levels of interest and knowledge. The management of the environment to maximise comfort and involvement was important.

Public involvement in the evaluation was daunting at first but hugely enjoyable and fulfilling, as well as enriching the process and outcomes. In particular, public involvement in the analysis and interpretation stages increased the authenticity of the evaluation findings.

Conclusions

This evaluation validated the training package and demonstrated the value and impact of Public Involvement at all levels in research. Findings and reflexive development offer practical guidance in the design and conduct of future participatory work.

Reflections on patient involvement in a research project on medical education

Adedoyin Alao, Bryan Burford, Hugh Alberti, Susan Hrisos, Roger Barton, David Kennedy, Gillian Vance

Newcastle University.

Background

There is an increasing emphasis on patient and public involvement (PPI) in healthcare research, which improves the quality of the research¹. Much of the literature on PPI is on clinical-based research, where the intended outcomes relate to patient behaviours and improved health outcomes². In contrast, medical education research tends to focus on the behaviours of educators and students, who are the end users of the research output. The role and impact of PPI in medical education research is less clear. In order to avoid tokenism, researchers need to better understand how to harness the resources of patient and public members when involved in medical education research.

As part of a study to enhance active patient involvement in medical education, we established a project advisory group to contribute towards the conduct and dissemination of the study. Our experiences and lessons learnt from this PPI initiative are hereby summarised.

Methods

A project advisory group was formed, consisting of three patient representatives. They were supported by the researchers to perform clearly defined roles relating to the conduct and dissemination of the project. Members were reimbursed for their time and travel through project funds reserved for PPI activities.

Outcome

The group attended project meetings and contributed valuably to the programme of activities. They reviewed project materials, suggested areas which needed further exploration, and co-facilitated discussions during a dissemination workshop. In addition to an induction, they required regular support in order to effectively perform these roles. Challenges included limitations due to members' health, and difficulty with integrating the PPI members into regular project meetings as they may not understand technical terms used.

Conclusions

PPI in medical education research requires exploration of feasible models. This example provides a model for PPI in medical education research, and further involvement to support the Implementation of this research is being planned.

Patient and public involvement in pancreatic cancer research

Nile Amos, Laura Elliot, Anna Jewell

Background

Pancreatic cancer is a deadly form of cancer, with five-year survival rates currently as low as 3% in the most common form of the disease. This poses challenges not only for researchers working in pancreatic cancer on studies and trials, but also practitioners of patient and public involvement. Discussion around the benefits of involving people affected by pancreatic cancer in research, which looks to understand the unique biological and pathological aspects of pancreatic tumours, is relatively new to the research community. However, it is important to highlight these benefits to each of the professional, patient and public audience as a means to both combat nihilism around patient involvement, and to increase the amount of funding for pancreatic cancer research from current levels of around just 2% of the UK's overall cancer research budget.

Materials and methods

This presentation will demonstrate some of the ways in which Pancreatic Cancer UK is working with pancreatic cancer researchers to involve people affected by the disease, to improve the design and development of research.

Pancreatic Cancer UK has recruited over 130 people affected by pancreatic cancer, to join their Research Involvement Network (or RIN). The RIN is an enthusiastic community who have contributed to over 25 research projects since its creation in 2015.

Results

This presentation will demonstrate some of the ways in which Pancreatic Cancer UK is working with pancreatic cancer researchers to involve people affected by the disease, to improve the design and development of research. This includes adaptations to research methodology, patient-facing materials and examples of impact successful funding applications.

Conclusions

Patient involvement in pancreatic cancer research can provide important insight, which can help researchers improve their study, and potentially make greater impact with research funders.

Comparison of formal and informal recruitment processes for Patient and Public Involvement advisory panel members.

Rupinder Kaur Bajwa, Clare Burgon, University of Nottingham Patient and Public Involvement Advisory Panel for Dementia, Frail Older People and Palliative Care.

University of Nottingham

Background

The University of Nottingham Dementia, Frail older people and palliative care, patient and public involvement advisory panel brings researchers and PPI members together on a regular basis. Increasing patient and public involvement in healthcare research through these groups is vital to advance research into dementia, frail older people and palliative care. The University of Nottingham PPI panel mentioned above, discussed benefits and barriers of different recruitment process methods.

Materials and methods

Members, together with meeting facilitators discussed differences between formal and informal recruitment processes. Informal recruitment processes include joining the panel by simply attending a meeting and providing facilitators with contact details to receive correspondence regarding upcoming meetings. Formal recruitment processes could involve members completing an application and providing references as prerequisite to becoming a PPI member and taking part in meetings.

Results

A formal process such as providing references could put off potential new members whereas an informal process providing facilitators with contact details and information 'about me' is quick, easy and less daunting. Being part of the advisory panel is voluntary and members are not paid for their time. Introducing a formal recruitment process could give the impression that being a member is a paid opportunity. For PPI members actively involved in projects as co-applicants or co-researchers, a single comprehensive application to facilitators when joining the group, compared to completing individual forms for each project would be more efficient for both the member and researchers.

Conclusions

Potential members could complete an 'About me' form, where they include contact details for facilitators and provide facilitators information on their background and reasons for becoming a PPI member. A formal recruitment process and application form could deter potential new members but would be more efficient for members who are also co-researchers/applicants.

Patient and caregiver involvement in the development and delivery of nurse education: an international multi – site evaluation

Toni Bewley Allen Bewley

User / Carer Council, Edge Hill University, Ormskirk, Lancs

Background

In the UK the professional body for nurses, the Nursing and Midwifery Council (NMC) make patient and caregiver involvement, a mandatory and assessed part of student nurse education. This study, which takes place in July / August 2018, aims to explore the ways that patient and caregivers are involved in the development and delivery of student nurse training at universities in China, India and South Africa. The aims include those of exploring the different methods of involvement being used elsewhere and aim to identify the barriers and facilitators of including patients and caregivers in the development and delivery of nurse education.

Materials and methods

This study will utilise Appreciative Inquiry as methodology and World Café as the method. Hence there will be both an ignite presentation plus photographs and discussion of results.

Results

The research is taking place in July / August 2018. Results will be analysed by using Content analysis.

Conclusions

As the Chair of the service user and carer council/ group across all professional health undergraduate programmes in the Faculty of Health at Edge Hill University. This research project may enable there to be sharing of practice and learning both in our university and across others in the UK and internationally.

Evaluating the strategy for Personal and Public Involvement (PPI) in cancer research in Northern Ireland - the NI Cancer Trials Network and NI Cancer Research Consumer Forum experience

Ruth Boyd, Margaret Grayson, Sandra McCarry, Gail Johnston

Northern Ireland Cancer Trials Network

Background

The NI Cancer Research Consumer Forum (NICRCF) is a group of patients and carers affected by cancer who work with cancer researchers from a range of organisations across NI and the UK. The NICRCF was established in 2011 and is facilitated by the NI Cancer Trials Network (NICTN). Since its inception, the work of NICRCF has routinely been measured by:

- The number of research studies reviewed
- Membership of research committees
- Anecdotal feedback by researchers
- PPI training delivered and received by members
- Awareness-raising activities related to research and PPI including posters and publications

In 2017, as part of a review of the existing PPI Strategy for Cancer Research in NI, a wider evaluation process was undertaken involving a Focus Group with NICRCF members, and an on-line survey distributed to stakeholders.

Evaluation Methods

In generating the on-line survey, PPI standards, strategies and NICRCF objectives were used to guide questions to benchmark PPI and supporting infrastructures. Surveys were distributed to NICTN staff, cancer researchers in NI and personnel in research management/strategy across NI. SmartSurvey™ was utilised to facilitate on-line survey completion. The focus group exploring the PPI experiences of NICRCF members was conducted by staff independent of the NICTN.

Results

The focus group and survey were conducted in November/December 2017. Forty-eight responded to the survey (18.3% response rate). Results across stakeholders indicated alignment in positive reinforcement of the work of the NICRCF and in areas identified for future development. The key area of concern was funding for PPI.

Conclusions

The evaluation surveys and focus group have proved to be a valuable tool to inform the development of a new strategy for PPI in cancer research in NI. In the future NICTN will adopt more robust methods of regular evaluation.

Engaging innovative and inclusive partnerships to inform dementia research: the Dementia Care Community

Greta Brunskill, Claire Bamford, Joy Adamson, Lynne Corner, Alison Wheatley, Louise Robinson

Newcastle University

Background

The PriDem research programme aims to develop and evaluate components of evidence-based, person-centred, primary care led post diagnostic support to better meet the needs of people with dementia and their families. This research addresses post diagnostic dementia care as recently defined by the World Alzheimer's Association; a 'system of holistic, integrated continuing care in the context of declining function and increasing needs of family carers' (2016). To ensure that this research is embedded in real life experiences and contexts, a wide, inclusive stakeholder group is being established; the Dementia Care Community (DCC). The DCC aims to bring together people with dementia and their family carers, and a wide range of professionals involved in support throughout the illness, including those employed by health and social care and key voluntary organisations.

Materials and methods

A range of approaches will be used to engage and involve the DCC throughout the research, including face-to-face group meetings, postal and email communication, and individual visits to people with dementia and their families. Key anticipated roles for the DCC will be in informing sampling and recruitment, developing data collection tools, contributing to data analysis, shaping intervention development, and advising on user friendly modes of dissemination.

Results / Conclusions

This presentation will describe the process of establishing this inclusive stakeholder group, and the early stages of working with the DCC to inform the work of PriDem, highlighting key benefits and challenges in this innovative approach to engaging the wider stakeholder community in research.

How to do research on my own? - Development and Piloting of a Leveraging, Practical Research Training for Patients with Mental Disorders

Anna L Brütt, Julia Magaard, Tabea Bernges,

Department for Medical Psychology, University Medical Center, Hamburg, Germany

Background

The importance of research involvement of mental health services users is increasingly recognized. Training can enable them to conduct research. The aims of the project were (1) to develop and (2) to pilot a practical research training.

Materials and methods

“How to do research?” was developed involving mental health services users and piloted with seven participants. Feedback was provided in a group discussion. Thematic analysis was used.

Results

The two-day research training includes practical units on developing a research question, planning a study, analysing data qualitatively and quantitatively as well as disseminating results. Participants positively emphasized practical relevance and training material.

Conclusions

“How to do research?” was evaluated positively. However, evidence about sustainable efficacy is lacking.

Patient involvement in a systematic review and meta-analysis

Anna L. Brütt, Ramona Meister, Rebecca Philipp, Tabea Bernges, Steffen Moritz, Martin Härter, Levente Kriston, Franziska Kühne

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Background

Patient-centered care health research denotes research that is informed by the perspectives, interests and values of patients. PPI has been widely promoted internationally. Nonetheless, a strategy for implementing PPI in Germany is still missing. We aimed to develop and evaluate PPI workshops for involving patients in a systematic review and meta-analysis on metacognitive interventions.

Materials and methods

We conducted two workshops: The first workshop and a subsequent focus group discussion aimed at the completion of the methods section of the review protocol regarding patient-centered outcomes. Lay information on systematic reviews and the MetaCog project was presented. Then,

participants discussed about outcomes of metacognitive interventions. Finally, participants prioritized outcomes. The second workshop included a presentation of the results of the review and meta-analysis followed by a discussion on results. Furthermore, participants gave feedback on dissemination strategies and the lay summary.

Results

Seven persons with experience in psychiatric care participated in the first, five of them in the second workshop. Participants prioritized outcomes pre-defined in the review protocol (e.g., meta-cognitive or cognitive changes, symptomatology, quality of life), neglected other outcomes (like satisfaction with treatment, acceptability), and added relevant new ones (e.g., scope of action/autonomy, applicability). Relevant new outcomes have been included in the review protocol. The second workshop resulted in a list of different dissemination strategies. Additionally, the lay summary has been revised.

Conclusions

Altogether, patients valued the workshops. However, some suggested to involve patients at an earlier stage. One participant suggested a reduction of the information given in the workshop. Furthermore, participants in the second workshop were disappointed about the findings of the review and meta-analysis, especially that none of the relevant new outcomes has been documented in included studies.

A protocol for a systematic review of apathy measures for older adults: Patient and Public Involvement in reviewing content validity

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School of Health Sciences, University of Nottingham

Background

Apathy is the most common neuropsychiatric symptom in dementia, and may predict development of dementia. Despite the various measures of apathy available, there is no gold-standard measure. Content validity refers to how well the content or items of a measure encompass and reflect the construct: without sufficient content validity, a measure will not assess what it is intended to. A systematic review of apathy measures has previously been conducted, but just one measure's content validity was assessed by the included studies. Given the lack of studies of content validity, independent content validity assessment will be particularly important. The opinions of one reviewer however may be insufficient for independent content validity assessment due to the subjective nature of content validity evaluation and the disagreement regarding the definition of apathy. Patient and Public Involvement (PPI) representatives can offer insights and alternative perspectives on symptoms of apathy, and can therefore enhance the assessment of content validity.

Methods

A systematic review of apathy measures for older adults will be conducted in accordance with COSMIN guidelines. The content validity of measures will be examined through reviewing results and methodological quality of studies that develop or adapt apathy measures, in combination with independent ratings by the reviewers and PPI representatives. PPI representatives will be asked to

rate the relevance (whether all items included relate to apathy and are appropriate for an older adult population), comprehensiveness (whether the measure covers all aspects of apathy) and comprehensibility (whether the measure uses clear and accessible language without ambiguity) of each apathy measure, alongside the reviewer.

Conclusions

PPI will play a key role in the independent assessment of the content validity of apathy measures. This will be combined with the results and methodological quality of studies for a comprehensive systematic review of measures of apathy for older adults.

Researching *together with* members of Centre for Dementia PPI group

Neil H Chadborn, Linda Birt, Alessandro Bosco, Carole Brewster, Dons Coleston-Shields, Michael Craven, Claudio Di Lorito, Julie Gosling, Miriam Stanyon, Jen Yates

School of Medicine University of Nottingham

Background

Co-research as a development of PPI is driven by three agendas: enhancing the quality of research by incorporating deeper '*lived experience*' perspectives, drawing on community-based participatory research, honouring grass roots dynamics of '*nothing about us without us*'. Participatory research, whilst serving to improve health outcomes, originates from an emancipatory perspective, upholding human rights and a dementia-united approach.

Materials and methods

With a basis of four ongoing projects, we explore theoretical frameworks and how these shape roles, relationships, governance, and benefits of co-research.

Results

Co-research involves new and emerging roles and relationships, formed and renegotiated within and between projects, indicating need for clarity regarding the purpose of co-research as well as clear description of the role of co-researchers, and communication of these amongst the research team, governance and funders and other stakeholders. We also highlight a need for capacity-building of both researchers and co-researchers, involving technical knowledge about research processes and/or negotiated ways of power-sharing that recognise and reward the skills people bring and the reciprocity of learning between academics and co-researchers.

Our co-research activities have involved peer-facilitated interviews and focus groups and analysis of research materials. Trust and rapport between lived experience interviewers and research participants can enhance data collection. Asking probing questions or identifying meanings and implications not obvious to an academic researcher.

Participatory design frameworks have also been co-developed, enabling creativity and innovation between future users of technology, designers and engineers.

Conclusions

Co-research is particularly important for dementia research where it facilitates a greater voice of people who may have cognitive or communication difficulties or difference. The emancipatory

values of this approach, where incorporated correctly, serve to redress the balance between 'researcher' and 'researched', reduce stigma and exclusion often experienced by people with dementia and their carers and realise mutual potential and skills of all participants.

Why evaluating impact isn't what's important in patient collaboration

Emma J Cockcroft; Kate Boddy; Kristin Liabo

NIHR CLAHRC South West Peninsula

Background

The title for this presentation is intentionally provocative. As a team of three researchers who work with communities to influence and collaborate on research led by others, we are committed to creating conditions in which people can truly work on research as equal partners and experts in their own right.

Materials and methods

In the past two years we have, with ethical approval and participant consent, audio recorded and observed several public involvement meetings. We have done this with the intention of understanding: a) how patients, carers and members of the public bring their expertise to the research, b) our own roles in facilitating conversations between researchers and members of the public, and c) the impact of involvement on research.

Results

The data speaks of a largely non-linear and multifaceted trajectory of impact, which we suggest is enabled by the *space* in which involvement happens. Our understanding of 'space' relates to the physical 'place' of the meeting (room, building, facilities) and the social and cultural 'space' of how the meeting is run, who is there and the roles given and taken by participants.

Conclusions

We propose that there is a direct link between *space* and impact in patient involvement. While it is possible to evaluate *space* and whether this allowed for impact, it is not possible in our view to truly evaluate impact itself. This is because impacts from involvement go in many different directions and often take unexpected turns. Trying to capture this impact through evaluation risks us creating an understanding of impact from involvement which misses important impacts simply because they happened in unexpected ways, or outside of our evaluative gaze. We therefore instead suggest that more emphasis is put on the involvement *space* and whether this facilitates collaboration.

Implementing PPI into the Clinical Research Facility

Fiona Evans, Linda Coughlan, Golaleh McGinnell, Joanna Gray, Elizabeth Sapey, Jo O'Neill

University Hospitals Birmingham

Background:

In recent years, it has become an increasing priority to involve patients and public with decision making within healthcare. This has evolved from merely informing the public, to actually including

them in the fundamental decision making that can alter the course how the NHS is run, and the way research is delivered. Professor Dame Sally stated ‘People-focused research in the NHS simply cannot be delivered without the involvement of patients and the public.... patients and the public always offer unique, invaluable insight.’ Using this statement, the Birmingham CRF wished to implement our own PPI group, with an aim to improve the quality and impact of research we are conducting.

Materials and Methods

To set up this PPI group we have had to:

- Gain a dedicated pot of money to PPI – this is to provide members with travel expenses and to reward them for their time
- Actively recruit members – our members are not one particular group of individuals. They do not need to have a certain type of disease. Although beneficial if they have an interest in research!!
- Set up our initial meeting – explain the role to our individuals, decide on a time commitment. Provide training in GCP and PPI.

Results/future of the group:

As our group is still in its infancy, I would like to discuss what we hope will come from this group. We would like PPI members to attend SAC (scientific advisory committee). We hope they become an integral member that is involved in reviewing trials and has the opportunity to give their opinion. In turn this will influence;

- What type of research is coming through (are some areas over/under represented?)
- Is the research valuable?
- Is what we are asking participants feasible?

We would also like to encourage researchers to use our PPI group for input when designing a study

Conclusions

How has/will PPI benefit the CRF?

Involving children in clinical research – perspectives from the Cambridge NIHR Clinical Research Facility children’s non-executive research board

Faye Forsyth, Caroline Saunders, Anne Elmer, Shirlene Badger

Cambridge Clinical Research Centre

Background

Advisory groups are a relatively common form of patient and public involvement in health and social care research. The Cambridge NIHR Clinical Research Facility (CRF) established a Non-Executive Children’s Board in 2013 to inform the development of paediatric services on the CRF. Although the field of PPI has significantly matured in recent years with the development of conceptual frameworks and impact assessments, little has been published specifically exploring advisory groups

as a type or form of patient and public involvement. This study attempts to assess the perceived impact of the Children's Board from both the clinical staff's and the public's point of view.

Materials and methods

The analytical method involved a purposeful maximum variation sampling of a population sample comprised of clinical staff, children and their accompanying parent. The study participants took part in a semi-structured interview. The responses were transcribed verbatim and subjected to qualitative content analysis.

Results

Staff members expressed varying levels of satisfaction with the board as a form of PPI. The purpose and direction of the board was often questioned, as was the level of engagement and feedback. Staff unanimously agreed they consistently underestimated the capabilities of the young board members and believed an element of reciprocity was important. Parents and children on the other hand found themselves conflated between the purpose of participating in the Children's Board and the research study, but they appreciated the opportunity to suggest improvements.

Conclusions

While all staff reported positive experiences of, and outcomes from, the advisory group form, they raised important questions about its suitability within the context of the clinical research facility setting. Other important themes included having regular schedule of meeting and ensuring appropriate feedback to drive motivation and commitment, being clear on purpose and direction and a strong desire to reciprocate in some way.

ProACT: Fostering PPI within the design of digital health solutions for people with multimorbidity

Dr Mary Galvin, Dr Emma Murphy, Dr Caoimhe Hannigan, Dr Julie Doyle, Ms Suzanne Smith, Ms Sarah Bowman, Prof Mary McCarron, Prof Anne-Marie Brady, Dr John Dinsmore

The Centre for Practice & Healthcare Innovation, Trinity College Dublin

Background

Within Europe there are 50 million people living with multimorbidity. However, healthcare systems have not been designed to effectively support them. ProACT (Integrated Technology Systems for ProActive Patient Centred Care) is a digital health EU H2020 research programme that seeks to address this problem by developing and evaluating a digital integrated care system to support older adults (65 +) living with multimorbidity. This presentation will illustrate how PPI was achieved within ProACT, with participants becoming co-design partners.

Methods

Vital to ProACT, is eliciting the voices of people living with multimorbidity (patients, formal/informal caregivers, health care practitioners). It was important that these voices were heard and responded to. We Included as many stakeholders as possible within community care, making them active participants in the design of ProACT, not just participants of the research, insuring that design happened with and not for participants. Therefore, a co-design methodology was adopted. Across

three stages: requirements gathering, co-design workshops and usability testing, and proof of concept trials, traditional qualitative research techniques (166 stakeholders) were combined with user-centred design methodologies (EU trials involving 120 patients and their care networks as well as creation of expert panel & usability testing (128 stakeholders)).

Findings & Discussion

ProACT illustrates how design theories and associated methodologies naturally align themselves with not only exploring the multifaceted nature of multimorbidity but also fostering PPI. They do so by identifying the factors (stakeholders, challenges, lived experience, etc.) that foster PPI, however, this presentation will also propose how we can sustain PPI once we achieve it. When we adopt methodologies that truly foster PPI, we open ourselves to a serendipity within our research projects. A serendipity that challenges project resources, the evolution of research questions, and the additional supports that researchers may require to respond to PPI.

Using a hub and spoke approach to patient and public involvement to enhance the quality of a trial.

Maureen Godfrey

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Background

A 'Falls in Care Home Multi-Centred Trial' (FinCH) has recruited 1698 participants in 87 care homes to date and is funded by the National Institute of Health Research (NIHR). NIHR advocate Public and Patient Involvement (PPI) collaborations to ensure high quality research is enhanced by collaborating with appropriately trained residents, carers or past carers or people who have had direct personal experience of the research topic. Broader perspectives are likely to improve research outcomes.

Methods

A hub and spoke approach to PPI was implemented in the FinCH trial. A lead role was advertised and a job description was distributed to various PPI groups within the East Midlands. In addition, job descriptions were produced for PPI group members and locally recruited from participating trial sites. The focus of the hub role was to provide leadership and to represent the PPI team at strategic trial meetings. The PPI team have contributed to the trial through attendance at the investigator meetings and through telephone conferences. A PPI budget of £21,352 was allocated across sites.

Results

Five PPI members, one located at the centre, and four located in Norfolk, Leicestershire, Nottinghamshire and Bradford were recruited. The PPI team was managed by a FinCH researcher. PPI members have contributed to all study documents, observed and documented the intervention being delivered. They have analysed interview data following training to capture PPI perspective. They have presented at conferences and are involved in all impact and dissemination initiatives.

Conclusions

This hub and spoke approach was an effective approach to collaborate with PPI members located in a range of geographical areas in this multi-centre trial (FinCH). More evidence is needed to evaluate

robust methodical approaches to PPI and cost effectiveness, to inform good practice and strengthen the current evidence base.

Lessons learned from improving the quality of involvement: a case study of the EPIC trial

Alys Griffiths

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The processes of public and patient involvement are infrequently evaluated or reported, particularly when things that have not worked well. The DCM-EPIC randomised controlled trial aimed to understand whether Dementia Care Mapping reduced behaviours typically associated with agitation for people living with dementia in care homes. To represent the experiences of people with dementia and their families in the trial design and delivery, a Lay Advisory Group was set up. This included people who were living with dementia, a relative of someone with dementia, or working in the care sector. They were initially consulted on trial design and recruitment documentation. However, the researcher co-ordinating the group moved institution, leading to the Lay Advisory Group not meeting or being involved for several months. Eighteen months before the trial ended, a second researcher began to co-ordinate the group. At this time, the group felt that they had not contributed much, despite being incredibly passionate about the research area and were concerned that involvement was just tokenistic. A new model of involvement was subsequently implemented led by the group itself. Rather than being asked to review documents, the group collectively designed and developed content, and reviewed further versions. The group set its own priorities and highlighted areas of the trial to be focused on. They are now writing dissemination outputs and have a plan of dissemination activities they will lead. This poster will present the group's experiences and future plans, and share how this model was facilitated. The lessons learned from these experiences will benefit researchers in the early stages of establishing Lay Advisory Groups or consulting with expert individuals.

A pilot project to initiate public involvement in animal research

Helen Hanson, Dr Kathy Murphy, Prof Andrew Mellor

The Newcastle upon Tyne Hospitals NHS Foundation Trust, Newcastle upon Tyne

Background

Public attitudes towards animal research vary widely. The extent of PPI in health research using animals is not known, but it appears involvement is less embedded in this area of research. The aim of this project was to pilot a workshop format to facilitate greater public involvement in health research using animals at Newcastle University.

Materials and methods

A programme was devised with three short talks and delivered to two existing patient groups. A veterinary surgeon talked about the care and welfare of research animals. An ethics committee chair discussed governance. A researcher reasoned that animal research is essential to understand and

develop new treatments for complex diseases such as cancer and arthritis. This was followed by questions and a group discussion in an informal atmosphere. Attendees completed a brief survey before and after the workshop to gauge impact on their knowledge and views of animal research.

Results

Sixteen people completed the survey. Responses showed very low knowledge of health research using animals at Newcastle University, which increased markedly after the workshop. Attendees tended to have neutral to positive views of animal research prior to the workshop, which remained constant. Group discussions highlighted that attendees supported wider public discussion and scrutiny of animal research. Anecdotal feedback from people invited to the workshops suggested that some strongly opposed to animal research chose not to attend.

Conclusions

Health research using animals is a controversial topic for public involvement and public knowledge may be limited. Including basic education from a range of perspectives enabled public attendees to participate fully in discussions. More work is planned, to repeat this workshop for larger audiences and attracting people with more diverse views. Furthermore, opportunities will be sought for some of those completing the workshop to become involved in specific animal research projects and grant applications.

From PPI consultation to co-production? Identifying the barriers and facilitators to further development of PPI at the Sir Bobby Robson Cancer Trials Research Centre. A qualitative study exploring views and perceptions of research active consultant oncologists.

Adrian Hawkins

Joint Research Office. The Newcastle upon Tyne Hospitals NHS Foundation Trust.

Background

There is key policy, moral and ethical drivers for including patient public involvement in health research. Evidence suggests implementation, delivery, evaluation of impact and actual added value can often be suboptimal. The aim of this study is to identify views and perceptions of barriers and facilitators to further development and utilisation of PPI, in the oncology clinical trial setting.

Materials and methods

A qualitative study using semi structured interviews. Eight oncology consultants from a single NHS Oncology Clinical Trials Unit were interviewed. Data was analysed using a thematic approach.

Results

Participants identified five main barriers to further development; (i) Lack of consistent demonstrable and measurable added value of PPI, (ii) Impact of current operational delivery processes, (iii) Communication, visibility and awareness of PPI group functions, (iv) Current culture and ethos towards PPI, (v) Availability of experienced PPI members for increasingly specialised oncology trials. Participants identified facilitators as; (a) Improving measurement and communication of the value and impact of PPI, (b) Improving visibility and awareness of the PPI group functions at site level, (c) Improvement of PPI group structures, access and feedback mechanisms, (d) Aligning PPI group

development with the needs of future oncology research priorities at local, regional and national levels.

Conclusions

The study identified key barriers and facilitators to further development of PPI resource at the Sir Bobby Robson Cancer Trials Research Centre. Overcoming the key barriers of perceived tokenism and measurable value and impact requires addressing at site level. Operational PPI delivery needs to be robustly aligned with ongoing clinical need, and easy to access to maximise its utility.

Utilising a PPI Group to Developing a Patient Resource for Early Phase Oncology Research Patients

Ben Hood, Sharon Sellers

Sir Bobby Robson Cancer Trials Research Centre

Background

Cancer patients, who have no proven treatment options available are referred to Sir Bobby Robson Cancer Trials Research Centre (SBRU) for consultation about participating in experimental medicine research. Weekly outpatient clinics are held for patients to discuss the possibility of participating in an early phase trial. During their clinic appointment patients will be given general information about participating in early phase research. The information given can be quite daunting and complex for patients to absorb in the time available.

Materials and methods

Working with patients participating in research at SBRU and our research PPI Group. We found out what essential information patients would need to be aware of, before their initial research appointment. Initial questionnaires were developed through our PPI group, which in turn were given to current patients on clinical trials. Information indicated what information a resource should have in it, when patients should receive it and in what format. The next stage of this development involved the PPI group meeting regularly to give feedback on the drafts versions of a booklet. From this, a booklet has been developed for future patients.

Results

We have developed a booklet resource which we hope will improve patient understanding and reduce anxiety of early phase trial participation. The booklet will go into practice in August this year, where we audit it, to see how useful patients attending their initial research appointment found it.

Conclusions

Working in collaboration with our PPI group we have been able to produce a valuable intervention for future clinical trial cancer patients. It is hoped that the resource would be a reference point of information that patients and their families and friends could utilize through their research journey. We hope this would lead to greater understanding of the research journey and make newly referred patients more comfortable with their initial consultation.

Evaluating the impact of a university-based public involvement in research group

Julia Jones, Sue Marks, Jennifer Cameron

Centre for Research in Public Health and Community Care (CRIPACC), University of Hertfordshire

Background

Patient and public involvement (PPI) in research is acknowledged as being important and increasingly a mainstream activity in health and social care research. However, research outputs, such as research articles, reports and conference presentations, often provide limited details regarding how members of the public were actually involved in the research being reported. At the University of Hertfordshire, the Public Involvement in Research group (PIRg) has been embedded within the Centre for Research in Public and Community Care (CRIPACC) since 2005. The PIRg have been involved in many research studies during that time, but there has been no tracking of what happened to these studies in terms of research outputs. Furthermore, the extent of involvement of PIRg members in the research studies and the impact of this involvement has rarely been reported.

Materials and methods

This poster will describe an evaluation study with the aim to identify research studies and outputs that have involved members of the PIRg since 2013. A retrospective approach was taken, reviewing records such as minutes and documents from PIRg meetings and on-line searches for projects and outputs. Researchers were contacted and PIRg members searched their archived documents. Members of the PIRg have been 'critical friends' to this project and an important source of information.

Results

To date, we have identified 29 funded studies which have received support from the PIRg in some way. Approximately 70% of these projects have mentioned PPI and/or the PIRg in one or more research outputs. Of the published research articles, approximately 36% report some PPI involvement. Using the GRIPP2 reporting checklist, the extent of PPI reporting in these research articles varies widely.

Conclusions

This evaluation offers a template for researchers & PPI groups who want to evidence the impact of their public involvement activities.

Patient Involvement underpinning a project to develop a new innovation in the treatment of Fistula-in-ano

Elizabeth Li, James Glasbey, Margaret O'Hara, Saloni Mittal, Victor Rose, Sarah Squire, Sharon Garner, Arlo Whitehouse, Mike Keighley, Thomas Pinkney

University Hospital Birmingham

Background

Fistula-in-ano (FIA) is a debilitating problem that affects >12,000 new patients a year in the UK. It often requires multiple treatments and reflects a burden of discomfort, hygiene issues and embarrassment. We are developing a new treatment device funded by the NIHR i4i Invention for Innovation scheme. It aims to provide a single step solution that improves quality of life, and reduces the burden of illness.

Materials and methods

From the projects' genesis, we worked with a patient partner as a co-applicant. His unique insight was pivotal to our success in the NIHR i4i application. Once funded, we recruited a larger group of patients. They were identified from clinical records and sent a letter of invite to take part in a focus group. Twenty-three patients responded and two meetings were held at different times of day. Those who attended covered a range of age, ethnicity, gender and socio-economic background. The research fellow and patient partner gave presentations on FIA and its treatment, patient involvement in research and patient partner's own experience of FIA and being involved in research. Time was allocated for free discussion to allow patients to speak in an unconstrained way about their experience of FIA.

Results

Co-presentation by the patient partner was instrumental in initiating discussion of this embarrassing and debilitating illness. Strong themes emerging included discomfort, fatigue, lack of awareness of FIA and value in speaking to other sufferers. In clearly explaining our intent in a letter, then defining our aims, we were able to capture themes that are little spoken about, but critical in how we can best meet the needs of patients in the device design. The strength of their input has already shaped the direction we take this project.

Conclusions

PPI is critical in eliciting the needs of patients and underpins the direction of this project.

Empowering children in medical research: children as co-researchers in a qualitative interview study

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Background

Because children differ from adults, medical scientific research with children and young people is needed to provide them with the best treatments. Children are sometimes seen as vulnerable,

raising ethical concerns including their ability to give informed consent in research participation. However, an alternative view is that young people can and should be involved not just in consenting to research, but in helping to design it and to ensure research reflects their priorities. In order to empower young people participating in medical research, we are involving children as co-researchers in the analysis of findings from a qualitative interview study about young people's experiences of medical research. The aim is to find new insights in the qualitative data that were collected, and to explore ways to involve children in the analysis phase of research.

Materials and methods

In a two-phase process, co-researchers aged 9-18 years old, mostly without research experience, will collaborate with (adult) researchers to help with the analysis of qualitative interview data collected in the Netherlands. Phase one consists of individual meetings between a young person co-researcher and a researcher. Together, they will watch a video of an interview with a child talking about their experience of taking part in medical research and discuss themes that the young person identifies. In total, a subset of five interviews of the entire dataset will be used in this phase. In focus groups, each with 5-10 young person co-researchers, the identified themes will be further explored, using video fragments from the total dataset of interviews that were conducted.

Results

This project will enable us to reflect on how young people can get involved in analysis of qualitative data and how this impacts the research.

Conclusions

The proposed study will empower children in medical research, and contribute to the evaluation of current practices in Patient and Public Involvement.

Development of an open-source tool for contemporaneous evaluation of PPI in basic and preclinical research

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Background

Involving patients in research broadens a researcher's field of influence, generating novel ideas, challenges and discussions. Basic, translational and preclinical research (hereto basic) is integral to the progression of innovative healthcare. These are not patient-facing disciplines and implementing meaningful PPI can be a serious challenge in the absence of well-defined support structures.

Materials and methods

A discussion forum (n=16) and thematic analysis identified key challenge areas of implementing PPI for basic researchers. A literature review was used to define questions for a patient-involvement satisfaction questionnaire. Patient partners (n=12) reviewed, ranked and assessed the questionnaire for language accessibility. Pilot study of the questionnaire (n=60) for face, discriminate and internal validity, with factor analysis to determine substructure. The quantitative analysis informed by the qualitative feedback refined the questionnaire. To adapt the questionnaire to a structure familiar to

basic researchers, we developed a flagging system based upon that used in standard quality control assays and a PPI reporting grade based on the risk matrix.

Results

Key challenges implementing PPI: (1) Barriers- institutional challenges (2) Worries- personal challenges (3) Concerns- research challenges. In response a personal “*PPI Ready*” planning canvas for researchers was developed. For contemporaneous evaluation of PPI, a psychometric questionnaire for patient partner satisfaction and an open source tool for its evaluation were developed. The questionnaire measures information, procedural and quality assessment. Combined with the open source evaluation tool, researchers are notified if PPI is unsatisfactory in any one of these areas. The open source tool is easy to use and adapts a psychometric test into a format familiar to basic scientists. Designed to be used iteratively across a research project, it provides a simple reporting grade to document satisfaction trend over the research lifecycle.

Conclusions

We have developed a tool for basic health researchers to facilitate the implementation and evaluation of PPI during a research project.

Toilets when travelling: a human rights, coproduction model to support inclusive living

Gill Mathews, Heather Wilkinson

University of Edinburgh

Background

Going to the toilet is a universal human need and a core consideration when travelling and accessing the community, yet its private and sensitive nature renders it invisible in debates and actions to address social inclusion. Barriers are wide ranging and vary across different conditions making it difficult for the transport industry to meet diverse, and often conflicting, needs. Our objective is to find solutions for designing inclusive, accessible, and findable toilets that enable travel and participation for all, to help as many people as possible to feel confident that they can go to the toilet whilst travelling.

Materials and methods

Co-production project funded by Disability Research on Independent Living and Learning. Human rights model involving people living with dementia and people living with a range of disabilities as participant coresearchers working in partnership with academics and experts in co-production, participatory and community action. Interactive workshops. Participant coresearchers use phones or cameras to gather real-time photographic and video images of toilets and signage in city and rural locations, e.g. airports, bus and railway stations, ferries. Cooperative approach to data analysis using constant comparative method and critically reflexive discussion to draw out themes and situate these within relevant conceptual debates.

Results

Initial challenges with research ethics led to coresearcher status changing to participant coresearcher. Two of five practice-based Gatherings with interactive workshops successfully hosted

by community partners. Twelve participant coresearchers recruited to the study. Data collection in process – will be complete by end of October with preliminary findings ready to present for November conference.

Conclusions

The partnership approach requires professionals to challenge current belief systems and conditioning regarding the capacity and abilities of disabled people in respect of what they can achieve and do. Current structures designed to protect people with vulnerabilities can impede participation. Time and money needed for authentic coproduction.

Identifying effective recruitment strategies for patient and public involvement (PPI) in trials

Holly McGrath

University College Cork School of Public Health

Background

Researchers have difficulty engaging public and patient partners in trials, especially people from vulnerable groups in society. Many studies which include PPI do not describe how they recruited partners, so little is known about the process. Also, research suggests that PPI partners may not represent the target population of a trial. The aim of this project is to identify effective method(s) for recruiting representative PPI partners for a feasibility trial investigating an intervention to increase diabetic retinopathy screening in primary care.

Materials and methods

A rapid review was conducted to identify existing strategies shown to be effective, appropriate and/or feasible. A recruitment profile was developed to establish the preferred characteristics of the PPI panel. Informed by the review findings, different recruitment strategies will be developed and carried out. Persons who respond to the recruitment call will be asked to complete a survey recording how they were recruited and some details relevant to the recruitment profile. Descriptive statistics will be performed to compare the number and profile (whether they match the recruitment profile) of partners recruited through each strategy.

Results

Recruitment strategies identified by the review were passive (people self-identify as potential partners) or active (people who are identified as suitable partners are approached by researchers or their healthcare/community partners.) Recruitment took place in healthcare and community settings, and online. The results of the survey will determine which method was most effective, in terms of (a) numbers recruited, and (b) partners fitting the specific profile

Conclusions

Findings from this study will contribute to the evidence base on effective and feasible recruitment methods for future trials involving PPI. It is hoped that researchers will be able to focus their efforts and resources on strategies likely to recruit appropriate PPI partners who can provide valuable and relevant insights from the target population of a trial.

Challenges of PPI Involvement, Recruitment and Retention in an NIHR funded trial.

Teresa Melody, Andrew Worrell (PPI), Catriona Frankling, Fang Gao Smith

University Hospitals Birmingham NHS Foundation Trust

Background

The Clinical Research Ambassadors (CRAG) group based at Heartlands Hospital in Birmingham was formed in 2013 and has been providing PPI input to researchers. Much of this work is done via researchers attending our regular meetings for opinions at particular time points in their studies, but CRAG members may also opt to become embedded as collaborators within a long term study.

TOPIC is a complex randomised controlled trial comparing the effectiveness of two anaesthetic techniques in surgical patients; the primary outcome assessed the incidence of chronic pain. The TOPIC feasibility trial was funded by a research for patient benefit (RfPB) grant and three PPI patient ambassadors were involved in the application process and two PPI representatives went on to become involved in the trial management group. The full trial has been funded by the National Institute for Health Research (NIHR) Health Technology Assessment (HTA) programme.

Objectives

To examine particular challenges of PPI involvement, recruitment and retention in complex clinical trials. Explore the impact of PPI as evidenced by changes made to the TOPIC trial based on input from CRAG members. To examine what are the challenges to effective patient involvement over the duration of the trial from a PPI and Researcher perspective.

Results

The TOPIC study demonstrates the impact of PPI on many areas of the research process including; Study Design; PPI costs attributable to a successful RfPB Grant application; Using PPI to deliver effective dissemination; Bridging the gap between feasibility and a more substantial HTA grant application.

Conclusion

Retention of PPI members within a long term programme of work is difficult, however, if researchers can provide an overarching positive experience from PPI members, this will lead to sustained momentum of engagement throughout the duration of the trial.

An Exploration Of The Perceived Impact Of Active Service Users And Carers Involvement On Adult Nursing And Social Work Academic Staff

Opeyemi Odejimi

University of Wolverhampton

Background

In the United Kingdom, the involvement of patients or services users together with their families or friends (also known as carers) in health and social care education, research, and practice is fast becoming common practice. However, there are few studies that have evaluated the impact of service users and their carers Involvement in health and social care education, especially on the

academic staff. This study explored the perceived impact on Adult Nursing and Social Work pre-registration degrees academic staff.

Materials and methods

A concurrent mixed-methods approach was employed in this study. Fifteen academic staff took part in this study. Individual semi-structured interviews followed by questionnaires were used to explore their views of the impact of service users and carers' involvement. Qualitative data was analysed thematically from the semi-structured interviews. Additionally, descriptive and cross-tab analysis of quantitative data was carried out. Then, a side-by-side comparison was used to identify aspects of the qualitative and quantitative findings that were convergent and conflicting.

Results

Academic staff initially struggled to identify any beneficial outcomes of service users and carers' involvement to them. They readily identified the benefits to students and service users/carers. After thorough consideration, they did identify some beneficial outcomes to their professional's roles and teaching skills, attitude and beliefs. They also reported a number of concerns which have made carrying out involvement challenging.

Conclusions

Academic staff members are one of the main stakeholders of involvement in Higher education. They are also gatekeepers with power that can potentially increase/decrease the scope and range within students' education. This study have provided insight into how best to address the concerns raised by academic staff and strategies to employ that will optimise its beneficial outcomes to them. This study may inform higher education providers, researchers, education commissioners as well as Professional Statutory and Regulatory Bodies about strategies to ensure best and effective practices of service users and carers' involvement in Higher Education.

Patient involvement in cancer research: are we underestimating our patients?

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Background

NHS England, NIHR and NCRI actively support inclusion of research within the NHS with the goal of 20% participation by 2020. This can only be achieved if research is embedded into every aspect of healthcare and cancer biobanking repositories are generated to fuel translational research. It is unclear what the obstacles to participation are; patient or professional factors?

Materials and methods

Patients with gynaecological malignancy in a tertiary cancer centre, alongside hospital staff and lay public were invited to participate by completing a semi-structured questionnaire. Analysis was undertaken stratified by cohort group, age, and where appropriate, cancer stage.

Results

One hundred responses were collected from 31 patients, 41 healthcare professionals and 28 public. Median age of respondents was 48 years (19 - 87). Patients at various time-points were included; diagnosis (6%), treatment (23%), follow-up (55%), relapse/palliation (16%). 56% and 59% of respondents thought that every patient should be universally approached about research and biobanking respectively. Of the 12(39%) patients approached for research during their treatment, all agreed to participate with a further 23(74%) expressing desire to have been invited. It was acceptable to approach patients prior to hospital referral (58%), at the first (74%) or second hospital appointment (95%), on admission (95%) or at relapse (92%). All non-invasive research methodologies were acceptable. Ninety-eight percent agreed that sampling tumour intraoperatively was acceptable and 62% were willing to consider additional invasive biopsy exclusively for research. There were no significant differences between subgroups. Thematic analysis of written comments showed strong desire to contribute to research advancing treatment for future patients. Many expressed concern for vulnerable patients, highlighting the importance of informed consent.

Conclusions

‘Protecting’ patients from the perceived burden of research is not justified and we should offer every opportunity to all. This study highlights the need to invest in information resources for clinical research for patients and professionals and to further explore reasons for non-participation.

Creating a living network map for team working in Patient and Public Involvement

Margaret E. O’Hara, Laura Chapman, Kirsten Chalk, Magdalena Skrybant, Laura Nice

University Hospitals Birmingham NHS Foundation Trust

Background

Researchers wishing to do PPI must begin by recruiting patients and members of the public, preferably adhering to the INVOLVE national standard for inclusive opportunities. Where researchers do not have access to a patient advisory group they may struggle to contact patients and even where one does exist, there is still a need to reach out beyond small groups of already involved lay people. Local PPIE leads play an important role in brokering relationships with groups in our communities and nationally through charities and other bodies.

Objectives

We aimed to develop a repository of contact points which we, as PPIE leads, can use to assist researchers in disseminating opportunities for involvement.

Method

We began by pooling our existing knowledge on a spider diagram in a brainstorming session mapping groups and organisations into one of five categories: UHB, UoB, Charities, NIHR and Regional. This was then transferred to an Excel spreadsheet.

Results

The initial spreadsheet comprised around 140 separate lines, which has now grown to around 190. There are 15 fields including name, category, organisation, relationship grading, keywords, contact

details, website, Twitter handle, description, notes. It is shared within a common drive to which we all have access.

Outcome

The document is a tool that facilitates team working between local PPIE leads. It is very much an evolving project and we continue to work collaboratively to share knowledge about different groups and how we can work most effectively with them. We have developed key elements such as keywords to enable filtering and a relationship grading to indicate how well known the contact is to a member of our team. It helps us to help researchers to recruit patients, ensure our processes are more fair and transparent and maximises our chances of hearing from a range of public voices.

The 'I Had No Idea' Log. Capturing the impact on Patients and Researchers from early interactions in PPI

Margaret E. O'Hara, Laura Chapman

University Hospitals Birmingham NHS Foundation Trust

Background

In interactions with researchers who are new to PPI, we are often struck by their reactions following initial conversations with groups of patients. They are often deeply moved and surprised, having not anticipated much of what the patients would tell them and the strength of feeling around it. Often, the researcher will begin by saying "I had no idea that..." followed by some aspect of the patient experience.

Objectives

We wished to capture detail around the impact that conversation with patients early in the PPI process have had on researchers.

Method

We wrote to researchers who had had a recent focus group with patients and asked them to record what had struck them most from the discussions. There was no template or structure imposed on the reply, we simply asked for free text. This was extended to patients in the groups to ask them the same question.

Results

Responses from researchers and patients have been varied and reveal numerous themes. For example, clinicians are often struck by the wider effects on the quality of life of their patients, their difficulties in navigating the healthcare system and the lack of information available to them about their health condition. Even though PPI group meetings are not primarily intended to serve a support function, patients often report that they have found the simple fact of speaking to others with their condition to be beneficial and empowering.

Conclusion

The "I had no idea..." Log is a simple way to capture the impact of early PPI on both researchers and patients. This is an evolving project which will adapt to the needs and inputs from both researchers

and patients. We plan to share the results with patients and researchers as a form of feedback on the impact that patients have had on the research.

Understanding the impact of patient and public involvement on cancer research outcomes: A mixed methods study

Raksha Pandya-Wood

NIHR RDS East Midlands

Background

In the UK and internationally, interest in patient and public involvement (PPI) in healthcare research has been growing. There is increasing demand for researchers to demonstrate the value of PPI to national funding bodies. This research offers an original contribution to knowledge by advancing the field of evaluating the impact of PPI on research outcomes and implementation science (IS). The PhD was motivated by observations made on the frontline by the author whilst advising researchers to consider the Impact of their studies. Literature demonstrated that there was poor quality reporting of PPI, that PPI *processes* are assessable, but little was known on how to evaluate the impact of PPI on research *outcomes*.

Materials and methods

End user involvement was woven through the study. A mix of interpretivism and pragmatism was adopted to understand how to evaluate the impact of PPI on cancer research outcomes. A mixed methods sequential design using interviews (n=23 patients, researchers and stakeholders) to help generate knowledge followed by a modified Delphi across England with n=35 experts to refine and enhance knowledge was used.

Results

Findings demonstrated that PPI in commissioning, PPI processes in research, PPI in dissemination, PPI in implementation, Information and communication technology, Power and leadership, Resources and the political context, Networks, and Wanting to make a difference, were vital towards understanding the impact of PPI on research outcomes.

Conclusions

Evaluation of PPI was achievable at at least three stages: post winning research funding, post research dissemination and post observed change. But the evaluation of PPI on research outcomes needed to factor in two hallmarks, that PPI was a complex intervention (Craig et al. 2009) and that the applicability of the consolidated framework for implementation research (CFIR) (Damschroder et al. 2009) can offer evaluators of PPI, a taxonomy of evaluable domains and constructs. Combining these two areas draws attention to and shows the possibilities that the impact of PPI on research outcomes are evaluable.

Participants' perspectives and preferences on clinical trial result dissemination: The TRUST Thyroid Trial experience

Emmy Racine

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Background

The results of clinical trials are not traditionally disseminated to clinical trial participants. While there is a growing awareness that participants should receive study results, little is known about the most appropriate methods of doing so. The Thyroid Hormone Replacement for Subclinical Hypothyroidism Trial (TRUST) was a multi-centre, double-blind, randomised, placebo-controlled trial which tested the efficacy of thyroxine replacement in subclinical hypothyroidism in older adults (≥ 65 years). Our aim is to use a Public and Patient Involvement (PPI) approach to identify, develop and evaluate a patient-preferred method of receiving the results of the TRUST Thyroid Trial.

Materials and methods

Using a mixed methods approach, an intervention study was undertaken at the Irish TRUST site. The first phase of the study used PPI (focus groups and 1-1 sessions with trial participants) to develop a patient-preferred result method. In the second phase, Irish TRUST participants ($n=101$) were randomised into the intervention (PPI method) and comparison groups (standard method). In the third phase, participants were sent a questionnaire. The primary outcome is difference in understanding of results between the two groups.

Results

Findings from the first phase clearly established that the preferred method of receiving results was a postal letter containing a 2-3page summary of the trial, condition, treatment and overall results. In phase two, all randomised participants received the results of the trial. In phase three of the study, 67 participants returned a completed questionnaire (response rate 66%). The results of the questionnaire showed no difference in patient understanding between the intervention and comparison groups.

Conclusions

Little is understood about the impact and effectiveness of PPI in clinical trials. While this study found that PPI has no real impact on patient understanding of trial results, it provides empirical evidence on participants' perspectives and preferences of clinical trial result dissemination. It also provides a template for other trialists who wish to enhance patient and public involvement.

Seldom heard: Evaluating the impact of involving patients and the public in a consensus process to inform intervention development.

Emmy Racine

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Background

Intervention development is a critical step when conducting large-scale trials. Emerging evidence suggests involving patients and the public in intervention development increases the likelihood of

developing interventions which are acceptable, engaging, feasible and effective. However, very little evidence exists supporting these claims. The aim of this Study Within A Trial (SWAT) is to evaluate the impact of involving patients and the public in the development of an intervention to improve uptake of eye-screening for people with diabetes.

Materials and Methods

This is a concurrent mixed methods design comprising three meetings to establish expert consensus on intervention content and delivery. Meeting 1 will involve patients and the public, Meeting 2 will involve health professionals and policy makers and Meeting 3 will involve both of these groups. 10-12 participants will be recruited for each meeting. Patients and the public will be recruited using online, community-based and health system recruitment methods. Health professionals and policy-makers will be purposively recruited through professional networks. Meetings will be audio-recorded, field notes will be taken and participants will be asked to complete an experience survey assessing individual experiences of group dynamics and decision-making processes. Each meeting will be compared to assess the impact of involving patients and the public on the (1) feasibility of the proposed intervention and (2) group dynamics and processes. The recommendations made by each group will be compared using the APEASE criteria (Acceptability, Practicability, Effectiveness/cost-effectiveness, Affordability, Safety/side-effects, Equity). Content analysis will be performed on qualitative data using NVivo software and compared across groups. Quantitative data will be analysed using SPSS V24 software. Each survey item will be compared across groups using one-way ANOVA's with post-hoc testing.

Results

The study is ongoing. The consensus process meetings are scheduled to take place in September 2018. Preliminary results of the study will be available in October 2018.

Conclusions

This study will provide evidence on the impact of involving patients and the public on a consensus process to inform intervention development. The results of the study will contribute to the evolving literature on how best to include PPI in intervention development and the potential impact of PPI on intervention development.

PPI in a national mixed methods study: eliciting and integrating advice into research practice.

Jessica Russell, Evey Howley, Charlotte Kenten, Kate Oulton, Mark Whiting, Jo Wray, Faith Gibson.

*ORCHID (Centre for Outcomes and Experience Research in Child Health, Illness and Disability)
Great Ormond Street Hospital NHS Foundation Trust*

Background

The absence of robust methods to measure and report the impact of lay involvement on research in the United Kingdom means it is difficult to know how best to make visible their contribution in health research. Evidence is needed that goes beyond describing patient and public involvement (PPI) that engages analytically with the way that advice is elicited, received and integrated into research studies.

Materials and methods

Advice given by the Pay More Attention Parents' Advisory Group via email or at face to face meetings was analysed using a three-tiered approach; data was coded thematically regarding delivery and content, whether advice was elicited or unelicited and its integration into our research practice. Coding was compared according to how advice was obtained and cross checked by a second researcher.

Results

The format of the Pay More Attention Parents' Advisory Group allowed for elicited and unelicited advice. Email advice had a higher proportion of elicited content compared to face to face meetings, but did not include the richness of the discussion from group meetings. Advice tended to be suggestions for consideration rather than demands and included aspects of study design, including recruitment procedures. The majority of advice was incorporated into our research practice.

Conclusions

Analysing the process of eliciting, receiving and integrating PPI advice into our research practices has enabled us to reflect on the different approaches used to gain feedback and to understand better how to tailor the way that PPI feedback is elicited depending on the needs of the study. Through sharing our PPI and its impact on our study, we provide some key messages and examples about the value of making the shared expectations of involvement explicit, clarity around contributions and how they are best elicited, and measuring and reporting of impact.

Involving carers of people with dementia in research – an example from a UK study

Kate Sartain, Sarah Goldberg, Rebecca O'Brien, Rowan Harwood

University of Nottingham Patient and Public Involvement advisory Panel for Dementia, Frail Older People and Palliative Care.

Service user involvement in research is important. This presentation, by a former carer of parents with dementia, will explore how service users have been integrated into a research study that aimed to develop and test the feasibility of a dementia communication skills training course for healthcare professionals (the VOICE study). The VOICE study involved conversation analysis of video recorded conversations between healthcare professionals and patients with dementia in the acute hospital. These findings were then used to develop a dementia communication skills training course. Prior to the initial funding application, the PPI group contributed their thoughts on the potential benefits of the study and the acceptability of video recording patients with dementia in the acute hospital. KS as a co-applicant contributed to the proposal prior to submission. She attends and contributes to all project management meetings alongside two other PPI members. Two PPI members sit on the project steering committee. KS reviewed all patient facing documentation for the observational study. The training intervention was developed over four days of meetings involving three PPI members and the research team and training experts. PPI contributions to the intervention included that the course be two days (a month apart) with a reflective diary between the two days. Some of the video clips used in the training were questioned in terms of how person-centred they were, which changed the focus of how and what was taught and resulted in a greater

focus on person-centred care in the training. KS has attended two courses to support the fidelity and acceptability to service users of the intervention.

In this study, service users have been integrated into the research team to enhance the study design, ensure governance from a service user's perspective, improve the intervention and ultimately benefiting patients with dementia and their carers.

Wessex Public Involvement Network (Wessex PIN) Diversity and Inclusion Project

Jackie Seely, Hazel Patel, Megan Barlow-Pay, Aniqah Nisha, Caroline Barker, Giselle Atkinson, Tess McManus, Kate Sonpal, Claire Ballinger

School for Primary Care Research University of Southampton

Background

The Wessex PIN is a collaboration of PPI Officers and Public Contributors across NIHR organisations within the Wessex region. The PIN collaborates on a number of cross-cutting themes one of which is diversity and inclusion. The aim of this working group is to improve diversity and inclusion within Wessex NIHR PPI, in line with recommendations from 'Going the Extra Mile' (NIHR 2015).

What we did

In order to appropriately address issues of inequality and lack of diversity within PPI we first needed to understand more about the people that we were already involving in our research. To achieve this, we co-developed a diversity monitoring questionnaire which we circulated amongst public contributors in the Wessex PIN organisations. In addition, we completed a report of the demographics of the local Wessex population. We received 120 questionnaire responses and compared these results against the demographics report. This enabled us to identify the inconsistencies between those involved in PPI within the PIN to those currently living in the region.

What we found

The results showed that we have an over-representation of females, those aged 66 and over and our representatives have achieved higher levels of education compared to the Wessex population. In contrast, those who are of working age and in employment are under-represented as are people aged 45 and younger and some ethnic minorities are not represented at all.

Impact

This exercise has, for the first time, provided the Wessex PIN with a profile of the public contributors involved in regional health research, and an understanding of the diverse nature of the local population. The findings are being used to focus outreach work to improve engagement with Wessex communities who are currently under-represented. This work will help us develop and deliver research that has maximum impact for those directly affected.

Living with a left ventricular assist device: Patient Involvement is crucial in developing Patient Reported Outcome Measures

Anita L. Slade, Margaret E. O'Hara, David Quinn, Stephen Griffith, Deirdre A. Lane

University of Birmingham

Background

Advanced heart failure (AHF) confers high mortality risk. Heart transplantation can offer good long-term outcomes however, shortage of transplant donors and complications related to AHF often results in patients' health deteriorating, meaning they are no longer candidates for transplant. Left ventricular assist devices (LVAD) are an alternative option for managing AHF, acting as a mechanical pump to assist the failing left ventricle. LVADs can relieve symptoms, potentially improve health-related quality-of-life (HRQoL) and enable patients previously classified as unfit for transplant to be reconsidered. However, receiving an LVAD requires major psychological, environmental and physical adjustments for patients and families. Current Patient Reported Outcome Measures (PROM) in heart failure were suspected to be inadequate to capture the particular issues pertinent to living with an LVAD.

Objectives

LVAD recipients (n=8) took part in a patient-public involvement (PPI) focus group to identify the issues for them in relation to living with an LVAD and whether current PROMs adequately captured these experiences.

Results

Issues identified by the PPI group included distress relating to body image changes, anxieties about the equipment and potential equipment failures, psychological issues relating to adjustment to the equipment and impact on families and relationships. Physical aspects such as fatigue, sleep disturbance, muscle fatigue and weakness were also problematic. Patients discussed the impact of living with the LVAD on work, activities of daily living, travel and their living environment. Group discussions also confirmed that current AHF PROMs did not capture the unique concerns of LVAD patients.

Conclusion

Involvement of PPI in discussions regarding PROMs for monitoring HRQoL is fundamental to the development of new PROMs for use in research and clinical practice. Ongoing PPI work will enable us to establish a conceptual framework for identifying domains and items which are relevant for capturing HRQoL in future LVAD recipients.

The impact of true collaboration - from unmet need through to global availability

Lise Sproson

NIHR Devices for Dignity Med Tech Co-operative

Background

Collaborative design is a widespread aspiration of many organisations. Some organisations excel at patient and public involvement at the unmet need stage, others in co-design or product evaluation. We present here the story of the HeadUp neck collar project, which incorporated true collaboration not as an isolated ingredient, but rather the central powerhouse throughout. The patient voice informed and transformed each and every stage – from initial suggestion of the unmet need right through to publicity and dissemination, harnessing social media and national TV and Radio.

Materials and methods

We will share the processes and resources used to achieve this collaborative working, incorporating reflections from the team and our expert patients on their involvement in this very successful project which is now enjoying global reach.

Results

Recent feedback suggests that the new neck collar, now available to all patients with MND or other neurological neck weakness, is being adopted at a rate of around 10 collars per day

Conclusions

True and meaningful collaboration between designers, engineers, clinicians and patients resulted in a product which fills the specifications patients determined and, since it is fit for purpose, the usually lengthy adoption and uptake into the NHS and commercial marketplace has been massively accelerated, bringing benefit to more patients more quickly

Creating value where patient experience of research participation and PPI meet: The NIHR CRN Patient Research Experience programme

Roger Steel

National Institute for Health Research Clinical Research Network.

Background

The NIHR Clinical Research Network has a remit to support the delivery of research in the NHS for patient benefit. We rely on positive relations with NHS patients and public to achieve recruitment across circa five thousand studies and nearly three quarters of a million people recruited in the last financial year. We have long recognised the importance of active patient involvement and engagement in this endeavour and among a number of other projects the organisation has instigated the Patient Research Experience Surveys. We believe that this compliments active patient involvement.

Materials and methods

The Patient Research Experience Surveys have been evolved over three years enabling us to tap into patient insight across England. This has brought not only a snapshot of patient satisfaction of participating in studies, but also a detailed understanding of what is important to patients in that experience. Recently we achieved our largest single collection of data with responses from over four thousand research participants. Our approach has always been pragmatic in order to elicit information that we can act on to implement assurance and continuous improvement in our business.

Results

We have published results via a page on the NIHR website, but most importantly we have embarked on a new programme to embed continuous improvement in patient experience of participating in research and have already disseminated a research and site team easy to use assurance checklist. The insight gain has already been useful to organisations beyond the NIHR CRN's immediate remit as well as to our Patient Research Ambassadors.

Conclusions

We do not see this work as in any way as a substitute for patient involvement and activism. Rather we see it as complementary. Understanding what is important in patient experience of research enables better positioning of patient activism and end points to consider in evaluating it.

Using case studies to evaluate PPI feedback in the research application and funding process; how are public and professional assessments of PPI fed back to study applicants?

Heidi Surridge, Doreen Tembo

NIHR Evaluation, Trials and Studies Coordinating Centre

Background

At the NIHR we commission, fund and manage health and social care research. During the research funding process applications are peer reviewed by a range of people with appropriate professional or experiential expertise including at least one patient, carer or service user. These reviews and applications are discussed further at funding committees. NIHR funding committees have both public and professional members.

Staff and public contributors raised the question of whether reviews of PPI in this process were adequately fed back to study applicants (research team). Researchers have also felt that feedback from funding committees could be more detailed.

Materials and methods

The PPI team at the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC) used a case study approach to explore the transfer of feedback on proposed PPI from peer review and funding committees to research study applicants. Documentary analysis of original documents was undertaken including the PPI section and Plain English Summary of funding applications, professional and public peer reviews, board members comments and applicant correspondence. During a six month period of funding committee meetings across four research funding programmes, 15 research projects were funded subject to requested changes. Data for these projects is being

analysed using qualitative analysis software, NViVO. A narrative of the PPI feedback journey will be produced.

Results and next steps

Results will be presented as project case studies exploring the nature of feedback on proposed PPI throughout the application and funding process. We will also present cross –cutting themes across the case studies. Internally results will be used to improve our application and funding processes. The feedback process is key to the efficacy and efficient use of peer and funding committee review. Adequate feedback will also serve to improve the quality of PPI in the research we fund.

Public reviewing with the National Institute for Health Research (NIHR): an interactive course for new and experienced reviewers of health and social care research

Heidi Surridge, Sylvia Bailey, David Green, Gary Hickey, Tracey Johns, Alison Ledward, Amanda Roberts, (lead), Doreen Tembo, Gail Thornton, Amander Wellings, Jane Whitehurst

Patient and Public Involvement and External Review, NIHR Evaluation, Trials and Studies Coordinating Centre

We are proud to announce the imminent launch (Nov 2018) of an open access co-produced online course hosted on INVOLVE's website [web link to be provided].

Who is it for?

It is mainly aimed at both **new and experienced public contributors** who want to know more about reviewing research documents from a patient and public point of view.

However, we believe that it will also help **researchers and research funders/managers** understand what criteria the public use when reviewing research plans and therefore use appropriate and good quality PPI in their studies and undertake research which is important and relevant to the end user (usually the patient, carer, service user, public).

What does it cover?

There are three modules covering:

Module 1: Introduction to NIHR and patient and public involvement (PPI) in research

Module 2: Introduction to public reviewing roles and skills

Module 3: How to assess research documents from a patient and public point of view

You can dip in and out as your learning needs change and develop.

Why we did it

NETSCC (NIHR Evaluation Trials and Studies Co-ordinating Centre) commissions, funds and manages health and social care research. We involve patients and the public in all of our research management processes. One of the aims of the NETSCC PPI Strategy for 2015-2018 was as follows: 'Development of online learning resources; access to externally-provided training for: Public reviewers of commissioning briefs and applications, and for public funding and prioritisation committee members'

Why we chose to focus on public reviewing

So in 2017 we set up a NIHR wide co-production project involving public contributors and PPI managers/leads. Over half the large project team are members of the public.

The public reviewing focus of the course was decided because it is the most common activity that members of the public involved in research are invited to do (for example, review a research proposal or funding application). We scoped the existing PPI resources and found a lack in the area of reviewing which was open access and online resource.

What we have learnt from co-producing this course

We have all learnt so much through the process of co-production. Such as;

- how best to work as a remote team,
- how to be uncomfortable with ambiguity when we were deciding our focus,
- how to divide tasks and share responsibility,
- how to tap into our creativity,
- how much variety there is in our experience and knowledge,
- discovering “my way might not be the only way”,
- gaining new skills and knowledge (few of us had produced a course before),
- how to remain positive with a ‘we can do it’ attitude and,
- how to compromise!

The course has been reviewed by potential users and subsequent changes made. It has also been reviewed by the Plain English Campaign and awarded their Crystal Mark.

Please try out the course and share awareness of its launch. We are happy always to receive feedback.

Evaluating innovative teaching about ageing using an inclusive approach to research

Ellen Tullo, Luisa Wakeling

Newcastle University

Background

Newcastle University Ageing Generations Education (NUAGE) is an innovative undergraduate course about ageing, open to students from any academic background. NUAGE was designed and is delivered in partnership with students and older people. This paper discusses the outcome of a project to explore the feasibility of extending this inclusive partnership to evaluation of the course.

Materials and methods

Following principles of inclusive research, we brought staff, students and older people together for exploratory group discussions to review the implementation of NUAGE thus far, to discuss possible methods of pedagogic evaluation, and to explore to what extent members of the public could or would want to take part.

Results

Older people, working with staff and students, prioritised longitudinal impact of participation in NUAGE on students as the most important outcome. The team agreed that a questionnaire administered to NUAGE alumni would be the most appropriate method to collect data. Despite members of the public expressing frustration at institutional bureaucracy, with appropriate training and support we determined that it is feasible and desirable for them to take an active role in data collection and analysis.

Conclusions

Using an inclusive approach we have co-produced a plan to continue our pedagogic evaluation of NUAGE. Based on the evidence of engagement of older people and students in the planning process, we are confident that their ongoing involvement in data collection and analysis is desirable and feasible.

Overstepping the Mark? Personal disclosure in user-led research

Dr Peter Unwin

University of Worcester

Background

Research has traditionally been elitist and hierarchical. Service users and carers are increasingly becoming involved in research but the question arises whether service user and carers can carry out effective research in the current research climate without the support of academic researchers. In order to become involved as researchers, do service users and carers have to become like academics in their demeanour and conduct or can they research to a different tune, particularly in the area of personal disclosure?

Materials and methods

A PowerPoint will be used as a framework and questions posed to the audience from a series of real world research vignettes posing questions about personal disclosure / boundaries.

Results

Using recent examples of service user and carer research involvement across a number of projects, a hybrid model of co-production in research is posited.

Conclusions

There is a case to be made for encouraging co-production between academics and service users and carers – much is to be gained by the rapport and insight brought to a research encounter by lived experience, but some of the traditional boundaries of academia are there for good reason. A hybrid, co-production model used at the University of Worcester which informs service users and carers about established research protocols, but which gives them meaningful influence across all stages of a research project is suggested as a positive way forward for our times.

The authenticity of the service user experience is the most important contribution.

The value attached to the service user experience is more important than the monetary reward.

Levels of reward and recognition create differences in value and power.

Penny Vicary, Dr Virginia Minogue, Dr Mary Cooke

University of East Anglia

Background

Reward and recognition in PPI is important and the structure of payments for involvement has been achieved after a long and hard process of negotiation with government departments. Payment is seen as a means of attributing reward and value to the PPI contribution.

As a volunteer/lay researcher, one of the presenters feels strongly that not accepting payment should not diminish her value. Her authenticity as a service user researcher is paramount. Value for the individual PPI representative can be demonstrated in different ways. Payment is not the only token of value.

This presentation explores the concept of value and reward in the context of different service user roles in research.

Materials and methods

The presenters have reviewed the evidence for reward and recognition of service user and carer involvement in research activity, and the impact of difference in value and power. The review has considered the impact that motivation, different types of reward and recognition, values and attitudes towards PPIE in research can impact on power relationships between the researcher community, and service users and carers.

Results

The embedding of PPIE in research is fully accepted, but contentions among PPIE volunteers as to their role, remuneration, power and effectiveness, and the responsibilities of researchers towards their PPIE members exist as 'the elephant in the room'.

Conclusions

PPIE members need support and recognition of their vulnerabilities as do employees in research teams. Paid or not, the transaction between health professionals and service users and carer volunteers has a power basis not always recognised by the health professional researchers.

Reasons and ideas for research by and with brain injury insiders

Philip M Wallbridge

IMPACT (service user & carer group), Worcester University

Background

The impact of a brain injury, such as a stroke, accident or infection, can alter people's lives forever. With no medical cure available, those affected have to use both their own resources and those of professionals to live with potentially long term physical, emotional, financial and social changes. In

contrast, brain injury research has been almost exclusively undertaken by professionals despite “insiders” writing, blogging and giving talks to help others affected by brain injury.

Purpose

We consider the reasons for research by and with brain injury insiders, focussing on non-medical brain injury research. We also identify some ideas and areas for such insider research.

Findings

We suggest there is both need and potential for insiders in non-medical brain injury research. Current brain injury research appears to have persistent gaps and limitations, including problems of theory, evidence, utilisation and accuracy evidence. Insiders in areas such as mental health and physical disability have been undertaking “activist” and “emancipatory” research for over 25 years to challenge traditional assumptions, approaches, services and policies. Brain injury insider produced material, including the limited research they have been actively involved in, suggests similar potential wisdom, ideas, skills and motivation for research, despite professionals suggesting barriers to this involvement.

There are a number of areas for research by and with brain injury insiders which appear to naturally flow from this. These include i) identifying research topics, ii) designing, undertaking and interpreting discussions with other insiders in “qualitative” research, iii) developing new concepts and approaches, and iv) making research more directly relevant to, and usable by, those affected by brain injury.

Conclusions

Insiders have a crucial role in research to improve the lives of others affected by brain injury. It is high time to recognise, welcome and encourage their fresh motivation, thinking, skills and wisdom in brain injury research.

Patient and Public Involvement in Dementia, Frail Older People and Palliative Care

Morag Whitworth, Rupinder Kaur Bajwa, Clare Burgon

University of Nottingham Patient and Public Involvement Advisory Panel for Dementia, Frail Older People and Palliative Care

Background

Members of the University of Nottingham Patient and Public Involvement advisory panel for Dementia, frail older people and palliative care, have current or previous experience of caring for people with dementia or have dementia themselves. The panel is well established, consisting of 22 members and has been running for around 8 years. Meetings are held monthly and are facilitated by researchers at the University of Nottingham.

Materials and methods

The group offers support to researchers at any stage of their research idea, from pre submission of a grant application to dissemination and implementation of research findings. Panel members’ roles include giving advice at meetings, acting as co-applicants, co-researchers, giving feedback on research materials (such as participant information sheets), assisting researchers with interviews,

focus groups and analysis. Meetings are held monthly, facilitators email and post out agenda and materials from researchers who are seeking PPI advice.

Results

Researchers across multiple disciplines and at all levels, from Masters Students to Professors, have benefited from group input at all stages of their research projects. Whilst PPI costs are often included in funded projects, there is a lack of funds at the grant writing stage, which has meant that many researchers ask the group for PPI input at this early stage. PPI input includes grounding research in reality, using lay language, planning how PPI input will be used throughout the research project. These meetings are important to PPI members themselves, giving them the opportunity to get involved in research by providing advice and insight at meetings and an opportunity to become co-applicants, co-researchers and steering group members.

Conclusions

There are mutual benefits. Researchers leave the meetings with ideas, solutions and offers of ongoing support and PPI members feel they have provided personal experience for research related to dementia, frail older people and palliative care.

Volunteers, champions, ambassadors or advisers? – developing a shared language for engagement and involvement

Jess Zadik, Moira Lyons

Northern Care Alliance NHS Group

Background

Patient and public involvement is central to NIHR policy, highlighting the importance of involvement throughout the research process. However for NHS Trusts, getting people involved in research as volunteers, contributing to development of grant applications and throughout the research, rather than as participants in a trial can be a challenging process. The expectations and knowledge of what is involved for both prospective volunteers and researchers can vary. This can be further compounded by individual researchers/teams developing their own process for PPI based on links with partner agencies i.e. Universities. In addition, many individuals are involved in PPI activities across a range of organisations, comparing what is offered in one organisation to that of a seemingly similar organisation.

Materials and methods

Evaluation of current Trust-wide PPI activities

Series of consultations with stakeholders

Development of PPI group

Year-long development process in partnership with the PPI group

Results

Research & Innovation developed a research volunteer programme to further facilitate participation and engagement. The programme was developed in collaboration with patients/public and research staff, providing a clear route for patients/public to effectively contribute throughout the research process. The programme is now part of the wider Trust volunteer programme, increasing the status

of the role and increasing knowledge and awareness of research. The programme provides guidance for researchers/ teams on how to effectively engage with patients/public who want to get involved in PPI in research.

Conclusions

We hope to find that in implementing the volunteer programme, the profile and importance of PPI is raised, encouraging involvement from a broader demographic.

Patients/public who want to get involved have a clearer understanding of the different roles on offer, how they can participate and the expectations and support.

Research teams have a clear understanding of how PPI is implemented at Trust level and how they can work with volunteers to enhance their research.

SOAPBOX PRESENTATIONS

Transforming perspective in research involvement: writing, drafting and crafting poetry

Ruth Chalkley, Christy Ducker, Sue Spencer

Person with Experience, Cleveland, UK

Communicating complexity and uniqueness within the lived experience of a long term and rare condition can be a huge challenge in sharing research findings. RC's experience of living with a rare neurological condition has many challenges and these are amplified by the repeated need to explain symptoms, the impact on lifestyle and mediating factors to professionals each time they are encountered.

Also, involvement in research projects can feel like the person is being treated as a specimen and a feature of interest rather than being seen as a person and this feeling of "otherness" can add to the distress of living with a condition with an uncertain and indeterminate trajectory.

These experiences are known to reduce agency and autonomy and the power dynamic is skewed to advantage the professional and the person is the object of the medical gaze; relationships are unequal and that imbalance silences and suppresses the person's viewpoint.

RC has written poetry as a way of processing her thoughts and feelings and these poems powerfully convey a message that many researchers and involvement professionals might heed in that small gestures can make a huge difference and that kindness, curiosity and seeing the person not the disease or their "interesting" symptoms can make a huge difference to engagement and well-being. Poetry's use of metaphor, imagery and concise use of language has a unique quality that can restore personhood, clarity and coherence and enable public involvement in health research to be more collaborative and humanistic.

Sharing RC's poems will help us communicate the inherent imbalances and we also hope to stimulate a debate about the utility and usefulness of poetry in communicating service user involvement in health care research.

Hitting the Street. An innovation in PPI recruiting

Dave Green

Public Contributor

The 'PPI community' often consists of the same people. Generally white, middle class, older and often professional or semi-professional.

Everyone, including those who do not identify with particular groups or 'communities' should get a chance to participate in research.

How do we achieve this? We go where people are, the street!

First Design a one day workshop for members of the public not already involved in research. Make it as interesting, lively and informative as possible. Ensure there is a direct link to involvement included.

Second Set up a stall in a busy pedestrian area, think Northumberland Street. Staff it with two PPI contributors and a researcher. Run over three days. Produce business card with details of the workshop and enrolling e-mail address. Display a trusted logo above stall i.e. Newcastle University, NHS whatever. Talk to public, give out cards, sell workshop.

Third Deliver workshop.

Fourth Assess ongoing participation after 6, 12, 18 months.

Fifth Collect OBE.

Design workshop... .Sell on street.... Deliver workshop... .Assess.

Diversity – free floating radicals

Julia Hamer-Hunt

Patient and Research (PAR) Group of the National Institute of Health Research (NIHR) Oxford Health (OH) Biomedical Research Centre (BRC)

Diversity in patient and public involvement (PPI) in mental health research is frequently under-represented whether demographically, socially or "skill-fully".

Inclusion is life-enhancing.

I propose to organise a festival float for the Cowley Road Festival. This festival takes place each summer in Oxford OX4, which is the most ethnically diverse area of the county. This will be an opportunity to reach out to a wider range of people and communities. The aim is to increase awareness for mental health research and present opportunities for learning about research in a fun setting.

The float will celebrate and illustrate mental health research in embryo, in practice and at work. The concept – a "White Elephant float" – may spawn "White Rabbits" (patients/researchers/community members) mingling with onlookers to distribute paper flowers providing telephone numbers/email contacts/website details of how to obtain more information and/or join the Research Contributors pool. The idea is replicable in other settings, e.g. agricultural shows, community fun days.

The festival float will be co-produced, i.e., it will be designed, made, and staffed with patients, researchers, public and clinicians to celebrate mental health research. Partners would include

Oxford Health NHS Foundation Trust Artscape, Restore, Elder Stubbs, the Recovery College and other groups.

Through meeting peers and researchers in a fun, informal, non-clinical setting people will learn about current research opportunities and develop the confidence and skills to contribute to projects. Our aim is to demonstrate that PPI is a collaborative and inclusive process, which gives space and a voice to everyone to share their experiences. We hope to encourage people from more diverse communities to get involved in PPI, so that we can work together to ensure that future mental health research is more inclusive. This is a goal that we aspire to within our Oxford Health (OH) Biomedical Research Centre (BRC).

Buddy programme for PhD students and patients

Helen Hanson

Newcastle upon Tyne Hospitals NHS Foundation Trust, Newcastle upon Tyne

PPI is now embedded in much health research and particularly in large projects involving patient participants. However, there remain significant challenges to including meaningful PPI in laboratory research and student projects. There is less expectation from funders and regulators that individual laboratory based projects will include PPI. Laboratory researchers, particularly at a junior level, may lack the skills to discuss their work with lay audiences and benefit from lay feedback.

Rheumatoid Arthritis Pathogenesis Centre of Excellence (RACE), funded by Arthritis Research UK, is a collaboration involving the three diverse universities and PPI groups in each corresponding area. RACE brings together expertise from the three universities, funding PhD studentships to address fundamental questions about why rheumatoid arthritis develops and how it could be treated and prevented. Through consultations to plan future PPI within RACE, patients and researchers thought of introducing a buddy programme, pairing each new PhD student with a patient or carer with personal experience of rheumatoid arthritis.

PhD students are the research leaders of the future and as such it is important for them to learn about effective PPI and develop the necessary skills early in their careers. Feedback from lay people in our PPI groups suggests that they would relish opportunities to learn about and become more consistently involved in individual projects. We will develop ground rules, an introductory training package and ongoing support network for both lay and student buddies. Through this programme, we anticipate student buddies will learn about living with rheumatoid arthritis, which may, for example, aid their interpretation of results or formulation of new research questions. Student buddies will learn to present and discuss their work more effectively with lay audiences, inspiring and enabling them to collaborate with patients and the public throughout their careers.

Generating research questions through collaborative map-making

Savi Hensman, Stan Papoulias

King's College London

Current UK health policy seeks to consolidate links between health and social care; tackle the challenge of multi morbidities through population-sensitive prevention, public health and self-management interventions; alleviate pressure on over-stretched A&E departments and health services more generally. Practices of patient and public involvement capable of engaging with marginalised and underserved populations are crucial for effective research and service delivery in this context.

We present the emerging outlines of such a model currently under development by the PPI team of CLAHRC South London and put forward in our annual Active Involvement in Research Day in March 2018. This is a model of collaborative research priority setting which makes use of participatory visual approaches. There is considerable evidence that such approaches are more likely to engage people with differing literacies and generate richer data than those available through more conventional text-based channels. We proceed in four stages with a focus on a particular population.

- Identify health issues relevant to that population through a combination of targeted outreach and literature reviews of user centred grey literature
- Use data to generate overarching themes around local health needs
- Set up workshops bringing together groups already identified through outreach, clinicians, commissioners and researchers. Presentation of the themes is followed by group map-making sessions (a device introduced by www.manualthinking.com) as a way of visualising how people's multiple health needs may connect with each other and relate to different aspects of the social environment. User groups to form majority in these sessions
- Refine topics for research or service development through further workshops

By visualising health needs, map-making may enable clinicians and commissioners to have a richer understanding of their constituents' needs and may additionally provide a launchpad for further collaborative work on integrated approaches to care and prevention.

Is the Banana Republic open to change? A new model for planning and evaluating patient involvement in health research

Kristin Liabo, Nigel Reed, Julie Harvey, Julia Frost

Institute for Health Research, University of Exeter Medical School

This soapbox idea is neither a researcher's nor a public advisor's. We will present a model shaped by studies that came before us, and our interpretation of this work paired with our own experiences of involvement. 'We' are two people with experience of contributing to research as patients or carers (NR, JH), and two researchers (KL and JF). Together, we have worked up a model of involvement during several meetings filled with honest discussions, critical thinking and laughter.

The term 'Banana Republic' was coined by O Henry to describe unstable countries exploited by stronger powers for their resources, run by dictatorship. Our model is based on personal experience and a critical literature review. It suggests that some involvement initiatives resemble 'banana

republics' while other resemble federations of collaborators, as in us developing this model, sharing knowledge and witnessing impact from working together.

Our model looks like a map and uses geographic terminology and symbols to highlight key features of the landscape that is 'PPI' in regards to its nations, borders, natives and strangers, interpreters, passports and border control. We do this to highlight where and what enable collaboration, and who and what risk involvement becoming a Banana Republic. We will bring along a large poster with our map and help participants navigate through it. We will invite comments on whether the metaphors and trajectories it contains would work for others in the involvement community, when they plan and evaluate involvement.

What we propose from this map is a democratised learning model that capitalises on soft borders between patients and professionals, with doors that are open enough to facilitate shared learning. Our map further suggests that the borders, while soft, are needed for some people to retain their perspectives and their unique identities. Others will revel in dual citizenship.

'Yoga for Bump' – engaging and involving pregnant women with research that is relevant to them

Magdalena Skrybant

Background

It is an exciting time for maternity care with extensive service redesign and innovation in the NHS driven by the 2015 National Maternity Review, 'Better Births'. Clinical and academic researchers, including researchers in our Centre, Collaborations for Leadership in Applied Health Research and Care West Midlands (CLAHRC-WM), are undertaking research to ensure that women and their babies receive the best care that is evidence-based. We know that meaningful involvement of women and their families ensures research is relevant, uses appropriate methods, and has the best chance of success.

The problem

Whilst we know that public involvement can bring real value to our research, it has been difficult to recruit women and sustain involvement. Pregnancy and childbirth are normal, physiological processes, and women are pregnant for a defined period. Moreover, we recognise the challenge of 1 National Maternity Review. Better Births: Improving outcomes of maternity services in England. A Five Year Forward View for maternity care. Available online at: <https://www.england.nhs.uk/wpcontent/uploads/2016/02/national-maternity-review-report.pdf> [Date accessed 25/07/2018] engaging/involving women with research during a period when they are busy preparing and caring for a new baby. Whilst groups have been set-up to involve pregnant women and women with recent experience of childbirth in research, they have struggled to continually recruit new members. Moreover, group membership has not reflected the diversity of local communities.

Our solution

We introduce 'Yoga for Bump' (www.yogaforbump.com). With funding from the Wellcome Trust, we create opportunities for pregnant women to engage with and be involved in research into two local communities. Sessions have the following structure:

- Engagement with/involvement in research. Researchers bring relevant projects to groups of women for feedback.
- Chat with other mums-to-be and Q&A with a qualified midwife.
- Free pregnancy Yoga Session.

We will do a mixed-methods evaluation of our 'Yoga for Bump' sessions using questionnaires. We will also explore alternative methods of engaging/involving pregnant women in research (e.g. establishing links with Children's Centres and attaching researcher sessions to community-based activities).

WORKSHOPS

Organisational support for PPI in Research

Dr Markella Boudioni

Independent Consultant – Patient and Public Empowerment in Health Research and Services

This workshop will explore organisational support for patient and public involvement in research. Organisational, departmental or team infrastructure, structures and mechanisms may enable patient and public involvement. Initially we will explore:

- what general organisational infrastructure, structures and mechanisms may enable / facilitate better quality / more effective patient and public involvement in research
- what organisational infrastructure, structures and mechanisms specific to patient and public involvement in research may enable / facilitate better quality / more effective patient and public involvement in research
- international and individual experiences/cases and what do we learn from these
- do we consider some more important than the others
- how we may take advantage of the organisational facilitators and support discussed
- how we can influence them
- how we may provide PPI in research in lack of those or some of these.

The main outcomes will evolve around:

- better understanding of the different organisational factors that affect / influence patient and public involvement in research
- understanding of organisational barriers and facilitators for patient and public involvement in research
- similarities/differences of organisational factors across organisations / nationally / internationally
- an action toolkit about influencing organisational support for patient and public involvement in research that may involve culture change, training, specific roles and other support.

Developing a practical approach to evaluating public involvement in research

Rosie Davies, Jo White, Michele Kok

National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care West (NIHR CLAHRC West) and UWE Bristol.

Aim: The session aims to share a prototype workshop on evaluating public involvement in research.

Background: Public involvement (PI) in research has been steadily advancing in recent years. In the UK, we have strong policy commitment to PI in research, including the recent development of National Standards for PI. It has become increasingly important to evaluate PI in research to (i) improve the quality of PI, and hence the quality of research, (ii) evidence the impact of PI and encourage stakeholders to commit to having PI in research, (iii) justify funding and other resources for PI, (iv) assure members of the public that they are making a difference or provide reasons if not, and (v) facilitate planning for future projects.

Several approaches to evaluating PI in research have been developed. These are wide-ranging, from simple to in-depth, depending on the level of robustness required. To help researchers select the most appropriate approach for their research, the lead author, in collaboration with PI colleagues at the University of the West of England (UWE) Bristol, published an online guidance document on evaluating PI in research in May 2018. This guidance document was downloaded 65 times in two weeks from countries including the United States, Canada and across Europe.

Recognising the demand for more practical PI evaluation tools, the UWE PI team then developed and internally piloted a workshop on evaluating PI in research. This workshop was delivered for the first time at UWE's Centre for Appearance Research Away Day in June 2018. Plans are in progress for further roll out of the workshop.

Methods: This 60-minute 'taster' of the longer prototype workshop will primarily be important to PI research leads, research team members, and public contributors. It broadly has four sections, starting with an introduction, where we 'set the scene', discussing the complex issues surrounding PI evaluation, e.g. whether PI should be thought of as an intervention or a conversation. We will then discuss three evidence-based PI evaluation approaches to help navigate through those issues – a pragmatic approach, a participatory action approach, and the comprehensive Public Involvement Impact Assessment Framework (PiiAF). Delegates will be signposted to other relevant key resources, such as the NIHR policy and National Standards for PI. They will have opportunity throughout the workshop to comment and provide feedback on the material being introduced.

Outcomes: This workshop is a learning process, where we aim to provide a safe and constructive environment for delegates to try something new. Delegates will have the opportunity to reflect upon developing a practical approach to evaluating PI in research to support their own PI practice. In addition, they may wish to share their learning on evaluating PI in research with others at their respective organisations – delegates may request to adopt and adapt workshop content for this purpose, with appropriate acknowledgements. We may set up an online 'aftercare' forum, where delegates can send us feedback on their experiences of using the resources, make suggestions for improvements, and generally discuss the issues they are facing in efforts to evaluate PI.

Co-producing evaluation to evaluate co-production: a workshop

Andrew Gibson, Jo Welsman

University of West England

Patient and public involvement (PPI) in research is a complex social process which crosses institutional and professional boundaries and travels into the 'lifeworlds' of patients and the public. In doing so significant inequalities in power between those who take part are negotiated. In light of this complexity and the need to maximise the effectiveness of public involvement we argue that evaluations should be participatory, identify important relationships and inter dependencies, and enable solutions to problems to be co-produced with public contributors. In previously published work we have developed a framework that facilitates this approach to thinking about involvement (Gibson, Britten and Lynch, 2012; Gibson, Welsman and Britten, 2017). In this workshop, based on further practical work, we show how the framework can be used as a participatory tool for critical reflection and evaluation.

In the workshop we will provide a brief introduction to the thinking behind the development of the framework and how this thinking has been applied to public involvement. This will be followed by a short discussion of how the framework sits in relation to other approaches to evaluating involvement. The majority of the session will focus on how to run a workshop based on the framework and how to use the outputs to reflect upon, plan and improve involvement practice, thus maximizing potential impact.

From frameworks to frameworking to support PPI in research

Lisa Hinton (Lead Facilitator LF), Teresa Finlay (Co-facilitator CF),

Nuffield Department of Primary Care Health Sciences, University of Oxford

This workshop has been developed to support patient and public involvement (PPI) in health research in our BRC and partner organisations. We began with a systematic review of Frameworks for PPI which found over 40 frameworks, but that they are only used by the people who developed them. We concluded that the interactions in the messy process of '*frameworking*' are key to successful PPI and developed resources for '*frameworking*' workshops.

Drawing partly on the results of our SR (particularly on eight frameworks rated best for usefulness and visual appeal), working with patients, carers, lay representatives, PPI policy staff and professional designers, we identified four components around which '*frameworking*' activities could focus:

- Underpinning values
- People and relationships
- Set-up and practicalities
- How to contribute.

The workshop will have two facilitators who will provide assistance and observe the workshop to make field notes and record participants' feedback. The workshop will comprise:

Introductions, orientation, agreeing ground rules and task

Welcome from facilitators, introductions round the group including a simple ice-breaker.

Presentation of background to the workshop and our aims for this session.

Brainstorm of ground rules, recorded on flip chart.

Small group work

Build the framework around a component using mixed media.

Each group will be encouraged to work creatively to create a visual map of elements they agree are relevant to their component.

Participants will be prompted to think about **how** their ideas would be achieved, rather than coming up with abstract ideas.

Plenary. Groups show and tell their visual map (photographed if desired) and how it would be operationalized and evaluated. Summarise and conduct reflection on and evaluation of the activity.

Outcomes

Participants will gain practical experience of the 'frameworking' process.

All will consider how this approach could inform evaluation of the impact and outcomes of PPI in research projects for wider dissemination

Facilitators will gain feedback on the workshop structure, process and tools

What is a PPI Café and how can I set one up?

Anna Lawrence-Jones, Amanveer Nathan, Will Kendall, Maria Piggin, and Marie Miller

NIHR Imperial Patient Safety Translational Research Centre (PSTRC)

What is a PPI Café?

The Patient and Public Involvement (PPI) Café is a new PPI methodology – a hybrid between a science café and a more typical PPI workshop. It opened for the first time at the 2018 Imperial Festival and was co-designed by five Imperial research centres in partnership with patient and public members. It is an informal and fun way to interact with the public to get feedback on ongoing research projects.

Aim: To engage the public with specific research projects, giving them a flavour of PPI by getting them to give feedback in a relaxed environment.

What will the workshop involve?

We will demonstrate the PPI Café by re-creating one in the workshop; we will recreate the look and feel of the interactive PPI Café. Participants will have cards on their seats with different coffees on. Five people will have an "Engagement Espresso" or "Lay Latte" indicating they should come up to take part in the discussion. Everyone else will be given cards to write ideas, with a narrator describing what is going on.

"Baristas" (patient representatives) will introduce participants to PPI, before the facilitators (researchers) give the background to a real-life Imperial research project. They will be posed questions that the researcher wants feedback on and invited to make suggestions on how to improve the study. Participants will be asked to write their ideas down on cards and fill up coffee jars with their ideas.

While we have evidence of this format working well – with 84% of Festival respondents learning 'a great deal' or 'a lot' – we are hoping to further develop the concept. Workshop participants will thus have the opportunity to make suggestions for improvement. We have since sought out collaborators from a wider group of researchers and will be running PPI Cafes in community cafes this autumn.

What will the outcomes be?

We hope to persuade participants of the merits both of (a) the PPI Café and (b) the value in experimenting with involvement methodologies. Practically, they will learn how the PPI Café can be replicated, taking away our 5-step easy guide for creating their own.

More broadly, participants will gain inspiration from the relative ease with which innovative ideas can be developed working collaboratively with patients. We hope to share our learnings and trigger creativity and large-thinking away from more typical engagement/involvement activities.

Patient involvement in course development – token gesture or the future of med ed? How do we evaluate?

Lindsay Muscroft, Mike Hopper, Kate Owen

Warwick Medical School

Outcomes:

To generate ideas to better evaluate patient involvement in different aspects of medical school work such as curriculum design, developing assessments and selection of future students

Our workshop will follow a design thinking format:

Design thinking originated in 2004 from a catchword in use at IDEO, a design studio in California, and involves taking a designer's approach to try and solve a problem, using elements like empathy and experimentation to arrive at innovative solutions (1). It can be especially useful for solving "wicked problems", and consists of 5 stages: empathise, define, ideate, prototype and test (2). Our workshop will aim to use the first four stages to approach the problem "how can we better evaluate patient involvement in different aspects of medical school work such as curriculum design, developing assessments and selection of future students?", as to date limited evidence has been published on this topic, and will run to the format below:

We hope to have a mixture of educators, and patients (preferably but not essentially with PPI experience) working in groups to the schedule below:

- Introduction to design thinking and our "wicked" problem
- Empathise: educators get into groups with patients and spend time exploring their experiences relevant to the problem we are trying to solve
- Define: Groups asked to re-define our given problem based on the findings from the "empathise" stage
- Ideate: Groups asked to synthesis as many ideas as possible – we will provide lots of different colourful resources to encourage creativity
- Prototype: Groups asked to focus ideas and hone in on one to present
- Presentations from the groups on their big idea and close

Evidence or experience? Different ways of knowing whether involvement makes a difference

Kristina Staley, Kristin Liabo

TwoCan Associates

We propose that in essence, public involvement in health research is a conversation that supports two-way learning. The public, researchers and clinicians work together to share their different knowledge and expertise, opinions and values. The public often learn about research and researchers and clinicians learn from the public's lived experience. Ideally they draw on this learning to make joint decisions about what to research and how to do it, so as to achieve their shared goal of generating better evidence to improve services and care.

What any individual learns from involvement will be unique to them, as it depends on what they don't know at the start. Often people don't know what they don't know, which makes the precise outcome unpredictable. Furthermore, their learning may change their thinking and behaviour in subtle ways that may not be easy to assess, even though such changes are important and highly significant. How can we evaluate this complexity in public involvement in a way that recognises and captures the wide range of impacts for different people, and different outcomes, over time?

In this workshop we will explore a different approach to capturing and reporting the impact of involvement, which acknowledges this complexity. This approach builds on involvement as a two-way learning process with conversations at the heart, driven by people's passion for improving health and health services. We suggest 'evaluation' of involvement therefore needs to focus on telling the story of people's experiences of impact, rather than trying to develop measurable outcomes for involvement.

Workshop participants will be invited to test out this approach to reporting and describing impact, and to assess its strengths and weaknesses. We will aim to address the following questions:

- What aspects of the experience of involvement are important to capture and why?
- What are the implications for 'how' to evaluate public involvement in research?
- What are the implications for reporting on involvement and its impact?

Measuring patient and public involvement: Principles, approaches and challenges

Sophie Staniszewska

Warwick Medical School, University of Warwick

This workshop will start with a brief introduction to the concept of measurement of social phenomena. Key principles of measurement will be introduced, with a worked example. We will think about the measurement of PPI impact from the perspective of how it adds value and how we capture this numerically.

The participants will work in small groups to develop a blueprint (or conceptual model) for what they want to measure. They will then identify key elements of the blueprint (dimensions of the conceptual framework), then design questions (items) and quantitative ways of measuring (scales) different parts of the blueprint.

The aim will be to draw on principles of measurement from other fields and bring them to the world of PPI. We will aim to make the workshop fun and interesting and to create 'spaces' for people to reflect on the concept of measurement, whether they think it's a good idea and how it might look in the future. We will finish with a brief discussion on what people feel are the key area where we should focus our efforts in the future to develop the measurement of PPI.

Patient and Public Involvement: one way to democratise research

Dr Nicky Wilson

King's College Hospital NHS Foundation Trust, London.

Our aim in a 60 min workshop is to share insights, stimulate debate and, together with participating delegates, create and record new perspectives on how PPI strengthens the stake that patients and the public have in research. Through this 'democratisation', research is moulded to be more relevant and accessible to a wider diversity of communities. In this workshop, using illustrative examples, we will explore how PPI can:

- Improve the strength and diversity of the patient's voice by increasing patient participation and retention in research.
- Encourage the adoption of evidence-based practice in low and middle income countries.

As hosts, we shall briefly share our own perspectives on how PPI has moved research beyond familiar academic territories. Providing opportunities to engage with new audiences, PPI has increased direct participation in research through partnership, making the research process and its outcomes more relevant to communities from different countries. We will:

- Explain how the involvement of community, non-clinical groups can facilitate access to seldom heard populations to engage with designing and developing accessible musculoskeletal research.
- Describe how a strong patient voice was included in developing a core outcome set for tinnitus through PPI input: the international COMIT'ID study benefitted from high numbers and retention of patient participants across the world.
- Outline how the principles and benefits of PPI in musculoskeletal research were introduced and adapted to strengthen mental health services in six low and middle income countries.

These short presentations will provide examples to stimulate round table discussions, exploring delegates' own ideas on how PPI may widen participation and embed research practice in communities. We will act as facilitators at individual tables, encourage ideas to be written down and direct a short plenary for spokespersons from each table to feedback their ideas to the room. We shall collate all written notes and contact details for those delegates who wish to contribute further. Together with these delegates we shall produce a report for publishing on INVOLVE's new online shared learning facility (under development). This will contribute to national resources on PPI in research and help stimulate further debate.

Helping PPI reach full impact - Normalisation Process Theory in user-friendly language!

Tricia Wilson, Elspeth Mathie

University of Kent

Maximum impact from patient and public involvement (PPI) can only be achieved if the necessary work and processes are in place to make sure PPI is embedded within teams, partnerships and organisations. As a first step towards a meaningful evaluation of PPI impact, this workshop focuses on a key perspective; assessing how PPI has become everyday practice or “normalised”. This is not only useful in contributing to an impact evaluation, but can also be used as a tool to identify areas for improvement in PPI processes and work.

The workshop will be delivered by Tricia Wilson and Elspeth Mathie who led the RAPPORT study; a NIHR funded national evaluation of PPI in health research. RAPPORT utilised Normalisation Process Theory (NPT) to understand amongst other objectives, how embedded PPI had become within the National Institute of Health Research (NIHR) infrastructure. NPT proved a useful tool in evaluating PPI, and specifically explores how PPI is understood as a different way of working to previous practices; how everyone involved “buys-in” to PPI and sees potential impact; how the work required in PPI is undertaken and driven forward; and how everyone involved assesses processes and outcomes of PPI and make changes in the light of this appraisal.

The specific objectives of the workshop are to provide participants:

- Understanding of NPT as tool to use in evaluating the implementation of PPI
- Familiarity with the online NPT Toolkit
- Opportunity to use NPT to evaluate how well-embedded PPI is within the participant’s own study or organisation
- Sharing of ideas of how to make best use of NPT as a tool to improve PPI processes, practice and outcomes.

The workshop will involve:

- An introductory overview of NPT and how it was used in the RAPPORT study
- Participatory small group work using the NoMAD NPT tool adapted for evaluating PPI
- Development of NPT generated visual “radar plots” to identify strengths and areas for development to further embed PPI
- Group discussion on potential use of NPT in PPI evaluation

