



## PPI Summer School – 13<sup>th</sup> & 14<sup>th</sup> June 2019

### Public and Patient Involvement (PPI) in Health Research

#### Day 1 Programme

Time	Description	
10.00 - 10.15am	Welcome address	<p>Prof. Anne MacFarlane, Professor of Primary Healthcare Research and Academic Lead of the <i>Public and Patient Involvement (PPI) Research Unit</i></p> <p>Prof. Rachel Msetfi, Executive Dean and Director Health Research Institute, Faculty of Education and Health Sciences, University of Limerick</p>
10.15 -11.00am	Keynote 1	<p>Effecting and evaluating policy change for public and patient involvement in health research</p> <p>Prof Jennie Popay, Professor of Sociology and Public Health at Lancaster University, UK</p>
11.00 – 11.30am	Tea/Coffee break	
11.30 – 1.30pm	Parallel Sessions 1	<ul style="list-style-type: none"> <li>• Finding Research Partners</li> <li>• Using Arts-Based Methods in PPI Health Research</li> <li>• Ethics, Governance and Partnership Agreements</li> </ul>
1.30 – 2.30pm	Lunch	
2.30 – 4.30pm	Parallel Sessions 2	<ul style="list-style-type: none"> <li>• Dilemma Café – Exploring your key questions in PPI practice</li> <li>• Patient and Community Perspectives: What do we expect out of a research partnership?</li> <li>• Dissemination Planning with Partners</li> </ul>
5.00 – 7.00pm	Summer School BBQ	Castletroy Park Hotel



## Day 2 Programme

Time		Description
9.00 – 11.30am	Parallel Sessions 3	<ul style="list-style-type: none"><li>• Dilemma Café - Exploring your key questions in PPI practice</li><li>• HRB: What goes into a successful PPI section of research grants?</li><li>• PPI in PhD Research Projects</li></ul>
11.30 – 12.00pm	Tea/Coffee break	
12.00 – 12.45pm	Panel Discussion	PPI Engagement in research prioritization: Avril Kennan, Michelle Gardner (MCRG) Harriet Doig (MSI) Liam O’Sullivan, Zoe Hughes (CAI) Cally Jeffers (LC-CDP) Moderator: Anne Cody (HRB)
12.45 – 1.00pm	Closing remarks	Prof. Anne MacFarlane, Professor of Primary Healthcare Research and Academic Lead of the <i>Public and Patient Involvement (PPI) Research Unit</i>



## **Day 1 – 13th June 2019**

### **Keynote 1: 10.15 -11.00am**

#### **Effecting and evaluating policy change for public and patient involvement in health research**

Changing academic culture to foster effective public and patient involvement requires far reaching policy change at all institutional levels. Professor Popay will discuss the challenges involved in influencing academic culture and ways of monitoring and evaluating its impact.

**Jennie Popay** is Professor of Sociology and Public Health at Lancaster University, UK

### **Parallel Sessions 1 (11.30 – 1.30pm)**

#### **Workshop 1: Finding Research Partners**

This workshop will discuss issues and strategies for identifying and engaging with appropriate research partners from the patient, community, health service and policy domains. It will include a workshop exercise and a take-home tool.

**Facilitators:** Jon Salsberg (UL GEMS)

**Jon Salsberg** is Senior Lecturer in Primary Healthcare Research – Public & Patient Involvement, in the Graduate Entry Medical School, University of Limerick

#### **Workshop 2: Using Arts-Based Methods in PPI Health Research**

This workshop will explore the use of arts-based methods to co-generate and analyse data in partnerships with community, academic and health sector partners. It will demonstrate how arts-based methods were used in an exemplar HRB-funded research project and will include take-home resources.

**Facilitators:** Helen Phelan (UL Irish World Academy)

**Helen Phelan** is Associate Professor in the UL Irish World Academy of Music and Dance, and Programme Director for the PhD in Arts Practice.

#### **Workshop 3: Ethics, Governance and Partnership Agreements**

This workshop will discuss ethical considerations particular to community and patient partnered research. It will also introduce different governance models used to allow partners



to share research decision-making. A roleplaying exercise will help participants work through some of the issues involved in creating a partnership agreement.

**Facilitators:** Virginia Minogue; Cally Jeffers (LC-CDP)

**Virginia Minogue** Is an independent researcher and former NIH (UK) Area Manager in Bioethics.

**Cally Jeffers** is Manager, Limerick City Community Development Project

## **Parallel Sessions 2 (2.30 – 4.30pm)**

### **Workshop 1: Dilemma Café: Exploring key questions in PPI practice**

#### **What is a Dilemma Café?**

A dilemma café involves people coming together to discuss several dilemmas experienced by participants. A dilemmas café may be on any topic, e.g. science, parenting, social work.

#### **What is the aim of the PPI Dilemma Cafes?**

The aim of the PPI Dilemma Cafés is to encourage collaborative dialogue about PPI issues that are of interest to Summer School participants, e.g., getting started in PPI, ethical issues in research partnerships, and methods for meaningful engagement. Experienced facilitators will guide conversations between participants in the café to stimulate learning about different ways of seeing and understanding the issues being explored.

#### **The café relies on submissions from you!**

Please use the form below to send us information on the PPI issue of interest to you.

*Name:*

*Organisation:*

*Role in your organisation:*

*Overall goal of my work/project*

*My query about PPI is (350 words max)*

We will accept all submissions via email to [hri@ul.ie](mailto:hri@ul.ie) until 5pm on **Friday 17th May**.

### **Workshop 2: Patient and Community Perspectives: What do we expect out of a research partnership?**

This community-led interactive workshop will look at PPI research from the perspective of patients, carers and charities and other community-based organisations that represent their needs.

**Facilitators:** Liam O'Sullivan (CAI); Community Carer (TBD)



Liam O'Sullivan is the Executive Director of Care Alliance Ireland.

CAI Carer (TBD) Care Alliance Ireland will identify a community member to co-facilitate

### Workshop 3: Dissemination Planning with Partners

This workshop will explore the role stakeholders can play in effective knowledge diffusion and dissemination. It will explore the relationship between *message-messenger-audience* through use of a dissemination decision-making tool.

**Facilitator:** Jon Salsberg (UL GEMS)

**Jon Salsberg** is Senior Lecturer in Primary Healthcare Research – Public & Patient Involvement, in the Graduate Entry Medical School, University of Limerick

## **Day 2 – 14<sup>h</sup> June 2019**

### **Parallel Sessions 3 (9.00 – 11.30am)**

### **Workshop 1: Dilemma Café: Exploring key questions in PPI practice**

#### **What is a Dilemma Café?**

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### Workshop 2: HRB: What goes into a successful PPI section of research grants?

Most funding opportunities now require a statement about how researchers will involve patients or members of the public. In this workshop, representatives from the Health Research Board will discuss what they are looking for in these sections, what constitutes meaningful involvement vs. tokenism, and how to maximise your chances of satisfying reviewers.

**Facilitators:** Anne Cody (HRB)

**Anne Cody** is Head of Pre-Award, Health Research Board (HRB) and Lead for PPI in the HRB

### Workshop 3: Public & Patient Involvement in PhD Research Projects

This workshop will discuss issues that students may encounter when undertaking a participatory project as part of their PhD thesis research, and strategies for navigating them.

**Facilitator:** Ruth McMenamin (NUIG)

**Ruth McMenamin** is Lecturer in the Department of Speech & Language Therapy, NUI Galway

### Keynote 2: 12.00 – 12.45pm

#### Panel Discussion: Building Capacity for Participatory Health Research among Patients and the Public

What is the role and significance of research training for patients, carers and other community members? Where are we and where do we need to be in building this capacity for PPI in Ireland?

**Discussion Panel:** Zoe Hughes (CAI), Liam O’Sullivan (CAI), Cally Jeffers (LC-CDP), Michelle Gardner (MRCG), Avril Kennan (MRCG), Harriet Doig (MSI)

**Moderator:** Anne Cody (HRB)

**Zoe Hughes** is Policy and Research Officer, Care Alliance Ireland (CAI)

**Liam O’Sullivan** is Executive Director of Care Alliance Ireland (CAI)

**Cally Jeffers** is Manager Limerick City Community Development Project (LC-CDP)

**Michelle Gardner** is Research Support Manager, Medical Research Charities Group (MRCG)

**Avril Kennan** is CEO of the Medical Research Charities Group (MRCG)

**Harriet Doig** is Information, Advocacy & Research Officer, Multiple Sclerosis Society of Ireland (MSI)

**Anne Cody** is Head of Pre-Award, Health Research Board (HRB) and Lead for PPI in the HRB



### *Full Speaker and Facilitator Profiles*

**Anne MacFarlane** is Professor of Primary Health Care Research in the Graduate Entry Medical School, University of Limerick. She is founder and academic lead for the PPI Research Unit, theme lead for PPI in the Health Research Institute (HRI), and PI for PPI Ignite UL.

Anne is a social scientist with 25 years' experience using qualitative research methods in health services research. She is the first social science Chair in the field of academic general practice and primary care in Ireland. She has a total research income of approximately 9 million euro and has specialist expertise in participatory health research, particularly in relation to migrant health. Academic bio: <https://www.ul.ie/gems/about/staff/academic-faculty/Prof-Anne-MacFarlane> .

**Jennie Popay** has been Professor of Sociology and Public Health at Lancaster University's Institute for Health Research since January 2002. She was previously at the Nuffield Institute, University of Leeds, and at the University of Salford.

Jennie spent five years teaching in East Africa and studied social sciences in New Zealand before returning to the UK in 1974 to undertake postgraduate work. She began her research career at the Unit for the Study of Health Policy at Guy's Hospital in London and has worked as a sociologist in the public health field ever since. She is currently convenor of the Campbell Collaboration Process Implementation Methods Group and the proposed Cochrane Collaboration Qualitative Methods Group. Academic profile: [http://www.research.lancs.ac.uk/portal/en/people/jennie-popay\(b4cf253a-15ad-4df2-8d0d-0cb1c9a0e6a8\).html](http://www.research.lancs.ac.uk/portal/en/people/jennie-popay(b4cf253a-15ad-4df2-8d0d-0cb1c9a0e6a8).html) .

**Jon Salsberg** is Senior Lecturer in Primary Healthcare Research – Public & Patient Involvement, in the Graduate Entry Medical School, University of Limerick.

Jon is a qualitative health researcher with a background in public health promotion and the anthropology of development. He is co-author of Canada's Guide to Researcher and Knowledge-User Collaboration in Health Research (<http://www.cihr-irsc.gc.ca/e/44954.html>) and has undertaken partnered research involving patients, health practitioners, community members, policy makers and health service decision-makers. Academic Bio: <https://www.ul.ie/gems/about/staff/academic-faculty/dr-jon-salsberg> .

**Helen Phelan** is Associate Professor in the UL Irish World Academy of Music and Dance, and Programme Director for the PhD in Arts Practice. Helen specialises in arts practice research, ritual studies, ritual song, chant, singing & migration.

**Virginia Minogue** Is an independent researcher and former NHS (UK) Area Manager in Research and Bioethics.

Virginia is an experienced Executive and Senior Manager working at national, regional and local level, leading on commissioning, research policy, strategy and governance. Within NHS England, she has worked in areas such as NHS wide transformation programme, research prioritisation, evidence gathering and analysis, knowledge mobilisation, and building partnerships. Virginia has specific



interest and expertise in the ethical issues surrounding patient and public involvement in health research and care.

**Cally Jeffers** is Manager, Limerick City Community Development Project. Cally has recently moved in to this role, and is responsible for directing LC\_CDP's day-to-day activities within the community. Cally is also a core member of PPI Ignite @ UL.

**Liam O'Sullivan** is the Executive Director of Care Alliance Ireland. Liam holds professional qualifications in Social Work, Youth and Community Work and Social Research. His work with Care Alliance since 2004 has included bringing National Carers Week to Ireland, developing collaborative and impactful relationships with third level institutions in Family Carer research and progressing the development of a Carer Needs Assessment. He has a particular interest in Implementation Science and in bridging the gap between research policy and practice.

**Anne Cody** is Head of Pre-Award, Health Research Board (HRB) and Lead for PPI in the HRB. Anne has been with the HRB since 2002 and her previous roles have included Head of Clinical and Applied Biomedical Research, and Head of Research Infrastructure and Special Initiatives.

Anne comes from a background in cell biology (PhD - Martin Luther University Halle-Wittenberg), with postdoctoral work in chemistry (TCD).

**Ruth McMenamin** is Lecturer in the Department of Speech & Language Therapy, NUI Galway. Ruth joined the Discipline of Speech and Language Therapy in November 2004. Prior to taking up this position she worked as a senior speech and language therapist in Neurology at the Mater Misericordiae hospital. She obtained a BSc with 1st class honours in Speech and Language Therapy from the University of Ulster, and a Master's degree in Health Informatics from TCD. Ruth obtained her Postgraduate Diploma in Academic Practice and PhD from NUI Galway. Her research is focused on people living with aphasia.

Day 2 Discussion Panel:

**Zoe Hughes** is Policy and Research Officer, Care Alliance Ireland (CAI)

**Liam O'Sullivan** is Executive Director of Care Alliance Ireland (CAI)

**Cally Jeffers** is Manager, Limerick City Community Development Project (LC-CDP)

**Michelle Gardner** is Research Support Manager, Medical Research Charities Group (MRCG)

**Avril Kennan** is CEO of the Medical Research Charities Group (MRCG)

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