**Public and Patient Involvement Summer School**
**23rd and 24th June 2022**

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| **DAY 1 PROGRAMME** |
| **9.00 – 9.45** | **Registration** |  |
| **9.45 – 10.00** | **Summer School Opening** | **Welcome Address***Jon Salsberg, University of Limerick* |
| **10.00 – 10.45** | **Keynote** | **Building capacity for meaningful public and patient involvement in research in Ireland: the PPI Ignite Network**  *Seán Dinneen, NUI Galway*  |
| **10.45 – 11.15** | **Break** |  |
| **11.15 – 1.15** | **Parallel Session 1** | * **Introduction to Participatory Health Research for PPI**

*Jon Salsberg, UL* * **Arts-Based Methods in PPI Health Research**

*Helen Phelan & Fran Garry, UL* * **Developing a PPI Panel for Ageing Research**

*Katie Robinson, Rose Galvin (UL) & Monica Hannaford (PPI panel)* |
| **1.15 – 2.15** | **Lunch** |  |
| **2.15 – 4.15** | **Parallel Session 2** | * **Participatory research toolkit: creative research methods for meaningful engagement**

*Kim Ozano, Liverpool School of Tropical Medicine* * **Incorporating PPI in a grant application**

*Anne Cody, Health Research Board* |
| **5.00 – 7.00** | **Summer School BBQ** | The Pavilion, University of Limerick |

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| **DAY 2 PROGRAMME** |
| **9.15 – 10.00** | **Keynote** | **Storytelling and PPI Policy** *Anne Drabczyk, Fulbright Specialist -Fulbright Commission USA & University of Limerick*  |
| **10.00 – 10.30** | **Break** |  |
| **10.30 – 11.15** | **Plenary** | **PPI Lightning Talks** Short talks on topics related to PPI in research, followed by audience discussion. Lightning Talks are designed to raise awareness, generate interest, share an idea or an innovation.  *Speakers: Marian O’Mahony, Stacey Grealis, Kevin Quaid & Patricia O’Shea* *Facilitator:* *Avril Kennan, Health Research Charities Ireland* |
| **11.15 – 1.15** | **Parallel Session 3** | * **Putting the ‘co’ into co-research**

*Ailsa Donnelly, Graham Prestwich, Jess Drinkwater, Martin Rathfelder, Michael Kelly, and Robina Mir* * **PPI for Inclusion Health**

*Anne MacFarlane, UL; Clíona Ní Cheallaigh, TCD; Éidín Ní Shé, RCSI* * **Dilemma Café – Exploring your key questions in PPI practice**

*Facilitators: Anne Drabczyk & Úna McInerney* |
| **1.15** | **Lunch**  | **Summer School ends** |

\*\*Please note the programme above may be subject to change

***Day 1 – Thursday 23rd June***

***Keynote 1 (Thursday 10 – 10.45)***

Building capacity for meaningful public and patient involvement in research in Ireland: the PPI Ignite Network.

*Presenter****:***Professor Seán Dinneen, NUI Galway

Seán Dinneen is Professor of Diabetic Medicine at National University of Ireland, Galway and Consultant Endocrinologist with Galway University Hospitals. He graduated from University College Cork Medical School. He completed Internal Medicine Residency and Endocrinology sub-specialty training at the Mayo Graduate School of Medicine in Rochester, MN. After a period of postgraduate training and work experience in the USA (Mayo Clinic), Canada (McMaster University) and the UK (Addenbrooke’s Hospital, Cambridge), he returned to Ireland as an Academic Endocrinologist. He was part of successful bids that brought a School of Podiatric Medicine and a Clinical Research Facility to NUI Galway. He served as Head of the School of Medicine from 2013 to 2016. In June 2016 he was appointed National Lead for the Diabetes Clinical Programme of the Irish Health Service Executive.

His clinical/research interests include developing and evaluating programmes of self-management education and support for people living with diabetes, developing optimal models of community-based diabetes care and understanding the diabetic foot. He has served as Editor for Diabetic Medicine, Vice-Chair of Postgraduate Education for EASD and Clinical Lead for Schwartz Rounds in Galway University Hospitals. In March 2021 he became Programme Lead of a HRB/IRC funded PPI Ignite Network aiming to increase the capacity for high quality Public and Patient Involvement in health and social care research in Ireland.

***Parallel Session 1 (Thursday 11.15 – 1.15)***

**Workshop 1: Introduction to Participatory Health Research for PPI**

Participatory health research (PHR) is all about making sure that those who matter most are at the heart of research decision-making. This workshop introduces the principles of PHR and how they can drive meaningful public & patient involvement in health research. It will include a role-playing exercise where participants can experience collaboration from the perspectives of various stakeholders.

*Facilitator:* Dr Jon Salsberg, PPI Research Unit, University of Limerick

Jon Salsberg is Senior Lecturer in Primary Healthcare Research - Public & Patient Involvement in the UL School of Medicine, and UL Site Lead for the PPI Ignite Network. He is a public health researcher with a background in health promotion and the anthropology of development. Jon has more than 20 years of experience working in partnered research along with patients, community members and organisations, service providers and other decision-makers, and particularly in Indigenous communities. Jon’s main research interests are in understanding the social-relational dimensions of research partnerships and how they affect health outcomes.

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

This workshop explores the use of arts-based methods in PPI health research as a means of fostering participation, co-generating data and disseminating research findings. Models for collaborative research teams which include artists, as well as the development of arts-based expertise and confidence in researchers are proposed. The workshop will demonstrate the development of an interdisciplinary arts-based project in migrant health research with a particular focus on singing, and will conclude with performed examples of how arts-based approaches can contribute to the research paradigm.

*Facilitators:* Professor Helen Phelan & Dr Fran Garry, Irish World Academy of Music and Dance & PPI Research Unit, UL.

Helen Phelan is Professor of Arts Practice at the Irish World Academy of Music and Dance, University of Limerick, Ireland. She is an Irish Research Council recipient for her work on singing and migration. Her book, Singing the Rite to Belong: Music, Ritual and the New Irish, was published by Oxford University Press in 2017. She is co-founder of the female vocal ensemble Cantoral, specializing in Irish medieval chant; founder of the Singing and Social Inclusion research group; and IMBAS, a support network for artistic research in Ireland. Her most recent Health Research Institute funded project explores the use of arts-based methods in migrant health research.

Fran Garry currently works as a postdoctoral researcher with the Health Research Institute—PART-IM (Participatory and Arts-Based Methods for Involving Migrants in Health Research) cluster at the University of Limerick. She is a singer/songwriter, community music educator, and arts practice researcher. She completed her PhD Arts Practice (Music) at the Irish World Academy of Music and Dance in 2018. Her research interests include arts-based and arts practice research, community music, music and wellbeing, and arts-based research and migrant health. She has published in journals such as Transform-New Voices in Community Music, HRB Open Research, and the International Journal of Community Music.

**Workshop 3: Developing a PPI Panel for Ageing Research**

In this workshop the philosophy and pragmatics of developing a PPI panel for Ageing Research at the University of Limerick will be presented. Research studies where older adults have been centrally involved in all stages from study conception to dissemination will be presented as exemplars with key reflections from older adult and academic co-researchers. We will also discuss on-line collaborative work during the pandemic.

*Facilitators:* Dr Katie Robinson & Professor Rose Galvin, School of Allied Health & Ageing Research Centre, University of Limerick and Monica Hannaford (PPI panel member)

Katie Robinson is a Senior Lecturer Occupational Therapy, School of Allied Health & Ageing Research Centre, University of Limerick. She is an experienced qualitative researcher with a focus on rehabilitation research. She has a background in Disability Studies and has experience of participatory methods. She is currently collaborating on several studies where older adults have been involved in study conception, development of research grant applications, preparation of research materials, data analysis and dissemination.

Rose Galvin is Associate Professor Physiotherapy, School of Allied Health and Ageing Research Centre, University of Limerick. Rose holds a Health Research Board Research Leader Award in the area of Integrated Care for Older Adults. She is a recognised international expert in the development and evaluation of models of care for older adults. The impact of Rose’s programme of research evidences the benefits of the involvement of older adults in health services and rehabilitation research as partners.

PPI stakeholder panel members details to be confirmed.

Monica Hannaford is a member of the Ageing Research Centre stakeholder panel of older adults and a member of Clare Older Peoples Council.

***Parallel Session 2 (Thursday 2.15 – 4.15)***

**Workshop 1: Participatory research toolkit: creative research methods for meaningful engagement**

This session will present many creative ways of working with people and communities to understand needs, set priorities and develop actions together for social change. The methods will use knowledge exchange walks, photographs, storytelling, video, drawing and mapping techniques amongst others and are displayed in our participatory toolkit with instructions of how to apply them. You will hear how researchers and community partners globally have used these methods to co-create new knowledge together. You will then have the chance to pick a few methods to try yourself within a group or individually, so you can experience them first hand and reflect on being a participant, facilitator, or observer. A discussion of adapting methods to suit different contexts and communities will end the session.

*Facilitator:* [Dr Kim](http://dr.kim/) Ozano, Liverpool School of Tropical Medicine and founder of the Connecting Citizens to Science Podcast

Kim is a social scientist and public health practitioner with more than 15 years’ experience of working in collaborative research, education, management and consultancy. She works across ARISE, COUNTDOWN and K4D at LSTM to strengthen health systems through the application of co-production research approaches, capacity strengthening and multilateral knowledge exchange. She is experienced in implementation science, co-designing innovative participatory methods and methodologies, delivering and evaluating impactful collaborative researchwith communities and within district, regional and national health systems in sub-Saharan Africa, Asia, Latin America and the UK. Her recent research focus is on addressing power differentials in co-production research and sharing lessons from multidisciplinary research that connects citizens with science.

 **Workshop 2: Incorporating PPI in a grant application**

This workshop will explore things to consider, where to start and how to integrate PPI – which starts well before the writing of an application. We’ll look at how the Health Research Board reviews the PPI sections and will have some insights from a number of recent panels on the quality of PPI.

*Facilitator:* Anne Cody, Health Research Board

Anne is Head of Investigator-led Grants, Research Careers and Enablers at the Health Research Board. She has a background in cell biology and spent ten years as a researcher in Germany and Ireland. She has been working with the Health Research Board in a variety of roles for 20 years. During this time, she has gained experience across a wide spectrum of health research, funding instruments and research policy questions.

Anne has been the driver behind the HRB’s approach to Public, Patient and Carer Involvement (PPI) and remains committed to this agenda. She has been actively involved in tackling unconscious bias, has initiated transparency initiatives and has led a self-audit assessing the HRB’s performance against recommendations to maximising research value.

***Day 2 – Friday 24th June***

***Keynote 2 (Friday 9.15 – 10)***

***Storytelling and PPI Policy***

This keynote explores the nexus between storytelling and relevant policies that represent the shared values and vision of stakeholders. A synopsis of narrative trends, best aspects of storytelling, and the practice of sharing the story to form the policy, will be examined.

*Presenter:* Dr Anne L. Drabczyk, Fulbright Specialist -Fulbright Commission USA & University of Limerick

Anne is a visiting Fulbright Specialist with the United States Fulbright Commission, positioned with the Public and Patient Involvement Research Unit in the School of Medicine, University of Limerick.

Anne has extensive experience in public health and healthcare management as a practitioner, professor, author, and consultant. She was the national executive of a strategic public health preparedness initiative for a 2,800-member organization. As a professor she developed a healthcare management curriculum grounded on core-competencies for workforce readiness. Anne is certified in the participative action research Appreciative Inquiry protocol and believes in co-creating achievable and sustainable resource-ready solutions for stakeholders and clients.

***PPI Lightning Talks (Friday 10.30 – 11.15)***

Lightning Talks are 5-minute talks designed to raise awareness, generate interest, share an idea or put forward an innovation. There will be opportunity for audience discussion after each talk.

**Talk Title:** 3 Key PPI contributions to a research project
**Presenter:** Marian O’Mahony
**Bio:** Marian O ’Mahony’s interest in PPI began when she became a palliative carer for her 18-year-old son who developed leukaemia and died just months later. Finding the experience isolating and frightening she wrote their family story in her book ‘Goodbye, My Son’ providing an emotional account of a family experience of palliative care. She also has a website https://www.marianomahony.com. She is a UCC and IPPOSI graduate and her mission is to contribute experience and information to promote the best outcome for patients, carers, researchers, and professionals in the field.

**Talk Title:** PPI Stakeholder Mapping
**Presenter:** Stacey Grealis
**Bio:** Stacey Grealis shares her lived experience of living with Rheumatic Muscular Diseases as a Patient Partner with The European League Against Rheumatism (EULAR) and Centre for Arthritis Research in UCD (UCDCAR). She is an IPPOSI patient education programme graduate and member of the EUPATI National Platform. Stacey believes that the patients and public voice should be at the heart of all healthcare, policy and research.
 **Talk Title:** Involvement of people with dementia as research partners
**Presenter:** Kevin Quaid
**Bio:** Hi I am Kevin Quaid and 58 years old and married to Helena. I was first diagnosed with Parkinson, just over five years ago, then I was diagnosed with Lewy body dementia. I am Chair of the Irish dementia working group, vice chair of the European working group and co-founder of Lewy body Ireland. I am very involved in PPI and I am the author of two books about Lewy body dementia, I became one of the first people in the world to write a book about Lewy body dementia from the patients point of view when I wrote my first book called Lewy Body Dementia Survival and Me and I recently published my second book called I am KEVIN not Lewy.

**Talk Title:** The Organic Development of the PPI Relationship
**Presenter:** Patricia O’Shea
**Bio:** My name is Patricia O’Shea I am a retired Primary School Physical Education Teacher. I live in Killarney, Co. Kerry Ireland. I have a BSc. Health and Fitness. I am the patient representative of the Music Therapy and Chronic Pain special interest group of the International Association of Music Medicine. I am representing the patient lived experience of Music Therapy. I have been living with Chronic Pain since 2010. I have been a member of Chronic Pain Ireland (CPI) for a number of years and would highly recommend their services.

***Lightning Talks Facilitator:*** Dr Avril Kennan, Health Research Charities Ireland

Avril is CEO of Health Research Charities Ireland (HRCI), an organisation that supports a community of 40 charities to engage in all aspects of health research. Under her leadership, HRCI runs the Irish Health Research Forum (IHRF), manages a funding scheme for patient-focused research projects in partnership with the Health Research Board and hosts a patient and public involvement (PPI) ‘Shared Learning Group’ for over 30 charities. HRCI is also a national partner on the National PPI Ignite Network. Avril’s PhD and subsequent lab experience are in the field of molecular genetics. In previous roles in DEBRA Ireland and DEBRA International, she drove a range of patient-focused international initiatives. She’s passionate about improving lives through research.

***Parallel Session 3 (Friday 11.15 – 1.15)***

**Workshop 1: Putting the ‘co’ into co-research**

We are a group of members of the public, patients, GPs and academic GPs. We have been working together as a co-research group for around 7 years. We have been researching meaningful patient participation in general practice service improvement. We will reflect on our experiences of working as a co-research group, and the similarities and differences with other PPI roles we have. We are happy to be asked anything from practical questions to our thoughts and opinions. We will try to answer everything.

*Facilitators:* Ailsa Donnelly, Graham Prestwich, Jess Drinkwater, Martin Rathfelder, Michael Kelly, and Robina Mir.

The people who have been involved in this work are:

**Ailsa Donnelly** - I’ve been involved in Patient and Public Involvement for 15 years now, in a variety of roles and wearing many different hats, but mostly in primary care.  It’s been a whole new career since retirement, and I can’t believe how much I have enjoyed it and how much I have learned!  I hope I have contributed something, and I hope there is more to come. Twitter: @AilsaDon

**Graham Prestwich** - A lucky patient who believes that more people would have a greater slice of luck if they were helped and supported and encouraged to become more involved. I am convinced that when people are more authentically included in health and care decision making, service design, and the way services are tailored to meet individual needs we all benefit from better outcomes of care. I am a keen participant, supporter and enabler of public involvement in all shapes and forms. Email: graham.prestwich@gmail.com Twitter: @MrGPrestwich

**Jess Drinkwater** - I am a GP in Bradford (West Yorkshire) and a Clinical Lecturer at the University of Manchester. I have recently completed my PhD titled – ‘Participatory research to strengthen the role of patient and public involvement in general practice service improvement’. I have been interested in this topic since trying to set up a patient participation group in the practice where I trained to be a GP. I plan to continue doing research in this area and researching with people.

Email: jessica.drinkwater@manchester.ac.uk Twitter:@jessdrinkwater

**Martin Rathfelder** - I have been involved in the NHS as a patient or public representative since 1990 when I was chair of the South Manchester Community Health Council. Since then I have been involved in all the different sorts of public involvement in the NHS in Manchester, regionally and nationally.

Email: ma.rathfelder@ntlworld.com  Twitter: @rathfelder

**Michael Kelly** - Every day's a bonus for me after Manchester NHS team saved my life following cardiac arrest 7 years ago in my early 70s - plenty to give back any way I can!

Email: michael\_kelly8@sky.com

**Robina Mir** - I’m a patient with chronic conditions and have a professional background of working across many public sector agencies which began from a community development background. I currently work within a medical school where I mainly deliver the Professionalism and Communication strands of the curriculum and a Freedom To Speak Up Guardian. I have a history of developing and designing innovative services within the NHS and Voluntary Sector and understand how to bridge the gaps between healthcare professionals and the people they serve. I can identify gaps in service provision and train others on how to develop an inclusive practice. I am a Muslim woman of Pakistani origin, born and brought up in Leeds.

Email: r.mir@leeds.ac.uk or paisleyrrm@hotmail.co.uk

**Nick Hayward** - I have been a GP in Shipley (West Yorkshire) for 16 years, I am a GP partner at Affinity Care and GP trainer.  I am also currently Associate Clinical Director for Practice Engagement and Quality Improvement at Bradford Districts and Craven Clinical Commissioning Group (CCG), clinical lead for research at the CCG.  I have done a number of roles alongside being a GP over the years. I have worked for a number of NHS bodies in Quality Improvement training and patient safety. For the last few years I was Primary Care Lead for Bradford Districts CCG, and patient engagement lead.

**Phil Gleeson** - 25 years ago (1995) I became involved in PPI, ensuring the patient voice is central and at the top table ensuring services are fit for purpose. Research is vital to ensure we work co-productively with health professionals. I believe that it's my responsibility to give back to those who are helping me, to ensure even though I might not benefit, future generations will and until my last breathe I will.

Email: phil.gleeson@gmail.com   Twitter: @philipcgleeson

**Ruth Chadwick** - I am a person who is a patient, a Healthcare professional, and a university academic. I have a passion for, and longstanding educational interest in, public involvement and professional standards.  I am driven to seek excellence in all aspects of care for the benefit of my fellow human beings.

Email: r.chadwick@salford.ac.uk   Twitter: @chadwick\_ruth  Blog: https://musingsazpro.wordpress.com/

**Delia Muir** - I lead Public Involvement and Engagement for the Leeds Institute of Clinical Trials Research. I am particularly interested in creative facilitation approaches. I interviewed the co-research group about their experiences of the project. When lockdown allows, I will also be working with the group to help turn some of their learning into theatre workshops. Email: d.p.muir@leeds.ac.uk   Twitter: @delia\_muir

**Workshop 2: PPI for Inclusion Health**

Inclusion health is an approach that aims to address theextreme health inequalities experienced by socially excluded people. It is important to advance and develop research capacity to generate evidence to reduce these health inequalities. Socially excluded people need to be respected partners in research so that their voice and perspectives are understood and used to drive evidence-based changes in practice and policy. This workshop will explore values, principles and best practice for PPI in Inclusion Health Research with particular reference to refugees and migrants and people who are homeless.

*Facilitators:* Professor Anne MacFarlane, UL; Professor Clíona Ní Cheallaigh, TCD; Dr Éidín Ní Shé, RCSI.
Anne is Professor of Primary Healthcare Research and Academic Lead for the Public and Patient Involvement Research Unit & WHO Collaborating Centre for Refugee and Migrants’ Involvement in Health Research, School of Medicine, University of Limerick.

Clíóna is an Associate Professor in the Department of Clinical Medicine, Trinity College Dublin and a Consultant in Infectious Diseases and General Medicine in St James's Hospital, Dublin. Clíona is also Clinical Lead of the Inclusion Health Service in St James’s Hospital dedicated to improving access to specialist hospital care for homeless and other marginalized individuals.

Éidín is a Senior Lecturer at the RCSI Graduate School of Healthcare Management and is an Honorary Senior Research Fellow at the Australian Institute of Health Innovation at Macquarie University. Éidín has a disciplinary focus in co-design, public and patient involvement and applied health systems research.

**Workshop 3: 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.
**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. ethical issues in research partnerships, methods for meaningful engagement, increasing diversity in research partnerships. 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 send us information on the PPI issue of interest to you.

*Name:*

*Organisation (if applicable):*

*Role in your organisation (if applicable):*

*Overall goal of my work or project:*

*My query about PPI is:*

We will accept submissions to email: ppi-ignite@ul.ie

*Facilitators:*  Dr Anne L. Drabczyk, Fulbright Specialist -Fulbright Commission USA & UL and Úna McInerney, PPI Research Unit, UL.

Anne is a visiting Fulbright Specialist with the United States Fulbright Commission, positioned with the Public and Patient Involvement Research Unit in the School of Medicine, University of Limerick.

Anne has extensive experience in public health and healthcare management as a practitioner, professor, author, and consultant. She was the national executive of a strategic public health preparedness initiative for a 2,800-member organization. As a professor she developed a healthcare management curriculum grounded on core-competencies for workforce readiness. Anne is certified in the participative action research Appreciative Inquiry protocol and believes in co-creating achievable and sustainable resource-ready solutions for stakeholders and clients.

Úna is UL Programme Manager for the HRB/IRC funded PPI Ignite Network. She is manager of the PPI Research Unit in the School of Medicine - a designated World Health Organisation Collaborating Centre for Migrant’s Involvement in Health Research. Úna has a background as a therapist, trainer and project manager and has led and managed projects in both university and community settings in Ireland, Romania, Bosnia-Herzegovina and Rwanda. She has been actively involved with the NGO Music as Therapy International for many years and is a member of their advisory panel. She trained as a music therapist at University of Bristol and has a Professional Diploma in Human Rights and Equality.