



PPI: Drivers for Change



UCD Charles Institute

18 Oct 2022



IRISH RESEARCH COUNCIL
An Chomhairle um Thaighde in Éirinn



WELCOME

FÁILTE

I am delighted to welcome you to Dublin and to University College Dublin for the first UCD symposium on public and patient involvement (PPI). Public and Patient Involvement (PPI) is an approach to research that fosters collaboration between people with lived experiences, researchers, and research institutions. The goal of PPI is to improve research and increase the ability of research to make a positive impact.

Since March of 2021, UCD has been part of the PPI Ignite Network. The Network is based at seven Universities in Ireland, with a National Programme Office. There are ten national partners and fifty three local partners. UCD is one of the Lead Sites for the Network. The PPI Ignite Network is funded by the Health Research Board (HRB) and the Irish Research Council (IRC) with co-funding from each of the Lead Universities.

This symposium is part of the National PPI Festival. The ambition of the National PPI Festival is to celebrate the progress in public and patient involvement (PPI) in Irish research and allow a creative space for innovation in PPI.

The symposium will be focused on showcasing PPI at UCD in addition to understanding the needs of the UCD community for PPI. We are focusing on building towards a sustainable future of PPI in research, both within UCD and beyond. Throughout this conference, I ask you to stay engaged, keep us proactive and help us shape the future of Public & Patient Involvement in Research at UCD.

Prof. Thilo Kroll

Site Lead, PPI Ignite Network @ UCD



PROF THILO KROLL

Prof Thilo Kroll is the site lead for PPI Ignite Network @ UCD. Thilo is Professor of Health Systems Management in the UCD School of Nursing, Midwifery and Health Systems.

Conference Programme

PPI: Drivers for the Future

Registration

Tea, Coffee & Networking

09.45-10.00h

Conference Opening

Prof Colin Scott

10.00-10.15h

Session 1

Future Looking: Engaged Research,

10.15h-10.35h

Prof. Jason Last

Key Note

10.35h-11.10h

Dr. Bettina Ryll

Session 2: Seed Funding Awardees

11.10-11.30h

STAND UP – Exploring STANDardised outcome measures Use with Parents

Grainne Hickey, Barnardos,

on behalf of Hannah Stynes, Barnardos, & Prof Eilis Hennessy, University
College Dublin

*What is research? Promoting the role of adults with an intellectual disability
in conducting and participating in research.*

Caroline Howorth , St. Michaels House,

on behalf of Prof Suzanne Guerin, UCD, ACT Service User Consultation

Information Transformers Consultation Group (SMH Dublin), Teresa Gadd (SMH), Sabrina Barrett (SMH), & Sarah Hewitt (SMH)

Establishment of an Irish Acquired Brain Injury Public and Patient Involvement Group (Irish ABI-PPI-G)

Ellen Conlon, ABI Ireland

On behalf of Prof Alistair Nichol UCD, Dr Leanne Hays, UCD, Dr Kate Ainscough, UCD, Dr Lorraine Crawley, ABI Ireland & Dylan Keegan, UCD

Supporting homelessness: Co-development of a Peer-led evaluation of a novel supported accommodation model

Trina Harper, Dundalk Simon Community,

On behalf of As Prof Kate Frazer, UCD, Prof Thilo Kroll, UCD, Katie Carrigan, Dundalk Simon Community, Christopher Duffy, Dundalk Simon Community and the Dundalk Simon Community Peer researchers .

Comfort break

11.30-11.45h

Session 3

Panel Discussion

Patient Advocate Panel- Lessons for Researchers

11.45h-12.25h

Mandy Daly, Mark Byrne, Siobhan Gaffney, Moderated by Emma Dorris

Session 4

Evidencing impact of PPI

12.25-12.40h

Liam Cleere

Future forward: what next for PPI

12.40-12.55h

Prof Thilo Kroll

Close

12.55-1.00h

Dr. Emma Dorris

Lunch & Networking

1.00-2.00h

SPEAKER BIOGRAPHIES

Prof Colin Scott

Colin is the College Principal for the UCD College of Social Sciences and Law. He is also the Vice-President for Equality, Diversity and Inclusion. He is a Professor of Law, focusing on EU regulation & governance. His main research interests lie in questions concerning the limits of regulatory governance, processes of accountability and non-state governance. Substantive fields of interest include media and communications regulation, the regulation of government, non-state governance and consumer law. He was appointed as the Taoiseach's expert nominee to the National Economic and Social Council in 2022.



Prof Jason Last

Jason is the Dean Of Students at University College Dublin. Professor Last has responsibility for the student experience in UCD, and is committed to the continued enhancement of UCD's programmes and educational environment. He is a medical graduate and began teaching in the UCD School of Medicine in 2000. He is a member of the IPPOSI Board and is the current Chairperson of the Campus Engage Steering Committee.



Dr Bettina Ryll

Bettina holds a medical degree from the Free University of Berlin, Germany and a PhD in Biomedical Sciences from University College London, UK. After losing her husband to melanoma, she founded the Melanoma Patient Network Europe and developed a special interest in patient-centric clinical research. Dr. Ryll is involved in numerous initiatives promoting evidence-based advocacy. She focuses on the enormous potential and capacity of patient networks to both educate and support patients as well as to capture data at the primary data source – the patients themselves – and to generate evidence at a granular level non-accessible to outsiders.

Dr. Ryll is a member of the EU Cancer Mission Board and works with Nollvision Cancer, the Swedish Cancer Mission.



Mandy Daly

Mandy is a medical and disability underwriter and a parent of a preterm infant born in 2006. Since that time she has been advocating in the neonatal space and in 2013 she founded the collaborative multi-stakeholder platform, The Irish Neonatal Health Alliance (www.inha.ie). She has extensive experiential and sectoral knowledge and specialises in the areas of Advocacy, Education and Research. Mandy is a chair committee member of group that developed the European Standards of Care For Newborn health, is a public reviewer for the Health Research Board and the British Medical Journal Open Pediatrics, is a member of the National Office of Research Ethics Clinical Trials Committee, the PPI Ignite Network, works with the National Clinical Trials Office Stakeholder Management Committee and the Health Products Regulatory Authority.



Mark Byrne

Mark Byrne is a graduate of the IPPOSI patient education programme. Mark has spent 25 years working in the FMCG Retail sector and now splits his time between working in Management and contributing to PPI projects.

He was diagnosed with Stage 4 metastatic breast Cancer in April 2020. In the past he has been involved with Breakthrough Cancer Research Cork, the 96FM Giving for living Radiothon and The Marie Keating Foundation Men's positive living group and has a keen interest in Survivorship groups. He hopes that his experiences as a patient and advocate can be of benefit to others as they embark on their own journey's as patients and PPI contributors.



Siobhán Gaffney

Siobhán lives a varied, interesting, always fun filled, life globally with T1 Diabetes for over four decades. Since the mid 1970s she has interacted, collaborated and contributed with and to many national and international clinical trials/research studies investigating the physical and mental health effects that living with a chronic lifelong health condition such as T1 Diabetes can have on people. Advocate of peer support networks for people with diabetes and chronic lifelong conditions. Siobhán is an independent voice in the diabetes sphere with no affiliation to any organisation, commercial or otherwise.



Liam Cleere

Liam is the senior manager for Research Impact and Analytics at UCD Research. This team helps to develop research impact and public engagement, promote the research reputation of the university and inform research strategy through the use of advanced analytics and systems.

An engineer by background, Liam has an MBA, and over 16 years of experience in research systems, strategic planning and business intelligence.



Prof Thilo Kroll

Thilo is the site lead for PPI Ignite Network @ UCD. He is also a Professor of Health Systems Management in University College Dublin.

Since 1992 Thilo 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 carried out social and health-related research in various health systems and care environments internationally. His research focuses on individual and system-level change processes related to public, physical and mental health and social participation. Much of his work has been focused on socially marginalised groups, especially people with disabilities and survivors of violence.



Seed Funding Awardees



Image by PIRO4D

This year, the PPI Ignite Network @ UCD launched seed funding under the theme ***Equality of opportunity for public and patient involvement in research.***

The aim was to encourage the development, design or implementation of processes and mechanisms to ensure greater inclusive practices in PPI in health & social care research. Applicants could apply for up to €4,000 for a period of 12 months.

To be valid, applications had to be collaborative between PPI contributors and UCD staff or research students. The goal of this seed funding is to support and foster relationships between UCD academics and PPI contributors that demonstrate

good practice in PPI.

PPI contributors typically include: patients, carers, service users, families of service users, people with lived experience, or relevant patient and community organisations.

We had sixteen valid applications. A panel of assessors, including external and international members was convened to evaluate the applications. The quality of application was exceptionally high.

This year we were able to fund four applications.

STAND UP – Exploring STANDardised outcome measures Use with Parents

Presenting Author: Grainne Hickey

STAND UP is a new project which is currently being established within Barnardos. The main aim of the overarching project is to embed the use of standardised outcome measures (SOMs) with parents attending Family Support services. The mission of Barnardos is to work with families, communities, and partners to transform the lives of vulnerable children who are affected by adverse childhood experiences. In 2021, 14,234 children and parents benefited from Barnardos' supports. However, the collection of high-quality data in relation to the needs and outcomes of service users is central to ensuring that the work of Barnardos is needs-led and evidence-informed.

Involving service users, through PPI activities, in the development and implementation of routine data collection and needs and outcomes measurement in health and social care settings is desirable and worthwhile, but this is not yet widespread practice. Accordingly, the STAND UP project seeks to develop, establish and run a parent/carer service user panel which will serve to provide collaborative input to the process of implementing SOMs into Barnardos Family Support services.

Our next steps are to run a series of workshops in which parent/carer service users will collaborate with Barnardos and UCD researchers in order to develop understandings around three key domains:

1. Identifying parents/carers priorities in relation to outcomes and areas of interest that can inform the selection of SOMs which can be used in Barnardos Family Support services
2. Developing better understanding of structural and pragmatic barriers/facilitators to routine data collection at the service level
3. Exploring acceptability and perceptions of research activities amongst parents/carers

We anticipate this project will help us to better tailor measures to their needs by focussing on outcomes that are valued by families and using measurement tools that are accessible and acceptable. Establishing this PPI group will also serve as a pilot/model for future PPI work within Barnardos relating to other issues.

Barnardos are uniquely placed to recruit and run a PPI initiative with a 'seldom-heard' group, given our existing work and engagement with vulnerable children and families. A large majority (78% in 2021) of families who engage with Barnardos services would place on level 3 and 4 on the Hardiker Level of Need Scale, indicating the presence of complex difficulties including neglect, abuse or mistreatment within the family or at the most severe end of the scale complete family breakdown or involvement with the criminal justice or care systems. We aspire to develop our PPI activities into something that is mutually beneficial, by giving a voice to service users, developing our understandings of their needs, concerns, and priorities and ensuring we have the tools to design a SOMs framework that is fit for use.

We also believe the model we develop through this project will be of significant value to Barnardos and other similar organisations as it will provide the opportunity to effectively pilot a universal design for PPI within a research-performing children's charity. This will provide a template for further, sustainable engagement and participatory work together with service users. It will also enable us to have a foundation to extend PPI to include our younger service users in the future.

Applicants: Hannah Stynes (Barnardos), Grainne Hickey (Barnardos), Eilis Hennessy (University College Dublin)

What is research? Promoting the role of adults with an intellectual disability in conducting and participating in research.

Presenting Author: Caroline Howorth

Adults with an intellectual disability (ID) have an important role to play in setting the research agenda in health and social care settings, and in society. However, they may experience limited opportunities to engage in research and even less opportunity to be a researcher and identify research priorities. St Michael's House (SMH) has a history of supporting individuals with ID to achieve their potential as a member of their community. Some adults in SMH engage in research as part of their lifelong learning and development. However, they may not understand that this is research, or recognise its wider value. For these individuals it is important to expand their experience of research and for others to introduce research as an area they can contribute to.

This project will build capacity and confidence amongst adults with ID to participate in and lead research. It adopts a staged approach by developing and delivering a series of accessible workshops supporting adults with ID to understand what research is, how to set a research goal, how research is conducted, and how they can influence the research agenda more broadly.

Adults within SMH have already had the opportunity to engage in research locally and nationally. These adults will be part of this project, supporting and guiding the planning process, creating accessible workshop content and co-facilitating their delivery, thus enabling peer-to-peer learning and support. They will input as a group of Experts by Experience.

Accessible workshop content will act as a template that can be modified for other groups across the organisation and the sector. SMH has advisory groups led by persons using services and supports. These groups are available as partners in this project and can advise on facilitating engagement with their peers, developing introductory information, and contribute to development of the workshop, template and resources. They have the opportunity to share their knowledge and experience of research during the project.

A broader understanding of research will give participants more confidence to engage in their learning and to share findings with the wider organisation and beyond. This project has been developed as part of a longstanding research and teaching memorandum between SMH and UCD. Developing a formal framework to support the contribution of people with ID to the development of research will add significantly to this partnership.

The project promotes equality by bringing together staff with backgrounds in social care, advocacy, psychology and speech and language therapy and individuals with ID who have experience supporting research as part of the ACT and Information Transformers groups in SMH. The project also has the potential to increase equality beyond the direct impact of the workshops. Some participants may be accompanied to the accessible workshops by staff members. In this way the project can also impact on wider staff knowledge and attitudes about the role of people with ID in research, supporting them to be more involved in research.

Applicants: Caroline Howorth (SMH), Suzanne Guerin (UCD), ACT Service User Consultation Group (SMH); Information Transformers Consultation Group (SMH) with Teresa Gadd, Sabrina Barrett & Sarah Hewitt (SMH Staff Members)

Establishment of an Irish Acquired Brain Injury Public and Patient Involvement Group (Irish ABI-PPI-G)

Presenting Author: Ellen Conlon

Every year in Ireland, 19,000 people will have an acquired brain injury (ABI). ABI is associated with significant mortality and disability. Due to the high personal and societal impact, it is essential that we conduct high-quality research to improve outcomes for these patients and their families. Significant research is already being conducted throughout Ireland. To ensure this research is accessible, important and meaningful to these patients, their families, carers and advocates, their involvement as key stakeholders is required. However, there is no such group in Ireland to provide this PPI input, oversight and advice.

ABI Ireland is the leading not-for-profit organisation in Ireland providing assisted living, support and care services for ABI survivors. The ICC-CTN at UCD is the Irish critical care clinical trials hub with an established acquired brain injury research program. To date, the ICC-CTN have completed some of the largest ABI trials. Both groups wish to conduct high-quality research which is patient-centred and -involved. We realised that no formal PPI group exists in Ireland representing ABI survivors, families and carers. This patient cohort are seldom heard due to their care needs and accessibility issues. In collaboration, ABI Ireland and the ICC-CTN will establish this Irish ABI-PPI group. The project will use inclusive and equality approaches throughout to ensure this patient cohort is well represented. The major aim of this seed funding is to establish the Irish ABI-PPI group.

There are five key deliverables in this start up phase. ABI Ireland and the ICC-CTN, UCD will work closely to deliver this project. Both groups have extensive experience working with patients and public representatives. The team is multidisciplinary: ABI Ireland have extensive experience with this patient cohort and their needs, the ICC-CTN have expertise in establishing and developing PPI relationships for research.

Following this initial seed funding ABI Ireland and ICC-CTN would maintain the group (quarterly meetings, regular communication) and develop tools for increased accessibility, particularly for patients with communication difficulties. It will be an invaluable addition to the Irish research landscape for ABI Ireland, ICC-CTN and all researchers. It will ensure these hard to reach patients' voices are heard and establish a formal process for this in Ireland.

Applicants: Alistair Nichol (UCD), Leanne Hays (UCD), Ellen Conlon (ABI Ireland), Kate Ainscough (UCD), Lorraine Crawley (ABI Ireland) and Dylan Keegan (UCD)

Supporting homelessness: Co-development of a Peer-led evaluation of a novel supported accommodation model

Presenting Author: Trina Harpur

This project aims to co-develop a peer-led evaluation of a novel supported accommodation model introduced by Dundalk Simon Community for clients. In 2021 an alternative model of accommodation was piloted. The model differed from usual accommodation offerings as this was a four-bedded home for four people, keyworker support was during daytime only, clients engaged in activities for development including training, employment, personal development, community work schemes, and volunteering in the community and it helped to build confidence in returning to independent living.

This project aims to co-develop a peer-led evaluation to understand the experiences of previous residents, and all involved in the development of the alternative model, to inform the development of a supported housing programme. The research will be conducted by individuals with a lived experiences of homelessness in partnership with Dundalk Simon and University College Dublin (UCD) and provides an opportunity learn from a marginalised and seldom heard group.

The planning of this research is embedded in the ethos of the patient and public involvement (PPI) and co-design. Clients (previous residents from a low support house) are members of the planning group. They provided a roadmap for this research idea sharing personal and wider societal impact of living in a 'home' environment. They noted transformative experiences in comparison with previous experiences (such as living in hostels) as the only option with managing the chaos, stressful sleeping facilities and lack of opportunities for independent living including to plan and learn to cook for oneself and others.

This project will use engaged participatory discovery research methods. A project working group made up of applicants and peer researchers from Dundalk Simon will co-develop the project.

This research project is led by Dundalk Simon. This is an opportunity for engaged research with a community that has not previously been involved in PPI research and represents seldom heard voices, specifically from younger aged clients who are homeless and living in rural areas (Dundalk and Drogheda). Usually, the perspective and voices heard in relation to housing and homelessness are Dublin centric.

The research will be co-developed and peer-led with individuals with lived experience of homelessness, mainly experiencing services of Dundalk Simon Community. Having lived in larger homeless hostel environment (the usual), they will have a unique perspective to bring when designing the study. The intention is that peer researchers will develop the questions that will lead structured interviews based on their own observations and experiences and co-facilitate a workshop to present data from the study to provide recommendations that will have considerably more influence on service development, due to the strength that lies in their voice and experiences. This process is supported by Dundalk Simon and UCD co-applicants.

Applicants: Trina Harpur (Dundalk Simon Community), Kate Frazer (UCD), Thilo Kroll (UCD), Katie Carrigan (Dundalk Simon Community), Christopher Duffy (Dundalk Simon Community), and Peer researchers .

About PPI Ignite Network @ UCD



University College Dublin
Ireland's Global University

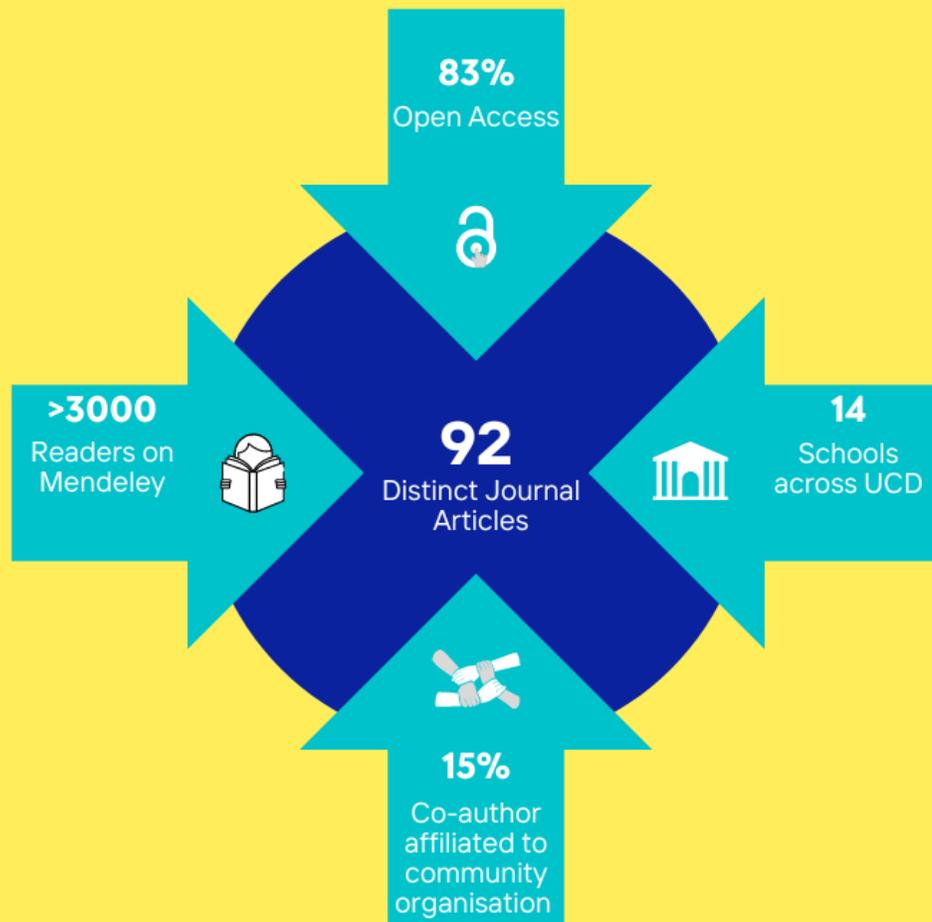


The PPI Ignite Network @ UCD is part of the National PPI Ignite Network. Based in the UCD Research office, the PPI Ignite Network @ UCD is led by Prof. Thilo Kroll, with operations led by the Programme Manager, Dr Emma Dorris. Our aim is to embed PPI in health and social-care related research and to empower community partners to develop their own research capabilities and capacities.

We are guided in our work by our Local Partners. We have nine local partners. Dr Éidín Ní Shé, the Ireland East Hospital Group, the Transgender Equality Network of Ireland (TENI), the Disability Federation of Ireland, the PKU Association of Ireland, SAGE Advocacy, Family Carers Ireland, Dublin Simon Community and Spinal Injuries Ireland.

We work closely with the other six lead sites of the PPI Ignite Network and the ten national partners [Health research Charities Ireland (HRCI), Irish Platform for Patient Organisations, Science & Industry (IPPOSI), TUSLA the child and family agency, the Health Service Executive Research & Development, Campus Engage (part of the Irish Universities Association), SPHeRE (Ireland's national research training programme for population health and health services research), HRB-Trials Methodology Research Network (HRB-TMRN), Maynooth University, Queen's University Belfast and the International Collaboration for Participatory Health Research (ICPHR)].

Building on Phase 1



The Health Research Board and Irish Research Council Awarded UCD under Prof Thilo Kroll funding in 2017 in the first phase of supports for public and patient involvement in UCD. This three year funding was focused in three key areas: (1) Research, (2) Capacity and Capability and (3) Knowledge Mobilisation and Network Formation. The learning and progress from this first phase led to the participation of UCD as a Lead Site in National PPI Ignite from 2021.

To understand our foundations, we have analysed some key metrics in public and patient involvement in UCD between 2017 and July 2022.

1. Publications

As the figure shows above, UCD produced 92 distinct peer reviewed journal articles in this period. This only includes publications with keywords related to PPI in their title or abstract, so the actual figure may be even more. These publications had authors from across fourteen different schools within UCD, demonstrating that the inclusion of public involvement is not siloed to any one individual school.

83% of the publications were open access, a figure higher than that of the average publications across UCD (and Ireland) more generally during the same time period.

Of the 92 publications, 15% has co-authors that were identifiably from a patient or community organisation.

2. Funding



Since 2017, UCD has received more than €975,000 in funding specific to public and patient involvement. This figure does not include PPI that was incorporated as part of a wider research project, rather it relates to funding for PPI-specific activities and research.

Of note is that the funding was awarded from nine different funding bodies. Given the Health Research Board's (HRB) long standing commitment to PPI, it is perhaps not surprising that they awarded the most amount of funding. However, what may surprise people is the research funding awarded by UCD for PPI-related activities. UCD has contributed more than a quarter of a million euro to support PPI in research during this time period. The Irish Cancer Society is the other funder that has awarded more than €100,000 in PPI-specific funding during that time period.

3. People

Of particular note is the breadth of researchers within UCD that have been active with PPI.

- ⇒ One hundred distinct researchers affiliated to UCD were authors on PPI literature published within that timeframe.
- ⇒ A survey of lecturers in the UCD College of Health and Agricultural Sciences and the UCD College of Social Science and Law in 2019 identified twenty nine modules within those Colleges where the public and/or patient groups were involved in some form in the design and delivery of the module.

It is clear that there is an appetite for PPI within UCD. Our goal in this new phase of PPI Ignite Network @ UCD (2021-2026) is to harness, share and advance the expertise that exists within our UCD community, and develop the structures and supports to foster it.

Key Milestones since 2021

The PPI Ignite Network @ UCD officially started in march of 2021. A programme manager was in place by September 2021, and we officially launched on 03 Dec 2021– you can watch that event on our YouTube Channel [PPI Ignite Network @ UCD]. Some of our key milestones from the last year are highlighted in this section.

UCD PPI Informal Shared Learning Group

The UCD PPI Informal Shared Learning Group (SLG) was an initiative originally set up by Dr. Éidín Ní Shé during Ignite phase 1 but had been paused since 2020. The SLG was restarted in Nov 2021. It is aimed at informally sharing our knowledge and experiences of PPI within UCD so that we can all improve our research involvement practices. This shared learning network is open to all UCD researchers & research students and community/patient partners. People with all levels of PPI experience are welcome, including those yet to start with PPI. The SLG meets monthly. It is reflexive to the needs of the group. The members choose the topic for each monthly meeting. It is designed to be a “safe space” where people can speak honestly, openly and respectfully. Thus, the meetings are not recorded, and attendees are asked not to share identifiable details of what was discussed on public platforms such as social media.

Engage your research: An introductory guide to engaging & involving the public in research

December 2021 saw the release of the Engaged Research guide onto the UCD Research portal. This guide was prepared by Dr. Emma Dorris, Liam Cleere and Prof. Thilo Kroll. It is a central UCD resource to introduce UCD staff and students to the concept of engagement and involvement in research. It is aimed more broadly than health and social care research. It covers Why to Engage, How to Engagement, and gives examples of how to collaborate with public stakeholders throughout the research cycle.

The guide can be found here: <https://www.ucd.ie/research/portal/t4media/Engage%20Your%20Research%20Final%20Dec%202021.pdf>

Seed Funding 2022

The Call for Seed Funding applications was launched in April 2022. There were sixteen applications to the seed funding for PPI in research scheme which closed on 30th May 2022. The theme was “Equality of opportunity for public and patient involvement in research”. Each application was a collaboration between a UCD researcher(s) and PPI contributor(s). There were four applications awarded funding in this round. The total amount awarded across the four projects was €15,797.44.

Ignite Involvement Podcast

We launched our PPI Ignite Network @ UCD podcast during the summer under the name *Ignite Involvement*. Series one has five episodes. Each episode is approximately 20 minutes long and features an interview with someone with experience of PPI and a connection to UCD. The goal is to promote learning of PPI through the sharing of peers’ experiences.

The podcast is available on Spotify, Amazon Music, Anchor and Google Podcasts.

Website Launch

This September saw the launch of the new PPI Ignite Network @ UCD web presence: www.ucd.ie/ppi. Designed to be a useful resource for PPI across the lifecycle, the website represents a significant improvement in our visibility. The website aims to provide enough practical information to be useful, but not have too much information so as to be overwhelming.

With the launch of the website, we are piloting a bespoke training facility. UCD Colleges, Schools and Research Institutes, in addition to Community and Patient Organisations can request PPI training specific to their needs. We also have a central News and Events section. This is aimed to help the wider community keep up to date with our work. In addition to PPI resources, we have a section focusing specifically on evaluation of PPI and its impact. We also have a case study section so people can see what has been achieved by a variety of researchers across UCD.

Working as part of the National Network

Work Package 3

We co-lead work package 3 for the PPI Ignite Network with our colleagues in PPI Ignite Network @ RCSI. Work Package 3 focuses on *Embedding PPI locally and Nationally*. The rationale of WP3 is to review institutional policies and procedures, to determine the extent to which PPI has been embedded across the national arena. A key deliverable of WP3 is to prepare and produce a report on the landscape of PPI in Higher Education Institutions across Ireland. We developed a toll to conduct this work in Higher Education Institutions. We received and analysed data from all seven lead sites and one national partner. This was a significant amount of data, which underwent analysis focused on identifying key strengths and areas for improvement in the embedding of PPI into institutional policies and procedures. In September, we presented the key findings of the analysis to the wider working group of the National Network. The report on the institutional PPI landscape is currently being prepared, with release expected Q4 2022.

Work Package 1

Work package 1, *Building national PPI capacity across communities* is led by the HRCI, University of Galway and DCU. This group identified PPI in lab-based research as a specific target for capacity building. Emma Dorris (PPI Ignite Network @ UCD) is a member of this subgroup and Chairs the key task to develop training in this area. The key task working team are developing two open education resources: a 5 credit graduate module on PPI in lab-based research, and a companion module for PPI partners about lab-based research. The core concept is the interweaving of the two modules, with shared elements and a collaborative workshops between the research students and PPI contributor students. This is at an advanced stage of development.

Work Package 5

Work Package 5 is led by the National Office. It focuses on ensuring that the National PPI Network presents a unified voice for PPI in Ireland, creating and facilitating opportunities for collaborative working within Ireland and internationally. They coordinated the launch of the national PPI Ignite website: www.ppinetwork.ie. The website contains centralised resources, local site contacts and an events calendar. UCD submitted a Case Study for the National Website highlighting a project with the Dublin Simon Community. We also made a number of items available as resources.



PPI IGNITE
NETWORK

Website: www.ucd.ie/ppi

Contact: ppi@ucd.ie

PPI Ignite Network @ UCD is funded by UCD, the Health Research Board and the Irish Research Council

