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PPI in Health Sciences Research

The context and progress of PPI Public and Patient Involvement (PPI) in Trinity

Prof Mary McCarron

Lead, Trinity PPI Ignite Office

Chair, Ageing and Intellectual Disability

Director, Trinity Centre for Ageing and Intellectual Disability

Principal Investigator, IDS-TILDA

Executive Director, National Intellectual Disability Memory Service

8 March 2022



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PPI and its Relevance for Researches and Clinicians

Public and Patient Involvement

Where it is appearing



- In National Policy

Public and Patient Involvement

Where it is appearing



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- In National Policy
- In Health Research Strategy

Public and Patient Involvement

Where it is appearing



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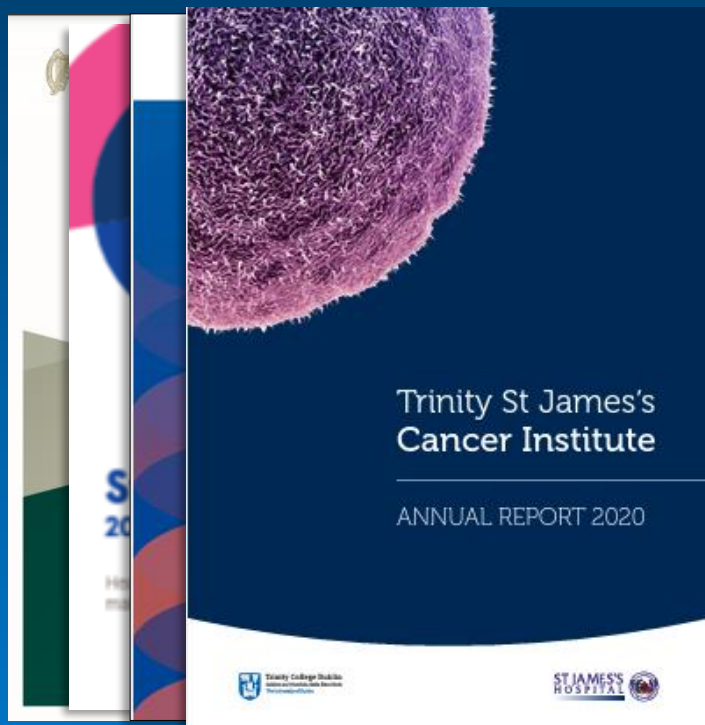
- In National Policy
- In Health Research Strategy
- In European Funding Strategy

Public and Patient Involvement

Where it is appearing



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- In National Policy
- In Health Research Strategy
- In European Funding Strategy
- In Requirements for Designation

Public and Patient Involvement

Where it is appearing



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- In National Policy
- In Health Research Strategy
- In European Funding Strategy
- In Requirements for Designation
- In Consent Declaration Requirements

Public and Patient Involvement

Where it is appearing



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- In National Policy
- In Health Research Strategy
- In European Funding Strategy
- In requirements for designation
- In Consent Declaration requirements
- In Health Charity Partnerships



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Embedding PPI within Trinity

Embedding PPI at a Strategic Level

Laying the groundwork



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Embedding PPI at a Strategic Level

Metrics for consideration in promotion



1. Publications:

Co-authoring international peer-reviewed journal	1 POINT
Co-authoring national peer-reviewed journal	0.5 POINTS
Co-authoring a book chapter	0.5 POINTS
Co-authoring an international report of international significance	1 POINT
Co-authoring a national report in the national significance	0.5 POINTS
Co-authoring a book	5 POINTS
Evidence of Public Patient Engagement (PPI); For example, co-authored by public research stakeholders, including patients, members of the public, public or professional service providers, policy makers, civil and civic society organisations and other external partners.	0.3 POINTS

Embedding PPI at a Strategic Level

Metrics for consideration in promotion



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Research Support System

Portal Home Portal Help L
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Main	Themes	UN SDGs	ENGAGEMENT	Impact	Keywords	Tags	Institutes	Sponsors
Identifiers	Languages	Sources	Related IDs	Accessibility	Share	TARA	Publications	CV

Apply Close Cancel

[Click here to access the Engagement section of MyRSS](#)

Indicate how "Minding the gap: identifying values to enable public and patient involvement at the pre-commencement stage of research projects." aligns with the engagement framework

Engaged

With the Community

For the Community

Involves TCD Students

Description: This brought researchers and PPI contributors together to work on values



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PPI in my Research

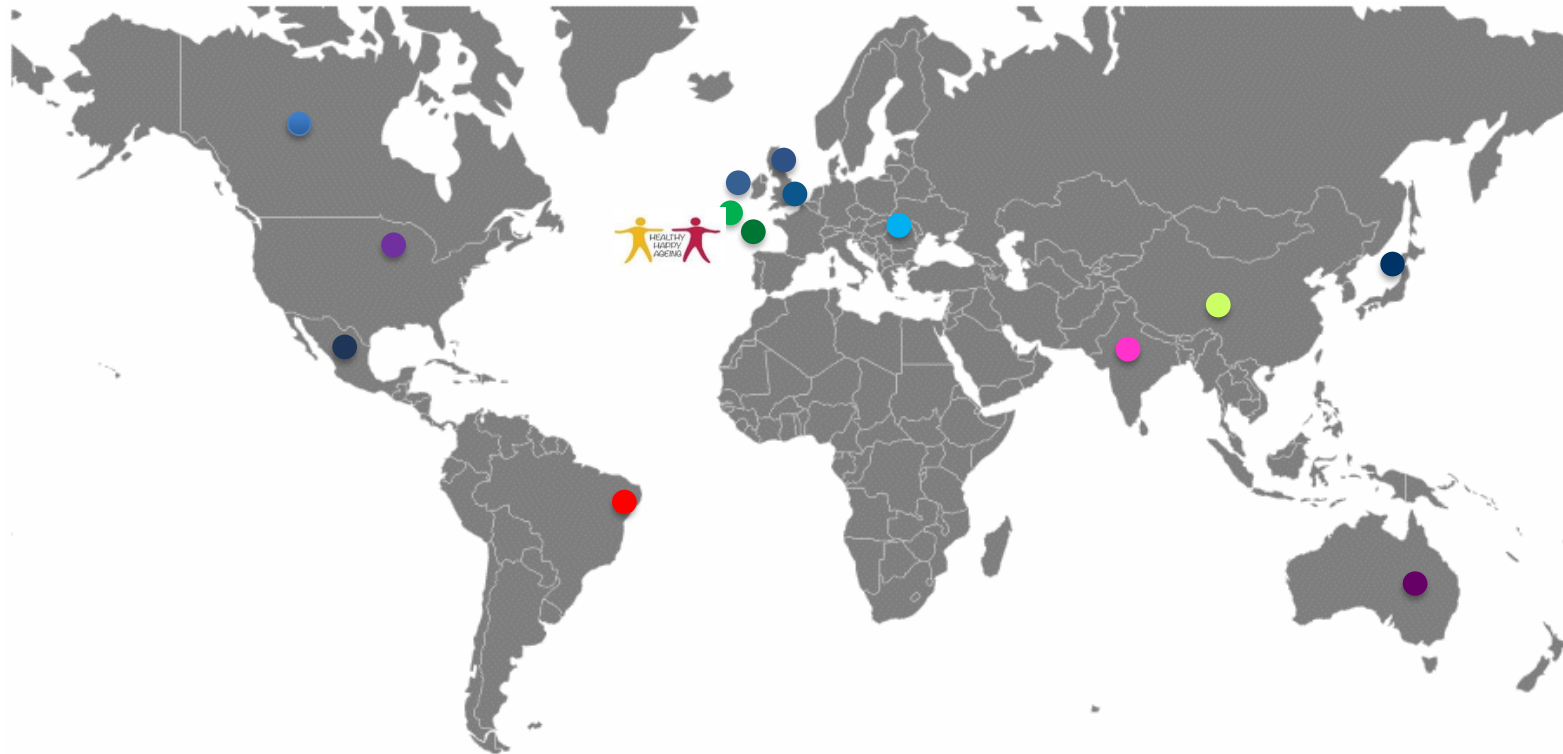


Public and Patient Involvement

Why do I do it? – IDS-TILDA



The Intellectual Disability Supplement to
The Irish Longitudinal Study on Ageing
(IDS-TILDA)



Public and Patient Involvement

Why do I do it? – IDS-TILDA



The Intellectual Disability Supplement to
The Irish Longitudinal Study on Ageing
(IDS-TILDA)

National Photographic Exhibition Tour

“Celebrating Ageing in Persons with Intellectual Disability” proves to be a huge hit

The first national photographic exhibition “Celebrating Aging in Persons with Intellectual Disability”, was displayed first at the launch of the IDS-TILDA in 2008. Since then, the photo exhibition has travelled to various services, galleries, festivals and different key events throughout the country. It’s currently on nationwide tour. If there is an event coming up where you would like us to display this exhibition, please contact the ISA-TILDA office.

GALWAY





The Intellectual Disability Supplement to
The Irish Longitudinal Study on Ageing
(IDS-TILDA)

Public and Patient Involvement

Why do I do it? – IDS-TILDA

First nationally-representative longitudinal study on ageing with an intellectual disability comparable to the general population



Public and Patient Involvement

Why do I do it? – IDS-TILDA



The Intellectual Disability Supplement to
The Irish Longitudinal Study on Ageing
(IDS-TILDA)

Public and Patient Involvement

Why do I do it? – IDS-TILDA



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People with intellectual disability input across the research cycle in ways that are appropriate to their skills, their interests and their effectiveness



The Intellectual Disability Supplement to
The Irish Longitudinal Study on Ageing
(IDS-TILDA)



**Co-designing
protocols**



**Steering
Committee
members**



**Training
fieldworkers**



**Disseminating
results**



**Translating
Findings**

Public and Patient Involvement

Why do I do it? – IDS-TILDA



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Contents lists available at [ScienceDirect](#)

Research in Developmental Disabilities

journal homepage: www.elsevier.com/locate/redevdis



Recruitment and retention in longitudinal studies of people with intellectual disability: A case study of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA)



Mary McCarron^a, Darren McCausland^{a,*}, Eimear McGlinchey^b, Sarah Bowman^a, Michael Foley^a, Margaret Haigh^a, Eilish Burke^b, Philip McCallion^c

^a Centre for Ageing and Intellectual Disability, 1.25 Chemistry Extension, Lincoln Gate, Trinity College, Dublin 2, Ireland

Public and Patient Involvement

Why do I do it? – IDS-TILDA



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“When the 172 deaths are excluded, the 506 original participants remaining at Wave 4 **represents 87.1 %** (506/581) of those who were still alive at this point. A sample refreshment exercise recruited an additional 233 new participants at Wave 4, bringing the overall sample back up to 739”

^a Centre for Ageing and Intellectual Disability, 1.25 Chemistry Extension, Lincoln Gate, Trinity College, Dublin 2, Ireland

Public and Patient Involvement

Why do I do it? – IDS-TILDA



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“You have given me a platform and a voice to advocate for people like me.”

Mei Lin Yap,
Ambassador Liaison
Officer



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Engaged Research for Societal Impact

Dementia and Intellectual Disability

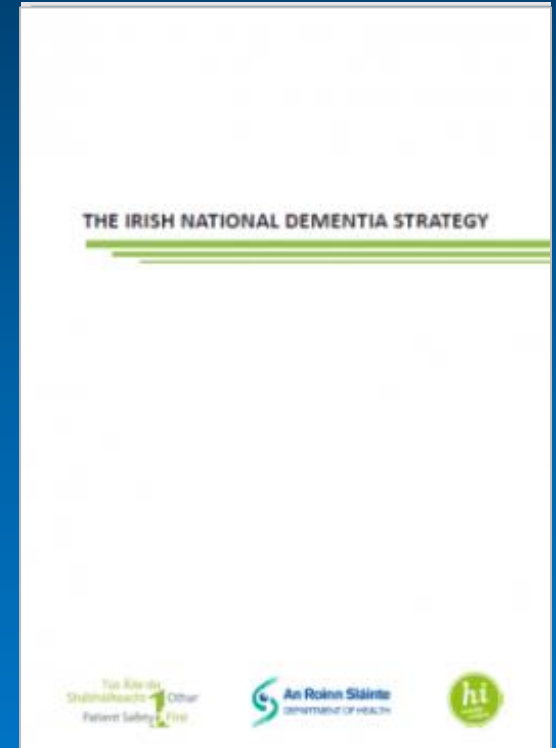
Ensuring Visibility



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Writing it into the National Dementia Strategy:

“promote timely diagnosis of people experiencing early onset dementia, including people with Down Syndrome”



Dementia and Intellectual Disability

Building Partnerships



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Working with the Federation of Voluntary Bodies' 60 member services, initially exploring service responses to dementia

Dementia and Intellectual Disability

Building Momentum



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Convening clinicians,
international
academics and
researchers,
PPI contributors and
public sector
representatives.



Dementia and Intellectual Disability

Securing Support



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Securing funding from the Dormant Accounts Fund for the establishment of a pilot National Intellectual Disability Memory Service



Dementia and Intellectual Disability

Solidifying partnerships



Signing a
Memorandum of
Understanding
between Tallaght
University Hospital,
Trinity & the
Daughters of
Charity

Dementia and Intellectual Disability

Sustainable Funding and Scalability

The National Intellectual Disability Memory Service aims to provide access for every individual with an intellectual disability in Ireland to a Brain Health Clinic and to specialist assessment and comprehensive diagnostic work-up for memory concerns.



National
Intellectual Disability
Memory Service



Dementia and Intellectual Disability

Establishing Quality



National Intellectual Disability
Memory Service

**Help us to Build a Good
Memory Service:
Have Your Say!**



It is important to me that the Clinic
is easy to get to.

It is important to me that the Clinic
is easy to move around in.



It is important that I can say if my visit to the
Clinic was good or bad

It is important that my carers and doctor get
a report about my health so they can support
me



Developing Key
Performance
Indicators with
people with an
intellectual
disability

Dementia and Intellectual Disability

Sustaining Interest



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PPI remains an integral component of NIDMS strategy.

Brain Buzzers is a club about Brain Health which will also act as a PPI panel to provide advice and perspectives from the intellectual disability community about the ongoing development of the NIDMS

The Trinity Center for Aging and Intellectual Disability and the Global Brain Health Institute present...

Brain Buzzers

Your brain is amazing!

We've started the Brain Buzzers Club in order to learn more about how to keep your brain healthy and we would love for you to join us.

We will call you to talk about brain stuff like getting the right food, sleeping well, good mental health and taking exercise.

We want to hear your opinion about the research we're doing. We will ask your advice to help make our research better.

We will also play a few brain games too.

Brain Buzzers is run with support from Down Syndrome Ireland, Alzheimer's Society of Ireland and Trinity Equality Fund.

To find out more about Brain Buzzers, email Eimear on mcgline@tcd.ie

The flyer is a vertical rectangular graphic with a blue background. It features a central illustration of a woman with dark hair, wearing a yellow jacket over a red top, pointing upwards. The text is arranged in a clear, readable layout. The top of the flyer includes the names of the presenting organizations. The main title "Brain Buzzers" is in a large, bold, yellow font. Below the title is a white speech bubble containing the main message. The bottom of the flyer has a yellow banner with contact information. There are decorative elements like white clouds and a yellow sun on the right side.



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PPI Ignite Phase I in Trinity 2017 - 2021

PPI Ignite Phase I

Awards in the first phase of PPI Ignite



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Phase I Achievements

- 22 Training Workshops
- 37 Network Events
- 66 Funding Proposals Submitted
- 37 Funded Proposals
- 131 Clinics
- 12 Publications
- 17 Awards

PPI Ignite Phase I

Trinity partners in the first phase of PPI Ignite



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Partner Council Projects: Funding and In-Kind Support

<ul style="list-style-type: none"> • Changing Gears for Chronic Illnesses • Is Ageism Ever Acceptable? • Mad, Bad and Dangerous: A Celebration of 'Difficult' Women 	Age & Opportunity
<ul style="list-style-type: none"> • Hearing Voices: In recovery from addiction and mental health in the community 	Recovery Academy Ireland
<ul style="list-style-type: none"> • Patient Education Programme: Phase I • Citizen Jury on Electronic Health Records 	IPPOSI
<ul style="list-style-type: none"> • PPI In Health Research Support • Introduction to Research: Dementia Research Advisory Team • Research Prioritisation Event • PPI Webinar with ASI DRAT 	Alzheimer Society of Ireland
<ul style="list-style-type: none"> • Public Engagement and Involvement Specialist • Working with the Research Community: Developing a PPI Induction Toolkit • Launch of Making a Start PPI Induction Toolkit 	Health Research Charities Ireland
<ul style="list-style-type: none"> • World Sight Day PPI in Vision Research Workshop • Retina 20 - Challenges for PPI Panel Discussion 	Fighting Blindness
<ul style="list-style-type: none"> • Musgraves Social Responsibility Citizen Science Event • Access Philly Mapping Event (Philadelphia) • Access Earth and Trinity Graduate Students Union Mapping Event 	Access Earth
<ul style="list-style-type: none"> • TUSLA Research Ethics Community - Guidance for including PPI contributors 	TUSLA
<ul style="list-style-type: none"> • The Value of Engagement: Exploring the benefits of public engagement 	Connect the Dots



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PPI Ignite Phase II

2021 - 2026



Phase II - National PPI Ignite Network

Launching the Network



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Phase II - National PPI Ignite Network

National Network Partners



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National PPI Ignite Network

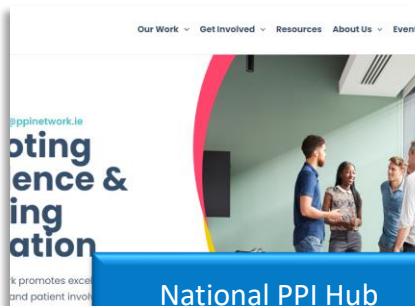
Benefits of a national network



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National PPI Festival



National PPI Hub



Community Outreach
Events



Publicising Partner Events



Developing National
Positions



Promoting Ireland's PPI
Internationally

National PPI Ignite Network

Tasks of a national network



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How to improve the quality of PPI in Ireland

How to build a culture of impact assessment in PPI

How to embed PPI into Undergraduate and Postgraduate activity

How to build community capacity to engage in PPI

How to further embed PPI in university structures

PPI Ignite Phase II

Trinity Partner Council



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- TILDA
- GBHI
- IDS-TILDA / TCAID
- Prof Louise Gallagher, School of Medicine
- Prof Deirdre Daly, MAMMI Study
- Dr Fintan Sheerin / Dr Imelda Coyne, School of Nursing & Midwifery
- Dr Catherine Darker, Trinity Institute of Public Health
- Prof Linda Hogan, Professor of Ecumenics – Faculty of AHSS



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Reflections and Considerations

Embedding PPI at a Strategic Level

Further challenges



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- Enhancing metrics to reward in
- Embedding PPI and engaged r
- Improving budget and financ
- Integrating PPI skills into cur
- Creating accessible spaces fo
- Ensuring institutional recognit
- Engaging PPI activity with ethica
- Developing communications plans re

In strategy, Trinity has begun this culture change – we must now ensure that junior academics are recognised, facilitated and rewarded for embracing PPI

Embedding PPI at a Strategic Level

Further challenges



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- Enhancing metrics to reward in-depth PPI
- Embedding PPI and engaged research in HR practices
- Improving budget and financial processes
- Integrating PPI skills into curricula and training
- Creating accessible spaces for PPI work
- Ensuring institutional recognition of PPI contributors
- Engaging PPI activity with ethical review
- Developing communications plans for PPI activity



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Thank You

Prof Mary McCarron

Lead, Trinity PPI Ignite Office

Chair of Ageing and Intellectual Disability

Director, Trinity Centre for Ageing and Intellectual Disability

Principal Investigator, IDS-TILDA

Executive Director, National Intellectual Disability Memory Service

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