



**Trinity College Dublin**  
Coláiste na Tríonóide, Baile Átha Cliath  
The University of Dublin

# **Celebrating Trinity PPI Ignite**

## **Achievements of Phase I and Ambitions for Phase II**



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@PPI\_Ignite\_TCD



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# Achievements of Phase I



# Success of PPI Phase I – Our Metrics

## 1. Training Workshops

- 2017-2020: PPI Ignite Programme Target: 6
- **2017-2021: Actual Delivery: 22**

## 2. Networking Events

- 2017-2020 PPI Ignite Programme Target: 6
- **2017-2021 Actual Delivery: 37**

## 3. Proposal Development Assistance

- 2017-2020 PPI Ignite Programme Target: 15
- **2017-2019 Actual Delivery: 66 Submitted and 37 Funded**

## 5. Face-to-Face PPI Clinics

- 2017-2020 Target: 120
- **2017-2021: 131 Delivered**

## 5. Publications:

**12**

## 6. Awards:

**17**



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IRISH RESEARCH COUNCIL  
An Chomhairle um Thaighde in Éirinn

# Success of PPI Phase I – Our Metrics

## **PPI Networking:**

37 Events

3,426 Researchers & Support Staff Engaged

## **Training Workshops:**

783 Researchers and Support Staff Trained

Evaluated: 4.5/5

## **Face to Face Clinics:**

131 Delivered & 56 Projects

4 PPI project (2021)

12 PPI project(2020)

26 PPI projects (2019)

14 PPI projects (2018)

## **Proposal Development:**

66 Submitted & 37 Funded

€262,522 (2018)

€3,130,244 (2019)

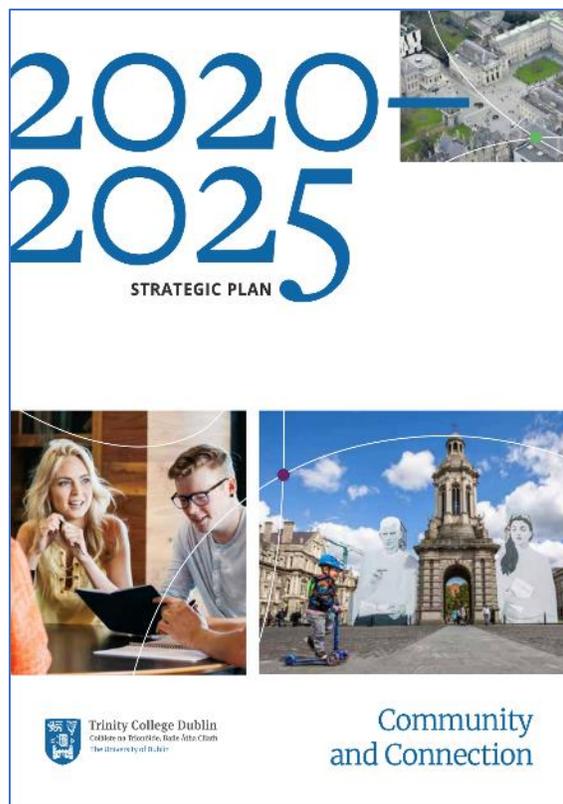
€3,993,695 (2020)



## **Awards: 17**

European Research Council  
Health Service Executive  
Health Research Board  
Irish Cancer Society  
University of Edinburgh

# Embedding PPI at a Strategic Level



2020-2025  
STRATEGIC PLAN

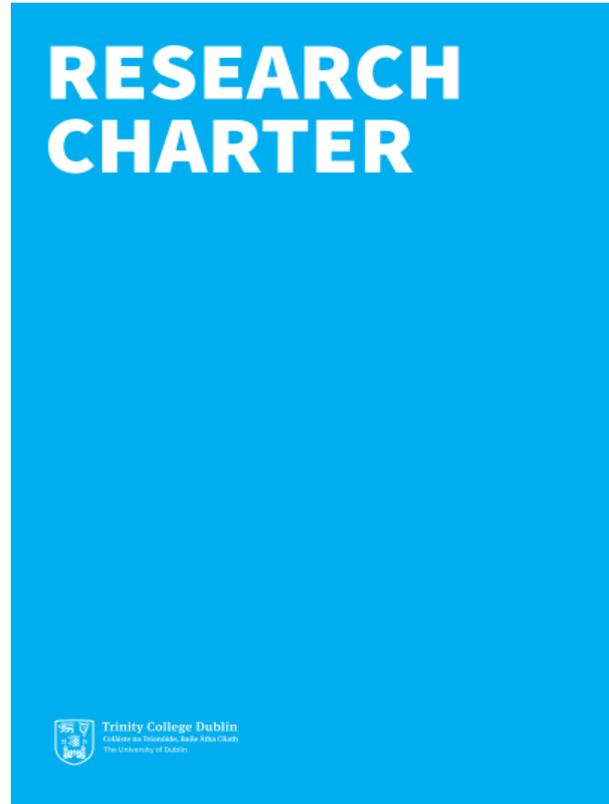
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Community and Connection



We will stand up for research, its quality and impact. >

04



RESEARCH CHARTER

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A LIVING RESEARCH EXCELLENCE STRATEGY

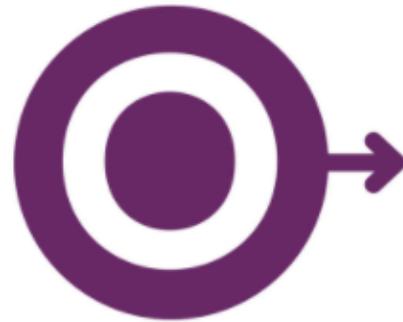
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# Trinity's Strategic Plan



## Civic action >

Through our teaching, research and public engagement, we courageously advance the cause of a pluralistic, just and sustainable society.



## Organisation >

We foster an effective and flexible organisation, which values all members of our community.



## Research >

Pursued at the frontiers and intersections of disciplines, our research benefits our students, Ireland, and the world.



## Education >

We challenge our students to think independently, communicate effectively, act responsibly, and develop continuously, equipping them for lives of active citizenship.

# Trinity's Research Excellence Strategy

*6.3 Understand how new forms of engaged research and research co-creation can drive discovery*

**PPI activity has also been embedded in the metrics for consideration in promotion in the Faculty of Health Science.**

**01. STIMULATE AND BUILD STRATEGIC RESEARCH COLLABORATIONS**



In deciding our path, we need to make the best use of the research expertise and research

**02. MAKE IT EASIER TO DO RESEARCH**



We need to use the resources we have in more effective ways, and find innovative solutions to the various challenges we face.

**03. GENERATE THE RESEARCH FUNDING AND RESOURCES WE NEED**



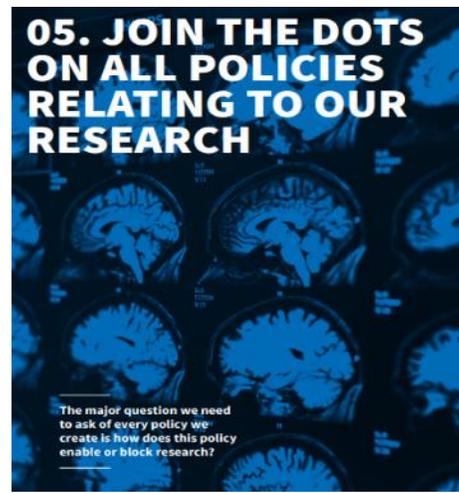
We need to unlock existing resources within Trinity and refocus them on research activities which are important for driving the research agenda forward.

**06. BE BOLD IN PLANNING OUR LONG-TERM RESEARCH FUTURE**



Trinity is 427 years old. It has stood the test of time. However, we need to be able to step back and ask whether we can and should do things differently.

**05. JOIN THE DOTS ON ALL POLICIES RELATING TO OUR RESEARCH**



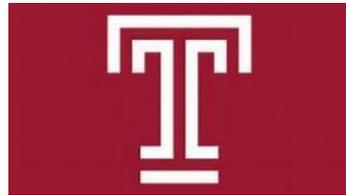
The major question we need to ask of every policy we create is how does this policy enable or block research?

**04. RADICALLY REVISE HOW WE DO RESEARCH COMMUNICATIONS**



How effectively we communicate the research we do to the outside world has a profound effect on our standing, our influence, our rankings, and our ability to attract funding.

# Success of PPI Phase I – Our Partners



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

# Impact Stories from PPI Ignite Phase I



Living with COVID-19



GET WISE ABOUT YOUR HEALTH  
ONLINE TOOL



People with an intellectual disability co-created evidence based interventions in sport, in mental health, in health promotion.

And they are also playing an active part in the development of the National ID Memory Service

# Impact Stories from PPI Ignite Phase I



**TUSLA developed new guidance  
on the ethical implications of  
PPI contributions in Research  
Ethics Committees**

**February 2020**

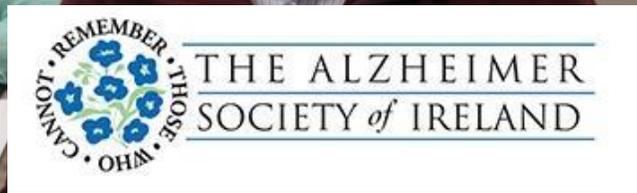
(with PPI Ignite  
NUI Galway)

# Impact Stories from PPI Ignite Phase I



**ASI now has a panel of PPI  
Contributors living with  
dementia or supporting those  
who do**

**April 2019**



**THE ALZHEIMER  
SOCIETY of IRELAND**

# Impact Stories from PPI Ignite Phase I



**Public and Patient Involvement in Vision Research - A Multi-Stakeholder Workshop**  
 Dr Karen Lester, Dr Laura Brady, Sarah Bowman, Michael Foley, Prof Mary McCarron

**FIGHTING BLINDNESS**  
 PPI IGNITE  
 HRB

Fighting Blindness, Dublin, Ireland

**Background:**  
 Public and patient involvement (PPI) serves to create a working relationship between those living with and affected by sight loss and those undertaking research to enhance understanding, and to develop therapies. It is research carried out 'with' patients so that their perspective play a key role in informing and shaping the R&D pathway. This approach can lead to improved quality in the research process and higher impact for the results of such research.

**Goals:**

- To empower the sight loss community and help them to recognise their role as important stakeholders in guiding research and healthcare
- To identify starting points for vision researchers and clinicians wishing to incorporate PPI in to their work
- To identify common ground between researchers and the sight loss community as they work together to identify the WHAT, HOW, WHY of PPI

**Process:**

**CANVAS**

- Survey sight-loss clinicians and researchers to identify appetite for, and barriers to, PPI
- Survey sight-loss community to gather perspectives on PPI

**BUILD**

- Design workshop, informed by patient-informed steering group
- Recruit external facilitators

**LAUNCH**

- Hold a multi-stakeholder event: clinicians, researchers, people with sight-loss, family members
- Run interactive sessions where participants learn about the WHAT, HOW and WHY of PPI

**Workshop Activity Sample:**

**ASK A QUESTION**

**SORTING THE RESEARCH CYCLE**

Participants were invited to sort how they thought the research cycle runs

**Workshop Outcomes:**

**Pre-Workshop Researcher Survey**

80% of respondents were from a basic or translational science background

**Engagement:**

80% engagement

**Involvement:**

33% involvement

**Post-Workshop Survey**

100% better informed

**Understanding the Research Cycle**

Understanding the research cycle and where PPI fits proved most beneficial for all attendees

**Feedback:**

"I felt that it was a really well run event and I would be happy to change it / gain a better understanding of the difference between engagement, involvement and participation and how people can be involved at all stages of research."

"I felt really motivated / following the results. I am confident that our group can now incorporate more PPI into our research."

**New partnerships were formed**

... inspiring Retina International to repeat the model

**October 2019**



# Impact Stories from PPI Ignite Phase I



**A toolkit was codesigned to support research charities and their new PPI contributors, with Health Research Charities Ireland and Bec Hanley**

**June 2020**



# Impact Stories from PPI Ignite Phase I



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## Women's Health After Motherhood

Massive Open Online Course  
Launching October 21<sup>st</sup> 2019

**Register today**



<https://www.futurelearn.com/courses/womens-health-after-motherhood>



**The Women's Health After Motherhood (WHAM) co-designed online course wins a Health Service Excellence Award**

**July 2020**

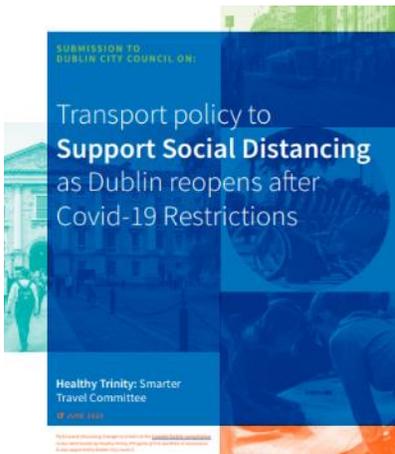
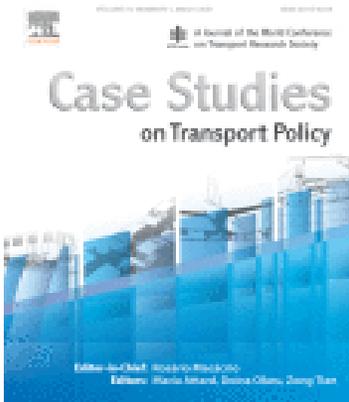


# Impact Stories from PPI Ignite Phase I



The public landscape has changed in partnership with Healthy Trinity and Dublin City Council

April 2020



# Impact Stories from PPI Ignite Phase I

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

PPI Contributor Mei Lin Yap

who has co-created a health promotion video based on IDS-TILDA data, has spoken at events, sits on the Steering Committee for IDS-TILDA and who is now employed part-time as an Ambassador for TCAID.



Chair yoga is great for older people in the sense that they might not be able to move around as much.

Ageing with PrIDE - Learning from Ten Years of IDS-TILDA

1,178 views

Trinity College Dublin  
Published on 20 Mar 2019

SUBSCRIBE 12K

Over the past ten years, the intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) has been researching the lives of people with an intellectual disability who are ageing in Ireland. Join Mei Lin Yap as she discusses the findings with Prof Mary McCarron, the

SHOW MORE



# Impact Stories from PPI Ignite Phase I

## PPI IGNITE CASE STUDY The Alzheimer Society of Ireland



Image | PPI Trinity College Dublin

### Goals of the project:

The Alzheimer Society of Ireland (ASI), as part of its commitment to developing public and patient involvement (PPI), set up the Dementia Research Advisory Team (DRAT). This is a PPI group made up of people living with dementia and carers/supporters of people with dementia. The DRAT was established to provide support, insight and encouragement to research teams in all aspects of the research cycle, to become part of the dementia research infrastructure and, ultimately, to begin to play a role in setting the agenda for dementia research.

### How were people found who wanted to be involved?

The ASI called upon its Advocacy Groups – The Irish Dementia Working Group and The Dementia Carers Campaign Network – for volunteers. In addition to their advocacy work, members of these groups had participated in research for many years. Some, however, were tired of just being research participants and felt that they saw few tangible results from their participation. The DRAT brought an opportunity to take a step further and become meaningfully involved in the design, prioritisation and delivery of research. In addition to these members, we found members by posting on social media (e.g. Twitter). In October 2020, The ASI and DRAT hosted a PPI Webinar. The clips were posted on YouTube and across our social media platforms which led to some membership enquiries. We are now working to increase the diversity of voices on the DRAT.



Image | PPI Trinity College Dublin

### How were people involved?

The ASI's vision is 'An Ireland where people on the journey of dementia are valued' and it is essential, as a research-promoting organisation, that people with dementia and those who support them are present in research too. The ASI developed the DRAT, a research-specific PPI group of people with dementia and family carers/supporters to facilitate that. The DRAT are encouraged and empowered to work with research teams on dementia-related topics, to feed into research activities and to deliberate on funding decisions within The ASI.

### What training and support was offered?

We began by co-producing and co-delivering a workshop with Trinity PPI Ignite on how research works, using the HRB-funded Making a Start toolkit. The workshop focused on helping members to relate to researchers and the realities of research. It drew out their preconceptions and also, in a good-humoured way, provided a reassurance that what they were being asked to do was both achievable and worthwhile. In fact, it was the enjoyable aspects of the workshop that ignited interest from members.

The response from the research community was a little slow and it was clear we needed to do more work on promoting the DRAT and PPI in dementia research. After a few months, it was clear that some DRAT members' motivation was understandably beginning to dwindle. To tackle this, we brought in a UK PPI Expert, Bec Hanley, who provided case studies (including from The Alzheimer's Society UK) to inspire members to stay involved and help them to see what could be achieved. Bec also delivered a useful session on providing feedback to researchers constructively and on managing challenging conversations.

Members also attend regular meetings every couple of months with The ASI where they can update each other on their work, troubleshoot challenges, and shape the direction of the group's future work and activities.

## CASE STUDIES

Trinity PPI Ignite Office is creating a series of case studies to celebrate the impact of PPI-supportive projects that can be shared with the HRB & IRC



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# **Ambitions for Phase II – 2021-2026**

# At a National Level

## PPI Ignite Phase II is developing a National PPI Network



# Benefits of a National Network

## Objectives

- Create a shared, coherent and vibrant **national voice** for PPI
- Develop a nationally-coordinated and internationally recognised **network of PPI excellence**
- Plan for the **sustainability** of the National PPI Network beyond five years

# Benefits of a National PPI Network



National PPI Festival



National PPI Hub



Community Outreach Events



Publicising Partner Events



Developing National Positions



Promoting Ireland's PPI Internationally

# Tasks for the National PPI Network

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

# National PPI Network

PPI Ignite Phase II will have six co-funded PPI Ignite Offices



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UCC  
Coláiste na hOllscoile Corcaigh, Éire  
University College Cork, Ireland

# Trinity and the National PPI Network

Trinity's task within the National PPI Network is to promote excellence.

## Objectives

- To improve the **quality** of the Network's PPI activities
- To develop a **culture of impact** assessment in PPI



# Building a Shared Definition of Quality

Rapid Review  
of QI  
approaches  
within PPI

Workshop  
appropriate  
values basis  
for QI with  
Network

Consider  
how those  
values  
should be  
reflected in  
Structure,  
Process &  
Outcome

Work with  
larger cohort  
of PPI  
Contributors  
to consider  
values and  
their  
implications

Develop  
principles  
and  
indicators for  
QI in PPI

Devise  
National PPI  
Network QI  
Projects

# Developing our Impact Framework

Rapid Review  
of Impact  
approaches  
within PPI

Gather initial  
thoughts and  
experiences  
from Network

Systematically  
review of  
appropriate  
Impact  
Frameworks

Workshop  
with  
stakeholders  
about  
prioritising  
indicators of  
impact

Capture  
Impact on  
projects

# New to Trinity PPI Ignite Phase II

Flagship  
Impact  
Projects

Mentoring  
Competition

PPI Ethics  
Module

Capacity Building

# Trinity PPI Ignite Flagship Impact Projects



PPI Contributor-led Research



IDS-TILDA as a Long-term Case Study



Equality, Diversity and Inclusion in Trinity PPI

# Trinity PPI Ignite Mentoring Fund

## The Trinity PPI Ignite Planning Fund Competition

- Aimed at PhD candidates and early-career Fellows
- Application to develop a PPI group or PPI activity
- Prize is a small grant plus the opportunity to present to a funder at the end of the activity / once the group is established

# Trinity PPI Ignite Office Ethics Module

## Trinity PPI Ignite Ethics Module

- Exploring the Ethical Implications of PPI Activity
- How PPI fits with the Ethics Infrastructure of Trinity
- Incorporating PPI into Ethics Applications
- Dealing with Unforeseen Ethical Issues



# Trinity PPI Ignite Office and Capacity



## Trinity PPI Ignite Building Capacity

- The PPI Ignite Office wants to further embed the capacity for PPI within the Schools, within the programmes and within events
- It is a finite resource so it will encourage activity *through* the PPI Ignite Office rather than *from* the PPI Ignite Office
- By the end of the programme, the functions of the Office should be absorbed into the infrastructure of Trinity
- The Ignite Office is already building capacity, e.g. supporting GBHI to build out its own PPI training and supporting TCAID with building its new Ambassador role