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PPI in Health Sciences Research

The role of the PPI Ignite Office

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Programme Manager

Trinity PPI Ignite Office

8 March 2022



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What is Public and Patient Involvement?

What is Public and Patient Involvement?

The Irish Context



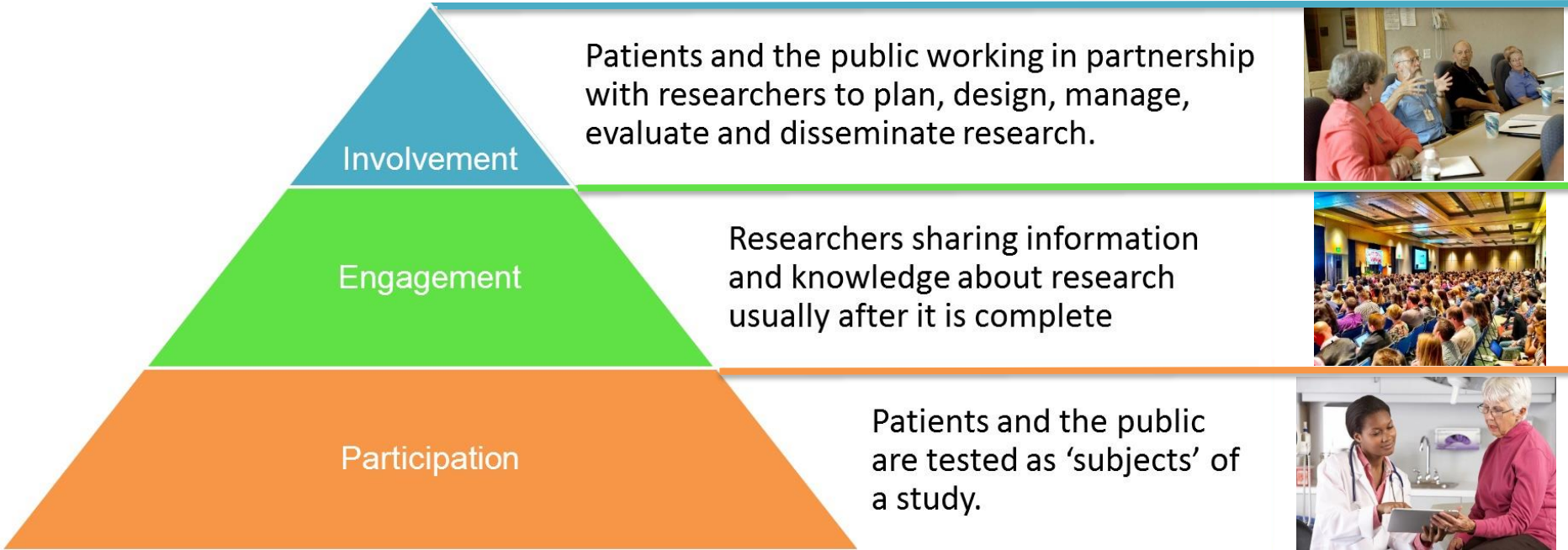
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Public involvement in research is: “Research carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them.”

Health Research Board definition from NIHR

What is Public and Patient Involvement?

Participation vs Engagement vs Involvement

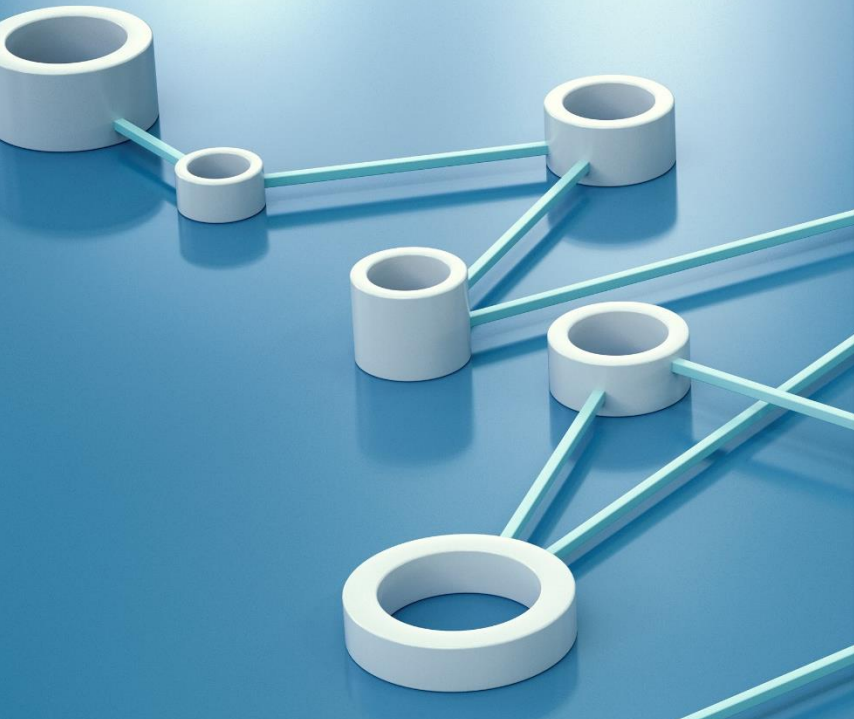


What is Public and Patient Involvement?

Allied concepts



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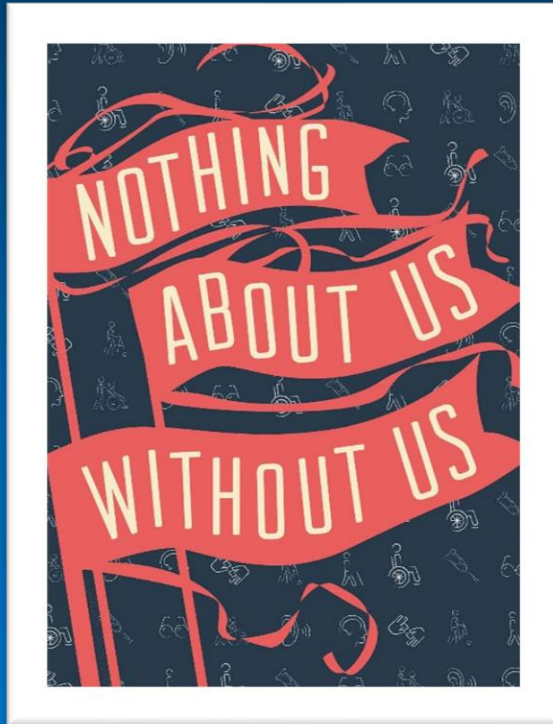
- PPV (Public and Patient Voice); Patient Involvement; Public Involvement; Public Engagement
- Engaged Research
- Co-Creation; Co-Design; Design Thinking
- Public Consultation
- Citizen Science
- Participative Action Research; Community Action Research

What is Public and Patient Involvement?

Beliefs driving PPI



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- Those affected have the right to influence what is researched and how it is done
- The public, using health services, should have a say in prioritising publicly funded health and medical research
- This is about equity across the research cycle for those who have often been excluded

What is Public and Patient Involvement?

Why do patients do it?



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Laurie Proulx
@ProulxLaurie



Replying to [@TO_dpr](#)

To bring meaning to the misery I've suffered. I know that sounds harsh but it's why it's important that researchers don't take my involvement lightly or to engage me meaningfully. Or else, this means suffering that same misery twice.

11:09 PM · Feb 6, 2021 · Twitter for iPhone

What is Public and Patient Involvement?

Why do patients do it?



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Jolitta Belton @MyCuppaJo · 4h



Replying to @TO_dpr

Integration of lived experience (a 'way of knowing') into our understanding of pain & complex human conditions is necessary, yet often missing. We need the science/research, the clinical training/expertise, AND the invaluable knowledge gained from patient's experiences & insights



1





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Support from the PPI Ignite Office

PPI Ignite Phase II

Metrics for the first 10 months, March – Dec 2021



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1. Training & Workshops

- **2021 Delivery: 33**

2. Networking Events

- **2021 Delivery: 30**

3. Face-to-Face PPI Clinics

- **2021 Delivery: 38**



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IRISH RESEARCH COUNCIL
An Chomhairle um Thaighde in Éirinn

PPI Ignite Phase II

Supporting PPI in Trinity



Flagship
Impact
Projects

Small
Mentoring
Fund

PPI Ethics
Module

PPI Ignite Phase II

Flagship Projects



PPI Contributor-led Research



IDS-TILDA as a Long-term Case Study



Equality, Diversity and Inclusion in Trinity PPI

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Supporting PPI in Trinity



Flagship
Impact
Projects

Small
Mentoring
Fund

PPI Ethics
Module

Capacity Building

PPI Ignite Phase II

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

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Building Capacity – Online Module



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Faculties and Schools Courses Research A-Z

Search Trinity Centre for Ageing and Intel

Trinity Centre for Ageing and Intellectual Disability

Menu Home About TCAID: In Focus Research Collaborations NIDMS People Contact Gaelige

A group of approximately 15 people, including men and women of various ages, standing in a modern hallway with large windows and wooden accents. Some are wearing name tags.

What is Public and Patient Involvement (PPI)?: Trinity PPI Ignite Introductory Module

This module introduces the researcher to public and patient involvement (PPI) in health-related research.

It encourages researchers to use their skills and knowledge in order to bring the voices of patients and members of the interested public into the research cycle in a way that is satisfying for all concerned and of benefit to the research.

Section 1: Introduction to PPI >
What is PPI, where it occurs in the research cycle and why PPI contributors get involved

Section 2: Planning for PPI >
Planning your PPI activity and communicating it in your funding application

Section 3: Implementing PPI >
Implementing your PPI plans across your research cycle

PPI Ignite Phase II

Building Capacity – Templates



Resources

Templates

PLANNING MY PPI

Here are a few questions to help you to work out what roles PPI contributors will play.

Stage	What role will PPI contributors play?*	What PPI activities are needed to help it contribute a role?	How does this benefit the research, the impact or the team?
Identifying & recruiting stage			
Design stage			
Undertaking & Management stage			
Analysing & interpreting stage			
Dissemination stage			

Planning Your PPI Template
➔

BUDGET COSTS

The following proposed PPI budget template is a reminder of the types of costs that often occur for PPI activities. Some may not be relevant to your project. There may be other costs which are not included here. This is to remind you to consider costs that may be relevant to you. Your final budget may not be as detailed, e.g. many activity costs may be aggregated into Travel and Accommodation.

Budget Item	Per item cost	Total Cost
PERSONNEL		
PPI specific team member	€ per day	
PPI Office support time	€ per day + prep time	
External facilitator	€ per day + prep time	
SGO facilitator	€ per day + prep time	
ACTIVITY COSTS (including induction and training)		
Room hire for activities	€ per event	
Tea / Coffee	€ per PPI contributor + other attendees	
Lunch	€ per PPI contributor + other attendees	
Train, Bus, Taxi per event	€ to and from	
mileage (if permitted)	€ per km	
Overnight (if required)	€ each night + breakfast	
Stationery, materials	€ per event	
Data Costs (for online contributions)	€ per hour	
Fees for Conference or Event attendance	€ per contributor per event	
CONTRIBUTOR AND/OR EVENT COSTS		

Budgeting for Your PPI Template
➔

YOUR FEEDBACK IS IMPORTANT

Please provide us with your feedback about the discussion that took place on (DATE) in (LOCATION). This will help us to improve future discussions.

Pre-meeting information and support

Before the meeting, how good was the information we supplied to you so that you could take part?

Excellent	Good	Fair/Okay	Poor
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments:

Before the meeting, how prepared did you feel in order to take part?

Excellent	Good	Fair/Okay	Poor
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments:

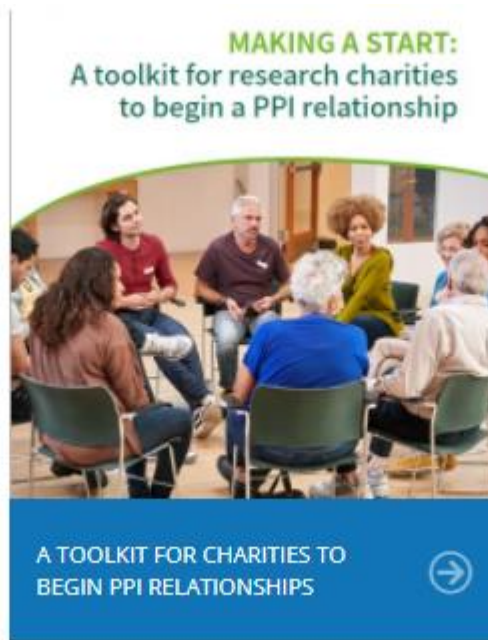
Feedback to Your PPI Activities Template
➔

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Building Capacity – Resources



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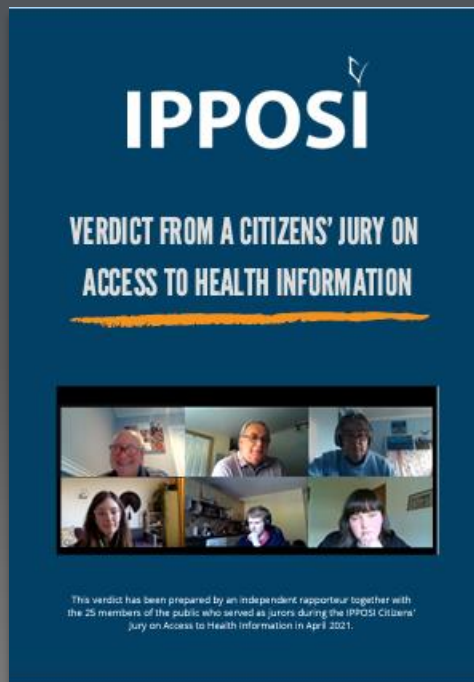


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Building Relationships in 2021



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Questions from the Schools

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Questions from the Schools



- How researchers can build their own networks
- How to involve patient groups and research charities
- How to involve patients and the public from the beginning, particularly when you already have many years of experience
- What ethical implications must be considered for PPI activity



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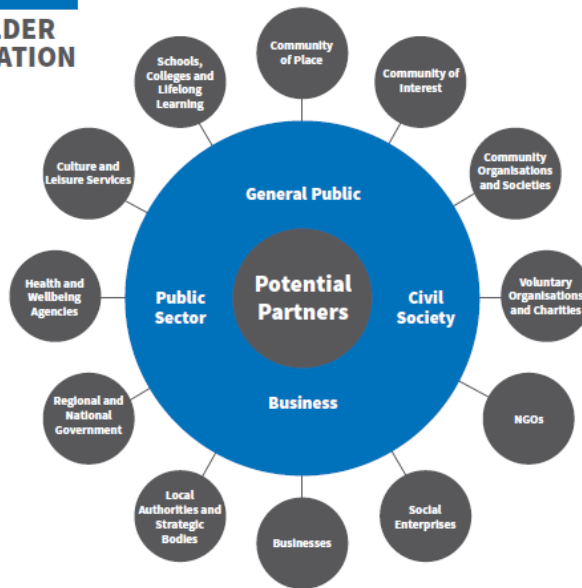
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Building Your Own Network

Building Your Own Network

Stakeholder Mapping

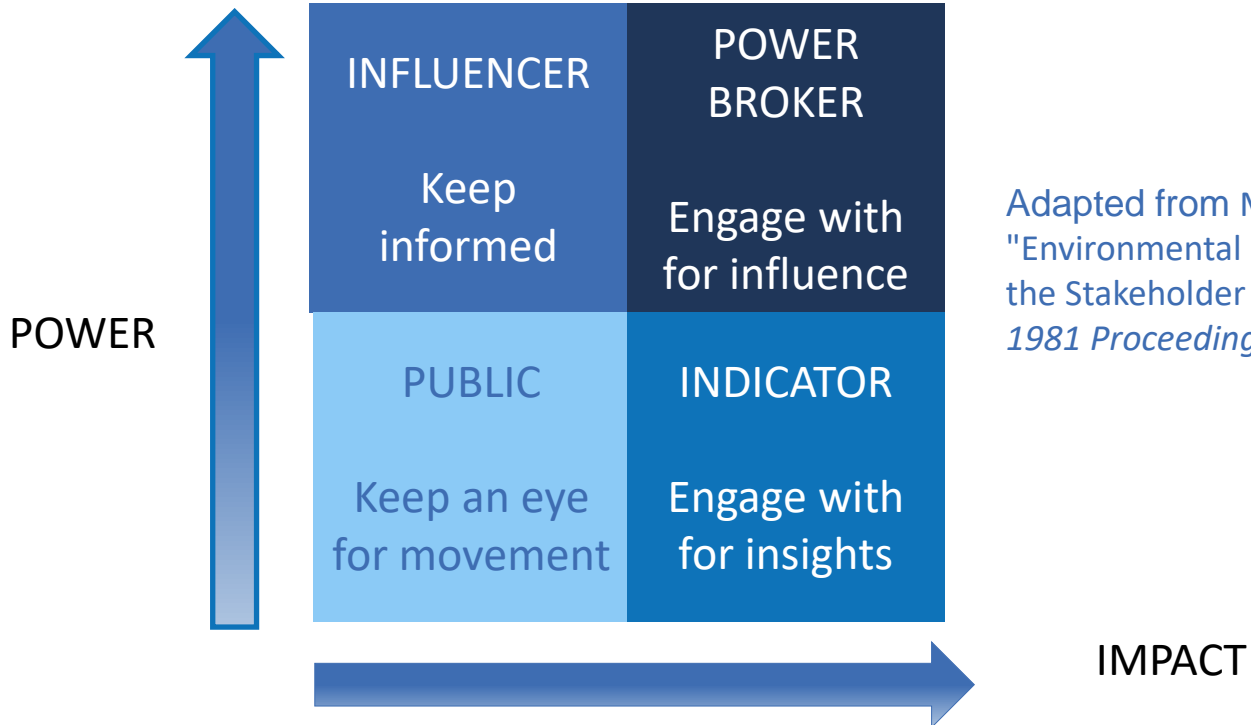
STAKEHOLDER IDENTIFICATION



Credit: National Co-ordinating Centre for Public Engagement - UK

Building Your Own Network

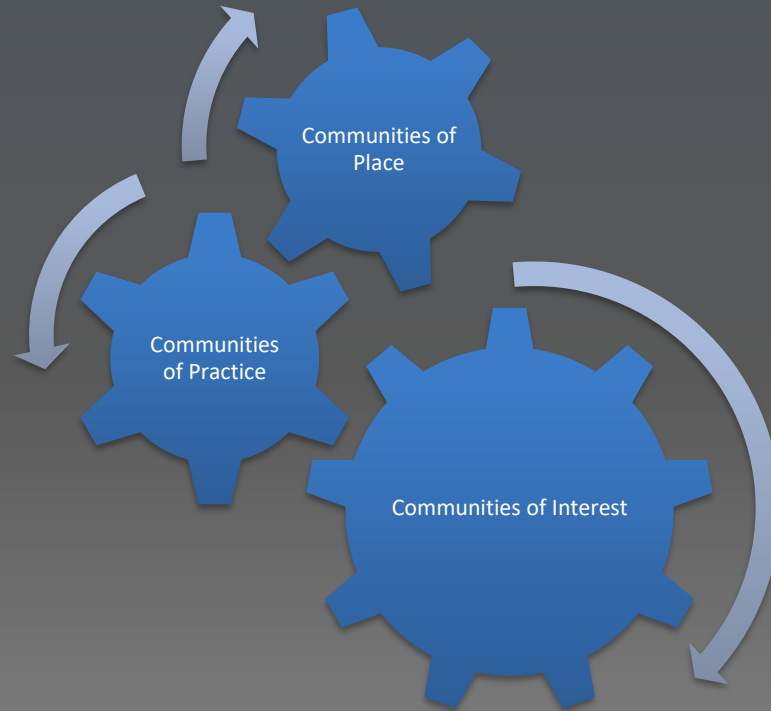
Stakeholder Mapping



Adapted from Mendelow, A. L., "Environmental Scanning--The Impact of the Stakeholder Concept" (1981). *ICIS 1981 Proceedings*. 20

Building Your Own Network

Existing Communities



Building Your Own Network

Existing Communities



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Who are they?

- Funders
- Colleagues
- Clinicians
- Civil & Public Servants
- Politicians
- Advocates
- Research Charities
- PPI Contributors



Communities
of Interest

Do these communities
know you exist?

How could you be visible to
them?

Where are they?

- Public Events
- Public Consultations
- Charity AGMs
- Online Events
- Twitter
- Facebook Support
Groups



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Involving Patient Groups and Research Charities

Involving Patients and Charities

Research Charities and Patient Representatives



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Involving Patients and Charities

Research Charities and Patient Representatives



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Health Research
Charities Ireland



Involving Patients and Charities

Research Charities and Patient Representatives



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- Dedicated Research or Involvement Staff
- PPI and Research Budgets
- Existing PPI Panels or Support Groups
- National Networks
- Insight due to working with large numbers of patients, families
- Their own national research & policy agenda

Involving Patients and Charities

Research Charities and Patient Representatives



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- Passionate advocates
- Access to otherwise difficult-to-reach patients, families or carers
- Run on trust and personal relationships
- Often funded by those involved
- Grateful for interest in their issue
- Often over-committed and managing multiple issues

Involving Patients and Charities

Research Charities and Patient Representatives



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- Rare disease charities can be small but international

Involving Patients and Charities

Research Charities and Patient Representatives



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European Cancer
Patient Coalition



- European and International bodies can provide connections and inspiration



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Early Stage Working with PPI Contributors

Early Stage Working

Agenda Setting



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WHAT'S NEXT IN AUTISM GENOMICS*?

Sharing 20 Years of Autism
Research Progress, Potential &
Opportunities for Public
Involvement

JOIN THE CONVERSATION!
THIS FREE EVENT IS FOR
ANYONE INTERESTED IN
AUTISM RESEARCH

10AM - 2PM
26TH FEBRUARY 2019
**TRINITY INSTITUTE OF
POPULATION HEALTH, TALLAGHT,
DUBLIN 24**

* Genomics means the study of our
DNA. Don't worry, we will explain it on
the day!

Early Stage Working Agenda Setting

A promotional poster for an event. The background is red with a teal circle on the left. The text "WHAT IS IN AUTISM GENOMICS" is written in large white letters. Below it, smaller text reads "Sharing 20 Years of Research Progress and Opportunities for Patient Involvement". On the left, there is a white silhouette of a head with a brain inside. In the top left corner, logos for Trinity College Dublin and the Health Research Board are visible. On the right, there is a blurred photograph of a woman with long dark hair smiling and talking to someone off-camera.

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HR^B Health Research Board

WHAT IS IN AUTISM GENOMICS

Sharing 20 Years of Research Progress and Opportunities for Patient Involvement

Early Stage Working

Agenda Setting



- This event brought a new generation of autism researchers together with people in the autism community
- It gave the community an insight into the latest on autism genomics
- It provided a space where people could ‘come to help’ with offers of time, money, etc
- It showed that Trinity was a ‘good neighbour’, a potential ally and willing to listen as well as to tell

Early Stage Working

Agenda Setting



James Lind Alliance

Priority Setting Partnerships

- Home
- About the JLA
- The PSPs
- Top 10s
- JLA Guidebook
- News and Publications
- Making a difference

You are in: Home

The James Lind Alliance

The James Lind Alliance (JLA) is a non-profit making initiative established in 2004. It brings patients, carers and together in Priority Setting Partnerships (PSPs) to identify and prioritise the Top 10 unanswered questions or evidence uncertainties that they agree are the most important.

The aim of this is to make sure that health research funders are aware of the issues that matter most to the people who use the research in their everyday lives.



How
ing priorities
were
patients,
to contribute

Sign up to our newsletter and stay up to date on the latest news from the JLA

Early Stage Working

Agenda Setting



James
Lind
Alliance

Priority Setting Partnerships

Home

About the JLA

The PSPs

To

You are in: Home

The James Lind Alliance

The James Lind Alliance (JLA) is a non-profit made up of researchers and patients who work together in Priority Setting Partnerships (PSPs) to identify and address the greatest uncertainties that they agree are the most important for research.

The aim of this is to make sure that health researchers know what to research and to use the research in their everyday lives.



- No research is 'starting from scratch'
- PPI contributors are not *telling* researchers what to research
- Agenda-setting activities help researchers to understand what are the *current priorities* for PPI contributors
- They can also begin a useful relationship that can create new opportunities for the research team, for the contributors, for the sector, for the university



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Ethics of PPI activities

Ethical Issues

Differences in relationship

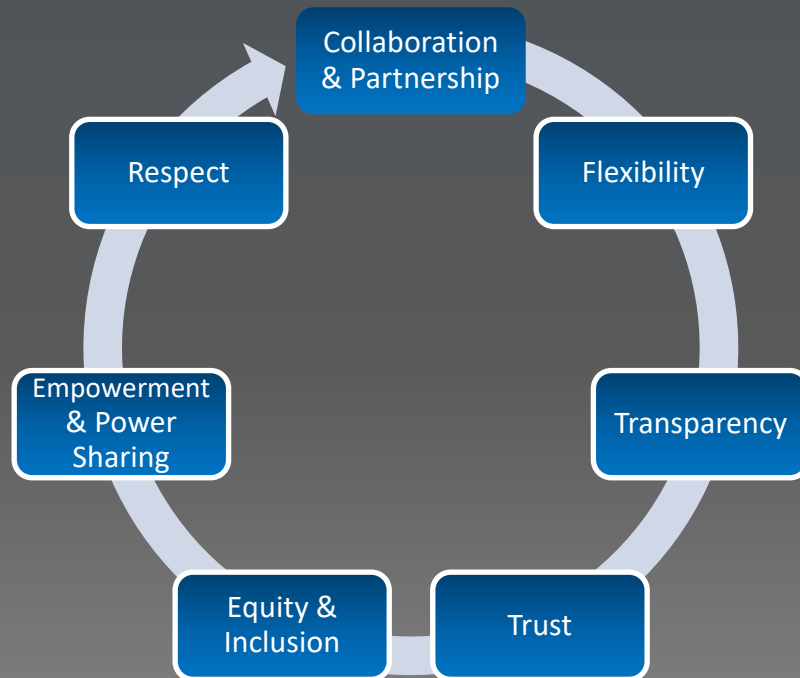


- PPI contributors often share personal experiences
- The PPI relationship may be more in-depth and longer lasting than the participant interaction
- PPI relationships can change and evolve over time
- It may not be fully clear at the beginning what the roles, responsibilities and expectations are on either side
- As this is more of a partnership, there are issues around recognition, acknowledgement, IP



Ethical Issues

Values Identified by PPI Ignite



Ethical Issues

Differences in relationship



- PPI can often be an iterative process which does not lend itself to a clear pre-defined protocol.
- How do we ensure that a research team acts ethically with its partners and stakeholders?
- Who is best placed to review this work, to consider legal, moral and reputational risk and to handle complaints?
- What responsibilities does the institution have in facilitating these relationships?



PPI Ignite Phase II

Acknowledgements



Trinity PPI Ignite Office is part of the national PPI Ignite Network. It is supported by the Health Research Board, the Irish Research Council, the Office of the Dean of Research, the Office of the Dean of Health Sciences and the School of Nursing and Midwifery. For more information, contact:

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Thank You

Michael Foley

Programme Manager

Trinity PPI Ignite Office

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