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PPI in Health Sciences Research

The role of the PPI Ignite Office

Michael Foley
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?

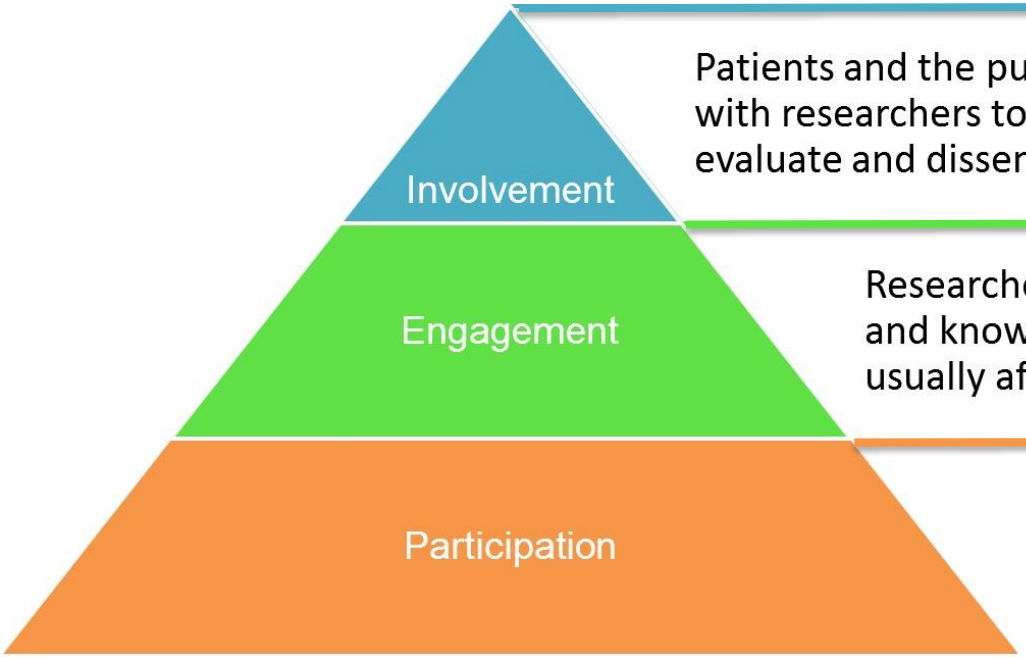
The Irish Context

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



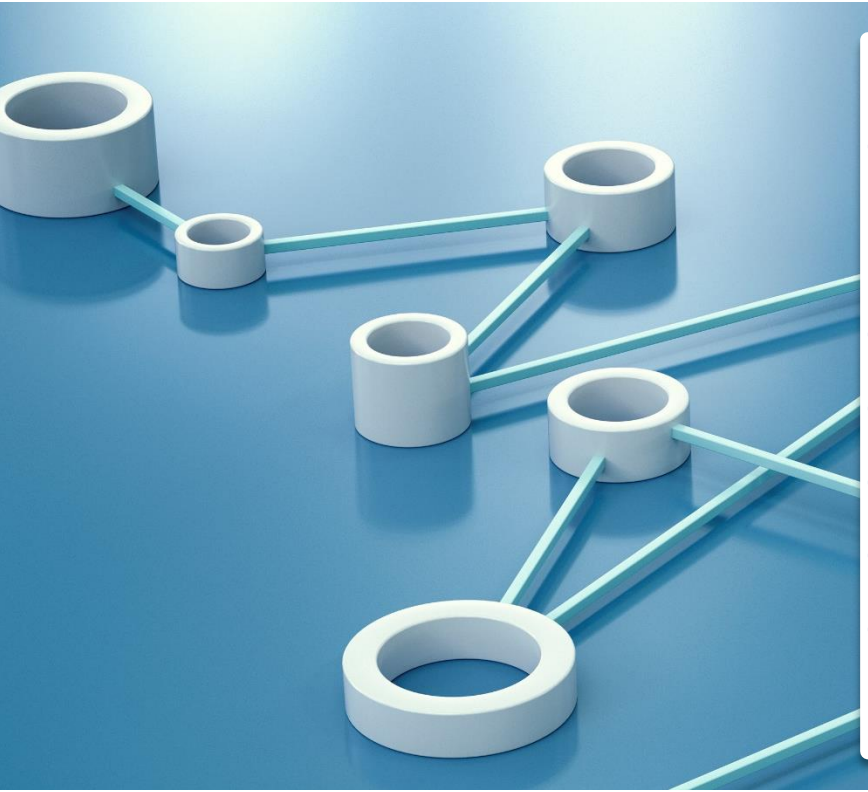
Patients and the public working in partnership with researchers to plan, design, manage, evaluate and disseminate research.

Researchers sharing information and knowledge about research usually after it is complete

Patients and the public are tested as 'subjects' of a study.

What is Public and Patient Involvement?

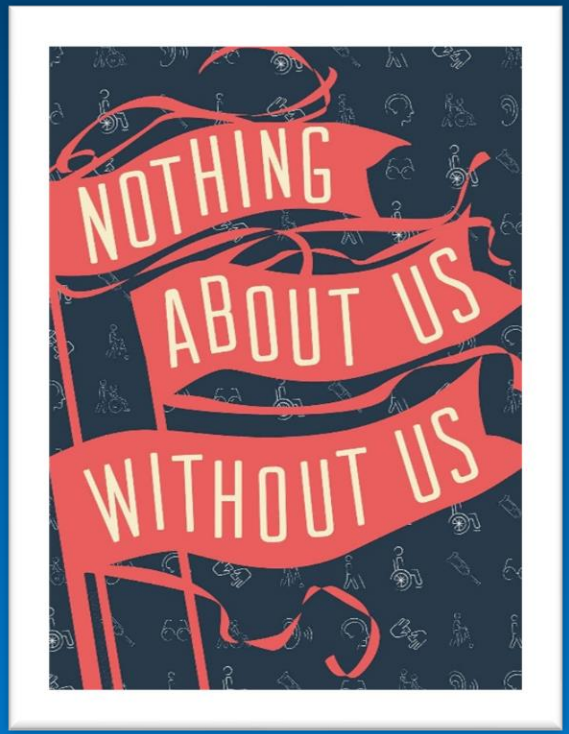
Allied concepts



- 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?

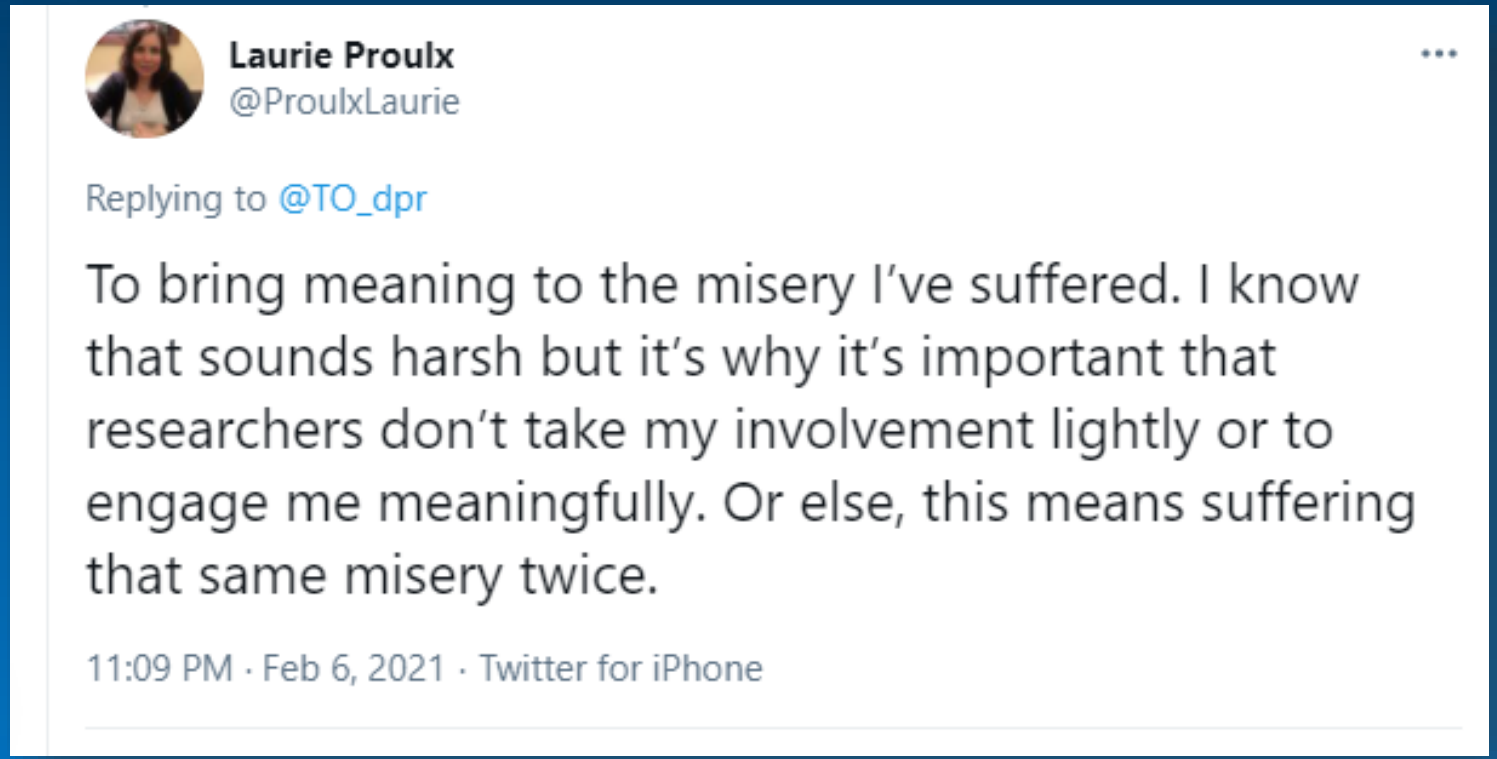
Beliefs driving PPI



- 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?



What is Public and Patient Involvement?

Why do patients do it?

Joletta 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

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Support from the PPI Ignite Office

PPI Ignite Phase II

Metrics for the first 10 months, March – Dec 2021

1. Training & Workshops

- **2021 Delivery: 33**

2. Networking Events

- **2021 Delivery: 30**

3. Face-to-Face PPI Clinics

- **2021 Delivery: 38**

PPI Ignite Phase II

Supporting PPI in Trinity

PPI IGNITE NETWORK

TRINITY PPI IGNITE OFFICE

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

PPI Ignite Phase II

Supporting PPI in Trinity

PPI IGNITE NETWORK

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Flagship Impact Projects

Small Mentoring Fund

PPI Ethics Module

Capacity Building

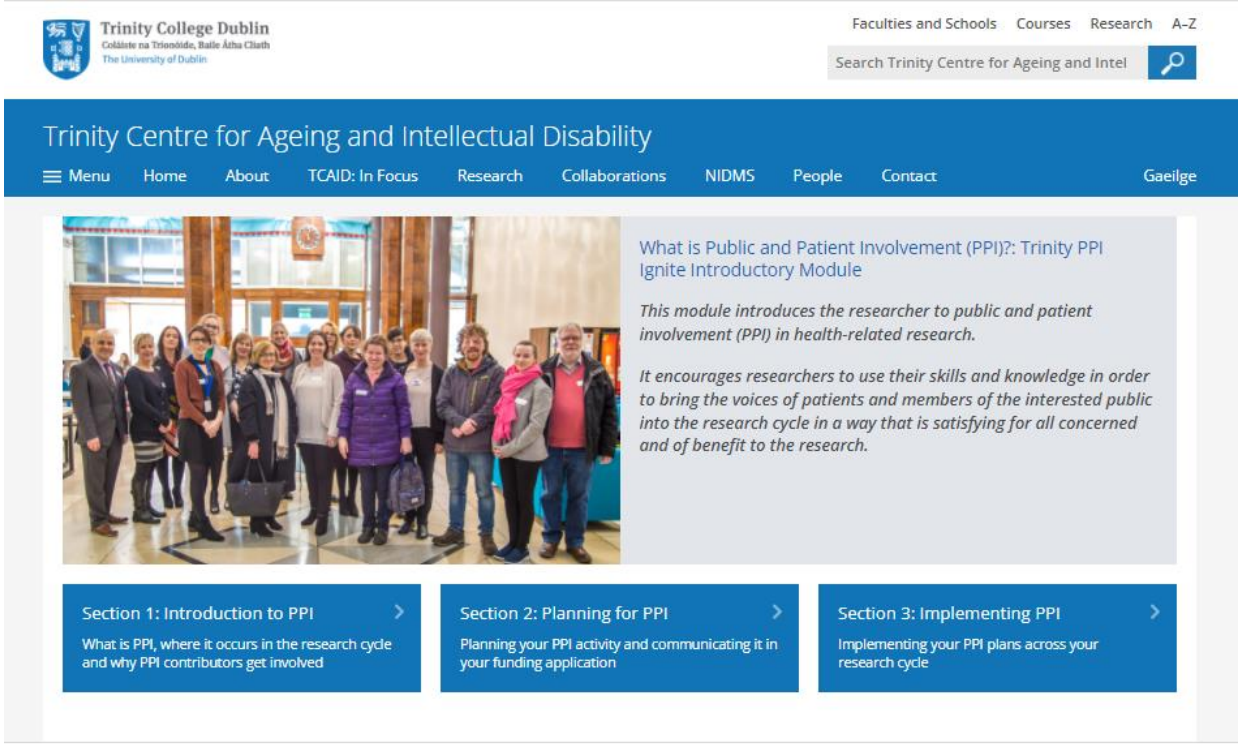
PPI Ignite Phase II

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

PPI Ignite Phase II

Building Capacity – Online Module

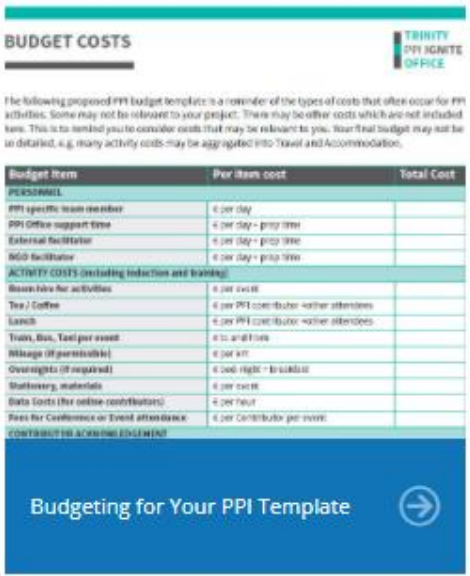


PPI Ignite Phase II

Building Capacity – Templates

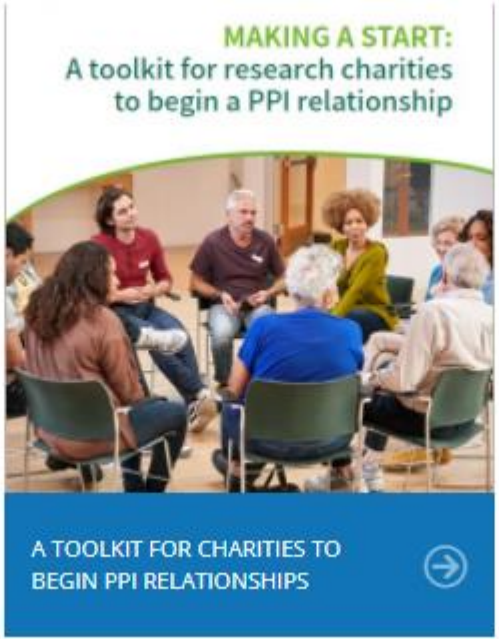
Resources

Templates



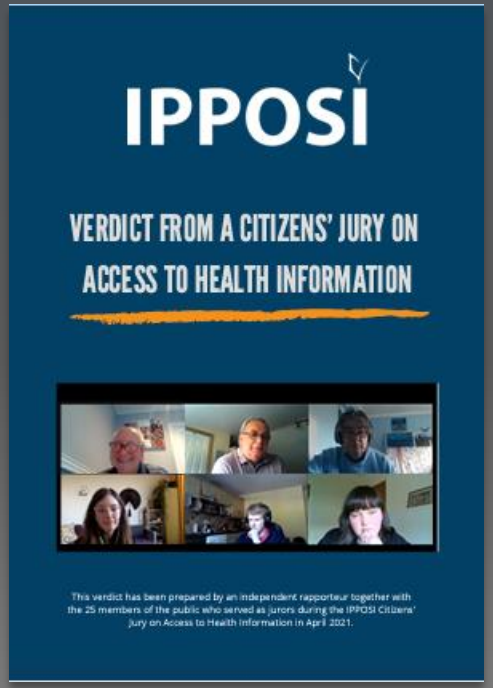
PPI Ignite Phase II

Building Capacity – Resources



PPI Ignite Phase II

Building Relationships in 2021



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Questions from the Schools

PPI Ignite Phase II

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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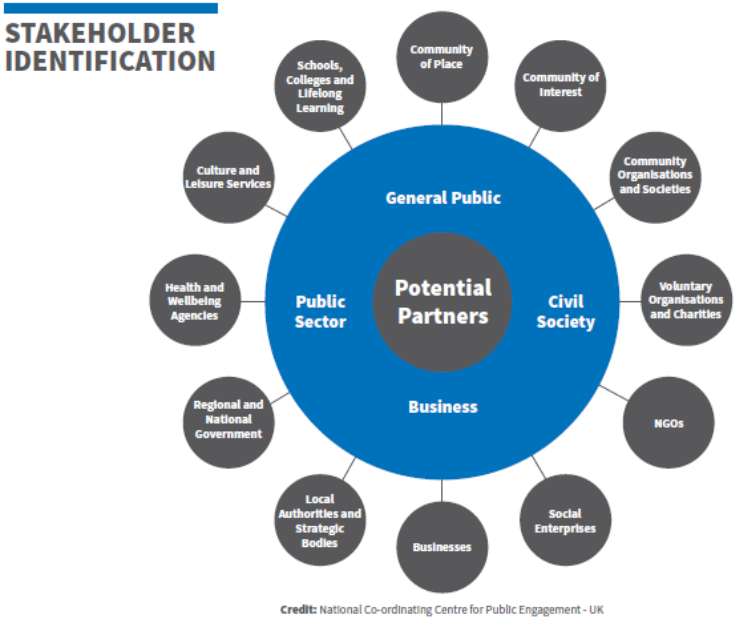
Building Your Own Network

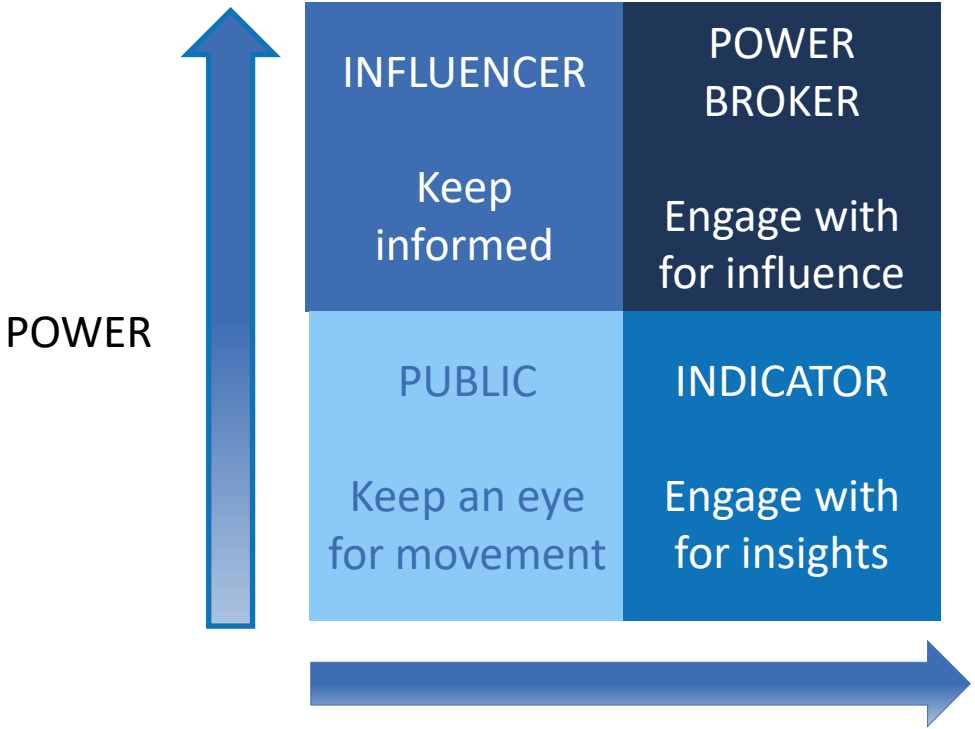
Building Your Own Network

Stakeholder Mapping



Building Your Own Network

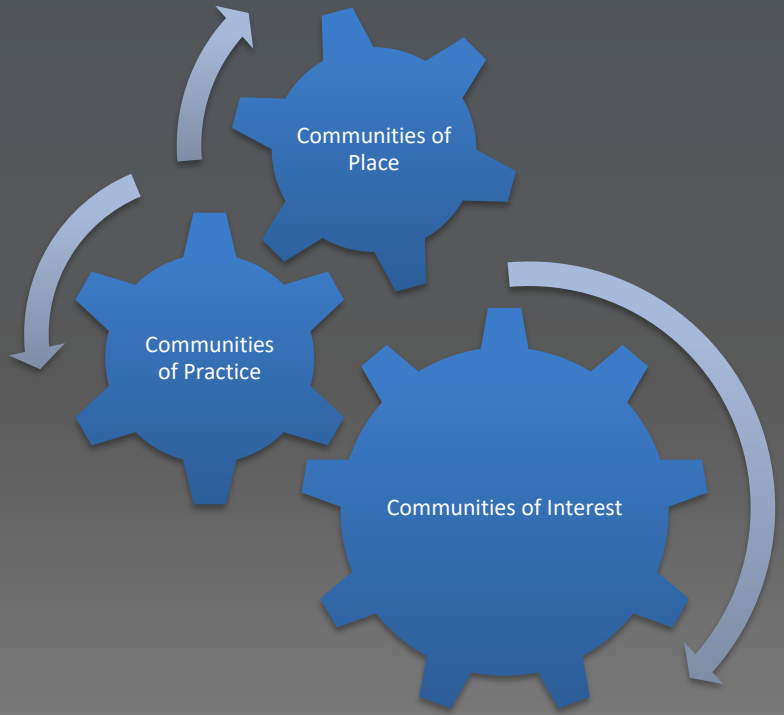
Stakeholder Mapping



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

Who are they?

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

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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HRCI Health Research Charities Ireland

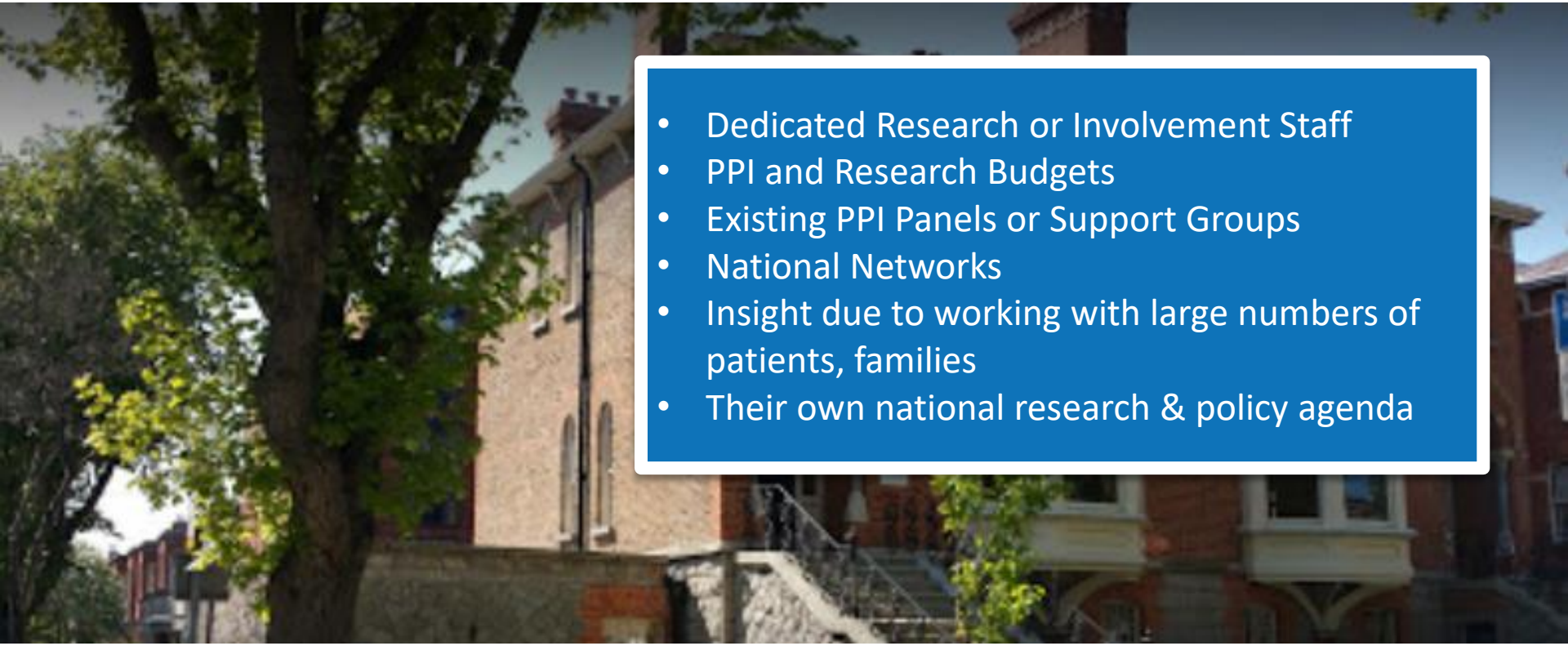
Involving Patients and Charities

Research Charities and Patient Representatives

Health Research Charities Ireland

Involving Patients and Charities

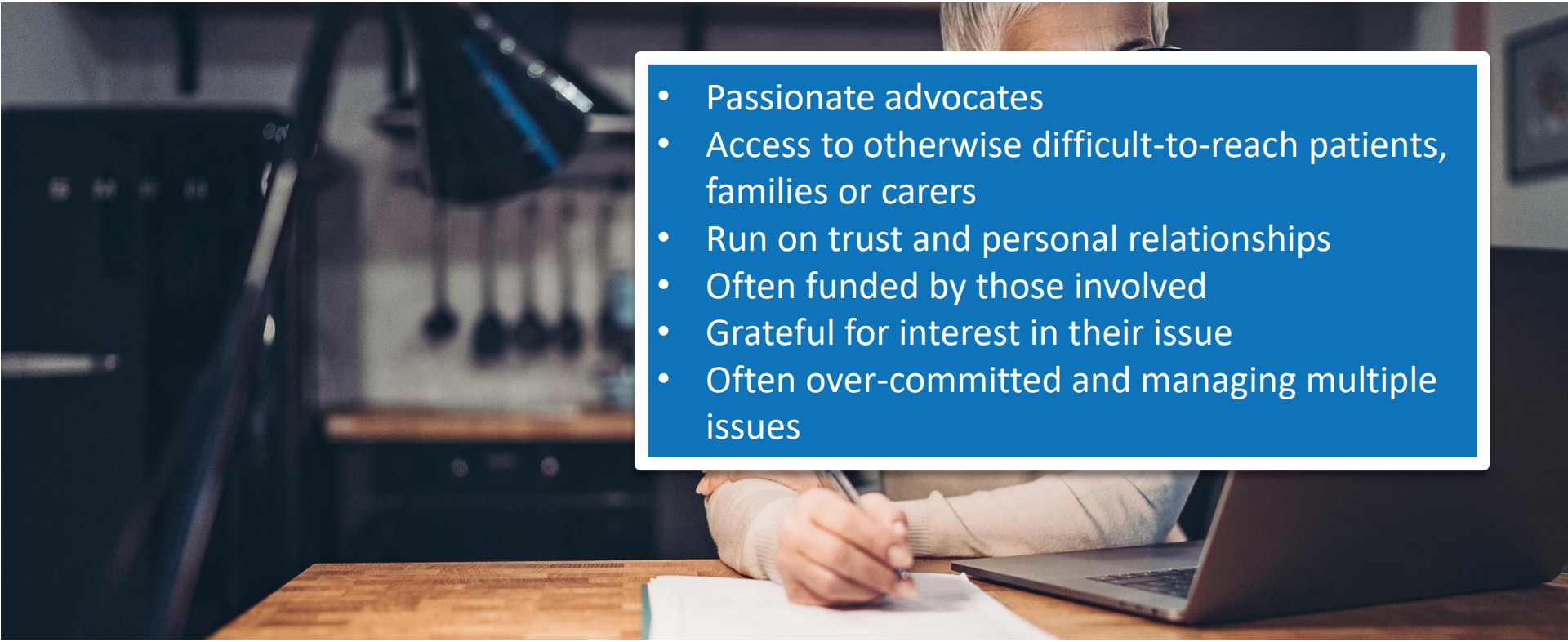
Research Charities and Patient Representatives



- 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



- 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

- Rare disease charities can be small but international

Involving Patients and Charities

Research Charities and Patient Representatives

European Cancer Patient Coalition

- European and International bodies can provide connections and inspiration

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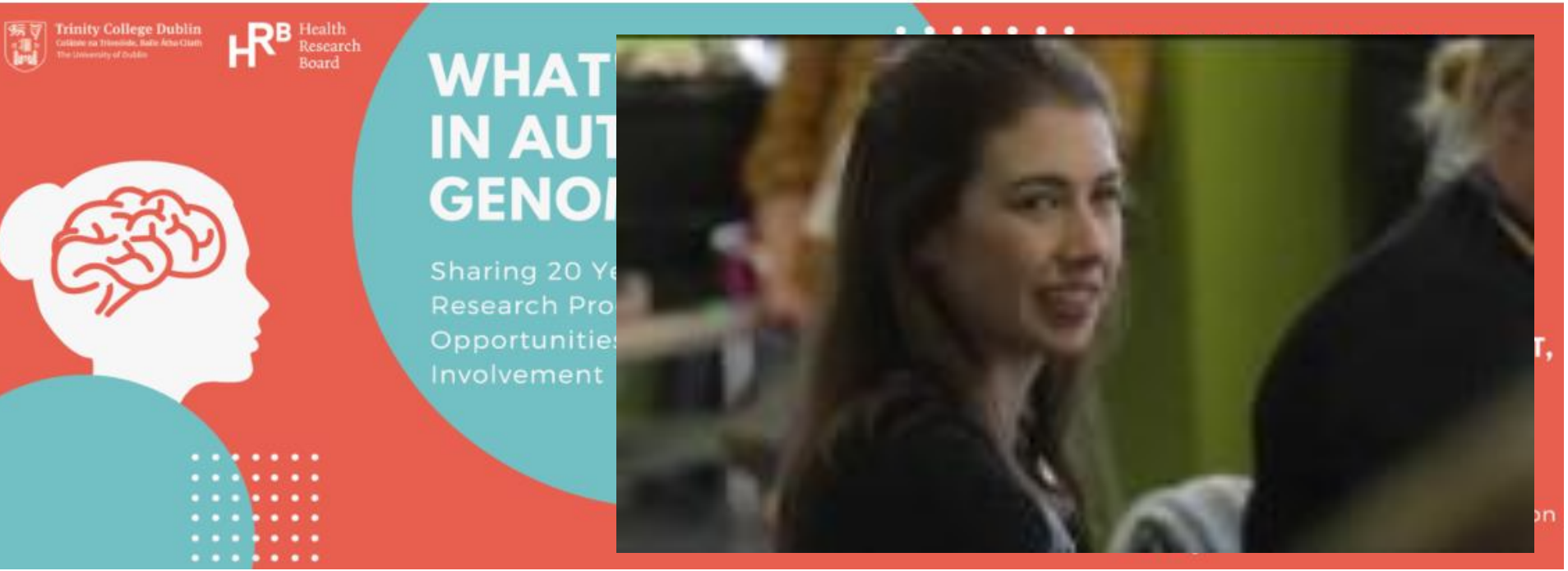
Early Stage Working with PPI Contributors

Early Stage Working

Agenda Setting

Early Stage Working

Agenda Setting



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

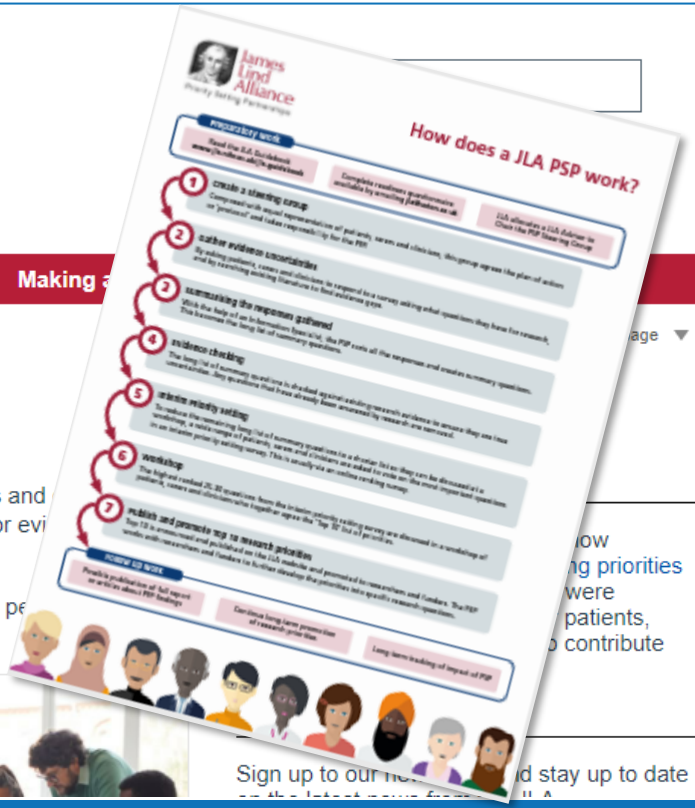
Home | About the JLA | The PSPs | Top 10s | JLA Guidebook | News and Publications | Making a

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 evi
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 pe
to use the research in their everyday lives.



Early Stage Working

Agenda Setting

- 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

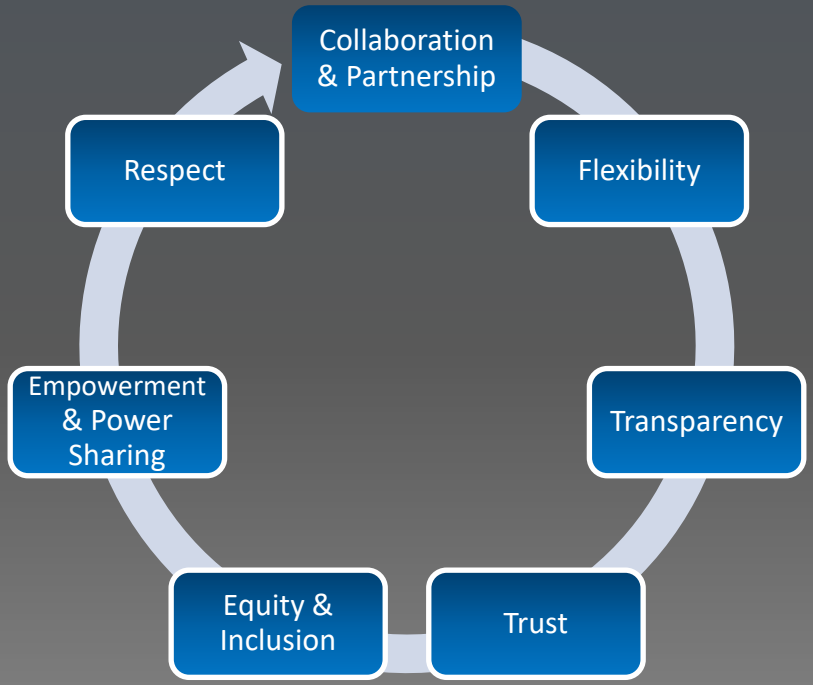
Ethical Issues

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

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