



PPI **IGNITE**
NETWORK

Embedding Equality, Diversity and Inclusion (EDI)
across the PPI Ignite Network:

Our Strategy

“EDI is something you do, not something you achieve”

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This document defines our strategy to develop an environment and practices underpinned by the principles of equality, diversity and inclusion across all the activities of the PPI Ignite Network.

The document also includes an EDI Strategy Implementation Plan, defining how we will deliver on this strategy.

Background

Established in March 2021, the PPI Ignite Network promotes excellence and innovation in public and patient involvement (PPI) in health and social care research in Ireland. Working across 7 Lead Universities (Lead Sites), 10 national partners and 53 local partners, the Network aims to develop a shared voice for PPI across Ireland and to become an important contributor to improved health outcomes for the public (see Appendix 1 for more information). 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, and builds on the initial PPI Ignite Programme (2017-2021).

Equality, diversity, and inclusion (EDI) are the foundations on which good PPI practice is built. The PPI Ignite Network is committed in everything it does to create a safe and inclusive environment for public and patient involvement in Network activities, where all voices and cultures from all communities are welcome, supported and respected. Importantly, through its education and training initiatives, by modelling best practice and by becoming a shared voice for PPI in Ireland, the PPI Ignite Network is uniquely positioned to develop and drive a focus on equality, diversity and inclusion in all PPI in research across Ireland and further afield.

We are committed to developing an environment in Ireland that ensures that under-served groups and individuals are included and supported to become active PPI contributors in Network activities and across health and social care research in Ireland. This expands on Principle 13 of the Declaration of Helsinki¹ (*'Groups that are underrepresented in medical research should be provided appropriate access to participation in research'*).

Aim of EDI strategy

By developing an EDI strategy for the PPI Ignite Network, we aim to:

- Promote a PPI culture in the Network that is underpinned by equality, diversity and inclusion
- Build on and share information about existing initiatives and experience at Lead Sites and among our partners
- Build partnerships that will help advance our EDI focus
- Generate a shared vision of what EDI means in the context of the Network and the Network's sphere of influence
- Set goals for what we want to achieve in the context of equality, diversity, and inclusion
- Drive a strong EDI focus across all PPI in research activities nationally, with additional impact on international PPI practice
- Monitor and evaluate our progress and revise our EDI strategy as we progress

Definitions

We use the term **PPI contributor** to mean any individual, including patients, family members, carers, children, young people and other members of the public, who work with researchers to help shape, plan and acquire funding for research studies, to conduct research and to share the research results

According to the World Health Organization (WHO), **equality** is considered to exist when all individuals and groups of people are given equal treatment, regardless of need or outcome, and **equity** is defined as the absence of avoidable or remediable differences among groups of people, whether those groups are defined socially, economically, demographically or geographically².

Diversity refers to the diverse nature of society and the many ways in which people differ. In a PPI context, diversity can be related to social background, ethnicity, ability, level of education, health

condition, or many other dimensions, and to the complexity that arises with the intersection of two or more of these dimensions

Drawing on the work of the NIHR INCLUDE project³, we use the term **under-served** in our EDI strategy. The term ‘under-served’ is highly context-specific, no single definition can encompass all under-served groups or individuals. The term ‘under-served’ emphasises that the PPI Ignite Network and the broader research community have a responsibility to identify the diversity of PPI contributors appropriate for a given research topic.

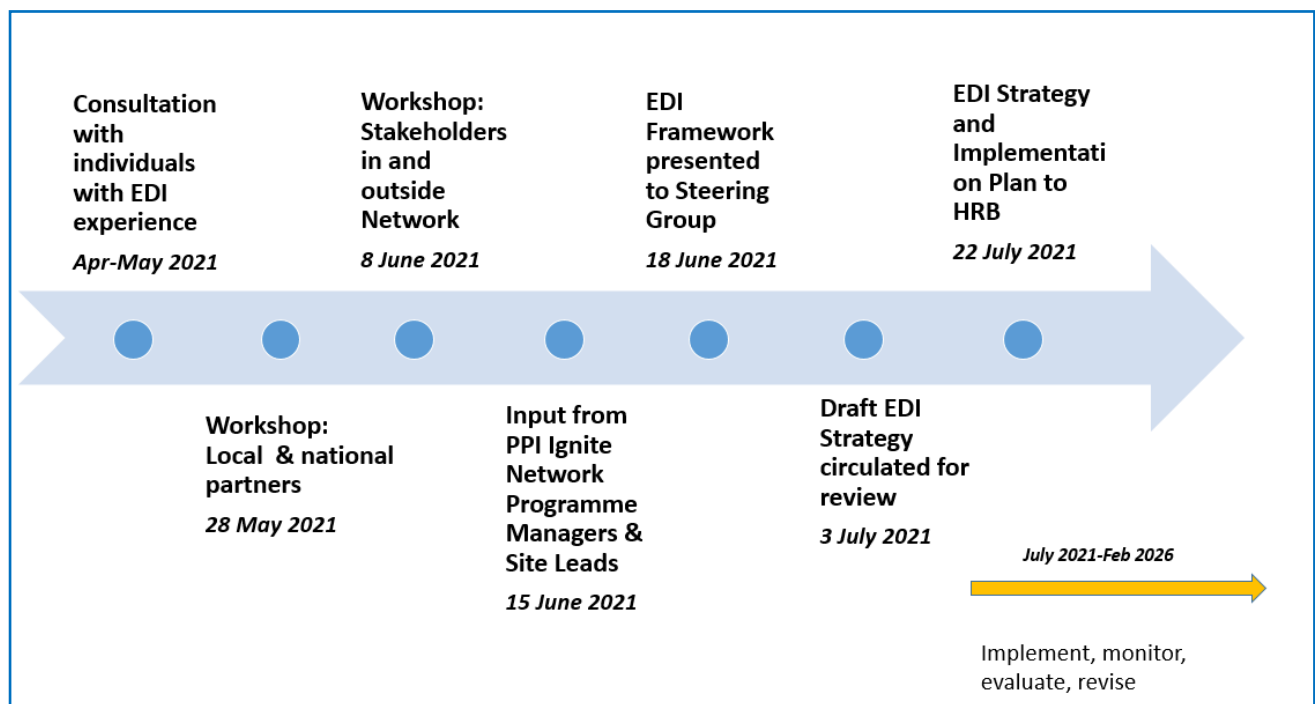
We use the term **inclusion** to refer to a PPI environment where everyone is welcome, supported and respected, on equal terms, and where PPI contributors feel they belong and can contribute to their full potential.

In developing and implementing our EDI strategy, we commit to considering all issues from all perspectives: equality, equity, justice, diversity and inclusion. While we recognize that disadvantaged groups and individuals may need more support or resources to become active PPI contributors and to achieve the same outcomes as more advantaged groups, we also commit to changing *our* practices to align them better with the needs of historically under-served populations.

Developing our EDI strategy

We worked with a wide range of stakeholders, from both within and external to the PPI Ignite Network, to develop our EDI strategy (see Figure 1).

Figure 1: EDI strategy development process and timeline



We consulted initially with a range of people with specific expertise in equality, diversity and inclusion. We gathered advice from the perspectives of patient organisations and from people involved in EDI initiatives in the workplace. We also consulted with academics with experience of involvement of under-served groups as PPI contributors and partners, including people with intellectual disability and with chronic progressive conditions, as well as ethnic minorities and social care service users.

We then organised two workshops, the first attended by representatives of national and local partners, the second also attended by organisations not yet part of the PPI Ignite Network, as well as additional representatives from national partners (see Table 1 in the Appendix for more details on workshop attendees). We asked workshop attendees to develop advice for the PPI Ignite Network on equality, diversity and inclusion in the areas of:

- Network training and education
- Other Network activities, for example, supporting researchers or organising PPI events
- Monitoring and evaluating progress on the implementation of our EDI strategy

Drawing on the initial consultations and the two workshops, we developed a draft EDI strategy, and gathered feedback from the PPI Ignite Network teams at the Lead Sites and subsequently from the Network Steering Group. We have circulated a draft document for review by workshop attendees (optionally), national partners and Lead Site PPI Ignite Network teams, before finalising our EDI Strategy (22 July 2021). We will publish our EDI Strategy on our online hub in Autumn 2021.

Strategic goals for EDI

The overall purpose of our EDI strategy is to ensure that equality, diversity and inclusion considerations underpin all Network activities, influencing in particular our capacity building activities and our focus on improving the quality of PPI approaches.

Our strategic goals are:

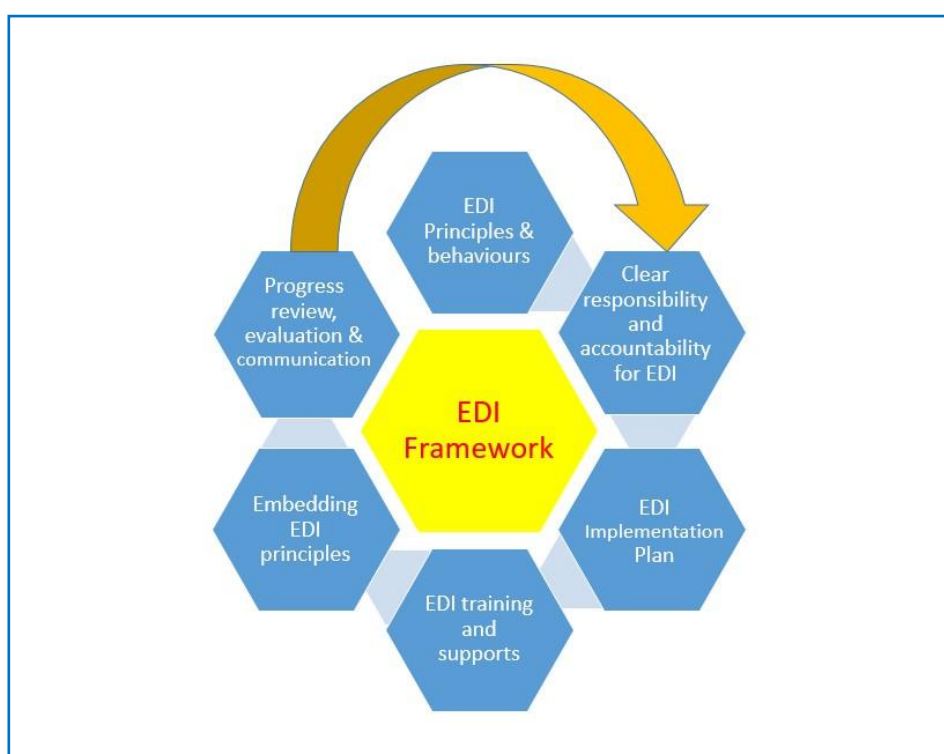
1. Co-produce an all-island agreed set of principles for EDI in PPI that will underpin all PPI Ignite Network activities, including the implementation of the EDI strategy
2. Model best practice across all PPI Ignite Network activities.
3. Develop a widespread understanding of the EDI principles in action, through education and training, including the development of accessible and online resources.
4. Identify institutional and other barriers that limit the implementation of the EDI in PPI principles, highlight these barriers to relevant institutional management and work to remove them where possible.
5. Embed ongoing evaluation, reflection and review of our EDI strategy as a core Network activity.
6. Share progress and learnings from across the Network within our sphere of influence to inform future EDI developments and increase the impact of the Network.

PPI Ignite Network EDI Framework

We developed the PPI Ignite Network's EDI Framework (see Figure 2), drawing on the Irish Human Rights Equality Commission's *Framework for Building a Culture of Equality and Human Rights in the Workplace*⁴. Using this Framework to develop and to implement our EDI strategy will help the Network to take a planned and systematic approach to embedding a culture of equality, diversity and inclusion across all Network activities.

The EDI Framework is a cyclical process, with continuous review and evaluation leading to revisions to the implementation plan, refreshing of EDI training and supports, and requiring innovation to address gaps in the progress on embedding the Network's EDI principles.

Figure 2: PPI Ignite Network's EDI Framework



PPI Ignite Network EDI strategy

Drawing on the EDI Framework, our EDI strategy is built on four pillars, as follows:

Committed Network:

The PPI Ignite Network leadership, the Programme Managers, and national and local partners are committed to creating an inclusive, diverse and equitable environment for PPI.

Educated stakeholders

The Network commits to building an understanding of and capacity for EDI among all stakeholders.

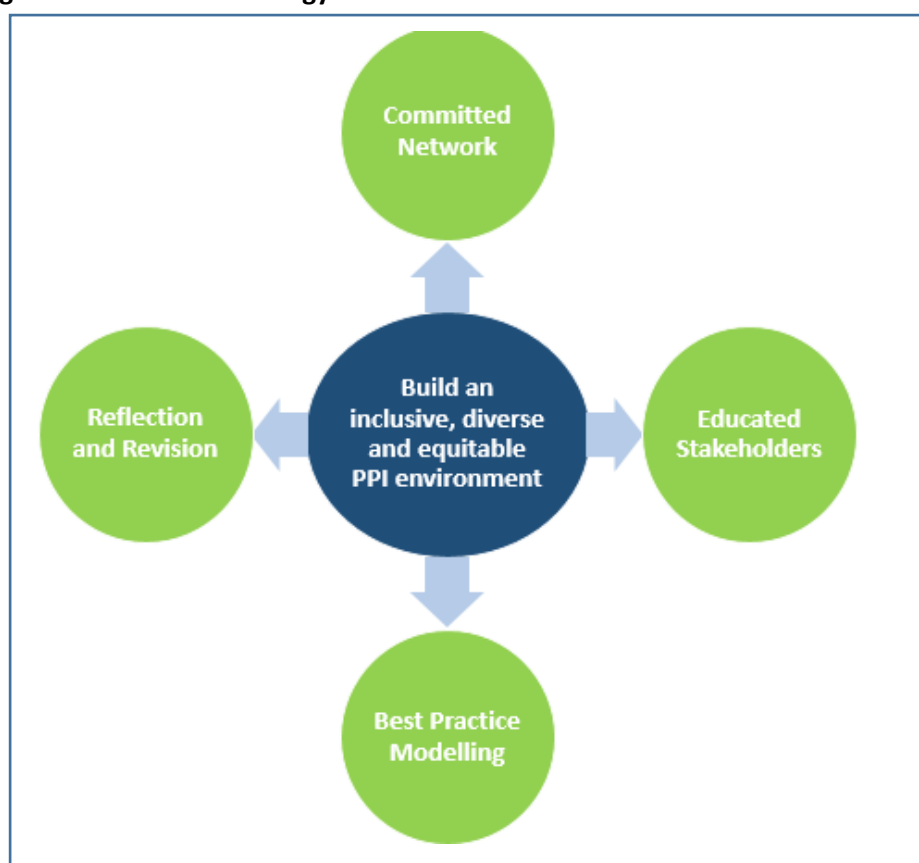
Best practice modelling

The Network strives to demonstrate EDI best practice in all governance, training, education and support activities.

Reflection, review and revision

Working with partners, the Network will develop approaches for reflection, evaluation and revision of EDI plans in keeping with the advice from the HRB Review Panel that *“EDI is something you do, not something you achieve”*. When beginning to implement this strategy, the Network will co-produce an all-island agreed set of principles for EDI in PPI, which will inform the subsequent and ongoing implementation of our EDI strategy.

Figure 3: PPI Ignite Network EDI Strategy



Bringing the EDI strategy to life – Implementation Plan

The implementation plan outlined here covers the period July 2021 to February 2026. The plan will be reviewed and revised during the annual EDI strategic review (see Reflection and Revision below).

Committed Network

Action	Desired outcome	KPIs (exemplars)	Timeline
Co-produce an all-island agreed set of principles for EDI	Shared understanding of EDI across all stakeholders	EDI principles published	Q4, Year 1
Identify an EDI champion on each Network governance entity ¹	Constant EDI lens	# champions at Lead Sites, in partners, in working groups	Q3, Year 1 onwards
Build EDI into the Terms of Reference (ToR) for all Network entities	Responsibility for EDI defined	# ToR with EDI	Q3 , Year 1 onwards
Include EDI as a recurrent agenda item at Network meetings	Constant EDI lens	# meetings	Q3, Year 1 onwards
Working with partners, target opportunities to bring a national focus to EDI	Increased national awareness of EDI in the context of PPI	# initiatives contributed to	Q2 , Year 1 onwards
Ensure an EDI focus in establishing the Public Advisory Panel & External Advisory Panel	Provision of additional EDI perspectives	Evidence of EDI focus during establishment of both panels	Q3 and Q4, Year 1

¹ Network entities include eg Steering Groups at each Lead Site, work package teams

Educated stakeholders

Action	Desired outcome	KPIs (exemplars)	Timeline
Embed an EDI focus in all PPI training delivered by the Network	Awareness of centrality of EDI to PPI	# training events with EDI embedded # attendees	Q2, Year 1 onwards
Embed an EDI focus in UG & PG education	Awareness of centrality of EDI to PPI	# PPI education components that includes an EDI focus # students	Q3, Year 1 onwards
Co-develop short training (video) to define EDI in PPI	Co-developed training building on agreed EDI principles	Video available # views	Q1 Year 2
Co-develop and share illustrative examples of inclusive, diverse and equitable PPI environments	Increased clarity and enhanced understanding of EDI principles	# examples available # usage/views	Q4, Year 1 onwards
Embed EDI section in PPI case study template	Increased clarity and enhanced understanding of goals	Case study template # case studies	Q3, Year 1
Support researchers and organisations to seek and find diverse partners	Increased diversity of PPI contributors/ partners	# researchers and organisations supported	Q3, Year 1 onwards
Engage with underserved groups and allied organisations	Raise profile of PPI amongst underserved communities	# interactions with underserved groups # outputs from these interactions # new PPI contributors	Q2, 2021 onwards

Best practice modelling

Action	Desired outcome	KPIs (exemplars)	Timeline
Model best practice in training and invite critical review by attendees	Enhanced learning by attendees Learning by doing for trainers	# training events impacted # revisions to training	Q3, Year 1 onwards
Model best practice in Network governance meetings and invite critical review by attendees	Enhanced learning by all participants	# meetings with critical review # reported revisions to operation of meetings	Q4, Year 1 onwards
Co-develop, embed and promote EDI aspects of PPI events	Guidance by example	Recommendations developed # Uses of recommendations in planning events	Year 2 onwards

Reflection, review and revise (continuous improvement)

Action	Desired outcome	KPIs (exemplars)	Timeline
Develop, pilot and share appropriate metrics to measure progress on embedding EDI	Relevant, appropriate metrics supporting Network ethos	Agreed metrics published	Q1, Year 2
Develop appropriate and accessible methods to gather input from PPI contributors on the implementation of our EDI plan	Gather PPI contributors feedback	Methods developed # times used # Case study learnings shared	Year 2 onwards
Review feedback at local and Network levels and identify actions	Continuous learnings	# researchers and organisations supported	Year 2 onwards
Sharing learnings via case studies and shared learning events	Shared learning #	# shared learning events	Year 2 onwards
Annual strategic review of EDI initiatives (Public Advisory Panel involved)	Revise strategy (if required)	Annual review Revised strategy	Q1 annually

Oversight and monitoring

Overall progress on implementation of the EDI Strategy will be reviewed on a quarterly basis by the Network Steering Group. In each Work Package, one core team member will champion the EDI strategy, providing EDI input to the work package report for the Steering Group. Each Lead Site will identify an EDI champion and the governance structure at each Lead Site will review progress on the implementation of the EDI strategy regularly, reporting on progress to the Network and funders in the annual report. National and local partners will be encouraged to identify an EDI champion, when appropriate.

The Public Advisory Panel and the External Advisory Panel will each have a brief to offer insights and advice to ensure progress on implementing the EDI strategy. Professor Thilo Kroll, the PPI Ignite Network Lead at UCD, is the EDI champion on the Network Steering Group. Prof Kroll will lead the annual review of EDI initiatives and will report to the Network Steering Group on progress and recommended revisions or areas for improvement. The National Programme Office will be responsible for updating the EDI strategy and implementation plan, as agreed by the Network Steering Group. Through our progress reviews at Lead Sites and our annual EDI review, the Network commits to a culture of continuous learning and improvement on EDI aspects of our work.

Appendix

Table 1: Workshop attendees

Local Partners	National Partners	Other Organisations
AIHPC	HRCI	St. John of Gods
Disability Federation of Ireland	HRB TMRN	Irish Cancer Society
Family Carers' Ireland	HSE R&D	Bangladeshi Community
Global Brain Health Institute	IPPOSI	Fighting Blindness
International Network Towards Alternatives and Rights-Based Supports	Maynooth University	The Wheel
NUI Galway Public Advisory Panel	SPHeRE Programme	
PKU Association of Ireland	Tusla Child and Family Agency	
Sage Advocacy	Queens University Belfast	
UNESCO Knowledge for Change programme		

Figure 4: PPI Ignite Network Lead Universities



Figure 5: PPI Ignite Network National Partners



References

1. [World Medical Association Declaration of Helsinki – Ethical Principles for Medical Research Involving Human Subjects](#) (accessed 15 June 2021)
2. [World Health Organisation](#)
3. [National Institute for Health Research \(2020\) Improving inclusion of under-served groups in clinical research: Guidance from the NIHR INCLUDE project. UK: National Institute for Health Research. Available at: \[www.nihr.ac.uk/documents/improving-inclusion-of-under-served-groups-in-clinical-research-guidance-from-include-project/25435\]\(http://www.nihr.ac.uk/documents/improving-inclusion-of-under-served-groups-in-clinical-research-guidance-from-include-project/25435\)](#) (accessed 15 June 2021)
4. Irish Human Rights and Equality Commission (IHREC) [7 Steps Towards Human Rights and Equality in the Workplace: A Framework for Building a Culture of Equality and Human Rights in the Workplace](#) (accessed 14 May 2021)