✓ **What is UDL?**
Background
Introduction to the framework

✓ **How does it relate to PPI?**
Alignment with PPI values & principles
Examples of where it can be used

✓ **Actions**
Individual activities you can embed

RCSI PPI in RESEARCH

PPI IGNITE NETWORK

What is Universal Design?

Ronald Mace

The design and composition of an environment so that it may be accessed, understood and used
- to the greatest possible extent
- in the most independent and natural manner possible
- in the widest possible range of situations
- without the need for adaptation, modification, assistive devices or specialised solutions, by any persons of any age or size or having any particular physical, sensory, mental health or intellectual ability or disability.

In relation to electronic systems, it means any electronics-based process of creating products, services or systems so that they may be used by any person.

The Disability Act 2005

Design for all   **Inclusive design**   **Accessible design**   **Barrier-free design**

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Universal Design for Learning (UDL)

UD for Education framework developed by CAST (US)

Latest edition: UDL Guidelines 3.0

Based on three core principles that guide the design of equitable learning opportunities

Multiple means of engagement

- the **'WHY'** of learning (motivation)

Multiple means of representation

- the **'WHAT'** of learning (content)

Multiple means of action and expression

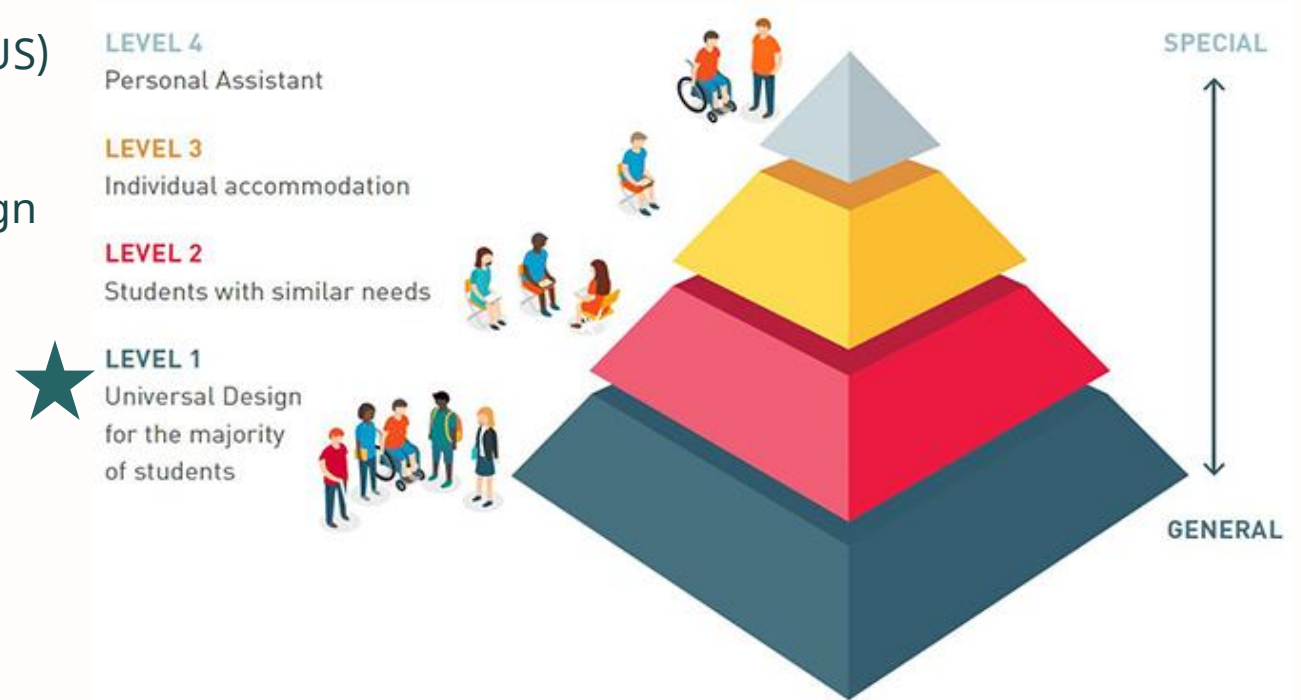- the **'HOW'** of learning (executive function)

LEVEL 4
Personal Assistant

LEVEL 3
Individual accommodation

LEVEL 2
Students with similar needs

LEVEL 1
Universal Design for the majority of students

SPECIAL

GENERAL

Image credit: https://www.ahead.ie/udl-pyramid

Design Multiple Means of
Engagement →

Design Multiple Means of
Representation →

Design Multiple Means of
Action & Expression →

Support

Design Options for
Sustaining Effort & Persistence (8) →

- Clarify the meaning and purpose of goals (8.1) >
- Optimize challenge and support (8.2) >
- Foster collaboration, interdependence, and collective learning (8.3) >
- Foster belonging and community (8.4) >
- Offer action-oriented feedback (8.5) >

Design Options for
Language & Symbols (2) →

- Clarify vocabulary, symbols, and language structures (2.1) >
- Support decoding of text, mathematical notation, and symbols (2.2) >
- Cultivate understanding and respect across languages and dialects (2.3) >
- Address biases in the use of language and symbols (2.4) >
- Illustrate through multiple media (2.5) >

Design Options for
Expression & Communication (5) →

- Use multiple media for communication (5.1) >
- Use multiple tools for construction, composition, and creativity (5.2) >
- Build fluencies with graduated support for practice and performance (5.3) >
- Address biases related to modes of expression and communication (5.4) >

Executive Function

Design Options for
Emotional Capacity (9) →

- Recognize expectations, beliefs, and motivations (9.1) >
- Develop awareness of self and others (9.2) >
- Promote individual and collective reflection (9.3) >
- Cultivate empathy and restorative practices (9.4) >

Design Options for
Building Knowledge (3) →

- Connect prior knowledge to new learning (3.1) >
- Highlight and explore patterns, critical features, big ideas, and relationships (3.2) >
- Cultivate multiple ways of knowing and making meaning (3.3) >
- Maximize transfer and generalization (3.4) >

Design Options for
Strategy Development (6) →

- Set meaningful goals (6.1) >
- Anticipate and plan for challenges (6.2) >
- Organize information and resources (6.3) >
- Enhance capacity for monitoring progress (6.4) >
- Challenge exclusionary practices (6.5) >

PPI

Public involvement in research is research carried out 'with' or 'by' patients or public rather than 'to', 'about' or 'for' them

It is an **active partnership** between patients, carers, family members, service users, friends, and members of the public (intended to be a very inclusive term) with researchers that **influences and shapes research**.

(NIHR, UK/HRB)

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PARTICIPATION

ENGAGEMENT

INVOLVEMENT

People giving their data to researchers in a research study , as 'research subjects' or 'research participants'

Researchers communicating about their research with people

Researchers collaborating with patients/public across the research cycle

PPI

The 'what'

Involvement in what is being researched.
How have the public and patients been involved in identifying the research aim/topic etc.

- Working with a Parkinson's charity to identify research priorities for Parkinson's disease
- Co-writing a research grant with people with epilepsy for an epilepsy research project

- Helping the researchers explain their work better on a patient consent form for a clinical trial
- Suggesting different routes to finding participants for an interview study on teenage mental health

The 'how'

Involvement in how the research is taking place
How have/will patients have input into how the research is designed, undertaken managed etc.

Decisions

Having a voice in decisions.
Who makes the decisions about 'what' and 'how'?
The "acid test".

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PPI IGNITE NETWORK

PPI Ignite Network Values and Principles

The PPI Ignite Network believes that, in order to improve public and patient involvement (PPI) in health-related research, there must be a shared understanding of the values and principles that underpin the work. We invite all researchers, PPI contributors, institutions and funders to consider how to uphold these values and principles when engaging in or supporting PPI activity.

Transparency

The need for **clear, open, mutual communication** between the research team and PPI partners about research decisions and progress.

We want transparency in developing a **clear, shared understanding of aims, roles, processes and other terms of involvement.**

Trust

The **building of reciprocal trust; this takes time to develop, is relationship based** and needs to be consistently worked on.

We want **everybody's opinion to be fully heard** and we want **confidentiality to be negotiated and respected.**

Collaboration & Partnership

The **inclusion of PPI partners** throughout the research lifecycle with commitments and expectations agreed from the outset, as much as possible.

We want true partnership where **all contributions are valued and respected equally.**

Respect

The **recognition of the roles, knowledge, insights, experiences, strengths, limitations and contributions** across the research team and PPI partners and throughout the research lifecycle.

We want **to benefit from the diversity of the team and partners**, and work together effectively and enjoyably.

Empowerment & Power Sharing

The inclusion as early as possible **in funding decisions, strategy and decision-making, the co-design and co-production of research.**

We want **a wide range of involvement strategies** to ensure that this happens.

Flexibility

The **recognition of the time and other commitments involved in PPI** and that this **is acted upon in the research plan.**

We want **to co-design appropriate changes and responses** to the experiences and to the views of PPI partners.

Equity & Inclusion

The active identification and **removal of barriers and creation of entry points** throughout the research lifecycle.

We want real co-design and partnership to take place that **values equally people's diversity of opinions, experiences, abilities, backgrounds and expertise.**

Aligning Values & Principles

Universal Design	RCSI	PPI Ignite Network	National Access Plan
Equitable use	Respect	Respect	Inclusivity
Flexibility in use	Collaboration	Transparency	Flexibility
Simple and intuitive	Scholarship	Empowerment & Power sharing	Clarity
Perceptible information	Innovation	Trust	Coherence
Tolerance for error		Flexibility	Sustainability
Low physical effort		Collaboration & Partnership	Using an evidence-driven approach
Size and space for approach and use		Equity & Inclusion	

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PPI IGNITE NETWORK

UDL & PPI

UDL: supporting learners to become competent and confident at learning itself (CAST)

PPI: the public and patients are involved in planning and doing research from start to finish and help tell the public about the results of research (PPI Ignite Network)

UDL Benefits for colleges

- A reduction in the need for individualised supports

and the associated cost savings

- Better outcomes for all students, not just students

with disabilities and international students

- Lower drop-out rates

- A more diverse student body

PPI Challenges
- Finding PPI contributors
- Time & resources
- Expectations
- Disengagement

Barriers to PPI that occur a great deal or a lot (N=26)

Barrier	Percentage
Lack of dedicated time	54%
Lack of budget	43%
Requests from researchers for PPI support at short notice	27%
Poor communication between researchers and your organisation regarding PPI	27%
Lack of understanding on the part of researchers about your responsibilities to PPI contributors	27%
Issues maintaining PPI contributors' interest	15%
Issues in reaching PPI contributors	8%
Lack of expertise in patient involvement	4%
Lack of support for patient involvement within the organisation	0%

The role of health research charities in PPI: Results of a HRCI member survey HRCI June 2024

Evaluation

"The most important kind of assessment, from a UDL perspective, is formative assessment.

These kinds of assessments (check-ins, pause-and-think exercises, and other forms of reflection) play an essential role in guiding and redirecting learning toward the appropriate goal"

RCSI PPI in RESEARCH

Framework for
QUALITY IMPROVEMENT IN PUBLIC AND PATIENT INVOLVEMENT
in health and social care research

Public Involvement Impact Assessment Framework (PiiAF)

Introduction

Structure

Part 1: PiiAF ➡

Part 2: Assessment Planning ➡

Resources

Summary of our Research

Welcome to the PiiAF website
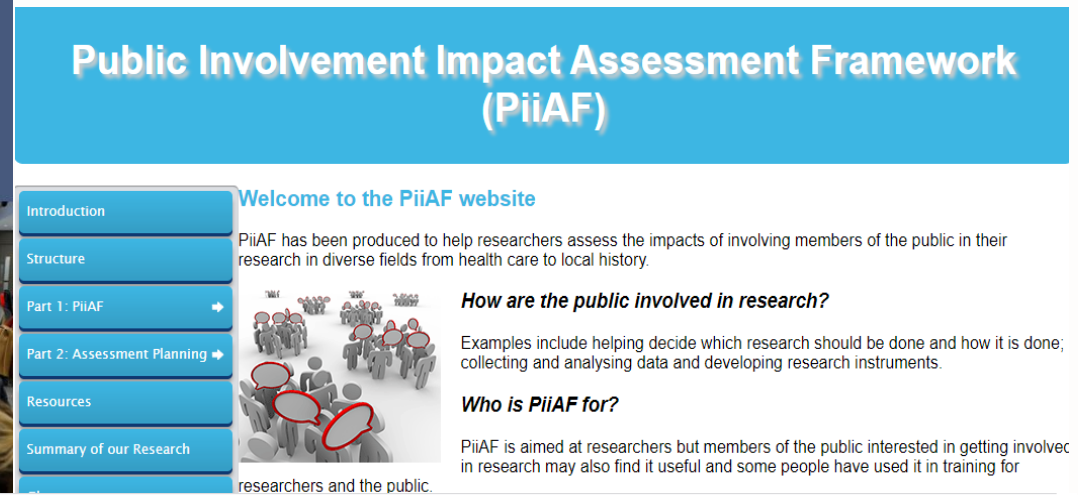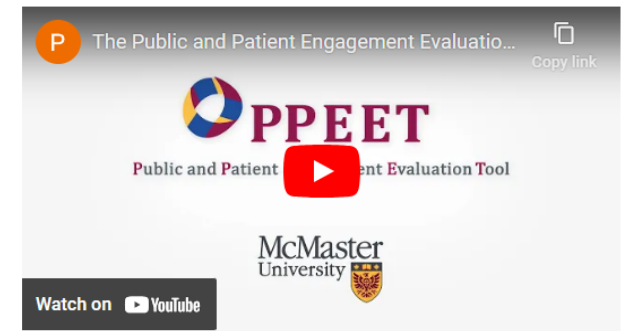
PiiAF has been produced to help researchers assess the impacts of involving members of the public in their research in diverse fields from health care to local history.

How are the public involved in research?

Examples include helping decide which research should be done and how it is done; collecting and analysing data and developing research instruments.

Who is PiiAF for?

PiiAF is aimed at researchers but members of the public interested in getting involved in research may also find it useful and some people have used it in training for researchers and the public.

Public and Patient Engagement Evaluation Tool

The **Public and Patient Engagement Evaluation Tool (PPEET)** is a series of three questionnaires to evaluate public and patient engagement. The tool was developed primarily for use within health system organizations but has also been used to evaluate engagement within other contexts (e.g., health research).

PPEET
Public and Patient Engagement Evaluation Tool

McMaster University

Watch on YouTube

Public Involvement in Research Impact Toolkit (PIRIT)

PIRIT
Public Involvement in Research Impact Toolkit

Where to start?

Plus One Approach

You do not have to try apply all principles at once

Add one more choice for learners to support their learning/interaction

'Pinch Points'

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Readability

Write accessible text
- Left align your text
- Use bold and italic sparingly
- Avoid all UPPERCASE and underlined text
- Ensure your colour combinations have sufficient contrast
- Do not convey information using colour alone

Avoid putting text into images
- If you absolutely must use an image of text, ensure the Alt Text exactly matches the text in the image.

Share a glossary of common terms contributors will come across

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Addressing inequalities in clinical trials

The lack of diversity of participants in clinical research has long been recognised as a significant challenge. National Voices undertook a consultation among its members and Lived Experience Partners to identify key barriers to diverse participation in clinical and research trials, and potential ways to address these.

Barriers to participation in clinical trials

Fear and mistrust, experience of racism, trials not designed inclusively

Failure to support additional communication needs; lack of outreach to raise awareness

Trials only available in certain places; lack of financial support; no support for carers

Potential Solutions

Offer financial support and incentives

Be proactive in making trials inclusive

Engage in outreach through trusted community organisations – and pay them for their work

Provide videos or audio versions; make sure there's someone to call with any questions

Explain what the research is all about and what support will be available

Recognise people as experts in their own conditions; diversify the workforce; provide feedback

Involve people with lived experience as equal partners throughout the trial process

Taking action

Build capacity in supporting inclusion and in working with people and communities

Proactively raise awareness of trials ensuring communications are accessible and inclusive

Share power and commit to co-production

Work with trusted intermediaries with links into communities

Provide support to cover the costs of participating, including transport, care and out of pocket expenses

PPI NATIONAL FESTIVAL 10-23 OCTOBER 2022

Slide Credit: PPI Ignite Network National Office

For more information, visit: www.ppinetwork.ie

Funded by: IRISH RESEARCH COUNCIL An Chomhairle um Thaighde in Éirinn   HRB Health Research Board

PPI NATIONAL FESTIVAL

Voices that matter: A live conversation

Tutorial Room 3, RCSI 123 St Stephen's Green

Thursday 17th October 2024   13:00 - 14:00
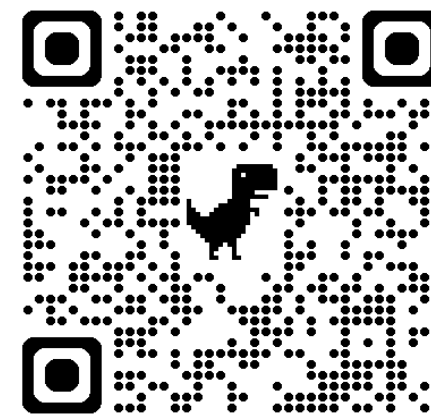
Let's talk about childhood cancer

Muchnik Theatre, RCSI 26 York Street

Thursday 17th October 2024   15:00 - 17:00

PPI NATIONAL FESTIVAL

📢 PPI in the Park

📍 St Stephen's Green, Dublin

📅 Monday 21st October 2024 🕐 11:00am - 12:00pm

❓ carrolpd@tcd.ie or niamhdillon@rcsi.ie

- Join PPI Ignite Network @ TCD and RCSI for a walk, talk & tea/coffee!
- Researchers, staff, students, PPI contributors & newcomers all welcome
- Pre-registration required – scan to sign-up!

PPI IGNITE NETWORK
PRESENTATION TITLE
Prof Name Surname, Title, Organization

HRB Health Research Board

IRISH RESEARCH COUNCIL
An Chomhairle um Thaighde in Éirinn

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

RCSI
UNIVERSITY OF MEDICINE AND HEALTH SCIENCES

References & Further Reading

The Centre for Excellence in Universal Design, established by the National Disability Authority in 2007. https://universaldesign.ie/ (contains useful guides on written and digital communication)

AHEAD (An independent non-profit organisation working with and for disabled people to shape inclusive and empowering environments in tertiary education and employment) https://www.ahead.ie/udl

CAST (2024). UDL Guidelines 3.0. Available in lots of different downloadable formats including multiple languages https://udlguidelines.cast.org/more/downloads/

CAST (2018). UDL and the learning brain. Wakefield, MA: Author. Retrieved from http://www.cast.org/our-work/publications/2018/udl-learning-brain-neuroscience.html

National Institute for Health and Care Research (NIHR) A practical guide to being inclusive in public involvement in health research: Lessons learnt from the Reaching Out programme, April 2021.

FOR EQUITY: Further resources for health equity sensitive research. https://forequity.uk/general-resources/ FOR EQUITY was produced by a team at Lancaster University. It was funded by the NIHR School for Public Health Research (https://sphr.nihr.ac.uk) and the NIHR Applied Research Collaboration North West Coast (https://arc-nwc.nihr.ac.uk).

Habibzadeh F. Disparity in the selection of patients in clinical trials. Lancet. 2022 Mar 12;399(10329):1048. doi: 10.1016/S0140-6736(22)00176-3

RCSI PUBLIC and **PATIENT INVOLVEMENT** in **RESEARCH**

Thank you!

ppi@rcsi.ie

@RCSI_PPI_Ignite

RCSI UNIVERSITY OF MEDICINE AND HEALTH SCIENCES

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