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Let's have active involvement...

Patients should be colleagues...

Research

Welcome!

This keeps the research grounded & realistic

I bring real life expertise

Hello... I'm a user and I am not the problem.

User

I see!

Developers
Some terminology-PPI

Research carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them (INVOLVE)

When using the term ‘public’ we include patients, potential patients, carers and people who use health and social care services as well as people from organisations that represent people who use services. Whilst all of us are actual, former or indeed potential users of health and social care services, there is an important distinction to be made between the perspectives of the public and the perspectives of people who have a professional role in health and social care services.

Involving patients and the public in research is key to ensuring all aspects of research are relevant and accessible to the community in which the research is directed.

http://www.invo.org.uk/public-involvementparticipationengagementin-research/
Definitions

Involvement

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

Engagement

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

Participation

Patients and the public are tested as ‘subjects’ of a study.
Examples of PPI involvement:

- As joint grant holders or co-applicants on a research project;
- involvement in identifying research priorities;
- as members of a project advisory or steering group;
- commenting and developing patient information leaflets or other research materials;
- undertaking interviews with research participants (Co-researchers);
- user and/or carer researchers carrying out the research.

What it's not:

- Participants in research project/clinical trial;
- Donating sample materials for research;
- Answering questionnaires;
- Providing opinions in focus groups/seminars/conferences etc.
Embedding PPI in Irish research culture - It's not going away!

- HRB PPI Ignite Awards 2017: Supporting Public and Patient Involvement in Research

- HRB survey: gap around need for support & advice about how to include public/patients in research to ensure meaningful collaboration & partnership

- Awards designed to address this gap through building capacity for PPI in research in Irish universities

- Working towards a National PPI Ignite Network
**Knowledge Mobilisation and Network Formation**
To establish/provide networks, structures and processes to facilitate meaningful and reciprocal knowledge exchange.

**Capacity & Capability**
To support and develop ongoing training and education that builds PPI Capacity both within UCD and externally with our partners.

**Research**
To capture best PPI research practice and transfer them into practice to enable immersion.

#ppi_ignite
Public Engagement

Based on Wellcome Trust Public Engagement ‘Onion’
Where does the project lie on the “avocado”?
A significant focus of the UCD PPI Ignite Connect program is to overcome the often-identified challenges as noted by UCD researchers and within the literature of engaging ‘seldom heard groups’. Seldom heard’ a term defined by NHS involvement:

“Describe groups who may experience barriers to accessing services or are under-represented in healthcare decision making.”

Being ‘seldom heard’ indicates that existing structures, organisations and services that target their needs are not adequately enabling their voice to be heard via their current participation processes.
Clarifying the mechanisms and resources that enable the reciprocal involvement of seldom heard groups in health and social care research: A collaborative rapid realist review process

Éilín Nic Shé, PhD; Sarah Morton, PhD; Veronica Lambert, PhD; Cliona Ni Cheallaigh, MD, PhD; Vanessa Lacey, BA; Eleanor Dunn, PhD; Cliona Loughnane, PhD; Joan O'Connor, MSc; Amanda McCann, PhD; Maura Adshead, PhD; Thilo Kroll, PhD
Environmental and Social Planning: changing the physical space of meetings 7 mechanisms and Linked Resources

Service Provision: to enable reciprocal involvement 6 mechanisms and Linked Resources

Guidelines: creating protocols/policies of best practice 4 mechanisms and Linked Resources

Fiscal Measures: having core funding for PPI 6 mechanisms and Linked Resources

Communication and Marketing: using diverse modes of communication 4 mechanisms and Linked Resources

Regulation & Legislation: changing funding calls 6 mechanisms and Linked Resources

33 Programme Theories on the mechanism and resources that enable the reciprocal involvement of seldom heard groups in health and social care research
SAFE
Systematic Approach to Improve Care for Frail Older Persons

Where's the older person in all of this?

THE FRAILTY PATHWAY
Enabling public, patient and practitioner involvement in co-designing frailty pathways in the acute care setting

Deirdre O’Donnell1, Óidín Ní Shé1, Mary McCarthy2, Shirley Thornton3, Thelma Doran2, Freda Smith4, Barry O’Brien4, Jim Milton4, Bibiana Savin5, Anne Donnellan6, Eugene Callan7, Eilish McAuliffe1, Simone Gray8, Therese Carey8, Nicola Boyle8, Michelle O’Brien8, Andrew Patton8, Jade Bailey9, Diarmuid O’Shea8 and Therese Cooney Marie8
Using a Co-design Approach

The co-design employed in this study was guided by principles of authentic collaboration with older people and representatives of frail older people.

Ten participants were recruited from the membership of NGO and community-based patient and public advocacy organisations.

Eight healthcare practitioners were involved on a rotating basis along with three academic researchers from UCD.
Four Pillars of Involvement

1. Research environment and receptive contexts;

2. Expectations and role clarity;

3. Support for participation and inclusive representation and;

4. Commitment to the value of co-learning involving institutional leadership.
<table>
<thead>
<tr>
<th>Priority Area</th>
<th>Interventions</th>
<th>Co-design Outcomes</th>
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<tbody>
<tr>
<td>Collaboration along an integrated care continuum</td>
<td>a) Early identification of frail patients upon admission</td>
<td>Rockwood frailty: Numbers screened</td>
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<td>for frail older patients</td>
<td>b) Addressing organisational barriers on integrated care pathway</td>
<td>Development of frailty index and its association with length of stay, mortality and discharge destination</td>
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<td>Improved bi-directional flow between primary care, acute and community based rehab or step-down institutions</td>
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<td>Improved discharge planning processes to the integrated community care team</td>
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<td>Continent care</td>
<td>a) Intentional rounding (IR)</td>
<td>Rapid access pathways between GP and day hospital (bi-passing ED).</td>
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<td>b) HCA skills fare</td>
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<td>Improved mobility</td>
<td>a) Introduction of FITT team in the emergency department</td>
<td>Hours from ED admission to first FITT therapy attendance</td>
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<td>b) End PJ Paralysis scheme</td>
<td>(OT, PT, Dietetics and SLT)</td>
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<td>Numbers screened as frail who had FITT service and their average length of stay</td>
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<td>Patients mobilising on the ward</td>
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<td>Patients sitting out of bed on the ward</td>
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<td>Access to food and hydration</td>
<td>a) HCA dedicated role in ED</td>
<td>Access to a drink on ward (IR)</td>
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<td>b) Intentional rounding</td>
<td>Access to a drink in ED (HCA)</td>
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<td>c) Red Tray</td>
<td>Energy and protein consumption</td>
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<td>d) HCA skills fare</td>
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<td>Improved patient information and signage</td>
<td>a) IR and use of notice boards on ward</td>
<td>Comment and feedback from patients regarding</td>
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<td>b) Written daily care plans with goals</td>
<td>Information dissemination</td>
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<td>c) Patient information leaflet regarding mobilisation</td>
<td>Signs at the correct height</td>
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<td>d) Establishment of Environmental Dementia Committee</td>
<td>Writing large enough and easy to read (Colours and readability)</td>
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<td>Patients able to find their way around using signs alone</td>
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Thank you

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