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ORIGINAL RESEARCH PAPER

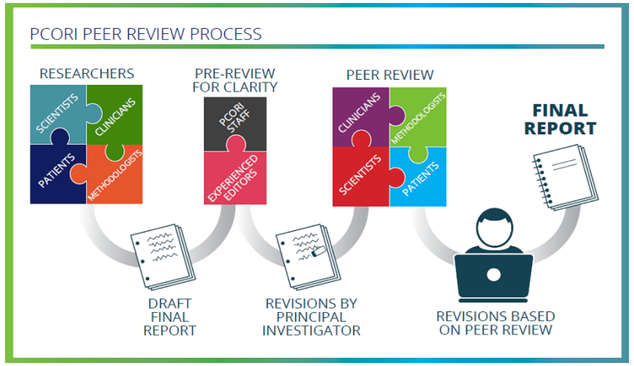
Reciprocal relationships and the importance of feedback in patient and public involvement: A mixed methods study

Elspeth Mathie MA, PhD | Helena Wythe PhD | Diane Munday | Paul Millac MA, BChir, MD, FRCP | Graham Rhodes BA, A.C.I.I | Nick Roberts | Nigel Smeeton MSc | Fiona Poland MA Econ, PhD | Julia Jones PhD, BA (Hons)

ISQua — Perspectives on Quality

It's not just 'What' you do, it's also the 'Way' that you do it: Patient and Public Involvement in the Development of Health Research

TRACEY J. DEVONPORT, WENDY NICHOLLS, LYNNE H. JOHNSTON, ROBIN GUTTERIDGE, and ANGELA WATT



RESEARCH ARTICLE — Open Access

Public involvement could usefully inform ethical review, but rarely does: what are the implications?

Kristina Staley and Jim Elliott

PARTNERING WITH PATIENTS

thebmj

REVIEW ARTICLE — Open Access

Patient and public involvement in reducing health and care research waste

Virginia Minogue, Mary Cooke, Anne-Laure Donskoy, Penny Vicary and Bill Wells

COMMENTARY — Open Access

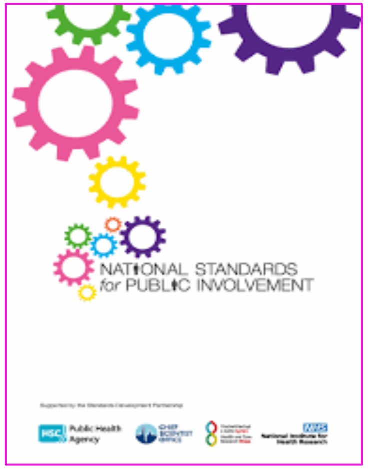
Advancing patient engagement: youth and family participation in health research communities of practice

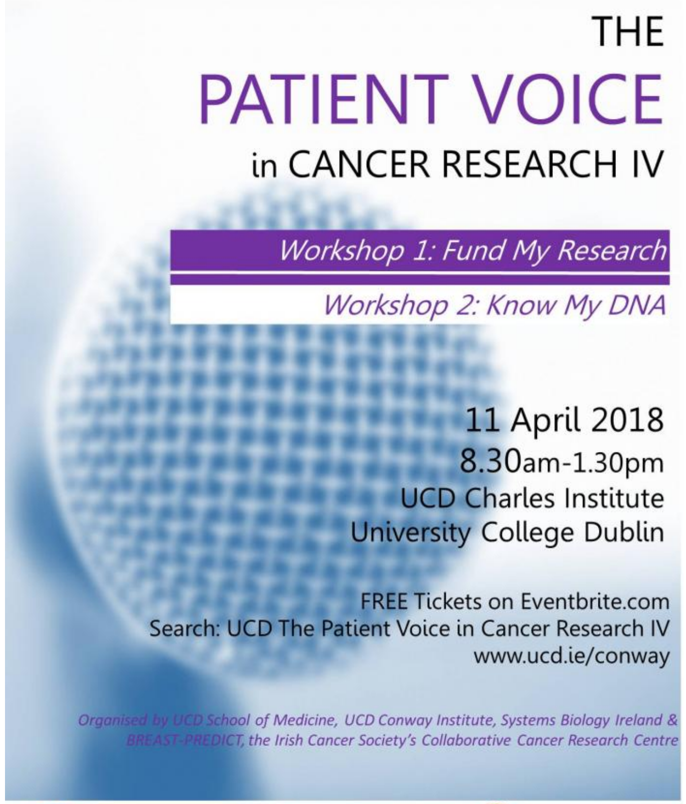
Roberta L. Woodgate, Melanie Zurba and Pauline Tennent

BMJ Open — Open Access — Research

Frequency of reporting on patient and public involvement (PPI) in research studies published in a general medical journal: a descriptive study

Amy Price, Sara Schroter, Rosamund Snow, Melissa Hicks, Rebecca Harmston, Sophie Staniszewska, Sam Parker, Tessa Richards



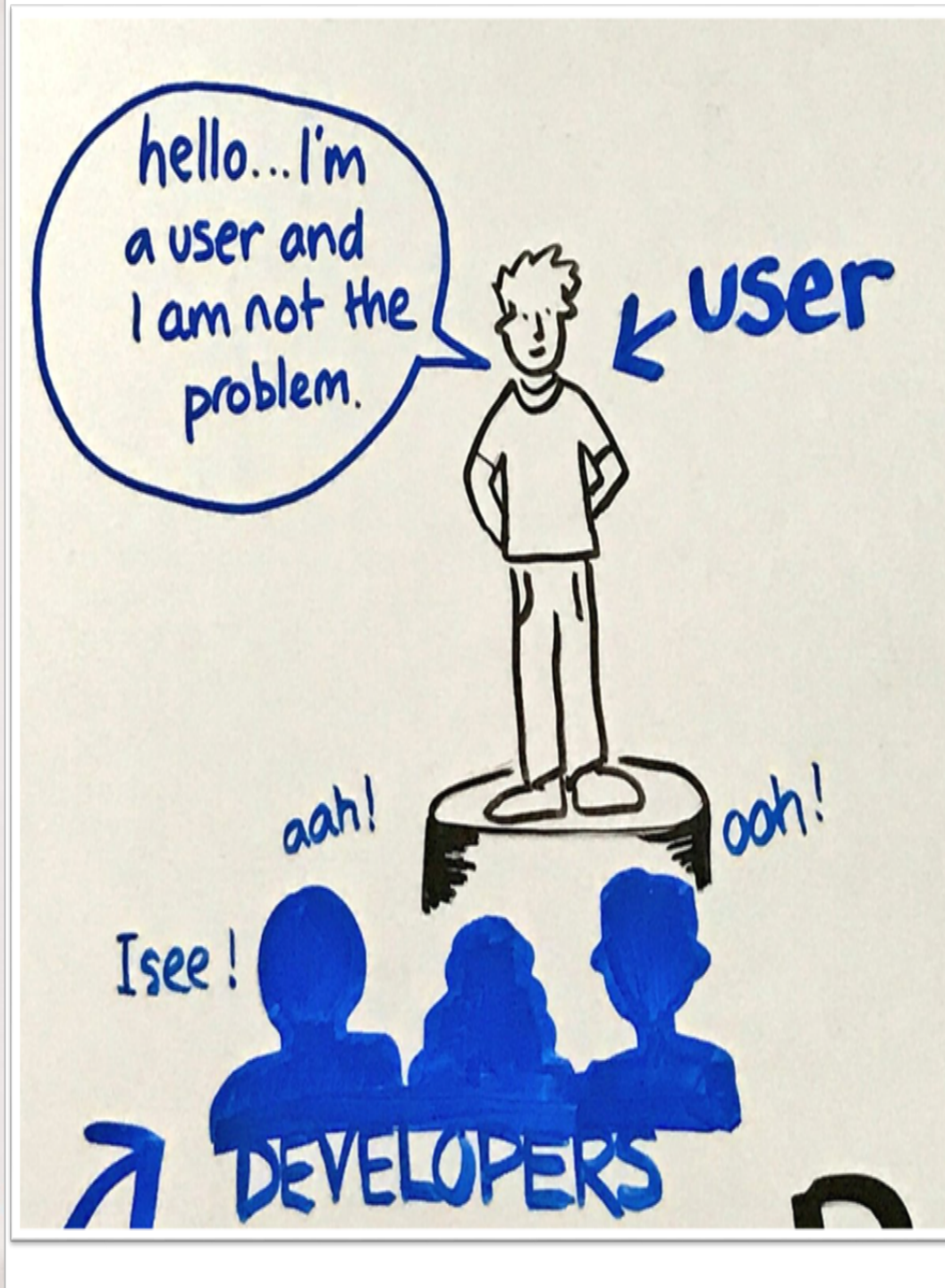


Patients Included

Cochrane Colloquium Edinburgh

16-18 September 2018 | Edinburgh, UK


Lets 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
aah!
ooh!
Isee!
DEVELOPERS

Some terminology-PPI

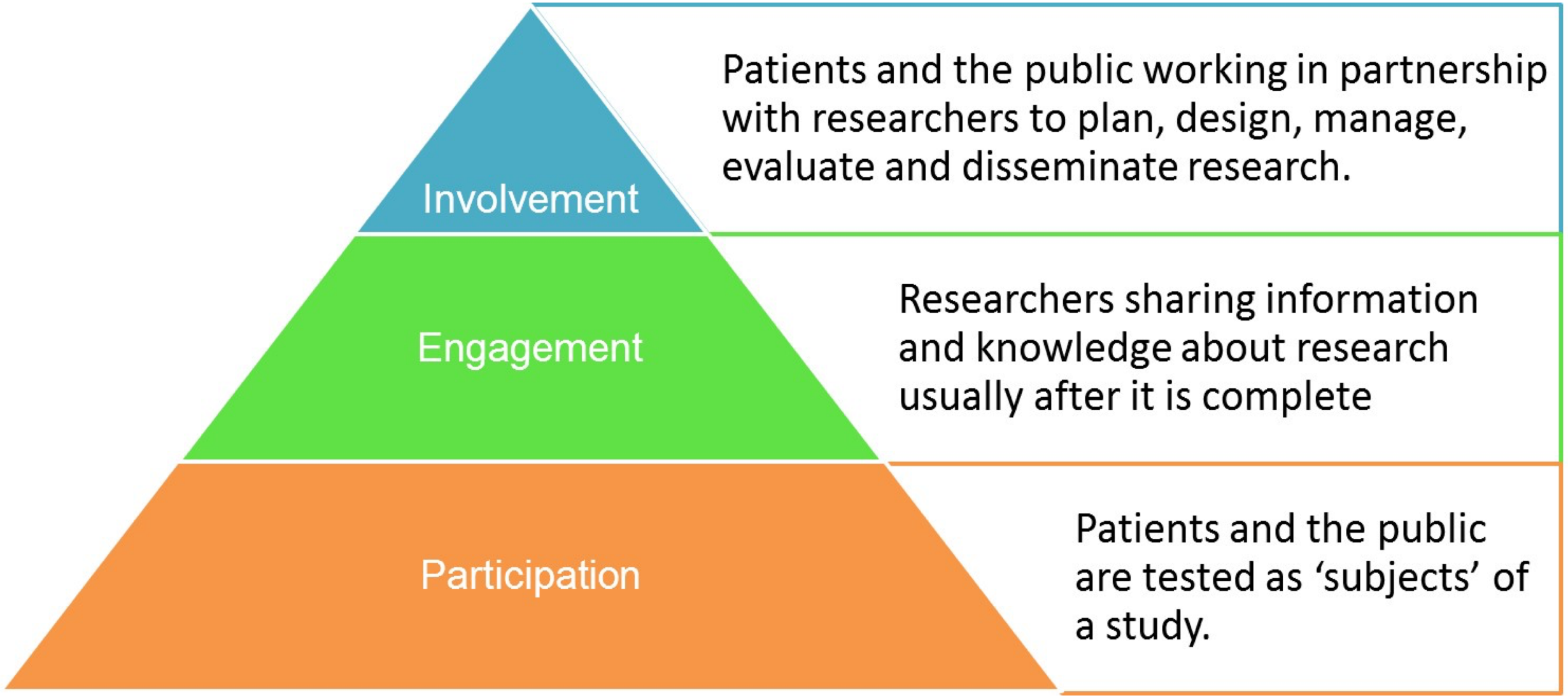
Research carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them (INVOLVE)

*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.*

*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.*

http://www.invo.org.uk/public-involvementparticipationengagement-in-research/

Definitions



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 its 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-Its 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

UCD PPI Ignite

CAPACITY & CAPABILITY

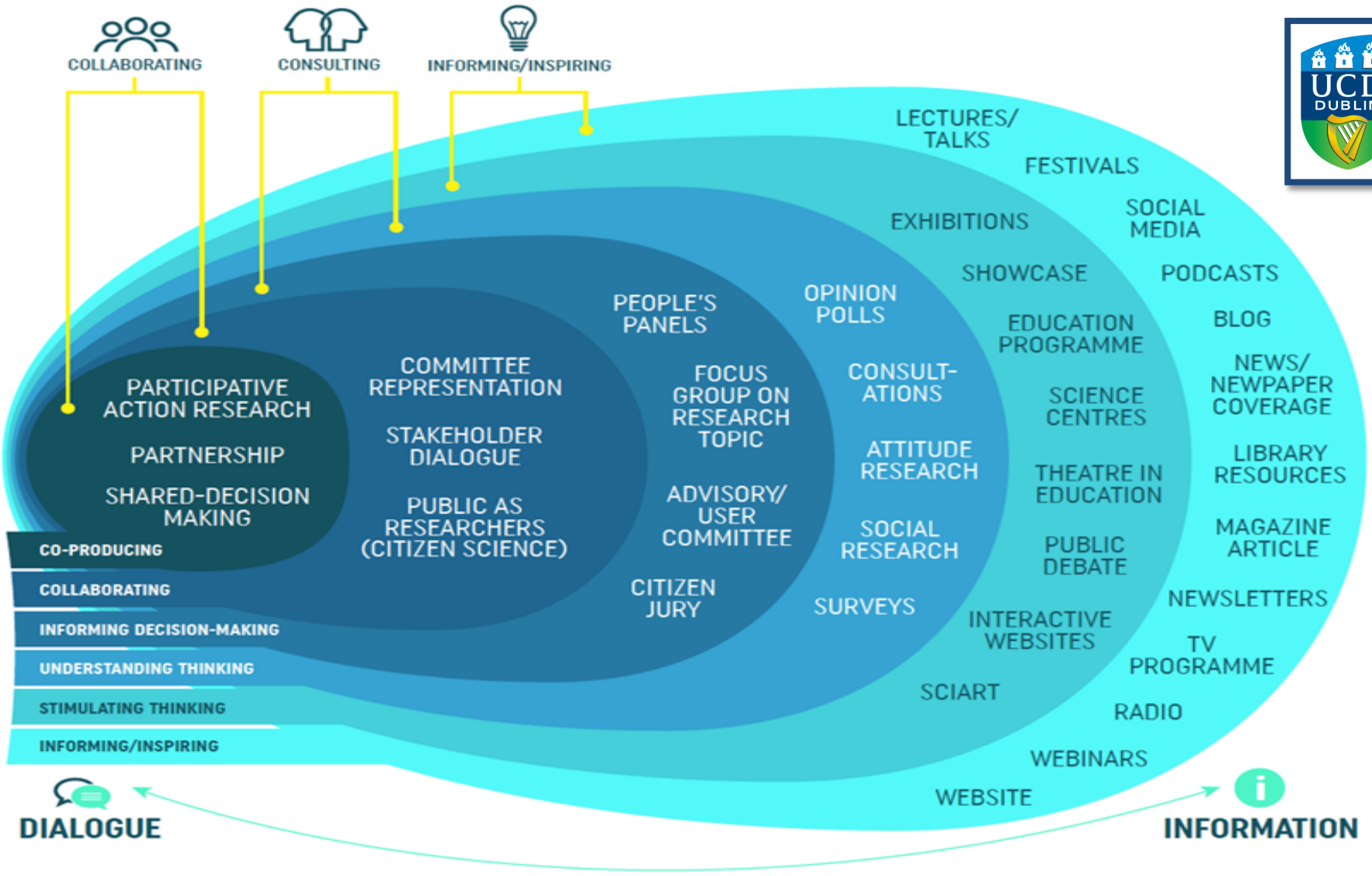
To support and develop ongoing training and education that builds PPI Capacity both within UCD and externally with our partners

RESEARCH

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

#ppi_ignite

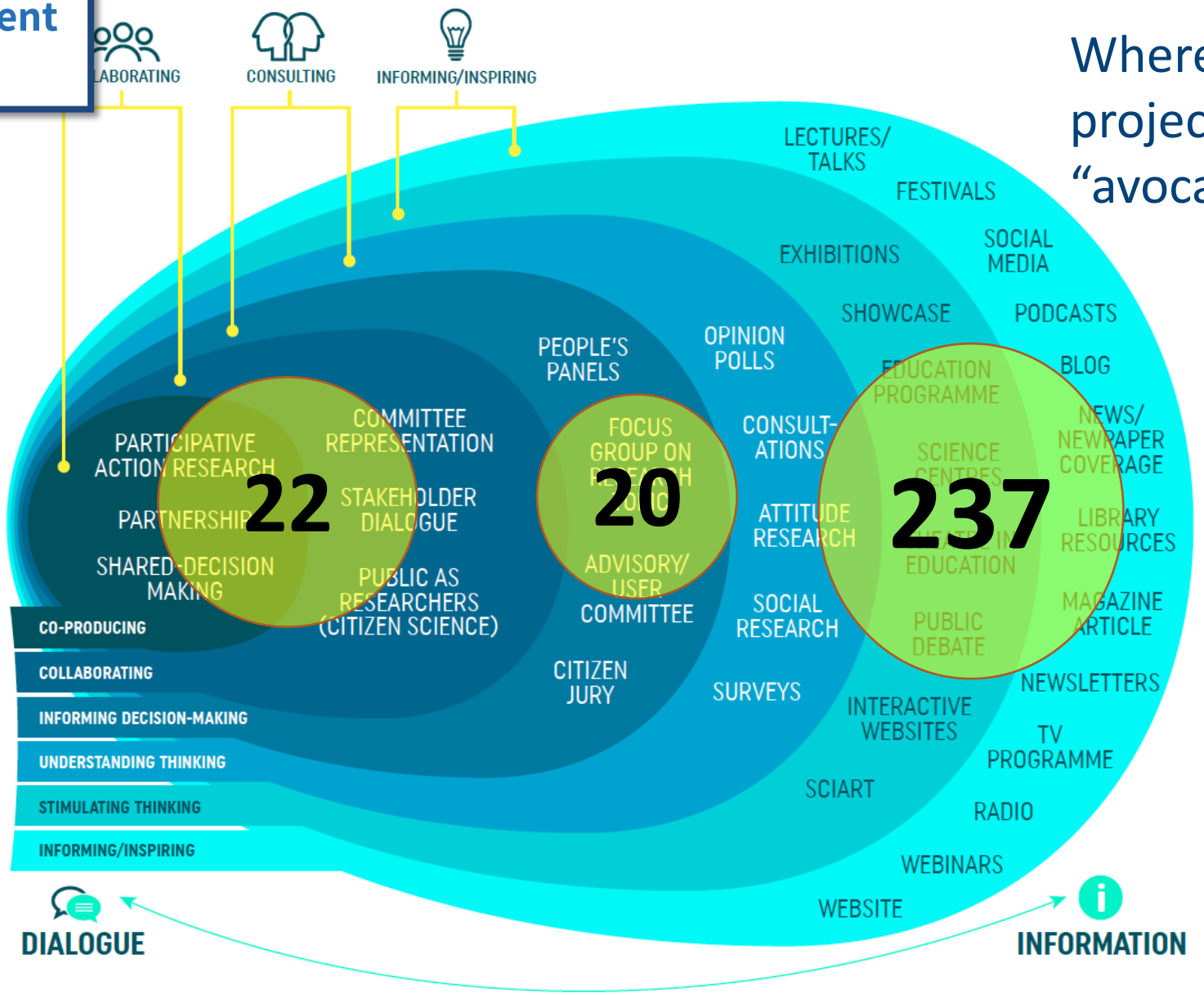
Public Engagement



Based on Wellcome Trust Public Engagement 'Onion'

Public Engagement

Where does the project lie on the "avocado"?



Based on Wellcome Trust Public Engagement 'Onion'

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.

UCD DUBLIN

UCD PPI Ignite

sage Support & Advocacy Service

Ireland East Hospital Group

Spinal Injuries Ireland

Cystic Fibrosis Ireland

HEAL

dfi

Family Carers Ireland

Dublin Simon Community

IPPOSI

Health Experience Research Group, University of Oxford

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REVIEW ARTICLE

WILEY

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

Éidín Ní Shé PhD[1] | Sarah Morton PhD[2] | Veronica Lambert PhD[3] | Cliona Ní Cheallaigh MD, PhD[4,5] | Vanessa Lacey BA[6] | Eleanor Dunn PhD[7] | Cliona Loughnane PhD[8] | Joan O'Connor MsC[9] | Amanda McCann PhD[10] | Maura Adshead PhD[11] | Thilo Kroll PhD[1]

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

33 Programme Theories on the mechanism and resources that enable the reciprocal involvement of seldom heard groups in health and social care research

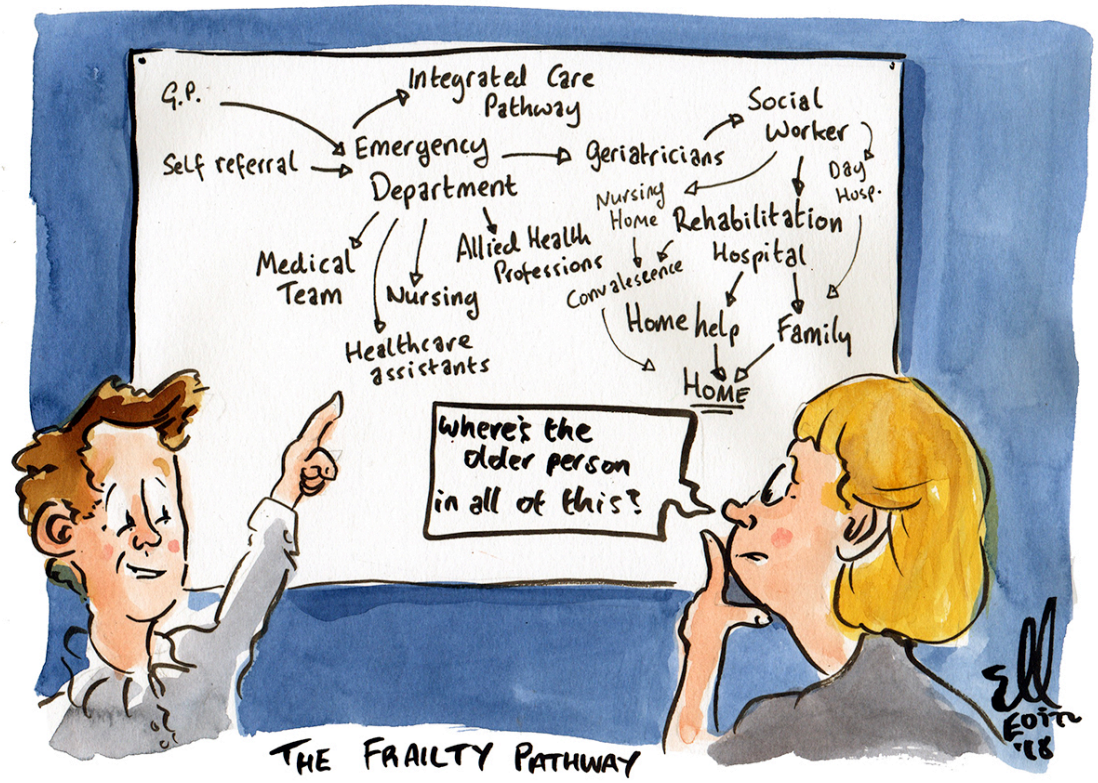
Fiscal Measures: having core funding for PPI
6 mechanisms and Linked Resources

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

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

SAFE

Systematic Approach to Improve Care for Frail Older Persons



O'Donnell *et al. BMC Health Services Research* (2019) 19:797
https://doi.org/10.1186/s12913-019-4626-8

BMC Health Services Research

RESEARCH ARTICLE Open Access

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

Deirdre O'Donnell[1*], Éidín Ní Shé[1], Mary McCarthy[2], Shirley Thornton[3], Thelma Doran[2], Freda Smith[4], Barry O'Brien[4], Jim Milton[4], Bibiana Savin[5], Anne Donnellan[6], Eugene Callan[7], Eilish McAuliffe[1], Simone Gray[8], Therese Carey[8], Nicola Boyle[8], Michelle O'Brien[8], Andrew Patton[8], Jade Bailey[9], Diarmuid O'Shea[8] and Therese Cooney Marie[8]

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 1 Five priority areas for enhanced service delivery; related interventions and patient-centred evaluation outcomes

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

Thank you

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