The Mechanisms and Resources that Enable the Reciprocal Involvement of Seldom Heard Groups in Health and Social Care Research
Introduction
The UCD Public and Patient Involvement (PPI) Ignite program is actively embedding PPI in health and social care related research, education and training, professional practice and administration across UCD structures. PPI is increasingly embedded as a core activity in research funding calls and best practice guidelines. However, there is recognition of the challenges that prevail to achieve genuine and equitable forms of engagement.

Our objective was to identify the mechanisms and resources that enable the reciprocal involvement of seldom heard groups in health and social care research.
Key Terms Defined

Seldom Heard is a term defined by NHS involvement\(^1\) to: “Describe groups who may experience barriers to accessing services or are under-represented in healthcare decision making. Traditionally, some of the groups identified in engagement activities include rural communities, black and minority ethnic (BME) groups, gypsies and travellers, lesbian, gay, bisexual and transgender, asylum seekers and refugees and young carers. However, in reality, teenagers, employees, people with mental health issues and many others may be considered as seldom heard, due to the fact engagement may not be straightforward”.

Other population groups may also face marginalisation and exclusion from engagement, including people with disabilities, people with a rare disease, frail older people and people in institutional settings (e.g. care homes, prisons). 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 (Ryan et al., 2017)

Reciprocity implies give and take where there is a mutual negotiation of meaning and power. Reciprocity demands that the ‘research enables people to know and control their world by engaging participants from the start of the research planning and design’ (Baker et al., 2004: 182).

Method

We convened an expert panel consisting of 11 people who have experience in health and social care systems, PPI, co-design, emancipatory research and people and organisations representing seldom heard groups. The group agreed that a rapid realist review (RRR) would be undertaken as it allows for the engagement of knowledge users throughout the review process. In contrast to a systematic review, the RRR builds an understanding of why and how things work (programme theories).

The expert panel clarified the scope and the overarching RRR question as being: “What are the mechanisms that enable the reciprocal involvement of seldom heard groups?” A rapid realist review of the literature was undertaken that included: (i) a systematic search of CINAHL, PsycINFO, PubMed and Open Grey (2007-2017); (ii) documents provided by expert panel members of relevant journals and grey literature.

We undertook 6 reference panels which are local sounding boards undertaken in an RRR to ensure that the review and the developed programme theories is inclusive to the experience of those ‘on the ground’.

1. Dublin Simon Community: an organisation working to prevent and address homelessness in the Dublin, Kildare, Wicklow and Meath.
2. Disability Federation of Ireland (DFI): a 130-member organisation working towards equality for people with disabilities.
3. Pavee Point: a national organisation focused on improving the human rights of Irish Travellers and members of the Roma community.
4. Transgender Equality Network of Ireland (TENI): a national organisation working on improving conditions and advance the rights and equality of Trans people and their families.
6. Longford Women’s Network: a women’s centre based in the rural midlands town of Longford supporting women to fulfil their potential in a safe and equal society

\(^1\) NHS Involvement: http://www.nhsinvolvement.co.uk/connect-and-create/auto-generate-from-title/seldom-heard-groups
Results

From the review 20 documents were identified and combined with the six reference panel summaries. The expert panel reached consensus about 33 programme theories. These relate to environmental and social planning (7); service provision (6); guidelines (4); fiscal measures (6); communication and marketing (4); and regulation and legislation (6).

**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

**Programme Theories: Environmental and Social Planning - Focused on changing the physical or social context**

1. Ensure collaboration and engagement occurs in safe, accessible and inclusive spaces as identified by community partners.
2. Enable researcher/s presence in community spaces to develop connections and build trust over time.
3. Undertake an audit of involvement spaces, by all partners, prior to the start of the research project to ensure accessibility and continually monitor with feedback throughout the study.
4. Make available university resources such as access to the library and networking events to community partners; subject to the level of engagement and collaboration.
5. Provide financial resources to community partners to facilitate costs for engagement at community spaces.
6. Share research data and outputs with community partners in an agreed and appropriate way.
7. Provide inclusive women-only spaces.
Programme Theories: Service Provision-focused on supporting the delivery of the research

1. Engage community partners to support all co-production activities before, during and after the research process to enable ongoing feedback.
2. Provide ongoing education to researchers – this should involve active involvement of community partners to support researchers in developing a shared understanding of the social context for which the research is being undertaken.
3. Develop an accredited education program for community partners that is culturally appropriate to support capacity building.
4. Support the career opportunities and educational progression of community partners.
5. Prioritise consistent and regular follow up with community partners that reflect the ongoing needs of community partners.
6. Develop innovative and flexible methods of engagement and outputs with community partners.

Programme Theories: Guidelines-focused on creating documents and or procedures to mandate best practice

1. Create an engagement/co-design checklist at the start of the project and assign responsibility amongst partners to review and modify throughout the process.
2. Provide a diversity of involvement options for community partners.
3. Enable flexibility from the start.
4. Develop co-created guidelines regarding data ownership and usage.

Programme Theories: Fiscal Measures-focused on costing to enable the research

1. Include costs for psychological supports for researchers, service users and service providers.
2. Include costs for alternative outputs as identified by partners during the research process.
3. Ensure flexibility in payment methods to partner organisations by enabling vouchers or cash when requested.
4. Allocate funding to celebrate success with collaborators to acknowledge the ongoing partnerships.
5. Provide reasonable costs for all community partners engagements (e.g., food, transport, social and care costs, Personal Assistants, etc.).
6. Factor in the time and subsequent resources to develop equitable research partnership.
Programme Theories: Communication and Marketing-focused on supporting partner communication and diverse outputs

1. Allocate time, at the start of the project to allow all partners to articulate what they would like to achieve from the collaboration. This should be written up and agreed upon by all partners.

2. Allocate time, throughout the project, to enable shared decision making in implementing and adapting the study with all partners.

3. Establish a forum for researchers to share their motivations for doing research to overcome any community stereotypes.

4. Fashion research process and community outputs that are accessible and culturally appropriate language using plain English guidelines.

Programme Theories: Regulation and Legislation-creating new procedures and initiatives

1. Review ethics procedures to ensure that the competence of all partners is assumed as the default.

2. Ethics should prioritise a process of ongoing consent.

3. Funding calls need to ensure the time it takes to develop research with seldom heard groups is supported and resourced.

4. Funders should specifically host calls for co-design/PLA/Emancipatory research.

5. Include operational and budget flexibility in funding calls to enable community partners to identify the supports required during the research process.

6. Funders should consult with community partners in the development and evaluation of research processes and funding calls.

Impact for policy and practice?

An overarching conclusion from this review is the importance of reciprocity and its role in enabling people to know and control their world by engaging participants from the start of a research project. This requires the use of engaged methods such as co-design, co-production and emancipatory research. The 33 programme theories agreed by the expert panel and presented points to a variety of mechanisms and resources that need to be included to enable the reciprocal involved of seldom heard groups in health and social are research. Many of them are not surprising. They however point to the need for a radical shift in current practice to enable the reciprocal involvement of seldom heard groups.

It is recognised through this review of the literature and from our discussions via the reference panel processes that currently undertaking reciprocal PPI with seldom heard groups often requires heroic efforts from all parties involved. Community partners are often enabling research at the 11th hour and spending a lot of time ensuring the project was culturally appropriate and accessible. Researchers are often working beyond the scope of their funding calls to provide supports to their partners and spending significant time in being present with community partners to build relationships and trust.
The review noted structural challenges that need to be navigated such as ethics, payments and access to university resources for community partners and sustainable funding to enable participation. Having multiple partners working on a project often results in tensions given the remits of different agenda that can emerge. It is therefore important that time and adequate flexible resources are made available to celebrate success and achievements. The review also found that funders have a key role to play to enable reciprocal involvement of seldom heard groups. As the shift away from a ‘fund and forget model’ continues the need to resource pre-engagement and long term partnerships grows which reference panels participants stressed as crucial.

We would urge that further contributions be made to the literature on how reciprocal projects with seldom heard groups has resulted in reforms and changes linked to the six policy categories. Further work should also expand and refine these programme theories by engaging with other seldom heard groups in health and social care collaborations.

**Expert Panel Membership**

- Ms Joan O’Connor, Disability Federation Of Ireland
- Ms Eleanor Dunn, Dublin Simon Community
- Dr Cliona Loughnane, National Women’s Council of Ireland
- Ms Vanessa Lacey, Transgender Equality Network of Ireland
- Assoc Prof Maura Adshead, UL Engage, University of Limerick
- Assoc Prof Amanda McCann, UCD Conway Institute of Biomolecular and Biomedical Research, University College Dublin (UCD)
- Dr Sarah Morton, School of Social Policy, Social Work and Social Justice, UCD
- Assoc Prof Veronica Lambert, School of Nursing and Human Sciences, Dublin City University
- Dr Cliona Ní Cheallaigh, Consultant in General Medicine and Infectious Diseases, St James’s Hospital & School of Medicine Trinity College Dublin
- Dr Éidín Ní Shé, School of Nursing, Midwifery and Health Systems, UCD
- Prof Thilo Kroll, School of Nursing, Midwifery and Health Systems, UCD

**For further details refer to:**

- Protocol paper: Ní Shé É., Davies C., Blake C et al. What are the mechanisms that enable the reciprocal involvement of seldom heard groups in health and social care research? A rapid realist review protocol [version 1; referees: 3 approved]. *HRB Open Res 2018*, 1:7

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