

How to foster PPI with those excluded from public involvement itself?

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#### Involvement < PPI

- PPI seeks to go a step further with public involvement in healthcare
- "with recognition of the need to engage citizens not only in providing feedback on health-care delivery or interventions, but in processes whereby decisions are made..." (Baxter, Clowes, Muir et al., 2016).

#### Involvement ≠ Inclusion

 But what happens to those citizens who find themselves socially excluded from their healthcare needs?

## Healthcare Needs of Homeless Population

- Multimorbidity
- Unscheduled healthcare: emergency department & inpatient care
- Individuals aged 25–65 years
- Much more likely to leave the ED without being seen (41% vs 16% in housed patients) and to self-discharge (Cheallaigh et al., 2017)



Homelessness challenges PPI to go further in how it seeks to understand *involvement*.

# Healthcare Needs of Ageing Population

- Multimorbidity (27% 66.2% of housed Irish population)
- Twice as common in the over-75s as those aged 50-64
- Lack of formal support services (living at home ≠ community care)
- Need to promote self-management
- Multiple medications & doctors appointments

# How can researchers foster PPI in this context?

- Design methodologies can give us a way to respond in healthcare in a way that we have not seen before.
- Build upon methodologies presently used within health context,
   making them iterative, responsive and co-operative.

### Experience-centered Design

• The real excitement of experience centred design is ... "to give people the chance to have a richer life, to include people who otherwise feel excluded, and to ensure that everybody has a chance to have their say. Especially those who often feel voiceless" (Wright & McCarthy, 2010).

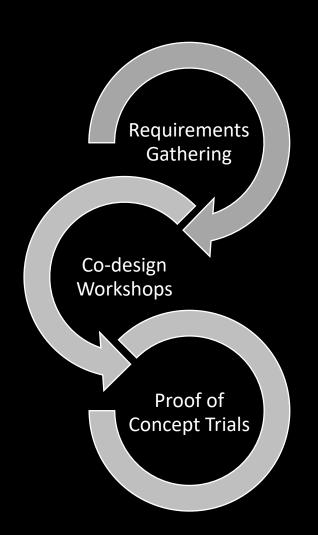
#### ProACT (Proact2020.eu)

- Important that voices of participants were heard and responded to.
- Include as many stakeholders as possible within community care, making them active participants in the design of ProACT, not just participants of research.
- Ensured that design happened with and not for participants.



# The Design of ProACT

- Interviews
- Focus Groups
- Expert Panel
- Usability Testing
- 12 month action research trial
- EU trial sites



#### Conclusions

- Design methodologies can ensure PPI across *all* health research contexts and not solely those of the socially included.
- Provoke thought and reflection within the PPI community upon how we can achieve PPI with groups that are excluded from public involvement itself.





# Design for the publics of PPI

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# Thank you.

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