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 & McCarth, 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
References

• Proact2020.eu
• Doyle, J., Hoogerwerf, E.-J., Kuiper, J., Desideri, L., Fiordelmondo, V., Jacobs, A., ... Smith, S. (n.d.). Whitepaper on the needs and requirements of older people with multiple chronic conditions to self-manage their health, 38.
• Savva, G., Hanly, M., McDaid, O. et al. Multimorbidity in the older population. CARDI Research Brief, 2011.


Thank you.

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