

# **PPI to guide an inclusive, viable approach to PhD study design exploring:**

## **Barriers to healthcare service access in socioeconomically deprived people living with Long COVID in Scotland**

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# Aims of this session



- Background of PhD study
- Identifying the need for PPI
- PPI strategy for research
- PPI strategy of recruitment

## Background for PhD study

Long COVID - 'ongoing symptomatic COVID-19' (symptoms persisting for 4-12 weeks after acute infection).

'Post-COVID syndrome' ( $\geq 12$  weeks after acute infection)

- 1.9 million people, in private households, self-reported Long COVID (March, 2023)
- This is likely an underrepresentation for socioeconomically deprived populations.
- Current research illustrates a **HIGHER** healthcare need for the **LEAST** economically disadvantaged populations.

## Identifying the need for effective PPI

Public involvement (PPI) is about members of the public working in active partnerships with researchers. Public involvement in research is research carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them.

Benefits of PPI:



- Inclusive
- Proactive stakeholder participation
- Marginalized perspectives.
- A significant voice in determining research objectives, design, recruitment, implementation, and dissemination

## PPI strategy for research study

- Grassroots groups

Shelter

Aberdeen  
Cyrenians



- 8 demographically diverse representatives; affected by Long COVID and economic disadvantage:



- A range of experiences related to symptoms
- Stigma experience
- Income barriers
- Healthcare access variances

PPI Group	Grass root Organisations	PPI participants	PPI Participants	PPI participants
Stage of Research	Literature Review	PPI Quantitative Research	PPI Qualitative Research	PPI Research Summary
<b>PPI Tasks</b>	Discussing findings/themes identified in literature review	<p>Wording of questionnaire</p> <p>Relevant question selection/ reflective of lived experience</p> <p>Advertisement/ Recruitment of survey</p> <p>Piloting questionnaire / feedback</p> <p>Understanding survey results</p>	<p>Develop semi structure interview guide</p> <p>Discussing findings from Qualitative results</p> <p>Design and set up of qualitative interview</p>	<p>Significant findings in research and relevance of these findings</p> <p>To inform strategies to best dissemination of findings</p>

## Recruitment of PPI participants

- Initial concerns regarding recruitment
- Previously established trusted relationships:
  - From previous health care employment co-workers
  - Social contacts
  - Other Research Students
  - PPI participants snowballing recruitment



# Initial feedback from PPI participants:



- Uncertain
  - What personal information would be required?
  - For what purpose?
  - Uncertainty of what PPI is and involves ?
- Mistrust of external agencies accessing their information.
  - Fear of sharing financial information
- Feeling no connection to a “university” research study.
- Keen to voice their experiences / feeling the drive and need for change.



## **PPI to guide a viable PhD Study**

- Highly likely that Long COVID research lacks representativeness, particularly among low income groups. PPI is central for the inclusion of underserved communities in population research studies.
- Recruitment of PPI participants involves effective networking with grass root organisations
- Established healthcare co-worker trusted relationships made for a successful recruitment of PPI participants. Using trusted relationships to recruit participants – snowballing recruitment methods.
- Initial feedback - Feeling the drive and need for change / Uncertainties what is involved from them
- The importance of developing and maintaining PPI relationships

Welcome any questions !  
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