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Patient and public involvement within epidemiological studies of Long Covid in the United Kingdom

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Several major epidemiological studies have been funded in the UK to better understand the epidemiology of persistent symptoms following SARS-CoV-2 infection. Investigators from nine of these studies formed the National Long COVID Research Working Group in 2021 to share key findings and methodological developments, and explore ways of working across projects [1].

Seven of these studies have substantively worked with diverse public and patient members and support groups, and have gone on to create patient involvement groups or panels specific to their research (Table 1). The large volume of patients living with Long Covid [2], and the willingness of patients and support groups to engage with these studies, as well as the barriers of operating during periods of pandemic control measures have provided unique opportunities and challenges for patient and public involvement (PPI).

A particular example of the success of PPI is the Therapies for Long COVID in non-hospitalised individuals (TLC) study [3], where patient partners identified the need to develop a new Symptom Burden Questionnaire^{TM} for Long COVID (SBQ^{TM}-LC)[4]. Patients with Long Covid were actively involved in the generation of item content for the SBQ^{TM} and assisted with recruitment from Long Covid patient groups. The SBQ^{TM}-LC has since been licensed over 90 times across 50 countries. In addition to this important contribution, patient partners also actively co-produced a study to test the feasibility and acceptability of delivering non-pharmacological, self-management interventions remotely in the community, shaping the study design and co-selecting intervention resources.

Advocacy and support groups have been invaluable to patients with Long Covid and a conduit for their involvement in research studies, through a diverse network of patients and carers with a wide range of lived experience. Members of these groups often assist with public engagement, which helps with the recruitment of study participants, as well as publicising events such as study webinars, the distribution of questionnaires, and dissemination of results. However, there is often a lack of diversity among patient contributors, who are often of similar age, sex, ethnicity, education level, and professional status. As a result, the CONVALESCENCE Long Covid study proactively recruited from under-served communities and included questions on equality and diversity in its PPI recruitment materials. Extensive training from the study PPI team was also provided so that patients felt qualified to contribute in areas such as quantitative data interpretation. When selecting patients, studies from the National Working Group have included a diverse PPI membership, delivering individualised training and discussions on preferences on involvement.

A particular area of learning regards the establishment of patient advisory groups (PAGs). Diversity of participants can be improved through recruitment from several PPI networks, avoiding recruitment from a single source. Clear pathways for inviting new members to join PAG’s are needed to ensure that they are sustainable. It is important that PPI members receive regular updates and information on the project and are clearly informed of the purpose and importance of their involvement. PPI activities can be greatly strengthened, coordinated and made sustainable throughout a project by a dedicated and trained PPI lead, which is a crucial role in long Covid research.

Researchers should continually revisit what different PPI members want to contribute and can contribute, based on skill set, interests, return to work and other commitments, and the restrictions that come with having a chronic condition with a relapsing and remitting nature where a main symptom is fatigue. Different studies, or different aspects of a study, may have different requirements of PPI members, or may benefit from PPI members with specific experiences, knowledge or skills. Certain studies are more complicated, more cognitively challenging, or more demanding on PPI members' time than others. Studies can benefit from working with PPI members with significant knowledge and extensive experience of Long Covid, as well as PPI members who are able to attend and actively contribute to frequent meetings, in order to ensure effective PPI is ingrained throughout the study. This can include working on various aspects of the study such as study design, contributing to patient-facing materials, interpreting results, co-authoring papers and participating in public engagement events.

Researchers may not always be aware of how much PPI is needed to improve their research. Researchers should consider the experience, skills, and capabilities of each PPI member and what they want to contribute to, rather than this being decided, perhaps inappropriately, by the research team.

Patients with Long COVID often suffer from fatigue and can also experience some cognitive dysfunction, which may require adjustments as with any disability. PPI meetings should be flexible (for example on timing and duration) and consider patient needs, with all materials and documents for review provided with sufficient advance notice. Other meeting adjustments should include the potential need for breaks and allowing cameras to be optional as PPI members may tire, be experiencing sensory or vision issues, or be concerned about appearing on camera.

The pandemic presented logistical challenges to working with patients on research due to strict public health measures such as social distancing. However, a rapid upskilling in the use of online communication technology has resulted in the studies from the Working Group having access to a wide range of patient contributors from across the UK. Although online PPI activities raise concerns around digital exclusion, studies such as CLoCk have found that online recruitment and virtual meetings helped achieve more representative geographical coverage and diversity from across the UK, both in terms of ethnicity and socioeconomic status.

The level of patient involvement we have experienced has undoubtedly strengthened the applicability and rigour of our findings, and increased public trust in the veracity of these studies. There remains a limited understanding on the causes of Long Covid and the development of effective treatments, and so placing patients at the heart of future research in this area continues to remain imperative [5].

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Competing Interests

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Unit (BTRU) in Precision Therapeutics, UK Research and Innovation (UKRI), UK SPINE and declares personal fees from Cochlear Ltd, Astra Zeneca, CIS Oncology, and Aparito Ltd. NC has received funding from AstraZeneca to serve on Data Safety and Monitoring Committees for clinical trials. KK is a trustee of the South Asian Health Foundation, chair of the Ethnicity Subgroup of the Scientific Advisory Group for Emergencies (SAGE), and member of SAGE. PE, ED, SH, RS and TS receive funding from NIHR and UKRI. TS is Chair of the Health Research Authority and therefore recused himself from the CLoCk Research Ethics Application. RAE receives funding from NIHR, UKRI/MRC, BMJ and Wolfson Foundation.

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Study	Number of patient advisors	Profile of participants	Regularity and location of meetings	Main outcomes
CLoCK	13	All aged 11-17 years; 67% white; all deprivation deciles included	Online quarterly meetings	• Delphi definition of Long Covid Dissemination of findings Changes to survey questions • Input into qualitative design • Input into data presentation • Long Covid artwork • Changes to newsletters • Awards for involvement
CONVALESCENCE	12	Diverse social and ethnic backgrounds	5 training workshops and 7 tailored workshops; 2 PAG members attend quarterly executive meeting	• Changes to questionnaires and other instrument design • Refinement of ethics • Communications • Materials development for internal and external use • Changes to researchers' interpretations of qualitative work
TLC	15	Diverse in terms of age, ethnicity and employment status	Ongoing online opportunities throughout lifetime of project.	• Identifying need for new Symptom Burden Questionnaire™ and need to survey patients about self-management strategies

				• Changes to recruitment strategy • Improved participant facing study materials • Coproduction of feasibility study • Co-selected pacing resources • Co-design of study processes and app testing • Supported community engagement and recruitment • Identified key messages for research outputs • Dissemination of research outputs
REACT-Long COVID	13 (plus 161 members of REACT: COVID-19 Community Network)	9 women and 4 men. Diverse group that includes people with lived experience of Long Covid and participants in the original REACT studies.	Quarterly online meetings. Each advisor is allocated to one of four work streams for close working with researchers; community network send updates and involvement opportunities	• Changes to questionnaire design • Improved participant-facing study materials • Interpretation of pilot qualitative findings • Involvement in publications and dissemination • Worked with researchers to establish an online research involvement hub on VOICE- Global

PHOSP-COVID	50 advisors and 11 charities	Diverse group in terms of age, ethnicity, socioeconomic status, including patients and carers with lived experience of acute COVID-19 and Long COVID, including hospitalised and non-hospitalised	PPI embedded throughout all stages of project, with regular meetings depending on project needs, conducted via email, phone or teleconference	• Input into study design and conduct • Joint Research Question Priority Setting [6] • Improved participant facing study materials • Reviewed and tested new study processes • Public webinars and newsletters for dissemination
STIMULATE-ICP	11	PPI advisory group represents social, ethnic and geographic diversity	PPI attendance at monthly consortium meetings and separate monthly PPI online team meetings	• Involvement in research publications • Educational videos • PPI blog on study website • Media and social media engagement • Policy and other articles in non-scientific publications • PPI-led eBook about experience of Long Covid
OpenPROMPT	3	PPI advisory group is comprised of 3 individuals, and OpenSAFELY Digital Critical Friends (DCF) Group, feeds into the group on specific issues	Online webinar at study start; PPI attendance at online OpenPROMPT meetings every 6 months, with additional email feedback on research plans;	• Adaptations to study protocols • Improved public facing study materials • Co-designed public explainer materials for OpenSAFELY

		related to the data collection platform	OpenSAFELY DCF online meeting every 3 months; Ad hoc PPI online focus groups on specific topics.	