NIHR | Applied Research Collaboration South London

Evaluation of the National Institute for Health and Care Research (NIHR) Applied Research Collaboration (ARC) South London, Public Research Panel

May 2022

With thanks

Thanks to everyone who has been involved or supported the work of the Public Research Panel.

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Background

1. ARC South London Public Research Panel

This Panel is aimed at providing a space for public members from diverse backgrounds living in south London, to work in partnership with the ARC in shaping their research and building meaningful engagement in this process. The Panel was originally set up as a Covid Research Panel for the Public in January 2021 to enable greater participation from diverse communities in Covid research. The Panel has now set out a broader remit to enable public involvement in all areas of the ARC's research and refined its terms of reference, as per below:

Key objectives of the Panel include:

- To help develop a broader model of patient/public involvement in research, grounded in principles of diversity and inclusion.
- To enable members from diverse communities to be involved in co-producing, co-evaluating and helping to develop key values for research as well as the delivery of services.
- Through working in partnership with ARC South London researchers, helping to build a community, diversity and participatory approach to research within the ARC, which, in so doing, helps to amplify the voices of service users and improve communication to bridge the gap between researchers and the subjects of their research.

This report describes the work of the Covid Panel since it was formed and key learning to emerge, which will drive the development of the wider Public Research Panel. The report is based on information from the first year of the Panel's work from January 2021 – January 2022.

2. The Covid-19 Research Panel for the Public

This was set up in January 2021 because of a widespread concern that the coronavirus pandemic and measures to tackle it were having a disproportionate effect on certain sections of the population, who already experienced considerable health inequalities.

This led to a small team in the ARC South London deciding to hold a community event via Zoom to discuss the impact of Covid-19. The aim of the event was to give service users, carers, and representatives of community organisations in south London, working across the protected characteristics (age, disability, gender reassignment, race, religion or belief, sex, sexual orientation, marriage and civil partnership and pregnancy and maternity) a chance to share their experiences. To make it action-oriented, we decided to link this Zoom event into a UK Parliamentary call for evidence on issues raised by the Women and Equalities Committee in its inquiry on 'Unequal impact: Coronavirus (Covid-19) and the impact on people with protected characteristics'. Although there was only one week to organise the event if we were going to submit evidence into the

Parliamentary call, 52 people from diverse backgrounds attended the event on the 27 April 2020. A report was subsequently produced on the key themes to emerge and submitted to the Parliamentary inquiry.

A key theme to emerge from the event was the way in which groups already facing some of the worst health inequalities in society, were frequently not heard in public involvement, engagement, and research initiatives. Developing a partnership approach with these diverse groups and communities was therefore seen as urgent if the impact of Covid-19 was to be addressed in the future.

This led to the proposal to set up the Covid-19 Research Panel within the ARC, initially to operate as a one-year monthly online standing panel, that would be piloted and co-evaluated with panel members for effectiveness.

Key aims of the Covid Panel were to:

- Enable diverse communities to embed their experiences of Covid-19 and the pandemic, including issues of inequity and discrimination, into the ARC's Covid research which has a strong focus on reducing health inequalities

- Enable ARC researchers to benefit from input from diverse south London communities into their Covid-related research

- Provide a forum for holding wider community engagement events related to Covid-19, beyond the ARC portfolio of research, if these topics seemed important and relevant to the work of the Panel

- Develop a broader model of patient/public involvement, grounded in principles of diversity and inclusion and a more democratic, co-produced and theoretically informed approach, to enable diverse communities to impact research and the delivery of services

- Explore how different methods could be used with the panel aimed at developing experiential insights on the ARC's Covid research, public insights on experiences of Covid-19 and identifying the strengths and limitations of researcher-public and university-community relationships, and how diverse groups can best be involved in co-producing change in health and social care research.

3. Recruitment of Panel members

Recruitment of Panel members was done through advertising externally and through an application and appraisal process. The advert asked people who either lived or worked in south London, to apply to join a Covid-19 Public Research Panel to help shape ARC South London research. We were looking for diverse representation on the panel from groups across the protected characteristics covered by the Equality Act 2010. We outlined in the advert what the time commitment would be generally and how much we would pay people for their time including preparation.

4. How the Covid Research Panel worked

Initially thirteen people were recruited (which later dropped to twelve when one person had to step down due to ill health), who had backgrounds covering several of the protected characteristics. Fifty per cent of Panel members recruited were from Black, Asian and minority ethnic backgrounds. Draft terms of reference for the Panel were discussed and agreed at the first meeting in January 2021. This set out aims of the Panel, how it would work, who members would be representing on the Panel, sharing of information and confidentiality, payment and suggestions for different methods which could be used in running the Panel.

ARC researchers were able to use the Panel by filling in a booking form beforehand setting out details of their research in ways understandable for a lay audience and key questions they might like to discuss at the Panel meeting. This form was then sent to Panel members in advance of the meeting. (See a template of the booking form in Appendix Section B.) Panel members agreed early on that the ARC Equity, Diversity and Inclusion lead, Dr Josephine Ocloo should chair the Panel meetings, at least at the outset, while meetings were run online and that the meetings would be minuted and shared afterwards. After the meeting, presenters to the Panel were asked to fill in a feedback form on their experiences of the meeting as were Panel members.

5. Who attended Panel meetings?

Thirteen members of the public with lived experience of health and/or social care services made up the Panel members (later reduced to twelve). Panel meetings were also attended by Dr Josephine Ocloo in her role as the Equity, Diversity, and Inclusion lead for the ARC and Panel chair; Dr Clare Coultas from the ARC's public health and multimorbidity theme (who was involved in setting up the Panel with Dr Ocloo) and Madelene Boyton (who took the minutes and provided administrative support).

6. Covid Research Panel presentations

Since the Panel was set up in January 2021, it has had twelve meetings. Eight meetings connected to the Covid Panel and four connected to the wider Public Research Panel. (See the complete list of meetings dates previous and upcoming meetings in Appendix D.)

Additionally, Panel members have participated in three Symposium events held by the ARC in 2021 which took place on 17 February, 17 June, and 3 November. These Symposium events have been established by the ARC to provide a space to exchange knowledge, experience, information, learning and ideas with a wide group of stakeholders, researchers, public members, service users and carers, local/national organisations, and other ARCs. The Panel have played an active role in the design and delivery of Symposium events, including involvement in presentations, commenting on presentations, and facilitating breakout sessions.

7. How Covid Research Panel meetings worked

The Panel met monthly and invited ARC researchers to present their work in different areas e.g., on funding ideas, funding application, research proposals for their study (pre-ethics or post-ethics) or about research currently being undertaken. Presenters were encouraged to come to the Panel early enough in their work to enable Panel members to be able to make suggestions for change. In some of the meetings there was one presentation and in other meetings up to two. The presentations covered a broad spectrum of research studies around Covid-19. The aim of the Panel was to discuss the ideas being presented and to make comments or suggestions for improvement. A specific agenda for each Panel meeting was drawn up in advance of the meeting and sent out to everyone providing a clear structure for what would be discussed and when (see template at Appendix B). Presenters were also asked to provide a lay summary and to fill in a booking form on their research project beforehand which was circulated to Panel members. The Panel meetings enabled ARC research staff to present their Covid research projects (see presentation titles listed in Appendix C), as well as enabling wider discussions on subjects such as developing a wider community approach to research, as well as Panel business. Each meeting provided up to an hour for each presenter to talk about their project (5-10 minutes outlining the research project and the rest of the time for a Q&A session with the Panel). Minutes were taken during all the meetings and written feedback was provided to researchers afterwards.

8. Key themes to emerge from presenters to the Covid Research Panel

After attending the Panel meeting presenters were sent a form to give feedback on their experiences of the Panel. Key themes to emerge from the feedback forms are listed below:

a. All presenters said that the Panel was hugely useful and offered “thoughtful and novel suggestions” for their respective studies. For some presenters their attendance at the Panel meeting provided the first opportunity for active involvement of a patient and public involvement (PPI) perspective in their research. The feedback of the Panel was described as lively and valuable, while the panel atmosphere was experienced by the presenters as welcoming.

b. Other presenters said: “it was very easy and a very rich discussion, no prompting required!”, and “The Panel also offered constructive challenge and practical suggestions for recruitment which was appreciated.”

c. Further feedback stated: “Although different and opposing views were expressed this was respected” and “The panel was also diverse in terms of ages and backgrounds (in as far as I could tell) and that meant a range of perspectives were offered.”

d. Presenters felt that the panel gave their feedback in a “very constructive and helpful way – direct and to the point – whether positive or more.”

e. A presenter described feeling more confident in conducting their research project after discussing it with the panel.

f. In several cases Panel feedback added directly to study design and methodology, as presenters were seeking advice in the initial stages of their research project.

g. The combined approach of receiving both verbal feedback during Panel meetings as well as written feedback afterwards has been perceived as particularly beneficial.

h. The preparation that some presenters had to do before the meeting was described as helping them to tell the story of their research project, which in turn helped them to write their research bid.

i. It was appreciated that Panel members came prepared (i.e., having read the project summaries before the meetings).

j. Presenters also expressed that they felt able to explain flaws in their grant proposal on engagement without feeling defensive, which was experienced as "a good lesson for anyone attending the panel". These presenters talked about the pressure to turn their bids around quickly, but that they were "learning more about participatory and inclusive methods" from the Panel.

k. Some presenters even felt inspired to connect with a social enterprise who advised them about inclusion strategies and communication materials.

The table below lists some examples of panellist feedback on specific research studies:

- In employment status I would add "self-employed" for future reference, as this may imply a mix of full-time and part-time, as working hours could fluctuate?
- "Household" needs to have the option for homeless. If you are homeless, none of the answer options are appropriate. Some people also live in shelters or homes, etc.
- Extremely clinically vulnerable is confusing. Will people know how this is defined?
- I felt the presentation was very strong and had concise objectives that were explained by both presenters. I think that a limitation is that the research project is only focusing on GPs and not the other key services which may give a limited amount of evidence.
- Would be good to see more focus on outcomes.
- Presenters have been very capable at putting across their project in plain English terms. It was easy to understand which helped everyone to engage well.
- I would like to see a co-production approach to the research where the people interviewed, and their families feel like they are the agents as well as the subjects of the research.
- The trust element will be fundamental in eliciting truthful and comprehensive results within a group that has been disproportionately hit by the virus but for a big part feels ignored and disempowered in decision making, due to ethnicity, cultural differences and sometimes language.

Building and strengthening the work of the Panel

- Some ARC researchers returned more than once to the Panel and were keen to have an ongoing relationship with the Panel. Other presenters noted they would like to return to the Panel in the future.

- Some presenters said they would find it helpful to receive information about the backgrounds of Panel members before the meeting.

Some presenters reassured Panel members that their contributions would be further acknowledged in their research outputs/published papers.

9. Engagement and accessibility of the Panel for panellists

Listed below are statements from Panel members giving feedback on engagement and accessibility of the presentations as well as suggestions for improvement.

- The lay summaries and booking form sent in advance to panellists means that the project information from the presenters is easy to understand. It was noted that having this information in advance meant that Panel members found the presentations easy to follow in meetings: *"The lay summary was clearly written in plain language and the presentation was easy to follow as a non-expert audience"; "The presentation was excellent, and it was helpful to have a written synopsis beforehand".*

- The Panel was seen as an important initiative that had been set up to specifically meet the needs of south London communities: *"Yes, the project is important to the public in south London. It relates to Covid-19 and the results will be beneficial to understanding the effects on the diverse population."*

- Having more than one presenter attend the Panel was seen as a good thing as it meant that one was able to take contemporaneous notes, while the other could present and answer questions from Panel members.

10. How the Panel could be further developed

In their feedback forms Panel members made several suggestions about how the Panel could be further developed. For example:

- Language (terminology and use of acronyms) was sometimes seen as difficult to understand, and it was felt that it would be good for presenters to speak in lay terms and use practical examples for illustration.

- That presentations should not be too long to allow adequate time for discussion.

- PPI representatives attending the meetings with researchers should be supported to contribute to the research presentations.

- It would be helpful to ask researchers to produce an A4 one page sheet on how they plan to address issues around PPIE involvement when presenting on their research studies. This could be done under headings such as amount of ringfenced PPIE budget, incentives for involvement, training, involvement in dissemination of research findings, representation on Trial Steering Groups, contribution to ethics committees, analysis of interviews, co-authorship, involvement with recruitment etc. This was seen as work that might need to be done as part of any research funding application, so this prior thinking for the Panel would contribute to a funding application process.

- Presenters making use of the chat to answer questions in the meeting and therefore to have broader interaction with Panel members not speaking was seen as a good idea.

- It was seen as helpful for presenters to think about how they present to Panellists, as lay members, to ensure the delivery was not too 'mechanical' and not over-tailored to 'medics'. This was seen as an issue that needed to be considered closely when presenting research findings to the public.

11. Patient and Public Involvement and Engagement (PPIE)

The points below from Panel members in their feedback forms highlight how patient and public involvement and engagement was dealt with in research studies and how this worked well and could be further developed.

Strengths of PPIE identified by the panellists in the research presentations

- Many identified entry points for patient and public involvement in different stages of the study.

- Public involvement is meaningful and respected by the presenters. They take on board any feedback given and are aware that some groups, prisoners, homeless etc may be underrepresented and explained the reasons for this.

- PPI is meaningful in the study but there are still systemic approaches that need to happen as the onus cannot be on the public to change deep-rooted injustices and inequalities in heath research.

- A PPI group will advise the study and there will be dissemination to lay audiences. It would also be good to think more about who they are in terms of representation, and how they are recruited.

- One presenter was seen as very clear and engaging and compassionate and calm in her manner, which it was felt, *"would receive an excellent response from service users and families"*.

Further development of PPIE identified by the panellists in studies

- The presenter is interested in talking to a couple of the Panel members on a one-to-one basis to further develop their research and to take onboard their specialist knowledge. There is a need to be careful with this approach to avoid researcher bias in speaking to people who are already aligned to the path the researcher is looking to take.

- Researchers need to have a strategy and assigned budget for how they are planning to engage with the public and to ensure different patients and the public are recruited and at the centre of their research and their contributions embedded across each research cycle.

- Consideration of different characteristics of patients will help researchers to think about who is being impacted and therefore how this needs to be addressed in the study.

- Researchers need to reflect on their the social and political context for their own identities and how this may affect their role in the research and explore anti-racist and anti-oppressive strategies – there is quite a lot about this published in both academic and non-academic spaces, and the best discussions are when panellists develop researchers' ideas, rather than when the researcher looks to the panel to tell them what is missing from their study.

- It is good to recruit and embed PPI as soon as possible in the research to help develop a PPI strategy for involvement in the study e.g., in areas such as developing the interview frame, analysis and write-up and dissemination, reimbursement of public members in the funding application and reasonable adjustments, training for those who are new to research.

- Patient and public voices need to be heard in different ways depending on the experiences of different groups and where they are located.

- Community participation needs to be funded from the start of the research and to enable voices from under-served groups in the community to be involved.

- It would be good to see more methods being planned by researchers for reaching out to groups and populations currently under-served by research, to gain a better understanding of why these groups are not being involved in the first place.

- Engaging with the community can be done quantitatively through surveys and qualitatively through individual interviews or participatory appraisal style small group discussions.

- With research being conducted online, there is a need to be mindful of digital poverty and digital exclusion. This is where a collaborative approach with community groups and organisations is fundamental.

Key recommendations and ways forward for the Panel

The recommendations below provide some suggestions for developing the Panel further within the research work of the ARC.

1. Panel members are keen to find out what happens with the research after their input at the Panel and the key findings

"I found the presentation and purpose of the research very interesting personally and valuable generally. I would be keen to hear on the progress of this research in the coming

months and find out which are the biggest difficulties and how they are being tackled and overcome".

2. Panel members would like to see their input and the work of the Panel firmly embedded in all the research work of the ARC and to see all ARC researchers coming to the Panel.

3. There is a desire to see more collaborative methods used in research studies with members of the public and service users and carers and a more community-based approach taken with community organisations working with a range of population groups and communities currently under-served by research.

4. Some approaches suggested to develop more equal collaboration with the public, service users and carers in research include more use of:

- PPI researcher interviewers.

- More research proposals and grants that are co-authored and co-produced with PPI representatives. *"It is much harder to relate to research if there is a power imbalance and lack of representation from the onset".*

- A meeting with the panel, and potentially other PPIE representatives, to identify the budget requirements for doing PPIE meaningfully; the findings from which could be used to develop a resource for researchers when budgeting projects.

- More use of participatory research/appraisal methods and training for panellists on this.

- Forming more long-term relationships with community groups and organisations as partners, where research needs, design, implementation, and write-up are done collaboratively, and the community groups/organisations appropriately remunerated.

- Providing anti-racist and diversity trainings for ARC researchers.

Appendix A – Template Agenda Previous Version

COVID-19 Research Panel for the Public

Date: Month, Date, Year 4-6pm

Items for discussion at meeting

1. Welcome/Apologies, Minutes and Matters Arising	Chair [10 mins]
2. Presentation 1 – “Presentation title” [Presenter(s)]	[45 mins]
3. Break	[10 mins]
4. Presentation 2 – “Presentation title” [Presenter(s)]	[45 mins]
5. Reflections on the Meeting	[10 mins]

Appendix B – Template Agenda Current Version

ARC South London Public Research Panel

Date:

Time: 4-6pm

(It was agreed to open the panel meetings half an hour early at 3:30pm to provide an informal space for any panel members wanting to join early and catch-up more informally).

Items for discussion at meeting

1. Welcome/Apologies, Introductions & Previous minutes	Chair [10 mins] 4:00-4:10 pm
2. Presentation 1 – “Presentation title” [Presenter(s)]	[45 mins] 4:10-4:55 pm
3. Break	[10 mins] 4:55-5:05 pm
4. Presentation 2 – “Presentation title” [Presenter(s)]	[45 mins] 5:05-5:50 pm
5. Reflections on the meeting	[10 mins] 5:50-6:00 pm

Appendix B – Booking Form Template

ARC South London Public Research Panel – Booking form for staff presenters

Thank you for agreeing to present your work to the ARC South London Public Research Panel.

Can you please complete your details and provide the following information below?

Title	
Name[s]	
Email[s]	
Telephone number	
Main Contact Person	
Date of panel meeting	

Please indicate below what you will be presenting to the panel:

Topic	Title of presentation	Inclusion of abstract/ summary
Funding idea		
Funding application		
Proposal on your research		
Pre-ethics or post-ethics		
Research idea		
Funding application		
Research work currently being undertaken		
Other		

Please also provide a Plain English Summary of your work either as an abstract of up to 300 words or by completing the form below in a way that can be understood by any reader including members of the public.

In providing this summary, please follow the headings below where they are applicable to your presentation:

Research question/aim and objectives
Background
Design and methods
Expected/desired outcomes/impacts of your study
Dissemination (this could cover any activities throughout the research aimed at disseminating information to patients and the public)
Patient and public involvement (please describe plans to involve patients and the public in your research, what you have done to date)
Reflections on diversity and inclusion as part of the research (e.g., what are the key issues, what have you done so far to make your research inclusive?)
Research work currently being undertaken
Any questions you would like the panel to consider and give you feedback on?

Please email this form and/or any supporting documentation to Josephine.ocloo@kcl.ac.uk

Appendix C – Presentation Titles

1. “General practice service use towards end-of-life among patients who died before and during the Covid-19 pandemic: a nationwide cohort study using the Clinical Practice Research DataLink”
2. “Disrupted bereavement among the Muslim Community”
3. “Covid-19 vaccination intention in the UK: Results from the COVID-19 vaccination acceptability study, (CoVAccS), a nationally representative cross-sectional survey”
4. “Priorities for research from Black, Asian and Minority Ethnic people who were hospitalised with Covid-19”
5. “Learning from the Covid-19 Health System Shock: towards building resilient health systems”
6. “Co-design and evaluation of personalised self-management support for people with Long Covid”
7. “Covid-19 vaccination intention in the UK: follow up longitudinal survey”
8. “Mixed methods evaluation of the impact of the shift to remote consultation in primary and secondary care in London”
9. “Co-creation through community involvement – Minority Ethnic Partnership for Clinical Trials”
10. “Prevent from Home: Young women’s Future cardiovascular heaLth and Lifestyle Improvement Study (PHYLLIS)”
11. “Stakeholder involvement in conceptualising the pragmatism and useability of implementation determinant and outcome measures”
12. “Priorities for research from Black, Asian and Minority Ethnic people who were hospitalised with Covid-19”
13. The Use of MRI to Improve Primary Lymphoedema Diagnosis and Understanding of Lymphatic Function”
14. “Integrated short-term palliative rehabilitation to improve quality of life and equitable care access for people affected by incurable cancer (INSPIRE)”

Appendix D – Meeting dates 2021 & 2022

Meetings 2021	**Meetings 2022**
January 21st	January 26th
February 24th	February 23rd
March 10th	March 23rd
March 31st	April 27th
April 14th	May 25th
May 19th	June 29th
Jun 23rd	July 27th
July 28th	no meeting in August
September 29th	September 28th
October 27th	October 26th
November 24th	November 30th
	December 19th