The impact of Covid-19 on involvement – what has changed?

Active Involvement in Research 2022 report

Implementation and Involvement team

NIHR Applied Research Collaboration South London

The National Institute for Health and Care Research (NIHR) Applied Research Collaboration (ARC) South London brings together researchers, health and social care professionals, local people and organisations to carry out research on how to improve health and social care in south London and beyond.

This is a report of an online Active Involvement in Research event on 29 June 2022, carried out as part of the work of the NIHR ARC South London at King's College

Hospital NHS Foundation Trust. The views expressed are those of people who attended and not necessarily of the NHS, the NIHR or the Department of Health and Social Care.

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To find out more about NIHR ARC South London, visit: arc-sl.nihr.ac.uk You can also follow us on Twitter @ARC_S_L or email: arc-communications@kcl.ac.uk

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We would also like to thank:

- the additional speaker and facilitators: Rashmi Kumar, Catherine Evans, Jane Ward, Beverley Randall, Lana Samuels, Katherine Barrett, Chris Pavlakis, Vita Moltedo and Mary Newburn
- the additional note-takers in breakout groups: Zoë Lelliott, Jane Stafford and Stan Papoulias
- all who took part, sharing their views and experiences.

Contents

Summary

The impact of Covid-19 on involvement was the focus of National Institute for Health and Care Research (NIHR) Applied Research Collaboration (ARC) South London’s annual ‘Active Involvement in Research’ event, held online on 29 June with 50 patients, service users, carers, local people and researchers. The event brought people together to discuss what has changed since the pandemic began and highlight some of the learning about, and through, involvement which might shed a wider light on research in health and social care. This combined reflection on examples of partnership and opportunities for all present to share their own experiences and views.

Patient and public involvement in a research project on empowering better end of life dementia care, amidst the pandemic, was explored in a presentation by Catherine Evans, a researcher at King's College London, and involvement co-lead Jane Ward. This was followed by dialogue on why and how research matters from communities’ perspective, in which Beverley Randall of Mosaic Clubhouse, one of the community members on the NIHR ARC South London Executive and Board, was in conversation with involvement coordinator Savi Hensman. Again, this drew on the experience of the previous couple of years. The importance of building trust and identifying how involvement had made a difference were mentioned.

After discussion in breakout groups, key points which emerged were shared with others attending. These included the effects of increased online working, which some of those involved found positive and others negative, and the challenges of strengthening partnership with diverse communities, including those badly affected by the pandemic.

A video of the opening presentation and conversation is available on YouTube. A news item was shared soon afterwards and issues raised at the event were considered in more detail by the implementation and involvement team, including lessons for ongoing involvement in the ARC.

The impact of Covid-19 on involvement

Examining involvement in a changing context

The focus of ARC South London's Active Involvement in Research event on 29 June 2022 was 'The impact of Covid-19 on involvement – what has changed?' This went beyond practical challenges to other learning about, and through, involvement during the pandemic, which also shed a wider light on research on health and social care.

The event was introduced and chaired by Dr Natasha Curran, ARC South London’s Implementation and Involvement lead and Medical Director at the Health Innovation Network, alongside Rashmi Kumar, public member and chair of the Involvement Advisory Group and a trustee of Lambeth patients and public participation group.

Natasha outlined some of the ways in which diverse people are involved in the ARC, including in its research themes and cross-cutting themes and at wider level. Involvement structures include public and community members on the Board and Executive, a Public Research Panel, Involvement Advisory Group, Involvement Learning Network, and implementation and involvement team.

"It’s exciting to see the developments that have happened since our event last year with the new involvement structures in place across the ARC," Rashmi said.

> “The last two years have been very challenging and ARC South London has been busy delivering research associated with Covid but it’s important that we reflect and think about what we have learnt. What barriers have there been to deliver effective meaningful research that will be applicable and can be implemented to address everyday challenges for researchers and for the public?” Rashmi Kumar

Empowering better end of life dementia care: patient and public involvement during the Covid-19 pandemic

Catherine Evans

Jane Ward

The first presentation was on ‘Empowering better end of life dementia care: patient and public involvement during the Covid-19 pandemic’ by Catherine Evans and Jane Ward. Catherine is a professor of palliative care at the Cicely Saunders Institute and an honorary nurse consultant and Jane, who had been a carer for her mother with vascular dementia, is the patient and public involvement (PPI) chair for the Empowering better end of life dementia care (EMBED-Care) programme.

> “The aim of the EMBED-Care programme is to empower people with dementia of all ages, carers and staff to identify and act on changing physical, psychosocial and spiritual needs, addressing these across care settings and their transition in care.” Catherine Evans

Using PowerPoint slides, they outlined how the research programme adopted to very different conditions in response to Covid-19, while involving a range of people with lived experience, including carers and people with different kinds of dementia. Instead of longer face-to-face public involvement panel meetings, with lunch provided and travel costs reimbursed, shorter virtual meetings were held, with expenses met for internet/electricity costs, as well as payment for time as originally planned.

They described how strong relationships were developed with PhD students. Even experienced health professionals can find it difficult to talk about dementia at the end of life, yet public members were able to build the skills and confidence of doctoral researchers preparing to undertake research in this area, as well as providing advice. A record was kept of the impact of involvement, showing what changes had been made as a result of involvement. Working remotely made it easier to involve people at a geographical distance, for instance in Bradford.

> “Using the ‘You said, we did’ approach to involvement highlighted the wider application on recommendations to maximise public and community involvement in research.” Jane Ward

Partners in EMBED-Care include the charity Marie Curie, University College London, Cicely Saunders International and King’s College London.

Why and how research matters from communities' perspective

Beverley Randall

Savitri Hensman

This presentation was followed by a discussion between Beverley Randall, associate programme director at Mosaic Clubhouse, which supports people living with a mental health condition in Lambeth, and Savi Hensman, ARC South London's involvement coordinator and a member of the Service User Research Enterprise. They looked at why and how research matters from a communities' perspective. During the pandemic, when Beverley helped Mosaic to become more engaged with research, she became an ARC South London Executive and Board member.

Savi, a carer who has been active in various communities experiencing health inequalities, explained that her own interest in health and care research largely arose from trying to make sense of issues facing her, her family and neighbours and asked Beverley what led her to get involved. Beverley explained that Mosaic was approached by researchers, in particular Josephine Ocloo (the ARC's equity, diversity and inclusion lead), during what was a particularly difficult time for members. There were conspiracy stories going around and a sense of mistrust. The government emphasised that people from Black, Asian and minority ethnic communities had a higher risk of dying from Covid, though some did not believe this. A couple of members died, others ended up in hospital because of underlying conditions. The members needed someone with whom to share their experiences.

> "I thought, this is a really good opportunity to share your story, and also to see if there was anything that could be learned from it, and the members really wanted to do that... It's important that researchers look like us, so that we can build trust and that they use language that is understandable to local people from diverse backgrounds" Beverley Randall

When asked what researchers could do to build greater trust and to address burning issues for people who were disadvantaged or pushed to the margins, Beverley suggested telling people how their information and experiences would be used, letting them know the outcome and how their input made a difference and having more diverse researchers. When working with Josephine, Mosaic members had felt that they were truly heard and it was a positive experience for them.

Reaching people and supporting communities in difficult times

When questions and comments were invited, one of those attending asked how EMBED-Care would address issues for the numerous care home residents with dementia and what it could add to the existing framework for palliative and end of life care. Catherine and Jane described the difficulties faced early in the pandemic, when researchers had to rely on staff to enable telephone or online conversations. It was now becoming possible to go into care homes again; the EMBED-Care intervention was being tested in a home in Eastbourne, for instance, with the hope that it might lead to improvements. There are still considerable challenges; for instance not everyone is aware that people with dementia can access palliative care and there is a shortage of specialist nurses.

> "I think that if we were to harness the power of our public in dissemination and implementation of research findings, we would do much better than doing it on our own… as we do much better if we involve the public in our research questions."
> Natasha Curran

Josephine emphasised the valuable part played by Beverley and Mosaic Clubhouse in helping researchers to connect with service users, making the point that "As researchers it's important that we work with community organisations and think about our research being outside in, rather than inside out." It was noted though that at times, during the pandemic, many community centres were not physically open, which left many people isolated, though these had largely reopened.

A change was called for in involvement in moving towards greater co-production, in which power is shared in decision-making, agenda-setting and interpreting data. As well as collaborating at the beginning, public members should be encouraged to drive research questions.

> "For me, the pandemic has drawn attention to a lot of the very challenging issues in society and who gets marginalised. And that includes a lot of social care users, a lot of people in in some of the Black, Asian and minority ethnic communities, including mental health service users, who may have already experienced disadvantage, as well as a wide swathe of people of all sections of society who have experienced suffering and hardship during this period." Savi Hensman

Reflections on what did and did not change

Those attending met in small breakout groups, with facilitators and note-takers, to share their views and experiences, using the discussion questions:

1. From your experience during the pandemic, what key things have you learnt which might strengthen health and care research, and involvement?
2. From this learning, what are the implications for involvement in health and care research, and more generally for ARC South London's research moving forward? (i. What would you like to keep? ii. What would you like to change? iii. Are there new possibilities?)

When everyone attending had gathered again, there was brief feedback from each group. The experience of recent years had shed light not only how people could be involved but also why it mattered. Points made included the following:

- Some people found it challenging to learn about and access communications technology (e.g. not everyone had a smartphone). Community groups sometimes provided support and training in accessing and using such devices.
- Financial pressures could get in the way of digital engagement for people who wanted to get involved. Some might not want to ask about expenses being paid and, if not helped with the costs, it could put them off from staying involved.
- Some people, such as people with mental health needs, felt that being inside during lockdown made their problems worse. To return to face-to-face meetings was better for them, rather than relying on online meetings.
- Yet the pandemic enabled other people with long-term health conditions or disabilities to get involved in research who were never given the opportunity to do so before the pandemic. The pandemic prevented access issues, therefore giving people the chance to get involved.
- Involvement during Covid was easier when arrangements were already in place, rather than getting this underway in new settings. In future, involving patients and the public should be more embedded in daily practice.
- It is important not to assume that everybody wants to go online but to consult people. Hybrid meetings often did not work.
- Covid is still here, some people are still shielding, although this is not how the situation tends to be described by the government.
- There can be a liveliness and joy when people are gathering face-to-face which does not easily translate digitally. It is worth looking at ways, when meeting online, to try to recreate 'that kind of chitchat… human contact, the energy and so on.'
- There are forms of involvement which are neither online nor face-to-face, for example initiatives involving young people through apps.
- Because of experiences during the pandemic, there was greater recognition that inequalities are real and have an impact. Some communities were unable to access the care and support that was available.

- Given particularly poor outcomes for Black, Asian and minority ethnic communities, the need to do something different was widely recognised.
- To make citizen science partnerships possible, it is important to engage with communities and those whose experience is being researched, in ways that make sense to them.
- Simplifying does not mean talking down to people: maintaining people’s dignity, respect and being aware of cultural differences is important. There is a skill in lay research writing. There can be elitism around research-related publications, which can get in the way.
- Better involvement and communication may increase the chance that research-based evidence is put into practice, yet there can still be a gap: politicians do not always want to listen. For example, good palliative care requires bringing together NHS and social care but this often does not happen.
- Involving new people who are representative of our populations can help in addressing health inequalities. It is important to also look at the retention of people who are involved, learning from the challenges from participation. This may enable people to stay on and share their contributions.
- To increase diversity in involvement, there is a need to build trust, share power with communities and be clear about the reasons why people are turned down (e.g. for not being in the postcode area). Healthwatch organisations are important. Offering various levels of involvement has sometimes made it easier for a range of people to get involved.
- Experience should be recognised and having mentor and buddy systems can help people become and stay involved. There is a need for more investment in involvement champion and expert contributors, offering a form of career development, with structured training, opportunities to take up more skilled roles and incentives.
- It has been helpful when researchers have provided feedback on how findings and recommendations have been implemented.

More detailed notes from breakout groups are provided in the appendix.

Feedback

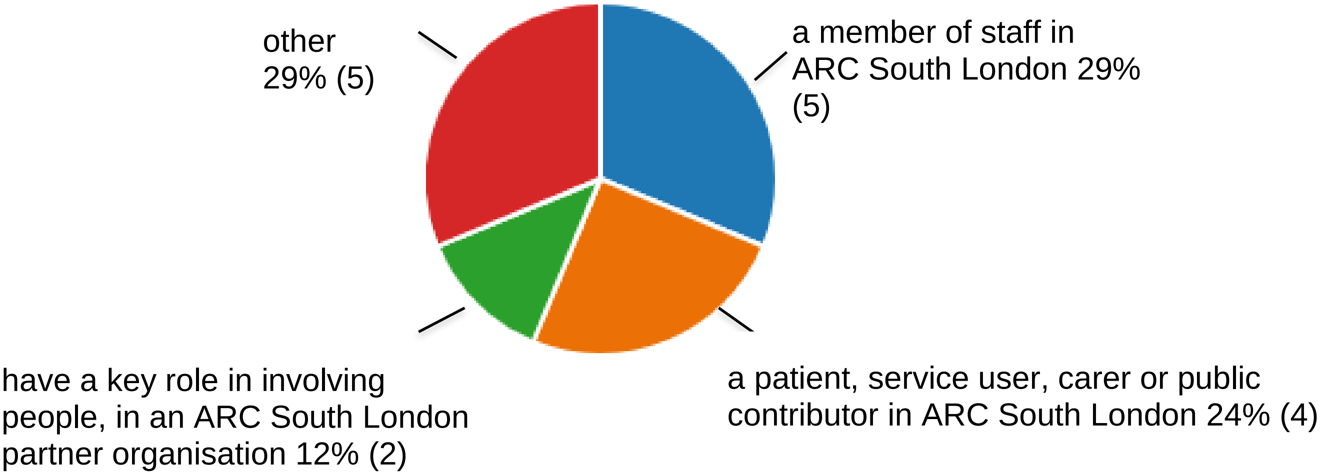
In total, 17 responses were received. Of those, 65% rated the event as 'very interesting', 35% as 'fairly interesting'. Most thought it was about the right length.

Comments on presentation 1, on a dementia project, included: 'A very thought-provoking presentation' 'This was very useful presentation. It was very informative and useful to hear how researchers quickly managed to adapt at the start of the Covid Lockdown to spread their engagement and involvement with wider members of the Public… It will be useful to find out how families can be better supported' and 'a lot to understand if you are new to ARC, but interesting.'

Comments on presentation 2, on communities' perspectives, included: 'This was an interesting discussion on how some communities are being left behind. This is particularly true in some parts of UK where social-economic deprivations and health deprivations is leading to significant health care discriminations and inequalities on provisions / availability of basic health care services.' 'Research matters at every level from globally to the south London community. The Covid pandemic has shown us this' and 'highlighted importance of diversity and inclusion.'

Suggestions for future topics included: 'I'd like to learn more about the role of the public co-investigator/ how various PPI roles can fit together within individual research projects and to influence wider research agendas' and 'Maybe involvement from other community groups such as Healthwatch. Future topics related to social care research.'

Those who responded were:



A diversity monitoring form (developed by the equality, diversity and inclusion working group at ARC South London) was circulated and responses were collected to help us understand the different groups of people, both staff and public members, that we work with and particularly groups protected by UK equality legislation. 16 responses were received but are not published here to avoid identification of individuals.

Appendix: notes from breakout groups

Notes from the breakout groups (A-G) are summarised below.

Group A
From what group members have experienced and observed:

- some of the processes behind research were easier during Covid: it was easier to set things up quickly and to get research out to communities;
- funding applications were often easier, with better guidance. There were increased opportunities to lead on research for non-consultant professionals, eg nurses, primary care and social services personnel. There was more streamlining, for instance on safety and ethics approvals, perhaps partly because of reduced panel resources;
- virtual platforms were quickly put in place, including in public engagement and involvement. A huge uptake in digital communication in primary care has opened up new possibilities;
- healthcare inequalities have increased significantly during the pandemic;
- there have been many applications from white middle class researchers. But aspiring researchers, particularly in socially and economically deprived areas, have experienced increased barriers;
- it is important to look at how we can bring new people into research who are reflective of populations, especially those facing health inequalities; which we witnessed during covid;
- there have been increased challenges and significant loss of experienced members of the public, though there have also been opportunities for some new public members of the public with increased flexibility to get involve;
- it was easier to maintain involvement in ongoing research than get this underway in new studies;
- involvement during covid was easier where it was already in place, including peer support, rather than in designing new studies;
- dissemination has reduced.

Group B
Key things learnt from experience during pandemic which might strengthen health and care research and involvement:

- inequalities are real, have a range of effects and result in unnecessary suffering;
- where care and support were available, some communities largely did not know how to access these;
- research is critical in identifying what can improve; and involvement is invaluable;
- there is not enough involvement of ethnic minorities and younger people, which should be promoted.

Implications for involvement and, more generally, for ARC South London research moving forward:

- there should be more development opportunities for people who get involved, with investment, chances to acquire new skills, structured training, ‘promotion’ and incentives;
- this might include mentoring new public members and removing barriers such as language, eg investing in interpreters (which might include BSL);
- not everyone involved in research wants to become a researcher: expertise in involvement (like being an expert by experience) should be valued.

Group C

Key things learnt from experience during pandemic which might strengthen health and care research and involvement:

- we are living in a new world now and use technology in a different way because of the pandemic;
- we need to think creatively about how we involve communities in research. Community leaders can have a vital role, as it can be hard to develop rapport with communities;
- people from Black, Asian and minority ethnic groups often have worse health outcomes. South London has a diverse population and it is important to recognise the impact of the pandemic on a large part of this;
- the pandemic has accelerated willingness to do something different to engage. Researchers need to meet people where they are. It can be a huge learning curve to do public engagement well; it can be useful to draw on the expertise of public contributors;
- research journals are important – research is peer reviewed for quality by the scientific community. But researchers need to communicate with wider communities as well about what has been learnt, in ways that are interesting, not just a rushed lay summary;
- there has been a surge of interest in ‘citizen science’, in the UK and beyond; e.g. the ZOE project and logging of symptoms really took off, as a way of making a contribution but also keeping up with what was learnt.

Implications for involvement and, more generally, for ARC South London research moving forward:

- the pandemic led to greater use of online formats in contact with public members. It is important to make sure there are other types of contact. In future there could be a mix of online and in-person contact, which some people have really missed;
- a bonus of digital meetings is that people from all over the country, plus people with caring responsibilities, can often contribute more easily;
- in care homes, infection control was prioritised but lack of contact had a hugely negative effect and made involvement harder too. There were not enough tablets to enable virtual meetings for all and residents with dementia are not necessarily able to use digital technology – it cannot be regarded as the answer in all situations.

What impact of pandemic might be for ARC themes:

- alcohol use went up a lot during the pandemic;
- many people felt isolated, which was distressing, especially when members of the community died. This was not how any of us wanted to live; we want to connect and, for many, this include physical contact;
- We have changed as a society; and are now trying to work out what do we want to sustain and what can we reintroduce.

Group D
Key things learnt from experience during pandemic which might strengthen health and care research and involvement:

- Covid is not going away so it is important to continue to find ways to manage it. Shielding will remain vital for some;
- moving online allowed people to access more meetings but a downside is that people miss face-to-face encounters. Screens can be impersonal. For some people going online has not worked: people may not have the means to use the internet or may lack the skills, or may simply not like using it;
- some of us have gradually adapted to engaging remotely. But working remotely continues to bring challenges – for example one's home circumstances (eg caring responsibilities) are brought into meetings. Additionally there are considerable costs in having reliable wifi, a smartphone with a large enough package etc;
- it is important to reach out and find new people and to think carefully about how you communicate, advertise etc, bearing in mind the need to reach people of different ethnicities, ages, sexualities, and with different experiences of illness. Otherwise you end up with the 'usual suspects' once more;
- hybrid meetings could be a way forward, so that people are given a choice. However these may mean that those online feel excluded from the 'real meeting'. It is important to be thoughtful around working in a hybrid way; there are instances when this has been done successfully;
- there have been NHS or related initiatives that brought in excluded voices during COVID, e.g. the Small Business Research Initiative (https://www.england.nhs.uk/aac/what-we-do/how-can-the-aac-help-me/sbri-healthcare/) and the INCLUDE project (https://www.nihr.ac.uk/explore-nihr/innovation-areas/include.htm). Yet despite such positive developments, groups such as prisoners, travellers or people over 75 are often ignored by researchers;
- researchers who are themselves white, educated and middle class may keep asking others to represent under-served groups. This does not work; and more positive action in research staffing is necessary, so that researchers themselves represent the community with whom they are working.

Implications for involvement and, more generally, for ARC South London research moving forward:

- we are living in ‘an endless transition into a new era.’ Yet some public contributors have been with the same organisation for many years. New people must be enabled – perhaps public contributors should have a time-limited tenure?
- calling for ‘lived experience’ is not enough - lived experience must be relevant to the project at hand;
- the online experience has brought both ‘digital delight and digital disappointment’;
- Since online work is likely to continue, we must find ways to ‘put the fun in.’ During in- person meetings, relationships develop through encounters and chit chat – this is usually completely missing from online work;
- will recruiting younger members make this easier? Perhaps developing apps could be a way forward – and younger people can often work together through apps in ways that may be better than face to face meetings or online;
- new technologies can also empower researchers to go out to a much wider population to get responses and that hopefully can drive better research;
- more broadly, during the pandemic, some of those present had come across older people with dementia or other long-term illness, abandoned and suffering at the end of their lives, sometimes wandering the streets or dying in hospitals alone. To take the example of one city, palliative care is currently largely non-existent; people needing such care can end up in older people’s wards in hospitals, which can be dreadful places in which to die. This is not only brutal but also expensive for the NHS. Charities in that area used to have beds for palliative care – they are all gone. Many people want end-of-life care at home but there are no staff to facilitate that;
- people spoke of how angry they feel having witnessed the terrible price these last two years have extracted: ‘We need change now.’ The NHS cannot survive without social care being integrated; but politicians will not allow it;
- the system is broken: people cannot access services, full ambulances are waiting for beds, paramedics do not know what to do when they are called to help. Structurally the NHS needs to change now - there are a lot of medical professionals who are decent, conscientious people who continue to sacrifice themselves to keep their work going but the situation is unsustainable.

Group E

Key things learnt from experience during pandemic which might strengthen health and care research and involvement:

- language is important. In addition to using plain English, it is worth considering body language and not talking down to people, in general being respectful and treating people with dignity. In written materials, colour/ shape/ size/ contrast matter, as well as the length of sentences (this is important not only for people with dementia but also for other conditions);
- other considerations will also apply in communicating with those for whom English is not their first language and there may be some specific cultural differences, e.g. the significance of writing a name in red in certain cultures, so research teams need to educate themselves more about the cultures they are working with;

- re face-to-face versus virtual gatherings, each has benefits. An example was given of membership having doubled in one instance and enabling people from different countries to join. It should be recognised that people are still reluctant to meet face-to-face given carers/comorbidities/illnesses etc, so virtual options should remain;
- on whether to involve people virtual/face-to-face, it is best to consult them, as this may differ depending on the topic being discussed or the group in question. Hybrid meetings can be made to work but this needs a lot of technical know-how and most are not set up for this.

Implications for involvement and for ARC South London research moving forward:

- to increase diversity in research involvement, it is important to build trust, which takes time; and not do things to the community but with, or through, the community. Power should be shared;
- if you are a researcher, you should be clear who you are including and why and, if you exclude people, particularly from disadvantaged groups, you need to explain, why so they are not deterred from putting their names forward in future. The example was given of someone from an East Asian background who was excluded, only because they were from the wrong postcode, but this was not explained to them so they thought it was because the researchers did not want people from their backgrounds;
- Healthwatch organisations can help to engage different groups in research. They are a (semi-) independent voice of the public;
- the recommendations made by researchers should be followed up to check that they are implemented. If research just sits on a shelf, it is a lot of wasted money.

Group F

Key things learnt from experience during pandemic which might strengthen health and care research and involvement:

- there were new opportunities for people in different parts of the country or who have disabilities/long-term illnesses or caring responsibilities which prevented them from joining in research involvement opportunities – some of those whose voices especially needed to be heard;
- many people prefer Zoom to Teams as a platform but you have to pay for a license for the upgraded version of Zoom for longer meetings. It seems like a small thing but can add barriers for universities and community groups who may have restricted funding. Budgets need to allow for funding for Zoom;
- a group member shared the example of their community group, which trained people by phone on how to use tech, using tablets bought with Lottery funding. They tried hybrid working but it was difficult. People with mental health problems, the client group, were badly affected by Covid; to encourage them to come out of their homes, Zoom meetings were after a time. Online activity can be brilliant when it works well but it does not always work.

Implications for involvement and, more generally, for ARC South London research moving forward:

- online working gives good opportunities to see how different ARCs around the country work and being able to search and access things online means there are no geographical boundaries;
- some people, particularly with mental health problems or neurodiversity, may not like to see themselves on camera so may prefer face-to-face meetings;
- people receiving mental health care often want to see their GP, have counselling etc face-to face and feel short-changed if others are having in-person appointments and they cannot;
- other solutions include alternating meetings online with face-to-face (or it could be one in four face-to-face then others online). It is important to provide a range of opportunities in different formats;
- researchers need to offer financial support for the cost of broadband and support with tech for ongoing involvement to enable people with limited resource to be involved.

Group G
Key things learnt from experience during pandemic which might strengthen health and care research and involvement:

- digital involvement does not always work for everyone. Often this is due to financial pressures – digital poverty – which will get worse with the rising cost of living. Connectivity is another issue: you need a good internet connection, which not everyone has. Also many people struggle with the technical side of online engagement and meetings;
- the health research system is not always capable of supporting effective online involvement; availability of support should be publicised better;
- people from Black, Asian and minority communities are not being reached effectively, because there is historical and justified mistrust of health research. Researchers and others need to learn how people from these communities feel and the wide range of different experiences and barriers people from different communities may face;
- there could be different levels of involvement for patient and public involvement (PPI) members, with more formal recognition of experience and support for mentoring and a buddy system in involvement.

Implications for involvement and, more generally, for ARC South London research moving forward:

- it is important to ensure that involvement payments are made promptly – researchers are often limited by slow financial systems at large universities;
- there is a need to look at retention of PPI members, as well as trying to get more young people involved in in research and ensure they feel equal and valued;
- plain English can be important in communicating about research.