

# Exploring south London health and care needs and inequalities through research: sharing insights from patient and community organisations and other knowledge

## Active Involvement in Research 2023 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 Active Involvement in Research events on 13 October 2023 in person and 24 October online, 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](https://arc-sl.nihr.ac.uk) You can also follow us on X (formerly Twitter) [@ARC\\_S\\_L](https://twitter.com/ARC_S_L) and [LinkedIn](#) or email: [arc-communications@kcl.ac.uk](mailto:arc-communications@kcl.ac.uk)

## Acknowledgements

The Implementation and Involvement team at ARC South London includes Natasha Curran (ARC Implementation and Involvement lead), Josephine Ocloo, Sophie Lowry, Savi Hensman and Ann McNeill. For further information please contact Savi, the involvement coordinator, on [savitri.hensman@kcl.ac.uk](mailto:savitri.hensman@kcl.ac.uk). Michele Harris-Tafri and Nick Sarson, ARC South London's communications team, also helped to organise the event and Madelene Boyton, Sarah Egbe and Alice Beaumont provided practical and technical support.

We would also like to thank:

- the additional speakers: Colin Wilson from Healthwatch Sutton and Mark Sladen from Opening Doors;
- the additional facilitators: Rashmi Kumar, Vita Molledo, Lana Samuels, Chris Pavlakis, Katherine Barrett, Mary Newburn, Stan Papoulias;
- the additional note-takers: Aoife Keohane, Lucy Gallagher, Jane Stafford;
- all who took part, sharing their views and experiences;
- staff at Coin Street Neighbourhood Centre.

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## Summary

Bringing together knowledge from patient and community organisations along with other sources is essential for addressing diverse health and care needs and inequalities through research. This was explored at Active Involvement in Research 2023, organised by ARC South London, with around 85 local people, service users, carers, community representatives, researchers, healthcare professionals and others in total, at two events.

An in-person gathering was held on Friday 13 October 2023 at Coin Street Neighbourhood Centre in Waterloo and a second event online, on Tuesday 24 October. These were jointly chaired by Natasha Curran, ARC South London's Implementation and Involvement Lead and Medical Director of the Health Innovation Network, and Rashmi Kumar, chair of the ARC's Involvement Advisory Group and a trustee of Lambeth Patients and Public Participation Group.

Opening the in-person event, Natasha Curran emphasised the importance of involving the public throughout the research process. After this there were three presentations, from:

- Colin Wilson, engagement and projects officer at [Healthwatch Sutton](#), on exploring the health and care impacts of the cost-of-living crisis through informal research through a survey at a community event, and on people who have chronic health conditions or are using care services;
- Mark Sladen, research and policy officer at [Opening Doors](#), a charity for LGBTQ+ (lesbian, gay, bisexual, trans, queer, non-binary or gender fluid) individuals over 50, who explored poverty among older LGBTQ+ people in London and various local and national factors affecting wellbeing;
- Savi Hensman, ARC South London's involvement coordinator, on bringing together knowledge from varied sources to address gaps and deepen understanding, including Census and other data and lived experience.

These presentations were turned into a highlight film and shared at the online event.

Smaller breakout discussions followed the presentations / highlight film, aimed at informing future research and considering implications for south London's health and care system, on:

- Relational care;
- Bringing lived experience and community concerns to work;
- Addressing issues for people with multiple conditions facing disadvantage and/or discrimination;
- Going beyond 'healthy lifestyles'.

Feedback followed, including on the role of systems, structures and power in health and care inequalities and the usefulness of working across sectors. Closing the events, Rashmi Kumar thanked all who took part, highlighting the value of sharing experiences and knowledge.

A [news item](#) was shared afterwards and issues raised at the event will be considered in more detail by the implementation and involvement team, including lessons for ongoing involvement in the ARC and beyond. Links are available to:

- [a recording](#) of the three presentations (37 mins)
- Presentation slides from [Colin Wilson](#) and [Savi Hensman](#)
- information on Opening Doors' [Precarious Lives research](#)

# Exploring south London health and care needs and inequalities through research: sharing insights from patient and community organisations and other knowledge

## Creating space to share knowledge and ideas

Addressing health and care inequalities and the needs of people with multiple conditions are key issues in much research, including in National Institute for Health and Care Research (NIHR) Applied Research Collaboration (ARC) South London. These have been the focus of working groups in the ARC, which brings together researchers, health and care professionals, local people and organisations to examine how to improve health and social care in south London and beyond. The issues are also of concern to many patient, service user, carer and community groups and networks, which have carried out research and helped to capture experience and gather knowledge in other ways.

The ARC holds an annual Active Involvement in Research event. In 2023, this was held in person on the afternoon of Friday 13 October, then on the evening of Tuesday 24 October online, using a video with highlights from earlier presentations. This enabled a wider range of people to take part. Breakout groups using the same sets of questions were held at each event, with detailed notes taken and brief feedback.

Opening the in-person event, Natasha Curran emphasised the importance of involvement throughout the research process.

“Involving people from the beginning to the end of research, and back again, and embedding that public involvement is really important”

Natasha Curran, ARC South London’s Implementation and Involvement Lead and Medical Director of the Health Innovation Network

Ways in which this might happen, including research led by people and communities with lived experience, were examined together and in smaller breakout groups. There were also opportunities, during lunch and a tea break, to chat informally, look at posters and develop and strengthen connections.



## Examining the health and care impacts of the cost-of-living crisis

After this there were three presentations. The first was from Colin Wilson, engagement and projects officer at [Healthwatch Sutton](#), a charity which serves as a local health and social care champion. This explored the health and care impacts of the cost-of-living crisis, including on people who already have chronic health conditions or are using care services.



Using these [slides](#), Colin explained how, as concern grew about the impact of the cost of living a survey was carried out at a community event, Carshalton Eco-Fair – an example of research other than by professional researchers. While surveys had been carried out on a larger scale, on the mental wellbeing of secondary school students (which helped to make the case for greater funding) and later of primary school pupils, this was on a smaller scale, with 108 responses. The [findings](#) indicated that many were affected, others concerned about family, friends and neighbours, which was all the more concerning since it turned out that there was an entry cost which would have put off some of the worst-off people in the borough.

Even so, many were already cutting back on heating, with 68% expecting to do so in winter, as well as on food spending. Mental health was a particular cause of concern, amidst intensifying stress, including potential suicidality.

He and his colleagues continued to work with the council, NHS and other local organisations also in touch with residents. A briefing with information from the Citizens Advice Bureau highlighted ways health was affected.

“I was talking last week to a local vicar who's in a church on one of the social housing estates which are a focus of deprivation. She was saying that lots of the women on the estate work on zero hours contracts and that therefore, if they take time off if they're pregnant to go to antenatal appointments then they lose pay, so they're missing those appointments. And we know that that leads to an increase in the level of stillbirths.”

Colin Wilson, engagement and projects officer, Healthwatch Sutton

A question and answer session followed. One person asked what support Healthwatch Sutton offered older people; they were particularly likely to approach with concerns, on GP access and other issues. With regard to maternity services, the organisation hoped to do more work more on these this year – including disparities such as increased death rates in Black and Asian women. Support for LGBTQ+ people was another concern.

On the question of what the NHS could do better, Colin mentioned that it often communicates badly, e.g. using acronyms without explaining what these mean or not explaining which doctors were on strike to avoid confusion.

## Conducting research with LGBTQ+ older people



The charity [Opening Doors](#), the largest UK charity for LGBTQ+ people over 50, provides activities and support, conducts training e.g. on inclusivity in care homes and conducts research. Mark Sladen (whose colleague Ben Thomas, head of research, had hoped to attend too but could not), a research and policy officer, explained that where possible co-researchers from the community had been involved in research, for instance in Dundee, where local queer people were trained to gather data and so forth.

His own work centred on '[Precarious lives](#)', a study of financial and material precarity among older LGBTQ+ communities living in London (mainly poverty but some people found that term stigmatising), a concern flagged up by some members especially in the light of the cost-of-living crisis.

Some factors were national, e.g. the downgrading of benefits, others local, particularly higher costs in London, with added risk for renters. Structural discrimination played a part, for instance being non-white, being older and on a lower income with higher costs related to health and disability. Minority

stress (living with long-term minority status can affect mental and physical wellbeing) may reduce ability to earn and save. Mark mentioned that trans people were facing appalling stigmatisation in the political realm, with a knock-on effect on public opinion. Other people might at some point have faced much stigma for having HIV, affecting their mental health.

The project was at a relatively early stage; with a literature review complete and a survey developed and beginning to be distributed. He said that co-researchers would be recruited to help with interviews and focus groups, to reach a wide range of community members.

When asked about the difficulty of finding services in some parts of south London, he mentioned that all boroughs should include diverse community needs in their joint strategic needs assessment, but some did this better than others. With regards to promoting the organisation to Black, Asian and minority ethnic queer people, there was a social group targeting this community, outreach at events such as Black Pride and work on diversity and inclusion policies. However, resources for marketing were limited. The widespread focus on the 'pink pound' was discussed: in reality, many LGBTQ people are far from wealthy. Being less likely to have children could also lead to lack of support in later life, while stigma around HIV weakened intergenerational connections, especially among gay men.



## Bringing together knowledge from varied sources, including Census and other data

The third presentation was from Savi Hensman, ARC South London's [involvement](#) coordinator, in the [Service User Research Enterprise](#) and a current or former carer for people with many conditions that are researched within our ARC. She has also been active in various communities, including looking at how research could help in getting their needs met.

She explained that she worked in Camberwell, just a mile from where she used to work thirty years before in a railway arch in Peckham, at the Black Lesbian and Gay Centre. While much was different in that area, health and social care inequalities persisted. She invited ideas on how to tell how much these changed; and why. To what extent was any improvement (or worsening) due to gentrification, with better-off and healthier people moving in; improvements in health and social care; initiatives aimed at reducing health inequalities; changes in society affecting people's health or access to care; or other factors? What sources of data and knowledge might assist? This might offer pointers on what helps or hinders positive change, locally and beyond.



Suggestions included going to spaces frequented by local people and asking what was affecting them and working with voluntary agencies in which people are involved to identify inequalities. Another person, as well as taking the view that health was closely connected to politics, was not convinced such approaches were enough to identify what had changed over time: people of different ages, even in the same community, might have different standards or express things in different ways. She thought a more standardised approach, using statistics, was needed. Other sources of information were put forward by someone present, including joint strategic needs assessments by local authorities and housing data.

Savi pointed out that the picture was complex, with word-of-mouth type sources, research data, census information, NHS, public health and social care statistics and statistics on factors affecting well, research in South London and elsewhere by researchers in universities, the NHS, local authorities and community and voluntary organisations, non-research based reports by patient, disabled people's carers and community groups and other organisations, observation, listening and experience contributing.

"Often those facing greatest inequalities are least likely to be counted or have their details fully and accurately recorded or, perhaps, talk about all the factors affecting their lives or be able to communicate easily with others for various reasons. Lack of safety, access and resources can get in the way of exploring diverse experiences, as well as weaknesses in research culture and structures," she said. Bringing together knowledge from varied sources and perspectives, especially from people with relevant lived experience, was important.



## Breakout groups

Those present chose one of four topics to discuss in small groups, which met after a break. Several ARC public contributors and staff agreed in advance to facilitate or take notes.

<b>Topic</b>	<b>Questions</b>
<b>1. Relational care</b>	
<p>In various fields of health and social care, caring and respectful relationships between professionals and patients or service users can make a huge difference. But these are not always easy to achieve, especially when longstanding inequalities exist and staff and organisations are overstretched. What can assist or hinder these and what further types of research might be useful?</p>	<ul style="list-style-type: none"> <li>● Have you come across good examples of developing caring and respectful relationships between professionals and patients/service users despite challenging situations? Why was this important and what helped or got in the way?</li> <li>● In your view, what further research in this area might be helpful and why?</li> </ul>
<b>2. Bringing lived experience and community concerns to work</b>	
<p>Some of those employed in research, including researchers and involvement staff, draw on their lived experience of the conditions or communities being researched. How can it be made easier to draw on the knowledge and insights they can bring; and what support might they need?</p>	<ul style="list-style-type: none"> <li>● How easy or difficult do you think it is for those employed in research, if they have lived experience of the conditions or communities being researched, to talk about this and knowledge or insights they have gained? Why?</li> <li>● How could this be made easier, while respecting people's boundaries?</li> <li>● What additional support might they need?</li> </ul>
<b>3. Addressing issues for people with multiple conditions facing disadvantage and/or discrimination</b>	
<p>Social and economic disadvantage and discrimination can get in the way of preventing ill health and accessing high quality services. This can be especially complicated for people with multiple health conditions, some of whom may also be in full-time education or new parents, or be using social care services too. Getting what is already known about what works well into practice is not always easy – but are there also areas in which further research would be helpful?</p>	<ul style="list-style-type: none"> <li>● There has been a lot of research in recent years on the issues affecting wellbeing for people with multiple conditions who also face disadvantage and/or discrimination. Yet the findings have not always been acted on. How can researchers work with the children, young adults and older adults who are most affected, and their communities, so that research is put into practice more often?</li> <li>● What further research in this area would be helpful?</li> </ul>

#### 4. Going beyond 'healthy lifestyles'

Often the effects of inequalities are played down when research findings are reported in the media. There can be a portrayal that people with high health and care needs simply just need to change their choices and behaviours, and thus lifestyles. How can researchers, patients, service users, carers and local organisations work together to increase public understanding of the complex factors which affect how people live?

- Why might the media sometimes focus on “lifestyle choices” rather than inequalities, when reporting research on people with high health and care needs?
- How can researchers, patients, service users, carers and local organisations work together to increase public understanding of how complex social factors and systems can influence health and wellbeing?



#### Breakout group feedback: in person event

There were thought-provoking discussions in the breakout groups. Some key points were shared and are summarised below. More detailed notes are provided in the Appendix.

##### 1. *Relational care*

- Long-term care (e.g. in a burns unit) can offer an opportunity to build trusting relationships between staff and patients; though it is questionable for example if dependency develops, whether this is universally helpful.
- The duty of care includes adapting services for people.
- One example is the Living Well Collaborative in London in which a group of mental health partners and service users got together to demystify the mental health system for those using it and make sure that community and patient voice is at the heart of services.
- A major obstacle in the NHS at present is an over pressurised workforce.
- Kindness is important; this is largely experiential.

## **2. *Bringing lived experience and community concerns to work***

- Sometimes researchers are seen as wholly distinct from the public and patients in their interests, priorities and so forth. Yet some people who are employed by a research institution or the NHS combine both types of concern in one person. These include mental health survivor researchers, patient and public involvement (PPI) leads with lived experience and service user ambassadors in NHS trusts.
- There is a risk of being expected to represent a whole group of people, which is not possible; public contributors can face the same problem.
- Other challenges can emerge, for instance an expectation of a certain kind of productivity, while you may have periods of ill health. Being truly inclusive requires effort.
- Researchers, ambassadors and others with lived experience can build bridges and help to build relationships of trust with research participants, among the advantages.
- Additional difficulties may include, especially in mental health, if someone who used to be a psychiatrist treating you is now your colleague, given the issues around power.
- Cultural, institutional and system change may be needed if the value offered by bringing lived experience to work is to be recognised. E.g. in universities the outputs which count most may be journal publications, emphasised in the Research Excellence Framework used to judge success – yet ‘softer’ outputs and outcomes may also be valuable.
- Activism which is inclusive and centres lived experience is needed.

## **3. *Addressing issues for people with multiple conditions facing disadvantage and/or discrimination***

- Building trusting relationships between researchers and communities is important, which requires closing feedback loops and demystifying research to make it more accessible.
- Having community and peer researchers can help in reaching out and breaking down divisions between ‘us’ and ‘them’.
- Some people (e.g. those with a mental health condition) may be in denial or face stigma which may stop them from being actively part of research, which can be a challenge.
- It is also important to seek to involve people in such circumstances throughout the research cycle and, when planning a project, set aside the adequate resources for this.

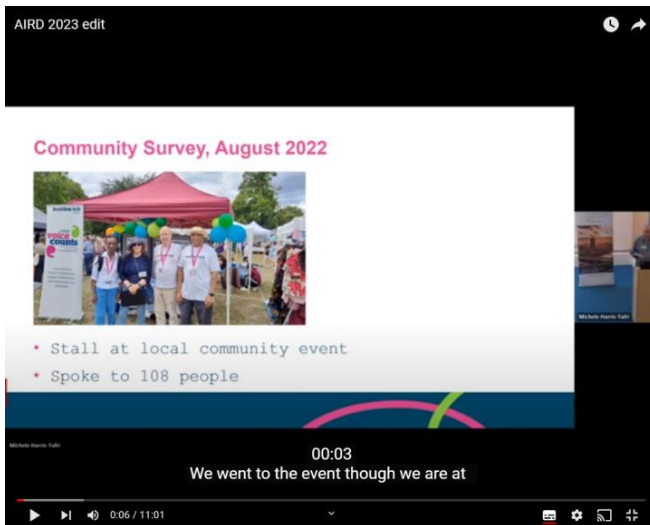
## **4. *Going beyond ‘healthy lifestyles’***

- Sometimes focus on ‘healthy lifestyles’ can actually get in the way of health, with an emphasis on personal responsibility and victim-blaming.
- Leading a healthy lifestyle may require privilege, in terms of time and social and economic background. For example a carer may not have enough time to take care of their own health. And eating healthily may be more expensive or you may need a car to get to places where food is cheaper. There are also more takeaways in deprived areas.
- Overemphasis on lifestyle can add to people’s burden and negatively affect their mental health if they feel they are not doing enough, as well as deepening stigma.

At the end of the event, Rashmi Kumar remarked on “the power of talking, the power of exchanging, learning and sharing information”, inspirational feedback from small groups and value of networking.

## Breakout group feedback: online event

At the shorter evening event on Zoom on 24 October, those attending were welcomed and a video shown with extracts from videos of the presentations given on 13 October.



Breakout groups were then held, with the same four topics and questions. This was followed by an opportunity to share key points. Some different issues to those raised in the in-person event, and are summarised below (detailed notes in Appendix)

### 1. *Relational care*

- Regarding bad experiences, lots of people do not know how to provide feedback or make a complaint.
- Treating people as individuals, asking what care they need and personalising their care; and also involving families can strengthen relational care.
- Carers and staff also need support.
- Care delivery and effectiveness should be monitored and communities worked with, to help shape research.

### 2. *Bringing lived experience and community concerns to work*

- There are challenges for people in the workforce with lived experience and/or from underserved groups, in working with both institutions and communities.
- Staff cannot be expected to 'represent' everyone with a particular condition or background. There may be individuals within communities or groups with dominant views, but it is important to take account of perspectives from a broad range of people.
- Intersectionality is important, as well as taking account of the risk of miscommunication and lack of understanding, even among people with a shared aspect of identity.
- Cultural background should be taken into account, for instance in responding to staff needs, but also diversity within these.
- Although lived experience can be valuable in research, it can have an impact and staff may need appropriate support. A trauma-informed approach is advisable.
- Mutual respect, support and trust should be promoted.

### **3. Addressing issues for people with multiple conditions facing disadvantage and/or discrimination**

- The scale of inequalities has not reduced but has increased. Many people live in terrible conditions or face challenges in getting appointments
- It is important to encourage and enable those who are not in the room, who may be the most marginalised, to shape research
- There is power in working together collaboratively, which is fundamental to making a difference
- Those who deliver research can find it difficult to engage with people with multiple conditions facing disadvantage and/or discrimination. There may be cultural barriers and difficulties in understanding what communities need. Even when research is useful, it may be hard to explain to communities why
- Addressing this includes working collaboratively with service users
- There may be an implementation gap which gets in the way of putting research into practice, due in part to lack of trust and communication which does not reflect the experiences of certain group
- Research needs to be coproduced and co-implemented

### **4. Going beyond 'healthy lifestyles'**

- When 'healthy lifestyles' are mentioned, it is useful to ask how feasible it is for everyone to find time to exercise and how affordable it is to live more healthily
- The media tends to focus on sensational stories, to get clicks and because of its political leanings of the media. It is easier to blame people for their own health issues than finding solutions
- To counter this, when conducting qualitative research, it may be possible to get personal stories as case studies into the media; as well as making findings understandable
- It is useful to engage with local groups and understand the people affected within local areas, to sustain collaborations and link up organisations which might be able to address health issues
- Employers have a role to play, including collaborations and coproduction. Moving beyond a one-size-fits-all approach is important, instead tailoring support to local areas
- Patients, service users, clinicians and communities should work together respectfully to be able to address social and systemic factors
- Working together with other bodies can help in avoiding; for example clinical research organisations and Healthwatch

# Event feedback

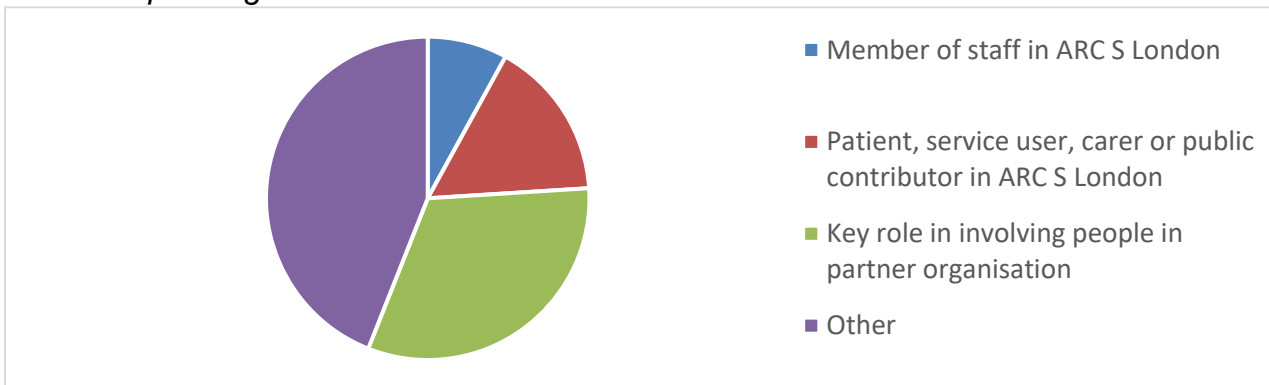
Feedback forms were distributed and collected by hand on 13 October and online for the 24 October event. The findings were considered by the implementation and involvement team and summarised below. Not everyone who responded completed all questions.

## Overall feedback: 13 October

22 responses received.

Interest	77% found it very interesting, 23% fairly interesting.
Usefulness	62% found it very useful, 38% fairly useful.
Length	91% about the right length, 9% too short.
Presentations	Comments were mainly positive, with suggestions, e.g. “The talks were very informative and insightful,” “Interesting talks. More questions than answers! Would be good to hear more about practical ways to improve access to research of underrepresented groups.”
Breakout groups	Most gave positive feedback though several felt these were too short, e.g. “Great conversation & networking,” “Excellent choice of topics - not enough time!”
Other comments and suggestions	“I feel inspired to get involved in my local health group because of this event,” “Needs to be the start of a conversation - practical next steps...what next?” “Would be helpful to have more practical tips on how to include these groups in research
Ideas about future events	“Maternity; continuity of carer”

Those responding were:



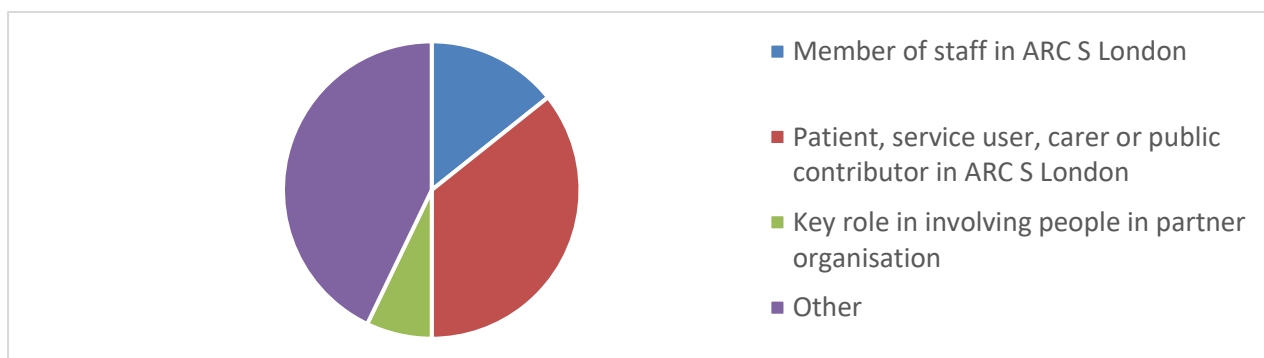
Note: ‘other’ may include local people and representatives of community organisations who are not ARC South London contributors, health and care staff, staff from local authorities etc.

## Overall feedback: 24 October

14 responses were received.

Interest	77% found it very interesting, 23% fairly interesting.
Usefulness	57% found it very useful, 43% fairly useful.
Length	86% thought it about the right length, 14% too short.
Highlights film	Comments were largely positive, though some would have liked more time, e.g. "Interesting and thought provoking," "It would have been helpful to have longer clips. The quality of the recording wasn't always ideal."
Breakout groups	Most gave positive feedback, e.g. "Good session & ability to put forward thoughts & have them noted," "There was a good-sized group with people from a range of backgrounds and perspectives, which made for an interesting discussion; it wasn't clear what the next steps might be though in taking forward ideas and suggestions."
Other comments and suggestions	"Consistent engagement and feedback needed to keep focused and relevant," "I think we are all struggling to show impact of research on health inequalities, though we share this as a key aim."
Ideas about future events	"Improvement ideas for inequalities."

Those responding were:



*Note: 'other' may include local people and representatives of community organisations who are not ARC South London contributors, health and care staff, staff from local authorities etc.*

## Diversity monitoring

Diversity monitoring forms were distributed and collected by hand on 13 October and online for the 24 October event. Information provided is summarised below, though it is worth noting that most attendees did not respond and not everyone who responded completed all questions.

### Diversity Monitoring: 13 October

26 people filled in forms.

#### Gender

Female	18
Male	7
Non-binary	1

#### Transgender?

Yes	2
No	22

#### Disability?

Yes	6
No	19

#### Carer?

Yes	5
No	21

#### Sexual orientation

Heterosexual/straight	16
Gay/lesbian	5
Bisexual/pansexual	2
Other (queer)	1

#### Ethnic group

White UK	9
White other/unspecified	7
Black/Black British	1
Asian/Asian British	5
Mixed/multiple ethnic groups	3

#### Age

16-24	1
25-39	13
40-59	6
60-74	5
75+	1

### Diversity Monitoring: 24 October

10 people filled in forms.

#### Gender

Female	9
Male	1
Non-binary	0

#### Transgender?

Yes	0
No	10

#### Disability?

Yes	6
No	3

#### Carer?

Yes	3
No	6

#### Sexual orientation

Heterosexual/straight	8
Gay/lesbian	1
Bisexual/pansexual	1
Other	0

#### Ethnic group

White UK	4
White other/unspecified	2
Black/Black British	1
Asian/Asian British	2
Mixed/multiple ethnic groups	1

#### Age

16-24	0
25-39	4
40-59	2
60-74	3
75+	1



# Appendix: notes from breakout groups

Those at each event often came up different insights and ideas on the same topic.

## 1. Relational care

In various fields of health and social care, caring and respectful relationships between professionals and patients or service users can make a huge difference. But these are not always easy to achieve, especially when longstanding inequalities exist and staff and organisations are overstretched. What can assist or hinder these and what further types of research might be useful?

- Have you come across good examples of developing caring and respectful relationships between professionals and patients/service users despite challenging situations? Why was this important and what helped or got in the way?
- In your view, what further research in this area might be helpful and why?

### 13 October

*There was not enough time to discuss further research explicitly, but the facilitator (Mary Newburn) and notetaker (Lucy Gallagher) later put together some research questions, based on the points raised.*

- **The group discussed the example of long-term care for patients with complex pain.** There is a stigma for chronic pain sufferers as they have an unseen health problem. They can be angry and there can be tension between service users and healthcare professionals (HCPs). They often see many different health teams and individual HCPs, perhaps resulting in them feeling 'passed around' and burdensome, rather than held and cared for. One participant described how she works differently, making a personal connection, not being afraid to challenge angry people, but doing so within a relationship and communication model of respect and care for the person. Making a person-centred connection was recognised by the group as a 'good'. However, it was recognised that this is not made easier by health delivery systems of fragmented care, and task orientation. It may be the exception rather than the rule and is certainly not universal.
- **It is important** that people with chronic pain, who may have multiple health problems and lead socially complex lives, feel valued and respected, and don't feel they are 'passed around' anonymously in a fragmented health system.
- **What gets in the way** includes the emotional labour for those HCPs who make an effort to provide more person-centred care in a system that is not set up to organise around this principal, and therefore in which for example, HCPs who are conscientious in this regard may be doing more than their fair share.
- **Potential research questions:**
  - Might specific education, such as from psychotherapists or specialist practitioners, make a difference to a more empathetic, whole-person approach to care, that also had clear boundaries?
  - Do patients become dependent on their doctors if they receive more holistic care from the

same small team of HCPs?

- Do different staffing models, such as smaller teams with specific caseloads, make a difference to patient experiences and health and wellbeing outcomes?
- Do different models of care, such as belonging to a team long-term so it is possible to re-enter care when needed rather than seek a new referral after fast discharge from an individual care episode, enable patients/people to benefit?
- **The Living Well Collaborative in Lambeth is an example of how mental health stakeholders have developed a partnership to address the complexity of the mental health system, and barriers from a service user perspective.** The collaborative includes commissioners, providers, third sector organisations, service users, healthcare professionals etc. To begin with, there was a lot of defensiveness around the way the service was run from commissioners and providers. To ameliorate these poor relations, the group started having breakfast together. This was open to all partners to discuss ideas around how to improve system for the service user. A skilled, retired HCP agreed to work with the group as an independent facilitator. Several initiatives from ground-up have emerged out of the Collaborative, some of them led by service users. Examples include Project Dare, a not-for-profit social enterprise in which women attend courses to help develop their body self-confidence; Mosaic Clubhouse's Evening Sanctuary, a service that gives short-term support to people in Lambeth experiencing a mental health crisis. This collaborative has now developed into the Living Well Network Alliance delivering a holistic service. This is an outcome of the trust that has been built over the years.
- **It is important** that service users and all the stakeholders responsible for commissioning, and delivering services, from primary and secondary care, the community, from both prevention and treatment perspectives, have a forum for communication and joint planning and learning.
- **What gets in the way** is no universal structure for this kind communication, reflection and planning.
- **Potential research questions:**
  - How does the Living Well Network Alliance function and what are the key components for its success? How might it be developed further? What does it cost? Could recommendations be made to improve provision of mental health services and enabling, preventative action in other areas?
- **GP services in England and in the Netherlands are organised differently, with less continuity of carer from GPs in England.** Patients at a GP practice in England now tend to get a different doctor at each visit, which has a negative impact on relationships.
- **It is important** that there is an opportunity for individual GPs and GP service users to be able to see the same person over time, to know the person and their family, to avoid having to repeat themselves at each consultation.
- **What gets in the way** is a move away from GPs carrying a caseload in England. Evidence on the relative value and challenges of delivering continuity of carer seems to be discussed rarely and the public are not involved in discussions about staffing models for general practitioners/practice.
- **Potential research questions:**

- An intervention study in which some practices re-establish GP case loading to test provider and service users' experiences and health outcomes, plus other key variables (e.g. prescribing, referrals, A&E use).
- Dissemination of existing systematic review evidence.
- **The group briefly discussed that there are differences between person-centred care and relationship-centred care.** A specific example of an activities manager at a care home was given. This person had worked hard to include every resident, trying different ways to make them feel comfortable. This relationship-building took time.
- **It is important** because older people have complex and individual needs which should be addressed to ensure quality of life and good health.
- **What gets in the way** may include a low threshold of societal expectation for quality services for older people.
- **Potential research questions:**
  - How are person-centred and/or relationship-based (continuity of individual carer) models of care delivered in care homes, what are the key factors for success?
- **Care in a burns unit.** This can be a life-long open-door service, allowing time to develop relationships which is arguably the main challenge in the NHS at the moment. We need to allow time to properly understand the complexity of the issues faced by the patient. We should work as an inter-disciplinary team to adapt our services for all as part of our duty of care under NHS legislation. E.g. someone with mental health issues.
- **It is important** because people with serious burns have long-term needs and psychological sequelae.
- **What gets in the way**, potentially, is lack of a long-term focus in planning and commissioning.
- **Potential research questions:**
  - Depending on what is already clearly established by research, identify whether more research or better dissemination of research findings is needed.
  - Is life-long, open-door burns unit novel or widespread (mapping study)
  - What can we learn from this model of care? This could be a comparative study across disciplines with long-term implications.
  - What stands in the way of long-term care commissioning?
- **The group also briefly discussed:**
  - Academic and community relationships. We should look at the strategies used to build trust here.
  - Often a paternal nature within the system. HCPs should always be respectful and acknowledge power imbalances.
  - General Medical Council have made it a requirement for doctors to 'be kind', but how do we implement and measure this? Doctors are not schooled in this, so it is often experiential learning. We need clear boundaries.
  - Continuity of midwifery carer and the evidence of better health outcomes.

- **What further research might be helpful and why?**
- What structures around relational care between professionals and patients exist, including for nursing and professional services staff?
- Another key area could be compassion fatigue. Where do NHS staff get support?

## **24 October**

- **Care at home** was the main topic of discussion
- **Bad examples** of relational care:
  - Supposed to have care at home for 3 weeks which never really happened – carers didn't turn up, didn't provide the care they were supposed to etc.
  - Due to have physiotherapy rehabilitation – was actually sent to an old people's home for this. Felt like had been 'put into a box' and was with people much older. Only stayed for half the anticipated time as felt it wasn't meeting needs, so ended up having care at home. Felt was given care over the top. Should have been asked the right questions and treated as an individual (and as a whole – could also include family/friends in this), then would have got more appropriate care
- **Good example**
  - Carer actually engaged with family member (grandmother), spoke about hobbies that they shared etc. This built a relationship, family trusted carer and felt much more relaxed leaving them together. Unfortunately now this carer has left and current carers don't speak to the person they are caring for (e.g. ask family what she would like for lunch, rather than just asking her). All trust and relationships lost.
- **Other points:**
  - Care works well when you treat people as an individual, and as a whole. By simply asking people what they need and personalising care based on their situation you can ensure you actually meet people's needs
  - Care varies across different locations, people don't always know what is available / how they can get support etc. When deciding the type of care you want – need a clear guide to the different types of care available
  - Location of care – where people feel safer and more relaxed can be so much more valuable
  - Experiencing that many (deprived areas especially) are employing more and more international carers. Fear that they are not experiencing an acceptable quality of life (low wages, low welfare quality, evidence that international nurses in hospitals experience racism) and that this could also impact upon care provision.
  - People often don't know how to complain or feedback when they experience poor relational care (and unsure what they should receive in the first place). People can often also feel too scared to complain and have a fear of repercussions. To ensure quality of care, need transparent and clear ways for people to be able to feedback (and then make changes based on this, 'you said, we did')
  - Need to consider how relational care is monitored. Is this regularly checked by the CQC /

care delivers? How do we know that the necessary quality is being met?

- Really important to work with community organisations and carers groups to further shape research
- **Potential research questions:**
  - How can we support carers (including those who have been recruited internationally) to ensure that their quality of life is acceptable, and this can then impact on quality of care translated to patients?
  - How can we monitor relational care delivery and effectiveness?

## **2. Bringing lived experience and community concerns to work**

Some of those employed in research, including researchers and involvement staff, draw on their lived experience of the conditions or communities being researched. How can it be made easier to draw on the knowledge and insights they can bring; and what support might they need?

- How easy or difficult do you think it is for those employed in research, if they have lived experience of the conditions or communities being researched, to talk about this and knowledge or insights they have gained? Why?
- How could this be made easier, while respecting people's boundaries?
- What additional support might they need?

### **13 October**

- **How easy or difficult to talk about lived experience, knowledge or insights; and why**
  - It is sometimes expected that as a service user researcher you represent a whole group of people, when that is impossible (this also applies to people in patient and public involvement and research participants)
  - Lived experience can be a real asset – you have the lived experience that enables you to understand and help you articulate the experience
  - Can also give you trust within a particular community
  - But important that your own challenges / perception don't dominate the research and close you off to what people are saying
  - Service user experience can, at times, hinder your 'productivity' when there is an expectation of this from the employer institution – but your value is also experience and insights. How is value measured? What other kinds of value can be introduced?
  - As a researcher with lived experience, you can come into contact with people in very different personal contexts with different power balances, which can be challenging
- **How could this be made easier, while respecting people's boundaries?**
  - One of biggest barriers is that people often don't listen. Without listening there's no learning. Other researchers need to listen first, without predetermined ideas, to see how you can use your skills to address / better understand their concerns
  - Research funders often have set traditional idea of outputs which don't necessarily work

with communities, when we could benefit from employing more creative approaches – eg inviting people to sewing class to talk about experiences of menopause. Paperwork and language tend to be orientated towards randomised controlled trials

- Lack of clarity on roles and in communication can be an issue: what is expected from you, clearer boundaries, what is needed from you and valued, what is necessary or not
- How can learning and experience be valued? Softer outcomes
- Systems change: how to get there? Activism which is inclusive and centres lived experience

## 24 October

- Those taking part approached the questions from **different angles**, for instance bringing lived experience to work in the voluntary or public sector or being active in research with people who do
- One person worked with a team of **community researchers**, working with communities and institutions and bringing their own experience to bear, which could be challenging. If analysis was conducted by one member, it was reviewed by another to reduce bias
- The community researchers usually discussed the topic in detail before starting the research, trying to be aware of people's triggers and reminding them that they could take a break when needed and so forth. They tried to mitigate the risk of a handful of people's views dominating by working in groups which brought different perspectives
- As lived experienced partners working with other (e.g. statutory) bodies, their role was to support meaningful involvement in research, not to share their personal experiences. They worked in partnership with staff from other organisations to advise on involvement processes from the start of projects; they were embedded in teams and acted as connectors to reach out to our personal and professional networks, to other experts by experience. Other researchers sometimes expected them to share more about their lives but they were clear about their role
- Another person was a public contributor, bringing in lived experience when involved in research. While researchers might have some overlapping experience, other aspects could be different and they **did not necessarily relate** to how he lived his life. For instance English was not his first language and he perceived them as coming from a more Westernised perspective. It should not be assumed that there will be no major differences or barriers between researchers and others with lived experience of conditions or communities being researched. **Intersectionality** was important
- There could be many types of lived experience. It depended on the **working environment** a researcher or other member of staff worked in, and how open and supportive it was, as to how it might feel to talk about one's lived experience. It could be difficult to expose a vulnerable side of oneself
- Bringing lived experience and authenticity into the workplace could be very difficult and working life often does not offer a psychologically safe environment. Hierarchy in the academic world is also a significant challenge
- For a lived experience researcher, negative experiences of healthcare for one's community could be difficult to hear. So a new structure for wellbeing, to give more support and enable

reflective practice for each researcher, was developed

- In creating supportive conditions, it was useful to consider what might be a culturally appropriate method of support. **Support needs to be relevant to people's diverse identities** without making assumptions
- Bringing lived experience to work can offer **advantages and strengths**

### 3. Addressing issues for people with multiple conditions facing disadvantage and/or discrimination

Social and economic disadvantage and discrimination can get in the way of preventing ill health and accessing high quality services. This can be especially complicated for people with multiple health conditions, some of whom may also be in full-time education or new parents, or be using social care services too. Getting what is already known about what works well into practice is not always easy – but are there also areas in which further research would be helpful?

- There has been a lot of research in recent years on the issues affecting wellbeing for people with multiple conditions who also face disadvantage and/or discrimination. Yet the findings have not always been acted on. How can researchers work with the children, young adults and older adults who are most affected, and their communities, so that research is put into practice more often?
- What further research in this area would be helpful?

#### 13 October

- If people with multiple conditions who also face disadvantage/discrimination are **involved throughout every step of research**, from the beginning, this can lead on to the implementation stage
- Researchers do not always have the skills. Given the necessary resources, **community organisations** could help build / repair relationships and **peer researchers** play a part
- Need to **demystify** research, which is sometimes seen as quite elitist, e.g. people to go out into the community to speak about what research actually is, and work with gatekeepers / trusted community members to do this
- Health champions and involvement registers in NHS bodies can also help to reach people but barriers can still exist
- In working with groups with multiple conditions who also face discrimination, understanding who the population is and how to access them helps to ensure research integrity
- Indeed it is important to **include all the right people** at all the right stages: patients, community, other stakeholders; which might include enabling them to track at what stage a project is
- Need to be transparent about project progress: this also means **evaluating and reporting on failure**, so that it can be learnt from, though there can be pressure to focus on success e.g. to get funding

- Some researchers are strong on dissemination. For instance the Centre for Longitudinal Studies, which includes looking at socioeconomically deprived areas, seeks to disseminate work to researchers, policymakers and communities. But sometimes there are not enough **funds to share findings**
- It can be useful to feed back to participants: but this requires staff with the time and skills
- The need for strong patient and public involvement and engagement has become clearer over time; but **budgets must be adequate** to do this well, which may require advocating for the importance of such activity
- Clarity on **payment** for involvement is useful. But often, especially because of Department for Work and Pensions rules, people with multiple conditions and facing disadvantage/ discrimination may not want to be paid for being involved, but instead to be provided with catering, childcare, transport, training courses enabling them to develop their skills and learn more

## 24 October

- **How can researchers work with those most affected and their communities so that research is put into practice more often?**
  - Hearing the issues raised in the presentations, it is deeply saddening that, after 25 or 30 years, the scale of inequalities is not reduced. Anyone who has a taste of what it is like to live in terrible housing or is having difficulty in getting appointments can testify that serious problems remain
  - Universities and people in the community trying to gather evidence are not coming together effectively
  - People face various barriers: for example as an immigrant you may learn to be grateful and not to complain
  - There are also issues with lack of secure housing, for example gentrification of areas and being priced out, leading to forced mobility. This means you cannot settle, put down roots or rely on services
  - From the perspective of someone who delivers research, it can be difficult to engage people in south London. There are cultural barriers and researchers may not really understand community needs. A lot of research is beneficial but it can be hard to explain why in ways people follow, dissemination of research findings is not always good and the way findings are identified can be patchy
  - 
  - It is important to be aware of who is not in the room; and get the most marginalised to shape research
  - Going into communities, asking people what is affecting them and making connections is very important. There is power in collaboration but people often do not use this to their advantage; they may not believe in collaborating or see it as yet another task
  - There are two models – philanthropy, where you are doing something on behalf of others, and self-help, which involves coming together to take action. It is important to push harder in research to do the second, using peer research and co-research models. This is a way of



flattening the current hierarchy

- What would accelerate this? Forcing people to think about putting co-research into practice, getting public members to input into the research environment, making the workforce more diverse
- **What further research in this area would be helpful?**
  - Working collaboratively with service users and embedding involvement in research is important
  - Research should be put into practice and implementation gaps considered
  - It is useful to think about whether we are producing the right knowledge – experiential knowledge may be undervalued, e.g. a medical person may come up with a view but may not have necessarily asked the right questions
  - A lack of trust from communities should be tackled, as research reports often do not reflect their experiences
  - Participatory action research – this is about co-producing and co-implementing

#### **4. Going beyond ‘healthy lifestyles’**

Often the effects of inequalities are played down when research findings are reported in the media. There can be a portrayal that people with high health and care needs simply just need to change their choices and behaviours, and thus lifestyles. How can researchers, patients, service users, carers and local organisations work together to increase public understanding of the complex factors which affect how people live?

- Why might the media sometimes focus on “lifestyle choices” rather than inequalities, when reporting research on people with high health and care needs?
- How can researchers, patients, service users, carers and local organisations work together to increase public understanding of how complex social factors and systems can influence health and wellbeing?

#### **13 October**

- The media often focuses on what might make ‘good’ stories, e.g. ‘five easy steps to getting a healthier lifestyle’, but there are complex reasons why people are unhealthy
- Having a ‘healthy lifestyle’ may require privilege. For instance, how can an unpaid carer achieve this if all their time is taken up with caring? People with Type 2 diabetes may be encouraged to live healthily but structural factors can get in the way. Good quality food tends to be more expensive or you may need to get a car to get to where you can buy this cheaply. Deprived areas have more takeaway shops, poor quality unhealthy food. Foodbanks offer prepacked, dried goods and tins
- In England, the culture tends to push people to carry on if ill, while carers, disabled people or people with long-term conditions are often judged negatively as though they are not contributing to society. Blame for not being healthier can add to the burden

- Healthy lifestyles and actual health are often in conflict, paradoxically. People feel pressured by the emphasis on healthy lifestyles and often feel as if they are never doing enough. This may further add to problems during a cost-of-living crisis
- Inequality is increasing due to the economic crisis. There are other factors that contribute to ill health such as pollution, poor housing. The media focuses on things that people can control but not the things they cannot, and on victim-blaming – because it is convenient to blame the people who have the least power
- The media and society tend to put responsibility on individual because it is easier than to fix things or to spend money on solutions

## 24 October

- **Why media might sometimes focus on “lifestyle choices” rather than inequalities, when reporting research on people with high health and care needs**
  - **Sensationalism / simplification of stories**
    - Media (tabloids) – are there to sell the story that they think audiences will listen to
    - ‘Lifestyle choices’ connected to a whole raft of things – social, health, access to services etc: media may not be so interested in this complexity
  - **Blaming narrative**
    - Often the effects of inequalities are played down when research findings are reported in the media. There can be a portrayal that people with high health and care needs simply just need to change their choices and behaviours, and thus lifestyles
    - Tendency to blame individuals for their choices. This can oversimplify the causes of health and care needs, overlooking the broader societal factors at play.
    - Some people are struggling to survive in today’s climate
    - But there are many other determinants of health that are not talked about
    - Statistics can be misrepresented. People’s stories are important to uncover, which can avoid the pointing finger and help to understand the complexity of the challenges to healthy lifestyles
  - **Commercial / political bias**
    - Political leanings of media mean they may not argue for investment to address complex causes of lifestyle choices
    - Media outlets tend to be businesses that prioritise stories that generate revenue or align with their commercial interests. This can influence the choice of stories and their framing, potentially leading to a focus on stories that can be monetised.
  - **Determinants**
    - Many determinants of health, such as feasibility, affordability, environmental, social, physical, and historical factors, contribute to lifestyle choices. However, these complexities may not be adequately addressed in media reports
- **Working together to increase public understanding of how complex social factors**

## and systems can influence health and wellbeing

- Use **personal stories**. People's stories help unpack inequalities (eg areas that are 'food deserts' – ie not close to affordable supermarkets or street markets)
- Open **discussion with diverse groups**. Important to have more discussions with a wider range of people and listen – culture of asking people, to really understand their needs
- **Different areas** have different social factors – so people and systems need to work together (this can be easier in cities)
- Need to identify **whom we can engage with** to bring about change
- **Collaboration and coproduction**: cannot be one solution for everyone. Engage with local community leaders and organisations; connect up these local organisations with bigger organisations that can bring about change
- Researchers, patients, service users, carers and local organisations should work effectively with the resources we have. Look at **community assets** and way in which they can be used
- Make **research studies understandable** – support with case studies and tell story in a compelling way
- **Employers** should also play a role in supporting health and wellbeing
- Can be a problem that funders do not want to address complexity, prefer simpler focused questions. Need to **advocate for addressing complexity**
- People with complex needs may give up, feeling no one really cares. Acknowledge they can become disheartened if they feel their issues are not cared about. This highlights the importance of **sustained engagement**
- Engage with **advocacy groups and non-profit organisations** to amplify the message and drive greater public understanding