Inside Research seminar – Tuesday 20 June – Improving access to care: ensuring health and social care gets to people who need it most – Breakout groups discussion summary

Breakout session questions:

Q1: What are the most difficult challenges people are facing including managing multiple long-term conditions, in relation to accessing heath and care services?

Accessing care homes and social care
- Difficulty of communication with staff and there is a disconnect between different health and social care services. Also, a lack of staffing which makes it difficult to prevent things like falls
- Language barriers, poverty and digital barriers make it harder for people to access services
- How you present an issue can be key to the level of service access you will have – this can favour some groups over others, intensifying health inequalities
- Health professionals therefore need to be smarter in identifying issues when people first present to services in relation to identifying both physical and mental health issues
- Using patient-centred outcome measures in routine care can help with the above. But we need to use measures that are developed with people concerned so that they are asking the right things
- One member talked about very positive experiences of care home delivering palliative care for family member in a care home outside of London
- Structured processes in place in care homes enable integrated care
- There are also examples of care homes that deliver very good culturally tailored care
- There is a shortage of staff and continuity is not there. People leave and the quality of care goes down
- If you have permanent staff there is career-based progression and quality of care is better. Career based employment is better as it is self-enhancing and will have more benefits. Those who are from agencies might not be 100% into their work
- With a multidisciplinary approach it is about putting minds together

Accessing GP appointments and hospital treatment
- Difficulties with accessing GP appointments and long waiting lists for operations
- Difficulties with having to go to different places if you have multiple health issues. Lack of integrated care
- GPs often focus on one issue leading to the risk of diagnostic overshadowing
- GPs want to get you out of their consulting room as soon as possible
- The pressure on GPs was also discussed
- People go to A&E because they are desperate for help, often parents with young children who can't get a fast response from the GP
- People in other countries can access a paediatrician without a referral. In England, we have to wait for referrals which takes too long
- Lack of communication about what services people need to access e.g. parents go to A&E when they could go to GPs but some services are not available
- People have a lack of information about accessing the system, so they go to A&E as a shortcut

- People with multiple conditions have to keep describing their conditions because different health staff don't have access to your notes, so the patient has to repeat the information each time. Lack of joined up data records

Q2: What social or psychosocial factors (e.g age, ethnicity, gender, language, socio-economic background, housing quality, lack of trust in the healthcare system) have influenced you/your family's/ patients' ability to access care?

- Education, ethnicity and class can play a significant part in determining how healthcare professionals respond to you and may influence what choices you have in care and treatment, for example, in relation to mental health care
- We possibly overstate people's health literacy in relation to their condition
- Where you live can play an important part in the care you receive: some parts of the country offer brilliant post-diagnosis care in relation to dementia, others far poorer
- Remember that what's routine for health professionals is not routine for everybody – this is important when thinking about how you communicate around health to people from a wide variety of backgrounds and experiences
- Also need to understand better how people are using online health forums, and what kind of information they are accessing there
- If you have language barriers you might not be heard and your views are not grasped
- Accents can be a barrier as they can make it difficult to understand / be understood
- Everything is digital now and this can be a barrier, especially for older people who are not tech savvy

Lack of diversity of staff and participants in research
- Lack of trust in the healthcare system was a strong theme that came out in all of the discussion groups as one of the biggest obstacles
- Healthcare staff should think about why there is a lack of trust
- Lack of training in providing care for people in different communities and from different cultural backgrounds. If they don't receive care in time then situations worsen
- The link between services and the community needs to be strengthened
- Example of cultural background linked to lack of trust in healthcare – a Muslim woman who was pregnant and rebuked for fasting while she was pregnant. So she avoided going to future appointments
- Ethnicity is a barrier. There has been distrust, particularly related to the history of research and the way people have been treated such as the syphilis trials, when the treatment was there, Black men were left to languish and die
- In research, people do not see a representation of Black, Asian and minority ethnic (BAME) groups
- As a research nurse, before coming into the position, there was a lack of recruitment of staff from BAME groups. This contributes to mistrust because people cannot identify with the staff that are working in these environments
- There are initiatives now that have been introduced to try and include the BAME groups, and people with low socio-economic situations
- There are also other disadvantaged groups within age and gender, which has contributed to a lot of disparities
- The research designs are failing because they are not including PPI members from minority groups, socio economic groups from low-income families that should be represented
- PPI members and underrepresented communities need to be included from the research design to the dissemination of research projects

What are the preconditions to encourage people to take part in the PPI opportunities?

- To educate, to use PPI from other citizen groups, talking to patients, families and their carers and work with them. This helps to develop trust and helps them to recognise the benefit of the research
- To also provide PPI members with benefits and incentives that will encourage them to participate in research. This might include financial support, such as paying for transportation, meals, or refreshments
- Minorities are not represented so the research is not 100% accurate. The NHS Workforce Race Equality Standard (WRES) report highlighted this
- A more diverse workforce is needed because when you have researchers that look like the various community groups, people tend to listen, ask questions, and want to get involved
- To get people to understand that the research being conducted might not benefit them now, but it will benefit the next generation. There needs to be a representation of different people and communities, encouraging people to understand that research is not bad
- There is also a need to ensure that people are making informed decisions without being coerced, while also encouraging them to see the benefits of taking part in research
- Researchers can be very impersonal. The aim will be to try and listen to people and try to develop a rapport, and this might encourage people to give up their time
- There are language barriers which prevent people who might be keen in taking part in the research but are unable to
- In some cases, the research experience can feel quite tokenistic

Q3: How can ARC South London balance carrying out research prioritised by local communities, with research priorities identified by local health and care providers?

- This question would benefit from being put out to a wider discussion
- In practice it's a balance, priorities need to match the expertise of our researchers
- Should we bring in new researchers to address areas highlighted as local priorities, for example related to local environmental concerns (eg impact of air pollution on health)?
- How do we intervene early enough to ensure that local organisation priorities are factored into a new organisation?
- Integrated care systems – a key stakeholder for us - have already done a lot of work to identify local priorities and so we should look at how to support them best
- Researchers and communities need to work together – co-production
- The demographic is different in different boroughs, so research may be more relevant to some boroughs than others
- It is a paradox that research priorities are not the same of that as those health and care providers and local communities
- The heart of the problem is that research is being conducted in a way that is not involving voices of residents, local concerns, which is why research proposals fail with minimal impact on people's lives
- By bringing research priorities in line with the needs, preferences, interests, and concerns of the people
- Q3 feeds into Q2. There are barriers or the issues with research being in secondary care. For example, people are more likely to have better access to care facilities when they are in their homes, in contrast to when they are in a care home
- In secondary care in hospitals, people are exposed to more research and its opportunities. This is the case for services like cardiac and cancer. There is an opportunity to know and be aware of research, whereas in the community there is a gap
- The ARC will need to develop connections with local communities and local charities
- They will need to carry out needs-based assessments

Main group discussion after the breakout group discussion

- The most difficult challenges for accessing health care are the lack of joined up conversations and thinking. The concern that clinicians tend to work and think in silos around their own conditions/subjects, and therefore not communicating with each other
- The role of a carer in the life of a patient or somebody accessing health care and the challenges
- There are societal challenges, such as failure to involve carers, especially with the increasing ageing population this will be a significant national problem
- There are challenges in coordinating health care, managing carers and managing people who are unable to consent for themselves
- What is good? People are unable to articulate what is good when they are asked by their doctors
- Regarding Q3, this can be achieved by patient reported outcome measures and shared decision making
- Shared decision making might be the new PPI, which is sold as a good idea but might actually not be. When are patients, carers and doctors ever meeting on an equal footing by virtue of the fact that we are asking for an opinion, or we are asking a doctor or a healthcare professional because we want to know their opinion and we do not yet know our own opinion
- There is a lack of communication between the services and the service users