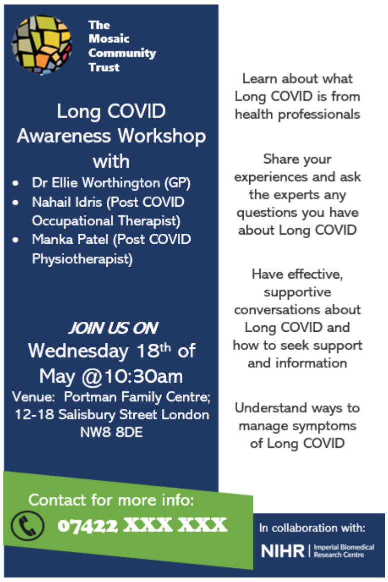
Working in partnership with Imperial College London to improve understanding of long COVID in our local community

On the 18th of May 2022, the Mosaic Community Trust collaborated with Imperial College, London to undertake a community awareness session on long COVID.

Long COVID was considered a priority area after many from the community raised that they were experiencing ongoing symptoms after a COVID-19 infection.



The Mosaic Community Trust

Long COVID Awareness Workshop with

- Dr Ellie Worthington (GP)
- Nahail Idris (Post COVID Occupational Therapist)
- Manka Patel (Post COVID Physiotherapist)

JOIN US ON
Wednesday 18th of May @10:30am
Venue: Portman Family Centre; 12-18 Salisbury Street London NW8 8DE

Learn about what Long COVID is from health professionals

Share your experiences and ask the experts any questions you have about Long COVID

Have effective, supportive conversations about Long COVID and how to seek support and information

Understand ways to manage symptoms of Long COVID

Contact for more info:
☎ 07422 XXX XXX

In collaboration with:
NIHR | Imperial Biomedical Research Centre

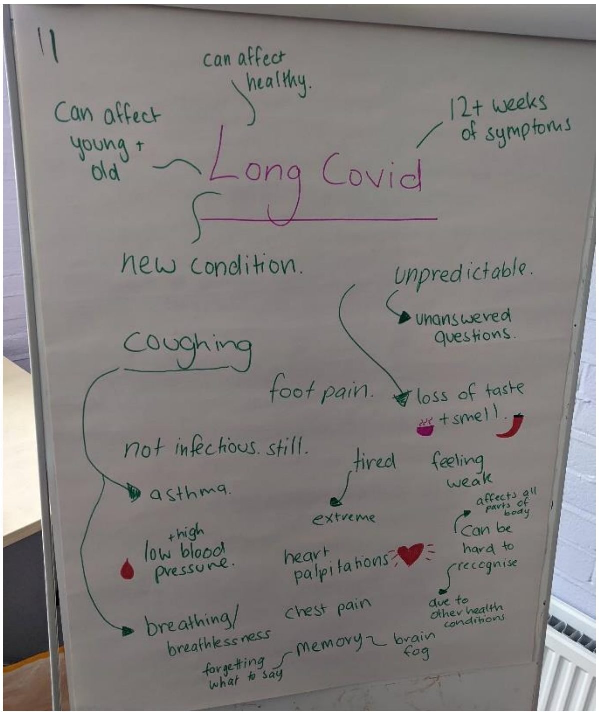
The session was developed and hosted by Mosaic in collaboration with Dr Ellie Worthington (GP/Clinical lead for NWL Respiratory and Post Covid services/Hammersmith and Fulham GP Federation), Nahail Idris (Post COVID Recovery Occupational Therapist, Central and North West London), Manka Patel (Post COVID Recovery Physiotherapist, Central and North West London) and Halle Johnson (Public Involvement Officer at the Patient Experience Research Centre).

The purpose of the session was to:

- Understand current perceptions and experiences of Long COVID in the Community
- Raise awareness of Long COVID (what it is, who is affected, symptoms)
- Share strategies for Long COVID symptom management; and
- Provide information on how to access support

Summary of the session:

Understanding perceptions of Long COVID and Long COVID Awareness

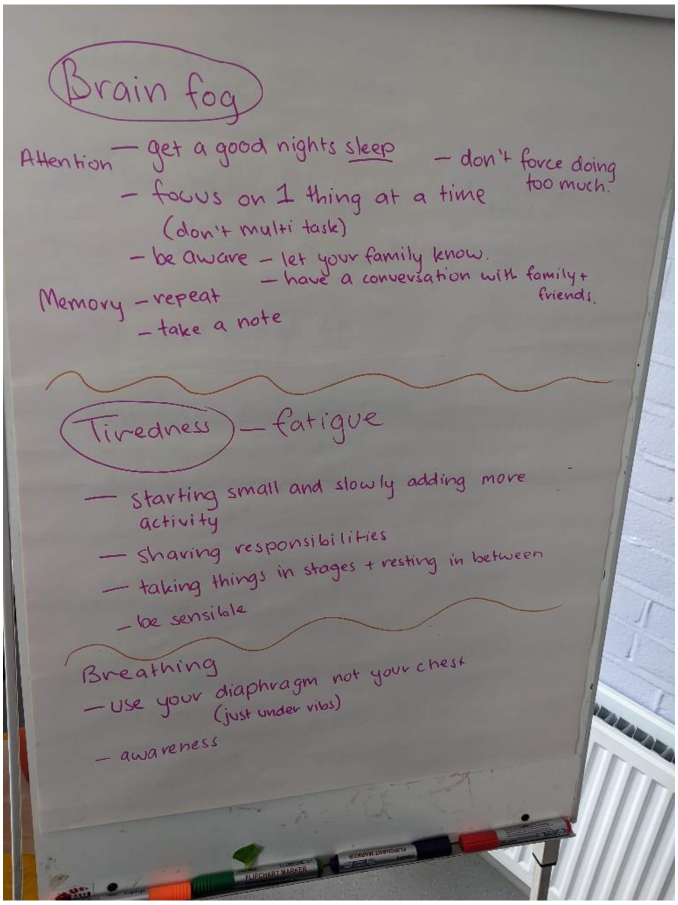


At the start of the session the concept of Long COVID was introduced. Only a handful of attending had not had COVID-19. Many also shared that they had continued to have symptoms after 1 – 2 months after infection. Four of the group also noted that they were still experiencing symptoms after 3 months and some attendees also knew family or friends within the community who were experiencing symptoms after 3 months.

Overall, there was some understanding in the community already about Long COVID, however many weren't aware that the classification of long COVID is ongoing symptoms 12+ weeks after COVID-19 infection.

Many also weren't aware of the range of symptoms associated with Long COVID, for example fatigue, joint pain, memory and attention issues, heart palpitations, and pain weren't currently recognised symptoms by the community.

As part of this section of the workshop, which was about raising awareness of long COVID, the group were encouraged to ask any questions or share any relevant experiences.



Brain fog

Attention — get a good nights sleep — don't force doing too much.

— focus on 1 thing at a time (don't multi task)

— be aware — let your family know.

— have a conversation with family + friends.

Memory — repeat

— take a note

Tiredness — fatigue

— starting small and slowly adding more activity

— sharing responsibilities

— taking things in stages + resting in between

— be sensible

Breathing

— use your diaphragm not your chest (just under ribs)

— awareness

Many from the group shared the range of symptoms that they had experienced, with some still experiencing issues with blood pressure, breathing and coughing, fatigue, and pain.

During this discussion attendees also queried how symptoms of Long COVID could be recognised in comparison to symptoms from other health conditions, as many in the community are living with multiple long-term conditions. The team highlighted that this can be quite complex, but any symptom that you did not have before a COVID-19 infection, and now have afterwards, should be

Issues for clinical care and service provision raised by the community:

While education and empowerment are a first step in helping the community understand the breadth of symptoms linked to Long COVID and the potential impacts of these, we need to ensure that the community are able to access appropriate treatment and care to alleviate symptoms and mitigate any further health issues.

The group raised experiences of GPs being dismissive about concerns around ongoing symptoms. Further education for health professionals about the experiences of Long COVID from communities could be one way to overcome this.

Further, those attending also raised the issue that current Long COVID services may not be appropriate for many members of their community who prefer face-to-face visits due to lack of technology, difficulties in communication, and also a preference for touch when trying to communicate symptoms and problems. An example which was given after the session was from a lady who had chest pain, but only had a mobile phone to do the online consultation with, she was trying to show the doctor where the pain was but struggled to do so while holding the phone. To reduce health inequalities linked to this, it's important that members of the community know and feel empowered to request face-to-face appointments. In parallel, services should do more to understand patient preferences for appointment types.

A further concern was raised about how to manage the social aspects of long COVID treatment and rehabilitation, where many of the community may not get the support for their family/friends to help and could not rely on them to take on any responsibilities while going through Long COVID. Continuing to listen to the community to understand adaptations of treatments and self-management tools which could work for them will be important and could also identify important learnings which could be transferred to other communities.

In addition to the above, and wider than Long COVID, access to primary care is continually raised by the group as a major issue in the community. The group shared a range of different negative experiences in trying to access appointments, and also not feeling like they were being listened to or acknowledged by their GP. Further work is needed to bridge the gap between communities and health services.

What impact has the session had on the local community?

- We were able to increase awareness and knowledge of the range of symptoms associated with Long COVID, which many of the group weren't currently aware of. This in turn has reduced some of the stigma that surrounded COVID and Long COVID in this community.

- Knowledge that was learnt is now being shared across the wider community including, in particular:
  - Those who had not been vaccinated, who now have ongoing symptoms and are afraid to seek help due to being reprimanded for not getting the vaccine – to share what they have learnt about Long COVID, including that in can affect anyone, to support them where they can and share the self-management tools which they have learnt.
  - To their family/friends overseas who don't have access to expert knowledge about COVID and Long COVID

- We raised key points and ways for the women to communicate with their GP about their concerns/worries, care and/or treatment. Including empowering those in attendance, and the wider community to:
  - Know that they have a right to request a face-to-face appointment
  - Understand that any symptom that wasn't present before COVID-19 infection, which is now present could be linked to Long COVID

What next?

Through our collaboration with the Patient Experience Research Centre at Imperial College, London we are able to share more widely the insights raised during this session. To date, the insights from the session have also been shared with the Imperial College Healthcare NHS Trust Long COVID clinic as well as researchers at Imperial College, London undertaking COVID-19 and Long COVID research.

To address some of the community's concerns around accessing primary care, Dr Worthington contacted the local Primary Care Network following the session to share some of the issues raised, and to suggest a further conversation between Mosaic and the local primary care services, which the primary care team has agreed to.

We continue to work collaboratively with Imperial College, London to identify further areas which the community could benefit from a health information session on.