Stroke session with Mosaic Community Trust – Monday 16 January 2023

We were asked to organise an information session on stroke to be delivered at the Mosaic Community Trust at the Portman Early Childhood Centre near Church Street, Westminster on Monday 16 January 2023.

Background

The Mosaic Community Trust (a registered charity; from here on in referred to as Mosaic) supports the local community in and around Church Street, one of the most deprived areas of Westminster in London. Their mission is to empower diverse, socially, and economically marginalised and disadvantaged Black and minority ethnic communities and promote community cohesion and integration.

Since having difficulty getting NHS 111 call handlers to recognise her husband's symptoms as a stroke in February 2022, Lena Choudhary-Salter (Mosaic's Founder and CEO), wanted to raise awareness of stroke which she felt was lesser known about within the community when compared for example to diabetes or cancer. Lena persisted on a 111 call for over 40 minutes before the call handler escalated it to a GP. An ambulance was then called, and he was admitted to hospital. Thankfully, Lena's husband was still able to receive treatment and this, together with his determination and good health prior to this has led to a good recovery. Lena's experience also highlighted the struggle some people face to get the healthcare they need.

The session was developed and hosted in collaboration with Dr Fatemeh Geranmayeh (Consultant Neurologist at Imperial College Healthcare NHS Trust and Clinician Scientist in the Department of Brain Sciences, Imperial College London) and Jenny Crow (Clinical Specialist Occupational Therapist in Stroke at Imperial College Healthcare NHS Trust and PhD student), with support from Halle Johnson and Maria Piggin (Patient Experience Research Centre (PERC), Imperial College London) and key leads across Mosaic including Habiba Haque (Head of Community Programmes) and Lena Choudhary-Salter (Mosaic's Founder and CEO). Prior to the session a planning call was held to introduce the proposed speakers to Mosaic and agree the session aims, which were developed around concerns from the community, and to plan the session format.

The session was attended by 32 women aged between 28-78 years old from diverse backgrounds including: Afghan, Bangladeshi, Chinese, English, Iraqi, Somalian, Sri Lankan and Sudanese (see Appendix for demographics). Attendees also included several of Mosaic's community-based health and wellbeing advocates, who are community members trained to disseminate health and wellbeing information throughout the Mosaic community.

Aims and format of the session:

The session aimed to increase awareness of:

- what a stroke is (what the different types of strokes are and what causes them)
- warning signs of a stroke

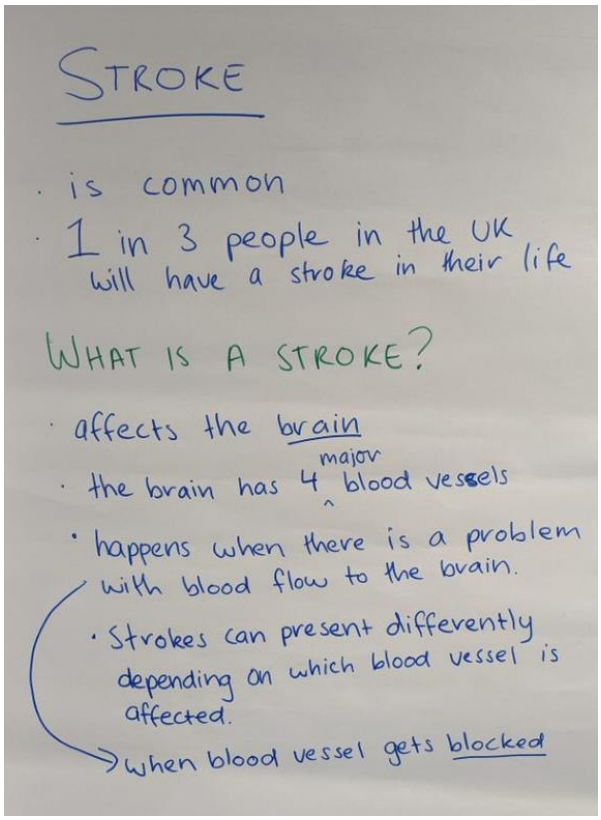
- what to do if someone is suspected of having a stroke
- stroke risk factors
- what other closely related health conditions may cause stroke (e.g. heart disease, high blood pressure, high cholesterol)
- what is the emergency response to stroke and what treatments are available
- the impacts following stroke
- what support is available in the community for self-managing post-stroke (including what happens after a stroke and what support someone can receive from physio, occupational therapy, speech and language therapy and psychology)
- approaches to stroke prevention

Lena's Choudhary-Salter provided an introduction to the session where she emphasised the importance of health literacy to reduce risk and to prevent disease and illness. The session was informal, and attendees were invited to ask questions as they came up. Notes were made by the PERC team on flip chart paper to capture key insights from the talks and discussion, which were then left with Mosaic after the session for their reference, use by the health and wellbeing advocates in dissemination of the content of the session to the wider community, and to enable the session to be written up as a resource. The session took place over 1.5 hours and was followed by lunch made by a Mosaic community member.

Part 1: What is a stroke, signs and symptoms, risk factors

Dr Fatemeh Geranmayeh led the first half of the session which provided an overview of what a stroke is, signs and symptoms of stroke and risk factors.

What is a stroke?

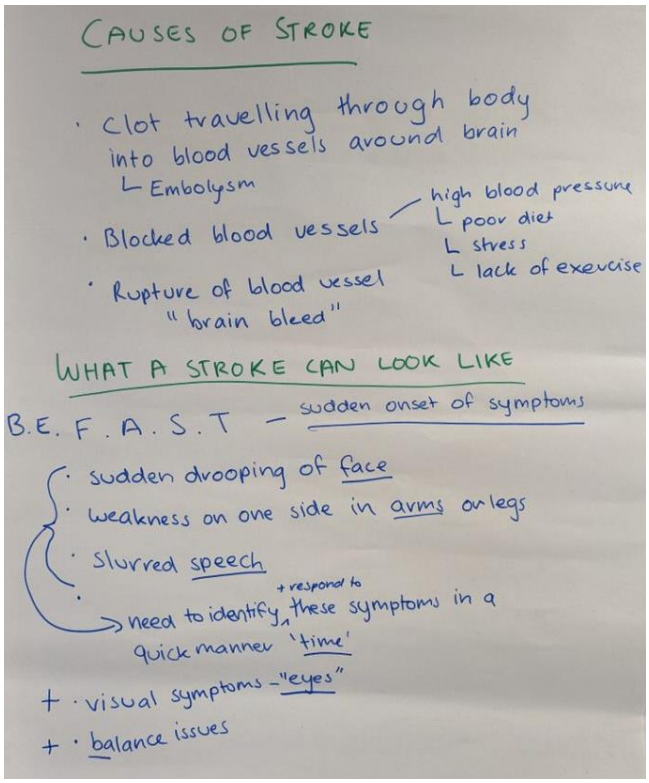


Dr Geranmayeh started by asking attendees to raise their hand if they knew someone who had had a stroke. Six attendees raised their hand at the start of the session; however, during the session as more was learnt about stroke and its symptoms, more community members became aware that they did in fact know someone who had had a stroke.

Dr Geranmayeh explained that stroke is the leading cause of disabilities and that 1 in 3 people in the UK will experience some form of stroke in their lifetime.

- Stroke is a problem that affects the brain.
- The brain is supplied by four major blood vessels from the heart.
- The majority of strokes happen when the supply of blood and oxygen to the brain from one of these blood vessels is restricted or stopped.
- Each of the four blood vessels supplies a different area of the brain, which means the

symptoms of stroke can present differently in different people. For example, the area at the back of the brain is responsible for vision, so if the blood vessel to this area of the brain was affected this would cause sudden blurred vision or loss of sight in one or both eyes.



What happens to the blood vessel to cause a stroke?

Dr Geranmayeh explained the most common cause is a blockage to the blood vessel. A blockage could result from:

- **a gradual blockage:** the narrowing of the arteries caused by a build-up of fatty deposits in the blood vessels developing over several years. This build-up could also break to form an immediate blockage. High blood pressure, high cholesterol, smoking and diabetes can cause this type of stroke.
- **a sudden blockage:** caused by something that shouldn't be there – this is called an embolism. For example, a blood clot travelling from somewhere else in the body.
- **a bleed:** caused by a rupture (breaking) of the blood vessel and the blood leaking out into the brain. Bleeds account for 10% of strokes.
- **an tear in blood vessel:** some accidents can rupture a blood vessel, or it can happen spontaneously.

However, the most common cause is from a gradual blockage (the narrowing of blood vessels over time) or a blood clot.

Recognising stroke early

Dr Geranmayeh noted that symptoms of a stroke would appear as a sudden onset rather than a gradual development. The UK public health campaign 'FAST' can help recognise the signs of stroke:

- **F**ace: sudden drooping of the face, mouth or eyes on one side
- **A**rms: sudden weakness or numbness in one side suddenly (in either arms or legs)
- **S**peech: slurred speech or not able to talk
- **T**ime: acting quickly and calling 999 is critical as the drugs used to treat stroke only work if given in the first few hours of stroke symptoms starting.

Dr Geranmayeh shared that in some countries the campaign has been updated to 'BEFAST' to include other symptoms missing from the earlier campaign. As well as 'FAST' described above, 'BE' helps recognise the signs:

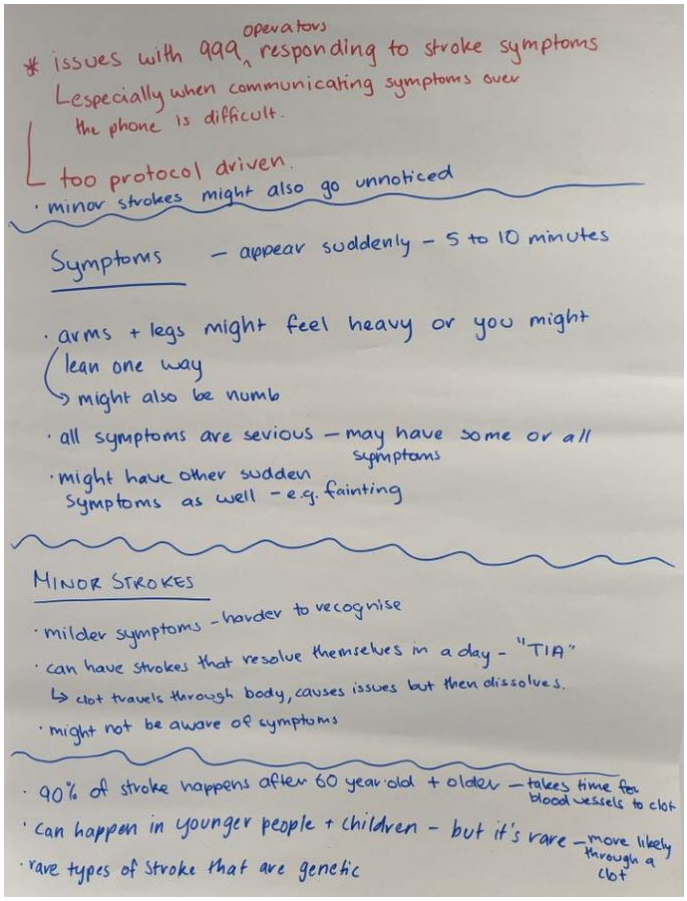
- **B**alance: loss of balance

- **E**yes: blurred vision or loss of vision

Lena highlighted that when she called NHS 111 the call handler was not aware that loss of balance, was a symptom of stroke, which lack of knowledge contributed to her husband's case not being escalated sooner.

Dr Geranmayeh shared that most ambulance crew, doctors and GPs will recognise the addition of 'Balance' and 'Eyes' to the warning signs, however, some NHS 999 call handlers might not yet.

Action: Jenny has contacts at the Stroke Association, so it was agreed Jenny could provide this feedback to the Stroke Association



Which symptoms are the most serious?

Dr Geranmayeh explained all stroke symptoms are serious. The different presentation of symptoms just depends on which part of the brain is affected. She emphasised if someone develops a sudden, new symptom e.g. over a few minutes, rather than a gradual symptom appearing over several days or weeks, to call 999 with a suspected stroke and get to A&E immediately.

What is a transient ischaemic attack (TIA)?

A transient ischaemic attack (TIA) is a stroke which has resolved within a few minutes or up to 24 hours. Most TIAs are caused by a blood clot which has travelled to the brain and temporarily blocks the blood supply in the brain. Although the stroke symptoms may have resolved, it is still important that urgent medical help is given to find the clot and get treatment, as the person will be at high risk for a major stroke.

Can you have a stroke and not realise it?

Dr Geranmayeh explained that sometimes patients can have a 'silent' stroke. For example, if someone had a small stroke in the front of the brain, an area of the brain responsible for most of our thinking or planning, they might not notice it happening. By the time we reach 80 years old, a brain scan would show that most people will have had small 'silent' minor strokes.

Can a stroke happen to anyone at any age?

Dr Geranmayeh noted that 25% of strokes happen in people aged below 65. There are very rare types of strokes which can happen in young people. Whereas 90% of strokes happen in people aged over 60 as most strokes are caused by a gradual blockage, which is a gradual blockage of the blood vessels building up over time as we get older.

Are strokes genetic?

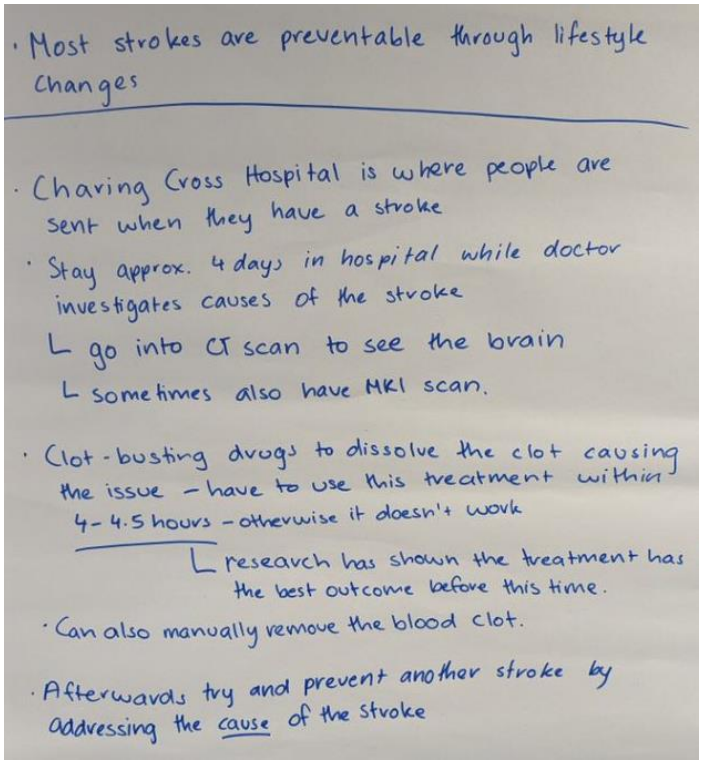
Dr Geranmayeh confirmed that in younger people, strokes could happen due to a clotting disorder, which could be inherited. Very rarely strokes are genetic, but this happens in younger people. A tear in a blood vessel can be caused by a genetic issue affecting the vessels however it is unusual to have these.

What if a vessel in the heart is blocked?

Dr Geranmayeh confirmed that a blocked vessel in the heart would cause a heart attack and the symptoms would include chest pains. Stroke affects the brain, whereas a heart attack affects the heart, but some individuals may have a heart attack which then leads to a stroke.

Which is more fatal: a heart attack or stroke?

Dr Geranmayeh answered that both can kill, it depends on the size of the heart attack or stroke. A stroke can lead to other physical disabilities (e.g. muscle weakness, paralysis) or communication problems, whereas if you survive a heart attack you are less likely to be left with neurological disabilities.



What happens to someone with suspected stroke in London?

There are 8 Hyperacute stroke units in London and the stroke unit covering Northwest London is Charing Cross Hospital's specialist stroke unit.

If someone is suspected of having a stroke, stroke doctors will be called to A&E to meet the patient on arrival so the person can be assessed immediately.

Doctors will carry out tests to confirm the stroke. They scan the brain using a CT scan (shaped like a donut), and sometimes a MRI scan (a noisy tunnel) as well, to find out what caused the stroke (clot or bleed). Often an angiogram is done at the same time to look at the blood vessels. Blood vessels don't show up clearly on ordinary X-rays, so a special dye is injected into the area being examined. The dye highlights the blood vessels as it moves through them.

Depending on the type of stroke, some people can be treated with clot-busting drugs to break down the clot and stop it from blocking the blood vessel in the brain. However, this clot-busting drug needs to be given within 4.5 hours of the stroke symptoms starting, which is why it is vitally important for a stroke to be recognised as soon as possible so it can be treated within this time period. Outside of this time window the surrounding brain tissue will die, therefore it becomes less beneficial to give the drug.

The length of time needed in the hospital will vary, some people will only need to stay for a day or two, whereas others who have had bigger strokes will be in hospital for weeks. Other tests will be carried out to investigate what led to the stroke and if further treatment is needed to reduce the patient's risk of another stroke.

What if the clot-busting drug is given after 4.5 hours since the symptoms started?

Dr Geranmayeh answered if doctors think there is brain stem involvement, the time in which the clot-busting drug can be given can be extended. Research has shown that the clot-busting drug works best if given within 4.5 hours of a stroke. Doctors can now also remove the clot physically in certain strokes (Thrombectomy) if the brain scans show that there is salvageable brain tissue that has not been completely damaged by the stroke.

Research

The importance of research was then discussed. Knowledge about health conditions and their treatments comes from research. Most people who take part in research studies are white and therefore the results of research studies don't reflect other ethnicities. Therefore, it is important that people from different ethnicities also take part in research studies, so the results are also relevant for them. There are different ways people can get involved in research, one way is by being studied (research participation) and another is by helping researchers to design their research (public involvement) so it is relevant to everyone. Maria from PERC explained that if anyone was interested in either of these to let her know.

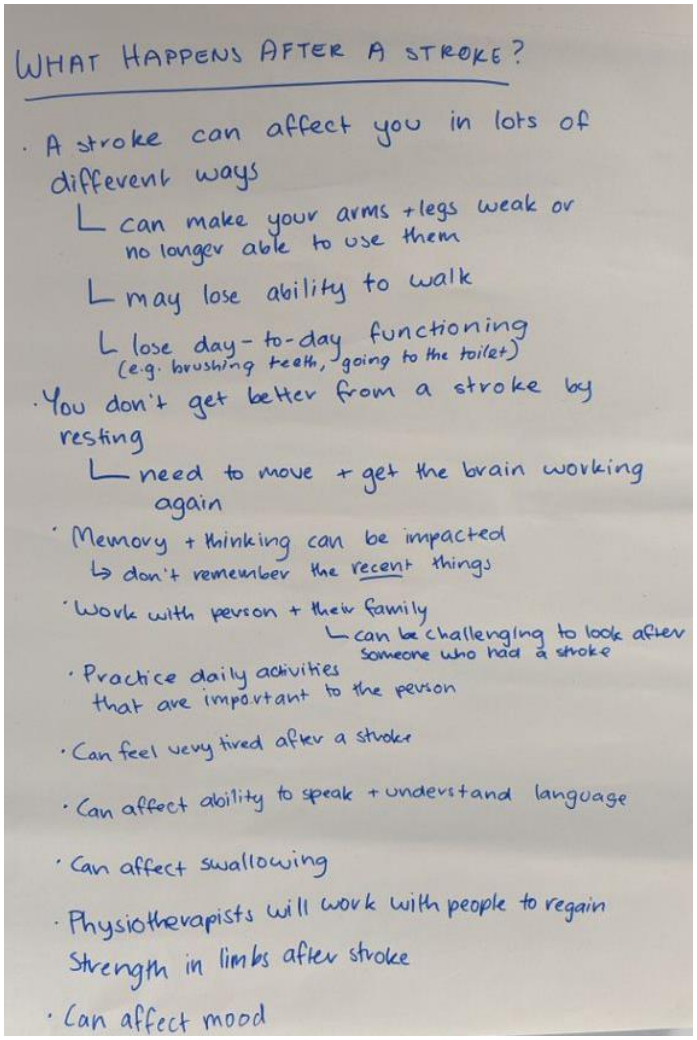
Stroke Prevention

Dr Geranmayeh explained ways in which people can make lifestyle changes to reduce their risk of having a stroke. These include:

- Reduce the risk of diabetes which is a risk factor for stroke
- Exercising
- Maintaining healthy blood pressure
- Reducing salt intake which causes high blood pressure
- Avoid too much/stop drinking alcohol
- Stop smoking

Part 2: Access to care & treatment for stroke (emergency and longer term) and management of stroke in the community

Jenny Crow led the second half of the session which covered care for stroke and the impacts of having a stroke.



When someone has had a stroke, what happens?

A stroke can affect you in lots of different ways. Occupational Therapists works with stroke survivors to enable them to regain as much independence as possible.

Depending on the type of stroke and how quickly treatment is received, some people may recover within a short time, while others may experience some long-term effects.

Jenny shared examples of some of the wide-ranging effects of stroke, which will influence what type of rehabilitation is required:

- **Physical:** swallowing difficulties, muscle weakness or paralysis on one side of the body – this may mean they have difficulty walking or picking things up.
- **Communication:** can affect their ability to speak but can also affect their understanding (e.g. it feels like someone is speaking another language)
- **Memory and thinking:** difficulty remembering recent things, e.g. forgetting to take medication.
- **Feeling tired, fatigue:** lacking energy, constantly feeling tired physically and mentally. This can affect young people too.
- **Emotional/low mood:** suddenly your life has really changed and dealing with this can be hard.

Jenny highlighted that you don't get better from a stroke if you lie in bed or rest as you might do for other conditions; with stroke you need to get moving. For example, starting with the basics and practising everyday things like getting out of bed, brushing your teeth, going to the toilet, etc. A team of specialists help with rehabilitation, this could include speech and language therapy, physiotherapy, psychologists, occupational therapy, and dietitians. Rehabilitation takes place across: the hospital; the home; and in the community. For example, there are psychologists based in the community.

Lena emphasised that it was the active engagement of physiotherapists, dieticians and occupational therapists in her husband's rehabilitation that helped him to make a full recovery. She also felt that

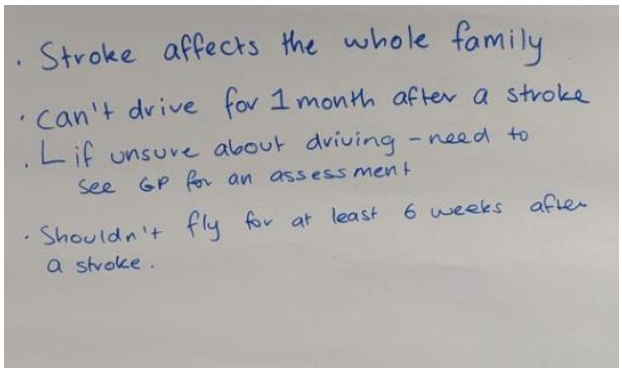
it was her husband's active lifestyle (regular exercising) before his stroke that helped him to recover well within a short period of time.

Jenny explained that Occupational Therapists carry out home visits and ask questions about the stroke survivor's situation at home, not because they want to change how the person lives, but to understand their needs and what they would normally do so relevant tasks can be practised as part of their occupational therapy.

Barriers to uptake of occupational therapy appointments

Community members raised the issue that letters arranging a home visit from occupational therapy did not clearly communicate the purpose of the home visit, often families were unsure of what would happen during the home visit and what it was for. Most people come across the word 'occupational' at work so understandably their first thought was that occupational therapy is referring to work.

Impact on families



Jenny noted that stroke affects the whole family. If that person can't do what they would normally do that has an impact on the rest of the family for example, if they were the main breadwinner in the household, or if they were responsible for cooking the majority of family meals. Support is available in the community, but it is not long-term.

Jenny made clear that you can't drive for one month after a stroke – it is against the law and your insurance and driving licence will not be valid. People are also advised not to fly for at least six weeks after a stroke.

A community member knew of someone who had an echocardiogram (a type of heart scan) which showed they had a hole in their heart and questioned if that could cause a stroke. Dr Geranmayeh confirmed that a lot of people who have a hole in the heart often don't need further treatment. In cases where treatment is needed a procedure is used to close the hole.

Questions asked by the community during the session:

- What happens to the blood vessel to cause a stroke?
- Which symptoms are the most serious?
- Can you have a stroke and not realise it?
- Can a stroke happen to anyone at any age?
- Are strokes genetic?
- What if a vessel in the heart is blocked?
- Which is more fatal: a heart attack or stroke?
- What if the clot-busting drug is given after 4.5 hours?
- Could a hole in the heart cause a stroke?
- Are you planning to do any research, and do you need volunteers?

- Where do you get migraines from? (this question was not answered as it was outside of the scope of the session)

Recommendations for clinical care raised during the session:

- During the session it was highlighted that NHS 111 call handlers may not be aware of the updated BEFAST tool to triage suspected stroke, and therefore are missing important symptoms of stroke leading to delays to treatment and poorer outcomes. It was agreed Jenny (who has existing connections with the Stroke Association) would feed this back to the Stroke Association.

- Review patient letters arranging home visits from occupational therapy to include more detail. These letters should give clear information on what occupational therapy specific to stroke survivors is, what the purpose of the home visit is, and what will happen during a home visit.

Recommendations for further collaboration:

- Following the session a community member expressed interest in being involved in research participation and/or public involvement with research. Maria (PERC) has been in touch with them to discuss their further involvement.

- Since the session Jenny has arranged to go back to Mosaic in late February to hold a 30-40 minute follow up session on stroke for the community health and wellbeing advocates to answer any further questions and reinforce the information provided in January's session. She has also asked for her participant information sheet for her stroke study to be reviewed by a Mosaic community member.

Feedback from attendees:

A total of 24 feedback forms were completed out of the 32 participants who attended the session.

79% of the attendees rated the session as "Excellent".

Of the 24 feedback forms returned, when asked if they knew about stroke and the risk factors before attending the session, 54% said "No, this is the first time I have heard about it", with 21% saying "Yes, I heard about it but did not know about the risk factors" and 25% saying "Yes, I heard about it and knew the risk factors".

When asked if they knew how to reduce the risk of stroke before attending the session, 62.5% said "No, this is the first time I have heard about it", with 12.5% saying "Yes, I heard about it, but did not know how to reduce the risk of stroke" and 25% saying "Yes, I heard about it and knew how to reduce the risk of stroke".

1. **Overall, how would you rate the session?** (Of the 24 feedback forms, 19 answered Q.1)

	Very bad	Bad	Average	Good	Excellent
No. of responses	0	0	0	0	19
Percentage	0%	0%	0%	0%	79%

2. **Did you know about stroke & the risk factors before attending the session?**

	Yes, I heard about it and knew the risk factors	Yes, I heard about it **but did not know** about the risk factors	No, this is the first time I have heard about it
No. of responses	6	5	13
Percentage	25%	21%	54%

3. **Did you know how to reduce the risk of stroke before attending the session?**

	Yes, I heard about it and knew how to reduce the risk of stroke	Yes, I heard about it, **but did not know** how to reduce the risk of stroke	No, this is the first time I have heard about it
No. of responses	6	3	15
Percentage	25%	12.5%	62.5%

4. **What worked well and what could be done better next time?**

- If you could record the sessions
- Liked to learn, easy to understand
- Lots of information
- Very good
- All was good
- Good
- I like the presenters taking time to answer all questions
- Excellent
- Very useful
- Good
- More explain
- Could understand and very good to find out

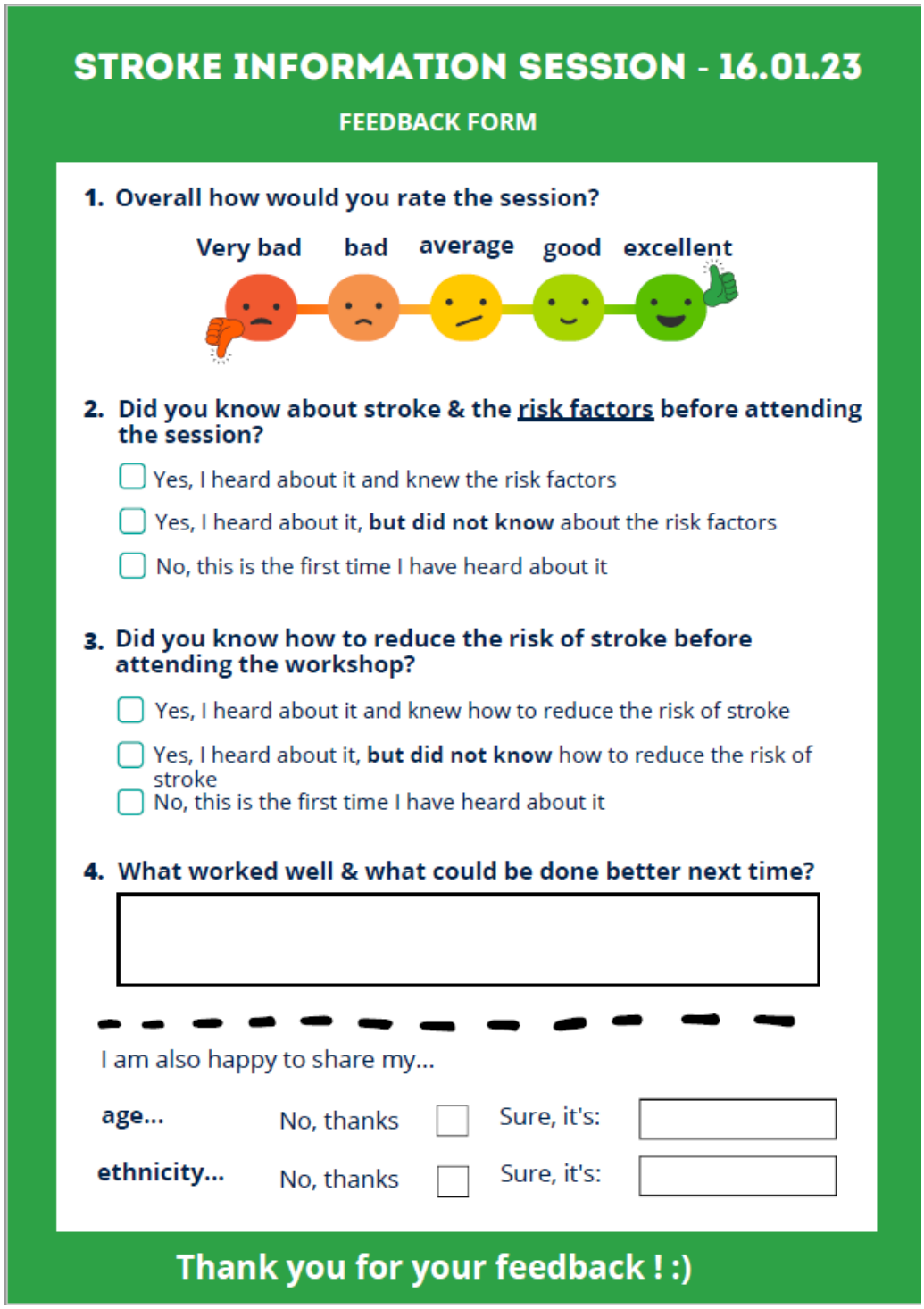
Appendix: Attendee demographics

Table: Demographic characteristics provided by those who completed these sections on the feedback form.

Characteristics	**n (%)**
Age (in years)	
Mean (range)	56 (28-78)
Age groups (in years)	
18-24	0 (0.0)
25-34	1 (4.2)
35-44	2 (8.3)
45-54	7 (29.2)
55-64	4 (16.7)
65 – 74	7 (29.2)
75+	1 (4.2)
Prefer not to say	2 (8.3)
Ethnic group	
White	
English/Welsh/Scottish/Northern Irish/British	1 (4.2)
Irish	0 (0.0)
Gypsy or Irish Traveller	0 (0.0)
Other White background	1 (4.2)
Mixed/Multiple Ethnicity	
White and Black African	0 (0.0)
White and Black Caribbean	0 (0.0)
White and Asian	0 (0.0)
Other Mixed/Multiple background	0 (0.0)
Asian/Asian British	
Indian	0 (0.0)
Pakistani	0 (0.0)
Bangladeshi	6 (25.0)
Chinese	4 (16.7)
Other Asian background	0 (0.0)
Black/African/Caribbean/Black British	0 (0.0)
African	0 (0.0)
Caribbean	0 (0.0)
Other Black/African/Caribbean background	0 (0.0)
Other	
Arab	0 (0.0)
Any other ethnic group: Afghan	1 (4.2)
Any other ethnic group: Iraqi	1 (4.2)
Any other ethnic group: Somalian	1 (4.2)
Any other ethnic group: Sri Lankan	1 (4.2)

Any other ethnic group: Sudanese	2 (8.3)
Prefer not to say	6 (25.0)

Appendix: Feedback form



STROKE INFORMATION SESSION - 16.01.23

FEEDBACK FORM

1. Overall how would you rate the session?

Very bad bad average good excellent

2. Did you know about stroke & the risk factors before attending the session?

- ☐ Yes, I heard about it and knew the risk factors
- ☐ Yes, I heard about it, **but did not know** about the risk factors
- ☐ No, this is the first time I have heard about it

3. Did you know how to reduce the risk of stroke before attending the workshop?

- ☐ Yes, I heard about it and knew how to reduce the risk of stroke
- ☐ Yes, I heard about it, **but did not know** how to reduce the risk of stroke
- ☐ No, this is the first time I have heard about it

4. What worked well & what could be done better next time?

I am also happy to share my...

age... No, thanks ☐ Sure, it's: ☐

ethnicity... No, thanks ☐ Sure, it's: ☐

Thank you for your feedback ! :)