ALL-PARTY
PARLIAMENTARY GROUP
ON WOMEN'S HEALTH

Call for Action:

Inquiry into heart attack and stroke

Acknowledgements

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Executive Summary

The APPG on Women's Health conducted an inquiry into a disparity in outcomes for women and men for heart attacks and stroke, resulting in this Call for Action. The Group gathered evidence from a range of stakeholders and found that despite common opinion that these conditions are 'men's diseases' women are equally affected, and often suffer worse outcomes.

The group is recommending:

1) An awareness campaign targeting the public focusing on the atypical symptoms that women can suffer with heart attacks, women-only risk factors for stroke and to broaden awareness that women are affected by these conditions

2) Education for healthcare professionals regarding the number of women affected and the atypical symptoms that women can present with for heart attack and women-only risk factors for stroke

3) Promote effective investigation of women's symptoms and promote diagnostic techniques that could help in this regard

4) More data/research into women's response to treatments as currently women are significantly underrepresented

Welcome and introduction from the Chair of the Women's Health APPG – Paula Sherriff MP

I am proud to have been Chair of the All-Party Parliamentary Group on Women's Health since 2016. We have been campaigning for women to have the right to make an informed choice about their own healthcare and are calling for women to be empowered. Women's healthcare covers a huge arena and affects everyone, either directly or indirectly through someone they love and care about.

As a group we have covered a range of issues but I wanted to focus on two conditions that affect women but are too often seen as 'men's conditions' and women consequently suffer as a result.

All too often I have heard of women being marginalised and side-lined when they try to seek help, dismissed and not taken seriously. This needs to stop. Women have a right to be heard and they deserve to be treated with dignity and respect at all times. This Group aims to bring women's voices to Parliament and to make a change.

This year the All-Party Parliamentary Group Report is focusing on highlighting the discrepancies in outcomes between men and women for heart attack and stroke.

This misperception that heart attack and stroke are men's conditions is costing lives. We need to act now to ensure that everyone has the information to act, and gets the treatment that they deserve.

I am committed to working with my Parliamentary colleagues and others to empower women, to make sure their voices are heard and represented at Parliament, and above all to campaign for change so that women can get the care and choices that they deserve.

Paula Sherriff MP
Member of Parliament for Dewsbury
Shadow Minister (Women and Equalities)

Background

Stroke and Myocardial Infarction (MI)/heart attack are two of the most common conditions that affect women. Stroke is still the 4th bigger killer in the UK (Stroke Association), and it is still the single biggest cause for adult complex disability (two thirds of those who survive will have an adult complex disability). The lifetime risk of stroke is 1 in 5 for women, whereas the lifetime risk is 1 in 6 for men. Coronary heart disease remains the most common cause of death in the UK with approximately one in twelve women dying from this disease compared to one in seven men (BHF). According to the British Heart Foundation, heart attacks kill 28,000 women in the UK each year[1]. That's three women every hour[2]. Coronary heart disease kills more than twice as many women in the UK as breast cancer.

The WHAPPG would like to shine a particular light on stroke and heart attack because the group feels that, typically, these two conditions are considered a 'man's disease', and therefore women patients may not recognise relevant symptoms, seek appropriate help or receive the investigations and treatment they need. It is also important to highlight additional risk factors and the need for wider data collection for women in these areas.

1 https://www.bhf.org.uk/informationsupport/heart-matters-magazine/medical/women/coronary-heart-disease-kills
2 Professor Chris P Gale, Professor of Cardiovascular Medicine, Honorary Consultant Cardiologist, University of Leeds, WHAPPG oral evidence session

Data

Stroke

The Stroke Association reports that some stroke risks are also specific to women – pregnancy-related diabetes, preeclampsia and the use of birth control bills can all increase the risk of stroke for women. The lifetime risk of stroke is 1 in 5 for women, whereas the lifetime risk is 1 in 6 for men. More women than men are dying of stroke every year, with the latest Australian Institute of Health and Welfare data revealing almost two-thirds of stroke victims were female.

Studies[3], including one undertaken by the Sentinel Stroke National Audit Programme (SSNAP), the Royal College of Physicians and King's College London in 2017, indicated that women do receive poorer treatment[4]. The study reviewed quality measures such as accessing a brain scan within one hour; 4-hour stroke unit admission; access to thrombolysis; physio assessment; speech and language therapy; and Early Supported Discharge (ESD). None of these quality measures were better for females. Indeed several actually showed better result for men. Results from 'door to needle time' for thrombolysis and access to physiotherapy, where the difference between male and female scores were most different, do indicate a lower quality of care for women[5]. International studies have also shown variance in women's treatment and outcomes compared to men. Heart and Stroke Foundation of Canada's national report 2018 shows that women are disproportionately affected by stroke throughout their lives[6].

Data on long term outcomes:
Stroke association:

There is some evidence that women tend to experience worse psychological and physical repercussions from stroke. This may be because women tend to have strokes when they are older and are often living alone[7].

The Stroke Association 2016 survey of 1174 stroke survivors, gives some insight into this. They asked stroke survivors to rate the care and support they received at home from professional carers for 9 different areas including things such as physical disability, continence, Speech and Language therapy (SALT), and fatigue. In 5 of these areas a higher proportion of men rated their care as good and very good than women did. And even in the 4 areas where a higher proportion of women rated their care as good or very good this was by a smaller margin. Women's scores were above men's by between 1%-3% compared to 1%-9%.

This is further backed up by the responses on overall care at home, where 52.7% men stated that the care they received was good or very good, for women this was only 45.3%[8].

Overall, there is a significant lack of post-acute data in comparison to acute care, meaning it is more difficult to measure women's outcomes in longer term care and rehabilitation. Improved post-acute stroke data would make it easier to identify, understand and stop any difference in stroke outcomes for men and women that exist.

3 M., McDermott., Sex Disparity in Stroke Quality of Care in a Community-Based Study. The Official Journal of the National Stroke Association. (2017) Available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5512589/
4 G., Dunn, Kings College London 'Do women receive the same stroke care as men? (2018) Available: https://www.kcl.ac.uk/lsm/Schools/population-health-and-environmental-sciences/newsrecords/Do-women-receive-equivalent-stroke-care-to-men.aspx
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6 Heart and Stroke Canada Lives disrupted: The impact of stroke on women 2018 Available: https://www.heartandstroke.ca/-/media/pdf-files/canada/stroke-report/strokereport2018.ashx
7 Reeves, M. J., Bushnell, C. D., Howard, G., Gargano, J. W., Duncan, P. W., Lynch, G., Lisabeth, L. (2008). Sex differences in stroke: epidemiology, clinical presentation, medical care, and outcomes. Lancet Neurology, 7(10), 915–926. http://doi.org/10.1016/S1474-4422(08)70193-5
8 Stroke Association Survey 2016

Heart

Similarly women aged under 55 are more likely to have poorer health outcomes after a heart attack compared to their male counterparts. The British Heart Foundation reports on a study conducted at the University of Leeds published in January 2018 which found that women are not being given the same treatments for heart attack, and are dying unnecessarily as a result[9]. The study found that in the year after having a heart attack, women were dying at higher rates than would be expected and had an excess mortality of up to three times higher than men who'd had a heart attack. After five years the excess mortality was nearly twice as high.

The research found that women were less likely than men to receive the recommended treatments after a heart attack, such as angioplasty and stent or heart bypass surgery where necessary, and less likely to be prescribed recommended medications (such as statins, aspirin and beta blockers) when they were sent home from hospital. However, in women who received evidence-based treatments, the gap in excess mortality decreased or disappeared.

At the WHAPPG oral evidence the group heard from Dr Sarah Clarke who explained that more deaths from coronary heart disease can be avoided especially in women. In females, death rates haven't decreased over the last 3-4 years, contrary to what has happened with death rates in males. In 2014, 4000 years of life were lost by females. Women are 10% less likely to get primary PCI[10]. Women with non-ST segment heart attacks are 20% less likely to get any revascularisation at all.

In the 'Impact of initial hospital diagnosis on mortality for acute myocardial infarction: A national cohort study', conducted at the University of Leeds, published in 2016[11], and funded by the British Heart Foundation, the study focused on patients who had had a definite heart attack. One third of patients had been wrongly diagnosed when they had initially gone to the hospital. It was found that women were much more likely to be misdiagnosed (50% increase risk).

The British Heart Foundation 'Sex Differences in Treatments, Relative Survival, and Excess Mortality Following Acute Myocardial Infarction: National Cohort Study Using the SWEDEHEART Registry'[9] is a key research publication. It found that in terms of heart attacks, excess mortality in Sweden is higher in women than in men. This happens for various reasons, including the fact that women tend to live longer than men, and heart attacks tend to be suffered by older people. However, when adjusted for the fact that women are less likely to get treatment, outcome disparity can be explained by the difference in care.

Data from Survey Monkey

The WHAPPG gathered written evidence and information from key stakeholders and the wider public regarding impressions around heart attack and stroke, and what more can be done to improve women's outcomes in these areas. The group found that:

- Over 80% of responders did not think that there is enough awareness and educational material to alert women that heart disease is not just a 'man's disease'

  The Group is calling for more awareness and education material. This is a key issue that was brought to the group's attention throughout our work in this area, and forms part of one of our key recommendations.

- 89% think that there is not enough awareness and educational material to alert women of the potential atypical

9 British Heart Foundation Sex Differences in Treatments, Relative Survival, and Excess Mortality Following Acute Myocardial Infarction: National Cohort Study Using the SWEDEHEART Registry 2018

10 Dr Cara Hendry WHAPPG oral evidence session

11 Editor's Choice - Impact of initial hospital diagnosis on mortality for acute myocardial infarction: A national cohort study. Wu J, Gale CP, Hall M, Dondo TB, Metcalfe E, Oliver G, Batin PD, Hemingway H, Timmis A, West RM. Eur Heart J Acute Cardiovasc Care. 2018 Mar;7(2):139-148. doi: 10.1177/2048872616661693. Epub 2016 Aug 29

symptoms at the time of presentation with a heart attack compared to their male counterpart

One of the reasons many believe women receive later diagnosis, treatment and result in worse outcomes is due to the atypical symptoms they can present with. The APPG is calling for more awareness of these symptoms in the general public and with healthcare professionals.

- The majority of responders thought that the best way to reach women was through leaflets in GP surgery's, at other health checks and through a national public awareness campaign

  There is a range of activity that could take place to aid awareness. In particular it is important to target women specifically with these messages, and certain responders suggested placing leaflets and information packs in specific locations, such as hairdressers and coffee shops. It is also vital to look at hard to reach groups.

- What are the barriers for women – predominantly include atypical symptoms, a reluctance to seek help and the public perception that it is a 'man's problem'

  These key barriers need to be addressed before women will begin to get the appropriate treatment and improve outcomes.

Other key points that were brought out in the qualitative data was:

- Need to educate professionals - particularly around atypical symptoms

- Very little information was offered – greater availability is needed

- Barriers to treating/managing effectively – lack of information and rehabilitation, time restrictions, lack of awareness and different symptoms.

- The most recent annual National Audit of Cardiac Rehabilitation (NACR) report highlights the scale of the problem with only 43% of women eligible for cardiac rehabilitation (CR) take it up, compared to 53% of men in England, which is well below the goal of achieving 65% uptake of CR set out in the 2013 CVD Outcomes Strategy - it is important to look at differences between men and women, and why women may not be going through cardiac rehabilitation to the same extent as men.

- How to encourage women into studies – better information about benefits, talk more about research, patient groups and patients speak to others, media. One of the three key areas the APPG has drawn out is a lack of research in women, and there is a need to target women to ensure more enter studies.

Case Study

Alison Booth

Alison Booth had been working as a nurse for 24 years, and described herself as *"a fit, healthy 48 year old – I'd recently been climbing in the Lake District and my blood pressure and cholesterol were normal".*

Yet one morning, Alison started to feel pain in her collarbone and her neck. She brushed it off and carried on with her day. As she describes:

"After work I went out for drinks with a friend. Jokingly I said 'I think I'm having a heart attack'. My friend said 'We'd better only get you a half then!'"

Two days later, Alison felt pain in her neck, her jaw, and in her chest. She spoke to her sister who insisted that she called an ambulance. When it arrived her blood pressure, pulse and ECG all came back as normal – the paramedics initially thought she might be having a panic attack.

It was only when Alison reached hospital and they did a troponin blood test that it was discovered that her cardiac enzymes were raised – and a heart attack was diagnosed. She was taken for an angiogram, and found out that she needed coronary artery bypass surgery. *"If my heart attack hadn't been picked up in hospital, the artery would have blocked completely and I wouldn't be here now."*

Alison has made a strong recovery, with the help of cardiac rehab, but wishes that she had gone into hospital sooner.

"Knowing how much this delayed diagnosis could have put my life at risk, I wish I'd recognised the symptoms and called the ambulance immediately. It's so important to act fast and get the medical help you need. I'm now more aware that heart disease can affect anyone at any time - but at the time a heart attack was the last thing I thought could be happening to me."

"If my heart attack hadn't been picked up in hospital, the artery would have blocked completely and I wouldn't be here now."

Cross-Cutting Issues

1) Research

In clinical trials, women tend to be underrepresented, and only 27% of the participants are women in heart-related trials in particular[12]. More needs to be done to educate the general public, the healthcare workforce and academics so that they are much more inclusive. The current gender gap in research needs to be reduced as soon as possible. Better data collection post-hospital will help us to understand the outcomes of all stroke survivors, and will enable us to really understand if women's outcomes are worse than men's, so it is vital. At the moment the data is not available, so we cannot know conclusively if women's outcomes are worse.

Key points:

- Need to research why women are being excluded
- One reason women can be reluctant to take part is that many are still carers, so it is hard for them to participate in follow-up cardiovascular studies.
- There can also be exclusion criteria as many studies exclude women as they have smaller coronary arteries.
- We need much better post-acute data for stroke to be able to fully investigate women's treatment, experiences and outcomes compared to men.
- Women are under-represented in research trials and studies with the majority of the study population being male. We, therefore need to consider gender specific analysis when designing research studies and look to recruit more women in cardiovascular studies and trials.

2) Diagnosis

Professor Chris Gale referenced the article 'Impact of initial hospital diagnosis on mortality for acute myocardial infarction: A national cohort study', published in 2016[11], and funded by the British Heart Foundation. He explained that the study focused on patients who had had a definite heart attack. One third of them had been wrongly diagnosed when they had initially gone to the hospital.

For heart attack different symptoms (such as jaw pain) are often shown by women and these contrast the typically recognised symptoms of heart attack, such as pain down the left arm and pain in the chest.

Public awareness campaigns have typically involved men and the symptoms which men suffer, and therefore women are often not aware of their symptoms. Although Public Health England's stroke public awareness campaigns are effective at reaching both men and women.

Healthcare professionals can be at a similar disadvantage and do not recognise atypical symptoms which women present with, resulting in under-diagnosis.

The position statement, 'Percutaneous Coronary and Structural Interventions in Women: A Position Statement from the EAPCI Women Committee' - Chieffo, A., et al. resulted in some interested findings. Despite the misconception that coronary artery disease is a 'man's disease', contemporary data shows a growing incidence in women. The aims of this position statement were to highlight the ongoing issues with the diagnosis and treatment of coronary artery disease in women, who are under-represented in randomised coronary

12 Dr Sarah Clarke – WHAPPG oral evidence session

clinical trials (approximately 25%). The generalisation of such studies is therefore problematic in decision-making for females undergoing percutaneous coronary intervention. Differences in pathophysiology between sexes are summarised, highlighting the need for a greater awareness amongst healthcare professionals to enable the best evidence-based therapies for women as well as for men.

3) Treatment

Women often present with atypical symptoms; this means that they can be late to present, and that healthcare professionals can misdiagnose symptoms and delay diagnostic tests and effective treatment. As is known it is vital that patients with heart attack or stroke are treated quickly to get the best outcomes, and often these atypical symptoms can mean that women miss out on the best treatment.

The article 'Sex Differences in Treatments, Relative Survival, and Excess Mortality Following Acute Myocardial Infarction: National Cohort Study Using the SWEDEHEART Registry' sets out some of these issues.[9] In terms of heart attacks, excess mortality in Sweden is higher in women than in men. This happens for various reasons, including the fact that women tend to live longer than men, and heart attacks tend to occur at a latter age in women. However, when adjusted for the fact that women are less likely to get treatment, outcome disparity can be explained by the difference in care.

It the 2016 article, 'Gender differences in coronary heart disease' - Khamis R.Y., Ammari, T., and Mikhail, G.W. the authors stated that women presenting with symptoms suggestive of CHD need to be treated appropriately and as 'aggressively' as their male counterparts. Atypical presentation patterns should not detract the physician from tackling the risk factors appropriately and arranging further investigation if there is a high-risk index of suspicion. More attention should be given to younger women as they may suffer significantly worse outcomes. The field is in urgent need of specifically designed trials that focus on women, collecting more gender-tailored data, and development of further technologies and techniques that may further close the gender gap.
At the oral evidence session the group also heard from Dr Cara Hendry that women are 10% less likely to get primary PCI.

More than 8,200 women in England and Wales could have survived their heart attacks had they simply been given the same quality of treatment as men, according to new research that we part funded, published in the journal Heart[13].

Other research has found that women who had an NSTEMI, a type of heart attack where the coronary artery is partially blocked, were 34% less likely to receive timely coronary angiography within 72 hours of their first symptoms compared to men[14].

Women who had STEMI, a heart attack where the coronary artery is completely blocked, were 2.74% less likely to receive timely reperfusion, emergency procedures including drugs and stents which help to clear blocked arteries and restore blood flow to the heart, compared to men.

Compared to men, women were 2.7% less likely to be prescribed statins and 7.4% less likely to be prescribed beta blockers when leaving hospital. These are drugs which help to lower their risk of having a second heart attack[15]. Statins also lower the risk of stroke.

13 Sex differences in quality indicator attainment for myocardial infarction: a nationwide cohort study. Wilkinson C, Bebb O, Dondo TB, Munyombwe T, Casadei B, Clarke S, Schiele F, Timmis A, Hall M, Gale CP. Heart. 2018 Nov 23. pii: heartjnl-2018-313959. doi: 10.1136/heartjnl-2018-313959. [Epub ahead of print]
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Case Study

Melissa Broad

Please do not initially rule out a stroke if all the symptoms point to it just because the patient is too young to fit the stereotype for diagnosis.

I had a stroke when I was 29, 3 weeks after giving birth to my son Elis. I was sat watching television whilst feeding him, when I suffered an intense, and severe pain in my head. It was constant. I couldn't think straight, and it was one of the worst pains I have ever felt in my life. I managed to get through the night without much sleep, and went to my GP the following morning as an emergency appointment. My GP said that the headache was a migraine, even though I'd never suffered with them before. Apparently that was a common side effect after having a baby. The confusion, slurred speech was down to the sleepless night, due to the pain, and of course having a new born baby to look after. She said that it wasn't anything serious, as my blood pressure was low, and I was too young to suffer a stroke or anything serious.

10 hours or so later my speech deteriorated significantly, and my husband sent me off to bed to rest. In hindsight, this should have triggered an alarm as my speech was significantly impaired. I kept saying that I had a daughter, when I had a son, and I was extremely confused. My husband Paul put it down to the migraine and the lack of sleep. As the GP had said previously in the day that it was nothing serious he didn't think anything more of it.

I woke up a few hours later. I was hitting my head against the bed, I was crying and my speech had gone entirely. I don't remember much after this time. My husband called an ambulance. The paramedic came out, and the diagnosis was a urine infection. Again he ruled out anything serious due to my age, and low blood pressure. He wanted us to contact my GP in the morning if the pain continued and if my speech didn't improve. Luckily Paul, didn't except this diagnosis and asked for me to be taken to the A&E department in Cardiff to be assessed further.

I arrived at A&E and I had a CT scan within the hour. The scan showed several blood clots in my neck and head, and I'd also had a haemorrhage.

At that time, I had been with Paul for more than 10 years. After the doctors explained the

situation, I saw my husband cry for the first time in those 10 years, and I think that's when I realised how serious my condition was.

Paul was told to consider calling my family to ask them to come to the hospital as it would be hit or miss if I would make it through the night. Paul tells me now, that he thought he'd be a single dad with a three week old baby to care for. He got upset because he thought I'd never know Elis, and would never see him grow up, and he would never remember me.

A delayed diagnosis can have a massive impact on a young stroke survivor's life. Family life and job/career can be seriously affected just by a few hours delay. (10 hour delay in my case). I went from being able to explain my symptoms to the GP to not being able to speak at all in A&E. That delay, caused me to suffer far more, and my recovery was far longer than it should have been.

I wasn't aware that I'd had a stroke until my 4th day in hospital, when my consultant brought around a group of medical students. He announced to the students that I'd had a stroke. I wasn't able to speak, and my husband wasn't there at the time to explain to me what he was talking about. It made me extremely anxious and upset, as I had been told previously that I'd had a blood clot and a haemorrhage. I had never linked my condition to a stroke.

Once I was discharged from hospital my recovery really started. I received speech therapy and group speech therapy for over a year. This did increase my confidence especially in a stroke survivor group setting, but once I left my confidence would disappear, and I'd struggle to even try to speak in public! I also saw an occupational therapist as well.

I has lots of appointments with a neuro phycologist who tried to help with my brain functions. I had lots of tests, and I was taught lots of tips to help my reading and memory.

I started trying to read again by reading books to my son, and luckily a baby doesn't notice your speech and reading problems. I found it incredibly frustrating though. I was a very independent person, and I felt completely alone and quite depressed. I did resent the delayed diagnosis as I thought my recovery could have been much faster if I had been diagnosed sooner.

The first year of my son's life should have given the two of us a chance to bond, and enjoy different experiences, classes, swimming, meeting friends with other babies for coffee mornings. Ours was spent in hospital, neurology departments, speaking to blood specialists, speech therapy classes and sessions to name a few. Not quite the start of my maternity leave that I'd hoped for!

Always listen to the patient! I knew something was seriously wrong, so did Paul, but we were told it wasn't anything serious as I was too young.

I hadn't at that point visited my GP before, l don't think I'd even met her. Even though I had told her that I hadn't suffered any migraines previously, and that I was confused, and I was noticeably slurring my speech, she just assumed I was a young new tired mum, and due to my age and low blood pressure it couldn't be anything more serious. That one decision that she made on that morning, had a huge impact on my life, my son's life, and my family and friends.

If she had just referred me to the hospital at that point, it could have significantly reduced my recovery time. She could have saved me the embarrassment of having aphasia in those early months of my recovery. Where people look at you and think you're drunk or a little bit crazy when you can't get your words out and your speech is slurred.

The depression that I suffered and the feeling

that I couldn't cope with everyday tasks that I always took for granted. Also the depression and the feeling of despair that I felt as I was convinced I was a bad mother. My child was missing out on all the fun and educational things that we could have been doing together, rather than spending every day for the first 4 months of his life in hospital.

I had a stroke when I was 29. It changed my life, my son's life and my husband's life. Looking back on it all now, I would say that being a stroke survivor and having been through all the struggles, the whole experience has made us all stronger as a family. We manged to make it through this, so we can make it through anything! I wouldn't want anyone else to go through this though. A stroke can and does happen to people of any age.

Recommendations and Call for Action

The All-Party Parliamentary Group on Women's Health is calling for a further focus on stroke and heart attack outcomes for women. For too long have the differences in outcomes gone have gone unchecked or unknown and there is a need to address the three key issues: under-research, under-diagnosis and under-treatment.

The group is calling for action at a national level and a further focus on ensuring women do not suffer unnecessarily.

1) *Awareness campaign:*

- General awareness campaign focusing on symptoms and information for women regarding heart symptoms and stroke
- Targeting of certain communities, such as BAME, which can be more difficult to reach. We need to look at further understanding of culture and other factors to take advantage of opportunities around healthcare and education.
- Public-place targeting e.g. GP surgery leaflets, hairdressers, coffee shops
- Aimed at women and their symptoms, and highlighting that these conditions are not 'men's conditions'
- Awareness around female-specific stroke risk factors needs further work.

2) *Education*

- General public – it is important to educate the general public about the atypical symptoms that women often present with, and the need to seek early treatment.
- Clinicians – it is vital to work with clinicians and educate them around the symptoms women sometimes suffer, to ensure that they do not rule out heart attack or stroke too quickly, as the symptoms are atypical.
- There is a need to start a conversation around female-specific stroke risk factors.

3) Promote effective investigation of women's symptoms and promote diagnostic techniques that could help in this regard.

4) More data/research - only with more research can we hope to better understand how to best treat heart attacks and stroke in women. We need much better post-acute data to be able to fully investigate women's treatment, experiences and outcomes compared to men.

Appendix

31 people and organisations responded to the APPG's call for evidence and an oral evidence session was held in Parliament. The Group met with a range of stakeholders to gather as much information as possible.

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