# Cross Party Group on Heart and Circulatory Diseases

Wednesday 8th February 2023, 6-7.30pm

Minutes

## MSP Attendees

Karen Adam MSP (Co-Convenor CPG on Heart and Circulatory Diseases)
Alexander Stewart MSP (Co-Convenor CPG on Heart and Circulatory Diseases)

## Invited attendees:

Professor Lis Neubeck (Speaker)
Jill McLaggan (Speaker)
Dr Ross McGeoch (Speaker)
Maggie Simpson (Speaker)

## Non-MSP attendees:

Jonathan Roden, BHF Scotland
Richard Forsyth, BHF Scotland
Kym Kestell, BHF Scotland
Kerry Ritchie, Health and Social Care Alliance Scotland
Brian Forbes, Astra Zeneca
Gemma Roberts, BHF Cymru
Sophie Bridger, Chest, Heart & Stroke Scotland
Gillian Kinstrie, NICCS
Natalie Elliot
Graeme Rose, Novartis
Sandra McLeod
Mairi Morrison, Cruse Scotland
Mary Galbraith
Jules Payne, Heart UK
Fiona Brownlie, Cardiac Rehabilitation Interest Group Scotland
Shirley McCulloch

## Welcome and apologies

Alexander Stewart MSP welcomed members to the meeting. Minutes from the last meeting held on the 3rd of November 2022, were agreed and are available on the Scottish Parliament website.

Apologies: Colin Smyth MSP, Paul McLennan MSP, and Jenni Minto MSP

## Topic discussion: Women's heart health

Maggie Simpson, Chair of the Women's Heart Health Subgroup for the Women's Health Plan and Cardiology Advanced Nurse Practitioner at Queen Elizabeth University Hospital. Maggie provided the group with some background to the development of the women's health plan.
Maggie highlighted the initial development of the Women's Health Plan (WHP), mapping exercise across Scottish Government policy areas by the steering group which was chaired by the Deputy Chief Medical Officer. The group with representation across healthcare professionals, third sector and lived experience, created subgroups including women's heart health.

Key recommendation from this group was these 4 principles: addressing inequalities, taking a life course approach to health, acknowledging and responding to gender equality and intersectionality, and ensuring respectful and inclusive services.

Political context to this work: First Minister's national advisory council on women and girls' vision for Scotland is that it's recognised as a nation that is committed to an equal society where women and girls can reach their potential – March and April 2019 had a spotlight on health and published a report on gender equality.

Royal College of Obstetricians and Gynaecologists made recommendations and highlighted health service constantly misses opportunities to ask women the right questions to prevent illness and to ensure best outcomes. Women's Health CPG wrote to Cabinet Secretary for Health and asked for a women's heart health champion to improve data collection and improve outcomes in women's health. Bias and Biology report published by BHF Scotland at similar time.

Maggie highlights that cardiovascular disease causes 35% of all deaths in women worldwide, but cardiovascular disease is understudied, under-recognised, underdiagnosed, and undertreated in women. Women also under-represented in clinical trials.

Awareness of heart disease: women in Scotland think they are more likely to die from breast cancer, when there is a significantly higher chance of dying from a heart attack. Women face challenges when they do present with typical symptoms and attend healthcare services. Women are less likely to have their symptoms attributed to heart disease and more likely to be told they're anxious or stressed.

Maggie highlights that women are less likely to have risk factors managed compared to men and experience sex specific risk factors such as premature menopause, polycystic ovary syndrome, and hypertensive disorders in pregnancy.
Also, we can't manage heart disease in women without acknowledging the overlap with sexual and reproductive health.

Cardiovascular disease affects women of all ages - those born with congenital or inherited disease need to access appropriate services to transition from paediatric to adult care.

Socioeconomic risk factors, there is an opportunity to optimise women’s health and reduce their risk of heart disease, e.g., childhood obesity, smoking, hypertensive disorders of pregnancy, premature menopause, gestational diabetes.

Maggie discussed the recommendations published in the WHP, including short term actions such as establishing a central platform for information on women’s health on NHS Inform; medium term, including improving collection and use of data; and long term such as adopting a life course approach in all services to improve women’s health holistically.

Maggie mentioned the relevant aims that came from other sub-groups such as abortion, contraception, endometriosis and menopause and gender and health.

We must consider our role, in services and policy, third sector and realise opportunities to develop policy, patient pathways, awareness campaigns to improve heart health of women in Scotland.

Dr Ross McGeoch, Chair of the Heart Disease Task Force and Consultant Cardiologist, University Hospital Hairmyres. Dr McGeoch provided the group with an update on the progress made so far around the heart health priority of the Women’s Health Plan.
Dr Ross McGeoch highlighted the excellent cardiovascular research in Scotland and recognised the role of the Heart Disease Task Force in overseeing the implementation of the Heart Disease Action Plan (HDAP) and to build on the excellent progress in cardiac care in Scotland over last couple of decades.

Dr McGeoch showed the group a google search of 'someone having a heart attack' and showed results of pictures of older men holding their chest, reinforcing how cardiac problems are often associated as being a male issue.

Risk factors such as smoking, diabetes, and high blood pressure, on an individual level affect women more than men and only 15% of women were aware that this was the case.

Regarding an update of the heart health priority of the WHP. Early in process of this and clear where deficiencies lie. What is being done now:

Two short life working groups established with representation across the board, including those with experience of heart disease.
Given issues raised around awareness and the framing of heart disease in women more generally, there has been a campaign launched with the key message that heart disease is a leading cause of death in women - campaign was formed through a lot of feedback from lived experience groups. The campaign poster reads 'heart disease is killing 10 women a day in Scotland' - this is being shared online, in leisure centres, pharmacies, doctor’s surgeries etc where it can be seen widely.

The NHS Inform website on women's heart health has been updated and relaunched, with additional focus on particular risk factors and links to pregnancy.

Awareness shouldn't be a complex issue in addressing. Dr McGeoch referred to a BHF survey where 1/4 of women were unaware that ischaemic heart disease is the leading cause of death amongst women in Scotland, and most women were more worried about breast cancer despite being 2.5x more likely of dying from a heart attack.

Positive outcomes from Scottish Cardiac Audit Programme (SCAP): having ownership of data, with a plan to look at gender specific differences in data, e.g., could look at if women presenting later in the process of a heart attack, what treatment do they receive? Meaning this data can be used for years to come and effectively used to see if the interventions implemented do help. Although SCAP in early stages, it is going to evolve and be a fantastic resource.

Jill McLaggan, Spontaneous Coronary Artery Dissection (SCAD) patient.
Jill highlighted her healthy lifestyle, and that she has no cardiac risk markers, but has experienced 2 heart attacks caused by SCAD.

Jill noted personal experience of A&E, recognising that often women only make a fuss over their health once things are very bad. Jill only decided to attend A&E after an appointment with a private GP through her partners healthcare, after disappointing experiences with doctors and NHS 111.
Jill was repeatedly asked if she was stressed by A&E clinicians, especially when her ECG was normal.
Symptoms experienced were very classic of heart attack.
Diagnosed with gastritis and to be discharged - however, before being discharged troponin blood tests showed 1 or 2 heart attacks, with an angiogram the following day showing a SCAD.
Acute medical care unit, experienced outstanding care.
Jill had the diagnosis and medication on discharge but was given no information.

Jill continued to have severe ongoing cardiac events for 3-4 months and on last time was given GTN spray, but with no information. Due to prior knowledge of GTN sprays and angina, began to research her symptoms and condition. Finding information on the BHF's website about microvascular angina being most common in women during the ages of menopause and coronary artery spasms occurring at a predictable time, usually late at night (the same as Jill's experience). Due to being perimenopausal, kept notes and realised the months where a period was missed, was when major cardiac events occurred.

Jill's treatment and rehabilitation: advice given at cardiac rehab appointment was no cooking, vacuuming, or lifting of heavy pots for 6 weeks then back to work. Given Jill's job as a sport massage therapist, this appeared concerning. Due to it being during the pandemic, Jill waited for her cardiology appointment.
At appointment, Jill was told main aim of appointment was reassurance and the GTN spray was a placebo effect and was refused a referral to specialist cardiologist Dr Adlam in Leicester.

Jill now has cardiac symptoms relieved by balancing fluctuating sex hormones and closely monitored HRT by a private menopause specialist. Highlighted it's interesting there is information on BHF's website on microvascular angina and menopause, but nobody in cardiology ever asked about this or gave information.

Jill reinforced the important point that only through her own research she made a connection between cardiac problems and menstruation, and worries about women who can't access information online, or go home after a misdiagnosis at A&E.
Need for information to be shared amongst healthcare professionals and the public, and an awareness raised of gender bias.
Noted even though 80-90% of SCAD patients are women, there was still a research study on men, who currently account for about 10% of patients.

Jill noted a positive outcome of her work – was being part of starting conversations between Dr Louise Newson, menopause specialist and Dr Adlam, SCAD specialist, and has since had messages from patients noting Dr Adlam has updated his knowledge and guidance on HRT.

Short discussion
Sandra McLeod – SCAD survivor, history going back to post-pregnancy. Highlighting pregnancy related cardiac symptoms, accused of being an anxious new mum. Perimenopausal, major SCAD needing 5 stents, left with a lot of cardiac drugs that were unnecessary. Feels particularly for SCAD, not a lot of knowledge given, more from researching on internet. Felt she had very similar experiences to Jill with diagnosis and treatment of her SCAD.
Karen Adam MSP highlights the need for change in systems in healthcare and perceptions around women's health.

Professor Lis Neubeck, Head of the Centre for Cardiovascular Health Research, Edinburgh Napier University. Lis provided the group with information of current services available in Scotland for SCAD survivors.
SCAD estimated to be responsible for 0.1%-0.4% of all acute coronary symptom (ACS) cases, but SCAD is estimated to be responsible for up to 25% of all ACS cases in women under the age of 50.

Prof Neubeck notes there has been a difficult history of people not recognising they're having a cardiac event, often symptoms being dismissed or being told they're anxious is all too common.

Certain factors will make someone more likely to have a SCAD: predisposing arteriopathy, atherosclerosis, hormonal changes in pregnancy and menopause, connective tissue disease, inflammatory disease, and fibromuscular dysplasia.

Predisposing arteriopathy can be often linked with precipitating stressors such as intense exercise, emotional distress, or stimulant use.

Management of SCAD:
Ideally wouldn't do anything interventional beyond diagnosing.
Screening for FMD and connective tissue disorders
Genomics

One study suggesting beta-blockers are effective.
Magnetic resonance angiography
Post SCAD chest pain syndrome – can last up to 2 years beyond a SCAD. Need to give people advice on how to cope with it.

Specific recovery needs:
If patient is on anti-platelet drugs they must be informed and be aware of the risk of menorrhagia.
Need advice on contraception and pregnancy.
Hypotension is common, need to manage this.
PTSD common
Exercise recommendations are typically not suitable and targeted for men in their 60's. Usually circuit based, not intense enough for most women and women would not choose these exercises normally, but would rather do yoga, dance, Zumba. Why are we offering a gym based cardiac rehab when we know 50% of the population would not choose this?
Avoid chiropractic treatments.

Prof Neubeck highlights there is no specific SCAD services in Scotland, majority of patients (if lucky) get sent to Dr Dave Adlam in Leicester and Scotland currently has no registry of how many SCADs there are. Service relies on goodwill of one cardiologist, that we don't pay for. Service is fragile and could be dismantled - to pay, it would cost £188.44 for first attendance appointment, £98.40 for follow up. This service takes 60 patients a year.

It is important we create a specialist clinic in Scotland which is a satellite clinic of Leicester to compare data and continue research together. If implemented, clinic estimated to be fortnightly, cost less than £20k per year, and would initially be supported by Dr Dave Adlam who would train cardiologists in this area for one year.

# Question and Discussion

Karen Adam MSP shared personal experience of losing her mother to a heart attack at a young age and discusses both herself and her brother presenting with cardiac symptoms in recent years. Karen's brother was seen by medical staff immediately and highlighted how she did not receive the same treatment.

When we're talking about women being underdiagnosed and under treated although we're presenting at GPs surgeries – are we not being good enough advocates for ourselves? Is it that we're often at the GP with the children? Despite spreading awareness, or women being aware of their symptoms, once they present at the GP and are then dismissed, what can we do?

Maggie Simpson, notes how she recently saw a couple of male patients who had been treated for suspected heart attack, but when you spoke to them it was clear it wasn't – sure this is uncommon, but seen the alternative where a male is assumed to have had one and hasn't.

Know from studies women use the right phrases and explain their symptoms, but something in that healthcare professional's mind has not gone to ACS. Same way we got the women's health plan was by a multi-pronged approach, similar, that's the only way we're going to improve this, we can make women and families aware but unless that also runs alongside improving the education and awareness amongst healthcare professionals we're not going to get anywhere.

Subgroup identified this and looking at pathways, and education particularly undergraduate in how we're training doctors, nurses, and allied healthcare professionals, that's again how this works for the long term – most of the time women are saying the right things they're just not being listened to, especially young women. Jules Payne, concerned about lipid situation in Scotland, people with raised and high lipids need to be treated. Concern when women are pre-menopausal are not as at risk as men with atherosclerosis, but that increases post-menopause.

People with familial hypercholesterolemia, are born with high cholesterol, 21,500 people in Scotland likely to have this condition, with only 10% identified. Big issue, probably causing very early heart attacks. Pleased to see within Women's Health Plan dyslipidaemia was in the plan, but FH does need to be considered, particularly with women.

Brian Forbes, regarding cardiac audit programme and the quality performance indicators, given the inequalities that we know exist for women in cardiac care, are we going to positively discriminate and look at the QPIs through the lens of gender, particularly around the unconscious bias that might sit in the clinical community?
Dr Ross McGeoch – a lot of work still to be done around this, but already put the QPIs through the short life working group for women's heart health. Ultimately this data will be used to identify any anomalies. Referred to Jill's story and recognising so many elements of a patients journey where things can be improved. Ensuring the data is collected and acted upon. Incrementally making small steps to make changes. Dr McGeoch acknowledges his position as a white male and recognises that cardiology is dominated by men, so looking at how the workforce is improved and make it easier for women to become cardiologists.

Karen Adam MSP, having any type of women's health centre that gives women a focus on their own health, where referrals could be made would be great.
Dr Ross McGeoch, priority 1 in HDAP is prevention. Work going on now about how we optimise prevention in community. Upcoming scoping project will hopefully identify this, e.g., where women will be best approached. Example study in America, black men not getting treatment for hypertension, (the barber shop study) where pharmacists were partnered with barber shops and had a sustained reduction in blood pressure. So, is there places women go where they could be engaged with.

Maggie Simpson, we interact with women constantly, e.g., cervical screening, vaccines, contraception, menopause clinics and it was great to have representation in all these groups in the women's health plan, and made us think, maybe we should do blood pressure checks at the menopause clinic as we then may identify women at risk. Enquiries into maternal heart disease, which is the leading cause of maternal death in the UK, showed 75% of those women had another health condition or risk factors and had been in the healthcare system but we missed opportunities to talk to them about

their risk and inform them. Evidence to show opportunities – we need to map what exists and identify easy opportunities where we can already interact with those women.
Karen Adam MSP, mention of neurodiverse women, comorbidities that have been mentioned. Neurodiverse people having shorter life spans, and sometimes due to not looking after health.

Jill McLaggan, as the work is ongoing to improve women's health, two of the things you could say to your healthcare professional, is one 'what can I do to make you believe me?' and for example, if your ECG shows as normal, you can ask for a troponin blood test. Also, as Maggie mentioned, we're at the doctor all the time, so surely there must be some opportunity.

Shirley McCulloch, with lived experience with not being believed, told my symptoms were anxiety and a digestion issue. If women are less likely to go to a healthcare professional, we're going to be even less likely to go if we're denied the reasonable response we'd expect to have. Completely different experience of being treated pre-test, to post-test when there was a concern.

Meeting close (7.35pm)