Draft minutes from joint meeting: Cross-Party Group on Heart Disease and Stroke and Cross-Party Group on Women's Health

AGM of Heart Disease and Stroke CPG

Tuesday 8th December 2020, 6-7:45pm

Attendees (30)

Colin Smyth MSP (Co-Convener Heart Disease and Stroke CPG)
Alexander Stewart MSP (Co-Convener Heart Disease and Stroke CPG)
Monica Lennon MSP (Convener Women's Health CPG)
Katie MacGregor, British Heart Foundation (Secretariat)
Professor Colin Berry, Professor of Cardiology at University of Glasgow, Consultant Cardiologist Queen Elizabeth University Hospital and Golden Jubilee Hospital (Speaker)
Maggie Simpson, Senior Nurse Specialist, Scottish Adult Congenital Cardiac Service (Speaker)
Mary Galbraith (Speaker)
Margaret Davis (Speaker)
David McColgan, British Heart Foundation
James Jopling, British Heart Foundation
Dr Stephen Yarwood, Herriot Watt University
Louise Taylor, Head of Service, NHS Lothian
Damian Crombie, Aztrazeneca
Brian Forbes, Astrazeneca
Dr Terry Quinn, University of Glasgow
Jo Broomfield, Boehringer Ingelheim
Gwen Currie
Dr Anna Maria Choy, University of Dundee and Ninewells Hospital
Colin Oliver, Stroke Association
Katherine Byrne, Chest, Heart and Stroke Scotland
Jane Holt, Crosshouse Hospital
Wendy Armitage, Chest Heart and Stroke Scotland
Helen McCabe, MSP staffer
Kirsty-Louise Hunt, MSP staffer
Eilidh Dickson, Engender
Gillian McElroy, the ALLIANCE
Dr Janine Simpson, University of Glasgow
Dr Christine McAlpine, Glasgow Royal Infirmary

Welcome and Introductions

Alexander Stewart MSP welcomed members to the joint meeting. Minutes from the last Heart Disease and Stroke Meeting were agreed and are now available on the parliament website.

Professor Colin Berry, Professor of Cardiology at University of Glasgow, Consultant Cardiologist Queen Elizabeth University Hospital and Golden Jubilee, presented on the scale of the problem of Ischaemic Heart Disease in Women.

- Professor Berry opened by describing the premature CVD death rate, age standardised per 100,000 population. Data shows the poorest areas of the country are, on average, more likely to die early from CVD than those living in the richest.

- Disability adjusted life years (DALYs) – ischaemic heart disease carries such a health imposition because it may affect the young. An individual aged 35 who has a heart attack, carries that diagnosis for the rest of their life.
- Professor Berry then moves onto to talk about some epidemiology which was supported by the BHF in relation to the devolved nations. Age standardised mortality ratios for men are compared with age standardised mortality ratios for women. From this, for women in Scotland there has been a rising trend for women who have died from Ischaemic heart disease in recent years.
- In the West of Scotland Prof. Berry and his team (and external partners) endeavoured to overcome some of the data gaps in our knowledge around heart attack and how patients are manged in a complex healthcare systems.
- Through this joint working project, they were able to link patient records and their journeys of individual patients. Over 75,000 patients were analysed for sex-differences.
- There does appear to be differences in how men and women who have had a heart attack are managed in the NHS in the West of Scotland. Also differences in what medicines were prescribed between hospitals and health boards. This will probably be similar in other parts of the world.
- When a woman experiences a heart attack, she is more likely to be at least 4 years older, and with age other morbidities accrue over time.
- Without having audit and research we wouldn't be able to better understand how patients needed to be treated. For example, care is optimised if a patient presents directly to the heart attack centre and not A&E but we know that higher proportion of women present to A&E and therefore don't receive treatment as quickly as would be optimal.
- Some solutions:
    - Support systems (from different stakeholders, BHF, NHS, Scottish Government women's health plan)
    - National audit MI (e-registry)
    - Women's Heart Health Champion at all levels to address the needs of individual patients (Health Centre, Hospital and Health Board). This would be multi-disciplinary linking together all the services that might be relevant.

Maggie Simpson Senior Nurse Specialist, Scottish Adult Congenital Cardiac Service, updated the group on the work of the women's heart health sub-group.

- Awareness and education of heart disease in women needs improvement, for health professionals too. Women think they are more likely to die from breast cancer than a heart attack when in fact the opposite is true. There isn't one type of heart disease, a whole systems approach must be taken.
- Not only older women who are affected. There are young women who are either born with, inherit or acquire heart disease as children or teenagers. Other facts that affect women include: race, ethnicity, a women's income, education, postcode (deprivation), social support to a women.
- **Women and pregnancy**. For women with known heart disease there is opportunities before a pregnancy what risk means for her in a pregnancy. Heart disease is the most common cause of death for pregnant women and women first year post-partum (accounting for ¼ of all deaths)
- **Interactions with healthcare professionals:** Looking to interactions with healthcare professionals, women have greater interactions than men. There is an opportunity here to

assess women's wider health needs (e.g. through their interaction with gynaecology or sexual health services, especially those with PCOS or endometriosis)

- **Cardiac rehabilitation** is a fantastic intervention. It is shown to improve quality life and outcomes after presentation of heart conditions. Despite this, women are less likely to be referred to cardiac rehab and less likely to uptake that invitation even though they might benefit as much as men do. Across Scotland there is a inequity of access to psychological support which is a further argument for a whole systems approach.
- **Women in research:** Unfortunately, in terms of research that guides practice women are in the minority and continually underrepresented in trials which makes it challenging to know that the intervention that we prescribe or carry out are going to have the same benefit as the majority of men in these trials.
- Group looked at the SIGN guidelines of heart disease and discovered there were no gender-specific recommendations, even where there is research to back it up. Following conversations with SIGN, it is hoped that the guidelines will be reviewed soon with the possibility of creating a women specific guidelines.
- **Data** is key to everything we do. Scotland collects a lot of data via the CHI number but there is no effort to link up all the data to show the inequities in care, outcomes in care and what the care means to the care user. The heart health sub-group is really focused on ensuring that the patients and validated measurement tools are used so that we get the user experience which will help us develop services that help us meet the needs of the women who use them.
- **Pathways**: there are big gaps in Scotland. Having transition care for young teenage girls with heart disease has shown across Europe and the World to lead to better engagement with healthcare services so they don't present in an acute situation. Also helps them think about their heart condition and it informs their contraceptive and pregnancy choice which has a massive impact on their life going forward.
- We do so many good things in Scotland at the moment, but we are not doing the in a joined up cohesive networked approach.
- Women's heart health leadership role would prove immensely beneficial as it would bring together all the different teams and stakeholders involved in a woman's care. A lot of this work is already underway with a number of clinicians ready to drive the work forward.

Mary Galbraith and Margaret Davis Lived Experience Perspective

- Mary explained SCAD and microvascular angina of which predominately affects women. SCAD is a cause of heart attack or sudden cardiac arrest but is not an atherosclerotic disease. SCAD can develop as either a bleed in the layers of the artery wall, or lining of the artery wall is quite fragile and for some reason it tears, causing a dissection flap that can impede the flow of blood to the heart which can cause a heart attack.
- Microvascular angina is another condition that predominately affects women and like SCAD it is under-recognised, under-diagnosed and under-treated. It is cause by problems in the tiny arteries within the heart muscle that play a crucial role in supplying blood to the heart. It can be quite painful, debilitating and can significantly affect people's quality of life as well as increasing the risk of major adverse cardiac events.
- In May 2018, Margaret was fit and healthy, had no heart issues, normal cholesterol, low to normal blood pressure and didn't smoke or drink excessively.

- She had just stopped taking her HRT treatment after being on the medication for 15 years She was on a walking holiday in the Lake District where she suffered a fall. The following day she had a SCAD and heart attack.
- Margaret is extremely grateful for the quality of care she received both in the Lake District and at her local hospital as she was seen by a SCAD expert.
- Margaret suffered with anxiety and had psychological effects following her heart attack and SCAD for which she was referred to Cardiac Rehab despite not being eligible. The local cardiac team worked with the specialist team at Leicester. The cardiac nurse realised that she was actually quite fit and it was psychological problems that were holding her back.
- The importance of cardiac rehab is well evidence. One study showed that we are 6x less likely to have an adverse follow up event if we have tailored cardiac rehab. SCAD patient's mental health often suffers as there it can't be predicted and it has not cure.
- Mary was 39 years old, a teacher living on South Uist when she had her first SCAD.
- Mary took ill at home and initially her ECG, performed by the paramedics, was normal. It was a troponin test that later diagnosed her with having a heart attack. While in hospital she had a second heat attack with ECG changes this time. Mary was then transferred to the Golden Jubilee where she was diagnosed with SCAD and was under the care of a SCAD expert. Mary also attended cardiac rehab. Following her return to work she had another SCAD and continued to suffer with chest pain which was later diagnosed with microvascular angina from her original cardiologist.
- Margaret and Mary are both so grateful that they have survived, that their cardiologists took their symptoms seriously and they are acutely aware that others don't. They are able to advocate for themselves and are aware that other women are not so fortunate.
- They have spoken with other SCAD and women heart patients and it became clear the quality of care is not equal. The realised that care for women in general is not equal.
- Margaret reiterates that women's heart health is not a level playing field and there are statistics to back it up. Something else needs to be done.
- Overall, they have four goals:
    1. To have a specialist SCAD clinic in Scotland
    2. To change the SIGN Guidelines to cover SCAD
    3. Cardiac Rehab available to all
    4. To support one another.

QUESTION AND DISUSSIONS

- Everything you have just said about heart attack is also true in stroke. The differences in outcomes are striking, what are the underlying reasons: biological, environmental, lifestyle, socioeconomic?
    - It is multifactorial. What I have learned is that we have become better positioned as Doctors with development of new tests, small vessel function. We are now able to diagnose these conditions as a result of these new tests that have become available in recent years.
    - It speaks to issues around medical education and how doctors understand clinical problems because if the teaching is traditional, you will look for traditional things (coronary artery disease is largely a male problem, but with small vessel problems, the opposite is true).
    - This presents a real issue for medicine because if we use test to detect coronary artery, we will systematically disadvantage those with small vessel disease who are mainly

women. Data is key. We just don't know what we don't know. We are not auditing heart attack or other forms of heart disease at this time.

- Women often present to gynaecology / sexual reproductive health and primary care to discuss menopause management - which is an ideal opportunity for us to discuss this. Do we have a way to record/capture if women are using/have used HRT in relation to developing IHD as in some European countries HRT is used in primary prevention.
    - Yes, but it is incredibly challenging. It is easy to look back and see if she has every had HRT but if you wanted to look at the number of women who have been prescribed HRT and then look at outcomes after that it is an incredibly challenging and costly process.
    - Just another example of where the data is there in the prescribing system, there is a women's health record but combining the two to come up with meaningful information is where the challenge lies.

- Were you socked about your condition? Did you think it was something that affected women? How do we, as Policymakers dispel this myth and seek help when need it?
    - I was the last person who would have thought that I would ever have a heart attack. I was extremely fit and it was not on my radar at all. I never ever thought of it as being a women's condition.
    - For me, there is a need for a very strong awareness campaign; Women tend to ignore symptoms. Awareness is needed for both women themselves but also for healthcare professionals. Symptoms are often different for women too.

- Views on whether there are systemic inequalities in how research is funded. How much is directed specifically for women in regards of heart health? IF there is an imbalance how do we address it?
    - Heart disease in men and women naturally differs, and if studies are funded on the basis of coronary artery disease that will systemically bias funding to male forms of heart disease.

- BHF is a response mode funder. We don't dictate what people research but analyse and reward the best science and research. How do orgs like the BHF, structure the committees and our approach to funding research to be less focused on coronary artery disease?
    - The other thing to mention is that research is based on the ability to answer the question. And coronary artery are in terms of size are relatively straightforward to analyse using standard NHS tests. We know have the tools, knowledge and increasingly treatment looking into micro-vessels now.

- It was good to hear Colin say the SIGN guidelines are being worked on. It would be good to hear whether progress is being made on cardio rehab provision and to what extent do we have a postcode lottery? And on women's heart health champions, is this something that could be actioned relatively quickly/easily in organisations? Does the Parliament and/or Government have a Women's Heart Health Champion?
    - For this plan it is important that we take a short/ medium and long-term approach. A women's health leadership role could cover a whole range of conditions. Could be overall women's health champion or specific to heart health.
    - This could lead to very quick wins in terms of quickly identifying clinicians in each area that can come together across the multi-disciplinary team to very quickly develop pathways to improve care for women.
    - Longer terms regard looking to things like education and build from there if we want to have an impact for the future.

- Cardiac rehab – still a bit of a postcode and condition lottery.
- Scottish government are driving forward with work in this area with the Cardiac Rehabilitation Champion
- Role of digital technology to make the case for cardiac rehab adopting these types of technologies to make it more inclusive.
- During the early weeks of lockdown, BHF worked with the cardiac rehab team to create an online cardiac rehab at home programme.

- How do we tackle the bias against women being taken seriously, especially those with vague symptoms and poor health literacy? As a member of a cardiac rehab team it can sometimes feel like an uphill battle to get them heard.
    - Education and awareness is vital, events where we can publicise these issues, healthcare professional's education, public health information not being stereotypes to male
    - Having a women's heart health sub-group is going to help with this and we are heading in the right direction but with a lot to do.
    - Need to try and reach those groups that doesn't have an established interest in women's heart health. Need to try and infiltrate other areas where they might not usually engage with women's services. Attend events where those attending won't be expecting to hear about women's heart health. Support a case and not just an array of statistics.

- It would be really great to see if it's possible to do some kind of evaluation of digital rehab for men and for women's outcomes to see if there are differences in outcomes (as a result of gendered life stresses)?
    - There are many practical reasons for why women can't attend rehab. Rehab are predominately (older)male so you can feel like a fish out of water. Women are more likely to do different types of exercise too. There are many difficulties in being refereed.

- There is evidence that the gender of the cardiologist influences outcome, and having more female doctors in the consultant body is important, but yet cardiology has the lowest number of female consultants in the UK.
    - A women's chances of surviving a heart attack are higher if she is seen by a female doctor but proportionally have the lowest number of women consultants.
    - There are some hospitals in Scotland where are there are no female cardiologists.
    - It needs to go into medical school
    - Female physicians should be inspired to go into cardiology
    - Need to highlight women who are successful in cardiology

AGM – Heart Disease and Stroke

- The Co-Conveners Alexander Stewart MSP and Colin Smyth MSP confirmed that they were happy to continue in those roles. Both were nominated and seconded as Co-Conveners into the next year.

- British Heart Foundation Scotland will continue providing the Secretariat role.

- The next meeting of the group will be the final one before the parliament dissolves and will be a roundup of everything that has been covered this parliamentary term.