



## Briefing for the Public Petitions Committee

**Petition Number:** [PE1602](#)

**Main Petitioner:** Carol Sunnucks

**Subject:** ECGs and heart echo tests within antenatal care

Calls on the Parliament to urge the Scottish Government to include ECGs and heart echo tests in pregnancy care for women in Scotland.

### Background

Recently in the UK there has been a decrease in the maternal death rate. Maternal deaths from direct causes (such as thrombosis and thromboembolism) have continued to decrease over time, but deaths from indirect causes (such as cardiac disease) remain high with no significant change in the rate since 2003<sup>1</sup>.

Cardiac disease is the largest cause of indirect maternal deaths in the UK. The Maternal, Newborn and Infant Clinical Outcome Review Programme (2015) report noted that there had been no significant change in the maternal mortality rate from cardiac disease between 2009 and 2013. Forty nine women in the UK died from a cardiac condition in 2011-2013, 25% of these were classified as Sudden Adult Death Syndrome, 20% had an aortic dissection, 20% had an acute coronary syndrome, 12% died from cardiomyopathy and 22% had other cardiac conditions.

The National Perinatal Epidemiology Unit is currently in analysing in detail UK maternal deaths due to cardiac disease. This report, with recommendations on actions to prevent further deaths including deaths from perinatal cardiomyopathy, is scheduled for publication in December 2016<sup>2</sup>.

Figures from the National Records of Scotland show that in 2014<sup>3</sup> the deaths of five women were recorded as related to pregnancy, childbirth and the puerperium (the first six weeks following delivery). The number of maternal deaths registered in Scotland between 2010 and 2014 are shown in the following table. However, it is important to note that these deaths occurred

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<sup>1</sup> Maternal, Newborn and Infant Clinical Outcome Review Programme. (2015). *Saving Lives, Improving Mothers' Care*. Available at: <https://www.npeu.ox.ac.uk/downloads/files/mbrrace-uk/reports/MBRRACE-UK%20Maternal%20Report%202015.pdf>

<sup>2</sup> National Perinatal Epidemiology Unit. (2016). Personal correspondence.

<sup>3</sup> Most recent figures available.

either during pregnancy or within 12 months after pregnancy but may have been unrelated to the pregnancy (from car accidents etc.).

### **Maternal deaths registered in Scotland, 2010 to 2014.**

Year	Number
2010	9
2011	16
2012	16
2013	9
2014	11

Source: National Records of Scotland. (2015). *Vital Events Reference Tables*. Table 6.1. Available at: <http://www.nrscotland.gov.uk/files/statistics/vital-events-ref-tables/2014/section-6/14-vital-events-ref-tabs-6-1.pdf>

### **What is peripartum cardiomyopathy?**

This petition focuses on peripartum cardiomyopathy (PPCM), also known as postpartum cardiomyopathy, which is a rare condition that can affect women towards the end of their pregnancy or in the first few months after the birth of their baby. It affects the heart's ability to pump properly. Cardiomyopathy UK reports that most women make a good recovery from PPCM and some recover completely. However, the condition can result in heart failure which can be life-threatening and in around five per cent of cases a heart transplant is needed<sup>4</sup>.

The most common presentation of PPCM is with symptoms and signs of systolic heart failure such as shortness of breath due to pulmonary oedema and a fast heart rhythm<sup>5</sup>. It can be difficult to diagnose because many of the symptoms including breathlessness, exercise intolerance, cough and shortness of breath when lying flat can be considered to be a normal part of pregnancy<sup>3</sup>. Cardiomyopathy UK suggest that greater awareness of the condition is needed and that improving understanding of the condition would have a significant benefit<sup>6</sup>.

There is a geographical variation in the incidence of PPCM. It is estimated that it occurs in one case per 229 livebirths in Haiti, one case per 1000 in South Africa and between one case per 2289 and one case per 4000 in the USA. The reason for this variance is unknown<sup>4</sup>. Figures from ISD Scotland

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<sup>4</sup>Cardiomyopathy UK. *Peripartum Cardiomyopathy*. Available at: <http://www.cardiomyopathy.org/downloads/peripartum-cardiomyopathy.pdf>

<sup>5</sup> Sliwa, K. Fett, J. and Elkayam, U. (2006). *Peripartum cardiomyopathy*. *Lancet*. 368, p.687–93. Available at: [http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736\(06\)69253-2.pdf?dialogRequest](http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736(06)69253-2.pdf?dialogRequest)

<sup>6</sup> Cardiomyopathy UK. (2016). Personal correspondence.

show that each year in Scotland only a few cases of PPCM are diagnosed. Typically, between 2 and 12 cases per year were recorded between 2000 and 2014<sup>7</sup>. Cardiomyopathy UK notes that PPCM affects between one in 5,000 and 10,000 births in the UK<sup>3</sup>.

## Tests for PPCM

A number of tests can be carried out to diagnose PPCM. These may include:

- Blood tests
- Electrocardiogram (ECG) which can show abnormalities such as a fast heartbeat and an irregular rhythm
- Chest x-ray to look at fluid levels in the lungs
- Echocardiogram which takes an image through the chest wall. This allows an assessment of the structure of the heart including how it is pumping, the health of the valves and whether there are any blood clots present in the ventricles
- Magnetic resonance imaging (MRI) which looks for inflammation in the heart, heart cell death and blood clots in the left ventricle
- Angiogram which can be used to rule out coronary artery disease or coronary artery dissection<sup>3</sup>

A position statement from the Heart Failure Association of the European Society of Cardiology Working Group on peripartum cardiomyopathy notes that patients who are breathless during pregnancy should have an electrocardiogram and brain natriuretic peptide blood test and an echocardiogram<sup>8</sup>.

The petition relates to early diagnosis through testing for PPCM in pregnancy care rather than screening. The UK National Screening Committee has never considered a screening programme for this condition and has not been approached to do so (Scottish Government, 2016)<sup>9</sup>.

A screening test is different from a diagnostic test as a diagnostic test is designed to assess whether someone has a disease whereas a screening test is designed for populations of individuals who do not necessarily have any symptoms of the condition. Screening identifies people with a risk marker for a condition and divides them into high and low risk<sup>10</sup>.

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<sup>7</sup>As recorded in SMR01 and SMR02. ISD Scotland. (2016). Personal correspondence.

<sup>8</sup> Sliwa et al. (2010). *Current state of knowledge on aetiology, diagnosis, management, and therapy of peripartum cardiomyopathy: a position statement from the Heart Failure Association of the European Society of Cardiology Working Group on peripartum cardiomyopathy*. European Journal of Heart Failure. 12. P767-778.

<sup>9</sup> Scottish Government. (2016). Personal correspondence.

<sup>10</sup> Sense about Science. (2009). *Making Sense about Screening*. Available at: <http://www.senseaboutscience.org/data/files/resources/7/Making-Sense-of-Screening-2nd-edition.pdf>

## Scottish Government Action

The Scottish Government published its revised strategy for heart disease and stroke in Scotland<sup>11</sup> in 2009, although this does not focus specifically on PPCM. [The Heart Disease Improvement Plan](#) was refreshed in August 2014 this seeks to further improve heart failure services in Scotland. Priority 5 outlines an aim to improve the journey of care for patients with heart failure by developing a whole system approach to the delivery of care<sup>12</sup>.

The National Advisory Committee on Heart Disease is a national group which coordinates implementation of the Heart Disease Improvement Plan. The Committee convenes three times a year and aims to promote Scotland-wide collaboration, peer support and dissemination of best practice<sup>13</sup>.

A subgroup of the National Advisory Committee is the Heart Failure Hub. This group was created to promote high quality care and management to people living and dying with heart failure in Scotland. Members of the Hub are comprised of a multi-disciplinary team of healthcare professionals from each health board in Scotland. The overarching aim of the HFH is to enable health boards to deliver clinical excellence in heart failure management through effective collaboration and communication. The 6 HFH work aim to:

- Promote quality improvement and evidence based care in heart failure
- Identify and share or develop models of care in Scotland
- Ensure strong links with existing NHS Board care networks to support and improve the provision of palliative and end of life care for those individuals with heart failure
- Improve information and monitoring of heart failure services through improved coding
- Consider different approaches to education and training of healthcare professionals and patients
- Improve the provision of psychological support for patients with heart failure<sup>8</sup>

## Scottish Parliament Action

This specific subject has not been discussed in the Scottish Parliament.

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03 May 2016**

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<sup>11</sup> Scottish Government. (2009). *Revised strategy for heart disease and stroke in Scotland*. Available at: <http://www.gov.scot/Resource/Doc/277650/0083350.pdf>

<sup>12</sup> Scottish Government. (2014). *Heart Disease Improvement Plan*. Available at: <http://www.gov.scot/Resource/0045/00458289.pdf>

<sup>13</sup> Scottish Government. *Heart Disease in Scotland*. Available at: <http://www.gov.scot/Topics/Health/Services/Long-Term-Conditions/Heart-Disease>

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Published by the Scottish Parliament Information Centre (SPICe), an office of the Scottish Parliamentary Corporate Body, The Scottish Parliament, Edinburgh, EH99 1SP