

3rd June 2013

Andrew Howlett
Assistant Clerk to the Public Petitions Committee Scottish Parliament
Edinburgh
EH99 1SP

Dear Mr Howlett

PE01446: Scottish Standards for the Care of Adult Congenital Heart (ACHD) Patients

Please find below my response to the Scottish Government's response of the 21st of May, 2013 in answer to the questions set out by the Public Petitions Committee.

As noted previously, I have been encouraged by the development of the SCCN. A MCN for congenital heart disease, which has been needed for many years, is a huge step forward for our care in Scotland. The results of the Patient Survey conducted by the SCCN seem to confirm the points raised in the petition; mainly that the National Services are doing a very good job and most patients, who have access to these services, feel safe when under the care of a trained specialist Cardiology team. However, difficulties arise when patients need local care, both in A&E and with GPs. For adults this is a particular problem given the adult specialist service does not have A&E provision and many adults remain unknown to the specialist service. It seems sensible to assume part of the problem arises from the lack of Healthcare Standards and protocols to guide medical professionals which then proves especially problematic for medical staff with no specialist training.

Of course, it is hugely encouraging that part of the SCCN's, as the lead service-improvement organisation, remit is to address these issues consulting with representatives from NHS 24, emergency care, primary care, obstetrics with support from lead clinicians and a Manager. Hopefully, we can be assured, by the Scottish Government, that any gaps that become apparent (for example, the lack of local Specialist liaison nurses for CHD inconsistent with provision for other long term medical conditions) will be met with appropriate planning, delivery, improvement and governance and that any extra resources required will be met without compromising our care by demanding more of those who are already stretched to capacity and that those involved in our care are always working within their competencies.

Regarding how exactly the missing patients will be located, the Scottish Government responds that:

"The adult congenital population includes a large cohort of patients with minor lesions, who do not need to be urgently followed up. The SCCN will examine data on the congenital cardiac population and will work to identify patients according to their need."

This is not consistent with the recommendation that:

*"All adults with congenital heart disease **whatever the level of complexity** are seen by an 'expert' from a specialist centre at least once and receive a written care plan."* (DoH, 2006 referenced in Scot Gov, 2009)

Only an expert can determine the severity of the condition and confirm that it is 'simple' enough to be managed totally or partly outside of the specialist centre. CHD is a serious and specialist condition that can only be properly diagnosed by an expert. Therefore, there needs to be adequate resourcing of SACCs to enable specialists to attend out-reach clinics to enable the whole CHD population in Scotland to have access to the proper expert care with others non-specialist but 'with an interest' to provide the local link between times.

I look forward to work voluntarily with the SCCN in whatever capacity will most benefit people like myself living with a heart condition from birth in Scotland.

Yours Sincerely,

Dr Liza Morton
Scottish Campaign Manager
The Somerville Foundation

References

Department of Health (2006) **Commissioning Guide for Young People and Grown Ups with Congenital Heart Disease.**

National Services Division, **Scottish Adult Congenital Cardiac Services Annual Report.**

NHS Specialist Services (2012) **ACHD Draft National Designation Standards and Proposed Mode of Care.**

Scottish Government (2009) **Better Heart Disease and Stroke Care Action Plan.**

Wray, J., Friglola, A. and Bull, C. (2012) Loss to specialist follow-up in congenital heart disease; out of sight, out of mind, **Heart**, doi:10.1136/heartjnl-2012-302831