

Petitioner's Response

29th March 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 March in answer to the questions set out by the Public Petitions Committee.

When does the Scottish Government expect to progress the development of national standards for the care of adult congenital heart patients in Scotland, and what action can be taken in this regard whilst it awaits the updated standards from the Department for Health?

As previously noted the development of the Scottish Congenital Cardiac Network (SCCN) is welcome news and hopefully it will facilitate the development of a model of care, across the lifespan, linking managers, clinicians and patients. However, this does not answer what will happen to patients in the mean time, especially regarding emergency care or give an estimated timescale for when we can expect standards of care and their implementation.

What funding has been made available to SACCS to ensure it is able to meet the increased demand for its services from the growing population of ACHD patients, as well as undertaking to locate and treat the large numbers of missing patients that there are estimated to be in Scotland?

Again it is encouraging that the SACCS budget has increased since it was initially commissioned. Of course, what matters is whether this budget is sufficient to meet the growing needs of the service, to overcome the areas of risk highlighted in the annual report and to implement any developments that arise from the development of National Healthcare Standards or other recommendations that may come from the SCCN. Further, there is the pressing issue around A&E cover, an area of concern for patients, and how this will be addressed.

When will the joint paediatric/adult national congenital cardiac managed clinical network referred to in your previous letter be launched, and what plans are there to utilise this to

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ensure that medical records of people living with congenital heart disease are accessible wherever a patient seeks or receives treatment?

I attended the conference to launch the network on the 8th of March 2013 giving a talk with Vicki Hendry on behalf of The Somerville Foundation on the Patient's View. I was encouraged by the passion, interest and commitment of the attendees, including Cardiologists, Surgeons, Specialist Nurses, Managers and patients. I have also met individually with Dr Marit Boot, SCCN Manager and Chris Myers, Commissioning Programme Manager, NSD to discuss my own experiences. However, both of these events further highlighted the many challenges we face regarding CHD care in Scotland. This includes the difficult experiences patients are currently facing, especially regarding out of hours care, non-specialist and local care, with GPs and obstetric care. Sadly, these are far from one off events. Further, it highlighted the desire for training and specialist input from local clinicians and the development of roles such as local Specialist Nurse Practitioners. It seems a big ask to expect this new network to be able to address the many challenges we face. Although this is clearly a significant development it is my understanding that while the network can bring together the clinicians, managers and patients to improve communication and propose more efficient pathways and standards it cannot be expected to implement changes and will clearly need the backing of the Scottish Government and any funding required to do so. Further, it is still not clear how the missing patients will be recruited.

References

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

National Services Division, **Scottish Adults 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

Yours Sincerely,
Dr Liza Morton