

27th January 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 various points made by relevant stakeholders in answer to the questions set out by the Public Petitions Committee.

Bravehearts

The organisation notes its **full support of the Petition**. It was following discussions with Gill Mitan, Chairperson of Bravehearts' Patients Association, Vicki Hendry, Regional Development Worker in Scotland for The Somerville Foundation, and Mary Hemphill (ACHD patient) that the decision was made to submit the petition as a result of our frustration with the current level of care offered to ACHD patients in Scotland and the lack of progress we seemed to be making via other mechanisms. Bravehearts signed the petition and has been actively involved in promoting it both to members of their Patient's Association and to the general public.

The Somerville Foundation

The Somerville Foundation has **actively supported the Petition** since its submission as stated above. Vicki Hendry, the organisation's Regional Development Worker in Scotland, presented evidence on their behalf at the PPC meeting on November 27th 2012 and I have accepted their invitation to continue my efforts as their Scottish Campaign Manager, further demonstrating their support for this cause.

British Heart Foundation – Scotland

BHF notes that Heart Disease Clinical Standards were developed over a two-year process and were published in 2010. Yet, ACHD is not covered by these Clinical Standards, which focus on services for coronary heart disease, arrhythmias, and heart failure. This clearly demonstrates the inequality of care that ACHD patients have received to date and that ACHD has not been a priority for The Scottish Government despite the fact that congenital heart disease is the most common complex birth defect and a lifelong condition with a growing population.

Further, the BHF notes that similar Clinical Standards should be developed for Congenital Heart Disease in Scotland in a timely fashion since they are currently in development as part of the NHS Specialist Commissioning review of ACHD services and "the review has [been] consulted on and agreed a model for provision of services for ACHD patients in 2012 and is now defining the standards against which service provision can be assessed" so the development of standards in Scotland "should be a far less labour-intensive process than that required for the Healthcare Improvement Scotland standards". BHF Scotland states that the Scottish Adult Congenital Cardiac Service (SACCS) has acknowledged areas for service improvement. BHF Scotland also **notes their support for the introduction of "national standards for the care of Adult Congenital heart patients"**. Their response states that they "believe that these should have the same status as the current Heart Disease Clinical Standards for Scotland published by NHS Quality Improvement Scotland" and that "**it is essential that following the introduction of such standards there should be funds available to support areas identified for service improvement.**" BHF Scotland also signed the petition.

Children's Heart Foundation

The organisation notes its **full support of the petition** specifically stating that **the needs of Congenital Heart patients are different to Coronary Heart patients** and that key principles should be enshrined in Healthcare Standards to "deliver better care, outcomes and improved patient experience". They also note the need for better data collection.

The Scottish Government*Development of National Standards*

The respondent notes that the *Better Heart Disease and Stroke Care Action Plan* (Scot Gov, 2009) states that NSD and GJNH (Golden Jubilee National Hospital) should "work towards" the standards set out in the *Commissioning Guide for Young People and Grown Ups with Congenital Heart Disease* DoH (2006). **However, there is no attempt to answer why the relevant recommendations set out in this guide are still not being met.** The respondent also notes that plans to develop National Healthcare Standards in Scotland were postponed in 2010 to await the outcome of the English review of their Standards. If we wait until these standards are formally adopted in England and then adapted for Scotland it is likely that we will not have Standards until 2016 at the earliest, meaning that Scottish patients will have waited at least ten years since the publication of the Commissioning Guide for formal guidance for their care. In the meantime this is having a detrimental impact on ACHD patients in Scotland. During the long wait for formal Healthcare Standards ACHD patients in England and Wales have at least benefited from this Commissioning Guide as an intermediate step. However, despite recommendations the guidelines set out in this guide are not being met in Scotland.

The development of a Scottish Congenital Cardiac Network with a specific working group on Standards is welcome news. Given that Standards have now been agreed by representatives of the professional associations of surgeons, consultants and nurses in England, I hope that this group tasked with looking at Standards are able to adapt and implement relevant standards expediently rather than waiting for the public consultation in England. Given the cost of not having formal guidance, standards and protocols in terms of actual lives, quality of life and efficiency of services, **this task should be prioritised as a matter of urgency.**

Adequate Resources for the Scottish Adult Congenital Cardiac Service (SACCS).

The Scottish Government has **not commented** on whether SACCS should be adequately resourced to meet the growing population of ACHD patients and to address the areas of risk highlighted in the SACCS' annual report or if 24-hour access to specialist services should be available.

Missing Patients

The response provided about this issue is little more than a tautology. It is well established that significantly more patients are estimated to exist than are actually known to services. Research also indicates that such "missing" patients do not receive adequate care (e.g. see Wray et al, 2012). Anecdotally, I know of several patients who were discharged following what was considered in the pioneering years to be curative surgery as a baby or at the point of reaching adulthood with no follow-up. In later life, these individuals presented to their GPs with complex heart difficulties, which in most cases were not recognised until matters were life threatening. Personally, I had difficulties gaining a referral to the specialist service from the acquired heart service I had been attending since reaching adulthood. I fear there is likely to be many more such individuals. Such misguided care is not an efficient use of resources potentially "doing harm" to patients for which the NHS then has to pay. This is even more expensive if sick pay and loss of earnings are considered and many of these individuals are parents of dependent children. Sadly, it seems likely that lives, once hard fought for, have already been lost as a consequence of inadequate or misguided care.

Other than acknowledging their existence, what does the Scottish Government intend to do about the estimated 8000 missing patients? Will there be any attempt to find and increase awareness about their existence among GPs, A&E or other health professionals to which they may present? Management of ACHD promotes a preventative and managed approach to minimise the development of further heart difficulties. This is not possible for patients who are not receiving the healthcare to which they are entitled. It is also difficult to offer this level of care to ACHD patients known to the system if the specialist services are under resourced.

NHS Specialised Services

The respondent notes that English Standards go for public consultation in 2014. Therefore, it seems unlikely that they will be formally adopted until 2015/2016. If they are then adapted and adopted by in Scotland it is likely that this will take us beyond 2016. This would mean that Scottish Congenital Heart patients have waited at least **10 years** since the original Commissioning Guide (DoH, 2006) for formal guidance for their care. **Surely, Health is devolved in Scotland to benefit rather than disadvantage Scottish Patients.** The advantage of having devolved power over our health should be that we do not need to wait until England publishes a commissioning guide then develops standards and then further reviews them. **Why are we**

waiting on the outcome of a review of English Standards at the cost of Scottish patients? Indeed, the respondent states that this is “a matter for the NHS in Scotland and the devolved administration in Scotland.”

Scottish Adult Congenital Cardiac Service (SACCS)

SACCS note the **challenge of offering care to patients who have been lost to follow-up** due to difficulties with “equity of access to services, failure of referral when patients move location, lack of transition or even historical discharge practices within paediatric services”. Further, SACCS “**completely support the drafting of Scottish Standards for ACHD care**” provided that “**there is an undertaking to provide the necessary resources to meet these Standards once agreed**”.

Scottish Association for Children with Heart Disorders.

Again the **organisation notes their support for the petition**. Specifically they note that growing numbers of patients are transitioning from paediatric care at Yorkhill, “current estimates suggest approximately 165 teenagers transition from the service at Yorkhill to the SACCS service along each year, this figure does not include those who transition to adult cardiac services in other parts of Scotland”. These individuals transit to an “**adult service (SACCS) that is already overstretched and therefore requires adequate resourcing**”. They also note that “**Healthcare Standards should be developed in Scotland without delay for this growing population**”.

The Health and Social Care Alliance, Scotland

The organisation **note their full support of the petition** advocating a “**person-centered approach to managing this life threatening, life-long condition**” and they have been actively involved in promoting it on their website and social media sites. This organisation also signed the petition.

Conclusion

In conclusion, there is overwhelming support for the issues raised by the petition. The relevant stakeholders reach a general consensus that the growing population of ACHD patients in Scotland need Healthcare Standards to ensure safe, equitable and effective care and that they should be developed in a timely fashion. These standards should promote a holistic account of living with a life threatening condition from birth to death. There is general agreement that they can be adapted from those developed in England by the NHS Specialist Commissioning review. Further, the specialist service and local healthcare providers should be adequately funded so that such standards should be met.

Yours Sincerely,

Dr Liza Morton

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**.
- Morton, L. (2011) Can IPT meet the psychosocial cost of life gifted by medical intervention? **Counselling Psychology Review**, 26, 3, 75-86.
- 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