Health and Sport Committee
NHS Governance – Corporate Governance
Submission from Evonne McLatchie

Last year on behalf of the SOS Edinburgh Cleft Group I submitted our views as part of the Health and Sport Committee consultation process. I am taking this opportunity to reiterate some of those points for the next stage of your review.

Just over 2 years ago I (and the majority of Scotland’s cleft patients and their families) was blissfully unaware of the proposed changes to the Cleft Surgical Services and found out only by chance via another patients parent and there began a 2 year nightmare where we have watched the wonderful award winning service in Edinburgh slowly but surely be destroyed. Despite a campaign to try and save it all our arguments, evidence to support the service, petition etc. were rudely dismissed and or ignored and sadly all the negative things we predicted that would happen, have happened despite Ms Shona Robison written and verbal “guarantees and assurances” to the contrary.

The following opinions are my personal opinions as I was not able in the time available to me to seek opinions of others but my answers are based/influenced with my interaction with other cleft patients and their families and the various Health Boards involved before, during and since the so called consultation period which I think I can safely say was considered by the families as merely a tick box exercise. It was generally felt the decision to close Edinburgh was already made and was expected to be quietly nodded through and the petition and campaign to try and save the Edinburgh Service was a complete surprise to the Boards involved.

Do you trust NHS Boards to make decisions that are in the best interests of the public?
The shortest answer to this is a resounding NO.
It is generally believed that a financial decision was made many years ago to centralise as many services as possible to the new Queen Elizabeth Hospital in Glasgow and that the various Health Boards involved would cooperate by whatever means necessary. To ensure services would be transferred they would if necessary be expected to go through the farce of a consultation for every service involved. We believe many more services have yet to face centralisation and the joys of a fake consultation. As the lead campaigner I sought advice and guidance from numerous sources and without exception every single person told me I was wasting my time as the decision was made and as the NHS boards know that there is no effective right of appeal they will get their own way sooner or later. I was advised that the best I could hope for was a year’s delay and we believe that is what we achieved.
**Are NHS board decisions open and transparent?**

Again this has to be NO. If you try and contact any of the board members you are met with a wall of indifference and claims of “proper procedures to be followed” yet they fail to follow their own written guidelines.

There is no immediate, effective or cost free right of appeal, assuming you even manage to find out about the decision in the first place. Do you have any idea how difficult it is for a patient to timeously get a copy of redacted board minutes? In our case the board did not correspond direct with patients choosing instead to ask a Charity to cascade any information despite being repeatedly told that the Charity only has a very small minority of Cleft patients as members so patients were still unaware of changes to their own or their child’s health care long after centralisation was announced. In the last fortnight I had 2 sets of parents’ contact me asking for the point of contact details as no one in Edinburgh could help and they didn’t have contact details!!!!

Whilst seeking guidance and before I even started a petition, I was told that any Complaints made to the Ombudsman have to be made post decision and only after we had have followed the NHS own time consuming complaint procedure which would probably mean the complaint to the ombudsman couldn’t happen as it would end up time barred. I was then told even if the ombudsman upheld our complaint all they could do was make recommendation which the Health Boards will usually ignore but announce “following the consultation process there are lessons to be learnt” It would seem that they are a very slow learning organisation as they have had many consultations over the years but are still making the exact same mistakes as following the decision to centralise cleft surgical services we too were told “there are lessons to be learnt…” Time for a new teacher?

We have repeatedly stated that there needs to be a completely independent organisation that oversees the consultation process, ensuring true patient involvement. The organisation also need to be given authority/powers to ensure procedures are followed and not only say that lessons need to be learnt but ensure changes are implemented and where necessary have the authority to have the whole process rerun if sufficient evidence that the consultation process was not followed correctly. The current system with the Scottish Health Council is farcical and the terms, chocolate fireguard, toothless beast/hamster attributed to their powers fairly accurately sums up their power. I have Freedom of Information documents that prove the SHC instructed/advised the NSD to minute consultation meetings, despite repeated requests from the patients to do so, not a single meeting was minuted. If the SHC can’t even get the NSD to take consultation minutes what hope have we that the Board can be trusted to following any of the process?

**How accountable do you feel NHS boards are?**
Not in the slightest. Once a decision is made they have washed their hands of it and moved on to the next service to be carved up and destroyed all in the name of centralisation safe in the knowledge their decision cannot be challenged successfully and always with false claims it is in the patients' best interest. Have they actually got any documentary independent evidence of this, more importantly have they any evidence that the majority of patients have agreed with their statement?

At a public meeting assurances were given that there was no intention to close Edinburgh Surgical Services yet weeks later the consultation process was announced. We had to constantly resort to Freedom of Information requests to obtain information which repeatedly gave us reason to distrust the NHS boards. Information obtained showed the board had been at best “economic with the truth” and if memory serves me correctly we found something that clearly showed the decision to consult on centralisation had been taken months before the public meeting was held where assurances were given there was no intention to centralise...

During the campaign to try and save the Edinburgh service I wrote to many different health boards and regrettably few even bothered to respond. I challenged some official stats and privately raised concerns with the then CEO of GG&C about these stats. Instead of getting assurances that my concerns would be treated seriously and looked into I got a very rude and bullying reply basically telling me he wasn’t interested and he point blank refused to answer my enquiries or later letter!! I got the distinct impression he felt omnipotent and I was not worthy of his time. It was the memory of his attitude and his letter (received on Christmas Eve 2015) that kept me focused and every time I thought of giving up the campaign I reread his letter and I was re-energised and continued fighting and hassling NSD, SHC and MSP’s in an attempt to save the Edinburgh service!

I attended both the Edinburgh and Glasgow Health Board annual public meetings but on both occasions was unable to publically raise questions regarding the Cleft service and centralisation concerns. I believe that this was a deliberate attempt to keep my concerns out of the public eye which gives me no confidence in the accountability of the board.

**How effective are NHS boards at delivering health services and improving the health of their population?**

Before centralisation our only experience of Cleft surgery/ team was with the Edinburgh team. The surgical service was outstanding as we were lucky enough to have an award winning world renowned surgeon achieving target leading outcomes. The surgeon and team also provided 72 local clinics per year. An easy to talk to cleft team who were always willing to help and guide their patients and support the parents. Revision operations were extremely rare and families had
confidence in the process. As stress free as possible care was provided and families were happy with the service provided and the care children and young adults were receiving.

Since the transfer of services to Glasgow families in the East report to me that they feel neglected and unsupported and complain of a fractured service where many parents don’t even know the point of contact. Consultant led clinics aren’t happening as promised, but exactly as predicted by families, we are convinced that this is deliberate attempt to permanently reduce the number of clinics provided. Families are extremely unhappy at the lack of clinics and then when they do get a rare appointment having taken time off work to attend the clinic they discover there is no surgeon in attendance! So much for Ms Robison’s assurances that consultant led clinics will remain unchanged! Families tell me that it is now down to them to be responsible for chasing review appointments (especially if surgery is not imminent) as the process appears to no longer be hospital driven and automatic. There is also a rising feeling that a one size fits all system has been operating rather than the more individual service previously provided. I think you would be hard pushed to find any East patient/ family familiar with the cleft service pre centralisation who thinks the service has been improved by centralisation. There was a desire by the NHS to remove what they referred to as a postcode service. Regrettably they have achieve this with centralisation but instead of improving the service overall in Scotland they lost the best Cleft surgeon is Scotland, destroyed a team with 12 years’ experience and reduced the overall service available to the patients in the East with no doubt a knock on effect to the national stats and presumably also to the service in the West. Centralisation has also removed the possibility of easily requesting a second opinion or surgery from a different cleft team which seriously restricts patient choice.

I hope this helps your review, if you require any clarification of anything I have said my contact details are below.

Kind Regards,

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