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**Cleft Lip and Palate Surgical
Service Proposal
Consultation Report
May 2016**

Contents

| | |
|---|---|
| 1. Introduction | 3 |
| 2. The Cleft Surgical Service Proposal Consultation | 4 |
| 3. Consultation Issues..... | 5 |
| 4. Outcomes..... | 7 |
| 5. Conclusions..... | 7 |

1. Introduction

- 1.1 Following the 2011/12 Review of the Cleft Lip & Palate Surgical Service the NHS Board Chief Executives asked NSD to work with NHS Greater Glasgow and Clyde and NHS Lothian to set up a single surgical service over two surgical sites to meet the needs of all patients with a cleft lip and or palate resident in Scotland. A Cleft Management Board was set up led by NHS Greater Glasgow and Clyde, with management representation from NHS GG&C, NHS Lothian, National Services Division with representation from CleftSiS (now Cleft Care Scotland) the managed clinical network for all involved in delivering local services for patients with cleft lip and palate and from CLAPA the main patient group.
- 1.2 During the period up to 2015 the challenges of trying to run a single surgical service on two different sites became increasingly apparent. The Cleft Management Board took a position paper to the National Specialist Services Committee in June 2015 setting out those challenges and proposing a number of options for the way forward for the specialist surgical component of the designated cleft lip and palate service commissioned by National Services Division of NHS National Services Scotland (NSD) on behalf of NHS Boards in Scotland.
- 1.3 The National Specialist Services Committee directed that National Services Division, as commissioners of the service, NHS Greater Glasgow and Clyde and NHS Lothian consider the options to move to a single surgical site or to continue with the status quo arrangement, to determine a way forward.
- 1.4 In reaching this decision NSSC noted that all other components of the specialist service, including support for outreach clinics, and the delivery of local services, including orthodontics, speech and language therapy and specialist nursing, were not subject to this additional review.
- 1.5 The three NHS Boards established a Review group to make recommendations on the way forward. The Review group issued a position paper in August 2015. This paper brought together comprehensive information on the various reviews of the surgical service and set out the Group's conclusion that the best way forward was to run an optional appraisal process.
- 1.6 The position paper was widely distributed and comments were received from a wide range of professional and public stakeholders.
- 1.7 A public engagement meeting was held on 27 October 2015, in the Scottish Health Services Centre in Edinburgh. This was organised with the support of CLAPA and also included an observer from Scottish Health Council. Patients and family members attended from across Scotland although the majority of those present were more familiar with the surgical service currently provided by NHS Lothian.
- 1.8 The Review group convened an Options Appraisal Group with membership ensuring appropriate clinical interest and expertise, and a range of NHS management and lay representation that provided a geographical balance. Participation included senior medical managers, strategic planners, service managers, patient representatives from CLAPA, clinicians nominated by Cleft Care Scotland and independent Cleft experts from NHS England and NHS Wales.
- 1.9 Dr Andrew Russell, Medical Director of NHS Tayside, agreed to act as the independent chair of the Group.

- 1.10 The Options Appraisal took place in October and considered the options of:
- A single surgical service based on one surgical site in NHS Lothian
 - A Single surgical service based on one surgical site in NHS Greater Glasgow and Clyde.
 - Continue to attempt to provide a single surgical service over the two surgical sites.
- 1.11 The outcome of the Options Appraisal was that the highest scoring option was the single surgical service based on one site in NHS Greater Glasgow and Clyde. The Report on the Options Appraisal was provided to the NSSC Meeting in December 2015.
- 1.12 The Review Group therefore requested approval from the National Specialist Services Committee at their meeting in December 2015 to go out to formal consultation on the proposal to consolidate the surgical service in Glasgow
- 1.13 National Specialist Services Committee approved the request to go out to formal consultation.
- 1.14 The rest of this paper describes the process and findings of the consultation and how it impacts on the proposal of the Review Group.

2. The Cleft Surgical Service Proposal Consultation

- 2.1 The Review Group established a Stakeholder Consultation Group with representation from Cleft Lip and Palate Association, Changing Faces and the Scottish Health Council to provide advice on the material and process for the consultation.
- 2.2 The Group prepared a Cleft Surgical Services Proposal Consultation Document and information sheet (NSSC 2016-16 B). The Consultation Document outlined the proposal, possible benefits and potential issues and provided an e-mail address, a post address and a telephone number for people to make their comments on the proposal up until the end of the consultation period.
- 2.3 It was agreed that these documents would be placed on the NSD website and that the information sheet would be sent to parents and patients through the databases of NHS Greater Glasgow and Clyde and NHS Lothian. It was also agreed that CLAPA would also promote the consultation through their website and social media channels.
- 2.4 The consultation Information Sheet was also sent to all 14 territorial NHS Boards Patient Focus and Public Involvement leads to promote through their usual engagement channels.
- 2.5 The Group agreed to hold a number of consultation events across Scotland and public meetings were planned for Edinburgh, Glasgow and Perth for patient and public consultation meetings as well as a consultation event with Cleft Care Scotland members. Following feedback about access for North of Scotland interests it was agreed to hold an additional videoconference event for NHS Grampian in Aberdeen.
- 2.6 There were issues about the distribution of the information sheets from NHS Lothian with a number of people communicating that they had not received theirs directly from the NHS. NHS Lothian apologised for the delay that some people experienced in receiving the information sheet through them. The people concerned had heard

about the consultation through other channels but were concerned that they had not had formal notification from the NHS itself.

- 2.7 The schedule meetings had a varied level of attendance with the largest in Edinburgh and the smallest in Aberdeen. In all about 50 people either attended in person or phoned in to at least one of the consultation meetings.
- 2.8 The Scottish Health Council agreed to provide feedback on an ongoing basis as well as a formal feedback at the end of the Consultation. A copy of Scottish Health Council's formal feedback is attached in (NSSC 2016-16D).
- 2.9 The Review Group understood that not everyone that attend any of the consultation meetings would be in agreement with the proposal and in fact were cognisant that most who would attend would be motivated to do so by concerns about the proposal.
- 2.10 The consultation was aimed at listening and identifying what those concerns were to try to provide answers where possible and at the end of the process demonstrate that views are accurately communicated through the consultation report to NSSC.
- 2.11 Detailed notes of each meeting were taken and put up on the website to ensure they were accessible.
- 2.12 At each meeting it was re-emphasised that people would have the opportunity to put in their comments on the proposal into the consultation through e-mail, phone or writing to NSD as well as through the consultation meetings.
- 2.13 At the meeting in Glasgow one person had a list of over 70 questions that they wanted to ask. In order to ensure that everyone could contribute to the meeting it was agreed these would be sent in electronically and would be responded to by the Review Group. These questions were responded to after the meeting following receipt by e-mail.
- 2.14 Whilst there was a degree of anxiety at each of the meetings the Review Group members tried to ensure that everyone attending got an opportunity to ask a question or make an observation. In general that was achieved with the exception of Glasgow where the 70 questions had to be addressed after the event.

3. Consultation Issues

- 3.1 It was clear that the majority of people who attended the consultation meetings had family members who were currently under the care of the East of Scotland Service and were concerned and disappointed about the proposal to consolidate surgery in Glasgow and therefore have the surgical service removed from Edinburgh.
- 3.2 The formal contributions to the consultation followed that general concern. In summary the consultation received 118 formal contributions.
- 3.3 The vast majority of contributions came from parents/patients who had a family member under the care of the East of Scotland Service.
- 3.4 The next largest number of contributions was from staff, generally clinicians, who were either directly employed or worked with the East of Scotland Service. They had similar concerns and objections to the proposal.

- 3.5 There are two posts which would be affected by this proposed change. The proposal is clear that any and all staff directly affected would be directly engaged with under TUPE conventions and processes.
- 3.6 The rest of this section describes the main themes from the consultation.

Local service access:

- There were a large number of concerns raised about the impact on the provision of local services and concerns that a centralised surgical service would lead to reduction in local clinics and availability of MDTs in local areas. This was despite this being clearly addressed in the proposal consultation document. The Review Group re-affirmed at each opportunity that the proposal was committed to the surgical service continuing to support the local services with outreach services designed to ensure that what can be provided locally would be provided locally and only that which was absolutely necessary would be delivered centrally.
- During the review we took every opportunity to reassure people that the outreach services would be maintained and therefore the change proposed had very minimal impact on access.
- We also confirmed during the consultation process that 23.6% of children aged 0-9yrs live within 30 minutes drive time and 48.7% of children aged 0-9yrs live within an hour's drive time of Glasgow Royal Hospital for Children. 11.6% of children aged 0-9yrs live within 30 minutes drive time and 33.8% of children aged 0-9yrs live within an hour's drive time of Edinburgh Royal Hospital for Sick Children. Glasgow is therefore a more accessible location for a single surgical site.

Single handed surgeon

- The case for change is not accepted by many patient and parent respondents. There were strong views that the current service on two sites should continue and there was no reason for change.
- The clinical input from the option appraisal process and from the Royal Colleges does not support that view and nor does the experience of trying to provide cover for recent absence. A single handed surgical service is not an acceptable model going forward for any clinical service.

Continuity of care

- There is a real concern that if the current Lothian surgeon does not transfer to Glasgow then continuity will be disrupted.
- It is important to note that a service needs to be durable for any potential sources of change to the consultant workforce and that durability is not deliverable with the current construct. In the medium term durable continuity of care will be delivered by a larger surgical team working in a single site.

- 3.7 Finally, there were a number of issues raised about outcome during the consultation process. The next section covers these issues in more detail.

- 3.8 The complete comments received for the consultation are included in Appendices (NSSC 2016-16 E & F).
- 3.9 A Question and Answer summary on the issues raised and how the Review Group believes the proposal answers those questions is included in (NSSC 2016-16G).

4 Outcomes

- 4.1 As noted above outcomes were raised as a significant issue throughout the options appraisal exercise and into the consultation period as well. There were inferences that Glasgow was unsafe and that children should be transferred to Edinburgh.
- 4.2 In order to address this NHS Lothian and NHS Greater Glasgow and Clyde provided their speech outcome information to the Craniofacial Anomalies Network (UK) to plot their results in comparison to the rest of the UK Services. This information did show that there were differential outcomes but that Glasgow was within the normal results of the UK Centres and improving as noted in the Outcomes Paper Appendix (NSSC 2016-16C).
- 4.3 Whilst these results need to be treated with caution due to the low numbers that applies equally to the two centres in Scotland. It should also be noted that Glasgow has a different surgical configuration from when these results are reported from and therefore not comparing the results of the current service due to the 5 year time lag for speech outcomes from surgery.
- 4.4 Similarly the Kindelan scores for Alveolar Bone Graft shown in the Outcomes Paper indicated that the surgical service in Glasgow performed as well as the Edinburgh service. Again with the same caveats as above.
- 4.5 The Review Group has taken into account the comments on outcomes made in responses to consultation and is certain that the proposal does give proper emphasis to outcomes. This is because the proposal is for a service for the whole of Scotland not for two discrete regional services. It is contended and supported by the Royal Colleges contributions that a wider team of surgeon working collaboratively together and learning from each other will improve outcomes over time for all patients in Scotland wherever they reside.
- 4.6 Therefore the Review Group is confident that the proposal not only provides a sustainable and resilient service but one that will continually improve on outcomes for all patients within Scotland.

5 Conclusion

- 5.1 The Review Group notes that there were aspects of the consultation process that could have been managed better but on the whole believes that anyone who would have wanted to contribute to the process and make comment into the consultation had an opportunity to do so.
- 5.2 The proposed model is based on sound care model and provides the sustainability and resilience where the current service model has a profound weakness. This was highlighted during the period of the consultation due to the absence of the surgeon in Edinburgh for a prolonged period and a significant backlog of patients awaiting surgery became apparent.

- 5.3 This backlog could only be managed through assistance from NHS Greater Glasgow and Clyde and elsewhere due to the reactive nature to the issue rather than as a planned managed service for the whole of Scotland. It is evident that the proposed model would address this risk for the future.
- 5.4 The level of concern and disappointment expressed by a significant number of families regarding the proposed model who have had their previous surgical service provided in Lothian is understandable but that in itself does not negate the soundness of the proposal. Nonetheless further communication and engagements with the families is needed to begin to overcome these concerns.
- 5.5 The Review Group has clearly heard the view that continued support for local outreach services is greatly desired. The Review Group will re-emphasise the requirement of the single surgical service to continue to provide effective and efficient support for local outreach services that ensures that patients as much of their care delivered locally as possible.
- 5.6 This should also be to ensure that patients can have all the necessary work done prior to their surgical interventions along the patient care pathway so that patients get their surgery at the right time.
- 5.7 The Review Group have also heard the desire for continuity of care wherever possible. The Review Group clearly agree that this should be part of the planning of the service but note that a wider team of surgeons can lead to sub-specialisation and therefore there may be appropriate times when a patient is transferred to one of the other surgeons in the team for a particular surgical intervention.
- 5.8 One of the benefits of the proposal is that a wider team of surgeons should be able to manage the workload more effectively and efficiently and ensure that they are aware of the patient's care plan in the absence of the named surgeon at any time. Therefore care or surgical intervention need not be cancelled in the unexpected absence of one of the surgeons.
- 5.9 The Consultation received formal support for the proposal from the Royal College of Surgeons (Edinburgh), the Royal College of Physicians and Surgeons (Glasgow) which highlighted that a single handed surgical service was not a sustainable model of care and that a wider team of surgeons working together would produce better outcomes over time for the whole of NHS Scotland as well as providing a sustainable, flexible and resilient service for NHS Scotland. Formal support was also received from NHS Grampian and NHS Borders Child Health Department but with an emphasis on ensuring local services are maintained and enhanced as much as possible to ensure a patient-centred service continues.
- 5.10 It is the overall conclusion of the Review Group that the consultation has not indicated issues that suggest that the proposal is not the best model for a specialist cleft surgical service for Scotland. Our assessment of the summary of the consultation was that the issues that were identified can be addressed within the proposed model with the exception of maintaining the discrete surgical service within NHS Lothian.
- 5.11 Therefore on balance we would continue to recommend the proposal with the areas around local service outreach support and planning for an element of continuity of care being strengthened.