





Consultation on

Proposed changes to the Specialist Cleft Surgical Service in NHS Scotland

Full Consultation Paper

Consultation period:

11 February 2016 - 11 May 2016

Introduction to Consultation Paper

This paper describes proposals to change the delivery of the specialist cleft surgical service for Scotland.

This consultation paper outlines:

- Why the proposal was developed (page 3)
- A description of the current service (pages 4-7)
- A description of the proposed change (pages 7-10)
 - The benefits of the proposed change (page 8)
 - The impact of the proposed change (pages 9-10)
- The main differences between the current service and proposals (pages 11 -13)
- How to make comment (pages 15-16)
- Frequently asked questions (pages17-19)
- Glossary of Terms (page 20-21)

The Consultation paper was written by representatives of NHS Greater Glasgow & Clyde, NHS Lothian and NSD.

The Consultation Paper was reviewed by representatives of CLAPA, Changing Faces and Scottish Health Council as part of a Stakeholder Consultation Group to assure that it would be understandable and informative for the purpose of the Consultation process.

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1. Why the need for change?

- 1.1 This proposal is intended to deliver a revised specialist surgical service for patients born with a cleft lip and/or palate. This is intended to be more sustainable, resilient and be able to provide consistent quality of care for all patients with a Cleft Lip and/or Palate in Scotland.
- 1.2 Such a service must enable the surgical team work with others in the provision of cleft care to provide a continually improving quality of service to all patients with a cleft lip and/or palate wherever they live in Scotland.
- 1.3 This proposal only affects the surgical service. The vast majority of care for patients with cleft lip or palate is unaffected.
- 1.4 The service should provide the safest, most effective and person-centred care possible, within available resources.
- 1.5 The service should aim to support the provision of other cleft care as close to home as possible, where appropriate.
- 1.6 The proposals outlined in this paper are being made as a result of a number of processes which are outlined in this paper. The conclusion of those processes is that the current configuration of surgical services is not sustainable and that there is a significant risk of major breakdown of the surgical service if this configuration continued long term.
- 1.7 Scotland currently has a configuration for specialist surgical services for cleft lip and/or palate that has two surgical services on separate sites. This includes a single-handed surgical service in Edinburgh and this is not a resilient, sustainable model of service delivery as it does not allow for surgical team working, learning and developing with each other as part of a surgical team. It also does not allow for an efficient and effective management of workload and can lead to missed waiting time targets and also procedures which need to be done at certain ages if there are periods of prolonged unplanned absence.
- 1.8 Therefore the current service is vulnerable to periods of pressure and is not sustainable or resilient.
- 1.9 Processes to establish a single surgical service over two surgical sites had failed to achieve the spirit and practice of a single surgical service and therefore an options appraisal exercise was undertaken which concluded that a single surgical service on one site was the optimal service configuration to achieve that aim.
- 1.10 The option appraisal process further concluded that the best option was the surgical site in NHS Greater Glasgow which had the paediatric surgical service at the Royal Children's Hospital (RCH) and the adult service at the Queen Elizabeth University Hospitals (QUEH) co-located on the old Southern General Hospital campus.

1.11 This consultation paper is the opportunity for stakeholders to have the details of that proposal and provide their views before a final decision is taken.

2. Current Service

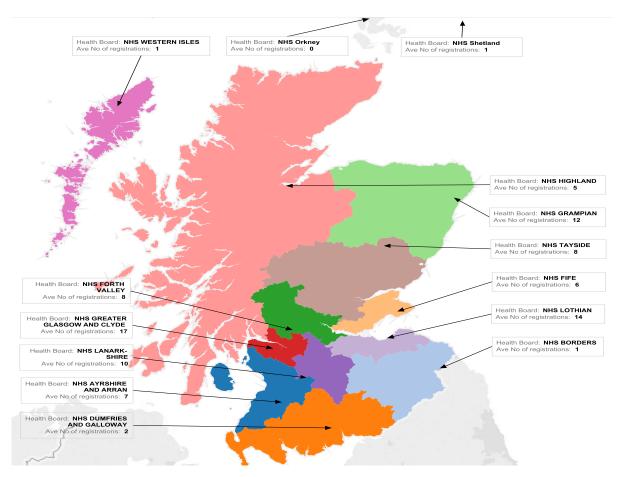
- 2.1 At present there are two surgical centres in Scotland performing primary cleft surgery. There are three surgeons in total.
- 2.2 In Glasgow the paediatric cleft surgical service has recently been relocated from Yorkhill Hospital to the Royal Hospital for Children in Glasgow within the new Queen Elizabeth University Hospital Campus along with all other paediatric services. A maxillofacial surgeon and a plastic surgeon specialising in Cleft Care perform the surgery.
- 2.3 In Edinburgh the service is located at the Royal Hospital for Sick Children (RHSC) and the surgery is performed by a plastic surgeon working wholly on cleft surgery.
- 2.4 RHSC Edinburgh and RHC Glasgow both being specialist paediatric facilities, have access to all other clinical disciplines (staff) and equipment for the comprehensive investigation and treatment of these patients, and to Paediatric Intensive Care should this be required.
- 2.5 Both hospitals provide a facility to allow a parent/guardian to stay beside the child on the ward when necessary.
- 2.6 In Glasgow, where the majority of the adult specialist cleft surgical procedures are performed, the adult service is now co-located with the paediatric service within the Queen Elizabeth University Hospitals Glasgow, the work is undertaken by the same surgical team with the Institute of Neurological Sciences.
- 2.7 In Edinburgh the adult procedures are undertaken at St John's Hospital some of which are undertaken by the cleft surgeon and others by the wider maxillofacial and plastic surgery team.
- 2.8 All other aspects of cleft care are delivered as locally as possible to the patient's home by clinicians employed by their NHS Boards to provide services in their particular field to cleft patients such as paediatric dentistry, speech and language therapy, orthodontics and psychological support. They are supported in this as part of a Managed Clinical Network now called Cleft Care Scotland.
- 2.9 Multidisciplinary combined outpatient clinics are held in Aberdeen, Ayr, Dundee, Edinburgh, Glasgow, Kirkcaldy, Inverness, and Larbert and are detailed in the following table (Table 1):

Table 1

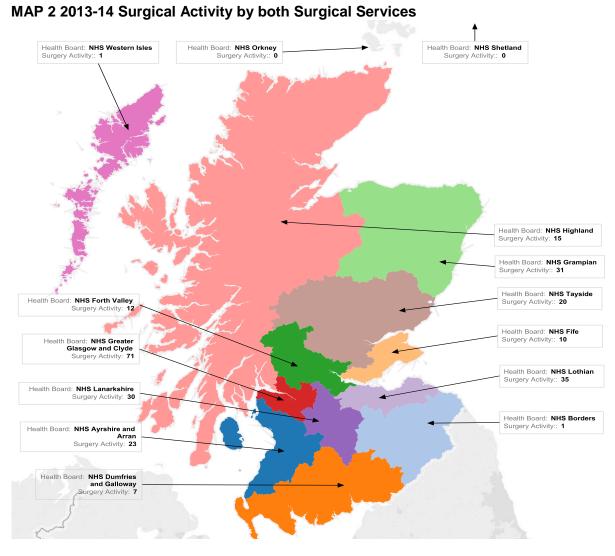
Venue	Clinic Numbers	
Aberdeen	Cleft MDT Clinic - 12 per annum (1 session per clinic)	
	Surgical Review Clinic - 12 per annum (1 session per clinic)	
	VP Function Clinic - 12 per annum (1 session per clinic)	
Ayr	Cleft MDT Clinic - 12 per annum (1 session per clinic)	
Dundee	Cleft MDT Clinic - 12 per annum (2 sessions per clinic)	
Edinburgh	Cleft MDT Clinic - 36 per annum (1 session per clinic)	
	Post Op Clinic - 24 per annum (1 session per clinic)	
	Palatal Function Clinic - 12 per annum (1 session per clinic)	
Glasgow	Adult/Transition/Bone Graft Clinic - 48 per annum (1 session per clinic)	
	General Cleft MDT Clinic - 24 per annum (1 session per clinic)	
	New Baby Clinic - 12 per annum (1 session per clinic)	
	Palatal Function - 12 per annum (1 session per clinic)	
Inverness	Cleft MDT Clinic - 3 per annum (2 sessions per clinic)	
Kirkcaldy	Cleft MDT Clinic - 6 per annum (1 session per clinic)	
Larbert	Cleft MDT Clinic - 4 per annum (1 session per clinic)	

2.10 Cleft Care Scotland record all the new births of patients with a cleft registered by the centres on the NSS Clinical Audit System. From April 2012 to March 2015 there were 270 births which indicates an average of about 92 per annum. Map 1 below shows the distribution of these new birth/registrations as an average of the 3 year cohort on a per annum basis.

MAP 1
Average Number of Cleft New Births/Registrations per Annum (Source: a 3 year cohort from the Cleft Clinical Audit system April 2012 to March 2015)



- 2.11 The service in the East can experience pressures due to absences whether planned or unplanned due to being a single surgeon service. This has been demonstrated by some waiting times being missed and age determined surgeries not always occurring within the appropriate timescales.
- 2.12 Furthermore the average total number of surgical procedures carried out by both the current services combined is around 250 per annum and Map 2 below shows the distribution of this by NHS Board on an annual basis taken from Services Annual Reports from 2013-14. (The NHS Island Boards will fluctuate depending where the births occur)



- 2.13 This shows that the way the service is currently configured the number of procedures annually would be difficult to deliver if any one surgeon was absent for any significant period in time.
- 2.14 This could lead to pressures on waiting times and potentially delayed age determined surgeries for patients.

3. **Proposed Change**

- 3.1 The proposed change means that the Cleft Surgical Service would be configured as a central surgical base which will provide the specialist cleft surgical procedures but will continue to support the majority of cleft clinical care locally within existing outpatient and other existing local services.
- 3.2 Whilst all specialist cleft surgery would be transferred to NHS Greater Glasgow and Clyde the majority of care will still be provided locally at outpatient services across

- NHS Scotland and through visits to paediatric dentists, orthodontists, psychosocial support as well as speech therapy.
- 3.3 All patients with a cleft lip and/or palate requiring specialist cleft surgery would have their procedures performed in the NHS GG&C hospitals. Patients would continue to receive their outpatient care where they currently do so at the moment.
- 3.4 There will not be centralisation of out-patient services. The surgical service will continue to support the provision of care as close to home as possible in an efficient and effective way.

Proposal Benefits

- 3.5 The benefits of this proposal are that a single surgical team will be formed out of three surgeons to provide surgical care for all patients with a cleft lip and/or palate.
- 3.6 They will work to support each other, learn from each other and develop as a team to build on existing strengths and aim to continually improve on outcomes.
- 3.7 Cleft patients, wherever they live in Scotland, will benefit from a wider team of surgeons who will know their case and who will have discussed the best treatment plan for their care management along with other clinicians involved in the Multidisciplinary Team.
- 3.8 Communication between the NHS Board management and the surgical team will be improved with clarity of job planning and workload management.
- 3.9 Communication between the surgical team will be improved by being physically colocated within the same base for part of the week.
- 3.10 All the surgeons will have knowledge of the patients clinical history and care plan and will participate in Multidisciplinary discussion about the need for and timing of future surgical interventions for the patients.
- 3.11 The service will be able to manage the workload more efficiently and ensure that periods of pressure are better managed and planned for.
- 3.12 Greater completeness of audit data will ensure that the commissioners will be able to monitor outcomes more effectively and ensure that continuous quality improvement is embedded in the service
- 3.13 Locating the single service in NHS GG&C would have the added advantage of the adult and paediatric service being co-located.
- 3.14 A small number of patients with certain co-morbidities such paediatric cardiac problems may benefit from having the paediatric cardiac surgical service on site and some may also benefit from having the National Complex Airways Service on site as well.

Proposal Issues

3.15 The proposed change will mean that some patients will have to travel further for their surgery. For patients from Grampian, Highland, and Tayside, Aberdeenshire and Tayside patients the need to travel for cleft surgery is already well established and the difference in the change to patients from these areas is relatively small. The tables below show the differences in car journeys from various places to the Royal Children's Hospital Glasgow and the Royal Hospital for Sick Children, Edinburgh.

From by Car	Royal Hospital for Sick Children, Edinburgh	Royal Children's Hospital Glasgow
Aberdeen Royal Infirmary	2hrs 33mins	2 hrs 48 mins
Inverness (Raigmore)	3 hrs 7 mins	3 hrs 15 mins
Fort William (Belford)	3 hrs 05 mins	2 hrs 23 mins
Dundee (Ninewells)	1 hr 18 mins	1 hr 32 mins
Perth (Royal Hospital)	1 hr 04 mins	1 hr 12 mins
Livingston (St Johns)	35 mins	46 mins
Bathgate	37 mins	44 mins
Dunfermline	39 mins	58 mins
Linlithgow	38 mins	49 mins
Melrose (Borders General)	1 hr	1hr 46 mins
Edinburgh	12 mins	1 hr 10 mins
Haddington	32 mins	1 hour 18 mins
North Berwick	48 mins	1 hr 34 mins

From by Train	Royal Hospital for Sick Children, Edinburgh	Royal Children's Hospital Glasgow
Aberdeen	2hrs 50mins	3 hrs 13 mins
Inverness	3 hrs 50 mins	3 hrs 53 mins
Fort William	5 hrs 20 mins	3 hrs 18 mins
Dundee	1 hr 40 mins	1 hr 53 mins
Perth	1 hr 40 mins	1 hr 33 mins
Livingston	42 mins	1 hr 23 mins
Bathgate	47 mins	1 hr 3 mins
Dunfermline	1hr 10 mins	2 hr 23 mins
Linlithgow	42 mins	1 hr
Melrose (Tweedbank)	1 hr 15 mins	2 hr 38 mins
Edinburgh	NA	1 hr 19 mins
Haddington (Drem)	48 mins	2 hour 03 mins
North Berwick	55 mins	2 hr 08 mins

Information obtained from AA Autoroute and National Rail Journey Planner.

3.16 Therefore whilst patients/parents in Fife, the Edinburgh area, East Lothian and the Borders would have longer travelling times, patients from West Lothian, Perthshire, Tayside, Grampian and Highland would only have a marginal change in journey times.

- 3.17 These maps demonstrate that for a lot of patients from NHS Highland, NHS Grampian, NHS Dumfries and Galloway, NHS Shetland, NHS Orkney and NHS Tayside, the requirement to travel for surgery is already the current reality.
- 3.18 For those that live around Edinburgh, Lothian, the Borders and Fife the difference is obviously greater. In making this proposal our view is that the benefits of a single surgical team working in a single surgical site outweigh the travel demands that would be experienced by these patients.
- 3.19 Until 2008 specialist cleft surgery for patients from Grampian, Highland, and the Islands was provided in Aberdeen, at which point this service transferred to Edinburgh. The evidence of that experience shows that out-patient attendances at Edinburgh from these areas are very few indeed, and so this proposal suggests that this can be replicated from a single site.
- 3.20 All patients/parents that are currently able to claim expenses for travelling will still be able to do so under the proposed change.
- 3.21 NHS GG&C has a new parent/patient accommodation on the site of the new hospital that can accommodate one parent for the length of the stay of the child at the hospital.

4. Budget

4.1 There is no change for the budget for cleft surgical services and this proposal is not made to save on costs. The proposal is to ensure a sustainable, resilient and quality cleft surgical service for current and future patients with a cleft lip and/or palate wherever they reside in NHS Scotland.

5. Summary of Main Differences between the Current Service and the Proposed Change

The proposed change to a single surgical service on one site at the Royal Children's Hospital (RCH) and the Queen Elizabeth University Hospitals (QEUH) in Glasgow aims to provide a safe, resilient and sustainable cleft surgical service which provides a quality service for all patients with a cleft of the lip and/or palate wherever they live in NHS Scotland. The changes proposed are not about saving money as the current budget for the service in NHS Scotland for cleft surgical service will remain the same but to ensure that resources are used more effectively and efficiently.

The table below outlines the main differences between the current services and the proposed change and the expected benefit of the proposed change:

Service Element	Current Service	Proposed Change	Main Impact of Proposal
Paediatric Inpatient/Day Case Surgery	Specialist cleft surgery provided on two sites in Glasgow and Edinburgh	All paediatric specialist cleft surgery to be provided by three cleft surgeons in Royal Children's Hospital, Glasgow	 Provides a team of three surgeons working together supporting and learning from each other. Building on current strengths for the benefits of all cleft patients in Scotland. Patients will have access to a larger team of surgeons than is currently the situation with greater capacity and flexibility to manage the surgical workload. The Surgeons working as part of a larger MDT will be able to discuss the best appropriate treatment plan for each patient. The Service will be able to plan to ensure that patients receive their age determined procedures in a timely manner. Improves ability to ensure patients will still be able to be treated when any one surgeon becomes unavailable Better communication between surgeons. Access to adjacent specialist services if required such as Complex Airways Service and Paediatric Cardiac Services which patients

			treated in Lothian don't currently have direct access to. • Better transition into adult cleft services where appropriate • For a number of patients there will be greater distance to travel for planned operations and possibly pre and post operative assessment but this will be kept to as few as absolutely necessary.
Adult Inpatient/Day Case Surgery	Adult specialist cleft surgery provided mostly in Glasgow currently. There are some procedures not requiring a specialist cleft input being performed in other NHS Boards.	All adult cleft patients requiring a specialist cleft surgical operation to be carried out by the cleft surgical team in QEUH. Patients will be assessed by the Cleft surgical Service and those not requiring a specialist cleft surgical intervention will be managed locally.	 More efficient management of workload More efficient and effective use of resources Ensures patients have access to a specialist adult service Reduced risk of patients lost to follow up as transition from paediatric to adult care should be seamless Only those requiring specialist cleft surgical intervention will have to travel to Glasgow Other procedures and care will still be carried out locally by current NHS Board services.
Outpatient Services	Provided across Scotland by a whole range of clinical staff with support from Surgical Services for Multidisciplinary Team Clinics	No change except MDT may have two surgeons present for MDTs to ensure shared knowledge of patients cases No change to patient access to these services	 Existing outpatient and other activity carried out by Specialist Nurses, Speech and Language Therapists, Paediatric Dentists, Orthodontists and Changing Faces Practitioners will continue. Each patient will have access to a wider team of surgeons who will support local outpatient services. Although every effort will be used to ensure continuity of care patients may not see the same surgeon at every encounter.

			The whole surgical team have knowledge of each patient's care and will discuss each patient's future treatment plan and management.
Link with Maternity Services	Maternity Hospitals currently notify birth of patients with a cleft lip and/or palate to either service in Glasgow or Edinburgh	 Maternity services will still notify births to the specialist nursing services in Edinburgh and Glasgow. Visits to new born patients will still be carried out by the existing staff. 	No change.
Management of Service	Whilst under the overall management of NHS Greater Glasgow and Clyde, line management of surgeons are employed by separate NHS Boards.	Line management of surgeons under one NHS Board (NHS Greater Glasgow and Clyde)	Improved staff communication Efficient distribution of workload and more efficient and effective use of resources Improved learning and staff development

6. **Invitation for Comment**

- We now invite comment on whether you are happy with the proposed change or whether you have any concerns about the proposed change?
- 6.2 If you have any concerns, what these concerns are?
- 6.3 Is there anything that can be put in place to address your concerns?
- 6.4 Details on how you can comment are provided below in section "How to Have Your Say".

7. Next Steps

- 7.1 Once all the comments are received a paper will be updated for the National Specialist Services Committee for them to consider whether to recommend the proposed change or whether some changes to the proposal are required. .
- 7.2 The recommendation of NSSC will then go to the NHS Board Chief Executives Group for approval and it will then go to the Cabinet Secretary for Health and Well-Being for sign off.

How to have your say

We would like you to tell us what you think about the proposed changes which are outlined in this paper.

Your comments will help inform the National Specialist Services Committee's consideration on the proposal at a future meeting as soon after the consultation period is completed as possible.

Once you have read the consultation paper, please give your comments by **1 May 2016**, using one of the following ways:

- Electronic email your comments to <u>NSS.nsd-administration@nhs.net</u>
- By post please provide a written response to Cleft Surgical Services Consultation, National Services Division, NHS National Services Scotland, Gyle Square, 1 South Gyle, Edinburgh EH12 9EB.
- By coming to one of the open meetings being held in venues across Scotland during March 2016.

The meetings are open to members of the public and will offer an opportunity to find out more about, and give views on, the proposals. Meetings will be held in Edinburgh, Glasgow and Perth and a telephone conference will be held on the afternoon of 10th March 2016 for those that cannot attend any of the other dates.

The public meetings will be held in the evening with suggested dates:

- Perth 10th March 2016
- Edinburgh 16th March 2016
- Glasgow 17th March 2016

Although the meetings are open, it would be helpful for us to have your contact details if you plan to attend. This means we can contact you if we have to cancel at short notice (e.g. bad weather). We would be grateful if you could register your intention to attend on one of the public meetings by either e-mailing NSS.nsd-administration@nhs.net or phoning 0131 275 6269 giving your name, telephone number or e-mail address and which meeting you would like to attend.

Details for the meetings such as venues will be finalised once numbers are known.

We will also consult with:

- NHS staff affected by the change via the two host NHS Boards of NHS Lothian and NHS Greater Glasgow & Clyde
- Other staff involved in cleft care across Scotland via Cleft Care Scotland, the National Managed Clinical Network, that all staff with a direct interest in cleft

care should be a member of. This will happen at an open meeting in Perth in March 2016.

• Details of the Consultation will also be sent to every NHS Board to request that the documentation is provided through their existing engagement channels.

If you need more copies of the consultation paper or questionnaire, please phone (*leaving your name and address*) 0131 275 6269 or e-mail NSS.nsd-enquiries@nhs.net.

More Information

The proposed change was developed by a Review Group including NHS Lothian, NHS Greater Glasgow and Clyde and National Services Division (NSD).

This followed an Options Appraisal exercise that involved NHS Scotland clinical and managerial staff, representatives of Cleft Lip and Palate Association (CLAPA) as well as independent experts in cleft care from NHS England and Wales.

Full details of the Options Appraisal process and outcome is documented in Cleft Surgical Services Options Appraisal Report and can be found at http://www.nsd.scot.nhs.uk/news/index.html.

Paper copes of the Appraisal Report can be requested by e-mailing <u>NSS.nsd-enquiries@nhs.net</u> (leaving your name and address) or telephoning 0131 275 6269.

Frequently Asked Questions

On the 9th December the National Specialist Services Committee (NSSC) agreed that the proposal to move all cleft surgical services onto one site in Glasgow (namely the Queen Elizabeth University Hospitals and Royal Children's Hospital) should go out to consultation to the parents, patients and professional staff that may be affected by the proposed change.

As part of that consultation it was agreed to address some of the frequently asked questions that had emerged through the earlier engagement about what a single surgical service on one site would mean so that everyone could understand the scale of the change proposed.

Q. Why is a single surgical service on one site being proposed?

An options appraisal was carried out on possible configurations to provide a safe, sustainable and resilient cleft surgical service for all cleft patients within NHS Scotland. The result of that option appraisal was to favour moving all surgical services to NHS Greater Glasgow and Clyde. This is to create a single surgical team that works, supports and learns from each other to ensure the best possible surgical service for all cleft patients in Scotland.

Q. What does the single surgical service on one site mean?

A single surgical service on one site means that all cleft specialist surgical procedures would be performed in either the Royal Children's Hospital or the Queen Elizabeth University Hospitals in Glasgow by the surgical team in Glasgow.

Q. What are the benefits of a single surgical service on one site?

The benefits of a single surgical service on one site are:

- Having a surgical team of three surgeons working, supporting and learning from each other, develop as a team to build on existing strengths to continually improve on outcomes for all patients;
- Working together they can manage workload more efficiently, managing pressures to ensure all patients receive their surgery when clinically required;
- Having more than one surgeon knowing about a patient's clinical history means that any unexpected absence of a surgeon can be managed within the surgical team and therefore provide more resilience to continuity of care;
- Having one surgical team can also ensure that appropriate referral onwards from paediatric to adult care can be seamless and prevent patients being lost that may require follow up into adult years.

Q Does this mean that my child won't have a named surgeon anymore?

No. All children and young people would continue to have a named surgeon in the future, and we will not be changing your current named surgeon.

The whole surgical team will become familiar with your child and their care. Future patients born with a cleft, lip and or palate will be managed through the whole surgical team.

By having the surgeons working as a team, we can make sure that someone is available all year round to provide surgery and advice whenever required, and to ensure the very best outcomes for all patients in Scotland.

Q. Are there any other benefits from the basing the Single Cleft Surgical Service on the Glasgow site?

For a very small number of cases the availability of the National Paediatric Specialist Airways Service and the National Paediatric Cardiac Service may be of benefit.

Q. Will I have to travel further?

For a small number of patients who live closer to the Royal Sick Children's Hospital in Edinburgh they will have to travel further for pre-operative assessment and surgery. For those that live in Grampian, Highland and parts of Tayside and Perthshire the difference in travel will be marginal.

For children born with a cleft lip trips to the hospital in Glasgow for surgery could be as a little as twice in their first year (pre-assessment and surgery).

For children born with a cleft lip and palate this may be about 4 times in their first year.

Q. Will Out-reach Out-patient Clinics be centralised in Glasgow?

NO. The local cleft clinics, for Speech and Language Therapy, Paediatric Dentistry, Orthodontics etc would still continue to be provided locally. These will continue to be supported by the Cleft Surgical Service.

Q. Were outcomes considered when scoring the preferred option?

Outcomes were considered by the Options Appraisal Group and were questioned by the independent external cleft experts from England and Wales. Variations were noted. Nonetheless the aim was to select the best option for a sustainable and resilient service for the whole of Scotland.

A statement on outcomes is available as part of this consultation process. It is important to note that outcomes of the single surgical service will be closely monitored to ensure they continue to improve for all patients in Scotland wherever they reside.

Q. Will there be a reduction in the number of surgeons?

No.

Q. Is this about saving money?

No. This is about providing a sustainable, resilient cleft surgical service for the whole of Scotland.

Q. Can NHS Greater Glasgow and Clyde cope with the increased workload?

Yes.

Q. Why are all cleft children patients cared for in HDU after surgery in Glasgow whilst this is not the case in Edinburgh?

The availability of HDU beds in Glasgow is there if a child needs that level of care. In Edinburgh Ward 3 of the Sick Children's Hospital is currently staffed to a similar level as an HDU ward for that same reason.

Q. What about the other specialists in Edinburgh such as Clinical Nurse Specialists and Speech and Language Therapists? Will they have to move?

No impact is envisaged on Clinical Nurse Specialists, Speech and Language Therapists and others providing services locally. They would still provide the service to their patients locally and meet with the surgeons as part of a MDT for those patients.

Q. Is there sufficient accommodation for parents to stay when their child is in hospital?

The new Royal Children's Hospital has a brand new parent and children's accommodation facility which has capacity for one patient to stay with child for all planned surgery.

Q. Will we get our travel expenses reimbursed?

The system for reimbursing travel expenses by patients and their carers would remain exactly the same as currently the case.

Q What about adults? Will those services change?

Many cleft procedures for adults can be done locally by surgeons, dentists and orthodontists, and this will not change.

Some patients may benefit from the input of a cleft surgeon. This need would be assessed at specific Adult Cleft Clinics that will be developed across the country.

Glossary of Terms

Age Determined Procedure

A required procedure which should take place when a child/patient is a particular age, according to best clinical practice and evidence.

- All patients with clefts requiring lip repair have the procedure complete by 6 months of age
- All patients with clefts have their palate reconstruction by age of 13 months
- All patients requiring Alveolar Bone Grafting have procedures undertaken before the age of 12 years.

Multidisciplinary Team Meeting (MDT)

An MDT is a meeting of all members of the team looking after a patient. It allows the whole team to consider all the care needs of the patients from the point of view of delivery of timely and appropriate cleft care and communicate the clinical plan to the family members/carers concerned. It also allows for the requesting of specialist investigations as determined by both the patient's presentation and the current clinical condition.

National Services Division:

National Services Division (NSD) is a directorate within NHS National Services Scotland (NSS) and is based at Gyle Square in Edinburgh. Each year, NSD receives top-sliced, ring-fenced funding from the Scottish Government Health and Social Care Directorates (SGHSCD) to commission and performance manage nationally designated specialist services and screening programmes, National Managed Clinical & Diagnostic Networks and National Network Management Service.

National Specialist Services Committee:

The overarching governance group for national specialist services which is composed of senior health care medical and operational managers, planners and finance representatives from each of the NHS Boards and Scottish Government and is chaired by an NHS Board Chief Executive. It provides advice and recommendations to the NHS Scotland Chief Executive Group. NSSC meets quarterly and considers proposals for national commissioning of highly specialist health services, and services for people with rare disease and /or complex needs. It provides oversight of existing nationally commissioned services, and reviews these every 3-5 years.

Non-Cleft Velopharyngael Insufficiency (VPI):

VPI is a failure of the separation between the nose and mouth which can lead to functional problems with speech, eating and breathing.

Option Appraisal:

An Option Appraisal is a process that is often used when considering a new way to provide services. Option Appraisals allow a wide number of views to be considered and as robust an assessment of options as possible to be created. Option Appraisals look at the ways in which a service could be provided and the most promising options are then assessed by comparing their benefits, risks and costs. The aim is to develop the best possible model for

the service within the resources available.

Professional Activity (PA):

A Professional Activity is a period of consultant work session (about 4 hours). A Direct Clinic Care is a period where the consultant is providing care to patients including, outpatient clinics, inpatient care and theatre sessions. A Supportive Activity is a period where the Consultant is doing other work like research or educational activity.