

Cleft and Dysfluency Consultation Plan Draft 8

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1. Introduction

This plan sets out the activity proposed for the formal consultation regarding proposals to change the cleft and dysfluency pathways that are currently delivered by Sheffield Children's NHS Foundation Trust (SCNHSFT). It draws on the learning from the Quality and Equality Impact Assessment process (known as QEIA) that is currently underway and service level patient experience data including friends and family test and complaints information (requested).

The plan also incorporates a recommendation to undertake immediate discussions and engagement with people who should have been accepted into the service from April 2021, to understand the impact this lack of service has had on them and if any mitigations can be put in place.

2. Background

- SCNHSFT has historically seen adult patients who have dysfluency and/or cleft lip and palate communication needs within their Speech and Language Therapy (SLT) service. To date, there has been no finalised service specification in place, however, there is an implied contract for this service, based on the agreements put in place from the transfer of primary care trusts (PCT) to clinical commissioning groups (CCGs).
- SCNHSFT have expressed concerns regarding the clinical risk to delivery of these adult pathways and they made the decision to temporarily stop receiving new referrals for adult patients from April 2021.
- After the recommendation from The Healthier Communities and Adult Social Care Scrutiny (known as OSC), SCNHSFT has now reopened the service to adult patients being referred, effective from 16/08/21 until 15/01/2022 (pending public consultation). SCNHSFT have advised they can be flexible on their notice if necessary, to aid the smooth transition of care for these patients. The rationale for this decision was based on the risks associated with:
 - The Speech and Language Therapy (SLT) service is treating patient significantly outside of the Trust's normal (and extended) age range
 - There is limited capacity in the service which cannot meet all the demands placed upon it (e.g. adult v paediatric patients). Referrals into SCFT SLT service are increasing by 7.8% / year – resulting in a disparity between capacity and demand.

- Lack of alignment with other therapy services for adults which hinders integration and provision of holistic care for these patients
- Data from SCNHSFT shows the withdrawal of the service for new patient may affect approximately 42 patients per annum (27 dysfluency and 15 cleft lip and palate patients, data accurate as of 13/09/21).
- The age range of patients who are referred to the service includes:
 - Adults referred into the service/transitioning at 16+ for dysfluency
 - Adults referred into the service for the first time at 16+ for Cleft Lip and Palate
 - Adults transitioning the service at 20+ for Cleft Lip and Palate (as per NICE guidelines which state children should be routinely followed up until the age of 20)
- On 14/07/21, OSC concluded that this constituted substantial change and full public consultation would be required for the future service provision and QEIA was required to be completed.
- The Trust may choose to close the service to all current patients in the future, so we are planning consultation on this proposal.

3. Plan

The plan covers two parts:

1. Engagement with those patients who have been referred to the services since 1 April when the service was closed to them. This is to monitor the impact this decision has had or is having and for the trust and CCG to mitigate, where possible, these impacts.
2. Consultation with current, past and potential patients, along with stakeholders, on the potential options for future service delivery in light of likely changes to the dysfluency and cleft services for adults in Sheffield.

Options for future service provision are being worked through and will be shared with OSC once appraised by stakeholders.

4. Purposes

The purpose of this engagement is to:

- Take immediate action to mitigate any negative impacts the closure of the waiting list from April 2021 has had on the 12 people directly affected, and to offer them an appointment with the service in a timely manner, according to when their initial referral was received

The purpose of this consultation is to:

- To consult on options for future service delivery. This will include consultation on a “no service” option and future options which have a change in location and/or mode of delivery.
- Raise awareness of and provide information on the changes being proposed to those people who currently use the services, those who could use the services in the future and wider stakeholders
- Understand the needs of people, particularly those from protected characteristics groups, in understanding the impact of the proposed changes
- Involve key stakeholders in discussions around the proposed options and draw out any issues, concerns, preferences and potential impact
- Work with stakeholders to consider potential solutions to any issues raised
- Ensure that all methods are considered and appropriate during the covid pandemic period whilst offering multiple opportunities for people to contribute
- Understand the needs of those who have previously used the service or could use the service in the future, to establish whether such provision should be maintained (and, if so, consider how this can most appropriately be achieved)

5. Objectives

The objectives of this consultation are to:

- To take immediate action to mitigate against any negative impacts, based on feedback from people who have not been accepted into the service from April 2021 and to take action to enable those people to access the service at the earliest possible opportunity
- To facilitate genuine and meaningful dialogue and involvement with patients, health professionals and wider stakeholders
- To reach as many people as possible who could be affected by this potential change, including those from outside Sheffield
- To generate discussion and feedback from stakeholders to help inform decision-making and to jointly identify solutions to issues raised
- To meet statutory requirements from both a provider and commissioner perspective, as is outlined in the Health and Social Care Act 2012 and the Equality Act.

6. Target Audiences

The key groups are:

- People whose referral was not accepted into the service since April 2021 (Section A)

- People who will be directly impacted by this potential change of permanently changing the service (methods outlined in section B)
- Wider stakeholders (methods outlined in section C).

Audience A

The initial target audience to engage are people who have been referred into the service between 1st April and 31st August 2021 and have received information that they cannot be seen by the clinical team. This involves 12 patients who have been referred into the dysfluency pathway. No referrals have been rejected during this time into the cleft pathway.

These 11/12 people will be contacted with an appointment. Information relating to equality analysis, communications needs and mitigating actions will be gathered at that time and will inform this consultation QEIA and communications plan. *(The service are planning to make this contact during the week commencing 6th September)*

| Action | Audience | Number of people | Communication Support requirement |
|---|--|------------------|--|
| Engagement with patients with immediate effect (and also as a key audience in the consultation) | People who have been referred into or have self-referred into the cleft palate pathway since April 2021 and have been contacted to say their referral cannot be accepted - to offer them an appointment and understand any impact the delay has had, including offering support relating to their health | 0 | N/A |
| | People who have been referred into or have self-referred into the dysfluency pathway since April 2021 and have been contacted to say their referral cannot be accepted – to offer them an appointment and understand any impact the delay has had, including offering support relating to their health | 12 | Information to be collected when patients respond to initial contact |

Audience B

Audience B includes all those who will be directly affected by potential future changes. This includes all those currently using the service (including the 12 listed above), people who have used the service in the past and been discharged (but may be re-referred) and people who may potentially use the service in the future.

A Quality and Equality Impact Assessment (QEIA) has been conducted for patients that would be impacted by a change in service provision. The QEIA analysis' for all future options are due to be tabled at the CCG QEIA group on 4th October. The information from the QEIA and wider research evidence has been used to shape how we will engage and communicate with current and potential service users to ensure the consultation is inclusive.

A first draft of the QEIA for dysfluency based on current service users (16+) and wider research show that two thirds of the people who use the service are male; this is in line with the prevalence rates for dysfluency across the sexes. The data shows that a broad range of people use the service, however, white British patients are underrepresented in the data. This may be in part be due to the data containing a high rate of “not stated” or “unknown” data. To account for this, we know that over 19% of Sheffield’s population is from BAME backgrounds, therefore Sheffield CCG will ensure translated consultation materials are available in key languages.

The cleft lip and palate draft QEIA based on current service users (21+) shows the majority of patients are “white British” or “other white”. The data shows that people who are impacted are more likely to be from areas of higher deprivation. The adult referrals are received from across South Yorkshire. However, it should be noted that any changes to the caseload because of the small volumes of patients affected may significantly change the proportions in both QEIAs above.

Research shows individuals who have downs syndrome, autism and/or Tourette’s syndrome have a higher prevalence for dysfluency; and adults who have cleft palate often have hearing loss. Consultation materials will therefore be made available in BSL and easy read to ensure the consultation is inclusive for all individuals who may be impacted.

The QEIA and research evidence will ensure targeted engagement with wider stakeholder groups will also be conducted to help reach potential future patients. This includes engaging with referring organisations and organisations such as Sheffield Autistic Society, Mencap & Gateway which are all are listed in the stakeholder analysis (Appendix A).

| | | |
|--------------------------------------|--|------|
| Patients as part of the consultation | People aged 21+ who currently use the cleft palate pathway | 20 |
| | People aged under 16 (and their parents / carers / guardians) who currently use the cleft palate pathway | 336* |

| | | |
|--|---|---|
| | People currently aged 16-20 who use the cleft pathway (and their parents / carers / guardians for those aged 16-18) | 66 (of those, 10 were referred in aged 16+) |
| | People aged 16+ who currently use the dysfluency pathway | 32 |
| | People aged under 16 who currently use the dysfluency pathway and their parents / carers / guardians | 226* |
| | People aged 16+ who have used the dysfluency pathway in the past | ** |
| | People aged 16+ (both dysfluency and cleft lip and palate) who might use the pathway in the future | *** |

*It is anticipated that a small proportion of patients under 16 would be expected to be re-referred into the adult services

**Anecdotal evidence from a poll conducted on social media via STAMMA suggests high rates of re-referral in patients who are (16+) for dysfluency. Further exploratory work on re-referral rates is ongoing within SCNHSFT

***This will be achieved through targeted engagement with key groups and referring organisations and wider general communications

Audience C

| | | |
|--------------------|---|---------------------------------------|
| Wider stakeholders | SaLT professionals who work on the adult pathways for Dysfluency and Cleft Lip and Palate | See stakeholder analysis – Appendix A |
| | Health Professionals who refer patients into the cleft palate and dysfluency pathways or who could do so in the future, in Sheffield and in a wider geography and health professionals who work with these patients | |
| | NHS commissioning organisations whose patients could be affected by this potential change outside Sheffield | |
| | Stakeholders in Sheffield and from a wider geography with an interest in speech and language therapy, including those in the third sector and Healthwatch | |

SCNHSFT have provided the referral routes for adult patients into the Dysfluency and Cleft Lip and Palate pathways. These will be used to help ensure the CCG and Trust adhere with their legal responsibility to pre-empt future potential patients. The referring organisations are included in the stakeholder analysis in Appendix A and will be included in the consultation engagement to reach potential future service users.

7. Methods

Section A – Engagement with people directly affected by the closing of the referral list between 1st April – 31st August 2021:

Personalised initial contact

The 11 of the 12 patients who haven't been seen since the service was closed to new referrals on 1 April will be personally contacted by the service team through a personalised letter.

Personalised contact will be prepared for each person that will:

- Highlight that the NHS team are keen to make an appointment as soon as possible with a speech and language therapist at SCNHSFT
- Make clear that the team is aware that distress may have been caused by their referral not being accepted initially
- Seek to understand any impacts of not being seen since being referred, and what could be put in place to mitigate the impact and what support might be needed.

The contact will also refer to the consultation that will be launched soon about future options and make clear that their input will be valued and appreciated.

In terms of asking the patient to respond to the engagement, a range of communication options will be offered so they can choose the most convenient communication for them, including a reply slip on the letter that can be completed and returned, a telephone call or email conversation with a member of the team. Any communication needs or accessibility support identified in response to the letter will be put in place so the person can contribute in a way that is most suited to them and detailed notes of the feedback must be retained. Mitigating actions will be prioritised.

Section B – Consultation on future options

As outlined in Audience B, consultation documents will be available in key languages, BSL and easy read.

Contacting current service users

Initial Contact – in most cases a letter but individual needs must be considered

A tailored letter, which will accompany the consultation document, will be sent to each person and carer / parent / guardian (for those under the age of 18) currently using the service. This will be in an accessible format and based on the information held within their patient record about their specific communication needs. For patients and/ or carers where it is known that written English is not the most appropriate form of communication, alternative methods will be used and tailored to meet their individual needs.

Email / Text

Information will be sent via a second communication method two weeks after the initial contact to alert relevant individuals to the consultation and to ask them to consider the implications and impact for them (and / or their family member) and to encourage them to respond. This exercise will be repeated half way through the consultation as a further reminder.

Contacting potential service users – past service users who may be re-referred and other potential service users

Where feasible, letters will be sent to previous service users with the consultation document as above. Where not possible, wider general communication routes will be used as detailed in the “additional ways to promote the consultation” section below. Targeted advertisement of the consultation will be made in key groups identified such as Mencap & Gateway as detailed in the stakeholder analysis (Appendix A).

Opportunities for people directly impacted to have their say:

Written response

Within the consultation documentation there will be a survey/ feedback form that we will ask people to complete and return using a freepost envelope address

Online response

The same survey/ feedback form as is included in the written documentation, will be available online for people to complete and submit

Telephone

A telephone number will be provided for people to call and leave a message and a member of the team will call them back to answer any questions

Email

An email address will be provided for people to respond in more detail than is possible via the online feedback form or to ask any additional questions

Online meeting

There will be three sessions made available on Zoom (one each month of the consultation) where people can come together to ask questions and staff leading the consultation can provide additional information. This will be clinicians and managers from both organisations. Sheffield CCG will work with STAMMA to ensure this setting is stammer-friendly and ensure individuals are aware of these arrangements in advance of the meeting.

Additional ways to promote the consultation and encourage people directly impacted and potential future service users to have their say:

Via SCNHSFT colleagues

SCNHSFT colleagues and volunteers who support people on the cleft and dysfluency pathways, will be trained and asked to reference the consultation during their contact with patients and their families and will be asked to encourage people to have their say about the proposed changes and anticipated impact

Websites

There will be a specific section on the Sheffield Children's and CCG websites that will offer the information contained in the consultation document. This will also include a link to the online feedback form.

Local and National Charities

We will work alongside local and national charities who support people with cleft and dysfluency, in order to provide a collective response and also to encourage the families they are in touch with to have their say via the methods outlined above

Section C

Communication with wider stakeholders:

Email

Personalised emails will be sent to the stakeholders informing them of the consultation and asking them to submit their response.

Discussions in established forums

There will be an open offer for a member of the Sheffield Children's and/or CCG team to attend meetings and forums with stakeholders and families in order to answer questions and to encourage people to have their say

Pre-established briefings

Briefings with MPs, councillors and other stakeholders will be added to relevant agendas during the consultation period

Local Charities

Based on the information contained in the quality and equality impact assessment, charities and community organisations that support people with other protected characteristics will be made aware of the consultation and asked to encourage people who may be affected to have their say, as outlined in the stakeholder analysis (Appendix A). This could include for example organisations based in geographical areas where there are a high proportion of people from minority ethnic communities.

Media and Social Media

Proactive statements will be prepared jointly by the Communications teams at CCG and Sheffield Children's when the consultation is launched and regularly throughout the twelve weeks. These will be shared with local media organisations and on social media. The aim will be to encourage people directly impacted to have their say. Reactive statements will be prepared by the communications teams as and when required.

8. Materials

A consultation document will be produced outlining the background and case for change, describing the people who will be affected and possible future options. There will also be information about the range of ways to ask questions and offer feedback, including a feedback form for people to complete and return to the freepost address or complete online. An equality monitoring questionnaire will also be included.

This document will be sent to the home of each person who is directly impacted (and/or their carer / parent / guardian) whilst being mindful of individual communication needs. The consultation documentation will be reviewed by patients who have utilised the cleft and dysfluency pathways prior to final sign-off to check the information is easy to understand, is relevant, whether all questions are answered, and if contains jargon or medical information,

A 'Frequently Asked Questions' section will be available on the Sheffield Children's and CCG website from the start of the consultation and will be added to as the consultation progresses.

A briefing will be available to staff who have direct contact with service users providing additional information and outlining the range of ways in which people can seek further clarification and have their say.

Staffing / financial resource

A collaborative approach will be required from colleagues at all levels of the Sheffield Children's and the Clinical Commissioning Group throughout the planning, consultation and decision-making phases. Senior members of both teams will be required to support this in terms of leadership, media enquiries and consultation with wider stakeholders.

During the planning phase, significant staff time will be required to undertake all necessary processes to ensure Sheffield Children's NHS Foundation Trust and the Clinical Commissioning Group are meeting their legal requirements.

Prior to its launch, this consultation will require resource from staff at Sheffield Children's in terms of identifying patients who are directly impacted. Tailoring the consultation documentation to individual communication preferences and needs will also be required which may involve translating information into languages other than English, utilising communication methods such as video calls with interpreters for people who have hearing loss and use BSL and translating the documentation into braille for people with sight loss etc. Care should be taken to meaningfully build in and enable these processes.

During the consultation, regular analysis of the feedback received will need to be undertaken to identify any gaps around who has responded and to tailor the approach to meet requests that arise for staff to attend meetings to discuss the consultation. These requests may be at short notice and senior staff should be mindful that this needs to be a priority.

Sheffield CCG's Strategic Public Involvement, Equality and Experience Committee (known as SPIEEC) which includes wider representation from organisations in the City, including Healthwatch in a 'critical friend' role, will oversee the consultation and commissioner legal duties. The People and Performance Committee will have responsibility within SCNHSFT and a Governor or non-executive director will have oversight.

Independent and comprehensive analysis of the consultation information received will be required once the consultation closes, prior to the feedback being made available for the decision makers within Sheffield Children's and Clinical Commissioning Group.

The Overview and Scrutiny Committee will require updates throughout the planning phase, during the consultation and in terms of the processes followed to make a decision.

Costings for printing of documents, independent analysis, support materials for people to access the consultation e.g. translated documents, interpreters / signers is being considered as part of the planning phase and a budget identified.

10. Independent Consultation Analysis

To ensure transparency and promote confidence in the consultation process, an independent company will be appointed to collate and analyse all feedback.

As well as responses to the feedback in paper and online formats, the analysis will cover all other sources of feedback, including:

- Transcribed notes from the three Zoom meetings
- Notes from conversations with individual service users relating to consultation
- Notes from other meetings that are requested and planned throughout
- Minutes from formal meetings
- Social media
- Other media sources
- Emails/letters
- Notes from telephone calls

11. Timetable

The planning phase for this consultation is underway and teams at Sheffield Children's and Clinical Commissioning Group are working through the following process to ensure that a coherent and considered consultation is available to those people directly impacted alongside wider stakeholders. This timetable is dependent on capacity within teams and collaboration across organisations. The section that is not moveable is the 12 week full public consultation in order to meet our legal duties and the Gunning Principles.

| ACTION | WHEN | WHO | RAG |
|---|---|--|-----|
| QEIAs completed <ul style="list-style-type: none"> Options 1-5 including service closure | By end of September | SCNHSFT & CCG teams | |
| Draft Consultation plan | By end of July (but to be informed by the QEIA outputs) | CCG Engagement Team | |
| Brief Communications Teams | By end of July | SCNHSFT & CCG teams | |
| CCG - SPIEEC verbal update | 3 rd August | Head of Commissioning for Children's Young People and Maternity Portfolio | |
| SCNHSFT - Executive Team Briefing | 5 th August | SCNHSFT Head of Planning and Performance | |
| Meeting with public representative and representative from STAMMA | 16 th August | Sheffield CCG Deputy Director of Commissioning, Sheffield CCG Commissioning Manager and Engagement Manager with Past service user representation and STAMMA Programme Lead | |
| Team to team online session re: due process and legal duties | 17 August | SCNHSFT Strategy Director, SCNHSFT Associate Director CWAMH, SCNHSFT Head of Performance and Planning, Sheffield CCG Deputy Director of Commissioning, Sheffield CCG Commissioning Manager, Sheffield CCG Contracts Manager and Sheffield CCG Engagement Manager | |

| | | | |
|---|---|--|--|
| Develop materials for people already affected by service change (see page 3, group A) | w/c 6 September | CCG & SCNHSFT service teams with support from Communications teams | |
| Contact people already affected by service change and have person conversations about impact and mitigation | w/c 6 September | SCNHSFT team | |
| Consideration of external resource requirements and suppliers e.g. independent analysis, printers of documents for consultation | w/c 13 September | SCNHSFT & CCG teams | |
| CCG – Strategic Involvement, Engagement and Equality Committee - Circulation of draft consultation plan | Deadline for papers 3 rd September, Committee meeting and feedback 14 th September | SPIEEC members | |
| SCNHSFT Internal governance process regarding sign off of the consultation plan | Circulation 6 th September, feedback from all teams and committees by 17 th September | Corporate Planning Team, Executive Team and People and Performance Committee | |
| Service user feedback on the draft consultation documentation – via individuals and STAMMA | Distributed w/c 6 th , comments by 17 th September | STAMMA representative, and a past service user representative | |
| Changes based on feedback to the consultation plan | 17 th and 20 th September | CCG & SCNHSFT teams | |

Below to be amended and dates TBC based on consultation plan feedback, and development of consultation documentation

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|--|--|--|--|
| Circulation for consideration by OSC members | Deadline for September OSC papers is 20 th . | CCG & SCNHSFT teams | |
| Appraisal of future service options | TBC | CCG & stakeholders | |
| Comments back from OSC | TBC | OSC | |
| CCG QEIA Group to meet to review all QEIAs and changes to be made to documentation as a result | w/c 4 th October | QEIA group / SCNHSFT | |
| Final changes to QEIA & Consultation plan | TBC | SCNHSFT & CCG teams | |
| Development of consultation documentation | TBC | Communications teams at SCNHSFT and CCG, alongside service teams; STAMMA and service user representation | |
| Preparing and printing of all resources required for consultation launch | TBC | SCNHSFT & CCG teams, external printers, external analysis team | |
| Earliest date for consultation launch | TBC | All | |
| Weekly analysis of consultation responses | Ongoing | External analysis team | |
| Zoom call with people directly affected | TBC – One each month of the consultation | Senior responsible managers at SCNHSFT & CCG | |
| SPIEEC updates re: process & responses | 26 th October, 7 th December, 18 th January & 1 st March | CCG team, SPIEEC members | |
| SCNHSFT – Ongoing updates to Executive Committees | Dates TBC | Corporate Planning Team, Executive Team and People and Performance Committee | |
| Independent analysis of all responses – draft | TBC | Independent analysis | |

| | | | |
|--|-----|---------------------------|--|
| report for SPIEEC & SCNHSFT committees | | | |
| Final report deadline | TBC | Independent analysis | |
| SCNHSFT – Full consultation report presented for consideration | TBC | SCNHSFT Trust Board | |
| CCG – Full consultation report presentation for consideration | TBC | Governing Body | |
| OSC – Full consultation report presentation | TBC | SCNHSFT & CCG Senior team | |
| SCNHSFT Decision making meeting | TBC | SCNHSFT Trust Board | |
| CCG Decision making meeting | TBC | CCG Governing Body | |
| OSC – re: information regarding the final decision made by the CCG and SCNHSFT | TBC | OSC | |

Appendix A – Stakeholder analysis

Stakeholder Analysis:

Patients

- Patients who had their referral rejected
- Adult patients (21+) currently on cleft lip and palate caseload
- All patients (20-) on CLP caseload
- Patients on the current cleft lip and palate caseload who are aged 16-20 but referred into the service at 16+
- Adult patients (16+) currently on the Dysfluency caseload
- All patients (15-) currently on the Dysfluency caseload
- Previous patients on Dysfluency pathway
- Previous patients on CLP pathway

Providers

- Sheffield Children's NHS Foundation Trust*
- Sheffield Teaching Hospitals*
- Trent Regional Cleft Network*
- Charles Clifford Dental Hospital*
- Primary Care Sheffield
- GPs* / Primary Care Networks
- Sheffield Health and Social Care SLT*
- Sheffield Adult Autism and Neurodevelopmental Service (SAANS) *

Commissioners

- NHS Sheffield CCG*
- NHS Barnsley CCG*
- NHS Bassetlaw CCG*
- NHS Cheshire CCG*
- NHS Derby and Derbyshire CCG*
- NHS East Riding of Yorkshire CCG*
- NHS Rotherham CCG*
- NHS England
- South Yorkshire and Bassetlaw CCG
- South Yorkshire Integrated Care System
- Sheffield Accountable Care Partnership
- Sheffield City Council

Politicians

- Sheffield OSC
- South Yorkshire OSC
- South Yorkshire and Bassetlaw CCG
- Sheffield Cllrs
- Sheffield MPs
- Sheffield Mayor

Third sector

- Healthwatch Sheffield
- Public Health BAME network
- STAMMA
- National Action for stammering children
- Cleft Lip and Palate Association (CLAPA)
- Sheffield Downs Syndrome Support Group (SHEDS)

- Sheffield Autistic Society
- Disability Sheffield
- Mencap & Gateway

Other

- Mainstream schools*
- Special schools*
- Parent Carer Forum
- Local media
- Sheffield Local Medical Committee (LMC)
- Wider stammering community
- Wider Cleft lip and palate community
- Save Our NHS (SONHS)
- Learning Disability Partnership

** Referring organisations into the adult Dysfluency and Cleft Lip and Palate service*

DRAFT