The Craniofacial Society of Great Britain and Ireland
& the Cleft Development Group

Supported by:
The Cleft Psychology Clinical Excellence Network & the
Cleft Registry & Audit NEtwork

Patient (and Parent) Reported Experience Measure (PREM)
Feasibility Study findings
August 2017[1]

1. PREM Feasibility Study Team – Recommendations

A feasibility study to test Patient (and Parent) Reported Experience Measure (PREM) data collection has been conducted. Based on the input received from cleft teams throughout the study, and from the Cleft Development Group (CDG) in May/June 2017, the feasibility study team make the following recommendations:

1. Data should be collected on the patient experience of patients of all ages (with no age-restricted basis).
2. Patient experience data are to be reported by appropriate age groupings.
3. Data collection should not proceed with Friends and Family Test (FFT) measure. Instead, the missing CHI-ESQ question – similar to the FFT ('If a friend needed this sort of help, I would suggest to them to come here') – should be incorporated into data collection.
4. Data should be collected for all twelve CHI-ESQ components.
5. All cleft teams should agree to achieve a minimum response rate per year. Specifically, a response rate of 30 cases for small teams, and 60 for larger teams.
6. All cleft teams should agree to this data collection being captured/recoded in the CRANE Database; using electronic and local paper methods to start with, with the aim of moving to electronic methods only over time.
7. These PREM data should be reported on nationally for two to three years. After this time, and with the agreement of key stakeholders including the CDG, this data should be recorded on by centre/networks.

2. Background

The Cleft Psychology Clinical Excellence Network (CEN), upon request by the Craniofacial Society of Great Britain and Ireland (CFSGBI) Council and the CDG, identified and piloted measurements[2] to evaluate patient (and parent) reported experience.

These measures were combined into one PREM questionnaire and, through piloting[3] by the Cleft Psychology CEN, adjusted to apply to cleft services.

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[1] This version (2.1) was released on 18 December 2018, and included corrections to Section 1 in the Recommendations section on page 1.

[2] (1) The Friends and Family Test (FFT) – developed by the Department of Health, and (2) the Experience of Service Questionnaire (CHI-ESQ) satisfaction assessment scales – developed by the Commission for Health Improvement (CHI).

[3] For full copies of documentation around the Cleft Psychology CEN review and pilot please contact Vanessa Hammond, Chair of Cleft Psychology CEN on vanessa.hammond@wales.nhs.uk.

The CRANE project team and the Cleft Psychology CEN collaborated to conduct a year-long feasibility study to test PREM data collection, analysis and reporting, with a view to developing a method to implement data collection, analysis and reporting nationally.

3. Rationale

The use of patient feedback for evaluating services is increasingly being seen as essential for both children's services and adult services[4].The National Service Specification for Cleft Services (D07/S/a 2013) includes the following two recommended standards relating to satisfaction:

- Standard 15: Arrangements must be in place to monitor parental satisfaction with the early care of the child and the effectiveness of the initial interventions, for example through a validated satisfaction questionnaire.
- Standard 41: The standard record set should be available, or else the reason for non- collection recorded, for 100% of all cleft individuals at each age band. Patient and Parent satisfaction questionnaires will be used to assess the team's performance in adolescence and at the end of routine care.

It is anticipated that these standards will become core standards in future and will comprise a part of the way in which Specialist Commissioners evaluate a cleft service. In addition, measuring satisfaction can also provide information for individual services to continue to improve services for their patient group.

4. Data collection

Data collection ran from Monday 30 November 2015 – Tuesday 31 January 2017.

530 PREM questionnaires were either completed online by parents/patients (referred to as self-completions throughout this document) or completed in paper format by parents/patients. Parents/patients had the option of completing one of 3 types of questionnaires:

1. A questionnaire for 10 or 11 year old patients,
2. a questionnaire for 15 or 16 and 20 year old patients, or
3. a questionnaire for parents of all patients – aged 4-24months, 10 or 11 years, or 15 or 16 and 20 years.

All information collected via paper questionnaires was subsequently submitted online by cleft teams.

Table 1 (below) shows that, over the 14 months of data collection, half of questionnaires were submitted as self-completions while the other half were submitted by cleft teams. In addition, the majority of submissions were by parents of patients (61%).

Table 1. Number of questionnaires submitted by either self-completion or by cleft teams, according to questionnaire type.

Questionnaire Type	Self-completion	Submitted by cleft teams	TOTAL
Parents	170 (64%)	153 (58%)	**323 (61%)**
10 or 11 year old patients	41 (16%)	60 (23%)	101 (19%)
15 or 16 & 20 year old patients	54* (20%)	52 (19%)	106 (20%)
TOTAL questionnaires	**265 (100%)**	**265 (100%)**	**530 (100%)**

*Originally, 56 but 2 cases were removed as those respondents' service delivered by Scottish Cleft Network.

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[4] Kennedy, I. (2010). Getting it Right for Children and Young People: Overcoming cultural barriers in the NHS so as to meet their needs. London: Department of Health AND Government White Paper 'Equity and Excellence'.

Table 2 further illustrates the breakdown of submissions, by cleft teams. It illustrates that some cleft teams such as Newcastle and West Midlands had higher rates of questionnaires submitted by cleft team than self-completions. Other teams such as North Thames and Spires had the opposite pattern of higher rates of self-completion than cleft team submitted. This was whilst, for North Thames in particular, still maintaining high total return rates.

Table 2. Number of questionnaires submitted by either self-completion or by cleft teams, according to cleft team.

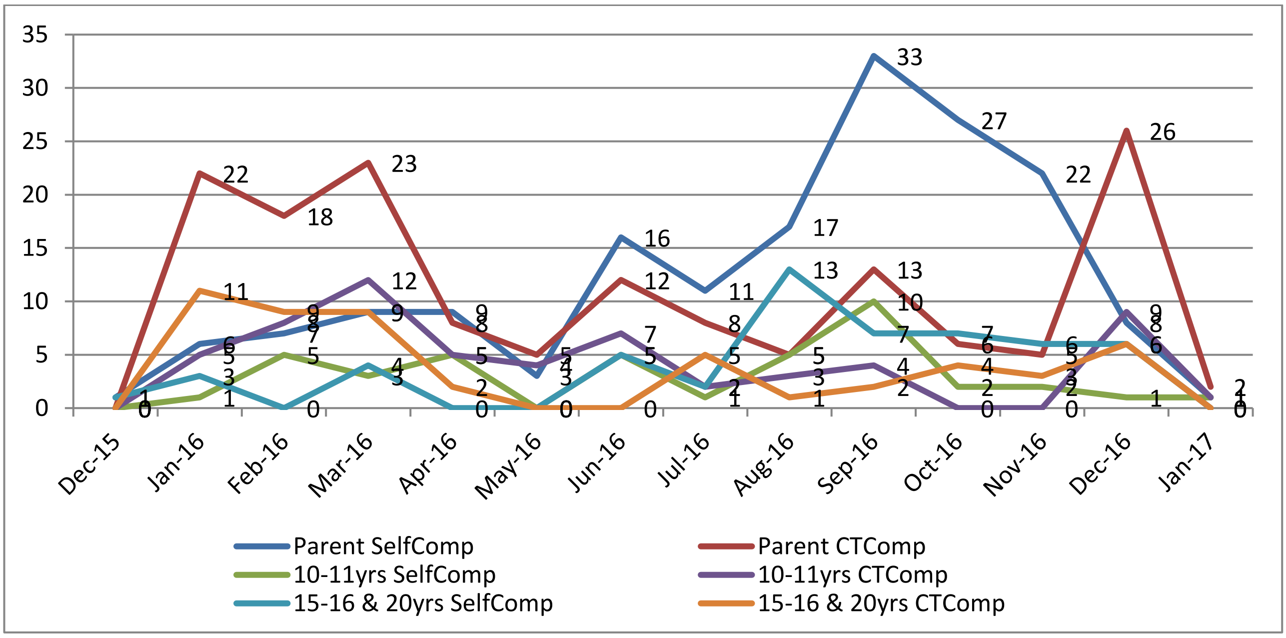
Cleft Team	**Self-completion**	**Submitted by cleft teams**
North Thames (n=132)	**106 (80)**	26 (20)
West Midlands (n=111)	23 (21)	**88 (79)**
Newcastle (n=99)	1 (1)	**98 (99)**
The Spires (n=56)	**55 (98)**	1 (2)
Bristol (n=56)	35 (63)	21 (37)
Swansea (n=36)	7 (19)	29 (81)
East (n=13)	13 (100)	0 (0)
Liverpool (n=10)	10 (100)	0 (0)
Manchester (n=6)	6 (100)	0 (0)
*Leeds (n=2)	2 (100)	0 (0)
**South Thames (n=1)	0 (0)	1 (100)
Unknown (n=8)	7 (88)	1 (12)
TOTAL questionnaires	**265 (50%)**	**265 (50%)**

*Cleft team was unable to collect data via paper questionnaires, as they had no resource to manage cleft team data entry. Their submissions resulted from parents/patients providing feedback via self-completions.

**Did not have the resource to participate in the feasibility study at the time it was conducted.

Figure 1, below, shows the volume of submissions by month throughout the feasibility study data collection period; by each of the six submission types – depending on whether or not they were self-completions or submitted by cleft teams (CT)), and the questionnaire type. As is illustrated below, September 2016 was the month when most submission were made, mainly by parents (n=46).

Figure 1. Number of submitted questionnaires by month, and by respondent group and submission type.



It is important to note, moving forwards through this report, that this feasibility study did not look at the total numbers of people (parents / patients) attending clinics compared to return rates[5].

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[5] It simply was not feasible at the time of this study.

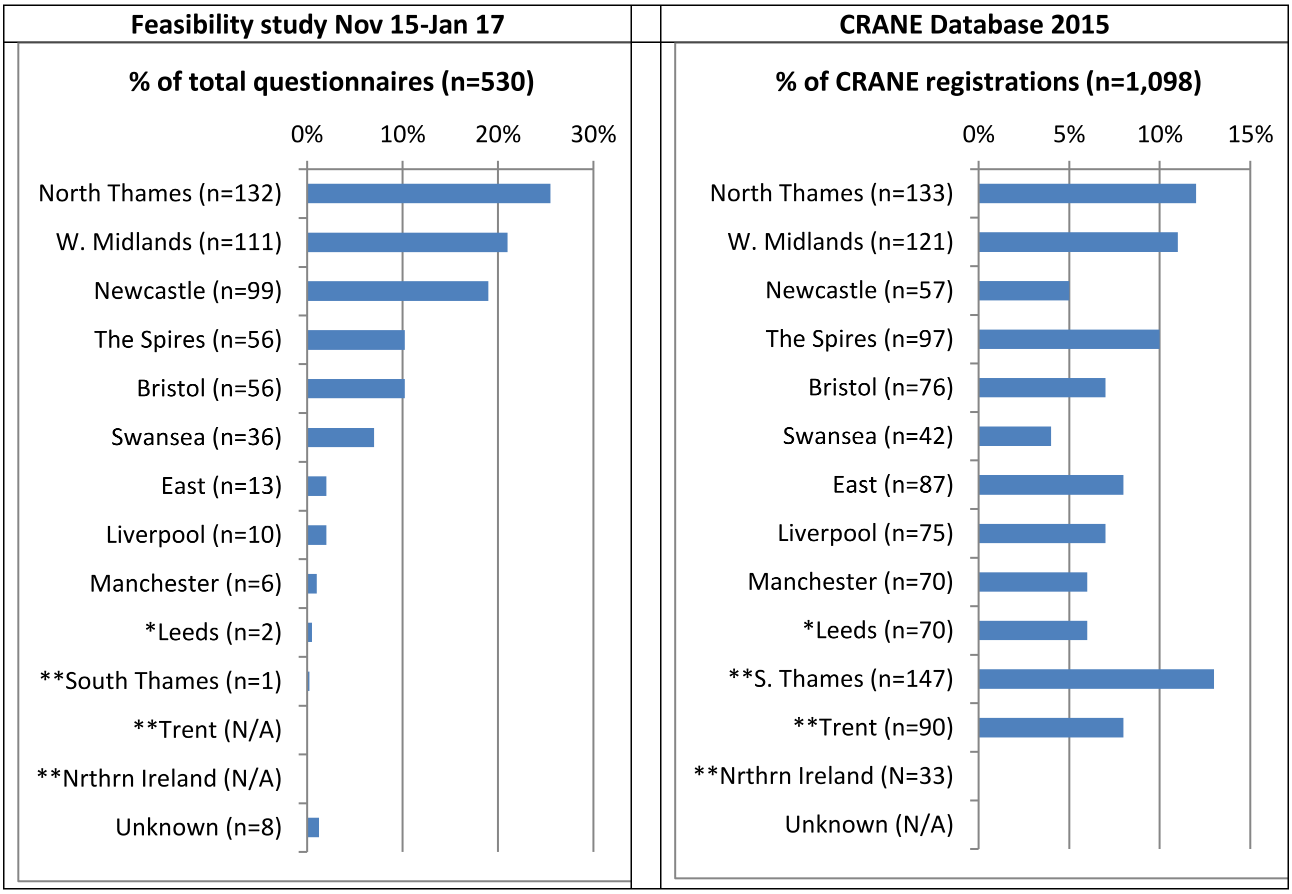
5. Submissions according to cleft team

Just over a quarter (n=132, 25.5%) of questionnaires submitted, throughout this feasibility study, provided information on the experience of parents/patients being cared for by the North Thames cleft team (see left-hand bar graph of Figure 2 below). In addition, 93% of data submitted during this feasibility study provided feedback on six cleft teams (see North Thames through to Swansea numbers in the left-hand bar graph of Figure 2 below).

To provide some context for the proportions presented in the left-hand bar graph in Figure 2, the right-hand bar graph in Figure 2 shows the number (and proportion) of children born in 2015 and registered in the CRANE Database, according to cleft team (as presented in the most recent / 2016 CRANE Annual Report).

The volume (and relative proportions) of registrations of 2015 births by each cleft team were typical of yearly registrations; and showed that feasibility study proportions were similarly distributed across cleft teams – for the most part. For example, Newcastle has received feedback from a higher number of respondents that would be expected, when considering their usual case rate (as roughly surmised from CRANE yearly registrations). It would be useful to understand more about the methodology employed by this cleft team; to capture any lessons that could be applied by other cleft teams to elicit similar levels of feedback.

Figure 2. Percentage of total feasibility study questionnaires submitted by cleft teams – versus the number (and proportion) of children born in 2015 with a cleft lip and/or palate in England, Wales and Northern Ireland registered on the CRANE Database (according to cleft team).



*Cleft team was unable to collect data via paper questionnaires, as they had no resource to manage cleft team data entry. Their submissions resulted from parents/patients providing feedback via self-completions.

**Did not have the resource to participate in the feasibility study at the time it was conducted.

6. Submission according to cleft type

The left-hand columns of Table 3 (below) report the proportions of cleft types reported by respondents to the feasibility study questionnaires. Most respondents had cleft palate (41%) or a cleft affecting both their lip and their palate (36%).

To provide some context for the proportions presented in the left-hand columns of Table 3, the right-hand columns of Table 3 show the number (and proportion) of children born in 2015 and registered in the CRANE Database, according to cleft type (as presented in the most recent / 2016 CRANE Annual Report). The 2015 numbers (and relative proportions) were typical of yearly CRANE Database registrations; and showed that feasibility study respondents were distributed similarly across cleft types.

Table 3. Cleft type reported by feasibility study respondents – versus the number (and proportion) of children born in 2015 with a cleft lip and/or palate in England, Wales and Northern Ireland registered on the CRANE Database (according to cleft type).

	Feasibility study Nov 15-Jan 17		**CRANE Database 2015**	
Cleft Type	**n**	**%**	**n**	**%**
Cleft affecting both L&P	189	36	321	31
Cleft lip only	81	15	254	25.2
Cleft palate only	**217**	**41**	441	43.8
Don't know	43	8	-	-
Total	530	100	1,098	100

7. Submissions by patients' age

The parent/patient experience questionnaires were designed to capture feedback from parents of 4-24 month olds, from 10 or 11 year olds, and 15 or 16 and 20 year olds. The questionnaires in fact captured the following:

- Data for 4 to 30 month olds – captured within 4-24 month olds' data. Therefore capturing feedback on services provided to (parents and) children at the end of the baby stage.
- Data for 3 to 7 year olds – A new category created from self-reports of 'other' ages. On reflection, considering this outcome of this feasibility study, it is encouraging that parents of 3-7 year olds want to provide cleft teams with feedback.
- Data for 9 to 13 year olds – grouped within 10 and 11 year olds' data. Capturing those in early adolescence.
- Data for 15 to 17 year olds – grouped within 15 and 16 year olds' data.
- Data for 18 to 23 year olds – grouped within 20 year olds' data. Therefore capturing data for young adults (of 18+ years).

Proportions of responses from these groups are presented in Figure 3 (below). Most parents / patients (41%) provided feedback on service provided to 9 to 13 year olds. It may be that this is the group with the highest rates of attendance at clinics. The small proportion of 18+ year olds was expected, as they do not attend clinic as often as the other age groups, and therefore it was harder to elicit their feedback; confirming what is feasible.

Figure 3. Proportion of respondents by age of the child / patient.

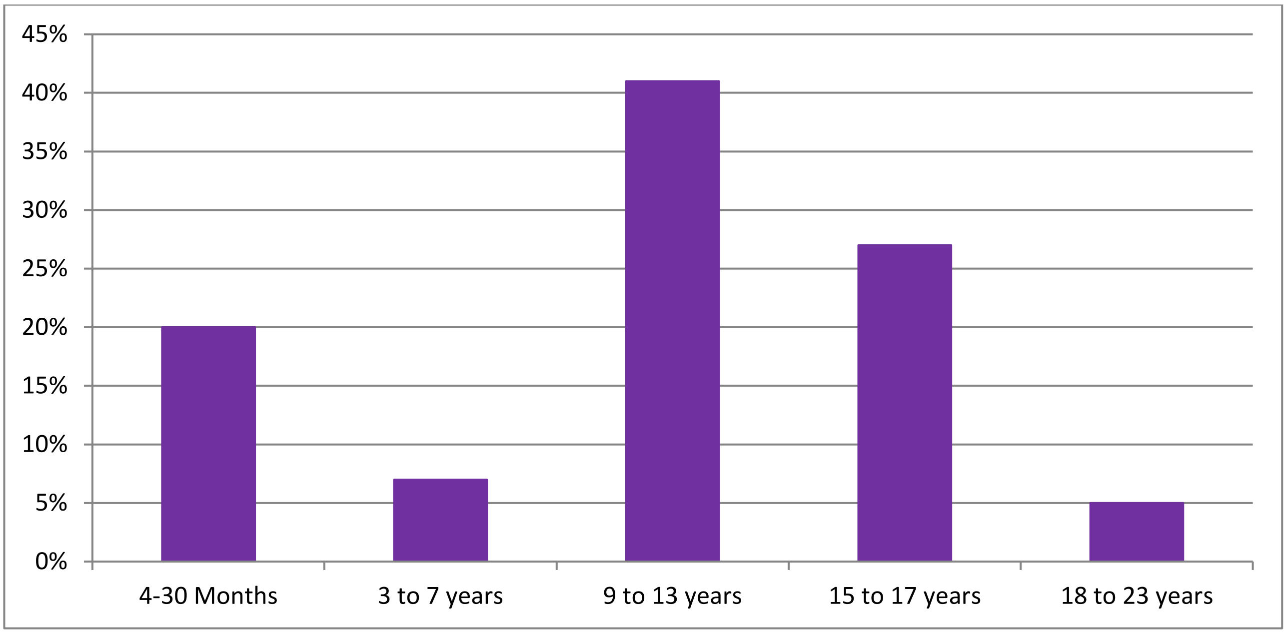
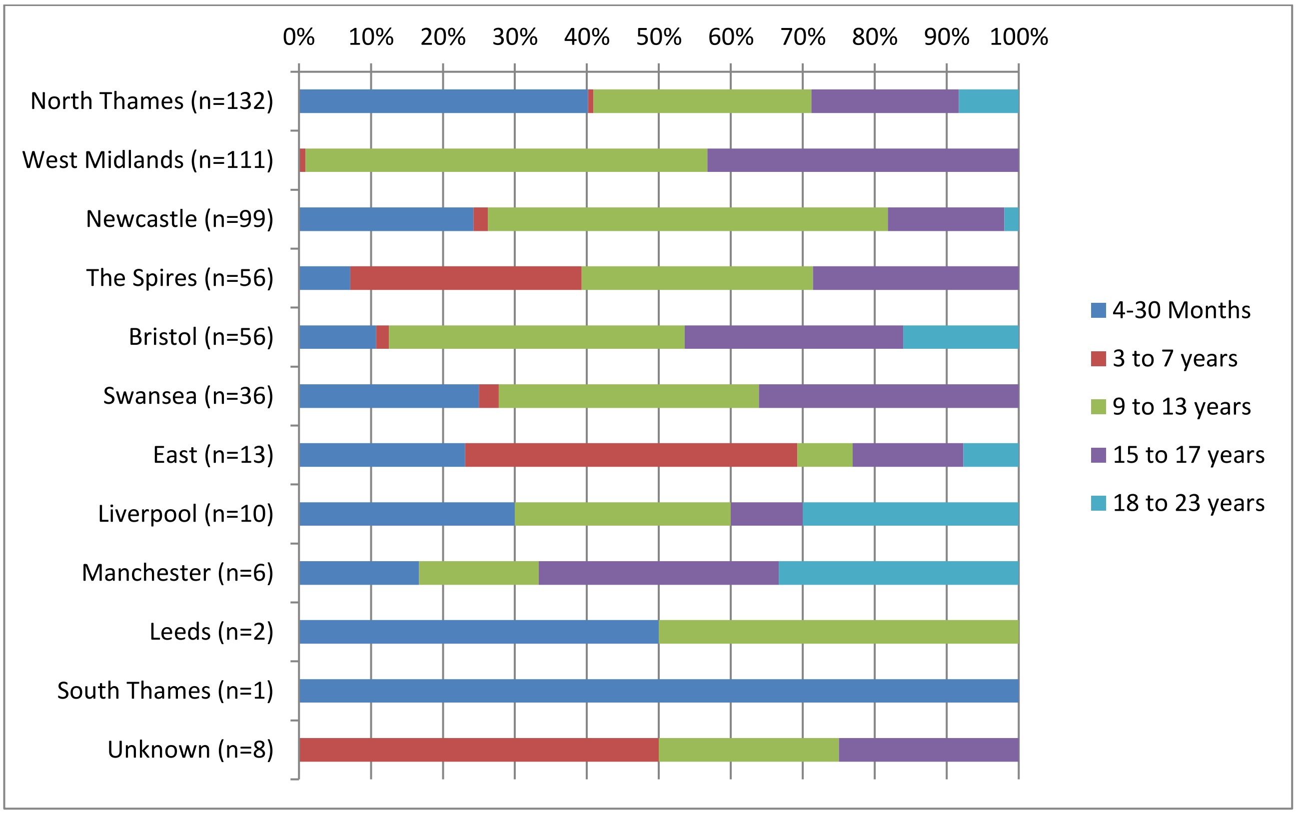


Figure 4 shows the proportion of respondents by cleft team and the age of the patient. Cleft teams such as Newcastle and the West Midlands receive more than half of their feedback on the care provided to 9 to 13 year olds (56% in both cases).

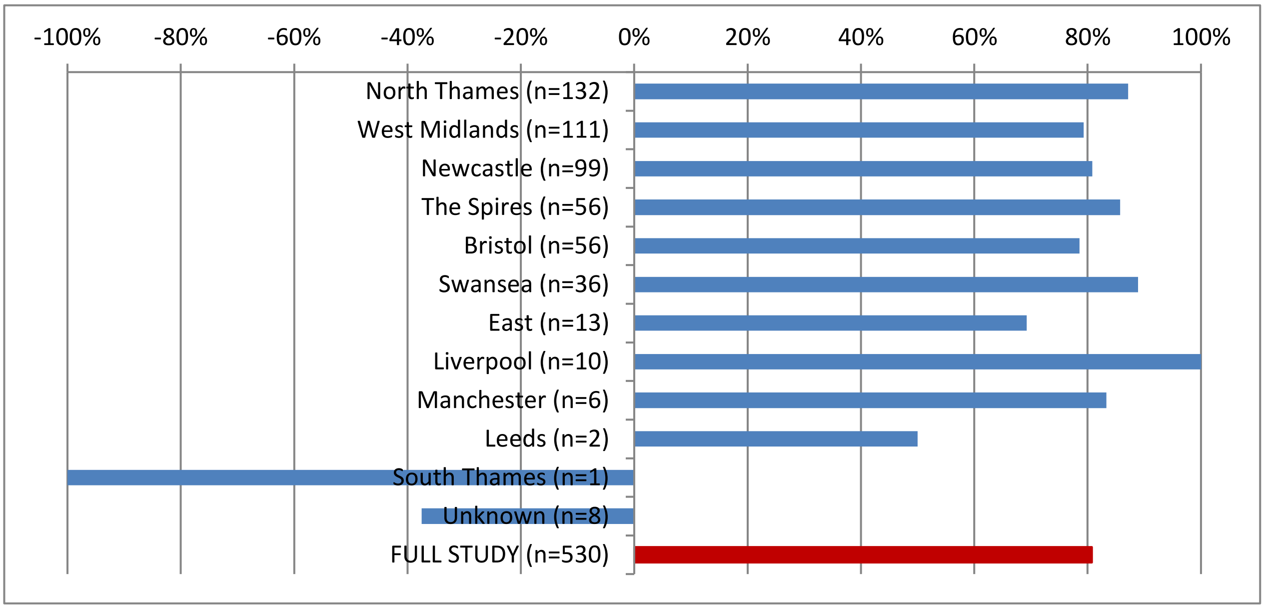
Figure 4. Proportion of respondents by cleft team and age of the child / patient.



8. Friends and Family Test (FFT) – responses

Responses to the FFT are presented using the FFT score. The FFT score is calculated by taking the proportion of people answering ‘extremely likely’ and subtracting the proportion answering ‘unlikely’ or ‘extremely unlikely’, giving a possible range of 0% to 100%. This feasibility study produced a FFT score of 81%[6], with some variance between the cleft teams (as presented in Figure 5 below); which could not be tested for statistical significance, due to the small numbers.

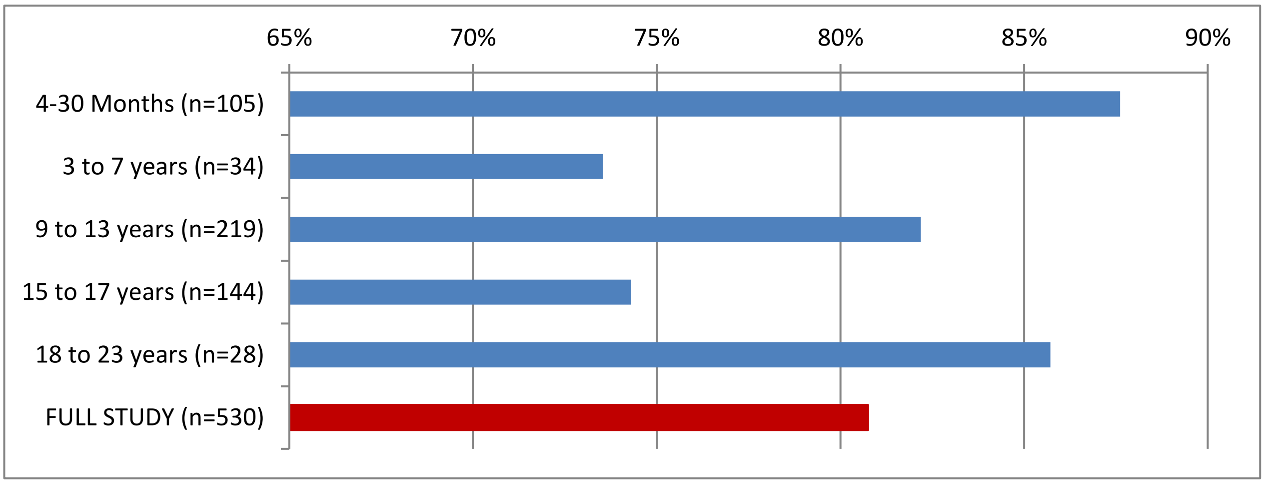
Figure 5. FFT Scores[7] by cleft team.



The findings presented in Figure 5 demonstrate the complexity in measuring satisfaction; and the challenge of comparing different services with different levels of returns.

Figure 6 shows responses to FFT Scores by age of the child/patient. Feedback on the care of 3 to 7 year olds, and 15 to 16 year olds, suggested lover levels of satisfaction with care at these ages (with a FFT score of 74% for both of these groups) compared to that expressed by other age groups.

Figure 6. FFT Scores by age of the patient.



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[6] As for pilot study for CFSGBI Council completed in 2013.

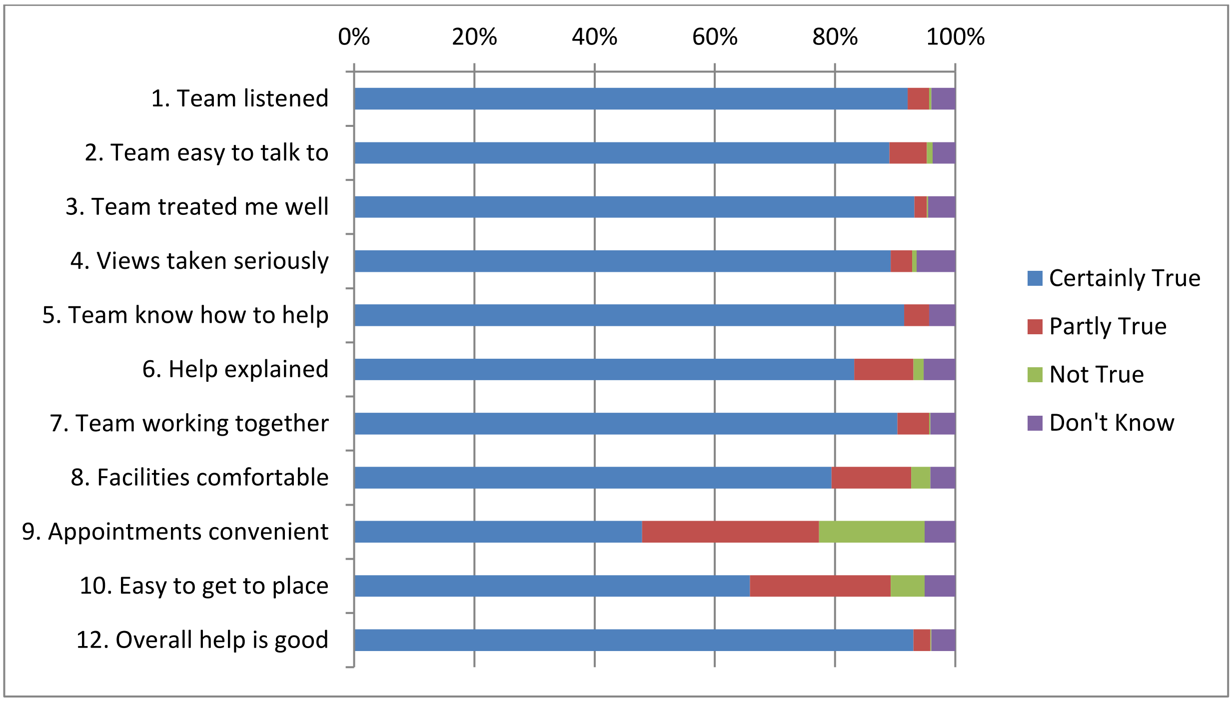
[7] FFT Score = Proportion of ‘Extremely Likely’ answers minus proportion of ‘Unlikely’ or ‘Extremely Unlikely’ answers.

The findings presented in Figure 6, suggest that more detailed research may be needed at a later date to unravel the reasons behind lower levels of satisfaction at these particular ages. For example, dissatisfaction a t 15 to 17 years of age may be associated with the reduced treatment options available at this time / for this age group.

In addition to quantitative / numerical responses to the FFT questionnaire item, parents/patients provided qualitative feedback on the main reason they selected their FFT score. This feedback along with that provided to an additional four question items was analysed using inductive thematic analysis. The combined qualitative result are presented in Section 7 of this report.

CHI-ESQ responses can be presented as for Figure 7 below; showing the proportion of responses to each CHI-ESQ item using the following four answer categories: 'Certainly true'; 'partly true', 'not true' and 'Don't know'.

Figure 7. Proportion of responses to each CHI-ESQ item, according to each available answer category.



Note: CHI-ESQ item number 11 was not collected during this feasibility study as it requested the same information collected by the FFT questionnaire item (CHI-ESQ item 11. "If a friend needed similar help, I would recommend that he or she come here").

CHI-ESQ responses can also be summarised into a 'satisfaction with care' construct (by adding up items 1 to 7 plus 11 and 12) and a 'satisfaction with environment' construct (by adding up items 8 to 10)[8]. We aim to explore the CHI-ESQ data in this way in future analyses.

In the next pages of this report, responses to the 11 items of the CHI-ESQ are presented using CHI-ESQ Scores (in Figures 8 to 18). These CHI-ESQ scores have been calculated – in line with the FFT scoring system[9] – by taking the proportion of people answering 'certainly true' and subtracting the proportion answering 'not true', giving a possible range of 0% to 100%. This is one suggested way of interpreting this data.

Alternatively, in future, these scores could be presented in the style of the KPIs on the Quality Dashboard, giving a mean and range for all cleft teams and comparing that with individual cleft team scores.

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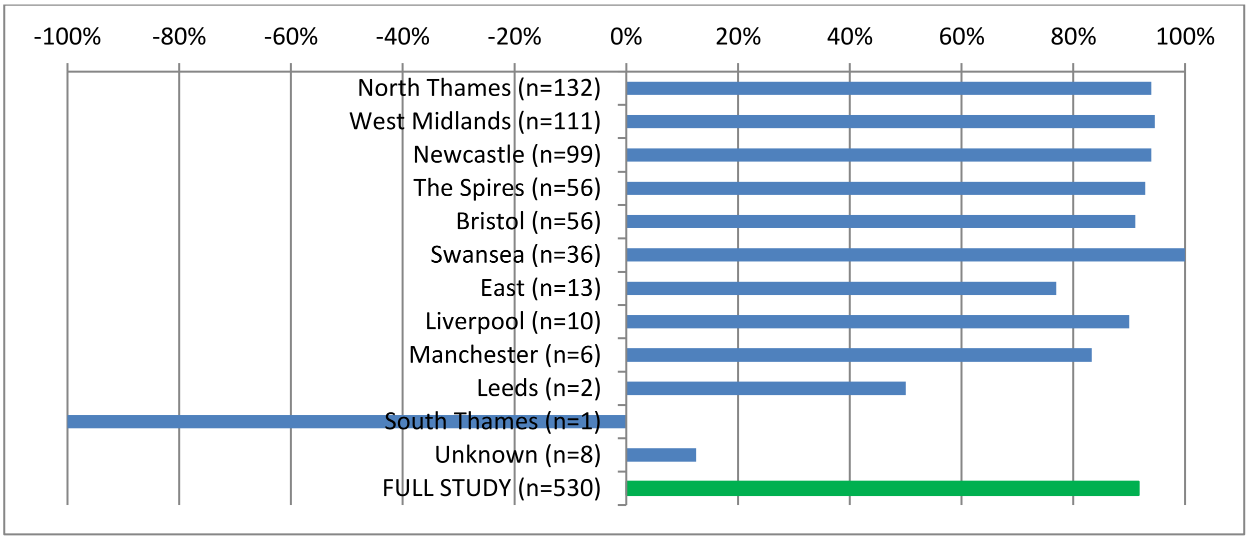
[8] Brown, A., Ford, T., Deighton, J. et al. Adm Policy Ment Health (2014) 41: 434. doi:10.1007/s10488-012-0433-9.

[9] As for pilot study for CFSGBI Council completed in 2013.

Figure 8 shows CHI-ESQ Scores[10] for **respondents feeling that the people who saw them/their child listened to them** by cleft teams.

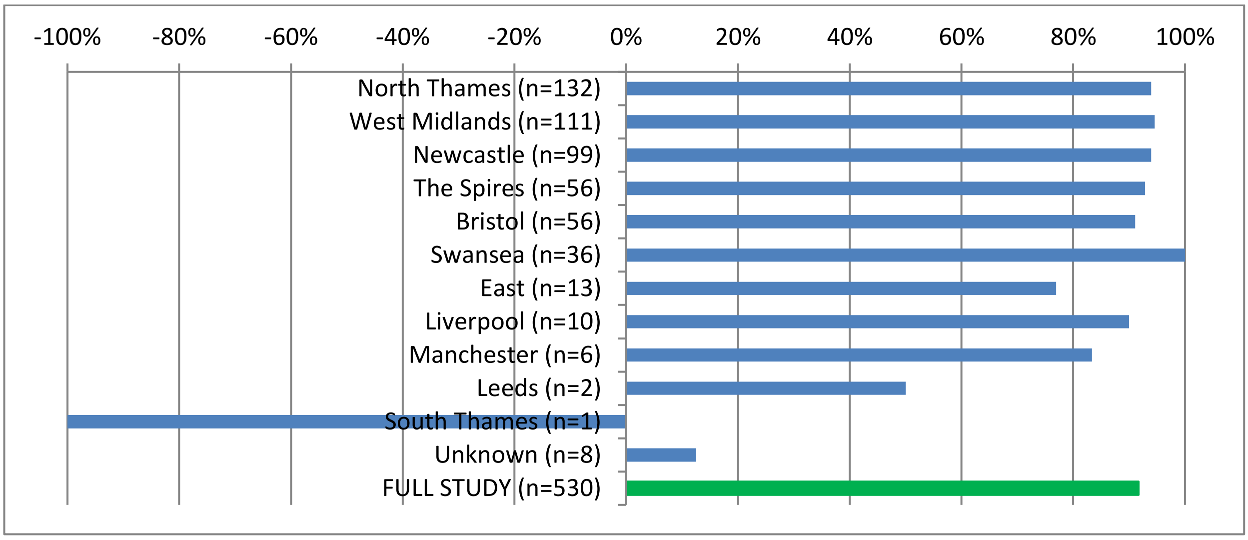
Figure 8. CHI-ESQ 'Team listened' scores by cleft teams.



This feasibility study produced a CHI-ESQ 'Team listened' score of 92%, with some variance between the cleft teams (as presented in Figure 8), which could not be tested for statistical significance, due to the small numbers.

Figure 9 shows CHI-ESQ Scores[11] for **respondents feeling that it was easy to talk to the people who saw them/their child** by cleft teams.

Figure 9. CHI-ESQ 'Team easy to talk to' scores by cleft teams.



This feasibility study produced a CHI-ESQ 'Team easy to talk to' score of 88%, with some variance between the cleft teams (as presented in Figure 9).

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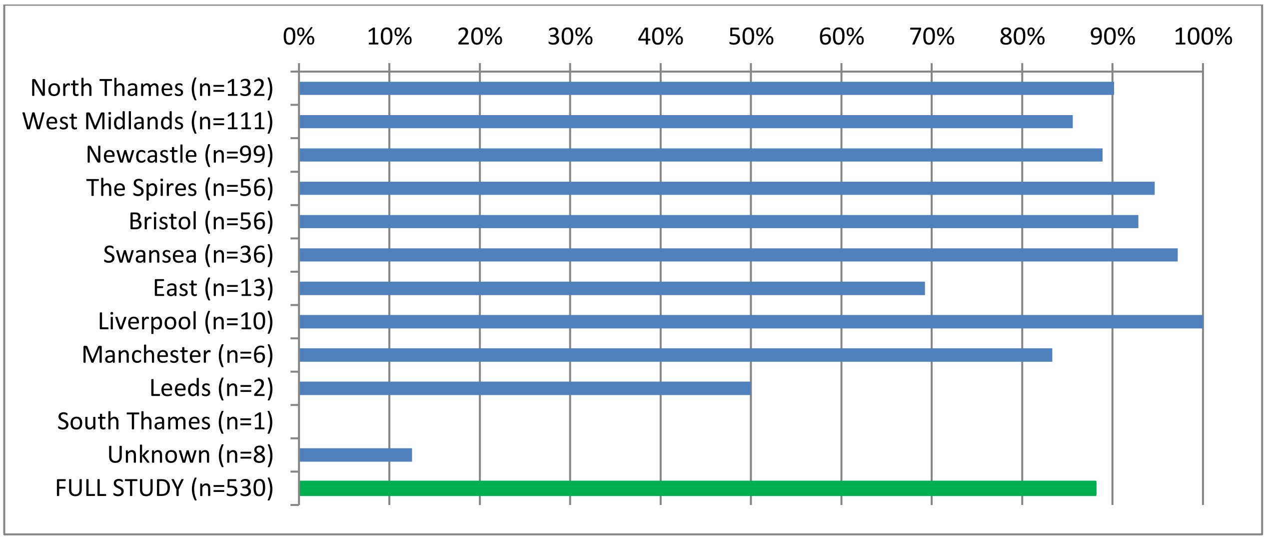
[10] CHI-ESQ Score = Proportion of 'Certainly True' answers minus proportion of 'Not True' answers.

[11] CHI-ESQ Score = Proportion of 'Certainly True' answers minus proportion of 'Not True' answers.

Figure 10 shows CHI-ESQ Scores[12] for **respondents feeling that they were treated well by the people who saw them/their child** by cleft teams.

Figure 10. CHI-ESQ 'Team treated me well' scores by cleft teams.

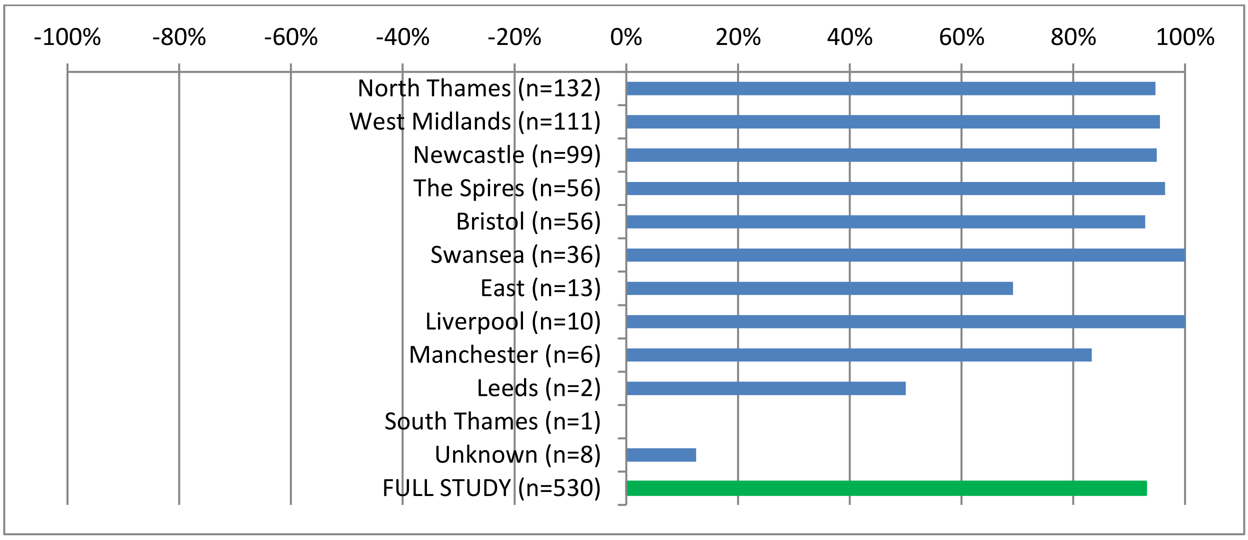


Note: Where a cleft team has a CHI-ESQ score of 0% this is because their respondents' answer(s) to the question was/were either ''Partly True' or 'Don't know'; which are the 2 answer categories not used to calculate CHI-ESQ scores.

This feasibility study produced a CHI-ESQ 'Team treated me well' score of 93%, with some variance between the cleft teams (as presented in Figure 10).

Figure 11 shows CHI-ESQ Scores[13] for **respondents feeling that their views and worries were taken seriously** by cleft teams.

Figure 11. CHI-ESQ 'Views taken seriously' scores by cleft teams.



This feasibility study produced a CHI-ESQ 'Views taken seriously' score of 88%, with some variance between the cleft teams (as presented in Figure 11).

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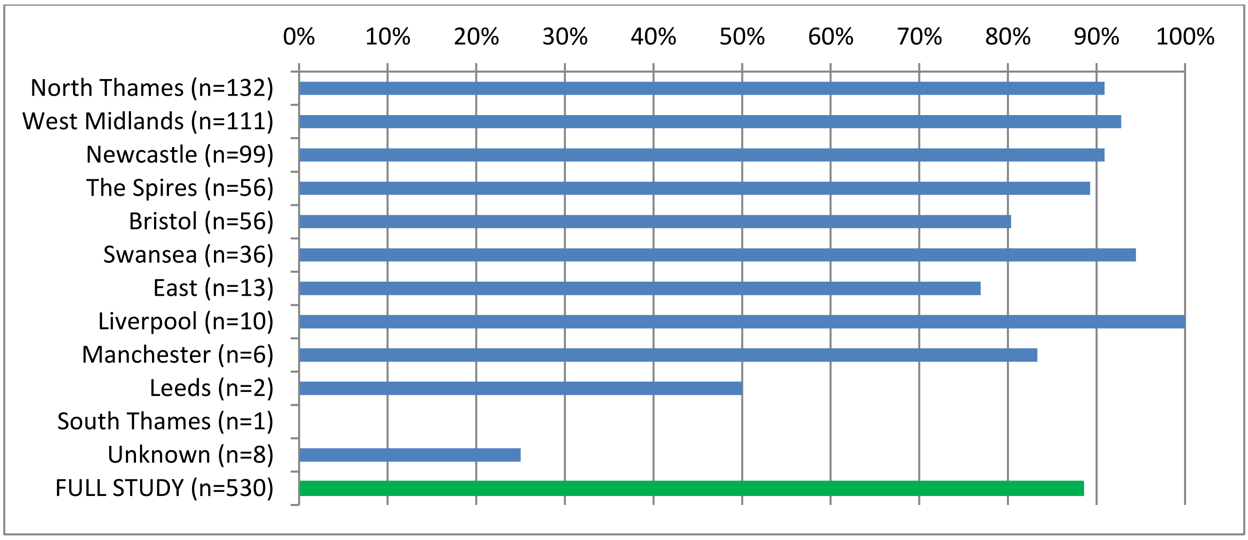
[12] CHI-ESQ Score = Proportion of 'Certainly True' answers minus proportion of 'Not True' answers.

[13] CHI-ESQ Score = Proportion of 'Certainly True' answers minus proportion of 'Not True' answers.

Figure 12 shows CHI-ESQ Scores[14] for **respondents feeling the people in the Cleft Lip and Palate service know how to help them/their child** by cleft teams.

Figure 12. CHI-ESQ 'Team know how to help' scores by cleft teams.

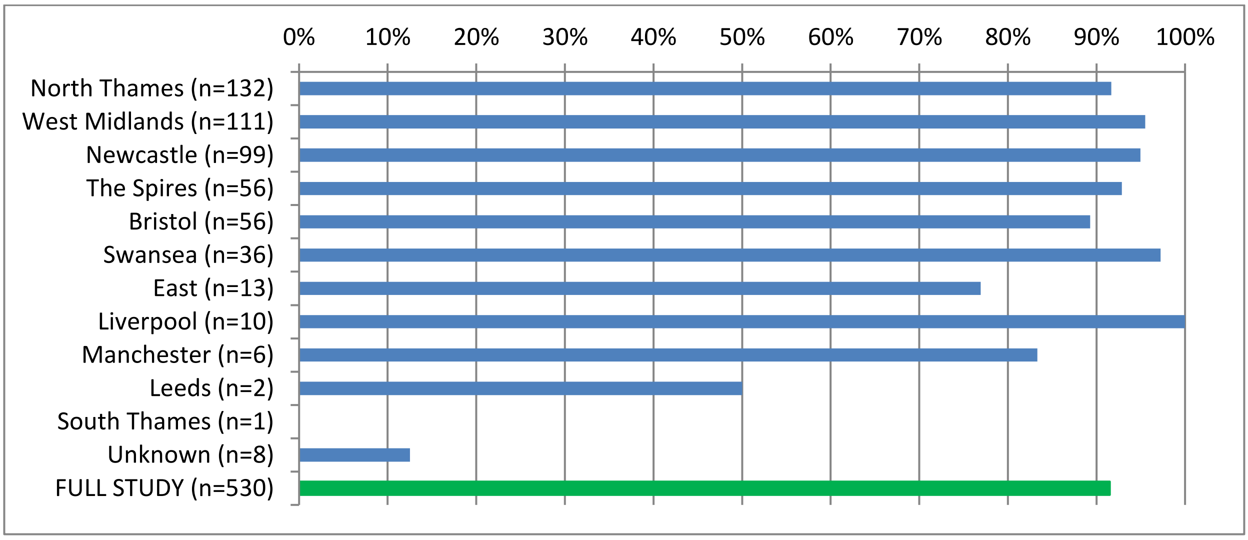


Note: Where a cleft team has a CHI-ESQ score of 0% this is because their respondents' answer(s) to the question was/were either ''Partly True' or 'Don't know'; which are the 2 answer categories not used to calculate CHI-ESQ scores.

This feasibility study produced a CHI-ESQ 'Team know how to help' score of 92%, with some variance between the cleft teams (as presented in Figure 12).

Figure 13 shows CHI-ESQ Scores[15] for **respondents feeling they have been given enough explanation about the help available from the Cleft Lip and Palate service** by cleft teams.

Figure 13. CHI-ESQ 'Help explained' scores by cleft teams.



Note: Where a cleft team has a CHI-ESQ score of 0% this is because their respondents' answer(s) to the question was/were either ''Partly True' or 'Don't know'; which are the 2 answer categories not used to calculate CHI-ESQ scores.

This feasibility study produced a CHI-ESQ 'Help explained' score of 82%, with some variance between the cleft teams (as presented in Figure 13).

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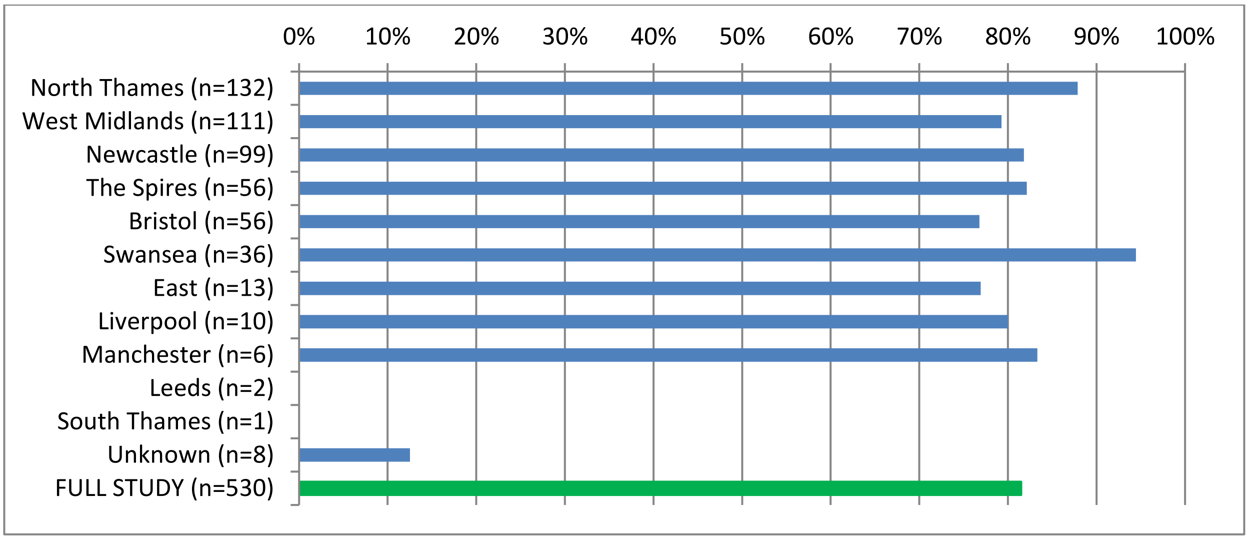
[14] CHI-ESQ Score = Proportion of 'Certainly True' answers minus proportion of 'Not True' answers.

[15] CHI-ESQ Score = Proportion of 'Certainly True' answers minus proportion of 'Not True' answers.

Figure 14 shows CHI-ESQ Scores[16] for **respondents feeling the people who have seen them/their childcare working together to help with any problems** by cleft teams.

Figure 14. CHI-ESQ 'Team working together' scores by cleft teams.

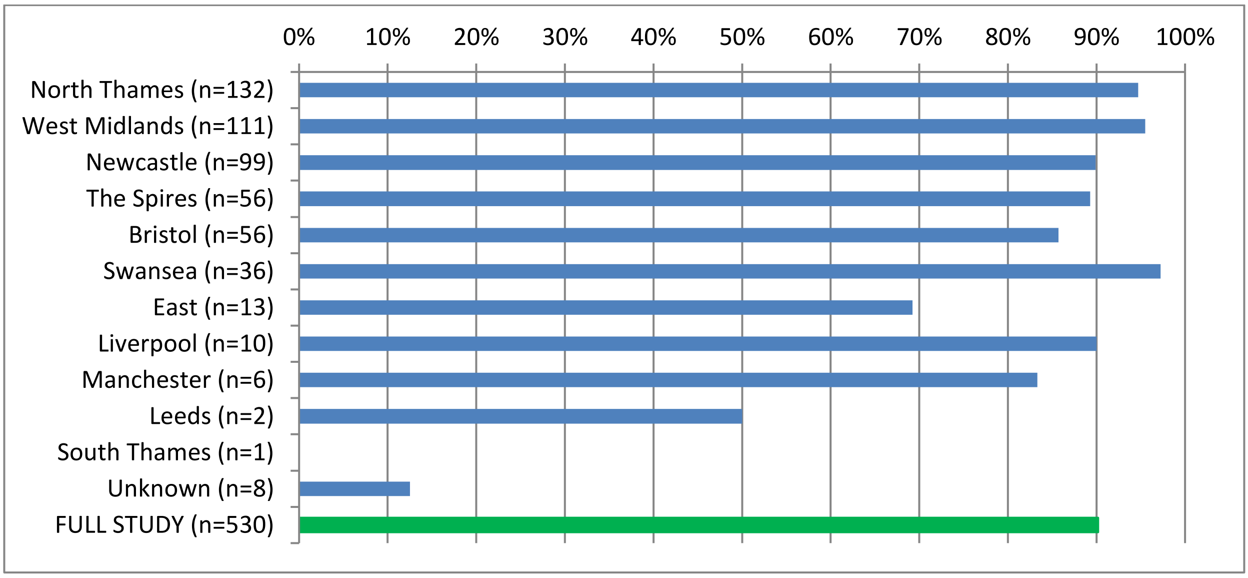


Note: Where a cleft team has a CHI-ESQ score of 0% this is because their respondents' answer(s) to the question was/were either ''Partly True' or 'Don't know'; which are the 2 answer categories not used to calculate CHI-ESQ scores.

This feasibility study produced a CHI-ESQ 'Team working together' score of 90%, with some variance between the cleft teams (as presented in Figure 14).

Figure 15 shows CHI-ESQ Scores[17] for **respondents feeling the facilities on the Cleft Lip and Palate service were comfortable** by cleft teams.

Figure 15. CHI-ESQ 'Facilities comfortable' scores by cleft teams.



Note: Where a cleft team has a CHI-ESQ score of 0% this is because their respondents' answer(s) to the question was/were either ''Partly True' or 'Don't know'; which are the 2 answer categories not used to calculate CHI-ESQ scores.

This feasibility study produced a CHI-ESQ 'Facilities comfortable' score of 76%, with some variance between the cleft teams (as presented in Figure 15).

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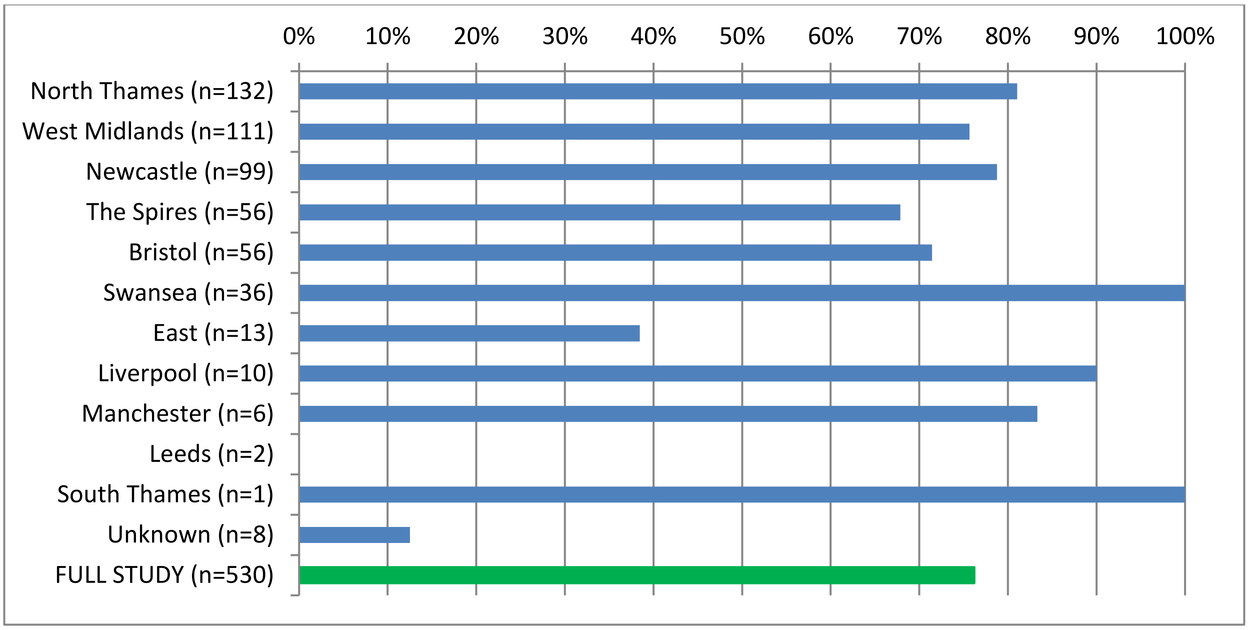
[16] CHI-ESQ Score = Proportion of 'Certainly True' answers minus proportion of 'Not True' answers.

[17] CHI-ESQ Score = Proportion of 'Certainly True' answers minus proportion of 'Not True' answers.

Figure 16 shows CHI-ESQ Scores[18] for **respondents feeling the appointments are usually at a convenient time** by cleft teams.

Figure 16. CHI-ESQ 'Appointments convenient' scores by cleft teams.

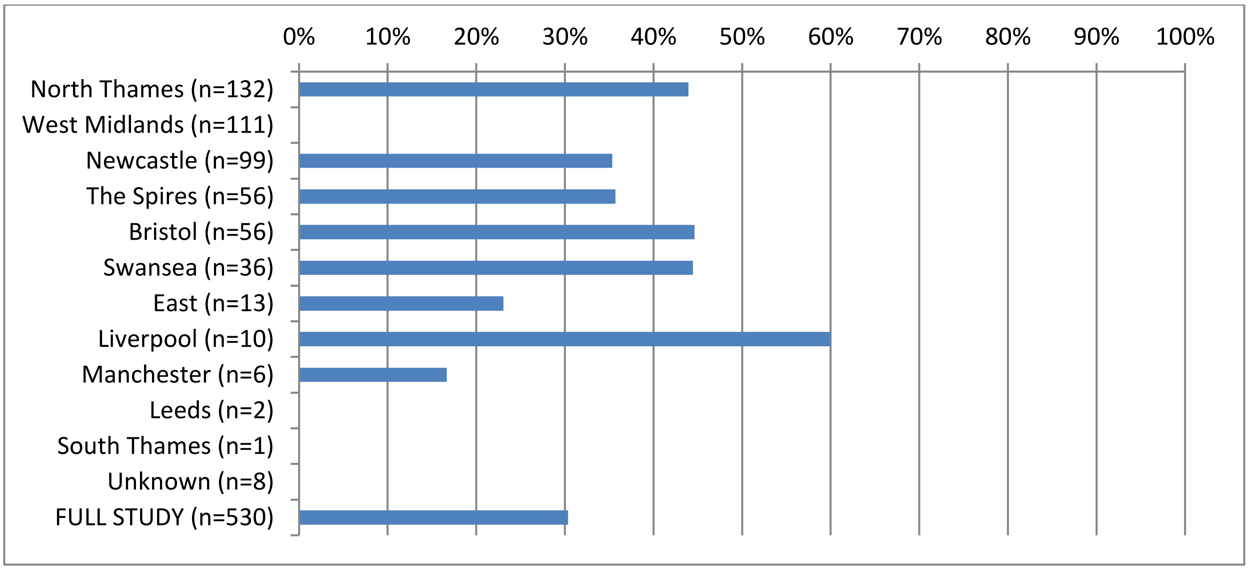


Note: Where a cleft team has a CHI-ESQ score of 0% this is because their respondents' answer(s) to the question was/were either ''Partly True' or 'Don't know'; which are the 2 answer categories not used to calculate CHI-ESQ scores.

This feasibility study produced a CHI-ESQ 'Appointments convenient' score of 30%, with some variance between the cleft teams (as presented in Figure 16).

Figure 17 shows CHI-ESQ Scores[19] for **respondents feeling it is quite easy to get to the place where the appointments are** by cleft teams.

Figure 17. CHI-ESQ 'Easy to get to place' scores by cleft teams.



Note: Where a cleft team has a CHI-ESQ score of 0% this is because their respondents' answer(s) to the question was/were either ''Partly True' or 'Don't know'; which are the 2 answer categories not used to calculate CHI-ESQ scores.

This feasibility study produced a CHI-ESQ 'Easy to get to place' score of 60%, with some variance between the cleft teams (as presented in Figure 17).

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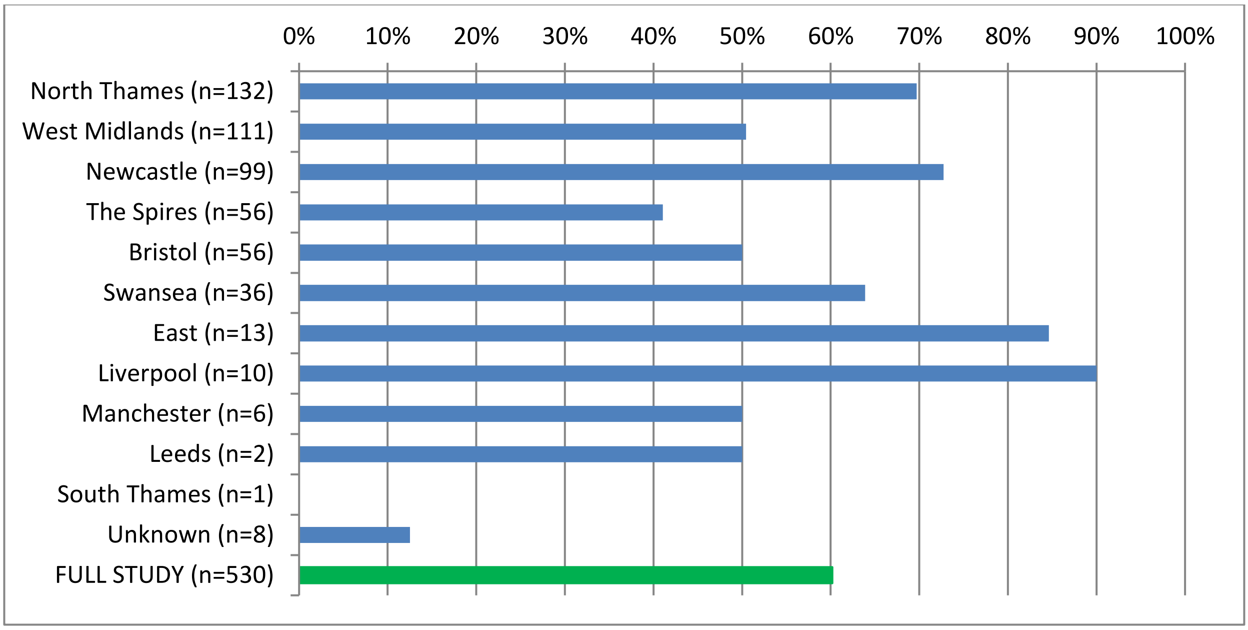
[18] CHI-ESQ Score = Proportion of 'Certainly True' answers minus proportion of 'Not True' answers.

[19] CHI-ESQ Score = Proportion of 'Certainly True' answers minus proportion of 'Not True' answers.

Figure 18 shows CHI-ESQ Scores[20] for **respondents feeling that overall; the help they/their child has received from the Cleft Lip and Palate service is good** by cleft teams.

Figure 18. CHI-ESQ 'Overall help is good' scores by cleft teams.



Note: Where a cleft team has a CHI-ESQ score of 0% this is because their respondents' answer(s) to the question was/were either ''Partly True' or 'Don't know'; which are the 2 answer categories not used to calculate CHI-ESQ scores.

This feasibility study produced a CHI-ESQ 'Overall help is good' score of 93%, with some variance between the cleft teams (as presented in Figure 18).

9. Overall experience of Cleft Lip and Palate Services

In addition to quantitative responses to the patient reported experience questionnaire items (described in previous sections), parents/patients provided qualitative feedback their experience of their cleft lip and palate service. Specifically:

- 82% respondents (437/530) provided feedback on the main reason they selected their FFT score (see Section 5);
- 87% respondents (461/530) provided feedback on 'what was really good about their care';
- 75% respondents (395/530) provided feedback on 'anything they did not like or anything that needs improving'; and
- 60% respondents (316/530) provided additional comments about the service they have received.
- In addition, 29% of parents/patients (316/530) provided feedback about their experience of completing the parent / patient experience questionnaire.

The qualitative responses have been analysed using an inductive thematic analysis, at a semantic level. This was conducted separately for parents (n=293), 10-11 years olds (n=84) and 15-20 year olds (n=95). Two researchers separately familiarised selves with data and completed coding and then worked collaboratively to compare and create final codes. Patterns within the data were identified and grouped together by colour codes. This then led to the development of themes. The themes and subthemes for each group along with examples of comments and detailed below. Comments regarding concerns or suggestions for improvement are shown in italics.

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[20] CHI-ESQ Score = Proportion of 'Certainly True' answers minus proportion of 'Not True' answers.

9.1. Parents. Candidate themes, subthemes and examples

Candidate Themes	Subthemes	Examples
Approach	**Supportive**	The support information and guidance has been professional and friendly. Very supportive from discovering my daughters cleft palate, throughout the operation and the aftercare. I don't feel like we were left on our own after the palate was repaired it has been a continuous service and level of care as my daughter has developed and grown. All the expenses were paid. Hospital stay was as comfortable as it could be. Staff were sympathetic and helpful. Aftercare visits from specialist nurse, follow up appointments were helpful and supportive. The way the nurses communicated with us helped us feel more confident in caring for our child. Answered every question we had. Very supportive. S***** always only a call away at anytime of the day. The help, advice and support which is available constantly. The cleft team feel like family and they have become good friends. Great support from antenatal through surgery and beyond. Fabulous repair.
	Caring	End to end patient care. Approachable staff, willing to answer questions, informative, helpful and genuinely caring. Right from the beginning when 1 day old we have always had excellent care. *Care is good but sporadic. We've had little contact for years then lots all in one go.* The pre-care and post-care following my son's surgery at Addenbrooke's was excellent. Prior to his birth my husband and I met the cleft nurse. She came to our home and answered the many questions on our mind and helped to alleviate any anxiety. We also had the opportunity to meet his consultant and schedule his surgery before he was born which once again was reassuring. The cleft nurse also came to our home to talk through the surgery and care needed after his surgery. We were given the opportunity to visit the ward and walk through the procedure at the hospital with the cleft nurse. After both his surgeries, we received care and support that can only be described as second to none. Six years on, and we still have the support from the cleft team, should we need it. I wouldn't change anything about the care and support we received and are still receiving and would highly recommend the service from Addenbrooke's to friends and family.
Expertise	**Competent**	Our overall experience has been super, always kept in contact with, talked through everything so we understand exactly what is happening. The cleft palate team put (child's name) at ease with information about her cleft palate and options that could be provided. Really friendly informative and smooth visit as always.

		Being kept informed at all times of the progress that was being made and what would be happening in the future. *Mr *** at Bristol has always been good. Initially when the cleft was diagnosed the hospital did not seem to know what advice was best to give.* All the staff knew what they were talking about and spoke so I could understand. Pleasant and informative, didn't feel rushed and our questions were answered satisfactorily.
	Outcomes	Outcome is good so far – physical appearance etc. Staff always friendly. Excellent overall result. Excellent surgery and follow ups. Operation went well. Monitoring speech, hearing etc. is very good. My daughter's operation and my nieces were both here, one palate one lip, both are very happy.
Organisation	**Team Work**	Team work with professionals. Being able to attend clinic with all professionals in one meeting. We never had to wait long to be seen and everyone is approachable. Seeing everyone in the same day but it does make for a very long day for 5 yr olds.
	Coordination	Clinic usually runs on time good to reduce anxiety and inconvenience. Did best to minimise waiting times. Efficient and fast. (Received very good support and care from the team, from before birth until now.) *The only criticism is the admin regarding changing appointment times and sending out wrong appointment time letters.* Clinic ran smoothly. With very little downtime.

9.2. 10-11 Year Olds. Candidate themes, subthemes and examples

Candidate Themes	Subthemes	Examples
Approach	**Support**	Everyone is friendly and want the best for me. The way they took care of me. People are kind and helpful. Everybody was really nice and gentle and had good support. I have had lots of support and help.
	Care (Listened to)	I was well looked after – all people involved were really kind and reassured me about the treatment and care I received. I feel like I'm being listened to. Because you take good/fantastic care about our patients.
Expertise	**Help**	It was good because no one decided to give up, and keep helping me. They can help me. They helped fix my lip and it is great ☺ I want them to keep on helping me.

		When my hand hurted with the needle and they were saying it was nothing and to stop complaining but when they took it out they had put it wrong and it was all bruised. Because they have helped me a lot and they sort everything out.
	Information	They explained everything very clearly. Getting the main information. Because all the staff are really nice, but they could explain things in more words I understand (eg. tell me the meaning [of] great long words)
Facilities	**Food**	The nice food and facilities. *The food wasn't great when I had my operation.*
	Entertainment	Having the iPad to play with. It is a place to meet new friends.
	Appointments	It was well planned, I wasn't sat around waiting for a long time. *It's a distance from where I live.* *It was too long*
	Waiting room/ Environment?	*The waiting room was quite hot.* *I wish it was warmer.* No nothing except *the uncomfortable chairs.* *Stop squeaky chairs.*

9.3. 15-20 Year Olds. Candidate themes, subthemes and examples

Candidate Themes	**Subthemes**	**Examples**
Approach	**Support** **(Friendly, Approachable, Helpful)**	Throughout all of my treatment at Alder Hey I have always felt that their priority was on me and how they can help. As well as everybody being very friendly and listening to my concerns, I have never felt that they didn't want to listen. I have had several orthodontic treatments by Alder Hey and even at 18 I am still not finished!! I can only continue to praise every body's efforts.
	Care **(Listened to, Respected, Continuity of Care)**	I am incredibly grateful for everything the people who looked after me did. High quality of care. I've been under the care of the Alder Hey cleft palate team since I was born to this current day. As well as providing me with surgery and several orthodontic treatments (brace after brace after brace!) they have also reassured myself and my mother throughout my treatment. Although my case of cleft palate is minor compared to the scale I have never felt as if I am less of a concern or less of a priority. I can only praise the efforts of all of the team and continue to thank them for all of their hard work!
Expertise	**Competent (Information, MDT, Skilled Professionals)**	All the different departments worked together and were all very happy and helpful when I saw them. All the departments were respectful and clearly explained all the things that affected me and my mouth.

		They knew exactly what to do regarding different aspects of my cleft. All the doctors are very good and explain clearly. Also they did my nose nicely.
	Outcomes (Surgery, Treatment)	*Some of the treatment didn’t work first time.* Extremely happy with the outcome. Because most people don’t even know I have a cleft palate. The team did a great job.
Organisation	**Accommodating**	(Thank you very much*) I would like to have had this form in Welsh.* *I think there should be a box you can tick at the age of 13-14. which says how many people you want in a meeting as having a therapist and speech therapist and a doctor and a nurse and more just for a simple meeting is too much like, whether you are shy or not. Also I feel like if you are going to ask questions about people’s mental health you should really let them do it on their own. Without a parent. And tell them how confidential it is. As I highly doubt people are accepting on a piece of paper given to doctors.* No*, however it would be nice if there was, for example, an online group in which I can talk to other teenagers with clefts like myself.*
	Appointments	*Yes. I am also not a huge fan of bringing people with cleft lips together as they grow up. People don’t need to be reminded they are different all the time. Let people live there’s lives. You’re making it worse by letting them see all the other people who are in your situation.* *As a patient I felt I ‘slipped through the net’. I was always contacting the cleft team for appointments etc as I was missed out often. They had very little time for me, always seemed over capacity and appointments always running behind, often by hours.* *Appointments during school time.*
	Facilities	*Children’s waiting room seems more targeted towards the younger children rather than teenagers like myself.* *The parking is not good.* *It’s a little intimidating having lots of people in the room for appointments.* *Waiting area too hot, too noisy.*

This qualitative feedback gives an insight into the factors that are important to parents and patients of different ages, which influence their reported satisfaction in a positive or negative way. Both positive feedback and feedback about concerns or suggestions for improvement are helpful in this respect. For individual teams this may lead to suggestions about what to do more of, what to maintain or what to do differently.

10. Conclusions

The feasibility study has shown that it is possible to collect patient satisfaction data using patient reported experience measures (PREM) with the protocol followed here. However, some cleft teams were very successful at collecting the feedback while others were less successful, and some teams felt they were unable to participate[21].

The data collected provides useful feedback, particularly when considering the quantitative data alongside the qualitative data, and shows the potential for teams to compare their data with cleft team means and ranges if certain criteria are met, such as a high enough number of returns. The data also provides the potential to identify teams receiving especially positive feedback, which could lead to a more detailed consideration of aspects of care provided.

Using this protocol allows cleft teams to meet the standards set in the National Service Specification commissioning document, which require teams to measure parent satisfaction with early years and patient and parent satisfaction in adolescence and at end of routine care (Recommended Standards 15 & 41). However, collection and analysis of the data has a cost in terms of resource, both locally in cleft teams and nationally in terms of coordination and analysis.

In terms of the detail of the protocol, a number of issues emerged as follow:

1. The paper and electronic methods of providing feedback each accounted for half of the data collected, suggesting it may be important to continue to have both methods available. Some teams had greater numbers of one type of return than the other and it may be important to explore the reasons for this in more detail.
2. The initial target ages were distinct bands but interim feedback from participating teams was that it was easier to ask everyone who came to clinic for feedback regardless of age, and so this was adjusted to continuous age ranges. Using continuous age ranges risks losing subtle differences in feedback given by different age groups but this is probably offset by the increased ease of collecting data and the resulting increased numbers of respondents.
3. It is challenging to compare the feedback given to teams where return rates are so varied. This study did not look at the numbers of people attending clinic i.e. the potential number of respondents, but this may be something that needs to be considered along with a target percentage return rate for teams.
4. A final issue is regarding anonymity. Respondents were not asked to give their name in this study to reduce response bias in the feedback. They were however asked to state the cleft team although this was not compulsory. This resulted in a small number of responses where the team was not identified and interestingly, these people gave the most critical feedback. In larger numbers this could be important feedback for the cleft team's generally but presents difficulties in terms of making sense of how it applies to individual teams.

The PREM Feasibility Study Team

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[21] **Leeds:** Was unable to collect data via paper questionnaires, as they had no resource to manage cleft team data entry. Their submissions resulted from parents/patients providing feedback via self-completions. **South Thames, Trent and Northern Ireland:** Did not have the resource to participate in the feasibility study at the time it was conducted.