

INTERVIEW QUESTIONS – LOCAL CLEFT TEAM PROVIDERS

Introduction

Thank you for taking the time to talk with me today. My goal over the next 30 to 45 minutes is to learn your perspective on the role of outcome measurement in treating children with cleft lip and cleft palate. **In particular, I would like to discuss measuring aesthetic outcomes of lip repair, dental outcomes, and speech outcomes.** I specifically wanted to talk with you because I think you may have some unique insights on this issue.

I would like to begin by hearing a little about your job on the cleft team. Could you tell me what your job is?

[if prompt needed] I think your job title is _____. Is that right?

And how you are involved in caring for children with cleft lip and cleft palate?

Do you have any other roles on the cleft team that you think I should know about related to our discussion?

How many years of experience have you had in cleft care?

How many years of experience working with your team?

Current practice for outcome measurement – cleft lip [maximum of 5 minutes]

Let's first talk about outcome measurement for cleft lip, then we'll cover the same ground for with cleft palate. **For cleft lip repair, think about the "outcome" as the appearance of the lip and nose after the lip repair.**

How do you know when a child has a good or bad outcome after cleft lip repair?

If answer globally, then ask: How do you evaluate individual outcomes?

Do you have any processes in place that help you evaluate outcomes of cleft lip repair?

If yes, what are they?

Does your team have any systematic processes in place for evaluating outcomes of cleft lip repair?

If yes, what are they?

What is the process for documenting results of those evaluations?

Current practice for outcome measurement – cleft palate [maximum of 5 minutes]

Now let's change gears and talk about treating children with cleft palate.

How do you know whether a child has a good or bad outcome from their cleft palate repair?

If someone gives the technical criteria, then: how do you evaluate patients using that criterion on a specific patient?

Do you have any processes in place that help you evaluate outcomes of cleft palate repair?

If yes, what are they?

Does the team have any systematic processes for evaluating outcomes of cleft palate repair?

If yes, what are they?

What is the process for documenting results of those evaluations?

Perceptions of Standardized Outcome Measurement

Now I would like to ask you some questions about the idea of “standardized outcome measurement,” by which I mean evaluating outcomes the same way, at the same age, on every child. **In particular, I am interested in your thoughts about measuring each child's aesthetic, dental, and speech outcomes in a standardized way when children are five years old.** *Go straight to the example for those that might struggle with the question (e.g. do you think taking pictures the same way each time for every patient would benefit the patient/provider?) (e.g. if a family didn't want to come into clinic what would you say to them to get them to come in?)*

How do you think standardized outcome measurement might benefit your patients?

If no benefit, why not?

Could you think of any specific treatment recommendation you might make after having done a systematic evaluation of appearance/dental/speech?

How might standardized outcome measurement benefit providers on the cleft team?

What do you think would be the downsides to doing standardized outcome measurement?

[optional as time allows] How do you think the patients treated by your cleft team would respond to collecting these standardized outcome measures?

----- Should be here no later than 20 minutes into the interview -----

Let's take a minute to discuss potential issues or challenges that your five-year-old patients might experience in trying to complete specific outcome measures.

What challenges might you encounter **in arranging for children to be evaluated at age five, or in making sure children present to clinic** at that age?

In terms of measuring the **appearance of a child's lip and nose**, what issues might you encounter in obtaining standardized photographs on your five-year-old patients?

What issues might there be to evaluating the presence of **dental carries (cavities)** in your patient's teeth?

What issues might there be in obtaining **dental models** in five-year-old patients?

In terms of measuring **speech outcomes**, what issues or challenges might your patients experience in having a standardized speech evaluation conducted at age five?

All cleft teams have unique strengths and weaknesses that impact how they serve patients. I'm interested in learning what you see as the unique features of your cleft team, so I can understand how that might impact the collection of outcome measures.

With this in mind, can you think of any unique features of your cleft team that would make it easier to collect standardized outcome measures?

Are there any unique features or aspects of your cleft team that you think might make it harder to collect standardized outcome measures?

[as time allows, elicit comments on each of the following environmental features]

How would affect collection of standardized outcome measures?

The medical records system(s) used by members of the team?

The organization of the team?

The team's leadership?

Having team providers practice at multiple locations?

Each cleft team serves a slightly different patient population. Thinking about the population of children served by your cleft team, what types of **challenges** might you encounter when trying to collect these standardized outcome measures at age five?

[attempt to elicit comments on each of the following environmental features]

How would affect collection of standardized outcome measures?

Different languages of the team's patients?

Social or culture issues unique to the team's patients?

Geographic distribution of the team's patients?

The insurance providers or medical payers in the team's region?

[optional as time allows] What could be done to address these challenges?

If the team wanted to start collecting standardized outcome measures on its patients, who would need to be involved to make that change successful?

[optional as time allows] Are you aware of any other cleft teams that have implemented standardized outcome measurement or similar programs?

Can you tell me what you know about the experience at those teams?

How has this information influenced your thoughts about outcome measurement in children with clefts?

[optional as time allows] In your opinion, how receptive would providers in your team be to implementing standardized outcome measurement?

Why?

Local experience with quality improvement initiatives

Implementing standardized outcome measurement could be a big effort for a cleft team, and I'm curious about your team's experience in general with making changes to processes for patient care.

Can you tell me about a recent improvement initiative or an implementation of a new process within your cleft team? This does not have to be a change related to outcome measurement, but rather it could be any change to your team's processes or patient care routines.

Can you describe the motivation to improve/implement it?

Can you tell me the major milestones or key accomplishments along the way?

What factors helped make it successful/fail?

Who were the key "players"?

Closing

Is there anything I have not covered that you think we would discuss?

Thank you for your time and for sharing your insights.

INTERVIEW QUESTIONS – PARENTS OF PATIENTS FROM LOCAL CLEFT TEAM

Introduction

Thank you for taking the time to talk with me today. My goal over the next 15 to 30 minutes is to learn your perspective on the role of outcome measurement in caring for children with cleft lip and/or cleft palate. **In particular, I would like to discuss evaluating appearance after cleft lip repair, dental outcomes, and speech outcomes.** I specifically wanted to talk with you because I think you may have some unique insights on this issue as a parent of a children with a cleft lip and palate.

I would like to begin by hearing a little about your experience as a parent. I believe your son/daughter has a cleft lip and palate, is that correct?

And how old is your son/daughter now?

And where has your son/daughter gone for treatment of their cleft?

Do you have friends or family whose children have been treated at other cleft centers?

What is your gender?

What is your ethnicity- Hispanic/Non-Hispanic?

What race do you identify with- Caucasian, Black/African-American, Native American/Alaska Native, Asian, Native Hawaiian/Pacific Islander, or More than one?

What is your highest Level of Education Completed?

What is your child's gender?

What ethnicity do you mark for your child?

What race do you mark down for your child?

What type of cleft- cleft lip, palate or both?

What is your child's birth order and out of how many children?

Current practice for outcome measurement – cleft lip

Let's first talk about evaluating the quality of cleft lip repair, then we'll cover the same ground for cleft palate.

As a parent, how do you evaluate **the appearance of your child's lip and nose after their cleft lip repair?**

When you see other children with a cleft lip, how do you decide if they have a good lip repair?

Current practice for outcome measurement – cleft palate

Now let's change gears and talk about cleft palate.

As a parent, how do you decide whether your child had a good outcome from their palate repair?

When you meet other children with a cleft palate, how do you decide if they had a good outcome?

Perceptions of Standardized Outcome Measurement

Now I would like to ask you some questions about the idea of “standardized outcome measurement,” by which I mean evaluating outcomes the same way, at the same age, on every child with a cleft. **I am interested in your thoughts about getting the same exact measurements in all children when they are 5 years old.**

For example, if we evaluated your child's nose or lip one way (took photographs a certain way or with certain angles) at the age of 5 and then evaluated another child a different way (took different pictures or angles, maybe didn't take as many pictures) do you think that would be ok?

Why or why not?

What do you think would be the downsides to doing the same outcome measurements in the same set of kids?

If we did a quick speech evaluation on your child which showed nothing concerning so we didn't do an in-depth evaluation and perhaps missed something, but in another child we did the quick evaluation which did show something concerning and they ended up with a full evaluation, would that be ok?

Why or why not?

What do you think would be the downsides to doing the same outcome measurements in the same set of kids?

How do you think children and families would respond if providers at the cleft team changed the clinic experience to include collecting these standard outcome measures?

----- Should be here no later than 20 minutes into the interview -----

Let's take a minute to discuss potential issues or challenges that children might experience in trying to complete specific outcome measures.

What challenges do you think children and families might have in **attending clinic appointments at age five**?

In terms of measuring **the appearance of a child's lip and nose**, what issues might children encounter if providers tried to obtain photographs of their lip and nose at age five?

What challenges has your child had in getting seen by a dentist (getting to a dentist and being at the dentist)?

What issues or challenges might children experience in having a **speech evaluation** conducted at age five?

All cleft teams have unique strengths and weaknesses that impact how they serve patients. I'm interested in learning what you see as the unique features of the Barrow cleft team, so I can understand how that might impact the collection of outcome measures by the team.

Can you think of any unique features of the Barrow cleft team that would make it easier to collect standardized outcome measures?

Are there any unique features or aspects of the Barrow cleft team that you think might make it harder to collect standardized outcome measures?

[optional as time allows] Are you aware of any other cleft teams that have implemented standardized outcome measurement or similar programs?

Can you tell me what you know about the experience at those teams?

How has this information influenced your thoughts about outcome measurement in children with clefts?

When we do the comprehensive evaluations, how would you like to receive the results?

Method- mail/phone/consultation

Specifics- overall general results, specific results for child, child compared to others

Focus on opportunities to improve things or status of child's care?

Closing

Is there anything I haven't covered that you thought we would discuss?

Thank you for your time and for sharing your insights.

INTERVIEW QUESTIONS – UNITED KINGDOM CLEFT SPECIALISTS

Introduction

Thank you for taking the time to talk with me today. My goal over the next 30 to 45 minutes is to learn your perspectives on the role of outcome measurement in treating children with cleft lip and cleft palate. **In particular, I would like to discuss measuring aesthetic, dental, and speech outcomes.** I specifically wanted to talk with you because I think you may have some unique insights on this issue from your knowledge of existing processes in the United Kingdom.

I would like to begin by hearing a little about your job in caring for or evaluating outcomes of children with cleft lip and/or cleft palate. Could you tell me what your job is?

Do you directly care for children with cleft lip and cleft palate?

If so, how are you involved in their care?

How are you involved in evaluating treatment outcomes of children with cleft lip and cleft palate?

Do you have any other roles related to cleft lip and palate care that you think I should know about related to our discussion?

Current practice for outcome measurement – cleft lip

Let's first talk about outcome measurement for cleft lip, then we'll cover the same ground for with cleft palate. **For cleft lip repair, think about the "outcome" as the appearance of the lip and nose after the lip repair.**

In your current role, how do you evaluate outcomes of cleft lip repair?

At what age are the children when you do those evaluations?

How do you document results of those evaluations?

How do you use results from those evaluations?

Current practice for outcome measurement – cleft palate

Now let's change gears and talk about treating children with cleft palate.

In your current role, how do you evaluate outcomes of cleft palate treatment?

At what age are the children when you do those evaluations?

How do you document results of those evaluations?

How do you use results from those evaluations?

Perceptions of Standardized Outcome Measurement

Now I would like to ask you some questions about the idea of “standardized outcome measurement,” by which I mean evaluating treatment outcomes the same way, at the same age, on every child. **In particular, I am interested in your thoughts about measuring each child’s aesthetic, dental, and speech outcomes in a standardized way when children are five years old.**

How do you think standardized outcome measurement benefits patients?

If no benefit, why not?

How do you think standardized outcome measurement benefits providers?

What do you think are be the downsides to doing standardized outcome measurement?

How do patients respond to collecting these standardized outcome measures?

Let’s take a minute to discuss issues or challenges that five-year-old patients experience in trying to complete specific outcome measures.

What challenges does your team encounter **in arranging for children to be evaluated at age five, or in making sure children present to clinic** at that age?

In terms of measuring **aesthetic outcomes**, what issues do five-year-old children encounter in obtaining standardized photographs?

What issues are there to evaluating the presence of **dental carries (cavities)** in patient’s teeth?

What issues are there to obtaining **dental models** in five-year-old patients?

In terms of measuring **speech outcomes**, what issues or challenges do patients experience in having a standardized speech evaluation conducted at age five?

All cleft teams have unique strengths and weaknesses that impact how they serve patients. What features or characteristics of a cleft team make it easier to collect standardized outcome measures?

Are there any unique features or aspects of a cleft team that you think make it harder to collect standardized outcome measures?

[as time allows, elicit comments on each of the following environmental features]

How does.... affect collection of standardized outcome measures?

The number of providers and staff on the team?

The physical layout of the cleft center?

The medical records system(s) used by members of the team?

The organization of the team?

The team's leadership?

Having team providers practice at multiple locations?

Each cleft team serves a slightly different patient population. What features or characteristics about the team's patient population make it easier to collect these outcome measures?

What features or characteristics about the team's patient population make it harder to collect these outcome measures?

[attempt to elicit comments on each of the following environmental features]

How do.... affect collection of standardized outcome measures?

Different languages of the team's patients?

Social or culture issues unique to the team's patients?

Geographic distribution of the team's patients?

[optional as time allows] What could be done to address these challenges?

In your experience, what changes does a cleft team need to make if providers wanted to collect standardized measurement at age five?

Who on the team needs to be involved to make these kinds of changes?

Are these changes possible for every cleft team? Why or why not?

When teams in the United Kingdom first started collecting standardized outcome measures, how did collection of these measure fit with existing work processes and practices by the teams?

What were the issues or complications that arose?

Intervention Characteristics and Processes for Standardized Outcome Measurement

When cleft centers started conducting routine audits of their patients, what changes did centers make to the measures or how they were collected?

Can you give any examples of these changes? Why did the changes happen?

Are there any ongoing changes to the outcome measures being collected? Either the actual measures or the process of collecting them?

If the process of routine audits in the UK was being completely revised, which components of the current system should not be altered (i.e. which elements are essential and indispensable)?

How complicated is the process of standardized outcome measurement for the five-year-old audits?

Consider the following aspects of the intervention: scope, intricacy and number of steps involved and whether the intervention reflects a clear departure from previous practices.

Who are the key influential individuals to get on board to be successful in implementing standardized outcome measurement?

Who should lead the implementation of standardized outcome measurement within a cleft team?

How should this person be selected? Appointed? Volunteered? Voluntold?

What attributes or qualities would this person have to make them an effective leader of this implementation?

Closing

Is there anything I haven't covered that you thought we would discuss?

Thank you for your time and for sharing your insights.