# What do young people with cleft lip with/without palate think about their appearance?

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## Introduction

Over one thousand babies each year in the UK are born with a cleft of the lip and/or palate which makes cleft the most common congenital anomaly affecting the face.[1] Repair of the cleft results in a scar and therefore a visible difference.[2] The literature reports that on average children born with a cleft will have 8.6 operations before they are twenty-one and these surgical procedures are often to improve the Young People's (YP) appearance.[3] Due to the existence of a visible difference, evidence shows that this can result in a greater risk of the YP experiencing problems with their well-being and self-esteem.[4] Whilst discussing their appearance at a focus group, the YP with cleft, aged 16-20 years, highlighted a concern about taking and sharing of photographs on social media, for fear of negative comments from their peers.[5] Therefore, as the YP have highlighted concerns with appearance, when looking at their image in photographs it is suggested that photo-elicitation may be a beneficial approach when exploring their views and experiences. Photo-elicitation is an approach that uses photographs to facilitate conversation during a research interview.[6]

## Methods

- Reflexive thematic analysis (Reflexive TA) was the qualitative methodology. [7]
- Photo-elicitation[6] was used to facilitate the discussion.
- Virtual semi-structured interviews were conducted
- The YP were asked to provide three photographs of themselves that they liked and three that they did not like, and these were discussed.
- Recordings from the interviews were transcribed verbatim and analysed using Reflexive TA.

## Results

Demographics

- n = 13 YP aged 16-20 years (Mean age = 17.8 years)
- 10 females and 3 males
- 2 with cleft lip (CL) only, 9 with a unilateral cleft lip & palate (UCLP) and 2 with a bilateral cleft lip and palate (BCLP)

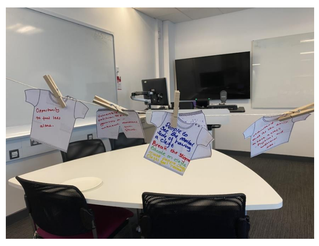
Reflexive TA led to the identification of four separate but overlapping themes which summarise the YP's thoughts about their appearance. It highlighted how they control how others see their self-image, their acceptance of their cleft and how they have learnt to feel empowered to share their journey both in-person and online. Quotes have been taken from the interview transcripts to convey the YP's experiences.

## Conclusions

- This study as with previous research[8] identifies the challenges of living with a visible difference such as cleft.
- It considers the views of the YP and explores what they think about their appearance. This can inform clinicians.
- It discusses the strategies they use when taking photographs of themselves, so they feel happy with their appearance.
- It hears how school was a challenging time for many but how they have come to accept their cleft with the support of family and friends.
- It discusses how empowered the YP have felt making connections with their peers with cleft, through sharing their 'cleft journey' both in-person and on social media.
- Finally, it explores how important it is to take control of their treatment as an adult and how they have learnt to accept their cleft following discharge. It is hoped that exploring the YP's experiences may highlight areas where further support can be provided and areas where further investigation is needed.

## Feedback from Young People

All participants were invited back to discuss the results of the research project and to see if they agreed with the themes. This was met very positively, and the themes were agreed with the YP. Also discussed were the YP's hopes and fears for the research results and where they would like the results of the research disseminated.



Hopes and fears

Where the results should be disseminated

## Future Research

Instagram posts of people with a visible difference can reduce stigma[9] and social media can have a positive influence in other areas such as obesity.[10]

Therefore, future research which encourages YP to feel confident about their appearance and to share images of themselves online should have benefit for both YP with cleft and the broader community through potential reduction of stigma.

A Doctoral study with the same authors has been agreed to look further into this area with the YP with cleft.

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