

# Understanding long-term impacts of cleft-related speech differences in New Zealand adults

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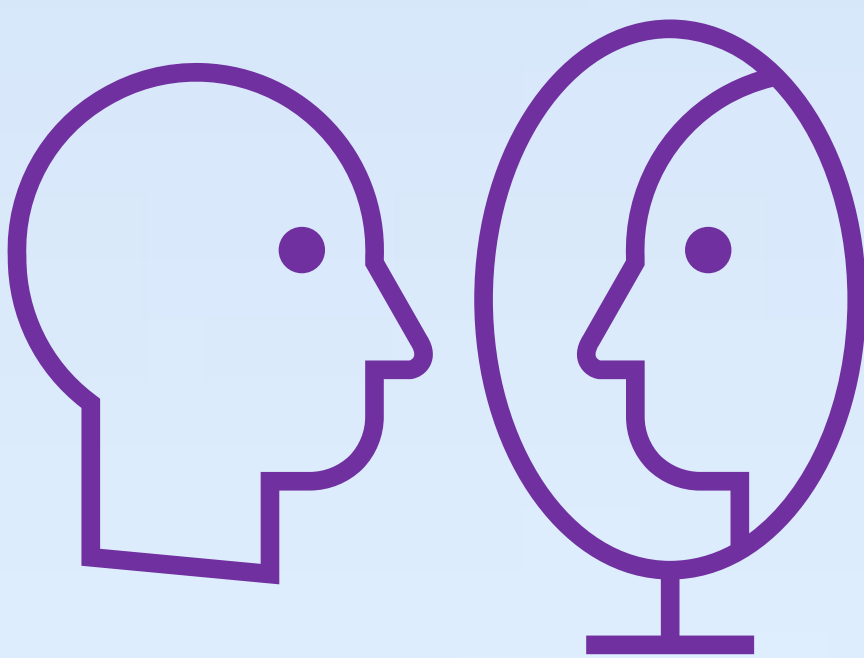
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## Background and Aims

The **largest group of people living with repaired cleft lip and/or palate are adults**. Previous research has identified **cleft-related concerns can persist well into adulthood**, and cleft is increasingly recognised as a lifelong condition. Although the physical impact of cleft on speech is well understood, the social and psychological impacts of cleft-related speech differences have not been widely explored. The aim of this study was to **examine people’s own perception of their cleft-related speech differences in adulthood**, and the impact that this may have had on **their education, work and social lives**.

## Methods and Participants

**Seventeen people with cleft aged 18-84** participated in a **semi-structured interview** (analysed using inductive thematic analysis) and completed **self-report measures of speech intelligibility and acceptability**, and **Harter measures of sociability and job competence** (compared to norm data and reported using descriptive statistics).



### Experiences of Speech Differences and Speech Language Therapy (SLT)

- More **concern with Speech Acceptability** than Speech Intelligibility
- Most participants reported some **ongoing cleft-related speech differences**
- Some participants **avoid activities which involve speaking** - e.g. talking on the phone
- Around half had received SLT input – **older participants were less likely to have received SLT services**
- Of those who had received SLT, **most were satisfied with the service**
- **Around half would like to see SLT now** for further intervention if available

### Educational, Vocational and Social Experiences

- People **perceived their cleft as positive, neutral, or negative** – e.g. some participants felt cleft had helped their career, others felt it had hindered them
- **Many had avoided opportunities** due to cleft-related differences
- **Most had experienced prejudice in their lifetime** – including bullying, overt discrimination, unconscious bias.
- People had **strong family relationships and friendships**, but **difficulty initiating new friendships and romantic relationships**.
- **Cleft-related concerns influence intimacy** – e.g. scars on hips from alveolar bonegraft, fear about function during kissing
- Most people **thought about their cleft when meeting somebody** for the first time

### Emotional Wellbeing

- Many reported **presence of a psychological disorder**
- **Low self-esteem and self-worth** were common
- Some engaged in **risky or avoidant behaviours** which they attributed to unmet cleft-related psychological need
- **Only three people had ever received psychological support**, and of those, **only one had their support publicly-funded**
- **No-one felt enough attention was given to the emotional wellbeing needs associated with cleft**
- **More than half would access Clinical Psychology services today if available**
- Cleft was generally viewed as a lifelong condition, and **all participants supported having access to cleft care at any age**
- Some participants developed a sense of resilience, however others felt they had not

## Key Recommendations



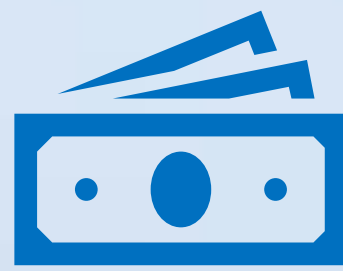
**Patient reported outcome measures**



**Clinical review at age 20 years**



**Cleft Service Specification**



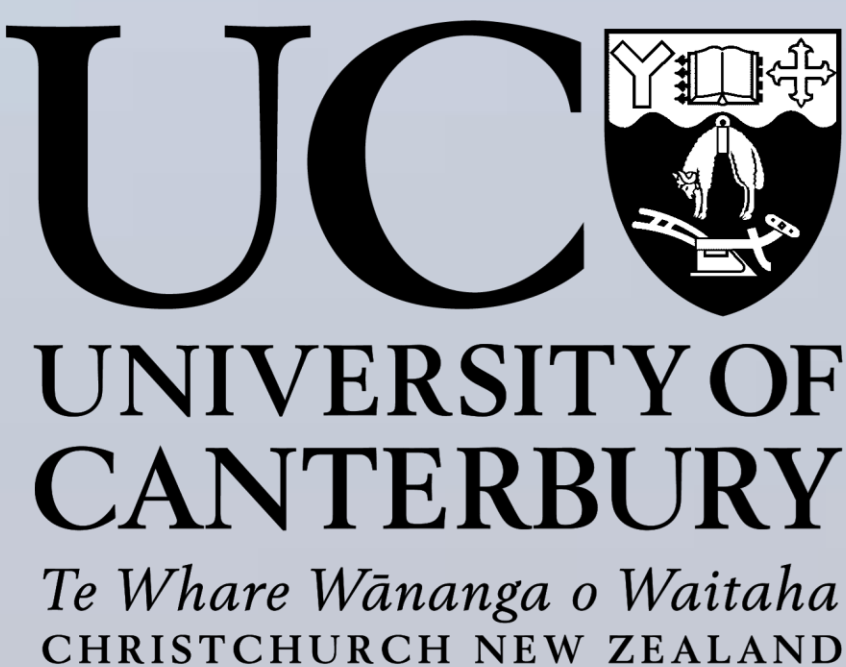
**Provision of lifelong cleft care**



**Clinical Psychology on Cleft Teams**



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