

# This is Personal: Understanding the Experiences of People with Lifelong Communication Disability Reading their Allied Health Reports

Harmony Turnbull, Leigha Dark, Phillippa Carnemolla, Ian Skinner, Bronwyn Hemsley

People with lifelong communication disability have a right to access and understand their health information

## AIMS

- To **understand** the experiences and views of adults with lifelong communication disability about accessing, understanding, appraising, and using information in their allied health reports.
- To **identify** barriers and facilitators for improving allied health reports.
- To **reduce** health literacy barriers for people with lifelong communication disability.

## METHODS

- In-depth interviews with 9 Australian adults, aged 25 – 54 with lifelong communication disability.
- Data analysed with reflexive thematic analysis underpinned by a health literacy framework.
- Participants reviewed interpretive summaries to confirm accuracy.



## RESULTS

### Theme 1: "This is personal"

#### We need to access and to understand

3 participants had not received their reports. Language and format make reports hard to read.

"I didn't know that in the background they write reports about me..." (P6)

#### This is emotional

Reading reports is highly personal and sometimes upsetting.

"It can be traumatic... and it is for me." (P9)

#### Build a trusting relationship with us

Trusting relationships were essential mean that reports are more useful.

"I have to (have a) good relationship with (the allied health professional) first..." (P2)



"That's the easy to read one. It's still very hard to read and understand." (P4)



### Theme 2: "These are our documents"

#### Your content to achieve our purposes

Reports should help people achieve their goals, not just for funding body requirements.

"It is written to make the person look the most disabled" (P1)

#### Our reports need to be an accurate representation

Participants want reports that reflect their strengths, needs, and lived experience.

"I think these report(s) are good to get funding. However, it's so hard to read." (P2)

#### We have feedback for you

Participants wanted opportunities to review and comment on reports before finalisation.

"[Inaccuracies] often get copied and written on the next report." (P9)

"Ask people for feedback on your reports and listen to the answers." (P8)



Turnbull, H., Dark, L., Carnemolla, P., Skinner, I., & Hemsley, B. (2026). 'I Didn't Know That in the Background They Write Reports About Me': Understanding the Health Literacy Implications of Allied Health Reports through the Experiences of People With Lifelong Communication Disability. *International Journal of Language & Communication Disorders*, 61(2), e70216. <https://doi.org/10.1111/1460-6984.70216>

