



# Unheard voices: The patient experience of people with communication disability

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# Background

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Measuring patient experience is important.

Provides an essential perspective on the safety and quality of patient care and provides direction for ongoing improvement.

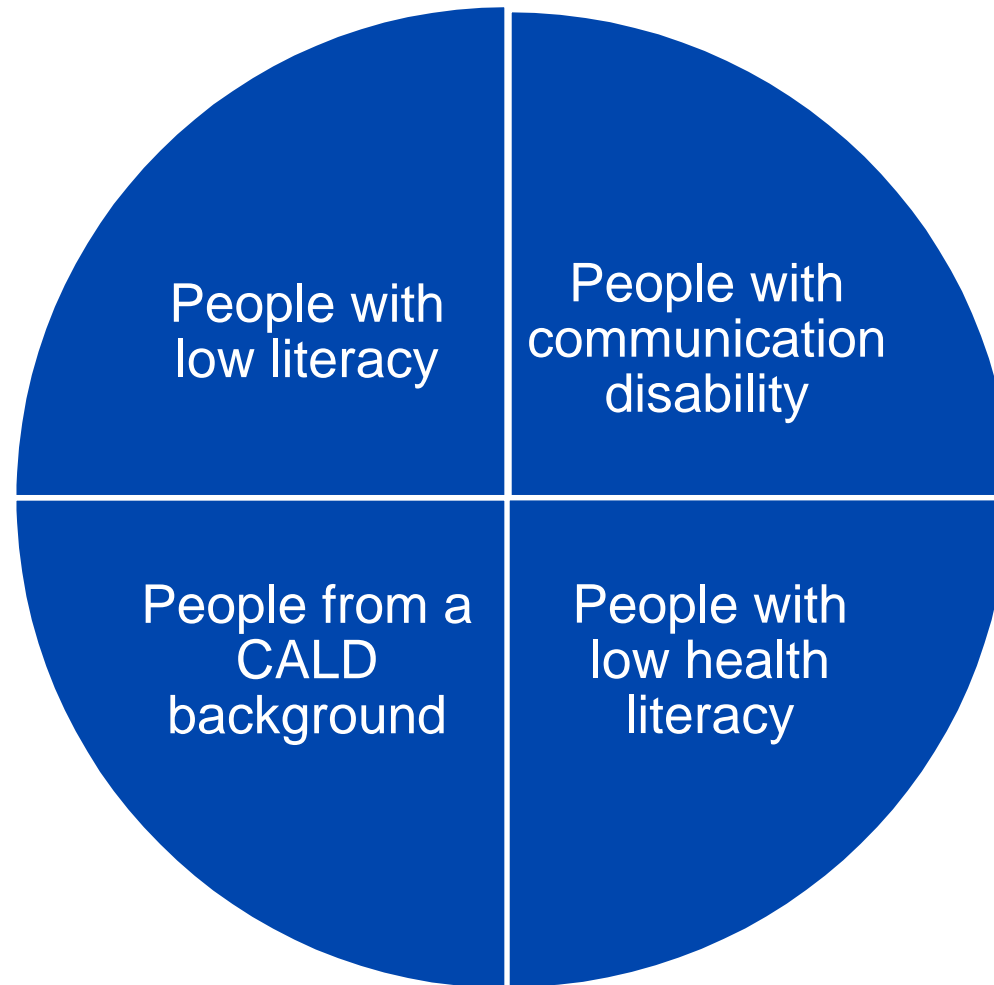
## **Targeting Zero: Recommendation 10.**

**The system must have a stronger focus on improving patients' experience of care.**

Department of Health. (2016). *Targeting zero. Supporting the Victoria hospital system to eliminate avoidable harm and strengthen quality of care.* Department of Health, Melbourne.

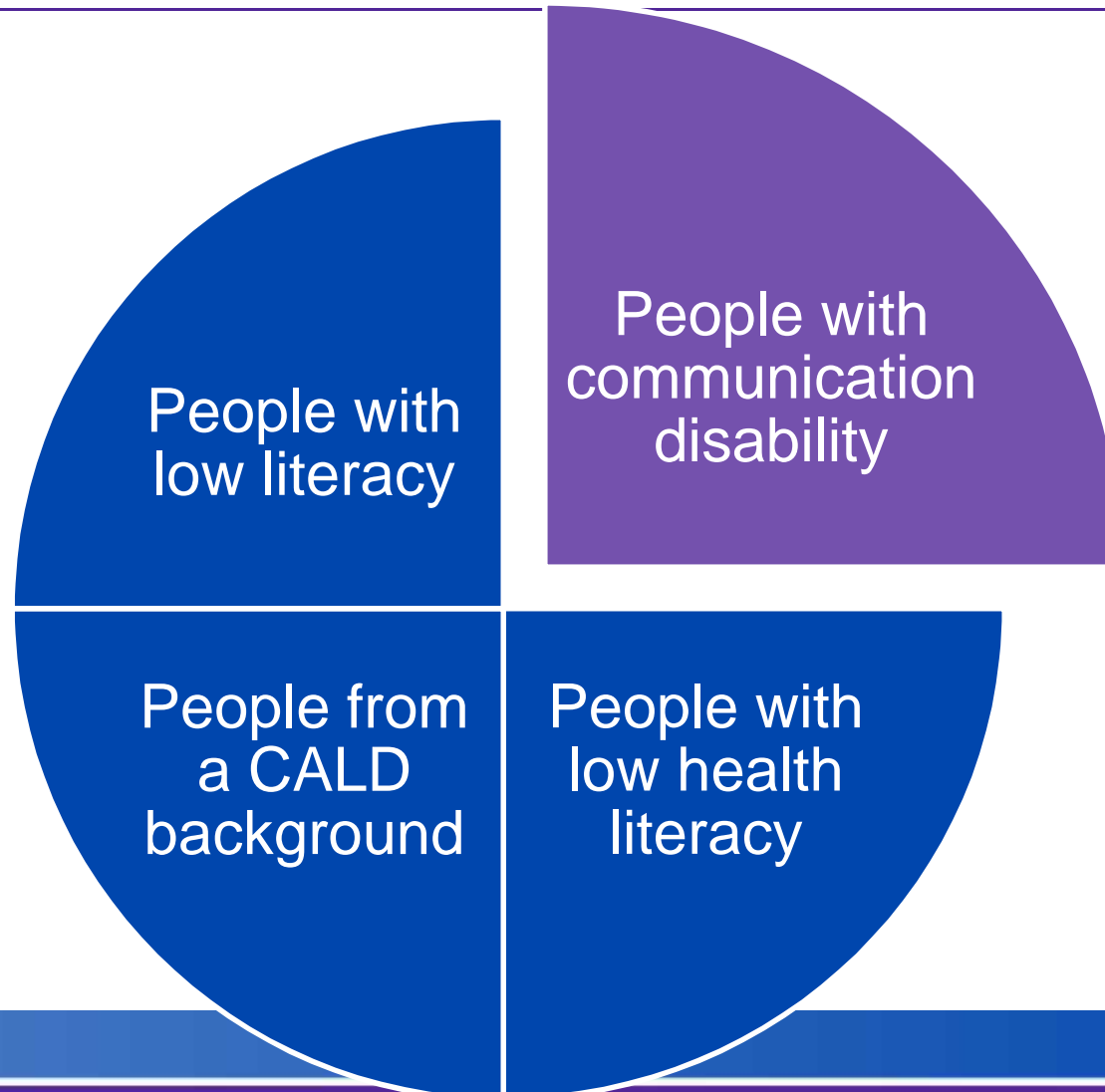
# People who may have difficulty communicating with healthcare providers

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# Overall research question: Are we hearing about the patient experience of people with communication disability?

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- DoH Victorian Healthcare Experience Survey (includes the Australian Commission of Safety and Quality in HealthCare (ACSQHC) national core common patient experience questions)
- Press Ganey Survey (SVHA)
- Volunteer surveys
- Analysis of complaints and compliments

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# The Victorian Healthcare Experience Survey (VHES)



## Your hospital experience

Reminder: Please complete this survey in relation to the hospital experience identified on the cover of this booklet. If you cannot answer a question, simply leave it blank.

### ADMISSION TO HOSPITAL

- Q1** Was this hospital stay planned in advance or an emergency?
- Planned in advance (waiting list)..... **Go to Q6**
  - Emergency
  - Something else

### THE EMERGENCY DEPARTMENT (ED)

- Q2** How would you rate the politeness and courtesy of staff in the ED?

- Q5** Overall, how would you rate the care and treatment you received from your nurses in the ED?
- Very good
  - Good
  - Neither good nor poor
  - Poor
  - Very poor

Emergency patients, now please Go to Q8.

WAITING LIST OR PLANNED ADMISSION



# Are we hearing about the patient experience of people with communication disabilities through the VHES?

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1. The survey questions would need to include aspects of care that are important to people with communication disabilities in hospital.
2. People with communication disabilities would need to be able to independently report on their patient experience on the VHES.





# Method: Q1. Do the VHES survey questions include what is important to people with communication disabilities?

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## *Participants*

- 8 patients with a documented communication disability (speech, language, cognitive, vision or hearing)

## *Procedure*

- After discharge, participants were interviewed about their experience in hospital.
- “What is important to you when you are in hospital?”
- Communication supports when needed
- Interviews audio/ videorecorded and transcribed
- Analysed for themes.

Compared these themes with the:

- The ACSQHC national core common patient experience question set (18)
- And remaining VHES patient experience question set (18 ACSQHC + 71)

# Results: Q1. Do the VHES survey questions include what is important to people with communication disabilities?



| No. of p'pants | Medical diagnosis                       | Acute/ Rehab | Communication Disability                     | Communication preference                      |
|----------------|---|--------------|--|---|
| 1              | (pre existing)<br>Acquired brain injury | Acute        | Speech, language and cognitive               | Verbal / Communication supports               |
| 5              | Stroke                                  | Rehab        | Hearing, speech, language and / or cognitive | Verbal/ Communication supports, including AAC |
| 1              | (pre existing)<br>Multiple sclerosis    | Rehab        | Language, cognitive                          | Verbal /Communication supports                |
| 1              | Head and Neck Surgery                   | Acute        | Speech                                       | Verbal/ Communication supports                |

Results: Q1. Three major themes, one moderately strong theme, two minor themes

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## 1. Feeling informed

- “understanding the purpose of going into hospital”
- “understanding diagnosis and treatment”
- “being included in treatment decisions if possible”
- “giving consent”
- “being supported so I can be informed”



## Participants said:

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**P6** “Well the physiotherapist and the OT were very good and they explained things”

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**P7** “But for me it’s important because I’m going into rehab for a reason and the details for why that is sort of .....

(I’m) just trying to get a handle on the situation”

\*\*\*

**P8**

R: What kind of information would you have liked?

8: Oh, just how I was travelling, you know?

R: Yeah


8 : And progress, you know?



# Results

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## 2. Feeling emotionally cared for

- “get to know the staff, the staff get to know them”
  - “felt thought of, not forgotten”
  - “being treated with friendliness”
  - “being encouraged and supported”
  - “being treated like a person”
  - “feeling comfortable”
  - “feeling comfortable because family is informed”
  - “being helped (simple tasks at my pace)”
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## Participants said:

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P6: “having the same people look after you, you feel comfortable then”

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R: Did you feel like they gave you enough time when they were with you?

P10: No, they did they had to

R: They did what they had to?

P10: And then they went

\*\*\*

P8: Sometimes some of them spoke to me more (pointing to himself)

Which is useful because, in the hospital you see it's nice to hear somebody talking to you (gesturing to himself)

# Results

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## 3. Feeling medically cared for

- “feeling medically safe”
- “good medical care”

## Participants said:

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- P8: the tracheostomy tube, that came blocked  
and you can't breathe  
That was at night time  
And [xx down?] eventually  
I was sitting up in bed  
I pressed the button  
And I was banging my thing on the side of the bed  
Nothing was happening  
What seemed like forever
- P8: And that was very serious and I couldn't call out for help  
I was stuck in the bed and drips and things everywhere



## Participants said:

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P8: they put me on a bed the second time near the door

R: Near the door?

P8: So I could see out to where the nurses were

And that felt happier

# Are we hearing about the patient experience of people with communication disabilities through the VHES?

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1. The survey questions would need to include aspects of care that are important to people with communication disabilities in hospital.

Do they?

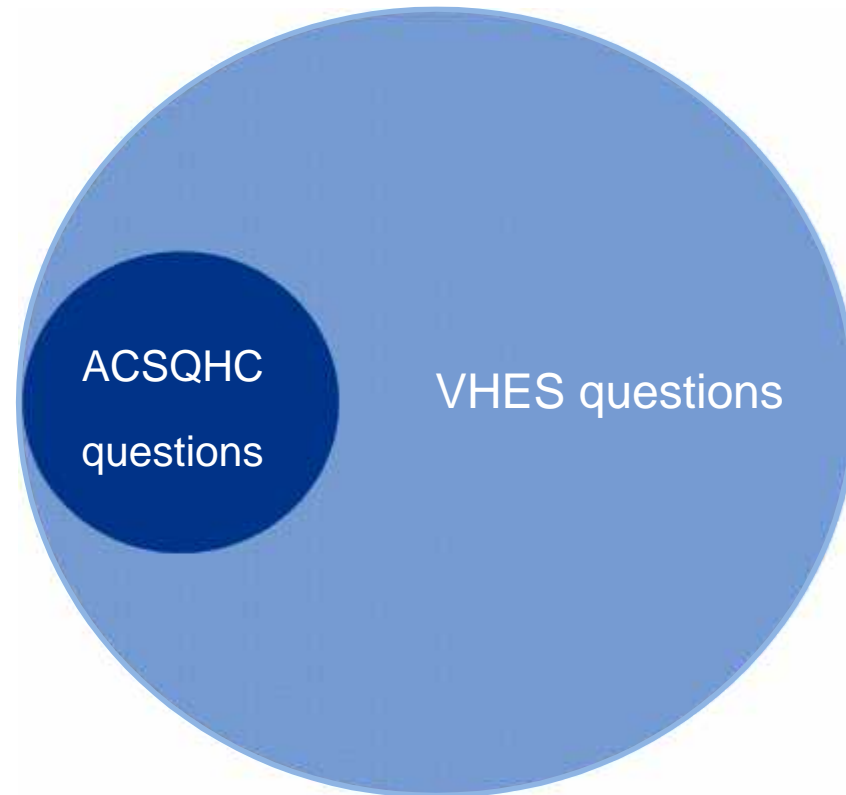


# Mapped themes to ACSQHC and VHS questions



| Major theme      | Subthemes of each major theme                                    | Categories in subthemes  | ACSQHC National core common pt ex questions  | VHS questions   |
|------------------|--|--|--|---|
| FEELING INFORMED | Understanding the purpose of going into hospital (planned rehab) | So I can judge/ decide if being in hospital is worth it for me personally              | Q. 3 were you involved as much as you wanted to be in decisions about your care and treatment?   | Q. 37 were you involved as much as you wanted to be in decisions about your care and treatment?   |
|                  | Understanding what's going on (diagnosis and treatment)          | Understanding what had happened<br><br>Understanding about what's going on / happening | Q. 2 Did the health professionals explain things in a way that you could understand?<br><br>Q. 2 Did the health professionals explain things in a way that you could understand? | Q. 33 How often did the doctors, nurses and other healthcare professionals caring for you explain things in a way that you could understand?<br><br>Q. 38 How much information about your condition and treatment was given to you?<br><br>Q. 33 How often did the doctors, nurses and other healthcare professionals caring for you explain things in a way that you could understand?<br><br>Q. 38 How much information about your condition and treatment was given to you?<br><br>Q. 51 Did you receive sufficient information about any medication you were given while in hospital (e.g. purpose, side effects and how to |



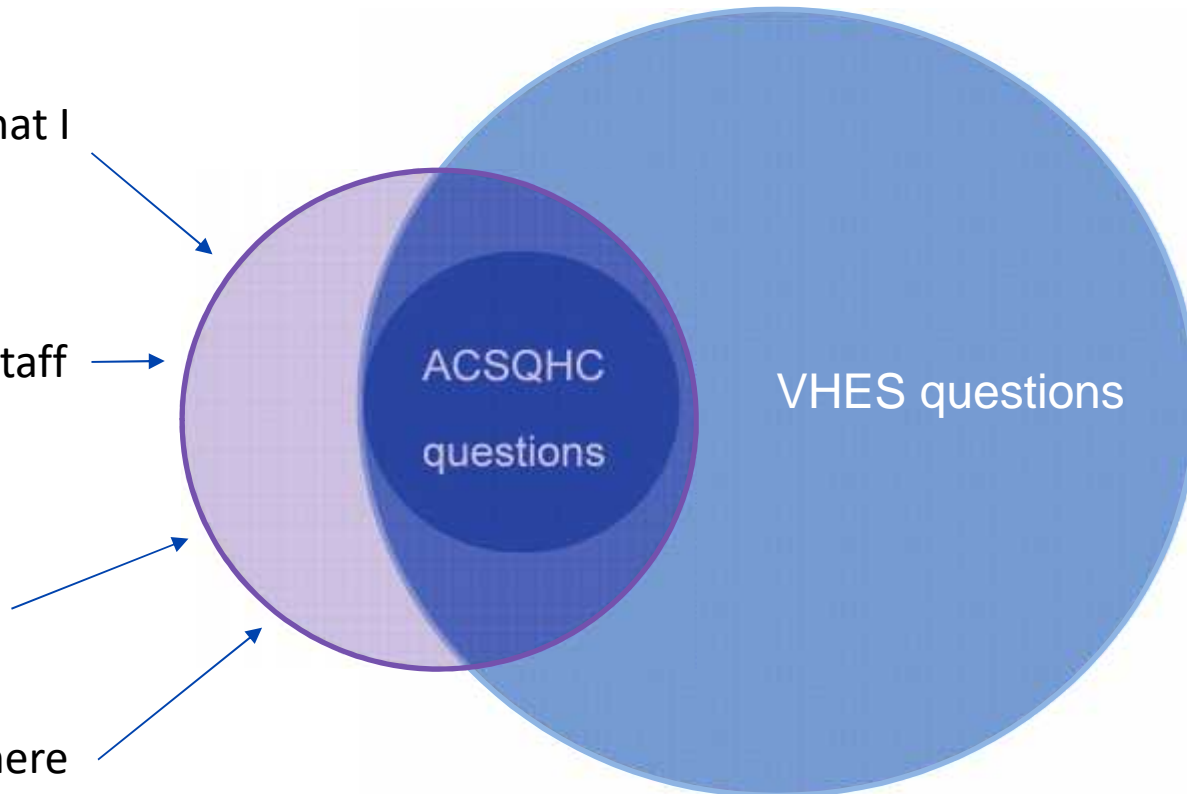


Being supported so that I  
can be informed

Getting to know the staff

Being thought of, not  
forgotten

Having staff close, where  
they can see me, hear  
me



## Summary: Are we hearing about the patient experience of people with communication disabilities through the VHES?

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Q1: Do the survey questions include what is important to people with communication disabilities in hospital?

A: **MOSTLY** (but there are some aspects of care important to people with communication disability that are not included in the survey)

Q2: Can people with communication disabilities independently report on their patient experience on the VHES?

A: **NO**



# Key messages

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- It is important that we understand what is important to patients with communication disabilities.
  - It is important that we accurately measure the experience of patients with communication disabilities.
  - The ACSQHC and the VHES survey *do not* capture all the aspects of care that matter to people with communication disability.
  - People with communication disability *can not* independently complete the VHES hospital paper and pen survey.
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# Thank you



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