AlfredHealth

Disability Data Systems to Identify and Support People with Disability Business Analysis Findings

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1 EXECUTIVE SUMMARY

Introduction

The SPEAK project is a service improvement initiative to improve the experience and quality of healthcare for people with disability (PWD) accessing Alfred Health. One of the objectives of the project is to:

- Improve data systems to enable proactive identification and planned support of people with disability to maximise outcomes and improve safety

This report details two areas of work undertaken to meet this objective:

1. Disability Identification Questions Review
2. Business Analysis

Background

Disability Identification Questions Review

Through implementation of the Rapid Response Disability Liaison Officer (RRDLO) service in Emergency and Trauma Centre (E&TC) as part of the SPEAK Project, there was improved awareness for the importance of early identification of disability to support patient care. A collaborative decision was made to review and update the existing disability identification questions used in the inpatient setting and implement them into the workflow of emergency nurses.

Business Analysis

A business analysis was conducted to understand the current problem for PWD and the staff caring for them, in relation to data systems. This included workshops with staff and consumers, and a review of data relating to patient experience and healthcare quality. The current processes used for disability identification and associated data systems were mapped for three areas: emergency, inpatients and specialist clinics. Limitations of the current systems and processes were identified.

Activities and Results

Disability Identification Questions Review

The questions had not been updated since 2018 when they were first introduced into the inpatient nursing assessment as part of the Electronic Medical Record (EMR) roll out. The questions were reviewed following feedback from consumers and staff. In June 2024, the questions were updated in the existing nursing admission forms and were added to the emergency Primary Nursing Survey to enable disability identification for presentations to Alfred Health's two emergency departments (ED). Training was undertaken with key groups and supporting education material created.

Business Analysis

Currently there is no standard process to identify PWD across Alfred Health. While there is a process to identify PWD when they present via the ED or when admitted to an inpatient ward, identification of PWD through other entry points, such as specialist clinics, is ad hoc.

The disability impacting care alert, a key part of the identification workflow, does not link to further information about disability type or support needs. The alert does not display in data systems used by specialist clinics or radiology.

There is no consistent location for disability information in the electronic medical record (EMR). There are multiple locations for staff to look which is inefficient and unintuitive.

There is not a consistent definition for disability at Alfred Health. Quality and safety outcomes are reported using the disability impacting care alert to identify PWD. This is a sub-population of the wider

disability cohort who have additional care needs. The disability identification questions do not align with definitions referred to in policies and procedures nor the staff disability awareness training.

Recommendations

Disability Identification Questions Review

- Evaluate the introduction of the questions in ED by measuring the incidence of disability alert activation.
- Determine if the questions reliably identify the target population.
- Incorporate further work with recommendations from the business analysis.

Business Analysis

- Adopt a clear definition for disability across the organisation.
- Develop a standard process to reliably identify PWD across all entry points.
- Review the utility of the disability impacting care alert and enable it to link to further relevant information.
- Create a central location for staff to locate patient access and support needs information within the EMR.
- Build capability to report on different cohorts of PWD for outcomes determined by disability experts.

Conclusion

The processes and data systems that collect, record and display disability information can be optimised to provide PWD a more positive patient experience and better support staff to meet their needs.

2 BACKGROUND

In April 2020, Alfred Health received an Information, Linkages and Capacity (ILC) – Mainstream Capacity Building program grant from the Department of Social Services to undertake the SPEAK (SPecialist Education And Knowledge) Project. The aim of this grant opportunity was to fund projects to produce improved practice approaches in health service systems that enable:

- People with disability (PWD) to use and benefit from the same mainstream health services as everyone else.
- Improved access and use of mainstream health services by people with disability.

Alfred Health partnered with Southwest Healthcare (SWH), a regional health service based in Warrnambool, Victoria, to deliver this project. The project commenced in September 2020.

Project aim

To build capability in the health workforce and improve processes to meet the healthcare needs of people with disabilities, particularly autistic people, and people with intellectual disability or communication disability.

Project objectives

1. Test a rapid-response secondary consultation model (key areas – emergency, acute wards and acute mental health services).

2. Provide evidence-based staff training to build the capacity of the workforce (improve communication processes between staff and people with disabilities and resource use).

3. Develop improved consumer feedback processes to amplify the voice of people with disabilities.

4. Improve the range of resources to facilitate improved communication between staff and people with disabilities.

5. Develop/enhance data systems to identify, plan and support people with disabilities to maximise outcomes and improve safety.

This report focusses on the delivery of Objective 5 and is split into 2 key pieces of work:

- Disability Identification Questions Review, and
- A Business Analysis.

3 DISABILITY IDENTIFICATION QUESTION REVIEW

Five disability identification questions were introduced into the inpatient nursing assessment Powerform when the Electronic Medical Record (EMR) went live in 2018 (see Figure 1). The first question was mandatory and if answered as 'yes' then the 5th question was also mandatory. The 5th question was used to trigger the disability impacting care (DIC) alert. The 2nd, 3rd and 4th questions were optional to answer. There was no staff training that accompanied the introduction of these questions into the nursing assessment.

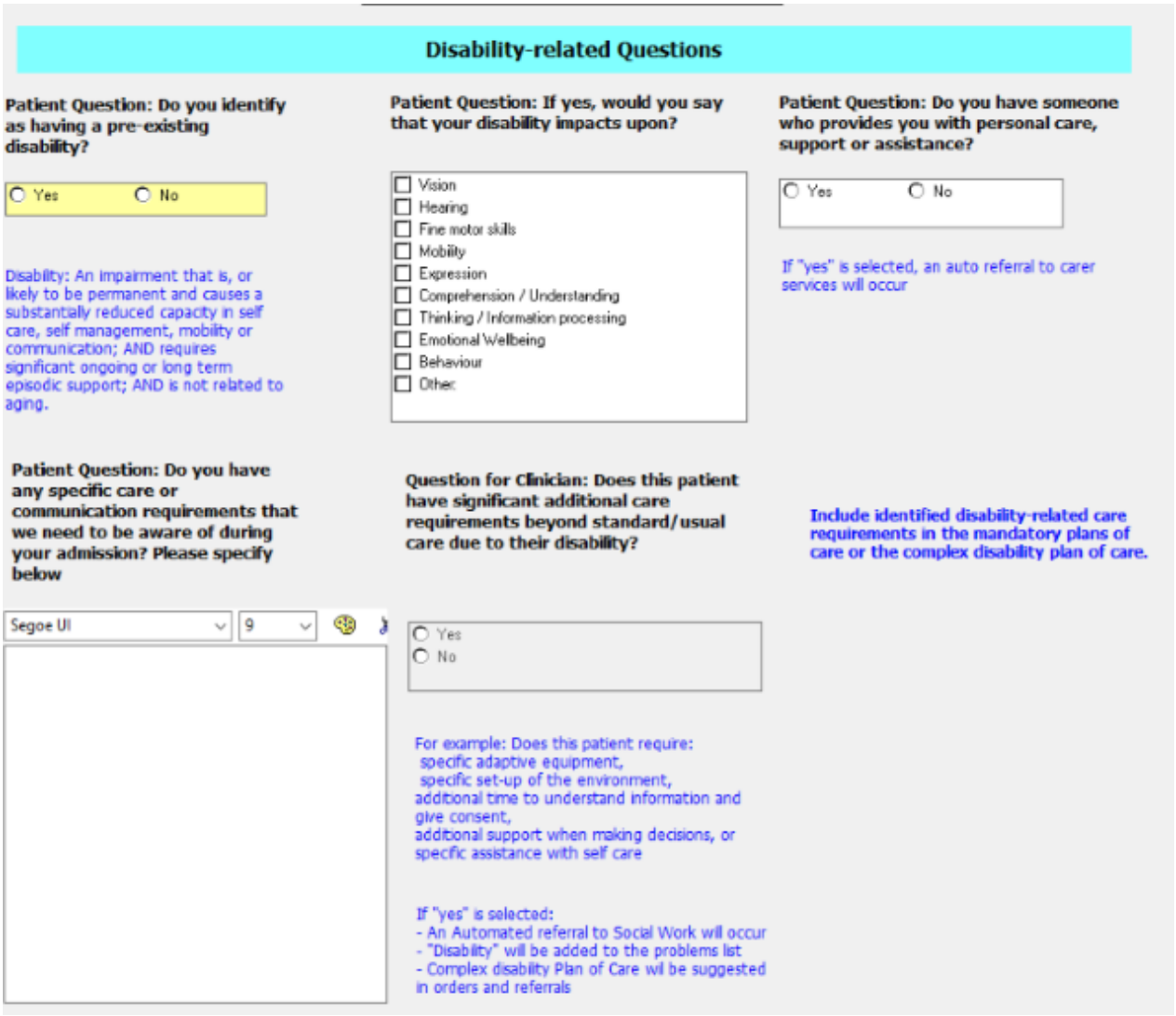


Figure 1. Disability Identification Questions Introduced in 2018

As part of the SPEAK project, a Rapid Response Disability Liaison Officer (RR DLO) service was implemented into the Emergency and Trauma Centre (E&TC) for a period of 20 months (10.10.22 – 25.08.24). Through the implementation of this service, there was improved awareness about the importance of early identification of disability to support patient care. Through collaboration between the SPEAK project and nursing leadership in the E&TC a decision was made to implement the disability identification questions into the Primary Nursing Survey, an assessment form used by nurses in the E&TC.

A working group was established with relevant staff from the disability team and the ED. This group recognised the need to update the disability identification questions prior to their introduction in E&TC. The questions were revised by the working group in consultation with consumers with lived experience of

disability, digital health leads, and members of the Alfred Health Disability Committee. The final updated version was endorsed by the Disability Committee followed by Alfred Health's Digital Health division.

To support the launch of the updated questions and introduction into ED, two quick reference guides were developed along with a training video:

1. Completing Disability and Supports Needs Questions QRG_Inpatient Nursing Powerforms.pptx
2. LaunchPoint – Completing Disability and Supports Needs Questions in the ED Primary Survey Powerform.pptx
3. Training Video_Disability and Support Needs Questions_720p.mp4

Prior to the launch, education was provided in various forums including staff meetings and within relevant newsletters.

The updated questions were implemented on 27th June 2024 where they already existed, in the Nursing Admission assessments, and introduced into the Primary Nursing Survey used in the ED.

There was intention to evaluate the staff experience of asking these questions within ED however this was unable to be completed due to competing priorities.

An evaluation is underway to determine the impact of the introduction of the questions in ED and the incidence of the disability alert activation. Results of this evaluation will be reported separately.

Any future modification of the Disability Identification Questions can be integrated with implementation of recommendations generated from the business analysis for disability data systems.

4 BUSINESS ANALYSIS - MAIN FINDINGS

A business analysis was undertaken in the first six months of 2025 to better understand current state data systems to record and convey disability information. The business analysis was completed for Alfred Health only as SWH operate different data systems.

A range of activities were completed as detailed in the business analysis plan.

4.1 DEFINING THE CURRENT STATE DATA SYSTEMS

The current state of Alfred Health's disability data systems was explored from the patient and staff perspective.

4.2 PATIENT EXPERIENCE

A wide range of information was accessed to understand the experience of PWD receiving healthcare at Alfred Health and how current processes and data systems may be contributing.

4.2.1 Patient Experience Surveys

There are two patient experience surveys utilised at Alfred Health to gain feedback directly from patients and their support people: the Alfred Health Patient Experience survey (PES) and the Victorian Healthcare Experience Survey (VHES).

PES and VHES data were analysed for 2024. For full details of these findings please refer to: Understanding the patient experience from patient experience surveys.docx.

The PES and VHES data identify the adult inpatient, outpatient and emergency care settings at Alfred Health as areas where care for people with disability or a long-term health condition are not equitable to those without.

These care settings receive lower ratings for overall quality of care from those with disability or long-standing health conditions than those without and fall below benchmark. In the ambulatory or community care setting, overall ratings of care were above the benchmark of 95% and consistent with those without a long-standing condition or disability.

Groups impacted across all settings are those with a mental health condition, those with a mobility impairment and those with a chronic condition or illness. The patient centred care domain of communication was below benchmark for all care settings, highlighting dissatisfaction by PWD.

4.2.2 Feedback

Feedback is recorded in an electronic system called Riskman. Feedback includes complaints, compliments, suggestions and enquiries.

When reviewing feedback provided from PWD in Riskman, there were two methods of identifying feedback:

Feedback provided by someone in the Disability Cohort

> With support from the Alfred Health data analytics team, a disability cohort was established. This was a group of PWD who accessed Alfred Health from the 1st January 2023 to the 31st December 2024. They were included in the disability cohort if they had a DIC alert, or required an Auslan interpreter, or had

a disability diagnosis on their problem list in the EMR. For full details of the method please refer to Understanding the patient experience from available data for people with disability V2.docx

Feedback determined to be disability related by the Patient Liaison Officer (PLO)

In Riskman there is a checkbox to record if feedback is disability related. This can be selected by the PLO when entering patient feedback. The PLO determines whether it is disability related, and if so, selects this check box.

Neither method of compiling feedback provided complete data for PWD.

Of the 539 complaints linked to a person in the disability cohort, only 69 (13%) of these were marked as disability related by the PLO. In the same time period, 377 complaints were marked as disability related by the PLOs with 93 (25%) matched to the disability cohort.

One reason why a smaller number of complaints were found using the PLO method is that if the disability checkbox is selected, it is then mandatory to also record Disability Support needs. This currently provides a limited selection of responses and no 'other' category (see Figure 2). If the required support need is not included in the set of responses or the support needs are not known, the PLO cannot proceed. This issue has already been identified by the PLO and disability teams and is awaiting an update by clinical governance.

A more consistent way of identifying feedback from PWD is required. A higher number of feedback entries was attributed to PWD when disability was identified using data points than when marked as disability related by the PLO.

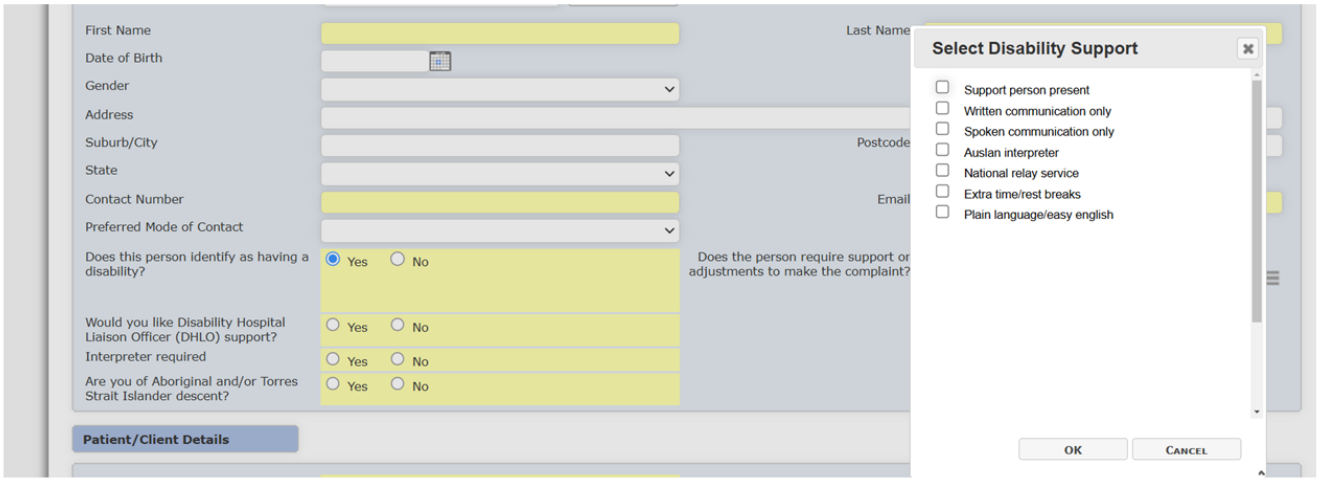


Figure 2. Screenshot of data entry screen in Riskman for submitting feedback by PLO

4.2.3 Complaints

Given there was a larger number of complaints found using the Disability Cohort method, results for this group are summarised.

There were 539 complaints received from PWD in the disability cohort: 303 in 2023 and 236 in 2024.

The highest number of complaints were received for:

- Specialist Clinics, 59 complaints (11%)

- Alfred Emergency and Trauma Centre, 58 complaints (11%)
- Inpatient psychiatry, 46 complaints (9%)
- General medical ward 4 East, 30 complaints (6%)

Complaints were most frequently related to the patient centred care domains of:

Effective Treatment (24%)

- Primary medical concerns were not addressed

"I have had to fight for my son all his life and very sad that he has been discharged with no follow up"- From mother of PWD

Communication (18%)

- Information not provided in a way that could be understood

"xxxx is blind and cannot see messages that come onto his phone"- From support worker of PWD

"Staff did not speak loudly or slowly enough"- From a person with disability

"Has found a lack of continuity in handovers, nurses don't often know that he can't lift one of his legs, has to tell his story over and over again"- From support worker of PWD

Comfort and Environment (15%)

- Environment not accessible for wheelchair users
- Ward environment 'crowded and chaotic' not conducive to rest and recovery

"As a wheelchair user I find the entry/exit door to the ward too heavy to use without risk of hurting myself."- From a person with disability

Respect and Compassion (15%)

- Time not taken to understand individual needs
- Respect not being shown to PWD, staff reported as rude
- The role of the support worker was not respected or valued by staff

"A 42 y.o. woman having autistic meltdown with nowhere else to turn to is getting escorted by 5 security guards out of the building" – From an Autistic person

"After I disclosed I was autistic, he said, "Yeah well, everyone's a little bit autistic aren't they?" It made my already stressful experience worse and made me realise that I was not going to have a disability friendly experience in this hospital." – From an Autistic person accessing the ED

Accessible Care (14%)

- Timely and equitable access to care compromised

"The impacts of us visiting this hospital is going to last throughout the weekend…. doctors need to understand that the autistic person is traumatised by the current process in place. As a carer I am traumatised. I'm tired and teary." – From mother of Autistic person following a presentation to ED

5 SPEAK PROJECT FINDINGS

The SPEAK Project began in 2020 and has conducted a range of co-design and evaluation activities with findings relevant to the patient and staff experience. The key activities which are referenced in this report are summarised in the table 1 below.

Table 1. SPEAK Project Activities

	Activity	Description	Date
	SPEAK Co-design workshops	Co-design workshops were conducted with people with lived experience of disability to improve healthcare services	Jul-Sep 2022
Stage 1 and 3 SPEAK project evaluation	**Surveys**	• Surveys were conducted with PWD and their support people to understand their hospital experience. • Health care worker (HCW) surveys focussed on staff experience caring for a PWD.	Stage 1: May-Aug 2022 Stage 3: Dec 2024- Feb 2025
	Interviews	Semi-structured interviews were conducted with PWD, their support people and HCWs for more in-depth data.	Stage 1: Jun- Sep 2022

Published reports were reviewed for findings relevant to the HCW and consumer experience relating to data systems. These reports included:

1. SPEAK Project Co-design report 2022
2. SPEAK Project Evaluation Surveys & Interviews (Stage1): Summary of Findings
3. SPEAK Project Medical Record (File) Audit (Stage 1)- Summary of Findings

Table 2 displays the key findings related to the consumer perspective of data systems from SPEAK project findings.

Table 2. Key findings related to data systems from SPEAK Project

Activity	Findings
Co-design workshops	Disability support information should be included in the EMR & include communication needs, reasonable adjustments to care, support needs and support person requirement.
	Information should be collected before the person comes to hospital and be available to all staff caring for the person in a consistent way. This includes at shift handover and transfer between services.
	Staff should know how to record disability information and where to find it. The information should support care provision to PWD and lead to better health outcomes and a more positive experience.
Surveys of PWD and their support person (Combined AH and SWH data)	PWD reported not being asked about their support needs when coming to hospital (0% reported being asked at Stage 1 evaluation, and 38% at Stage 3 evaluation).
	Most (75%) were not asked if they would like a support person present despite all respondents needing one (Stage 1 evaluation).
	Information was not provided in a way they could understand.
	Low ratings for involvement in decision making.
	Support people were concerned that PWD's basic care needs were not met and felt they were unsafe while in hospital.
Interviews	Support people play a crucial role when PWD are admitted to hospital and are an important member of the care team.
	Additional challenges are faced by those with hidden disabilities, and they are more vulnerable.

5.1 Patient Experience Problem Statement

A workshop was conducted in May 2025 with consumers with lived experience of disability. A problem statement was developed to describe the current problem that PWD experience relating to data systems when accessing Alfred Health. This was endorsed by the consumers who participated in the workshop.

People with disabilities and their support people must repeatedly share the same information and continually advocate for their needs when accessing Alfred Health.

This is exhausting and leads to frustration for both staff and patients.

It negatively impacts health outcomes and patient experience.

5.2 STAFF EXPERIENCE

The staff experience was explored by reviewing SPEAK Project evaluation findings and by conducting workshops with staff in key areas.

5.3 SPEAK PROJECT EVALUATION FINDINGS

To understand the staff experience, the results of staff surveys and interviews with Health Care Workers (HCW) (as detailed in Table1) were examined.

Survey responses were collected from a range of clinical and non-clinical HCW at two time points: Stage 1 (2022) and stage 3 (2023/2024) as part of SPEAK Project evaluation.

Key findings include:

- HCW were not confident that the disability type or support needs would be recorded in the EMR and staff lacked confidence to find relevant disability information.
- Nearly half of the HCW reported feeling somewhat stressed (44%) or very high stress (4%) when working with PWD at stage 1 evaluation.

More detailed information was elicited during semi-structured interviews with HCWs.

- They reported that better knowledge and attitudes towards PWD, and making reasonable adjustments to care, helped improve patients' overall experiences in hospital.
- Four out of five HCW interviewed either were not aware of the DLO program or did not know how to refer to them.
- HCWs wanted extra time to be able to meet the needs of PWD.

Having disability support information easily accessible in the EMR may better enable HCW to meet care needs which are essential for patient safety and the delivery of patient centred care.

The interviews highlighted that disability data should be captured early, be clearly marked on the medical record in a specific location, kept up to date, and referred to by staff throughout the patient's hospital admission.

5.3.1 Staff Experience Workshops

Four staff workshops were conducted with teams from inpatients, emergency, specialist clinics and the DLO team in March, May and June 2025.

For staff, two main issues were identified:

1. In specialist clinics there is not a standard process to identify and record disability in their main data system, Cerner Scheduling. Staff booking appointments do not routinely access the EMR. There is no way to reliably communicate disability information within a clinic or with other clinics/services. Cerner Scheduling does not display patient DIC alerts.

2. Staff using the EMR (Powerchart) report difficultly finding relevant information to support a PWD and that it is not an intuitive process. There are multiple locations to file / store information and multiple sources of truth for the same information. Staff find it hard to locate the care plan developed by the DLOs for some PWD called My disABILITY care plan. They find the alert useful to flag PWD, but most expect to be able to click on the alert to link to relevant information.

Relevant information that staff would like linked to the alert include:

- Type of disability
- Support Needs
- Relevant care plan i.e. My disABILITY care plan
- NDIS participant status and number
- Key contact for further information

5.3.2 Staff Experience Problem Statement

The problem statement below was drafted following the staff workshops to capture the staff experience.

Information about a person's disability is not easily found within electronic data systems.

Staff need to search multiple locations to find the necessary details to support individuals with disabilities as there is no centralized location for verified information.

This fragmented process is time-consuming and unintuitive.

5.4 CURRENT STATE PROCESSES AND DATA SYSTEMS WHICH IDENTIFY AND/OR SUPPORT PWD

5.4.1 Process Mapping

The areas of inpatient, emergency and specialist clinics were endorsed by the Alfred Health Disability Committee as areas requiring a detailed understanding of current processes.

Elicitation interviews were conducted with a range of staff representing the different craft groups from each area. Process maps were created to represent staff processes and the use of data systems for disability identification.

The process maps are available here: Data Systems and Process Mapping

The processes in place are summarised below under three main topics:

1. Disability Identification: the process by which a PWD is identified and their support needs recorded
2. Alert: the process by which the alert is activated and used to flag the group of interest
3. Location of disability information: where information related to person with disability is stored in data systems

5.4.2 Disability Identification

There is a standard process in place to identify disability when a person presents to ED or is admitted as an inpatient. A set of Disability Identification questions are included as part of the nursing assessment (see Figure 3). The first question is mandatory and asks if the person has a disability or support needs. The second, third and fourth questions provide the opportunity to record further detail relating to the nature of the disability and any support or carer needs.

The final question is mandatory if a disability is identified and is for the nurse to answer:

"Does this patient have additional care requirements beyond usual care due to their disability?"

Nurses are asked to make a subjective judgement on whether the support needs are more than the usual level of care they would provide. If they answer yes, then a DIC alert is automatically added to the patient's chart.

There is reference text to support decision making around if a referral to the DLO service is required, and a prompt to add relevant information to the nursing handover.

If they answer no, then no alert is added. The information that the person has a disability or support needs would be recorded in this form but is unlikely to be viewed by others.

The activation of the alert relies on the subjective judgement as to whether a person's support needs would be above the usual level of care provided. As well as being subjective, this is also context dependent, and the answer may be different across care settings. Inconsistent use of the questions across different encounters in the same setting by staff for the same patient was observed during the business analysis on viewing documentation.

The alert is activated for PWD whose care needs are above usual care, not for people who identify as having a disability who have no current support needs or their support needs are within usual care requirements.

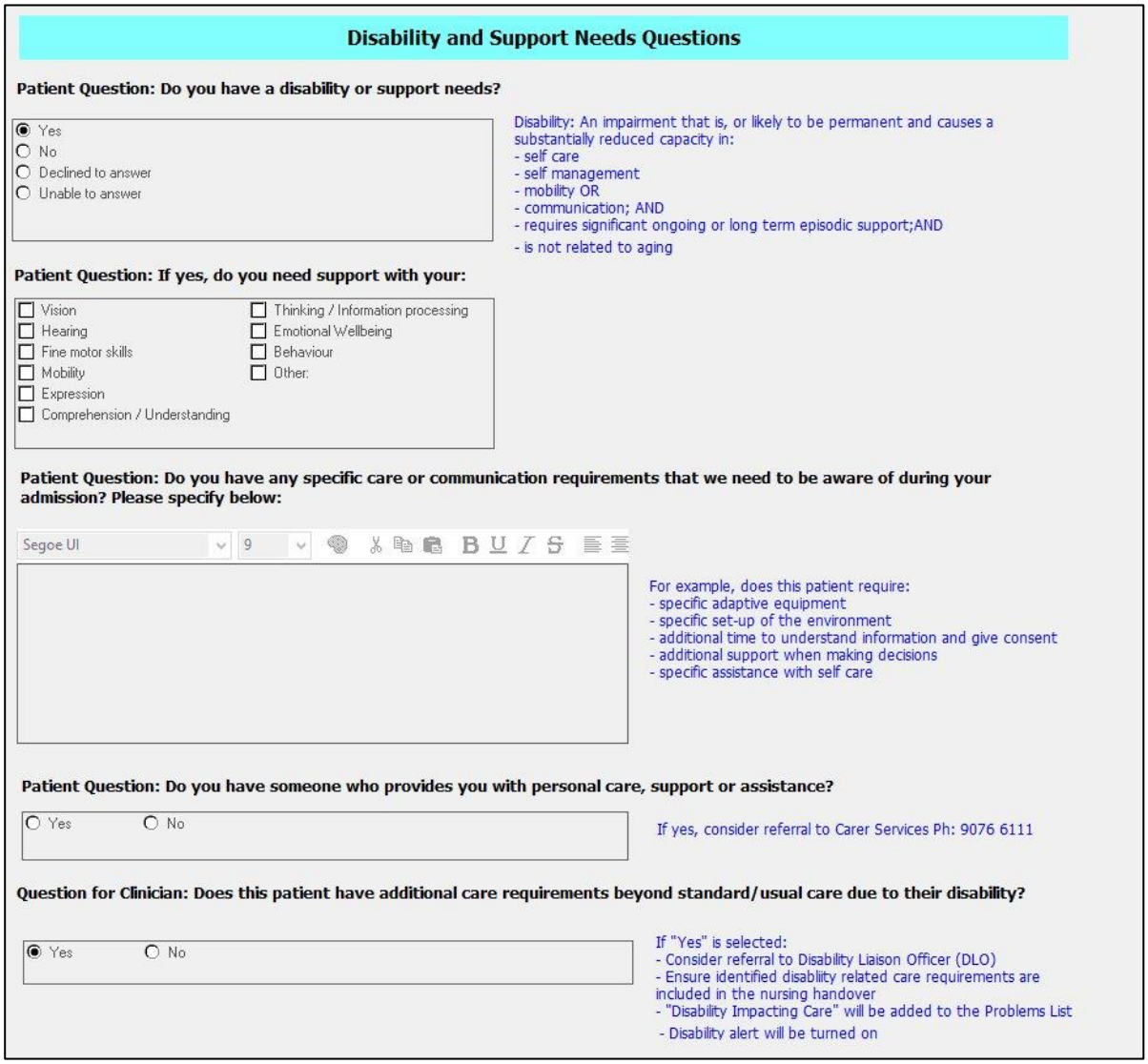


Figure 3. Alfred Health disability identification question set

There is no standard process in place to identify disability in specialist clinics or radiology or at other entry points to Alfred Health.

In specialist clinics and radiology, disability identification occurs in an ad hoc way and there is no dedicated place to record disability information nor reliable pathways to communicate information between staff in a clinic or with staff in other specialty clinics. Administration staff who are responsible for client bookings do not routinely access the EMR (Powerchart) where disability information is currently stored.

Disability identification is not part of the Victorian Integrated Non-Admitted Health data set, only NDIS participant details are required under the Contact Account Class.

5.4.3 Alert

The DIC alert is a tier 2 alert and can be activated automatically via the question on the nursing admission assessment or manually added to the person's Problem List in Powerchart. The DIC alert is visible in Powerchart to staff on the blue banner bar as an alert and in the alert column on First Net, the application used by ED staff.

The DIC alert is not visible in Cerner Scheduling, the application used by specialist clinics for client bookings, nor is it visible in the Radiology Information System (RIS), the main data system used by radiology.

If disability is identified by these areas, they do not routinely add the DIC alert.

The DIC alert does not link to relevant information about the type of disability or support needs.

This appears to greatly impact the utility of the alert as without rapid access to further information, staff cannot act.

5.4.4 Location of Disability Information

There is a range of information that may be recorded relating to PWD that is relevant for staff to know.

This includes:

- Support needs i.e. support person requirement, communication needs, process for consent
- Type of disability or related diagnosis
- DLO involvement
- My disABILITY care plan
- NDIS status and participant number
- Care coordinators contact details

Currently there is no dedicated place to view this information and it can be recorded in multiple places within a person's medical record.

This creates an inefficient process for staff who must search through a person's medical record to find relevant information. As a result, they often end up asking patients to repeat information that has already been provided. The challenge of locating information creates frustration for both staff and patients.

5.4.5 Reporting

Subject matter experts were interviewed to elicit current reporting requirements and outcomes used for monitoring PWD.

Current reporting related to disability were reviewed on Alfred Health's data analysis platform, daPortal.

Data systems were reviewed to identify data points related to disability and recorded in a data dictionary.

Full details on reporting findings are documented here.

5.4.6 Diversity and High- Risk Dashboard

The Diversity and High-Risk dashboard is a Quality and Safety report related to Standard 2 of the National Safety and Quality Health Service Standards, Partnering with Consumers, and is available via daPortal (https://daportal.alfred.org.au/?view_resource_id=141).

This dashboard reports selected outcomes for the diverse and high-risk populations and includes a tab for PWD.

The outcomes reported for disability use the DIC alert to identify people with disability. This is a sub population of the wider disability population as can be seen in figure 4. Outcomes for PWD are likely being underreported.

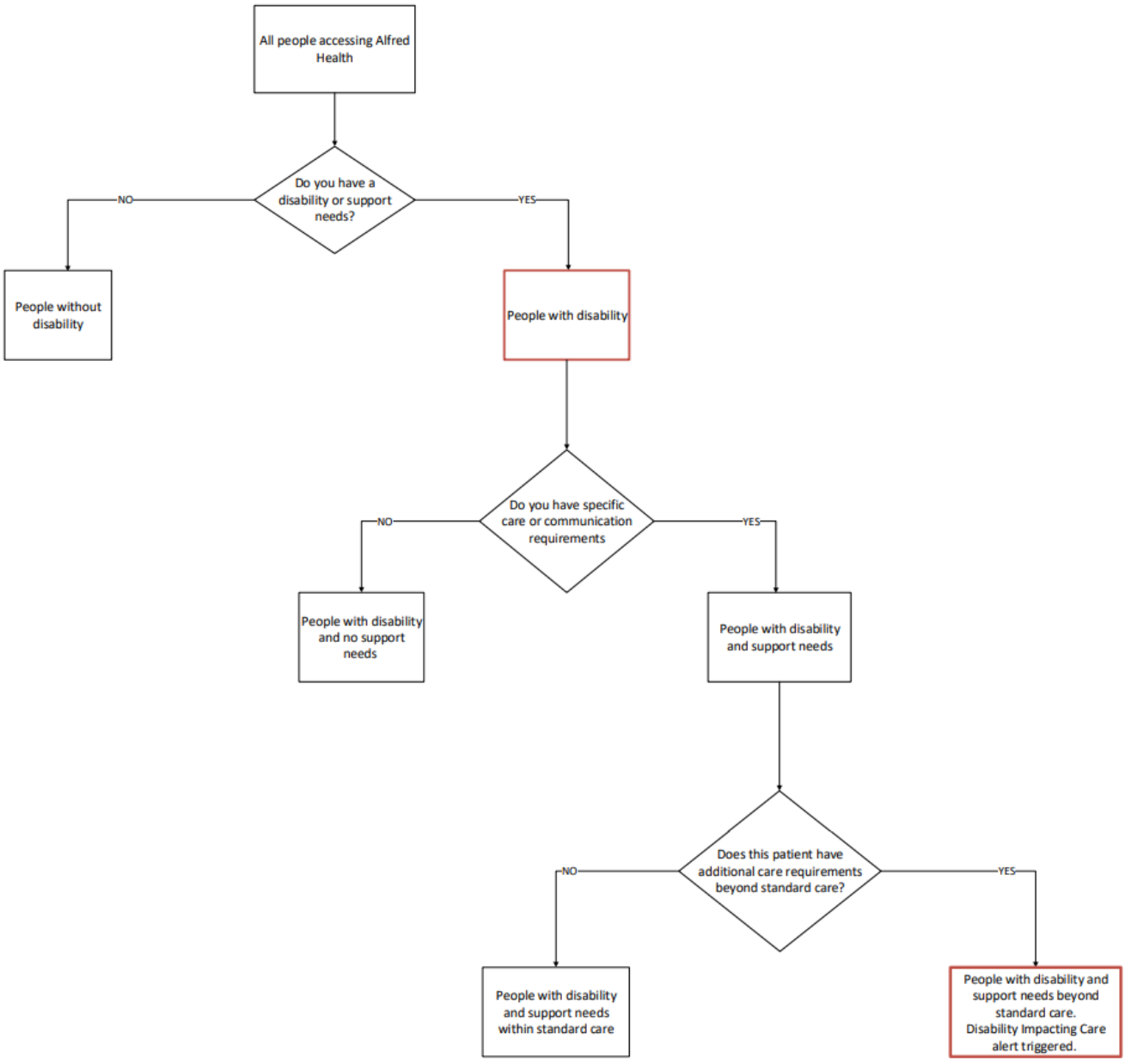


Figure 4. Reporting groups for people with disability

5.5 Reporting Gaps

5.5.1 Routine reporting from daPortal

There are a number of quality and safety outcomes monitored across the organisation via daPortal. It is currently not possible to filter this information for PWD, instead this data must be requested from the data analytics team on an 'as needs' basis.

Relevant dashboards include:

- Minimising Harm dashboard
    - Hospital acquired complications
- Prevention and Management of Clinical Aggression dashboard
    - Monitoring of restraint practices
    - Code grey incidents
- Quality and Safety dashboard
    - Code Blues and Met calls

Of note, the Royal Commission into disability recommends that the use of restraint is monitored in PWD and that targets are set to reduce its use.

It is recommended that in the future, a defined set of outcomes be routinely monitored to ensure safe and equitable healthcare is provided for PWD at Alfred Health.

5.5.2 Consistent definition for disability

Disability is defined by the United Nations Convention on the Rights of Persons with Disability (UNCRPD) as:

"Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."

It is based on the World Health Organisation's International Classification of Functioning, Disability and Health (ICF) and defines disability at the levels of impairment, activity and participation in the context of environment.

In Australia, disability data definitions adopt the UNCRPD definition, and define a long-term health condition as lasting, or likely to last longer thansix months (Fortune et al. 2022).

Currently there are a range of different definitions for disability used at Alfred Health. The relevant policies and guidelines, and the Online Disability Awareness Training all reference the UNCRPD definition, however the Diversity and High-Risk dashboard and the primary question of the disability identification question set are not aligned to this definition. (See table 6).

Table 3. Definitions of disability used at Alfred Health

Disability Awareness Training	Diversity and High-Risk dashboard	Supporting patients with disability guideline	Disability identifying question	Workplace Adjustment policy	NDIS Participant
References UNCRPD definition	Reports on disability using the disability impacting care alert	References UNCRPD definition	Disability is an impairment that is or likely to be permanent and causes a reduced capacity in: • Self-care • Self-management • Mobility OR • Communication AND • Requires significant ongoing or long -term episodic support AND • Is not related to ageing	References UNCRPD definition and Disability Discrimination Act	Permanent impairment with substantially reduced functional capacity requiring disability specific support

The initial question of the disability identification question set at Alfred Health is not consistent with the UNCRPD definition.

- It excludes disability related to ageing
- It places a requirement on the severity of disability
- It does not include all the domains of the ICF

The main dashboard reporting on outcomes for PWD uses the DIC alert to identify PWD and thus defines disability as those whose support needs are more than usual care. As previously stated, this is a sub-population of PWD and does not align with the UNCRPD definition.

It is recommended that a consistent definition of disability is adopted across the organisation and if required, the disability identification questions, and Diversity and High-Risk dashboard be updated.

5.6 IDENTIFY BEST PRACTICE FOR IDENTIFYING, SUPPORTING AND MONITORING PWD

5.6.1 Benchmarking

Benchmarking was undertaken with six Victorian health services and one in Queensland. Full results of benchmarking are recorded here benchmarking.

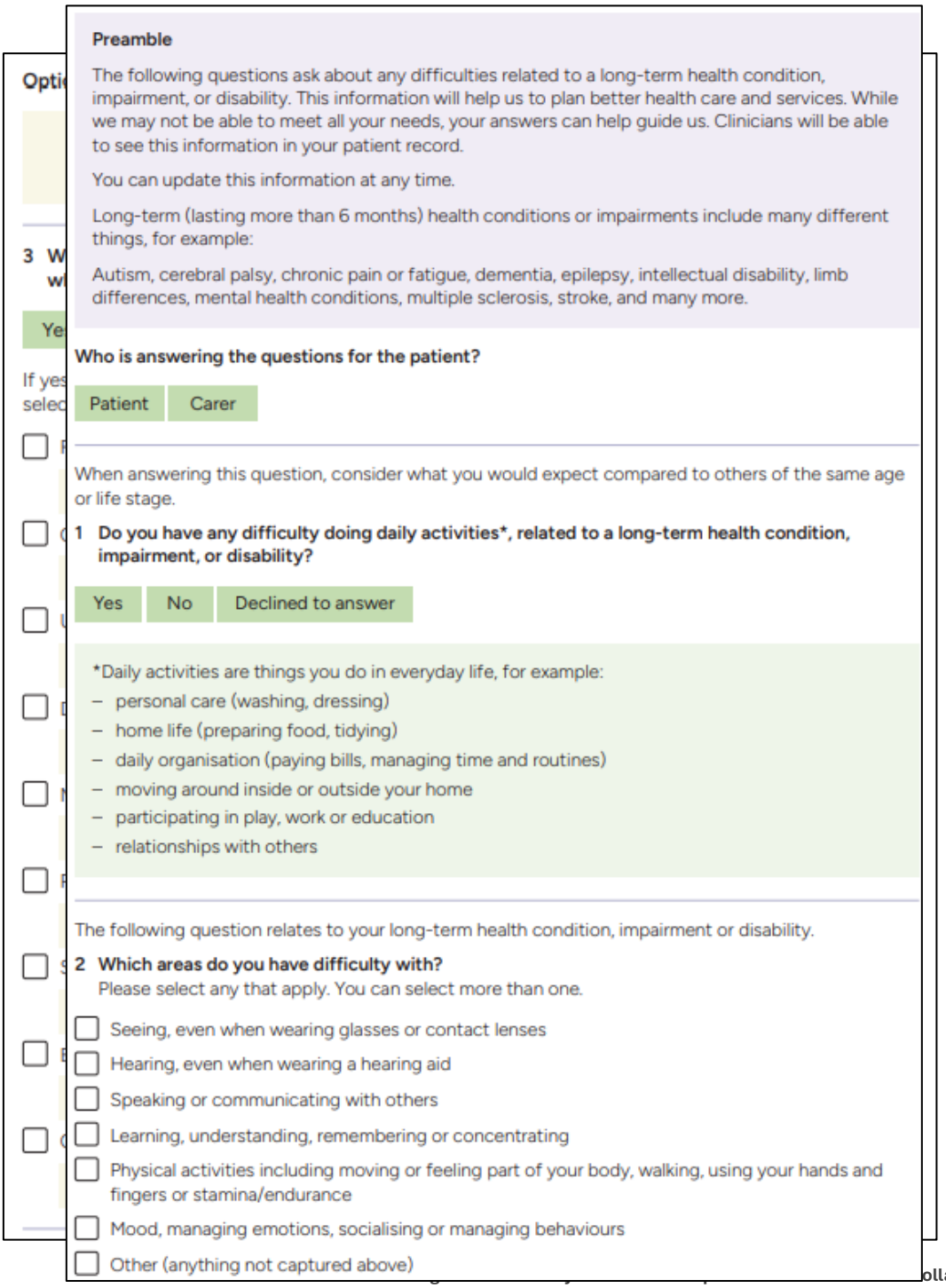
Five out of seven health services did not have a standard process in place for disability identification. Three had a disability alert or flag within their data systems and one had an alert for NDIS participants. Six had specific care plans in place for PWD and four had options for consumers to complete a care plan prior to coming to hospital.

5.6.2 Self-report disability identification research collaboration

The two organisations with a standard process in place for disability identification were The Royal Children's Hospital and Austin Health. They were part of a research collaboration funded by the Victorian

Department of Health that aimed to evaluate the use of a self-report disability identification approach in the EMR. They co-designed a set of disability identification questions and evaluated their utility and acceptability after implementation in two different EMR systems (Epic and Cerner Powerchart). They have published an implementation toolkit to assist other health services to do the same. Their approach has been endorsed by the Victorian Department of Health.

This self-report Disability Identification approach aligns with the UNCRPD definition of disability and can be mapped to other Australian disability data sets such as the Disability Flag and the Survey of Disability, Ageing and Carers. The three Disability Identification Questions can be viewed in Figure 5.



Preamble

The following questions ask about any difficulties related to a long-term health condition, impairment, or disability. This information will help us to plan better health care and services. While we may not be able to meet all your needs, your answers can help guide us. Clinicians will be able to see this information in your patient record.

You can update this information at any time.

Long-term (lasting more than 6 months) health conditions or impairments include many different things, for example:

Autism, cerebral palsy, chronic pain or fatigue, dementia, epilepsy, intellectual disability, limb differences, mental health conditions, multiple sclerosis, stroke, and many more.

Who is answering the questions for the patient?

Patient | Carer

When answering this question, consider what you would expect compared to others of the same age or life stage.

1 Do you have any difficulty doing daily activities*, related to a long-term health condition, impairment, or disability?

Yes | No | Declined to answer

*Daily activities are things you do in everyday life, for example:
- personal care (washing, dressing)
- home life (preparing food, tidying)
- daily organisation (paying bills, managing time and routines)
- moving around inside or outside your home
- participating in play, work or education
- relationships with others

The following question relates to your long-term health condition, impairment or disability.

2 Which areas do you have difficulty with?
Please select any that apply. You can select more than one.

- [ ] Seeing, even when wearing glasses or contact lenses
- [ ] Hearing, even when wearing a hearing aid
- [ ] Speaking or communicating with others
- [ ] Learning, understanding, remembering or concentrating
- [ ] Physical activities including moving or feeling part of your body, walking, using your hands and fingers or stamina/endurance
- [ ] Mood, managing emotions, socialising or managing behaviours
- [ ] Other (anything not captured above)

ollaboration

5.7 HEALTH PASSPORT PROJECT

Another project funded by the Victorian Department of Health, is underway at Peninsula Health. They have developed a Health Passport that can be completed by the consumer via a web link. The Health Passport, also known as the Needs and Preferences Tool, aims to capture a person's access and support needs and is similar to Alfred Health's My disability care plan. Once it is completed by the consumer, it can be viewed within the EMR by the HCW. Initially this was trialled on three wards and completion was supported by a dedicated ward facilitator. Interestingly, the project team has noted a good unsupported completion rate when included with their patient experience survey at three months following discharge. Formal results of this project have not yet been reported.

Following the release of the healthcare passport project findings and the merger by Alfred Health and Peninsula Health in January 2026, it is recommended that a single document be implemented that can capture patient provided information and by easily accessed by HCW.

5.7.1 Literature Review

A literature review was commenced for the research question: 'How should people with disability be identified and supported by data systems when accessing healthcare? '

A search strategy was developed and piloted in Embase. It returned 316 publications. Following screening of abstracts, 47 articles were selected as relevant to the research question. Further scoping is required to progress this review.

6 RECOMMENDATIONS AND ROADMAP

Recommendations for improvement to Alfred Health's data systems to identify and support PWD have been categorised into four areas:

- Disability Identification
- Alert
- Location of disability information
- Reporting

Key steps are provided as a roadmap to achieving an improved future state.

6.1 DISABILITY IDENTIFICATION

6.2 ROADMAP TO FUTURE STATE

6.2.1 A clear organisational definition of disability

Currently there is variation in how disability is defined at Alfred Health. A consistent definition is required across Alfred Health. Ideally this should align with the national definition of disability and disability data sets to enable data linkage and benchmarking with other health services.

6.2.2 A set of disability identification questions that reliably identify people with disability

The disability identification questions should identify people with disability according to the organisational definition.

A research team, funded by the Victorian Department of Health, has co-designed a set of disability identification questions which should be considered for implementation at Alfred Health. These questions have been tested and deemed acceptable by consumers and staff. They can be mapped to national disability data sets such as the National Survey on Ageing and Disability and the Disability Flag.

6.2.3 A standard process to identify disability across the organisation

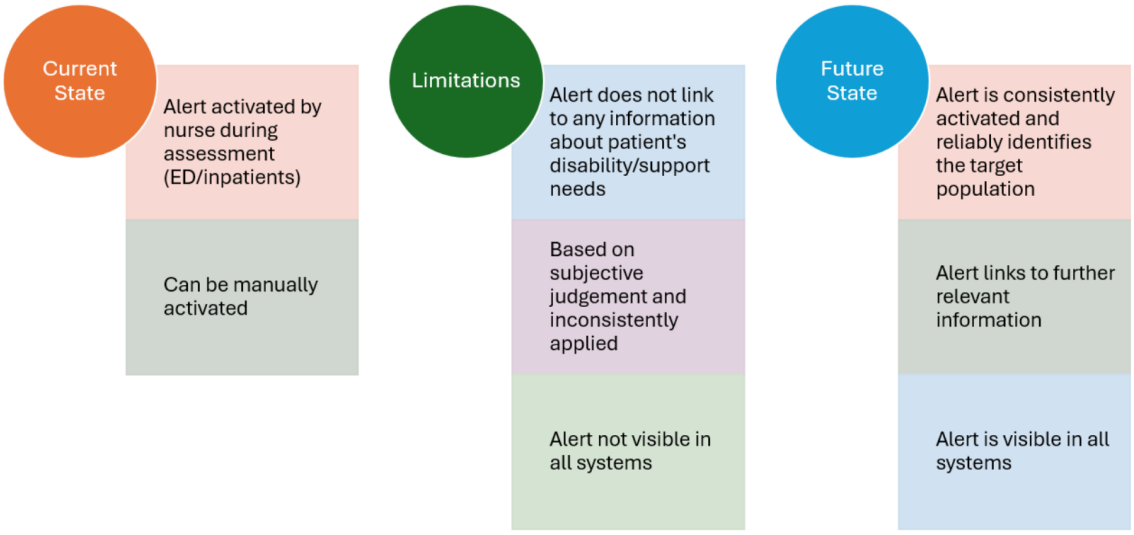
Currently there is only a standard process to identify people with disability when they present via the emergency department or when they are admitted on to an inpatient ward. There is not a standard process in place should a person with disability enter Alfred Health directly via specialist clinics, for an investigation with radiology or to a community service.

Adopting a standard process to identify disability across the organisation will ensure that all people with disability and their support needs will be identified no matter where they enter Alfred Health. This will help to foster an equitable health service.

6.2.4 Explore use of the Patient Portal for people with disability to self-report disability information.

Alfred Health has a patient portal that could potentially be used to capture disability identification information directly from consumers. Health services, such as Peninsula Health and the Parkville Precinct, that have implemented a process for consumers to self-report their support needs have found that it is well utilised. The patient portal would provide a means for consumers to provide information prior to entering the health service (i.e. admission or their first appointment) which meets their stated needs.

6.3 ALERT



6.4 ROADMAP TO FUTURE STATE

6.4.1 Consider if an alert is required

The DIC alert is currently a part of disability identification at Alfred Health. Depending on the standard process adopted for disability identification and the location of disability information, an alert may or not be required. For example, if the standard process involves disability identification occurring during patient registration and being recorded in the Patient Administration System, disability identification could be achieved by displaying disability status in a dedicated section of the banner bar.

Feedback from staff indicates that the disability alert in its current state is useful as a flag, but not sufficient to reliably identify disability and connect to relevant information.

6.4.2 Confirm which cohort of people should be flagged with a disability alert

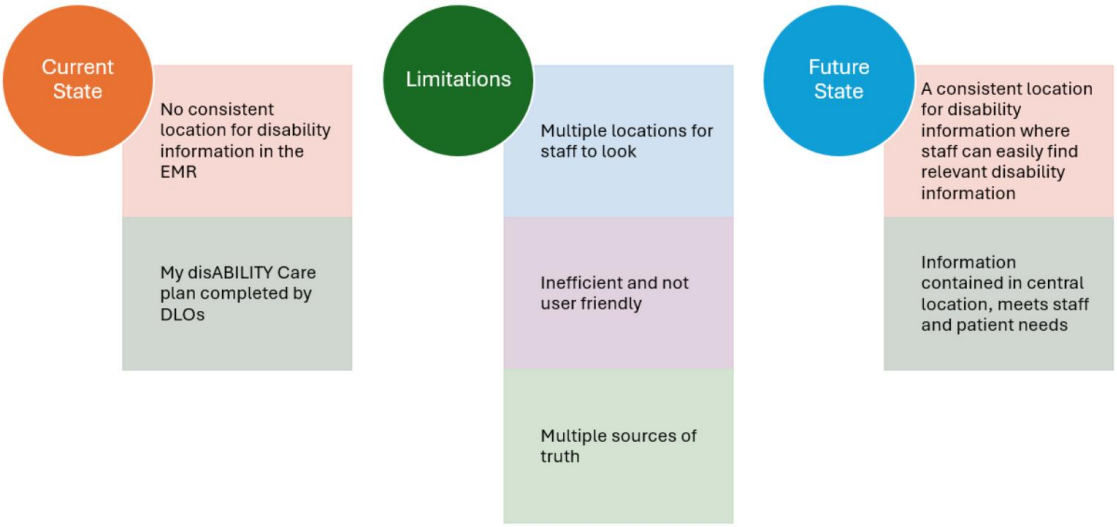
The disability alert used at Alfred Health is designed to identify people with disability whose support needs are in addition to standard care. Other organisations (Austin and Parkville Precinct), use or plan to use their disability alert/flag to identify **any** person who identifies as having a disability. Alfred Health should determine which cohort they wish to alert clinicians to.

6.4.3 Link the disability alert to further relevant information

Staff report they want the ability to click on the disability alert to view relevant information such as disability type and support needs. Currently, the disability alert does not contain this information, and staff must search the medical record to find relevant details (see Location of Disability Information).

An absence of relevant information attached to the alert greatly impacts its utility.

6.5 LOCATION OF DISABILITY INFORMATION



6.6 ROADMAP TO FUTURE STATE

6.6.1 Disability information is contained in a central and consistent location so staff can easily find what they need to support patient care.

Disability information is currently located in several areas of the EMR. Staff often need to search multiple locations to find out relevant information to support PWD. As there is no central location for disability information, there are multiple sources of truth which creates confusion. This can lead to duplication of effort, inefficiencies and a reduced patient and staff experience.

It is recommended that there is a dedicated location within the EMR for disability information to be displayed. At a minimum this should include:

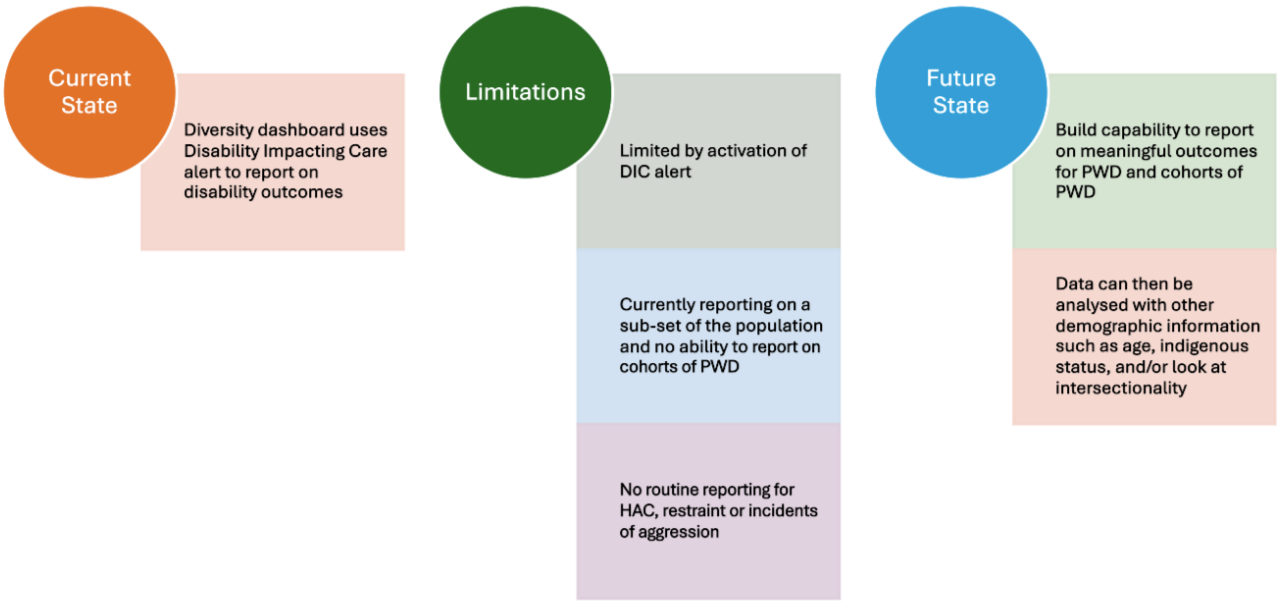
- The person identifies as having a disability
- Type of disability
- Support Needs
- Link to relevant care plan i.e. My disABILITY care plan or healthcare passport
- NDIS participant status and number
- Key contact for further information

Other information which could be included:

- Active DLO referral
- Reference text to support decision for DLO referral

It should be easy to locate within relevant data systems and intuitive for staff to find.

6.7 REPORTING



6.8 ROADMAP TO FUTURE STATE

6.8.1 Clear organisational definition of disability

Currently disability outcomes are reported using the DIC alert to identify people with disability. This is a sub-population of the wider disability cohort whose care needs are deemed more than standard care. Outcomes are likely being under reported at present and these should be reviewed once an organisational definition of disability is established.

Riskman feedback is currently categorised by the PLOs as 'disability related' however this approach misses approximately 75% of complaints from PWD. Some improvement may be achieved with the pending update to Riskman which will enable more flexibility with recording support needs. However, given the large gap, a more consistent way to classify feedback from PWD in line with an organisational definition is needed to ensure the voices of PWD are heard.

6.8.2 Agreed set of outcomes to monitor the quality, safety and patient experience for people with disability at Alfred Health.

The Diversity and High-Risk dashboard provide routine reporting for a small number of outcomes for PWD. There are other dashboards available on the daPortal but it is not possible to filter for PWD and separate reporting must be requested from the data analytics team.

It is recommended that routine reporting is set up which monitors an agreed set of outcomes (including the use of restraint) to support provision of a safe and equitable healthcare experience for PWD.

6.8.3 Build capability to report on different cohorts of PWD and Intersectional Analysis

There is no current way to report on different cohorts of PWD. PWD are a diverse group of people with different needs and challenges. In order to meet the needs of different populations it is important to be able to review outcomes for discrete groups. For example, people with intellectual disability are reported to have poorer health outcomes. It is necessary to understand if this is the experience of people with intellectual disability at Alfred Health and if so, to inform strategies for improvement.

With consistent and reliable reporting of PWD, data can then be used for intersectional analysis with other demographic information such as gender or indigenous status. This will help to better understand outcomes of underserved populations like women with disability or Aboriginal people with disability.

7 SUMMARY

The experience of people with disability and staff at Alfred Health can be improved by the implementation of a standard process for disability identification and by providing a centralised location to display key disability information.

Further development of routine reporting, based on an agreed definition of disability, will support monitoring of care outcomes and service improvement.

8 REFERENCES

Fortune, N., Bailie, J., Gordon, J., Plunkett, K., Hargrave, J., Richard, M., & Llewellyn, G. (2023). 'Developing self-report disability questions for a voluntary patient registration form for general practice in Australia'. *Australian and New Zealand Journal of Public health*, vol. 47, 2. https://doi.org/10.1016/j.anzjph.2023.100032

8.1 BUSINESS ANALYSIS REFERENCE REPORTS

Data systems to identify and support people with disability: Business Analysis plan January 2025

More details on the findings in this report are available in the following documents:

- Understanding the patient experience from patient experience surveys
- Summary of SPEAK Project findings related to data systems
- Understanding the patient experience from available data for PWD
- Current state reporting for PWD