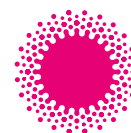


**Implementation of
a Patient Self-Report
Disability Identifier
in Electronic Medical
Records (EMR):
Evaluation of Utility
and Acceptability**

Implementation of a Patient Self-Report Disability Identifier in Electronic Medical Records (EMR): Evaluation of Utility and Acceptability

Produced in partnership with



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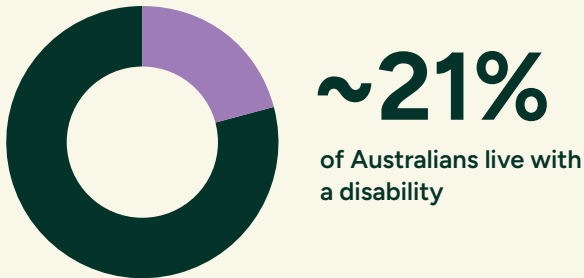
Note on terminology

Language plays a critical role in shaping our understanding and implementation of policies, especially in healthcare and other sectors where it directly impacts service delivery and the achievement of equitable outcomes. Consistent and precise use of terminology is important in these contexts to ensure clarity and inclusiveness.

In alignment with findings and recommendations from the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability: Final Report, and to support the recommendations outlined in relation to the Disability Discrimination Act (DDA), this report will refer to 'reasonable adjustments' simply as 'adjustments.' This decision reflects the evolving understanding of the term and its application, emphasising the importance of ensuring that all people, including people with disability, have equal access to services and opportunities. By using 'adjustments,' we aim to foster a more inclusive and supportive environment that acknowledges and meets the diverse needs of all individuals.

Executive Summary

Background



In Australia, about 21% of the population, or 5.5 million people, live with a disability, up 3.7% from 2018 (ABS, 2022). Despite higher rates of health service utilisation among people with disability, significant barriers to accessing healthcare services contribute to poorer health outcomes compared to people without disability (AIHW, 2020). The National Health Survey in Australia revealed that one in three people with disability require assistance to access healthcare services, underscoring the need for improved identification and support mechanisms (ABS, 2019). Historically, Australian health services have not routinely identified individuals with disability upon intake or admission, resulting in a lack of disability-related data within healthcare administrative datasets (Fortune et al., 2023). This gap hinders efforts to address disparities and tailor healthcare services to the needs of individuals with disability.

In response to this identified gap, a co-design process was undertaken from February 2022 to March 2023 to develop and incorporate disability identifier (DI) questions (Figure 1, overleaf) within the Parkville Precinct Electronic Medical Record (EMR) system. The Parkville EMR (Epic Systems, Verona, WI) is shared by The Royal Melbourne Hospital (RMH), The Royal Women's Hospital (RWH), The Royal Children's Hospital Melbourne (RCH), and Peter MacCallum Cancer Centre (PMC) in Melbourne, and is used by more than 18,000 clinicians and staff. Austin Health partnered with the Parkville Hospitals and adopted the same self-report question set within their own EMR system Cerner Powerchart (Oracle Cerner, Austin, TX). This collaboration provided a unique opportunity to better understand implementation of the approach to disability identification across different health services and EMR systems.

Study Purpose

This multi-site project aimed to evaluate patient/ carer and staff experiences of using a self-report DI approach in the Electronic Medical Record. Evaluation occurred during the first 9 months of implementation (1st March – 30th November 2023). Results presented in this report have informed the development of recommendations to guide practice in disability identification in EMR across the Parkville Precinct EMR users (RCH, RMH, RWH and PMCC) and Austin Health, with the potential to also inform practice across other jurisdictions.

Methods

Study Objectives

The study addressed the following objectives:

- 1 To assess the utility (operationalised as **reach** and **adoption**) of the DI questions during the first 9 months of its implementation (1st March – 30th November 2023).
- 2 To explore the **acceptability** of the DI approach through patient, carer and clinician perceptions of completing the self-report disability questions.
- 3 To make recommendations to guide optimisation and standard practice in disability identification in EMR across the participating hospitals and provide considerations for adoption in other jurisdictions.

Study Design

The study followed a convergent parallel mixed-methods design, collecting and analyzing quantitative and qualitative data concurrently. This included a retrospective audit of electronic medical records, online surveys, semi-structured interviews, and clinician focus group discussions.

Figure 1 The DI Questions evaluated in this study

Answering the following questions will help us provide you with the best possible care and help us understand what additional supports you may require. This information will be treated confidentially.

Respondent

Patient

Carer

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

Do you (Does the person you are caring for) have any difficulty doing daily activities*, related to a long-term health condition or disability?

Yes

No

Declined to answer

**Daily activities include all the things you do in your daily life, for example, self-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.*

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

Do you (Does the person you are caring for) experience difficulties in any of the areas listed below? Please tick the box next to any that apply. You can tick more than one box.

Seeing, even when wearing glasses or contact lenses

Hearing, even when using a hearing aid

Speaking or communicating with others

Learning, understanding, remembering or concentrating

Moving or feeling part of your body, walking, using your hands and fingers, or doing other physical activities

Mood, managing emotions, socialising or managing behaviours

Other

3 **Due to the difficulties, impairments or disabilities identified in the previous questions, do you (Does the person you are caring for) require any additional assistance during your inpatient stay or outpatient appointments?***

Yes

No

Preamble to the DI Questions

Statement to relativise the DI Questions to the age of the patient

Primary Disability Identification question

Areas of difficulty

Need for assistance

* Note that the Parkville precinct allowed additional information to be recorded by patients about the type of assistance required (refer to page 4 of the main report).

Results

Utility of the Disability Identifier

The DI questions demonstrated substantial utility in identifying individuals with disability and capturing relevant data about their difficulties and needs for assistance when accessing healthcare. Higher completion rates were observed in settings where the DI questions were integrated into routine workflows, such as the Royal Women's Hospital maternity services and Austin Health's nursing admission process. The high uptake of the DI questions by patients positively identifying with a disability via the patient portal at Parkville Hospitals further reinforced the potential of digital health platforms to facilitate self-reporting and enhance engagement of patients with disability.

When all settings were considered together, the prevalence of self-reported disability among the DI respondents was 17.9%. Variations in prevalence across age groups, genders, and specific patient cohorts, however, underlined the importance of considering demographic and contextual factors when interpreting disability data in each of the included settings. The high prevalence of disability among younger patients at the Royal Children's Hospital Melbourne, for example, reflected this hospital's focus on providing pediatric care to an often-complex population. In contrast, the prevalence of disability in pregnant women at the RWH, was low at just 3%, warranting further research, particularly given pregnant women with disability reported greater need for assistance to access healthcare compared to their non-pregnant counterparts with a disability.

Overall, the prevalence of self-reported disability in the 0-65 age group (15.4%) among the DI respondents was consistent with national estimates from the latest 2022 Survey of Disability, Ageing, and Carers (SDAC) (ABS, 2022) of 15.0%. While disability prevalence increased with age as anticipated, the steeper increase in disability prevalence among 65+ age group observed in the SDAC compared with DI data may indicate a need to better understand how older patients are interpreting and responding to the DI questions.

Of the set of 3 DI questions, Q1 served as the primary disability identification question, aligning with the International Classification of Functioning, Disability, and Health (ICF) framework. Inclusion of this screening question is important within the hospital context for identifying our priority target group—individuals who experience difficulties with daily activities related to a long-term health condition, impairment or disability, as distinct from those experiencing difficulties unrelated to disability. Subsequent DI questions (Q2 and Q3) enabled the identification of specific areas of difficulty and need for assistance, providing valuable insights into the diverse challenges experienced by patients with disability in accessing healthcare. The DI data

captured highlighted the need for tailoring support services and adjustments to improve healthcare provision, specific to the patient population in each setting. Higher rates of disability and need for assistance among individuals with behavioral flags, family violence flags, and high-risk flags compared to individuals without these flags reinforce the importance of considering intersectionality and the compounded effects of multiple vulnerabilities when delivering services.

Acceptability of the Disability Identifier

The acceptability of the DI questions was generally high among patients, carers, and clinicians, indicating a positive reception and a willingness to engage with the process. Patients and carers appreciated the opportunity to communicate their needs and felt that the DI contributed to raising awareness about disability within healthcare settings, promoting inclusion and accessibility. Clinicians also recognised the potential benefits of the DI questions to improve patient centred care and disability awareness.

Quantitative findings from the Theoretical Framework of Acceptability (TFA) survey revealed strong acceptability overall and across individual constructs. This suggests that participants found the DI questions useful, understandable, and relatively easy to complete. Patients who identified as having a disability and needing assistance to access healthcare showed slightly higher overall acceptability scores than the broader patient/carer cohort. They particularly scored higher in Intervention Coherence and Perceived Effectiveness, indicating a clearer understanding of how the DI questions worked and a positive perception of their potential benefits. Among clinicians, Opportunity Cost had a stronger positive correlation with General Acceptability compared with other constructs, suggesting that clinicians' perception about whether the DI questions are a priority in care delivery influenced overall acceptability in this group. Across all groups, Affective Attitude (how comfortable respondents felt completing the DI questions) scored the lowest (3.6/5 for clinicians and 3.8/5 for patients/carers). While still a moderate to strong score, this revealed some room for improvement in how comfortable respondents felt asking and completing the DI questions.

Qualitative findings provided further insights into challenges that could impact the successful implementation and utilisation of the DI questions. Clinicians highlighted the importance of better integration into clinical workflows, provision of sufficient training and support, and addressing concerns about the time and effort required to complete the DI process in busy settings. Patients also raised considerations regarding health service capacity and the ability of staff to use the information effectively to provide the necessary supports.

Implementation Challenges and Recommendations

The study identified several key challenges in the implementation of the DI questions, providing valuable lessons for future efforts to improve disability identification in healthcare systems.

Workflow Integration	Successful implementation of the DI requires seamless integration into existing clinical workflows. Sites that embedded the DI questions into routine admission processes achieved higher completion rates. Ensuring that the questions are easily accessible and integrated into daily practice is crucial for sustained adoption.
Training and Support	Clinicians expressed a need for more comprehensive training to feel confident and comfortable in asking the DI questions and using the information effectively. Ongoing education and support are essential to build clinician confidence and ensure consistent utilisation of the DI process. Training should be specific to what the DI is and why it is important, who should complete the DI, and how and when to complete the DI in relation to specific workflows. Training should also encompass how information provided can help inform processes to incorporate healthcare adjustments and supports within subsequent provision of care. This training, however, is more likely to be effective when embedded within wider capacity building approaches to improving disability awareness and the importance of equitable access to healthcare.
Balancing Burden and Benefits	Minimising additional workload and ensuring that the process does not interfere with other clinical priorities (Opportunity Costs) is important. Streamlining the DI process within workflows and providing clear guidelines on its implementation will help mitigate perceived burden.
Consistency and Follow-Through	Establishing clear protocols for reviewing, acting on, and monitoring how DI data is informing care is essential to ensure that the information collected leads to meaningful improvements in patient care. Equally important, is to ensure that patients and carers are clearly informed about why the information is being collected and how it will be used.
Customisation and Sensitivity	The study revealed that certain subgroups, such as patients with mental health conditions, chronic pain, and fatigue, may have found the DI questions less applicable to their individual difficulties. Providing examples of the breadth of conditions or impairments (including mental health conditions) that may contribute to activity limitations and participation restrictions in Q1 will further optimise the DI questions. The addition of 'stamina or endurance' to the 'physical' area of difficulty in Q2 broadens its scope to better encompass conditions characterised by fatigue or pain (refer to Appendix 1).

Additional research should be conducted exploring how best to capture more detailed information on support needs and care preferences that could link to the DI Questions and give further context to 'areas of difficulty' identified (for example 'Health Passports'*).

* Health Passports are a document used to collate detailed information about a person's support needs and care preferences designed to go with a patient when presenting at a health service. Peninsula Health are currently undertaking research to trial implementation of an electronic health passport with potential to integrate with the DI.

Implications for Policy and Practice

The findings of this study have important implications for policy and practice in disability identification and healthcare provision:

Standardisation of Disability Data Collection	Developing standardised approaches to disability identification, grounded in frameworks like the ICF and aligned with national surveys like the SDAC, can improve the consistency and comparability of disability data across healthcare systems, as demonstrated in this study. Current advancements in data linkage systems within Australia and the establishment of the National Disability Data Asset also provide a potential platform to utilise de-identified hospital administrative data to monitor health outcomes among the Australian population (Fortune et al, 2023).
Co-Design and Stakeholder Engagement	Engaging stakeholders, including patients with disability, carers and clinicians, in the co-design of disability identification processes, and evaluation of implementation has been a central component of this project. Continuing to ensure that this is prioritised will help ensure that the approaches and responses are relevant, inclusive, and accurately reflect the priorities and diverse experiences of individuals with disability within healthcare systems.
Leveraging Digital Health Platforms	Utilising patient portals and other digital health platforms can facilitate self-reporting and enhance patient engagement in the DI process. Ensuring accessibility and user-friendliness of these platforms is critical.
Continuous Evaluation and Improvement	Ongoing evaluation of the DI process, including regular feedback from patients, carers, and clinicians, is essential to identify areas for improvement and ensure that the process remains responsive to the needs of individuals with disability. Further research should examine how specific cohorts, such as older patients (over 65 years of age), younger cohorts (0-2 years), pregnant women with disability, First Nations people, and people from culturally and linguistically diverse backgrounds, are engaging with the DI questions and process.

In conclusion, the implementation of the DI questions in the Parkville Precinct and Austin Health EMR systems represents a promising step towards improving disability data collection and understanding barriers to healthcare access for individuals with disability. Addressing the identified challenges and building on the successes will be crucial for optimising the DI process. This study contributes towards developing a standardised approach to disability identification, emphasising the need for continuous evaluation, stakeholder engagement, and leveraging digital health platforms to enhance the inclusivity of healthcare services and achieve equitable health outcomes for all.

The DI Questions with integrated optimisation (Appendix 1) and accompanying 'Accessible Care Toolkit' are provided as a companion resource to assist with implementation of the recommendations presented in this report.

List of Abbreviations

Abbreviation	Description
ABI	Acquired brain injury
ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
BPA	Best Practice Advisory
CDIP	Cerner Documentation and Infusions Project
CHA	Centre for Health Analytics
DI	Disability Identifier
DLO	Disability Liaison Officer
EMR	Electronic Medical Record
FGD	Focus Group Discussions
ICF	International Classification of Functioning, Disability and Health
IT	Information technology
MCRI	Melbourne Children's Research Institute
NDIS	National Disability Insurance Scheme
PAS	Patient Administration System
PMC	Peter MacCallum Cancer Centre
RCH	The Royal Children's Hospital Melbourne
RMH	The Royal Melbourne Hospital
RWH	The Royal Women's Hospital
SDAC	Survey of Disability, Ageing and Carers
TAG	Technical Advisory Group
TFA	Theoretical Framework of Acceptability
UoM	University of Melbourne

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1 Introduction

1.1 Background

In Australia, about 21% of the population, or 5.5 million people, live with a disability, up 3.7% from 2018 (ABS, 2022). Despite higher healthcare utilisation rates, these individuals face significant barriers to accessing care, which contributes to poorer health outcomes when compared to the general population (AIHW, 2020). This is supported by the Australian National Health Survey, which revealed that one in three Australians with disability require assistance to access healthcare services, highlighting the urgent need for improved identification mechanisms and support systems necessary to meet the unique healthcare needs of this population (ABS, 2019).

Identifying patients with a disability early in the intake or admission processes is critical to enable necessary adjustments in care and appropriate referral for equitable access to quality healthcare. However, historically, Australian health services have not routinely identified individuals with disability upon intake or admission, resulting in a lack of disability-related data within healthcare administrative datasets (Fortune et al., 2023). This gap in data collection has hindered efforts to address disparities and tailor healthcare services to the needs of individuals with disability.

1.2 Disability Data in Health Care

The International Classification of Functioning, Disability, and Health (ICF) conceptualises disability as a dynamic interaction between health conditions and environmental and personal factors (WHO, 2001). This framework provides a comprehensive view of disability, emphasising both individual and societal aspects. The Australian Bureau of Statistics (ABS) Survey of Disability, Ageing, and Carers (SDAC) is the 'gold standard' for identification of disability within the general Australian population and is conceptually grounded in the ICF. The SDAC provides valuable insights into the prevalence of disability and the need for assistance among Australians (ABS, 2018b).

In Australia, despite the implementation of national surveys and data collection initiatives, efforts to collect disability data have been inconsistent, with variations in data collection methods, definitions, and measurement tools across different jurisdictions. ICF-related data standards have been developed for use in administrative data collections, including

a 'Standardised disability flag' developed by the Australian Institute of Health and Welfare (AIHW 2016), but adoption and implementation of these data standards has been limited (Fortune et al., 2023). Administrative data sources such as hospital records and health service utilisation databases offer opportunities to capture information on diagnoses, functional limitations, and healthcare encounters among individuals with disability. However, challenges related to the standardisation and interoperability of data collection processes remain barriers to maximising the utility of these datasets for informing healthcare policy and practice.

These challenges were further highlighted through the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability Report (Commonwealth of Australia, 2023) that outlined concerns about stigma and risks to privacy, which may lead people with disability to choose not to disclose their disability status. Technical challenges, such as information technology (IT) system changes and staff training, also hinder the recording and collation of disability information. Proxy measures, such as the use of disability services or participation in disability support programs, are sometimes employed to infer disability status. However, these proxies may not accurately represent the diversity of people with disability (for example, not all people with a disability are supported under the NDIS). Additionally, reliance on clinical or diagnostic data poses challenges. For instance, when a patient presents at a health service, diagnostic codes are often utilised only for the presenting concern. Further, the limited research conducted in this area suggests that diagnosis alone does not adequately capture the complexity of disability nor its impact on function, making it an unreliable standalone indicator for disability (Aitkin et al., 2021; AIHW, 2004).

There is a call for the implementation of disability identifiers in data collections for key mainstream services, including health, education, criminal justice, child protection, and housing (Royal Commission Report). This approach should be grounded in the ICF framework and align conceptually with existing disability data collection methods in Australia, particularly the SDAC (Fortune et al., 2023). Moreover, it should be co-designed with people with disability to ensure relevance and accuracy. Little evidence exists however, to inform a standardised approach to achieving this within health service registration or admission (Fortune et al., 2023; Morris et al., 2021).

1.3 Developing an approach to Disability Identification in Electronic Medical Records

In response to the identified gap, a co-design process was undertaken from February 2022 to March 2023 to develop and incorporate a disability identifier (DI) within the Parkville Precinct Electronic Medical Record (EMR) system. The Parkville EMR (Epic Systems, Verona, WI), which is used by more than 18,000 clinicians and staff, is shared by The Royal Children's Hospital Melbourne (RCH), The Royal Women's Hospital (RWH), The Royal Melbourne Hospital (RMH) and the Peter MacCallum Cancer Centre (PMC) in Melbourne.

The co-design phase of a Disability Identifier in EMR systems encompassed:

- Review and benchmarking of disability data collection tools
- Convening of a Technical Advisory Group (TAG), with expertise in mental health, neurodevelopmental conditions, disability and the collection and analysis of disability data (both population based and administrative data)
- Development of a DI question set with guidance from the TAG
- Stakeholder consultation with data users and consumers with lived experience of disability
- EMR build and workflow development.

The co-design phase built on existing approaches to disability data collection, in particular work recently undertaken by Fortune et al (2023) to develop disability identification questions for a voluntary patient registration for primary health care (general practice) in Australia. Our co-design approach involved extensive engagement with stakeholders, including clinicians, patients, Disability Action Plan working groups, and technical experts. Workshops and iterative design sessions were conducted to gather insights from stakeholders with the aim of developing questions that were:

- 1 Inclusive and accessible to individuals with diverse disabilities and communication needs
- 2 Relevant and aligned with existing workflows within the EMR system for clinicians and data users, and
- 3 Compliant with privacy and confidentiality regulations to safeguard patient information.

The culmination of the co-design process resulted in the development of a self-report set of 3 questions, as displayed in Figure 1.

Question 1 asks patients or their carers about difficulty doing daily activities, related to a long-term health condition, impairment or disability. This serves as the primary disability identification question and was designed to conceptually align with the ICF and the operational definition of disability in the SDAC, which is "any limitation, restriction or impairment which restricts everyday activities and has lasted, or is likely to last, for at least six months." (ABS, 2019). Question 1 incorporates a footnoted definition of "daily activities", to encompass all the ICF Activities and Participation domains, including self-care, domestic life, education, social and community life.

Question 2 is intended to capture information about the area of difficulty experienced by patients who have positively responded to question 1. These areas can be mapped to the disability groups used for reporting from the SDAC, which in turn are derived from responses to the list of 17 conditions, impairments and activity limitations used for disability identification in the SDAC survey (Sensory or speech, Intellectual or learning, Physical, Psychosocial, ABI and other). Respondents of the SDAC are not asked directly if they identify with these groups. Based on the co-design process undertaken for the DI questions with input from consumers and expert advisors, the areas of difficulty included in the DI questions maintained a focus on function and excluded medical or diagnostic terminology. Therefore, the DI does not capture an SDAC equivalent 'ABI' group.

Question 3 is intended to identify if there is a need for assistance to access healthcare services. This elicits a 'yes' or 'no' response. Question 3 can be directly linked to a referral pathway and/or additional questions about the type of assistance required (like a 'Health Passport'). The Parkville DI questions included examples of types of assistance with a free text option for respondents to add additional information (see Figure 2).

Figure 1 The DI Questions evaluated in this study

Answering the following questions will help us provide you with the best possible care and help us understand what additional supports you may require. This information will be treated confidentially.

Respondent

Patient

Carer

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

Do you (Does the person you are caring for) have any difficulty doing daily activities*, related to a long-term health condition or disability?

Yes

No

Declined to answer

**Daily activities include all the things you do in your daily life, for example, self-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.*

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

Do you (Does the person you are caring for) experience difficulties in any of the areas listed below? Please tick the box next to any that apply. You can tick more than one box.

Seeing, even when wearing glasses or contact lenses

Hearing, even when using a hearing aid

Speaking or communicating with others

Learning, understanding, remembering or concentrating

Moving or feeling part of your body, walking, using your hands and fingers, or doing other physical activities

Mood, managing emotions, socialising or managing behaviours

Other

3 **Due to the difficulties, impairments or disabilities identified in the previous questions, do you (Does the person you are caring for) require any additional assistance during your inpatient stay or outpatient appointments?***

Yes

No

Preamble to the DI Questions

Statement to relativise the DI Questions to the age of the patient

Primary Disability Identification question

Areas of difficulty

Need for assistance

* Note that the Parkville precinct allowed additional information to be recorded by patients about the type of assistance required (refer to page 4 of the main report).

Figure 2 Parkville types of assistance identified

3 Due to the difficulties, impairments or disabilities identified in the previous questions, do you (Does the person you are caring for) require any additional assistance during your inpatient stay or outpatient appointments?

Yes

No

If yes, please select the type of assistance required

Communication (e.g. Auslan or communication device)

Understanding information

Mobility

Details walker

Personal care

Environmental set up (e.g., low noise, lighting)

Details low light

Decision making and/or consent

Behaviour support strategies

Getting to the health service

Finding your way around the health service

Other (e.g., pressure care)

Are there sufficient supports in place to accommodate patient needs? If not, please place a referral order to Disability Liaison Officer (DLO) or other appropriate services.

Note: DLO prioritise complex admission and discharge planning, patient engagement and access to health care.



1.4 Implementing the Disability Identifier

1.4.1 Electronic Medical Record integration and workflow

Parkville Precinct

The DI questions were integrated into the Epic EMR system in two ways. First, they were accessible via the Parkville patient portal website and smart phone application, referred to as the 'Health Hub' at PMC, RMH, and RWH, and as the 'MyRCH Portal' at the RCH. Through this integration, patients and their carers were able to self-complete the DI questions at any time, provided they had an active portal account. The questions were also made available to clinical staff in Epic's clinical application, known as 'Hyperspace'. Within Hyperspace, these questions were strategically placed in various locations, to fit within clinical workflows, such as the admission

navigators as well as the patients' 'History' activity. Regardless of the mode of completion, the responses were automatically populated into the patient's record. If the patient indicated a positive response to the primary disability identification question (Q1) of the DI, an icon would also be displayed on the patient's 'Story Board', an essential element of the EMR that is visible to clinicians at all times. The DI questions could be updated at any time by either the patient portal or hyperspace mode.

The DI questions were launched in the Parkville EMR on the 29th March, 2023, with implementation varying across and within Parkville health services. While it was encouraged for use during intake or admission processes, the adoption of this new functionality by medical, nursing, and allied health staff remained optional, being at the discretion of individual clinical services and teams. To support uptake, education sessions were conducted precinct-wide by the Disability Liaison Officers, with specific sessions tailored by wards and sites. Online resources were also developed to further assist in uptake.

Figure 3 Parkville DI EMR Workflow

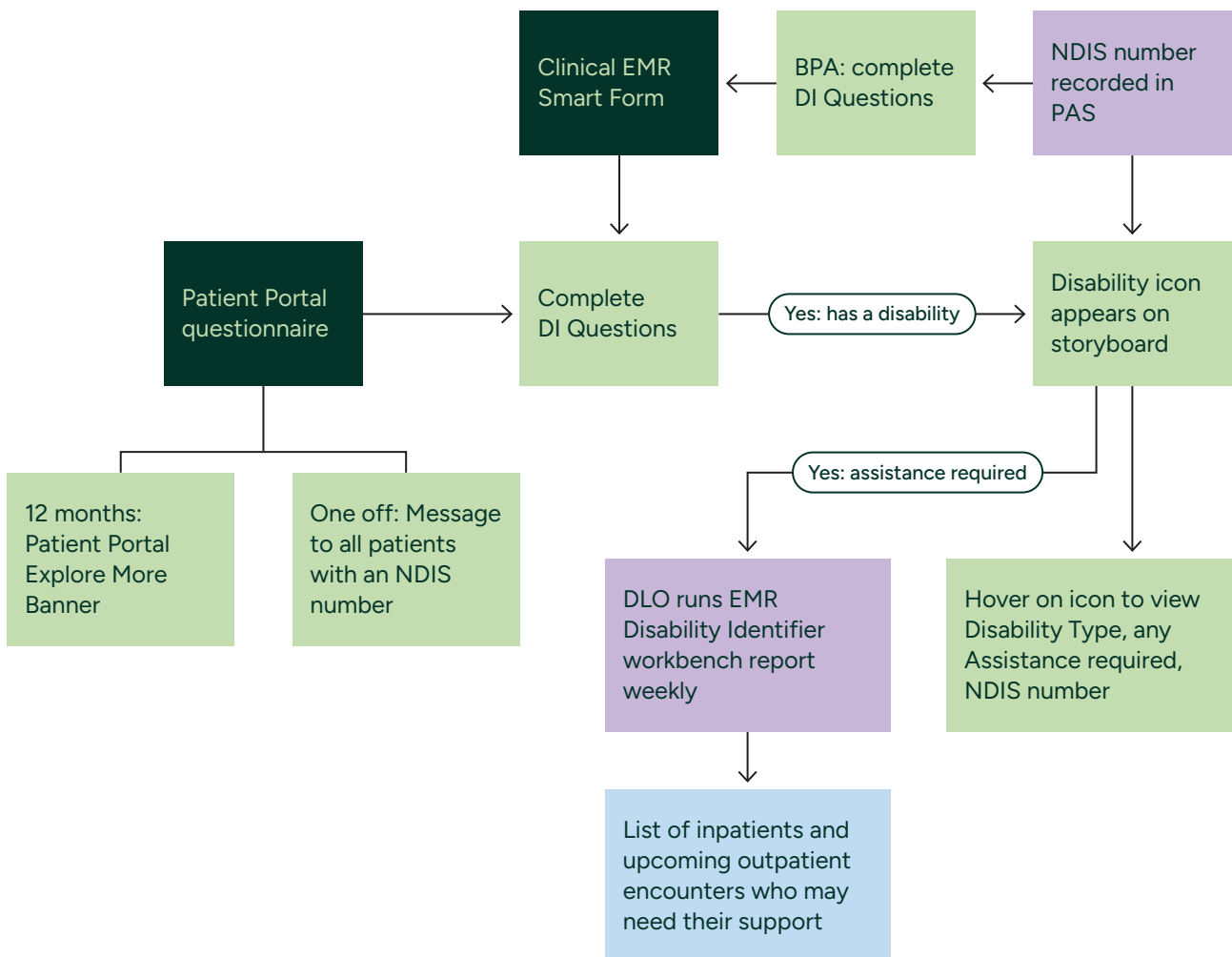
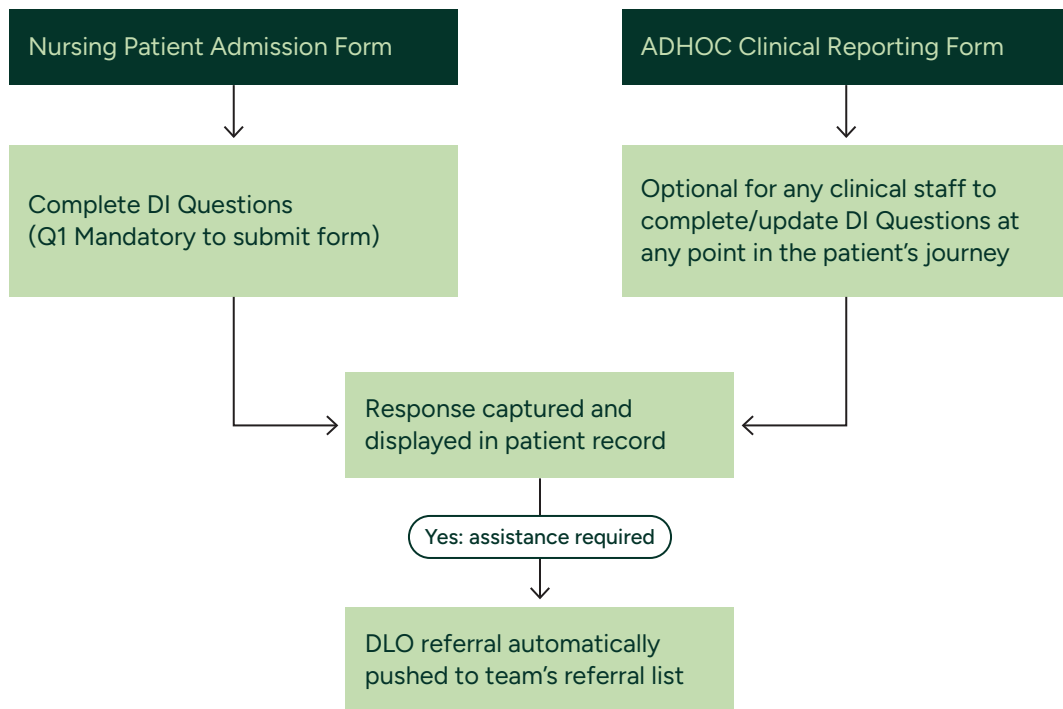


Figure 4 Austin Health DI EMR Workflow



Austin Health

Austin Health partnered with the Parkville Hospitals and adopted the same self-report question set within their own EMR system Cerner Powerchart (Oracle Cerner, Austin, TX). This collaboration provided a unique opportunity to better understand implementation of the approach to disability identification across different health services and EMR systems.

Key internal stakeholders at Austin Health were consulted on the workflow of the question set. It was decided that the question set should be incorporated into the admission process, which serves as an initial touchpoint for all Austin Health inpatients. The Nursing Informatics and Clinical Standards Committee, as part of the Comprehensive Care Standard 5 Committee, offered in-principle support for the inclusion of a disability identifier question set within the nursing 'Patient Admission Assessment'.

The DI questions were integrated into Austin Health's EMR on the 1st March 2023 as part of the Cerner Documentation and Infusions Project (CDIP). The implementation coincided with significant changes for the workforce, including upgrades to workflows and functionality within Austin Health. During the initial period, staff underwent mandatory training on the broader changes that would impact day-to-day practice. Beginning June 2023, the Austin DLO team also provided in-services directly to the nursing

workforce, with a ward-by-ward approach found to be most effective. Individual education was also provided to any staff initiating an automated referral to the Austin Health DLO Program through their responses to the question set.

Initially, upon implementation in March 2023, only the nursing workforce had the capacity to input responses to the question set. During this period, other members of staff, including those in medical, allied health and administration roles, lacked the ability to enter or modify existing responses to the DI questions. In June 2023, the position of the DI questions within the patient admission assessment was relocated from the first page to its own section on page eight of the electronic form. The adjustment granted other Cerner users, including those in the medical and allied health fields, the ability to enter and update the DI questions.

However, this change unexpectedly led to a significant decrease in the completion rates of the DI. This decline was initially observed through a reduction in automated referrals to the DLO Program. Upon identifying this impact, internal consultation with the relevant committees began, ultimately resulting in approval by the Nursing Informatics Committee for the question set to be made mandatory within the patient admission assessment. The question set was made mandatory in mid-October 2023.

There were key differences in the implementation of the DI questions across Parkville Hospitals and Austin Health.

- For the Parkville Hospitals, the DI questions were built with a 'cascade' so that Question 2 (Area of difficulty) and Question 3 (Need for assistance) would only be asked if there was a positive response to the primary disability identification question (Question 1) 'Do you have any difficulty doing daily activities, related to a long-term health condition, impairment or disability'. Austin Health was unable to implement a cascade due to Cerner's functionality limitations, therefore making it possible to skip questions 2 or 3 or complete Questions 2 & 3 despite a negative or 'no response' to the primary disability identification (Question 1).
- The Parkville DI question 3 included examples of types of assistance (as per Figure 2) whereas Austin Health did not.
- Austin Health employed targeted implementation in Nursing admission workflows and adopted mandatory completion towards the end of the implementation period. DI questions remained optional for Parkville clinicians and only one health service (RWH Maternity services) formally integrated it into its admission process (via Maternity booking appointments).
- Parkville Hospitals allowed completion via the Patient Portal while Austin Health do not currently have a Patient Portal.
- The DI Questions were implemented across all age groups at Austin Health but were not implemented in patients <2 years old at the Parkville Hospitals .

1.5 Study purpose

This multi-site project aimed to evaluate patient/carer and staff experiences of using a self-report disability identification approach in the Electronic Medical Record. Evaluation occurred during the first 9 months of implementation (1st March–30th November 2023).

Results presented in this report have informed the development of recommendations to guide practice in EMR Disability Identification across the Parkville Precinct (RCH, RMH, RWH and PMC) and Austin Health, with the potential to also inform practice across other jurisdictions.

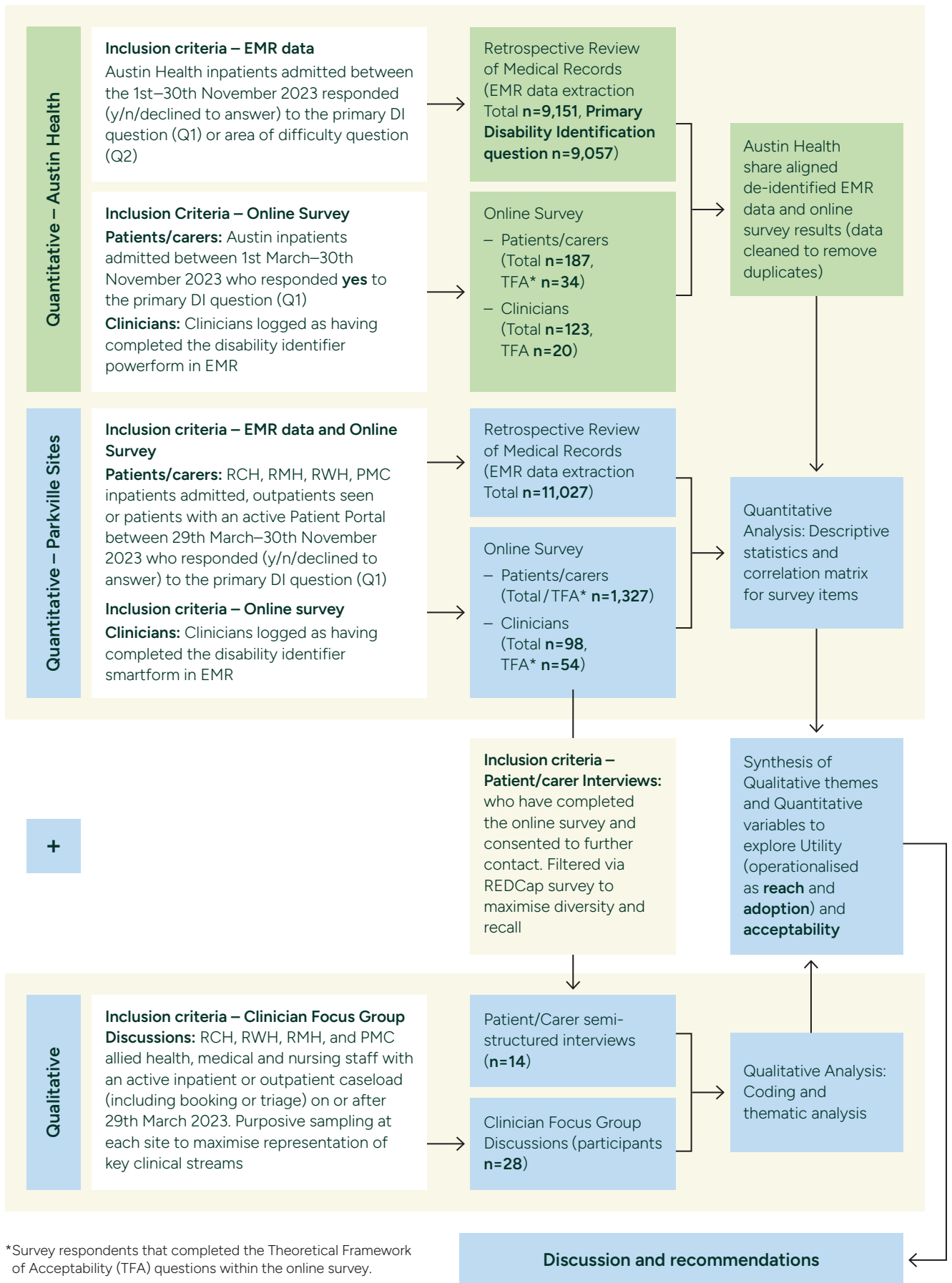
Ethical approval for this multi-site study was obtained by The Royal Childrens Hospital Human Research Ethics Committee (Project HREC/100979/RCHM-2023) and Austin Health's Human Research Ethics Committee (Project HREC 97208/Austin-2023) as outlined in Figure 5.



Figure 5 Study Design

HREC/100979/RCHM-2023

HREC/97208/Austin-2023



2 Methods

2.1 Study Objectives

The study addressed the following objectives:

- 1 To assess the utility (operationalised as **reach** and **adoption**) of the DI during the first 9 months of its implementation (1st March–30th November 2023).
- 2 To explore the **acceptability** of the DI through patient, carer and clinician perceptions of completing the self-report disability questions.
- 3 To make recommendations to guide optimisation and standard practice in disability identification in EMR across the participating hospitals and provide considerations for adoption in other jurisdictions.

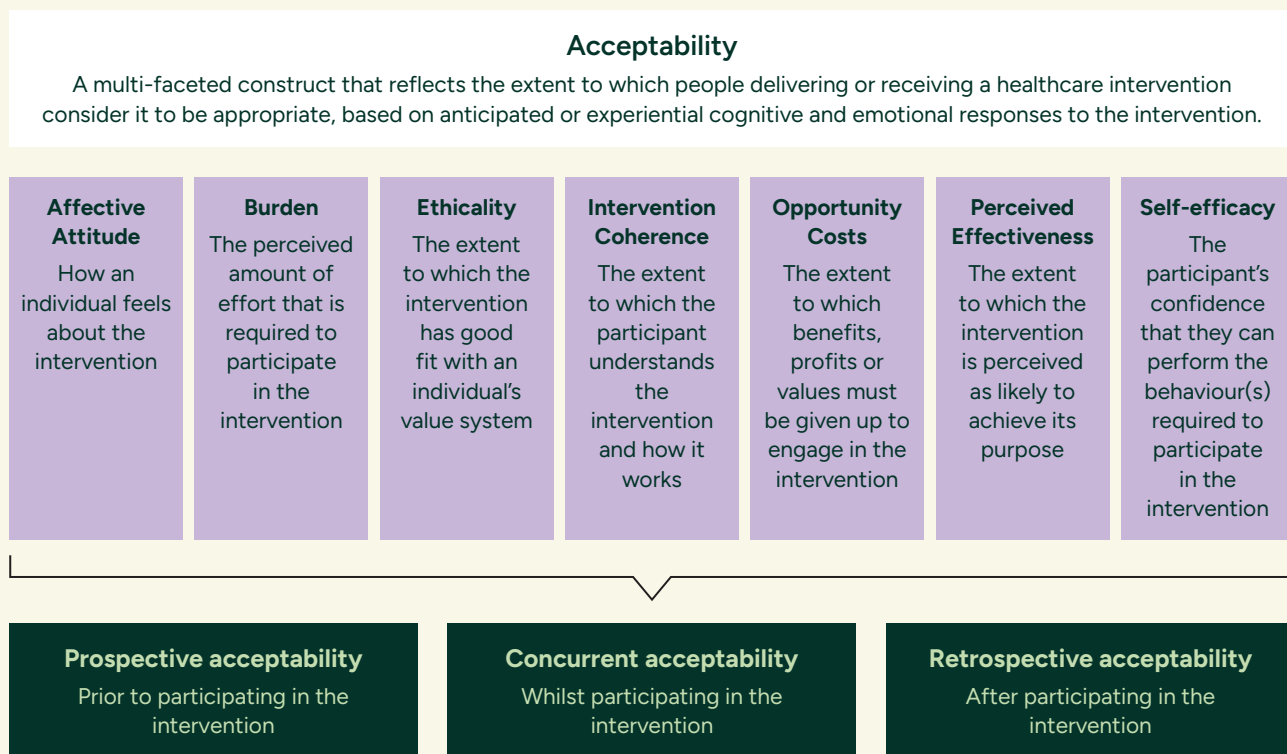
2.2 Study Design

The study followed a convergent parallel mixed-methods study design, as illustrated in Figure 1. Qualitative and quantitative data were collected concurrently and analysed separately before being synthesised to explore outcomes and make recommendations.

The study employed the Theoretical Framework of Acceptability (TFA), as developed by Sekhon et al. (2022). The TFA offers an evidence-based approach for evaluating the acceptability of healthcare interventions, considering the viewpoints of both intervention providers and recipients. Developed and informed by both empirical and theoretical approaches, the TFA consists of seven component constructs – Affective Attitude, Burden, Ethicality, Intervention Coherence, Opportunity Cost, Perceived Effectiveness, and Self-efficacy (Figure 6) – reflecting

Figure 6 Theoretical Framework of Acceptability

The Theoretical Framework of Acceptability comprises of seven component constructs. Note: The seven component constructs are presented alphabetically with their anticipated definitions. The extent to which they may cluster or influence each of the temporal assessments of acceptability is an empirical question.



the multifaceted nature of acceptability (Sekhon et al, 2017). The TFA has been increasingly adopted over recent years in public health, with examples of its application in quantitative, qualitative and mixed methods in evaluation and research (Paynter et al, 2023).

We applied the TFA in our study using a quantitative online survey along with qualitative semi-structured interviews and focus group discussions, described further below. Following review by the research team, the component Ethicality was excluded from the survey due to concerns regarding comprehensibility of the survey item. This construct was therefore not captured in the online survey, however, was explored qualitatively via semi-structured interviews and focus group discussions.

2.3 Participants

2.3.1 Inclusion/exclusion criteria

There were three types of participants: patients, carers and clinicians. Figure 5 summarises inclusion and exclusion criteria for patients, carers and clinicians for the survey, interview and focus group components of the study. All study participants were over the age of 18 years old. Inclusion criteria for participants taking part in the Patient/Carer semi-structured interviews included ascertaining capacity to provide informed consent, discussed further in recruitment below.

2.3.2 Recruitment to the survey

Parkville Hospitals

The research team invited eligible patient or carer participants to take part in the survey by either message sent via Patient Portal/Health Hub (for active users) or postal letter. Potential participants were sent a link (QR code and URL) to participate in the survey with a short explanatory message/letter. A participant information statement was included at the beginning of the survey that outlined that completion of the survey implied consent. One reminder was sent.

The Centre for Health Analytics staff identified potential clinician participants via an EMR audit. They were invited by the research team to participate via an email sent to their work address, that included study information. A participant information statement was included at the beginning of the survey that outlined that completion of the survey implied consent. Three generic reminders were sent.

Austin Health

Survey invitations were distributed to eligible Austin Health patients via email or text message, using contact information recorded for the patient in EMR. In the absence of a response to the initial contact, a single reminder was sent via the participant's primary contact method (text message or email) before the participant was considered lost to follow up. Eligible Austin Health staff who had completed a patient admission assessment on or after March 1 2023 were invited to participate in the survey via their staff email address. Two generic email reminders were sent to staff.

All surveys across Parkville and Austin Health sites included a participant information statement at the beginning of the survey, and outlined that completion of the survey implied consent to participate.

2.3.3 Recruitment to the qualitative components

Potential patient/carers participants for the qualitative interviews were existing patients or carers who had completed the online survey, could recall completing the DI questions within a healthcare encounter, and provided consent to be contacted regarding taking part in a follow-up interview.

From the pool of available patient/carers online survey respondents the team sought a sample that included patients and carers with diverse characteristics, including in relation to disability identifier question responses, gender, age, and hospital site.

Informed consent was obtained prior to the interview and confirmed verbally at the beginning of the interview. Capacity to provide voluntary and informed consent was ascertained via seven easy English true/false questions.

A purposive approach to sampling of clinicians was taken to achieve coverage across key clinical groups (Allied Health, Nursing and Medical) at each participating site. Six to eight focus group discussions were planned, comprising three to five participants in each, with one or two focus groups completed at each site. Potential participants were invited via email and provided with the Participant Information Statement and Consent form.



2.4 Data Collection

2.4.1 Retrospective audit of electronic medical records

Patient and clinician data related to the DI was accessed retrospectively via the Parkville and Austin health EMR to assess reach and adoption, according to inclusion criteria. Bulk extraction of data from the EMR was completed by the Centre for Health Analytics and Parkville and Austin Health EMR Teams. Data were accessed and managed by the site-specific investigators who have routine access to EMR through their roles at each hospital along with the Chief Allied Health Information Officer (for Parkville Sites). Data were de-identified prior to analysis.

The following data were extracted from the EMR: Responses to the DI question set, age, gender, identification as Aboriginal or Torres Strait Islander, presence of pregnancy flag, identification of English as non-primary language (at Parkville sites), and member of a culturally and linguistically diverse community (at Austin Health. Parkville also extracted data on presence of high-risk flags, which include vulnerable child (child protection involvement), vulnerable/at risk adults, family violence, and behavioural flags. Behavioral flags are often used following an experience of escalation or an adverse event within the hospital environment.

Austin health provided de-identified data to RCH for further analysis and comparison (as per Figure 5).

2.4.2 Primary data collection – online survey, semi-structured interviews and focus group discussions

Online Survey

A patient/carer survey and a clinician survey were administered electronically via REDCap. The objective of the surveys was to assess patient/carer and clinician experience with using the DI question set. The surveys were adapted from a generic TFA questionnaire developed by Sekhon et al (2022) and have been included in Appendix 2.

Patient/Carer semi-structured interviews

Patient and carer experiences were further explored through semi-structured interviews related to the DI questions and engaging with the DI process. Interviews also included preliminary cognitive testing of the DI question set with questions assessing consistency of understanding and interpretation of the DI questions.

Clinician Focus Group Discussions

Clinician Focus Group Discussions (FGD) were completed by the research team. The objective of the FGDs was to explore the implementation experience from the clinician's perspective, including barriers and enablers to adoption of the disability identifier. Recruitment of clinicians was coordinated through site investigators.

2.5 Data Analysis

2.5.1 Quantitative EMR and survey data

Retrospective EMR Data from the Parkville Hospitals and Austin health has been combined, analysed and reported descriptively. Missing values were evaluated and corrected by either combining variables or investigation to determine the correct values; they were omitted from the analysis in some instances. Respondents that skipped the primary disability identification question (Q1) were excluded from EMR data analysis except for a single comparison of responses to DI Q3 between those who positively responded to Q1 and those that either negatively responded or skipped Q1 (Figure 19).

Descriptive statistics were reported in terms of prevalence, means, percentages and other statistical estimates and tests, such as odds ratios and two proportion Z-Test. Prevalence estimates were calculated as the number of patients positively responding to the DI Q1 as a proportion of all DI respondents in the EMR dataset, and then stratified by age and gender. Where data were available, comparisons were made between DI and SDAC prevalence proportions and DI 'areas of difficulty' and SDAC 'disability groups'.

Online Survey respondents who did not complete all six TFA Constructs were excluded from the Survey data analysis. Survey data were analysed by generating a single acceptability score by: a) Computing the total mean score of the six TFA Constructs, and (b) using the score for the General Acceptability item. Higher mean scores for each individual TFA construct and the General Acceptability item indicated stronger acceptability, including for Burden and Opportunity Cost constructs which were both inversely rated in the online surveys. The relationship between each of the TFA Constructs and the General Acceptability item was investigated via correlation analysis.

Responses to open-ended questions in the Survey were analysed using simple thematic analysis and included in the overall synthesis of findings.

2.5.2 Patient/carer qualitative interviews

Interviews were recorded and transcribed verbatim, with two researchers (AD, MH) reviewing the accuracy of transcripts. Analysis commenced with familiarisation and immersion. Initial coding was completed deductively drawing on the TFA framework, with data categorised under the seven TFA Constructs. Inductive coding was conducted in conjunction with this process with data categorised into emerging codes and sub-categories to document patient/carer perspectives and experiences that did not align specifically with the TFA Constructs. Two researchers (AD, MH) participated in this process independently and via discussion. Ongoing discussions were similarly conducted with the wider research group to contextualise and triangulate findings.

2.5.3 Focus group discussions with clinicians

Focus group discussions were recorded and transcribed verbatim. These data were uploaded into NVivo (v14) for analysis where they were independently coded by two researchers (NM, IG). Data analysis commenced with familiarisation and immersion. Initial coding was completed inductively via an iterative approach, where codes represented the building blocks of the analysis. Codes were organised into content categories and sub-categories and then further analysis used a deductive approach, to understand clinician perspectives in context of the TFA. Three researchers participated in this step (NM, JR, IG) both independently and via reflexive discussions. There were ongoing discussions between the three researchers and the wider research group, to facilitate deeper engagement with the data and challenge individual assumptions.

3 Results

The results of this study are presented in two sections, the first addresses reach and adoption of the DI questions by examining the data extracted from the EMR. The second addresses acceptability of the DI questions by examining findings from the online surveys, patient and carer semi-structured interviews and clinician focus group discussions.

3.1 Utility: Reach & Adoption

Section 3.1 of the report provides a summary of EMR data related to the uptake and completion rates of the DI question. The data are considered in relation to the demographic characteristics of the sample. In addition, the prevalence of disability calculated from the data, based on positive responses to DI question 1, is compared with estimated disability prevalence in Australia based on SDAC.

3.1.1 DI Completion (by Hospital)

During the period 1 March to 30 November 2023, **20,083 patients** completed the DI across RCH, RWH, RMH, PMC and Austin Health. Table 1 shows the age and gender characteristics of this patient cohort. DI respondents span across all age groups, with the highest numbers within the 25-44 year old bracket representing 35% of total respondents (see Table 1). Most individuals in the 0-14 range were RCH patients, and the majority of those older than 45 years were RMH and Austin Health patients. There were more people identifying as females (60%) compared with males (40%), predominantly driven by higher uptake of the DI at the RWH (see Figure 8).

Table 1 Distribution of patient gender and age characteristics by hospital*

		RCH n (%)	RWH n (%)	PMC n (%)	RMH n (%)	Austin Health (all sites) n (%)	Total n (%)
Gender	Male	786 (57.2)	8 (0.18)	343 (46.7)	2,004 (44.2)	4,804(46.9)	7,945 (39.6)
	Female	589 (42.8)	4,371 (99.8)	391 (53.3)	2,531 (55.8)	4,249 (53.0)	12,131 (60.4)
	Other	–	2(0.05)	–	1 (0.02)	–	3 (0.01)
	Unknown	–	–	–	–	4 (0.04)	4 (0.02)
Age	0–4	322 (23.4)	–	–	–	218 (2.4)	540 (2.69)
	5–14	809 (4.0)	–	2 (0.3)	1 (0.02)	260 (2.9)	1,072 (5.34)
	15–24	244 (17.8)	232 (5.3)	16 (2.2)	339 (7.5)	468 (5.2)	1,299 (6.47)
	25–34	–	2,308 (52.7)	51 (7.0)	755 (16.6)	643 (7.1)	3,757 (18.71)
	35–44	–	1,652 (37.7)	97 (13.2)	746 (16.5)	788 (8.7)	3,283 (16.35)
	45–54	–	101 (2.3)	122 (16.6)	754 (16.6)	1,025 (11.3)	2,002 (9.97)
	55–64	–	52 (1.2)	194 (26.4)	766 (16.9)	1,393 (15.4)	2,405 (11.97)
	65–74	–	28 (0.6)	167 (22.8)	633 (14.0)	1,622 (17.9)	2,450 (12.21)
	75+	–	8 (0.2)	85 (11.6)	542 (12.0)	2,639 (29.2)	3,274 (16.31)
	Unknown	–	–	–	–	1 (0.01)	1 (0)
Total Patients*		1,375 (6.8)	4,381 (21.8)	734 (3.7)	4,536 (22.6)	9,057 (45.1)	20,083 (100)

* All % are column-wise (Hospital specific). The bottom row shows hospital totals as a proportion of the total data set.

Figure 7 Age distribution of DI EMR data by Hospital

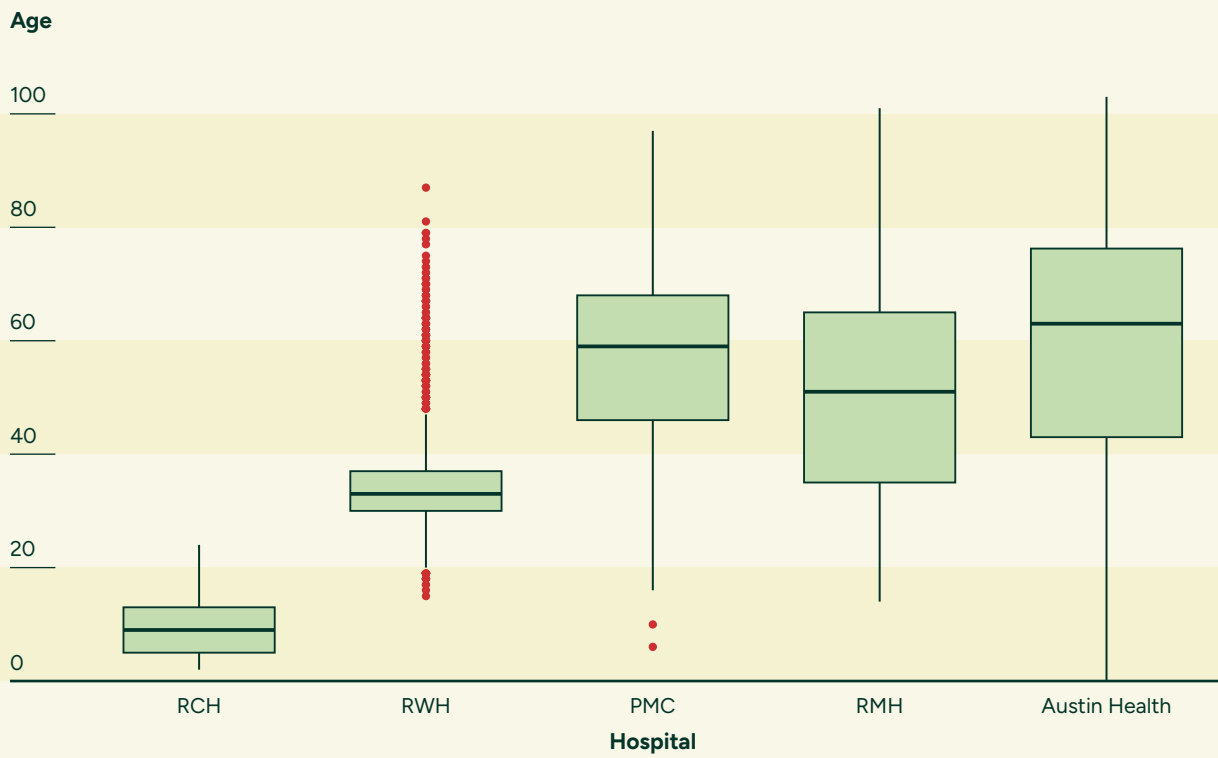


Figure 8 Sex distribution of DI EMR data by Hospital

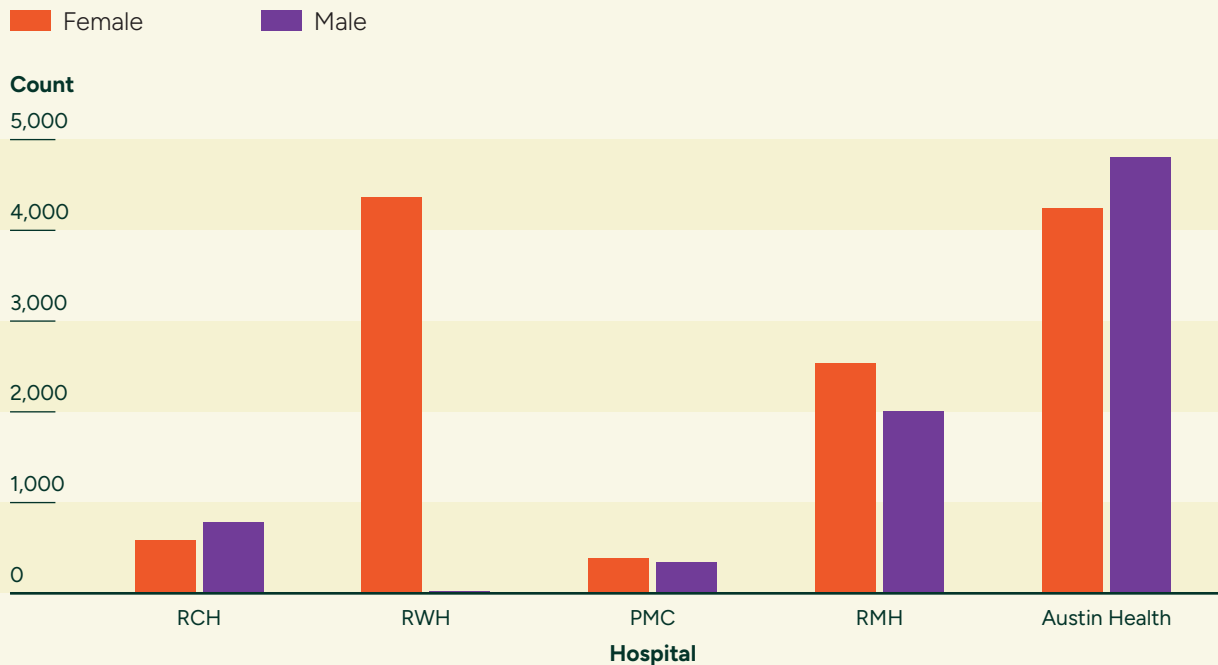


Figure 9 Proportion of DI completion by patient or carer – Parkville Hospitals

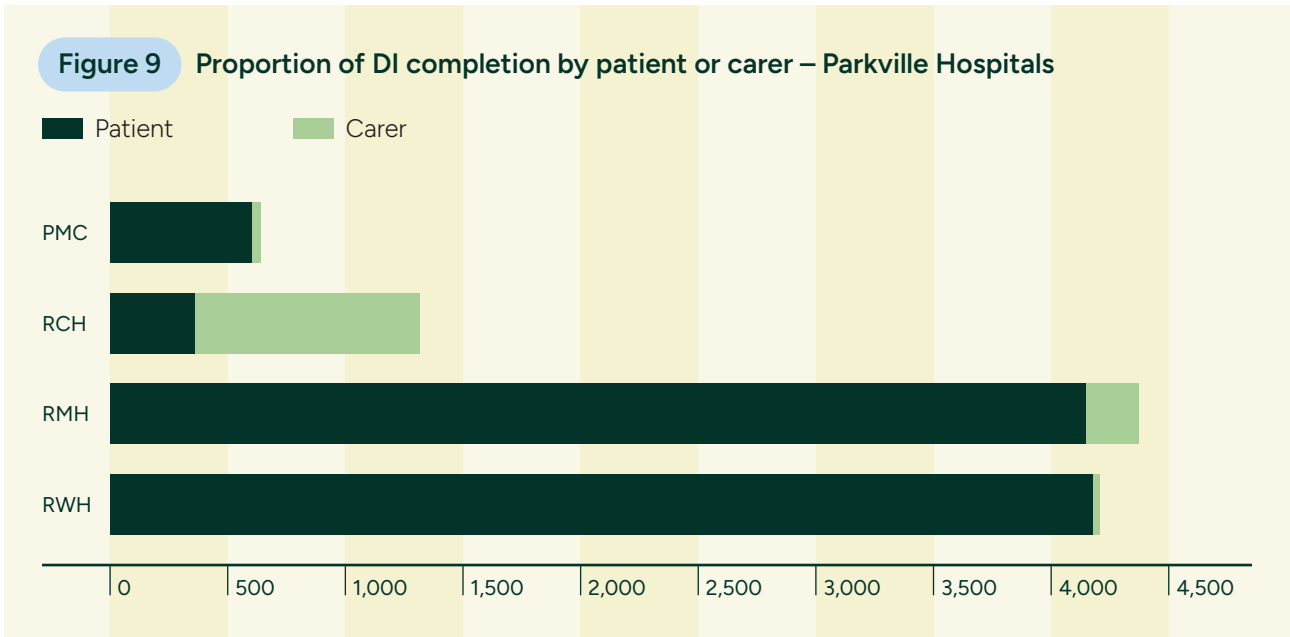


Figure 9 shows the proportion of patient (n=9,322; 84.6%) vs carer (n=1,248; 11.3%) completions of the DI questions at the Parkville Hospitals. Note that 456 (4.1%) of Parkville DI respondents did not indicate either patient or carer due to a delay in the introduction of this field as part of the DI data collection. The highest proportion of carer respondents was in patients under the age of 18 at RCH. Austin Health did not record whether the DI was answered by the patient directly or a carer on the patients' behalf.

The DI completion rate (summarised in Figures 10 and 11, overleaf) was calculated by determining the number of admissions where the DI was completed prior to discharge as a proportion of total admissions, at three separate time points (all admissions in the months of May, August and November 2023). Departments or units where the DI was not accessible (via EMR) were excluded.

DI completion rates showed an increased uptake and reach at the Parkville Hospitals across the implementation period, at 2, 4 and 8 months. The rate of completion for patients was higher at the RWH compared with the other Parkville Hospitals in month 4 (21.55% compared with 11.94%) and month 8 (37.73% compared with 14.10%). The differences in proportions were statistically significant at both time points (Table 2).

Similar to RWH, Austin Health's implementation approach integrated the DI into their Nursing admission workflow. Completion rates decreased in August compared with May, when the DI questions were relocated within the nursing admission form. However, following the DI questions becoming mandatory in October, completion rates surged from 12% to 96% of admissions.

Figure 10 Parkville DI Completion rate by site at 2 months, 4 months and 8 months

2 months 4 months 8 months

Rate

40%

30%

20%

10%

0

RCH

RWH

PMC

RMH

Hospital

Note that completion rates are not cumulative

Table 2 Difference in completion rate between the RWH and other Parkville Hospitals

Month	Difference	95% CI	P-Value
August (month 4)	9.6%	7.6% – 11.7%	<0.001
November (month 8)	23.6%	21.2% – 26.0%	<0.001

Figure 11 Austin Health DI Completion rate

Rate

100%

80%

60%

40%

20%

0

May

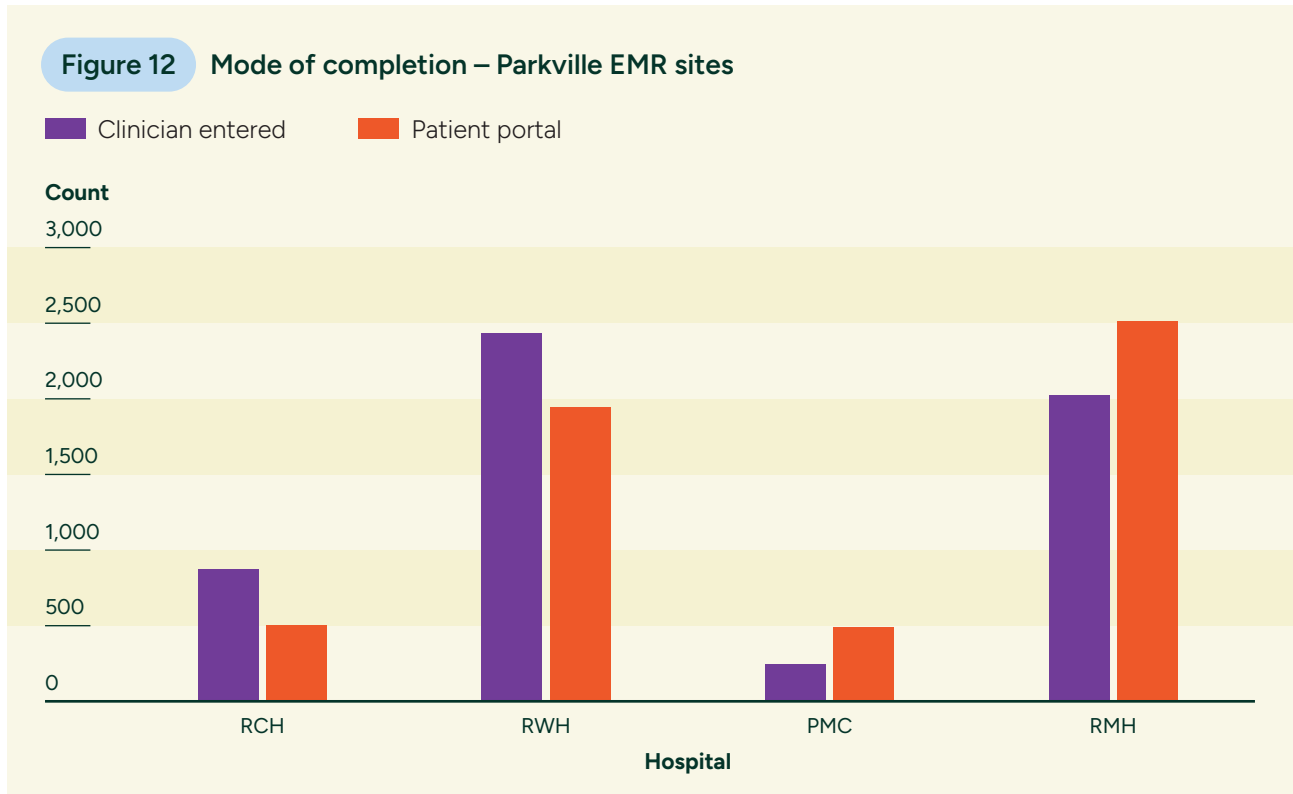
August

November

3.1.2 Mode of completion

Among all patients who completed the DI questions across the Parkville Hospitals, 50% did so via the patient portal (MyChart), the remaining 50% were completed with a clinician asking the questions and entering response into the EMR. Seventy percent of patients positively identifying with a disability

used the portal for completing the DI questions. When expressed as an Odds Ratio, patients identifying as having a disability had 2.9 (95% CI: 2.59 to 3.20) times the odds of completing the questions in the patient portal compared to those who did not identify as having a disability.



3.1.3 Disability Prevalence

As assessed using the DI questions, the overall prevalence of disability across the combined Parkville and Austin campuses was 17.9% (n=3,590/20,083). Disability prevalence differed by Hospital site as demonstrated by the Primary Disability Identification

(Q1) responses presented in Table 3. Prevalence across age groups, genders, and specific patient cohorts are presented next. Figure 13 displays prevalence by age group. Table 4 displays prevalence by age group, gender and Aboriginal and Torres Strait Islander status, and compares outcomes to SDAC data.

Table 3 Q1 Primary disability identification question response by Hospital*

DI Q1 Response	RCH n (%)	RWH n (%)	PMC n (%)	RMH n (%)	Austin Health (all sites) n (%)	Total n (%)
Yes [^]	385 (28.0)	214 (4.9)	156 (21.2)	1,224 (27.0)	1,611 (17.8)	3,590 (17.9)
No	969 (70.5)	4,129 (94.2)	565 (77.0)	3,209 (70.7)	7,279 (80.4)	16,151 (80.4)
Declined to answer	21 (1.5)	38 (0.9)	13 (1.8)	103 (2.2)	167 (1.8)	342 (1.7)
Total Patients*	1,375 (6.8)	4,381 (21.8)	734 (3.7)	4,536 (22.6)	9,057 (45.1)	20,083 (100)

*% are column-wise (Hospital specific). The bottom row shows hospital totals as a proportion of the total data set.

[^]Disability prevalence by Hospital site and in total

Figure 13 Disability prevalence by age group
(Parkville Hospitals and Austin Health combined)

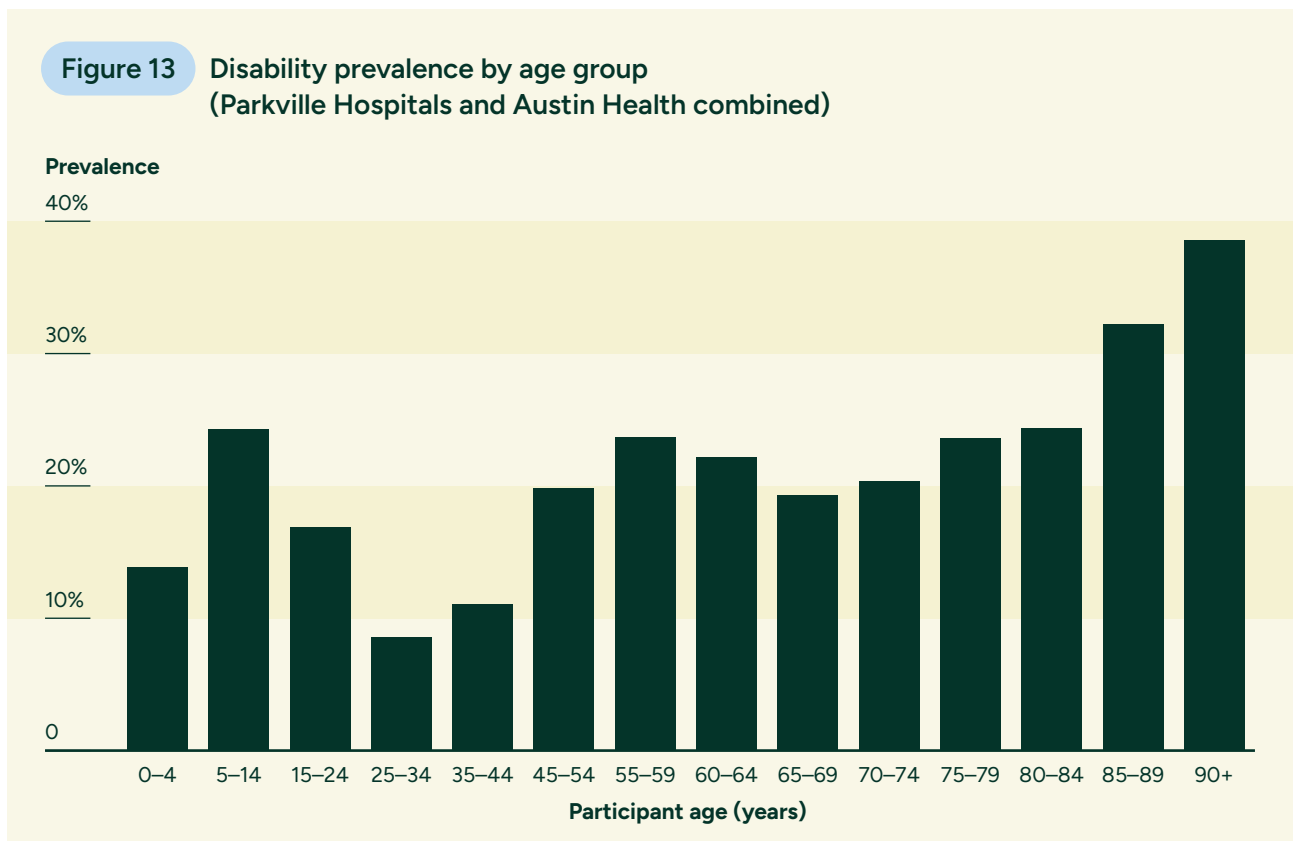


Table 4 Prevalence of disability by age group, gender, and Aboriginal and Torres Strait Islander status

		Overall disability %		
		DI	SDAC 2018*	SDAC 2022*
Whole population		17.9	17.7	21.4
Age group	0–4	13.9	3.8	5.7
	5–14	24.3	9.5	13.5
	15–24	16.8	9.2	13.9
	25–34	8.6	7.2	10.4
	35–44	11.1	9.7	11.5
	45–54	19.8	15.6	17.8
	55–64	22.9	24.1	29.7
	65–74	20.0	38.8	42.5
	75+	28.0	63.4	64.3
Gender	Males	20.7	17.6	21.0
	Females	15.9	17.7	21.8
Indigenous status	First Nations Australians	28.0	24.0	–
	Not Indigenous	17.4	16.9	–

* SDAC prevalence estimates obtained from the ABS website and ABS Table builder.

Figure 14 Disability prevalence by age group and gender (Parkville Hospitals and Austin Health combined)

Female Male

Prevalence

50%

40%

30%

20%

10%

0

0–4 5–14 15–24 25–34 35–44 45–54 55–59 60–64 65–69 70–74 75–79 80–84 85–89 90+

Participant age (years)

Overall, the prevalence of self-reported disability was similar in the combined DI data for 0-65 age groups (15.4%) compared to what we see in the general population in the 2022 SDAC (15.0%). While disability prevalence continues to trend upward in the 65+ age group in the DI data (24.6%), it does so less dramatically than what we observe in the 2018 and 2022 SDAC data (49.6% and 53.3% respectively). Stratifying the data further by gender and age provided additional insights (Figure 14).

The prevalence distribution of disability among females in the 24–44 year-old age group was impacted by the high number of maternity patients from the RWH compared to other patient groups across the dataset. Stratification of these data by pregnancy status, found a substantial proportion of females were pregnant (25.9%; primarily aged 15 to 34 years). Pregnant females had a lower prevalence of self-reported disability (3%) compared to their non-pregnant counterparts (22%). This observation contributed to a lower overall prevalence of disability among females aged 15 to 44, particularly within the 25 to 44 age cohort, explaining the disparity seen in the disability prevalence between males (20.7%) and females (15.9%) in the overall DI population (Table 4).

Vulnerability characteristics

Further exploration of the DI data revealed a higher prevalence of self-reported disability in patients with other vulnerability markers present in their EMR, including family violence, high risk of vulnerability and behavioural flags as summarised in Table 5.

Female patients with a family violence flag have 2.13 times the odds of positively identifying with a disability compared to those without this flag (95% CI: 1.37–3.30, $p = 0.001$). Patients with a high-risk flag have 2.73 times the odds of positively identifying with a disability compared to those without this flag (95% CI: 2.15–3.46, $p < 0.001$). The high-risk flag group within the Parkville EMR includes vulnerable child, vulnerable/at risk adults, and child protection involvement. Patients with a behavioral flag have 4.30 times the odds of positively identifying with a disability compared with those without a behavioral flag (95% CI: 3.35–5.50, $p < 0.001$). Behavioral flags are often used where there has already been an experience of escalation or an adverse event within the hospital environment.

Table 5 Odds ratio of positively identifying with a disability for patients with other vulnerability markers on their medical record (Parkville Hospitals)

Variable	Odds Ratio	95% CI	P-Value
Family violence Flag (Females only)	2.13	1.37 – 3.30	0.001
High Risk Flag	2.73	2.15 – 3.46	<0.001
Behavioral Flag	4.30	3.35 – 5.50	<0.001

3.1.4 Reported Area of Difficulty

The following table shows identified areas of difficulty as a proportion of total self-reported disability for the total DI data set and for each site.

For the combined DI population, difficulty with 'moving/physical activity' (63.7%) made up the highest proportion of reported areas of difficulty

followed by 'learning or understanding' (33.8%) and 'mood, emotions and behaviours' (26.1%). The largest differences in proportions between the Parkville Hospitals and Austin Health were in the 'learning and understanding' (41.1% compared with 19.3%) and 'mood, emotions and behaviours' (32.8% compared with 13.3%) constructs.

Table 6 Area/s of difficulty identified by patients with a long-term health condition, impairment or disability by hospital and in total*

Area of Difficulty**	RCH n (%)	RWH n (%)	PMC n (%)	RMH n (%)	Austin Health (all sites) n (%)	Total n (%)
Seeing	51 (13.3)	21 (9.8)	26 (16.7)	227 (18.6)	203 (19.6)	528 (17.5)
Hearing	40 (10.4)	15 (7.0)	13 (8.3)	109 (8.9)	126 (12.2)	303 (10.1)
Speaking	216 (56.1)	44 (20.6)	14 (9.0)	225 (18.4)	199 (19.2)	698 (23.2)
Learning or understanding	253 (66.0)	94 (43.9)	48 (30.8)	423 (34.6)	200 (19.3)	1,019 (33.8)
Moving... physical activity	191 (49.6)	91 (42.5)	99 (64.1)	828 (67.7)	693 (67.0)	1,903 (63.1)
Mood, emotions, behaviours	73 (19.0)	91 (42.5)	46 (29.5)	439 (35.9)	138 (13.3)	787 (26.1)
Other	40 (10.4)	34 (16.0)	26 (16.7)	156 (12.8)	93 (8.9)	349 (11.6)

* % are column-wise (Hospital specific) with combined hospital data shown in final column.

**Note – respondents can select more than one area of difficulty so the sum (%) do not equal 100%.

^ Includes only those with positive response to the primary disability identification question (Q1) and to one or more area of difficulty (Austin n=1,035).

Figure 15 Area of difficulty as a proportion of total self-reported disability (combined Austin and Parkville EMR data)

Proportion

80%

60%

40%

20%

0

Seeing

Hearing

Speaking

Learning

Moving

Mood

Other

Category

Note: 'other' category provided a 'free-text' option and responses included chronic pain, fatigue, anxiety. Refer to Figure 20: Other difficulties

Figure 16 Area of difficulty as a proportion of total self-reported disability (Austin Health and Parkville EMR data comparison)

Austin Health Parkville Hospitals

Prevalence

80%

60%

40%

20%

0

Seeing Hearing Speaking Learning Moving Mood Other

Category

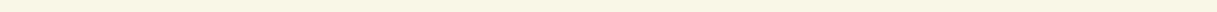


Figure 17 Prevalence of DI 'Area of difficulty' and SDAC 'Disability Group' 2022, as a proportion of total disability

Combined DI SDAC 2022

Prevalence

80%

60%

40%

20%

0

Sensory or speech Intellectual or learning Physical Psychosocial Other

Disability Type

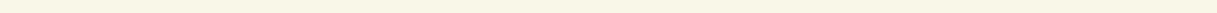


Table 7 Prevalence of DI 'Area of difficulty' and SDAC 'Disability Group' 2018, as a proportion of total disability

Disability groups	Parkville DI %	Austin Health DI %	Combined DI %	2022 SDAC %
Sensory or speech* (Seeing, hearing, speaking)**	50.5	51.0	50.7	35.0
Intellectual or learning* (Learning and understanding)**	41.1	19.3	33.8	20.7
Physical* (Moving and physical activity)**	61.1	67.0	63.1	67.6
Psychosocial* (Mood, emotions, socialising, behaviours)**	32.8	13.3	26.1	30.2
ABI* (no equivalent)**	–	–	–	6.4
Other	12.9	9.0	11.6	42.1

* SDAC = Survey of Disability, Ageing and Carers

**DI = Disability Identifier questions

Proportions of Physical and Psychosocial areas of difficulty in the DI data are closely aligned with population data from the SDAC (ABS, 2019; ABS, 2022) as seen in Figure 17 and Table 7. A higher proportion of Intellectual or Learning Difficulties (33.8%) are observed in the DI data compared with the 2022 SDAC data (20.7%), along with 'Sensory or Speech' difficulties (DI 50.7%; SDAC 35.0%). Figure 18 shows the distribution of prevalence for each area of difficulty captured in the DI questions, across different

age groups within the data set. Like intellectual and learning difficulties, speech and communication difficulties are observed in higher proportions within younger age groups compared with older age groups within the DI population (Figure 18). Conversely, seeing, hearing and moving difficulties become more prevalent as age increases.

Figure 18 Prevalence of DI 'Area of difficulty' by age

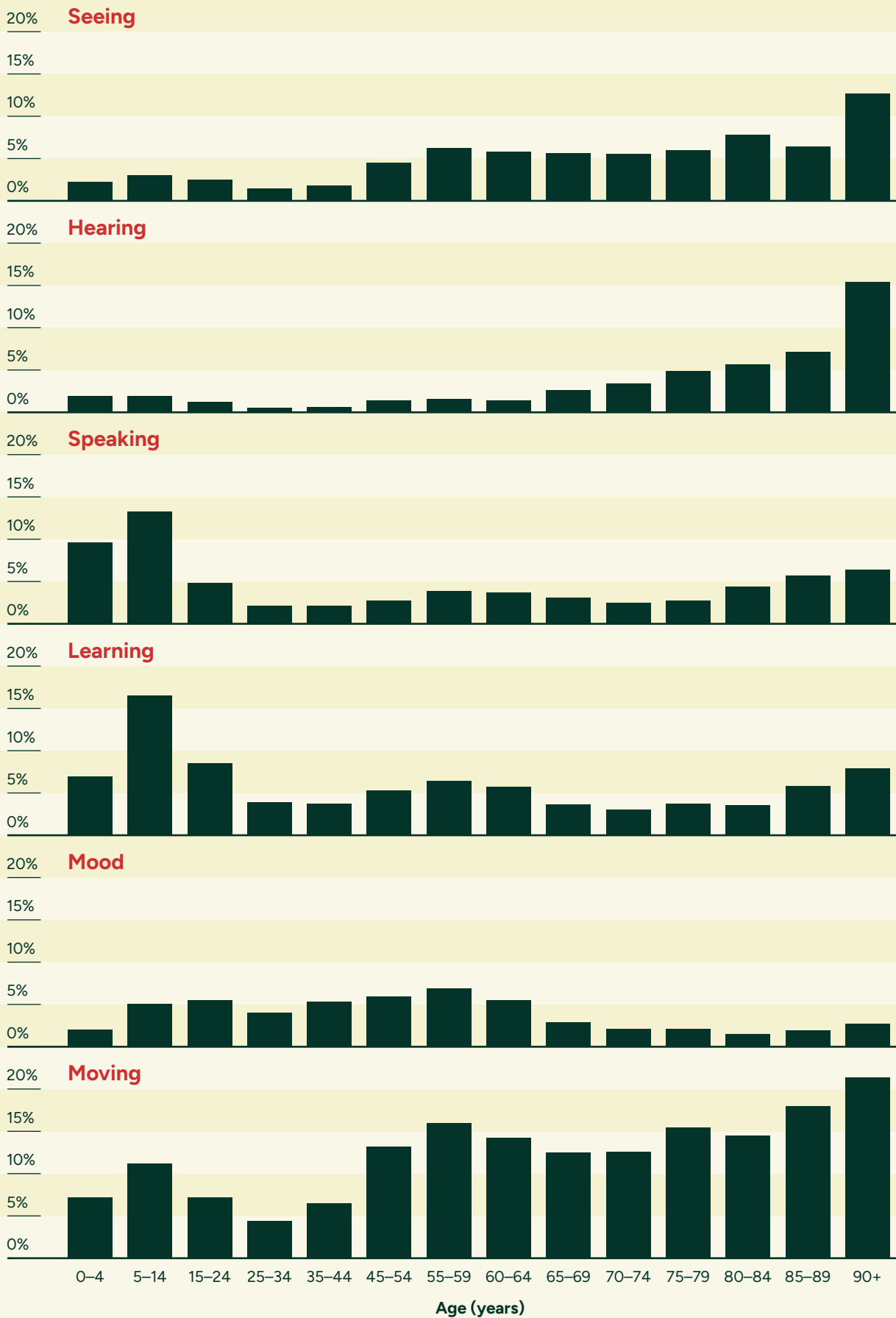


Figure 19 % Area of difficulty by response to Q1 (primary disability identification question) – Austin Health

■ No or no answer ■ Yes

Prevalence

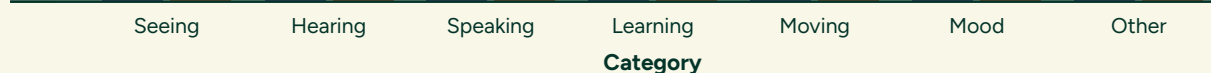
80%

60%

40%

20%

0



Area of difficulty according to response to primary disability identification question (Q1)

Due to variations in DI implementation at Austin Health, a number of patients either answered ‘no’ (n=673) or skipped (n=106) the primary disability identification question (Q1), yet still completed the ‘area of difficulty’ (Q2) and ‘need for assistance’ (Q3) questions. This has allowed additional insights into the data captured with the DI questions.

The distribution of areas of difficulty varied in those answering ‘No’ or skipping the primary identification question compared with those who answered ‘Yes’. In the ‘No’/no answer group, higher proportions were reported in seeing difficulties (39% compared with 19.6%), hearing difficulties (20.9% compared with 12.2%), and other (17.2% compared with 9%) when compared to the ‘Yes’ group. Conversely, lower proportions were observed in moving difficulties (27.1% compared with 67%), speaking/communication difficulties (8.5% compared with 19.2%), mood difficulties (8.6% compared with 13.3%) and learning difficulties (7.6% compared with 19.3%).

For respondents who answered no or skipped the primary disability identification question, a review of the ‘other’ difficulty category (n=54), which allows free text descriptions, indicated that 70% were

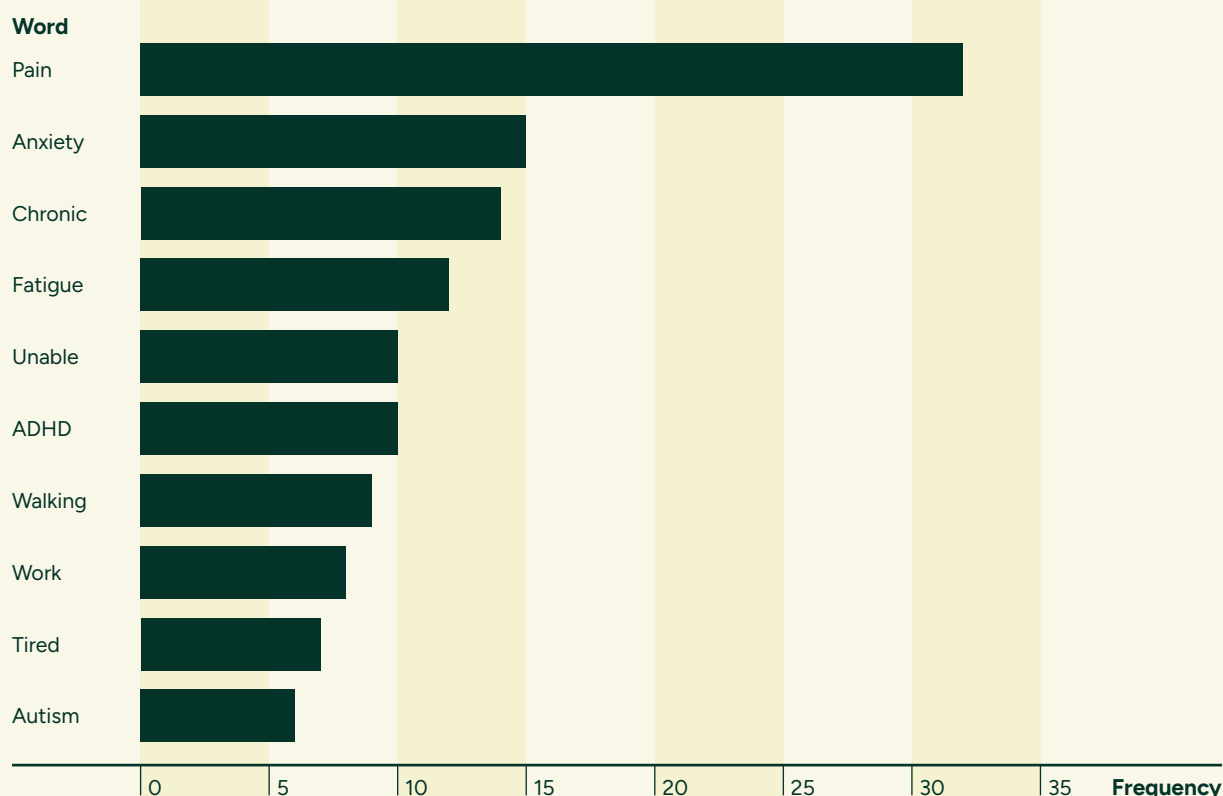
unrelated to a disability. These included non-English speaking background with need for a translator, need for glasses or reading glasses, hearing corrected by hearing aids, short term difficulty related to a presenting medical issue or using the other category to indicate no difficulties present.

Austin DI data suggested that the primary disability identification (Q1) is important in differentiating difficulty related to a disability from difficulties unrelated to disability, for example communication issues due to primary language other than English, use of glasses or hearing aids, and short-term difficulties arising from presenting medical issue or intervention.

Area of difficulty total DI data set: ‘Other’

The ‘Other’ category in the DI ‘area of difficulty’ question allows a free text option for completion. This provided additional insights into areas patients didn’t categorise into the other available options. Patients, carers (and clinicians when documented via EMR Hyperspace or Austin admission form) would sometimes use the free-text box to document a specific condition or diagnosis. Figure 20 on the following page indicates the most frequently documented difficulties in the ‘Other’ category, these include chronic pain and fatigue, anxiety and ADHD.

Figure 20 Top 10 word frequencies for 'Other difficulties'



3.1.5 Reported need for assistance to access healthcare

Table 8 summarises the number of patients who positively identified as having disability and indicated that they required additional assistance when accessing healthcare.

Overall, of patients who identified as having a disability and completed DI question 3, n=810 (33.8%) indicated that they required some form of additional assistance during an inpatient stay or for an outpatient appointment. These proportions vary across sites and subgroups. For example, examining proportions for

each hospital separately, patients reporting a disability at RCH had the highest proportion of assistance needed (47%). This was followed by the RWH and RMH (35%), PMC (33%) and Austin Health (20%). Noting that 69% (n= 1,118) of patients who positively identified with a disability at Austin Health did not complete the need for assistance question, therefore assistance required may be under recoded in this data set. Additionally, implementation of DI question 3 differed at Parkville sites (where it allowed further documentation of types of assistance/adjustments for display on a patients record) and Austin Health (where it was a direct yes/no response that triggered a referral to the DLO Team).

Table 8 Need for assistance identified by patients with a long-term health condition, impairment or disability by hospital

Need for Assistance*	RCH n (%)	RWH n (%)	PMC n (%)	RMH n (%)	Austin Health (all sites) n (%)	Total n (%)
Yes	171 (47.1)	70 (35.2)	50 (32.7)	419 (35.3)	98 (19.9)	810 (33.8)
No	192 (52.9)	129 (64.8)	103 (67.3)	767 (64.7)	395 (80.1)	1,589 (66.2)

* Includes only those patients positively identifying with a disability that completed DI Q3 (need for assistance field). A total of n=1,191 DI respondents positively identifying with a disability did not complete this field (n=73 from Parkville Hospitals and n=1,118 from Austin Health).

Of those at Austin Health who identified an area of difficulty (Question 2) but answered no or skipped the primary disability identification question (Question 1), 4% indicated a need for assistance. This suggests that those answering yes to the primary disability identification question are more likely to report a need for assistance to access health care, compared with those identifying an area of difficulty alone.

Other sub-groups

There were a number of patient groups positively identifying with a disability that showed an increased odds of requiring assistance to access healthcare.

While there was a low prevalence of disability in patients identified as being pregnant, a higher proportion (49%) of this group indicated a need for assistance to access to health care (inpatient and outpatient), compared to those not identified as being pregnant (22%). Converted to an odds ratio (OR),

pregnant patients had 2.23 times the odds of requiring assistance when accessing health care compared to non-pregnant patients (95% CI: 1.89–2.63, $p < 0.001$).

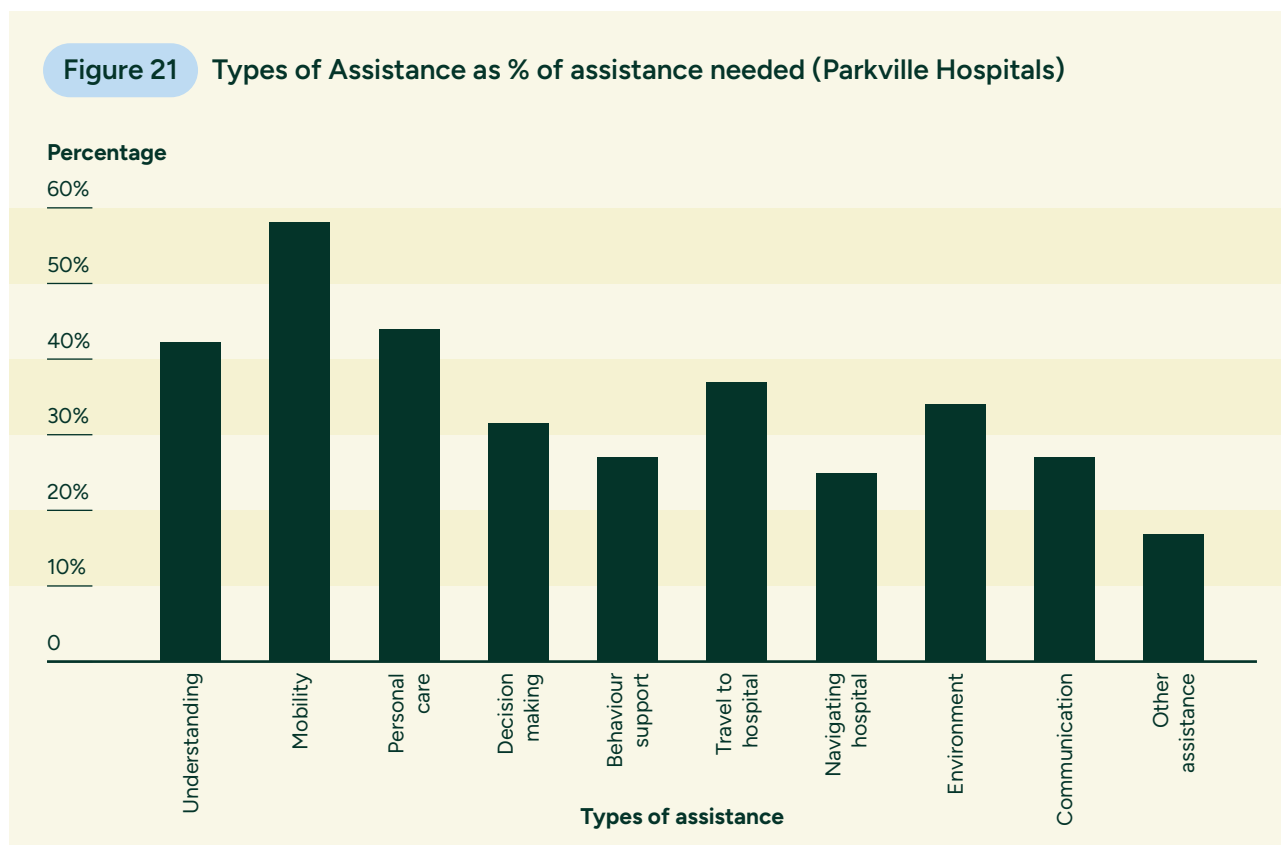
Patients with one more or more vulnerability flag had 3.35 (95% CI: 2.50–4.50, $p < 0.001$) times the odds of requiring assistance compared to those without a vulnerability flag.

Types of Assistance

The Parkville Hospitals used additional prompts and options for free text responses for those patients indicating that they require additional assistance for an inpatient stay or outpatient appointment, related to their long-term health condition, impairment or disability. This information, once completed, is displayed on the patient's record to inform treating clinicians about specific accommodations and healthcare adjustments. Figure 21 shows the proportion of different types of assistance requested by patients.

Table 9 Odds ratio of reported need for additional assistance when accessing health care

Variable	Odds Ratio	95% CI	P-Value
Patients identified as pregnant	2.23	1.89 – 2.63	<0.001
Patients with one or more vulnerability flag (Family violence, high risk or behavioural)	3.35	2.50 – 4.50	<0.001



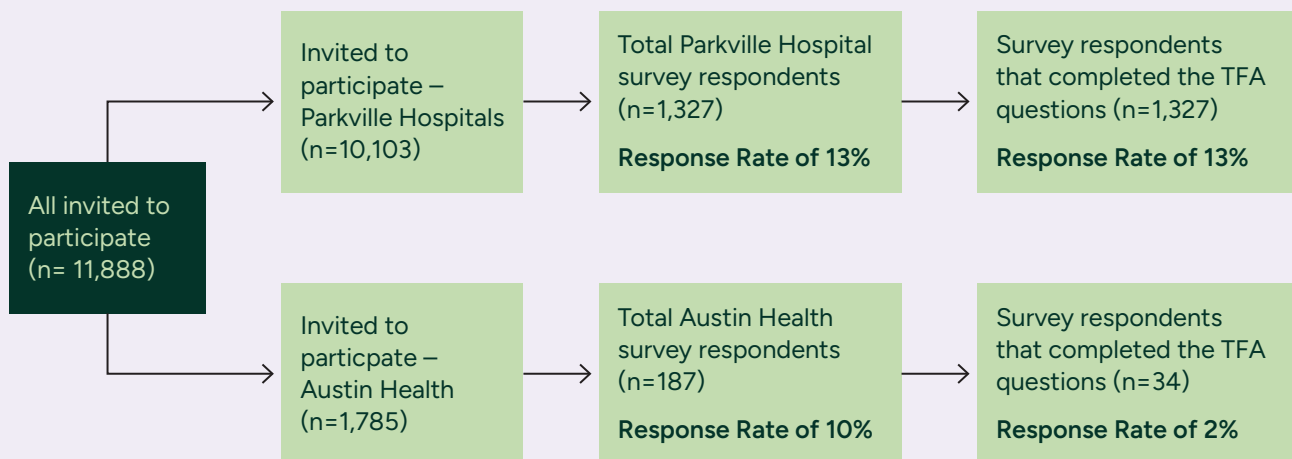
3.2 Acceptability: Perspectives of patients, carers and clinicians

In this section, we present the demographics of participants from the online surveys, semi-structured interviews and focus group discussions. Drawing on the TFA (refer to Figure 6), we then synthesise the overall acceptability of the preliminary implementation and utilisation of the DI within the EMR from the perspectives of patients, carers and clinicians. Within this we present the online survey results across the individual constructs of the TFA. Qualitative findings from semi-structured interviews with patients and carers, FGDs with clinicians, and the open-ended responses provided in the online surveys are then reported under each of the TFA Constructs.

3.2.1 Response rates and demographics for the Online Survey, Interviews and Focus Group Discussions

Of the 11,888 participants (Parkville Hospitals n=10,103, Austin n=1,785) invited to do the online survey, 13% (n=1,327) of patients and carers across the Parkville Hospitals, and 2% (n=34) of Austin Health patients completed the TFA questions. Responses to the Austin Health TFA survey were impacted by survey branching logic allowing TFA completion only for those who recalled answering the DI during a healthcare encounter. Total response rate to the Austin Health survey inclusive of patients who did not complete the TFA was 10% (n=189) (refer to Figure 22).

Figure 22 Patient and Carer Online Survey response rates



Demographics Online Survey – Patients and carers characteristics

Characteristics of patient and carer participants who completed the online survey on the acceptability of the DI are shown in Table 1. Over half of the respondents identified that they (or the person

they care for) had a disability via the DI self-report questions (52.6%), and there were more female (63%) survey respondents compared to male (35%) or those identifying as another gender (2%). Forty one percent of respondents identifying as having a disability indicated that they needed additional assistance when accessing health care.

Table 10 Distribution of patient gender and age characteristics by hospital*

Patient and carer survey demographics by Hospital (n=1,361)*

		RCH n (%)	RWH n (%)	PMC n (%)	RMH n (%)	Austin Health (all sites) n (%)	Total n (%)
Survey Respondent	Patient	6 (4.7)	296 (98.7)	201 (89.7)	644 (95.6)	34 (100)	1,181 (86.8)
	Carer**	123 (95.4)	4 (1.3)	23 (10.3)	30 (4.5)	–	180 (13.2)
Gender	Male	69 (53.5)	4 (1.3)	105 (46.9)	279 (41.4)	24 (70.6)	481 (35)
	Female	57 (44.2)	287 (95.7)	117 (52.2)	387 (57.4)	9 (26.5)	857 (63)
	Gender diverse	3 (2.3)	9 (3.0)	2 (0.9)	8 (1.2)	1 (2.9)	23 (1.2)
Age	0–4	26 (20.2)	–	–	–	–	26 (1.9)
	5–11	60 (46.5)	–	–	–	–	60 (4.4)
	12–17	35 (27.1)	3 (1.0)	–	–	–	38 (2.7)
	18–30	8 (6.2)	48 (16.0)	6 (0.4)	67 (4.9)	4 (11.8)	133 (9.7)
	31–45	–	197 (65.7)	26 (11.6)	127 (18.8)	3 (8.8)	353 (26)
	46–64	–	35 (11.7)	98 (43.8)	275 (40.8)	9 (26.5)	417 (30.6)
	65+	–	17 (5.7)	94 (42.0)	205 (30.4)	18 (52.9)	334 (24.5)
Disability	Yes	90 (69.8)	95 (31.7)	104 (46.4)	397 (58.9)	29 (85.3)	715 (52.6)
	No	39 (30.2)	205 (68.3)	115 (51.3)	271 (40.2)	5 (14.7)	635 (46.6)
	Declined to answer	–	–	5 (2.2)	6 (0.9)	–	11 (0.8)
Need for Assistance	Yes	58 (64.4)	39 (41.0)	28 (26.9)	156 (39.3)	20 (69.0)	301 (41)
	No	32 (55.6)	56 (59.0)	76 (73.1)	241 (60.7)	7 (24.1)	412 (58)
	Unknown	–	–	–	–	2 (6.9)	2 (0.2)
Total Patients*		129 (9.5)	300 (22.0)	224 (16.5)	674 (49.5)	34 (2.5)	1,361 (100)

* All % are column-wise (Hospital specific). The bottom row shows hospital totals as a proportion of the total data set.

**Note – all demographic data (age, gender, hospital, disability, disability type, assistance needed) relates to the patient for whom they provide care

Figure 23 Age and Disability

Q1 Primary disability identification question response

Declined to answer No Yes

Record count

250

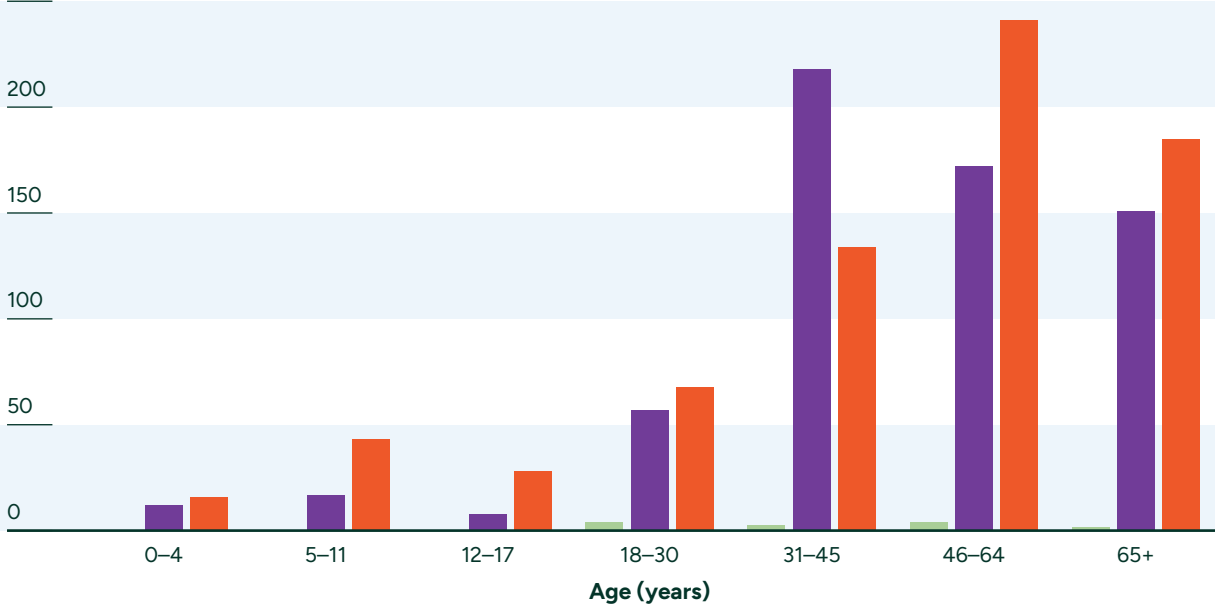


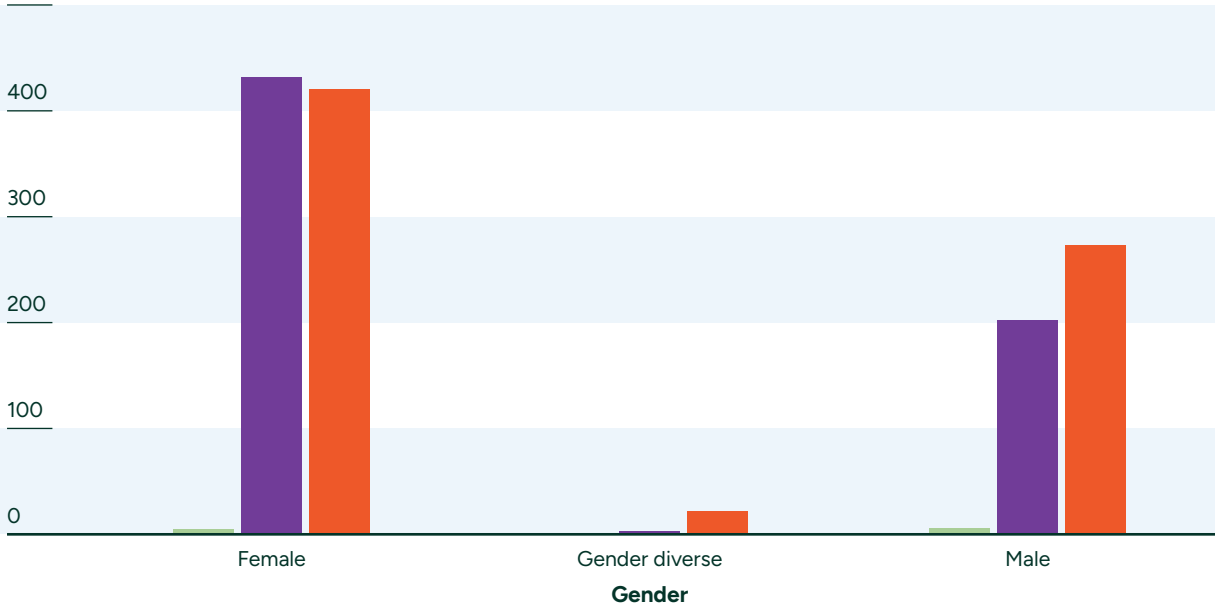
Figure 24 Gender and Disability

Q1 Primary disability identification question response

Declined to answer No Yes

Record count

500



Demographics Online Survey – Clinicians

Of the 3,512 clinicians (n=972 at Parkville Hospitals and n=2,540 at Austin Health) invited to take part, 221 clinicians agreed and completed the survey (see Table 11).

Patient/Carer semi-structured interview participant characteristics

Nine patients and five carers completed the semi-structured interviews. All carers who participated

in the interviews were the mother of a patient with disability. Demographics of the patients represented in the semi-structured interviews are presented below (those directly interviewed and those whose carer was interviewed). More females than males participated, with the most common age group represented being 46–64 years. Patients interviewed often reported more than one difficulty, with moving/physical difficulty being the most commonly reported area of difficulty, followed by cognitive difficulties (see Table 12).

Table 11 Clinician online Survey demographics (n=221)*

		RCH n (%)	RWH n (%)	PMC n (%)	RMH n (%)	Austin Health (all sites) n (%)	Total n (%)
Survey Respondent Discipline	Allied Health	1 (5.9)	1 (3.7)	1 (25.0)	19 (38.0)	12 (9.6)	34 (15.4)
	Medical	3 (17.6)	3 (11.1)	–	–	21 (17.0)	27 (12.2)
	Nursing	13 (76.5)	16 (59.3)	3 (75.0)	31 (62.0)	79 (64.2)	142 (64.3)
	Other	–	7 (25.9)	–	–	11 (8.9)	18 (8.1)
Total		17 (7.7)	27 (12.2)	4 (1.8)	50 (22.6)	123 (55.7)	221 (100)

* All % are column-wise (Hospital specific). The bottom row shows hospital totals as a proportion of the total data set.

Table 12 Demographics of patients represented in the Patient and Carer semi-structured interviews (n=14)

		Number of patients
Age	0–17	3
	18–30	1
	31–45	1
	46–64	7
	65+	–
	Not Reported	2
Gender	Male	3
	Female	11
	Other	–
Area of difficulty*	Seeing	2
	Hearing	–
	Speaking	2
	Learning	7
	Moving	9
	Mood	5
	Complex/other	2

Table 13 Focus Group Discussion participant demographics (n=28)

		Number of participants
Profession	Medical/nursing	10
	Allied health	16
	Administration	2

Clinician Focus Group Discussion participants characteristics

A total of 28 clinicians took part in FGDs. The characteristics of clinician participants in the online surveys are displayed in Table 13 above. These clinicians came from a mix of disciplines, such as allied health (including physiotherapy, occupational therapy, social work, prosthetists/orthotists, medical imaging), administration and medical (nurses, midwives and doctors). They also worked across a variety of clinical areas and departments within the RMH (n=8), RCH (n=11), RWH (n=5) and PMC (n=4).

3.2.2 General Acceptability

General Acceptability reflects the extent to which clinicians implementing the DI and participating patients and carers felt that the intervention (completion of the DI Questions) was appropriate, feasible and would contribute towards improved processes and outcomes. Results from the online surveys demonstrated strong General Acceptability of the DI across patients, carers and clinicians and hospital sites. Overall, patients and carers interviewed felt positively about the DI, as they felt it helped raise awareness about disability and demonstrated that hospitals want to improve supports and outcomes for people with disability. In turn, this was seen as contributing to broader disability inclusion within society. Yet, patients and carers commonly expressed concerns about the capacity of hospitals to effectively utilise the DI to improve care.

I think anything that I can do to contribute to bettering the experience of patients and carers of people within the healthcare system, I'm fully on board.

Carer interview

Clinicians participating in the FGDs also felt the DI provided an important opportunity to improve patient-centredness of care and raise disability awareness. They generally felt that the questions were understandable and could see the potential benefits of including the DI in EMR. Clinicians identified opportunities to improve the language of the questions to ensure some aspects of disability, such as neurodivergence, were captured. Despite identifying the need for more purposeful training, clinicians raised the need to balance this around the burden of additional training, confidence in initiating conversation with patients and the time required to complete the DI.

Overall, TFA survey results indicated strong acceptability across single TFA Constructs and the General Acceptability score (refer to Appendix 2 for the online survey TFA Constructs adapted from Sekhon et al, 2017). For the total patient/carer survey population n=1,361 (all respondents including yes/no and declined to answer the Primary Disability Identification Question), Perceived Effectiveness (3.7/5) and Affective Attitude (3.8/5) scored the lowest and Burden the highest (4.5/5), indicating low perceived burden to complete the questions (refer to Table 14, overleaf).

Table 14 Patient and Carer survey individual TFA Construct and General Acceptability Scores (all respondents)

All Patient and Carer survey respondents by Hospital (n=1,361)

		Parkville Hospitals Mean (CI)	Austin Health Mean (CI)	Total Mean (CI)
TFA Constructs*	Opportunity Cost	4.1 (4.0–4.2)	3.6 (3.2–3.9)	4.1 (4.0–4.1)
	Intervention Coherence	3.8 (3.8–3.9)	3.9 (3.8–4.1)	3.8 (3.8–3.9)
	Perceived Effectiveness	3.7 (3.6–3.7)	4.7 (4.4–5.0)	3.7 (3.6–3.7)
	Self-efficacy	4.1 (4.0–4.1)	3.9 (3.5–4.2)	4.1 (4.0–4.1)
	Burden	4.5 (4.4–4.5)	4.2 (3.8–4.5)	4.5 (4.4–4.5)
	Affective Attitude	3.8 (3.7–8.8)	3.9 (3.6–4.2)	3.8 (3.7–3.8)
	Grand Mean	4.0 (3.7–4.3)	4.0 (3.6–4.4)	4.0 (3.7–4.3)
General Acceptability		4.2 (4.2–4.3)	4.1 (3.9–4.3)	4.2 (4.2–4.3)

Overall Acceptability (percentage)

Completely acceptable	41.9%
Acceptable	42.8%
No opinion	13.9%
Unacceptable	0.3%
Completely unacceptable	1.2%

* TFA Mean score interpretation: Very Weak (1.0 to 1.5); Weak (1.6 to 2.5); Moderate (2.6 to 3.5); Strong (3.6 to 4.5); Very Strong (4.6 to 5.0) – i.e., high scores indicate greater acceptability.

Figure 25 Mean scores for individual TFA Constructs for all Patient and Carer survey respondents (combined dataset)

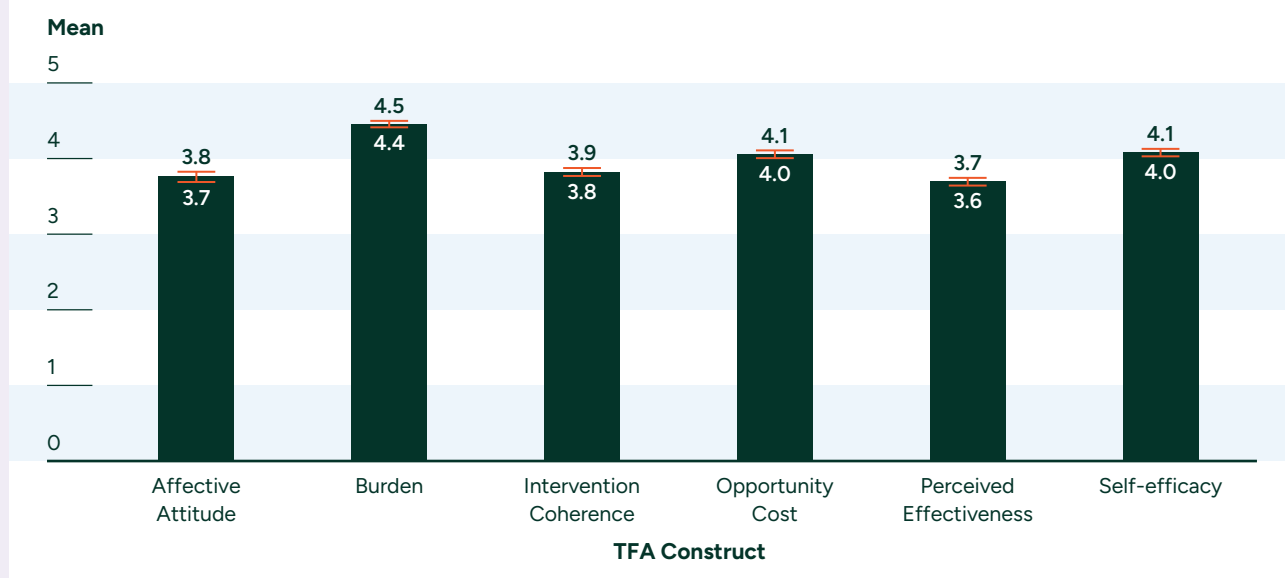


Figure 26 % Responses to General Acceptability item – all Patient and Carer respondents (combined data set)

Percentage

50%

40%

30%

20%

10%

0

Completely acceptable

Acceptable

No opinion

Unacceptable

Completely unacceptable

Acceptability scale

41.9%

42.8%

13.9%

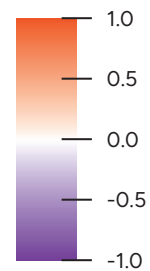
0.3%

1.2%

Figure 27 Correlation Matrix for individual acceptability construct scores and General Acceptability – Patient and Carer survey (all respondents)

General Acceptability	0.4	0.4	0.4	0.4	0.3	0.2	1
Affective Attitude	0.1	0.2	0.2	0.3	0.2	1	0.2
Burden	0.3	0.2	0.2	0.3	1	0.2	0.3
Self-efficacy	0.2	0.4	0.3	1	0.3	0.3	0.4
Perceived Effectiveness	0.1	0.6	1	0.3	0.2	0.2	0.4
Intervention Coherence	0.1	1	0.6	0.4	0.2	0.2	0.4
Opportunity Cost	1	0.1	0.1	0.2	0.3	0.1	0.4
	Opportunity Cost	Intervention Coherence	Perceived Effectiveness	Self-efficacy	Burden	Affective Attitude	General Acceptability

Correlation



-0.1 (purple) represents a perfectly negative linear correlation between variables, 0.0 (white) indicates no linear correlation and 1.0 (orange) represents a perfect linear positive correlation.

Figure 27 displays the correlations between individual acceptability constructs and the General Acceptability score reported in Table 14. For the overall patient and carer survey respondents, Opportunity Costs, Intervention Coherence, Perceived Effectiveness and Self-efficacy showed moderate, positive correlations with the General Acceptability score. Burden and Affective Attitude showed a weaker positive correlation suggesting effort to complete the questions and how comfortable patients felt, may be less important to General Acceptability compared with other constructs for the total survey group.

Focusing in on our priority target group, i.e. those who positively identified as having a disability and assistance needed to access health care, filtered to respondents who recalled answering the DI in a healthcare encounter, we found higher acceptability overall (Table 15).

Table 15 Patient and Carer survey individual TFA Construct and General Acceptability and Scores (priority sub-group)

Patients positively identifying with a disability who required assistance to access the health service (n=89[^]) by hospital

		Parkville Hospitals Mean (CI)	Austin Health Mean (CI)	Total Mean (CI)
TFA Constructs*	Opportunity Cost	4.2 (3.9–4.4)	3.4 (2.8–3.9)	4.0 (3.8–4.2)
	Intervention Coherence	4.0 (3.8–4.3)	4.1 (3.8–4.3)	4.0 (3.8–4.2)
	Perceived Effectiveness	4.0 (3.8–4.3)	4.6 (4.1–5.0)	4.2 (3.9–4.2)
	Self-efficacy	4.1 (3.9–4.3)	3.7 (3.2–4.2)	4.0 (3.8–4.2)
	Burden	4.0(3.8–4.3)	4.1 (3.5–4.7)	4.1 (3.9–4.3)
	Affective Attitude	3.8 (3.5–4.0)	4.1 (3.7–4.4)	3.8 (3.6–4.0)
	Grand Mean	4.0 (3.9–4.2)	4.0 (3.6–4.4)	4.0 (3.9–4.1)
General Acceptability		4.5 (4.4–4.7)	4.3 (4.0–4.5)	4.5 (4.3–4.6)

Overall Acceptability (percentage)	
Completely acceptable	52.8%
Acceptable	41.6%
No opinion	5.6%
Unacceptable	0.0%
Completely unacceptable	0.0%

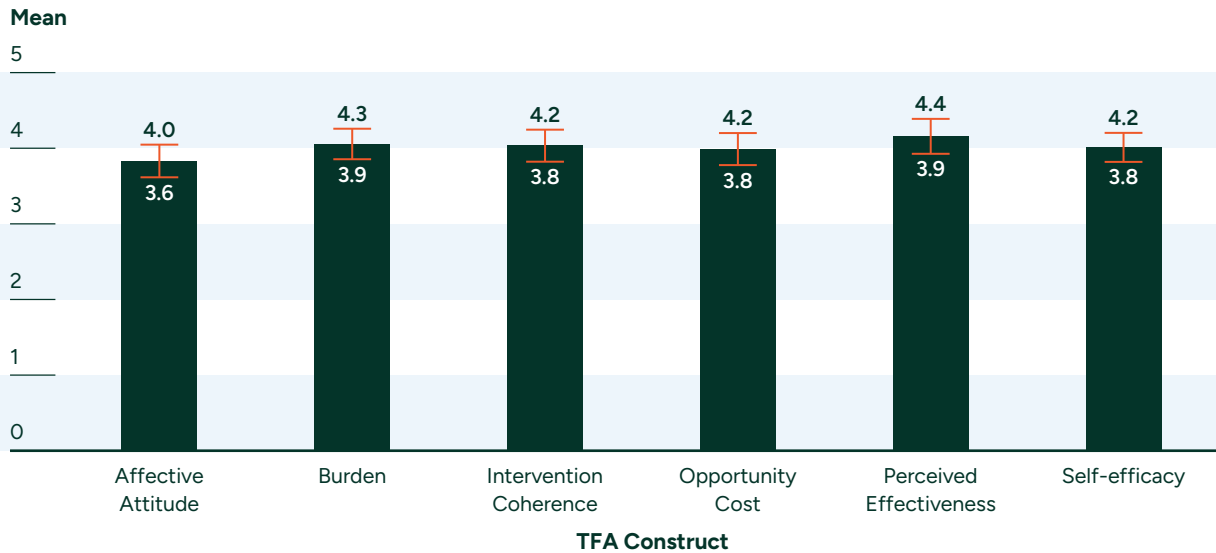
* TFA Mean score interpretation: Very Weak (1.0 to 1.5); Weak (1.6 to 2.5); Moderate (2.6 to 3.5); Strong (3.6 to 4.5); Very Strong (4.6 to 5.0) – i.e., high scores indicate greater acceptability.

[^] Filtered to patients/carers who recalled answering the DI previously within a health care encounter

The strongest single construct variation explaining higher overall acceptability in this group compared to the total patient/carer survey group were higher Intervention Coherence (4.0/5) and Perceived

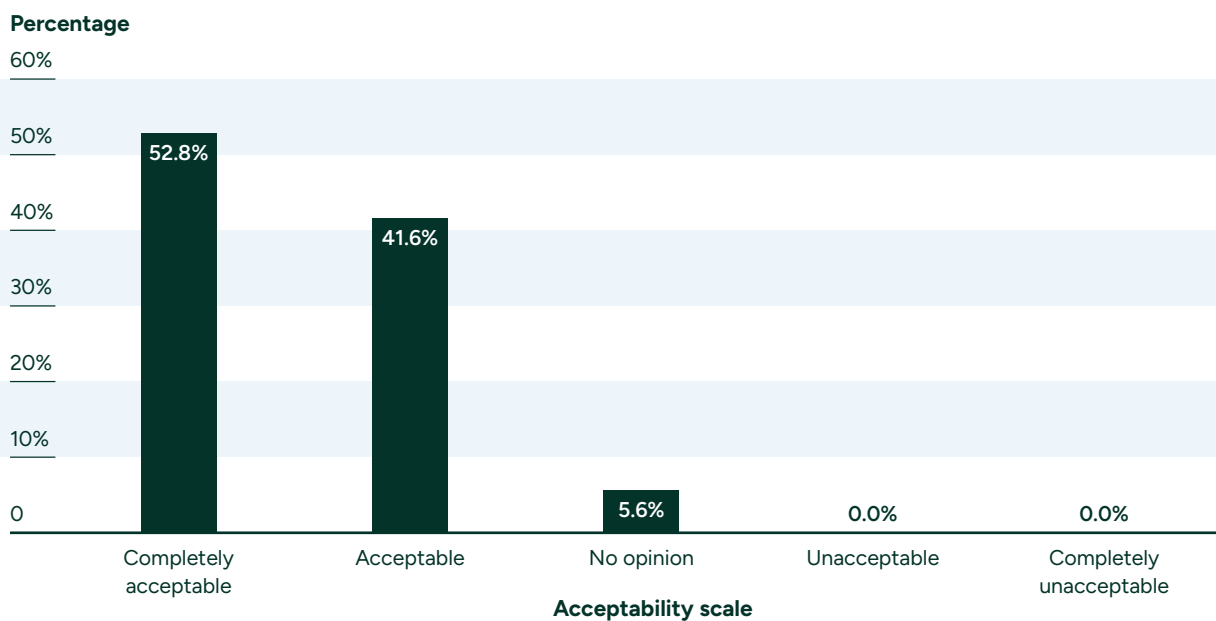
Effectiveness (4.2/5) scores. Consistent with the full sample, Affective Attitude (how comfortable a patient or carer felt in answering the questions) scored slightly lower than other constructs (3.8/5).

Figure 28 Mean scores for individual TFA Constructs for patients positively identifying with a disability who required assistance to access the health service



Filtered to patients/carers who recalled answering the DI previously within a health care encounter

Figure 29 % Responses to General Acceptability item – Patient and Carer respondents for patients with a disability who require assistance to access the health service



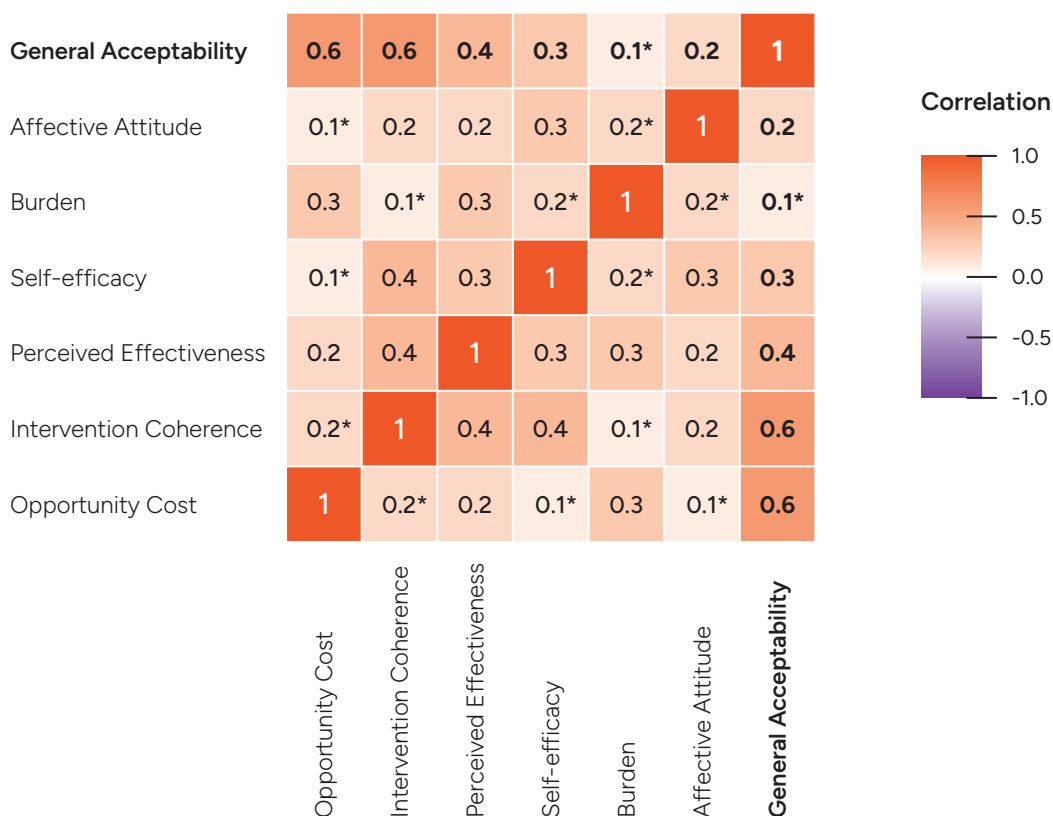
Filtered to patients/carers who recalled answering the DI previously within a health care encounter

For this subgroup Perceived Effectiveness , Intervention Coherence and Opportunity Cost constructs were more strongly correlated with the General Acceptability item (as shown below in Figure 30), while Burden showed a weak positive correlation with the overall General Acceptability

score. Therefore, despite a slightly lower Burden score in this sub-group compared to the total sample (i.e. higher perceived effort to complete the DI questions), it was not an important factor in relation to the General Acceptability score.

Figure 30 Correlation Matrix for individual acceptability construct scores and General Acceptability – Patient and Carer survey (priority sub-group)

Patients positively identifying with a disability who required assistance to access the health service and recall the DI questions



*CI crosses 0 (no evidence of a linear relationship), therefore caution should be taken interpreting correlation.

Survey – Clinicians

As displayed in Table 16, clinician's survey responses indicated strong acceptability for the DI overall and across single constructs.

Table 16 Clinician survey individual TFA Construct and General Acceptability and Scores (all respondents) by Hospital

		Parkville Hospitals Mean (CI)	Austin Health Mean (CI)	Total Mean (CI)
TFA Constructs*	Opportunity Cost	3.6 (3.3–4.0)	3.6 (3.0–4.1)	3.6 (3.3–3.9)
	Intervention Coherence	4.1 (3.8–4.4)	3.5 (2.8–4.0)	4.0 (3.6–4.2)
	Perceived Effectiveness	4.1 (3.8–4.3)	3.7 (3.1–4.3)	4.0 (3.7–4.2)
	Self-efficacy	3.9 (3.6–4.1)	3.7 (3.2 – 4.1)	3.8 (3.6–4.0)
	Burden	4.0 (3.8–4.2)	3.8 (3.3–4.3)	4.0 (3.8–4.2)
	Affective Attitude	3.6 (3.3–4.0)	3.5 (3.0–4.1)	3.6 (3.3–3.9)
	Grand Mean	3.9 (3.7–4.1)	3.6 (3.5–3.7)	3.8 (3.6–4.0)
General Acceptability		4.2 (4.0–4.4)	4.1 (3.8–4.4)	4.2 (4.0–4.4)

Overall Acceptability (percentage)

Completely acceptable	36.5%
Acceptable	47.3%
No opinion	14.9%
Unacceptable	1.4%
Completely unacceptable	0.0%

* TFA Mean score interpretation: Very Weak (1.0 to 1.5); Weak (1.6 to 2.5); Moderate (2.6 to 3.5); Strong (3.6 to 4.5); Very Strong (4.6 to 5.0) – i.e., high scores indicate greater acceptability.

Figure 31 Mean scores for individual TFA Constructs for Clinicians

Mean

5

4

3

2

1

0

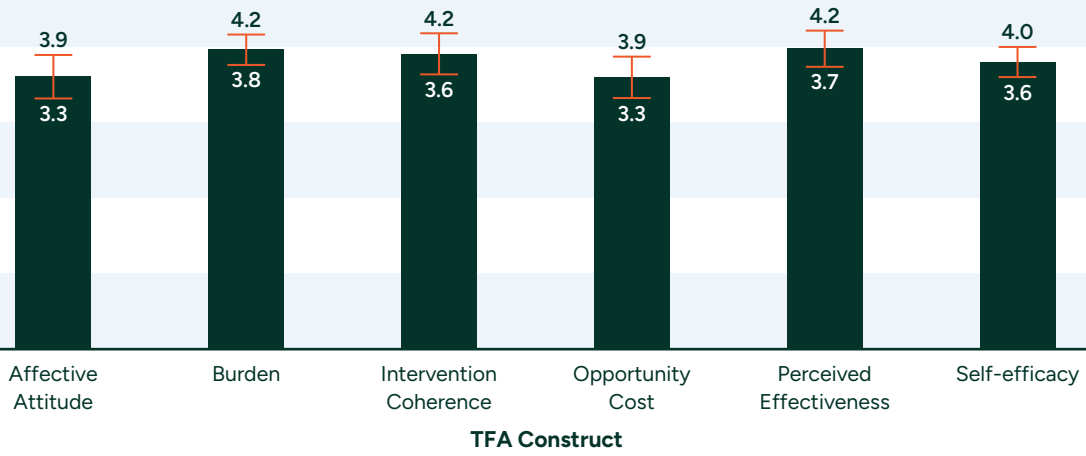


Figure 32 % Responses to General Acceptability item for Clinicians

Percentage

50%

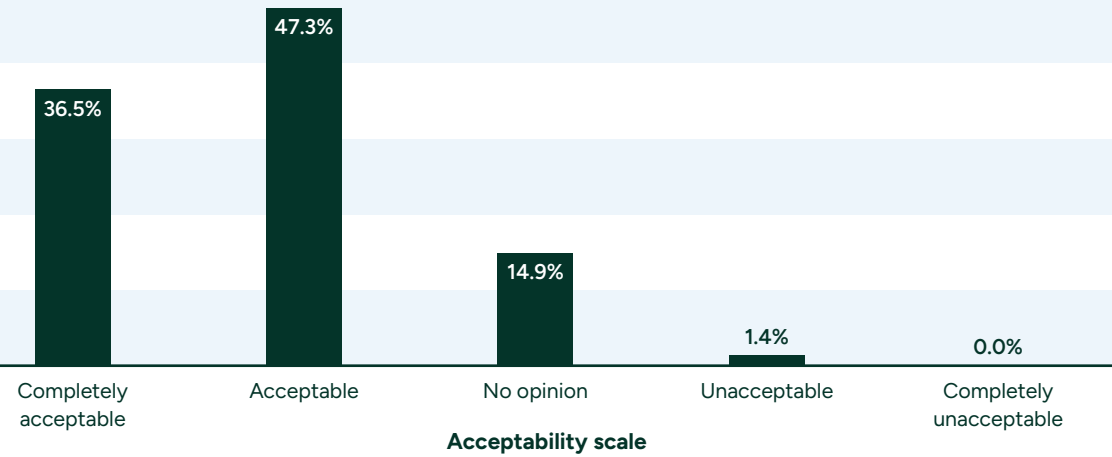
40%

30%

20%

10%

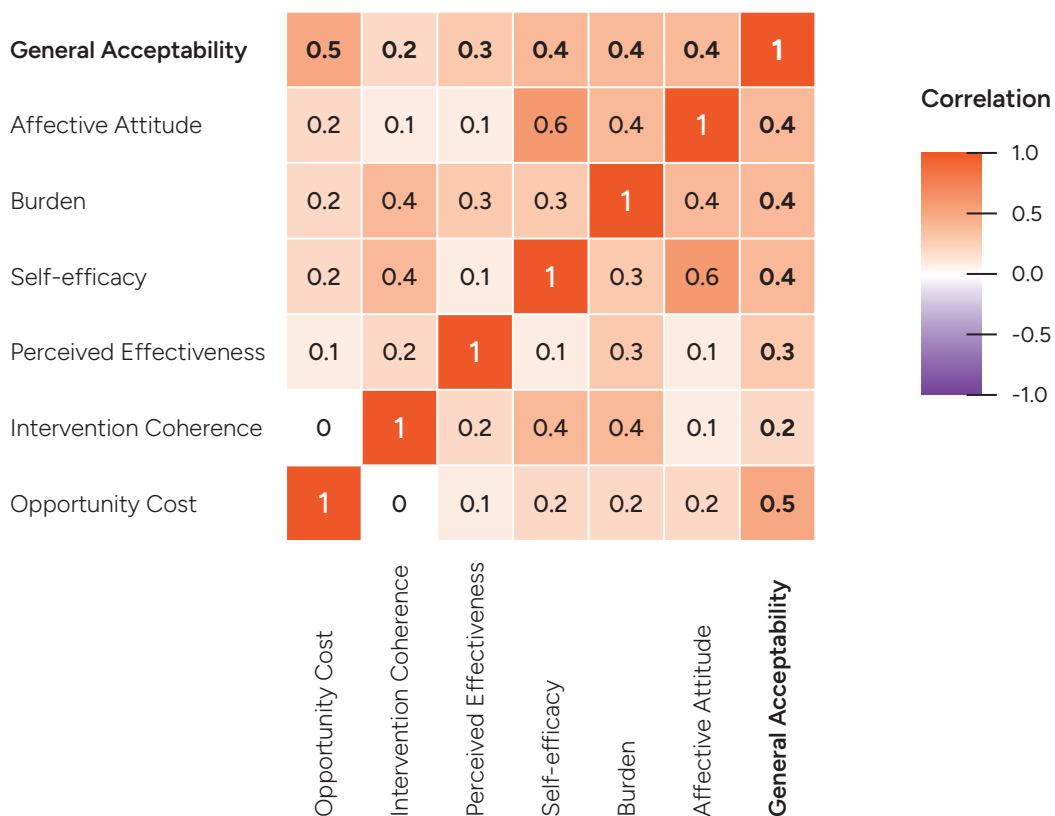
0



Of the single TFA Constructs from the clinician survey, Perceived Effectiveness, Burden and Intervention Coherence were the highest scoring constructs (4.0/5). Opportunity Cost and Affective Attitude were the lowest scoring constructs (3.6/5). Burden and Affective Attitude also had weaker correlations with General Acceptability. Opportunity Cost was the most

strongly correlated (moderate positive correlation of 0.5) with the General Acceptability score, suggesting that this was more important in relation to General Acceptability for clinicians, compared with other TFA Constructs (Figure 33).

Figure 33 Correlation Matrix for Individual acceptability construct scores and General Acceptability – for Clinicians



3.2.3 Affective Attitude

Affective Attitude reflects how an individual feels about the intervention, i.e. how did clinicians feel about implementing the DI questions and how did patients feel about completing them. The online survey focused more specifically on how 'comfortable' clinicians, patients and carers felt. As highlighted in the survey results presented in section 3.2.1, patients, carers and clinicians generally reported positive Affective Attitude completing the DI. Interviews with patients and carers and FGDs with clinicians explored these perspectives in more depth. Patients and carers were generally positive about having the option to complete the DI. For some, the questions helped them reflect on and understand their own functioning, disability and experiences within the health system. This prompted some participants to communicate with clinicians more proactively about their disability related care needs. Subsequent planning with clinicians improved feelings of safety and comfort within engagement with hospital. The potential of the DI to improve clinician understanding of individual functioning, disability and required supports, was also commonly highlighted. Patients and carers were optimistic the DI questions would more broadly help enhance disability awareness.

Being able to talk through my needs with the nurse was really helpful. Having a plan in place for my clinic appointments helped me to feel much safer to be able to come in.

Patient survey

Similarly, open-ended responses from the patient/carer survey highlighted that while disability and chronic conditions were complex and can be difficult to live with, they were comfortable discussing them and responding to questions such as the DI. There was also hope that providing this information would contribute to diagnosis and management.

I wish there was more awareness about silent disabilities and medical teams wouldn't brush off potential interconnecting illnesses ... [But] I'm glad to fill these out in order to increase conversations and hopefully, reduce time it takes for diagnosis and management.

Patient survey

Several patients and carers expressed concern that the information provided would not be consistently utilised by staff. This was sometimes attributed to heavy workloads undermining staff capacity to utilise and act on the DI, but also the pace of work in certain hospital departments such as Emergency, where the high volume and expeditious nature of the service, was also seen as making it harder for information to be used.

Although I wish all places had them, I am not actually convinced the doctors, or any[one] will look at them.

Patient survey

More broadly, there was uncertainty that staff and hospitals currently had sufficient resources to adequately respond to their needs. Patients/carers hoped that improved provision of supports would contribute to better patient and carer experiences and outcomes over time, along with a more inclusive and skilled healthcare workforce.

It is so important for the hospital to be asking these questions to understand what patients with a disability – especially invisible disabilities – need. The challenge is then making sure the hospital can support our needs. Asking is the first step and hopefully helps to better understand the issues we face.

Patient survey

Clinicians also generally feel that the questions were useful and had the potential to improve experiences for patients in several ways. For example, by increasing clinician understanding of how patients perceived their disability and what they needed, improved patient and family centredness of care and increased overall disability understanding and awareness.

Understanding the patient's perspective on ... how they perceive their disability or impairment is really useful so that we can, I guess tailor our interventions to what's going to be useful to them.

Clinician FGD

Clinician Affective Attitude was linked to and influenced by other constructs within the theoretical framework, such as Burden, Ethicality and Perceived Effectiveness. As such, clinicians believed the questions were a useful addition to the EMR but required further integration into routine practice to ensure the responses were checked by clinicians before seeing patients and providing required supports. Clinicians also felt the questions gave patients a voice and offered a prompt to initiate conversations about patient needs.

It's great to have the questions, but if you're not aware, if you don't look at it beforehand, then it can feel a bit tokenistic if the questions are being asked, but actually there's no follow through in terms of providing those requirements as well.

Clinician FGD

Clinicians identified potential challenges influencing Affective Attitude towards the DI questions. For example, the level of effort, time required or awkwardness felt in asking the questions. Clinicians thought there could be some reluctance to initiate the conversation based on perceived stigma.

I think time restraints and just trying to take what needs to get done and ... you know the stigma, like they're afraid to ask the questions. Because if they do feel rushed, they might not feel safe, or the person asked the questions might feel uncomfortable.

Clinician FGD

Despite this potential reluctance, clinicians described the benefit of the questions in providing a common language for patient-clinician interactions. This was seen as an opportunity to improve patient-centred care and to increase clinician awareness and understanding of disability. Asking the question also reduced the burden on patients to repeat their information during an encounter of service use.

It is really useful to be able to gather that information ... So they don't feel like they are constantly telling their story.

Clinician FGD

3.2.4 Burden

Burden reflects the perceived amount of effort required by clinicians, patients and carers to complete the DI question process. Key concepts related to Burden were time, ease and comfort. Generally, the DI questions themselves and the process were not seen as burdensome or contributing to difficulty or discomfort for most patient and carer interview participants. Similarly, patient/carer survey respondents generally expressed low burden completing the DI related to the ease of use.

The wording was succinct and to the point, and the questions broad enough to allow flexibility for tailored responses for everyone's needs.

Patient survey

Indeed, patients and carers were optimistic that the DI would ultimately decrease the burden associated with completing general hospital administration. Within this, the potential for reducing administration associated with moving between hospitals and/or transitioning between paediatric to adult services was specifically highlighted.

Moving over to the new hospital ... at least this flags up with them straight away ... I don't have to go through her medical history. ... that I might need extra support. ... So that everyone knows she's non-verbal. If you had to have an admission into hospital, the ward can see what they're dealing with as well.

Carer interview

Some patients and carers felt that the DI would have felt more burdensome or difficult earlier on in their journey, but that they were now more comfortable talking about their disability and used to completing paperwork within health and disability care.

If it was a while back, I would have felt that way. But I think it depends on the person as well. I feel like I've gone through some changes, so I didn't feel it was intrusive in any way.

Patient Interview

Nonetheless, some patients and carers described that they felt the DI questions may contribute to staff discomfort and burden. In turn, this perception exacerbated their own experiences of burden.

Staff that were helping us complete the disability identifier questions, I felt, were quite nervous about introducing us to the concept ... I guess, put us on the back foot. ... It felt it was an awkward, stilted conversation ... it wasn't allowing us to explore our experience and to give our details. ... in ways that we felt were relevant.

Carer interview

For clinicians, a lack of awareness about the DI questions and a lack of clear direction for implementation was described as contributing to barriers to incorporating the questions into usual workflow. Difficulty accessing the questions depending on the clinical scenario was also an issue and clinicians felt the process needed to be made seamless and easy to use, in order to reduce the burden they experienced. There were also issues raised around integrating the questions into workflow and the extra time required to ask the questions. Clinicians needed to understand the value in asking the questions when similar content is covered as part of a usual patient assessment. Needing to go out of the clinical notes to answer the questions seemed time consuming and inefficient.

In terms of seamless integration and workflow, it's around time constraints in an outpatient clinic ... those questions essentially are made-up as part of your normal subjective assessment.

Clinician FGD

Clinicians noted concerns around knowing when to ask and considerations around whether it was appropriate given where the patient was on their healthcare journey. They identified this as a potential cause for hesitance in clinicians asking the questions at all.

Thinking about the timing of when to ask the questions, if it's appropriate to do it.

Clinician FGD

Clinicians felt there was benefit to having the information flagged in the system for future rapid reference. They noted greater ease of use when the questions were built into the workflow, such as during bookings and admissions.

When doing a booking it flows really well ... the booking flow is easy but I'm not sure I would be as confident to update during an episode of care.

Clinician FGD

3.2.5 Ethicality

Ethicality reflects the extent to which the DI question intervention has a good fit with a person's value system. Ethicality was not measured in the online surveys, however, was explored qualitatively in the patient and carer interviews and clinician FGDs. Connecting closely with Affective Attitude, the patient and carer perception that the intent of implementing the DI was to improve outcomes for people with disability, resonated strongly with individuals' value systems of respect for people with disability and broader community inclusion.

I think these sorts of things really need to happen. And it wasn't till we had encounters with disability that I realised the impact of language and normalising language as much as we can, and especially for little ones growing up with disabilities. So, I think what you're doing is really incredible.

Carer interview

From an ethical perspective, one of the main concerns of clinicians was around tokenism. Essentially, clinicians felt that if they were going to ask the questions, they needed to follow through and provide the supports required to facilitate better care.

I think there's an ethical problem in documenting it and then not using the information. So just like if we document an allergy and then we give the patient the thing that they're allergic to.

Clinician FGD

Influencing these ethical considerations were concerns around structures and policies to meet patient identified needs and balancing the need to normalise disability in the face of existing stigma, with ensuring privacy of patient information.

If it is a vulnerable patient, they can decide.. what information they keep private.

Clinician FGD

3.2.6 Perceived Effectiveness

This construct reflects the extent to which individuals perceive that the DI question intervention has achieved its objective. As such, the patient/carer survey asked whether completing the DI questions provided them with an opportunity to communicate their care needs related to a disability or long-term health condition. While clinicians were asked whether the DI provided them with useful information about patients' disability and care needs. These themes were further explored within the interviews and FGDs and highlighted that clinicians perceived that the DI questions were a potentially useful tool, with patients and carers acknowledging it was 'too early to tell' if completing the DI questions would influence the care and support they received.

It's useful to understand how she perceives her disability and her health needs and what she feels she needs help with.

Clinician FGD

Well, if it's on her health file I expect them to read it, so they have a better understanding of my child. ... But then, whether they do something about it or not?

Carer interview

In contrast, some patients and carers already felt the DI was contributing to change. One patient described being more proactive in communicating their needs to clinicians. In addition, some carers reported in the survey that they had experienced improved communication about their disability or long-term health condition and related care needs as a result of the DI questions.

We were able to document key information about triggers that can seriously escalate her behaviour and lead to traumatic situations for her, us (parents) and others (e.g. staff). This helped to facilitate better pre-planning and getting us linked to important supports.

Carer survey

Many clinicians felt the language around disability was well structured, with a focus on function rather than a label. They also felt that the questions themselves provided an opportunity for "hidden" disability to be captured, where it otherwise could be overlooked.

For me – the biggest benefit is the wording of the question because it doesn't rely on 'do you identify as disabled?' language always has a different connotation to 'is there anything in your daily life' – I guess that is the main benefit for me.

Clinician FGD

There were, however, mixed views from clinicians around the DI questions effectiveness in identifying certain disabilities. Some clinicians praised the focus on identity and function, while others felt some of the terms used needed greater clarity to achieve meaningful responses. Clinicians also raised whether some of the language used potentially limited recognition for some patient groups, e.g. those with mental health conditions or experienced fatigue.

A lot of women, for example, with MS ... these questions don't really prompt them because they just live with this MS fatigue ... And I feel that it's these questions aren't really capturing those women.

Clinician FGD

Similarly, some patients and carers across the interviews and surveys also expressed varied perceptions of how effectively the DI enables them to provide sufficient information that comprehensively reflects the diversity of experiences and the dynamic and fluctuating nature of disability. Others found it difficult to relate to the areas of difficulty provided, particularly those with chronic pain, shortness of breath and fatigue. Several patients and carers also felt that more comprehensive information should be collected and contextualised if the DI process is to be really useful.

Very limited parameters that measure and define disability. Some are transient and some are permanent pending the clinical picture at the time of being a patient inpatient/ outpatient.

Patient survey

I think the questions by themselves, if they had have been asked straight as they were, wouldn't have allowed me to give an accurate picture of [son] and his experiences within the healthcare system, and how his disability informs that. I think, given that I was aware of that, it enabled me to add extra things into my responses that better served him.

Carer interview

Low usage by clinicians was highlighted as undermining effectiveness. Accessing the information in a consistent way, integration into workflow and managing patient-clinician interactions were challenges to completing the questions. Further, clinicians identified a lack of general accessibility for users; specifically raising that there was no audio for vision-impaired patients. There was a need to maintain momentum and bolster the system with reminders in the EMR to ensure the questions were completed.

Relying on clinicians to fill it in is potentially where it's stumbling.

Clinician FGD

More broadly and across the cohorts, uncertainty was raised as to whether the DI would lead to improved care. Reasons for this included:

- inconsistent disability awareness, knowledge and skills of healthcare workforce, with an urgent need to address existing discrimination within the healthcare system;
- an over-stretched health system means clinicians don't necessarily have sufficient resources to appropriately implement and utilise currently available information, let alone engage with the DI question process; and
- sufficient resources and systems are not currently available to effectively and adequately respond to potential need and demand.

Because everybody's so busy ... hospitals are so short staffed. Staff don't have time to actually read all the information to be prepared. So, you know, if they had more hands-on-deck, then it would be lovely if all the staff knew everything that you had given them. But it's not realistic at the moment, in this day and age ... nurses are just run off their feet.

Patient interview

3.2.7 Intervention Coherence

Intervention Coherence reflects the extent to which the participant understands how the DI intervention is intended to work. Among patients and carers, there were differing understandings on what, why and how the DI questions might work. Some recognised it would be routinely asked of all patients. Whereas others felt it was specifically asked of them because they were seen as having disability. One or two interview participants also questioned whether the questions were asked to assess their mental health or cognition.

I guess it was to find out that I am a person with disability. Access to medical services within the hospital, be it at admission, during clinical care, and perhaps at discharge, and at any point of care throughout their staying in hospital. Outpatient and inpatient or a through patient.

Patient interview

So, it was pretty clear ... Probably repetitive. ... And you're wondering, am I answering that the same way as I did before? Are they trying to trick me?

Carer interview

Some survey responses similarly indicated not all patients and carers felt they were provided with sufficient information about the DI.

Wasn't specifically explained to me the objective of the questionnaire.

Patient survey

Despite differing perspectives on the intent of the DI questions, several patients and carers felt the DI questions should be implemented across all jurisdictions as they understood and agreed that the intent of the DI questions was to ultimately improve outcomes for people with disability.

I think it's definitely something my hospital should do. It should have been done long ago. Our hospital ... deals very poorly with disabled people ... It is something that definitely needs to be looked at right across the board.

Patient interview

Clinicians participating in the FGD generally understood the intention behind the questions and found the questions themselves easy to understand. They highlighted potential benefits from using the questions, such as improving patient care and disability awareness across disciplines. Understanding how the patient identified with their disability and what accommodations and support they might require during service use was the main benefit highlighted by clinicians.

Recently we had a woman who said yes to that, who had ADHD, and even at the time I hadn't considered that you would say yes for ADHD so I think that it's a good learning opportunity for people who don't know much about disability in particular, and then can understand how to look after people better or in a way that meets their needs and getting them into the right service.

Clinician FGD

Clinicians noted the importance of establishing systems and policies to ensure the required supports could be provided in meaningful ways.

Family violence ... is a really good example ... There was a time where midwives were terrified to have to ask the questions ... No one knew what to do if someone actually disclosed. Now it's a much more integrated part of what we do, like everyone, the system in place ... and so it's about getting [the DI questions] to that place as well.

Clinician FGD

Clinicians also felt that the questions were clear and easy to understand. While clinicians generally found that asking the questions flowed well during patient encounters in one-on-one settings, other clinical settings were less supportive for asking the questions and these clinicians found the process more "clunky" due to different access to the questions within the EMR.

It's a bit clunky. I work predominantly in an outpatient way so I'm using the outpatient interface on EMR and that's much more clunkier. I have to go into history to add it in, whereas [other sections] are much easier to access ... there's other particular ... screening tools and things that I have to go through the back way but ... you have to click through a number of things to get there versus it just being there.

Clinician FGD

There were, however, some clinicians who completed the online survey who were not aware of the DI questions or who had self-orientated to the function in EMR and were therefore not clear on its intended use or purpose.

I have not received adequate education about use of the identifier ... More education should occur.

Clinician survey

3.2.8 Self-efficacy

Self-efficacy reflects an individual's confidence that they can perform what is required to participate in the DI. Patients and carers were asked about how confident they felt in providing responses within the DI, with clinicians asked about their confidence in asking the questions and using the information. Most participants reflected confidence in their capacity to complete the DI questions, although there was variation among participants in personal motivation to complete the questions, their individual behaviours around completing the DI questions, and their sense of control over the environment in which the DI questions were completed or would be used.

Off the top of my head, I don't think so [any difficulty completing DI] but if there was, I would have just googled it to find out what it was anyway.

Patient interview

Several participants reflected that the longer they had lived with disability and its impact on functioning and health, the more able and willing they were to respond to questions: progressing to a point where they proactively wanted to share information and their expertise to help themselves, clinicians and other people with disability. However, some participants expressed less confidence in their capacity to complete the DI questions or engage with the process, despite clearly having responded appropriately. Anticipated improvements in the disability awareness of clinicians and wider communities, further facilitated the confidence to share disability-related information, as did the expectation that better awareness should continue to be facilitated with continued roll-out of the DI question process.

In the beginning it would have been a lot worse to think. You know she is [disabled] now. You move on. But in the first years it was, you know, it was really hard.

Carer interview

Clinician confidence and self-efficacy was higher for some clinicians than others. Some raised issues around confidence in having the conversations and how to initiate them with patients. There were also concerns around delivering the support identified as required by the patient during these conversations.

I think clinicians find the questions like that uncomfortable. And if they're uncomfortable often just choose not to ask it. They're too awkward or uncomfortable and they just like, skim past it.

Clinician FGD

Clinicians highlighted lack of disability understanding and awareness as potential drivers of low confidence and self-efficacy, while having pre-planned prompts for initiating the conversation increased confidence for clinicians.

It's maybe a little bit awkward or you feel like the first time you're going to say the wrong thing, but the once you've got your spiel ... It's fine.

Clinician FGD

Clinicians identified that despite concerns around confidence and comfort in asking the questions, it was important to do so and underlined a need for improved training and support to equip clinicians with the skills and understanding to facilitate the conversations.

I can imagine for people that are more junior ... this kind of pointed questions that maybe it would be a bit challenging ... It's like them asking the family violence questions as well, like it's maybe a little bit awkward or you feel like the first time.

Clinician FGD

Consistent with patient and carer perspectives around the relative difficulty in engaging with these questions when disability may be newer, some clinicians expressed concerns around knowing when to ask the questions and whether it was appropriate given where the patient was on their healthcare journey.

I feel that it would be hard for a lot of families, especially with our families of young children, the very beginning some families are still trying to take in the diagnosis for their young person ... then going to the hospital and being asked that (the questions) it might be quite traumatic for them.

Clinician FGD

3.2.9 Opportunity Costs

This construct reflects the extent to which benefits, profits or values must be given up by participating in the DI questions either as a patient, carer or clinician. As most patients and carers did not find the questions burdensome, they didn't feel that there were Opportunity Costs in completing the DI questions. Furthermore, even though they may not individually 'benefit' from completing the DI questions, they felt positive about the DI questions being asked, and doing so therefore was not seen as a cost. Many participants felt they did benefit from having the opportunity to 'contribute' to the DI question process and thus to the hospital and health systems, and other people with disability and their carers.

I think that's really going to help going forward hopefully. This [completing the DI] helps the next person that comes through the door with a child that [is non-verbal and relies on carer/advocates].

Carer interview

Some patients and carers, however, perceived clinicians as the ones who would have to 'give up' something by allocating time to the DI question process despite how busy they were, to ensure they could focus solely on the patient/carer in front of them, and actively listen. It was felt this may be difficult for some clinicians. Similarly, while communicating disability status and individual needs might be a priority from a patient's or carer's perspective, some perceived that this was not always the case for their treating clinicians, who often focused on clinical or treatment priorities.

My doctors are only interested in eliminating my cancer, not in the pain that I feel or the function that I have lost or the obvious scarring due to several surgeries or the mental health issues that these sometimes cause me. I have regular private physiotherapy because no one at the hospital has offered it or asked me if I need it.

Patient survey

Opportunity Costs were more commonly reported by clinicians. Clinician perspectives around Opportunity Costs were directly related to Intervention Coherence and perceived burden. Clinicians generally expressed that they feel the questions were useful but it was difficult to integrate them into their usual workflow processes. Time constraints, which varied according to clinical situation, were considered the main barrier.

I used it early on, but I've just stopped using it because it's just another, like there's just not enough time basically. Where we've got other admin to do within an hour appointment.

Clinician FGD

Clinicians also questioned the value in asking the questions when they are already included as part of their usual assessment. They noted frustrations around accessing the questions and suggested it needed to be easier to find them, and for there to be reminders. Practical considerations, such as not having a computer in front of them to complete the questions with a patient, were also raised. Most clinicians felt it would be beneficial if the questions were completed prior to seeing the patient.

Some clinicians felt that more training was needed to communicate the value in using the DI questions, but also noted the burden of training as a concern. Ultimately, they wanted the process of using the questions to be easier.

I suppose it's just about making it easy, as easy as possible for clinicians, 'cause (sic) I mean I suppose it's getting into that habit.

Clinician FGD

4 Discussion – Key Reflections and Implications

People with disability are known to experience systemic health disadvantage (VicHealth 2012, AIHW 2024). Australia's Disability Strategy (2021–2031) (DSS, 2021) calls for greater inclusion and equality for people with disability and addressing community attitudes towards disability. Further, the recent Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Commonwealth of Australia, 2023) reinforced the need for steps to be taken to ensure Australia fulfills its obligations under the Convention on the Rights of Persons with Disability (CRPD, United Nations, 2006) and create a more inclusive Australia, where disability is treated as a normal part of human diversity.

The implementation of a patient 'self-report' DI approach in the Parkville Precinct and Austin Health EMR systems represents a significant step towards improving healthcare access and outcomes for individuals with disability in Australia. The addition of a patient 'self-report' disability identifier in EMR systems aligns with the broader national priority of enhancing disability inclusion and equal access to healthcare services, while promoting patient-centred care and aiming to reduce the disadvantage experienced by people with disability in the healthcare system. This study evaluated the initial implementation of the DI questions, assessing both their utility and acceptability among patients, carers, and clinicians.

The findings offer important insights into the successes and challenges encountered, as well as implications for future practice and policy development.

4.1 Utility of the DI

When used, the DI questions demonstrated substantial utility in identifying individuals with disability and capturing relevant data about their difficulties and need for assistance when accessing healthcare. The reach and adoption of the DI varied across sites, with higher completion rates observed in settings where the DI was integrated into routine nursing admission workflows.

After 8 months of implementation within the Parkville Precinct, 13.4% of admissions at RCH, RMH and PMC were completing the DI questions compared with 37% of admissions at RWH. The key implementation difference within the Parkville campus was integration of the DI questions within the RWH maternity admission workflow, where the DI is completed during maternity service booking appointments. Patients accessing maternity services make up the highest proportion of patients seen by the RWH. Similarly, the shift in DI completion rate at Austin Health over 8 months (reaching 95% of admissions in November), was related to changes to where the DI questions were placed within the admission workflow, and instigation of mandatory completion. If the health services are serious about understanding and supporting people with disability during health care encounters, mechanisms to increase reach of the DI questions, related to both workflow and education, need to be considered. In addition, the high uptake of the DI questions via the Patient Portal for those with a disability at Parkville Hospitals reinforces the potential of digital health platforms to facilitate self-reporting and enhance engagement of patients with disability.

Question 1 of the DI questions serves as the primary disability identification question, aligning with the International Classification of Functioning, Disability, and Health (ICF) framework. Inclusion of this screening question is important within the hospital context for identifying our priority target group—individuals who experience difficulties in daily activities due to long-term health conditions, impairments, or disabilities, as distinct from those experiencing difficulties unrelated to disability.

When all settings were considered together, the prevalence of self-reported disability among the DI respondents was 17.9%. Variations in prevalence across age groups, genders, and specific patient cohorts, however, underlined the importance of considering demographic and contextual factors when interpreting disability data in each of the included settings. The high prevalence of disability among younger patients at the Royal Children's Hospital Melbourne, for example, reflected this hospital's focus on providing pediatric care to an often-complex population. In contrast, the prevalence of disability in pregnant women at the RWH, was low at just 3%, warranting further research, particularly given pregnant women with disability reported greater need for assistance to access healthcare compared to their non-pregnant counterparts with a disability.

Overall, the prevalence of self-reported disability in the 0-65 age group (15.4%) among the DI respondents was consistent with national estimates from the latest 2022 Survey of Disability, Ageing, and Carers (SDAC) (ABS, 2022) of 15.0%. While disability prevalence increased with age as anticipated, the steeper increase in disability prevalence among 65+ age group observed in the SDAC compared with DI data may indicate a need to better understand how older patients are interpreting and responding to the DI questions.

Subsequent DI questions (Q2 and Q3) enabled the identification of specific areas of difficulty and need for assistance, providing valuable insights into the diverse challenges experienced by patients with disability. The prevalence of identified difficulties related to seeing, hearing, moving/physical, mood/emotions and communication emphasised the need for tailored support services and adjustments to improve the provision of healthcare in all the included settings.

The prevalence of physical and psychosocial areas of difficulty in the DI data are consistent with physical and psychosocial disability groups from the SDAC. A difference was observed in the prevalence of intellectual or learning disabilities and speech or communication difficulties which were higher in the DI data compared with SDAC data. This difference may be due to the distribution of age within our cohort, where a high prevalence of disability was observed among children, attending the RCH. Overall, the trends in the age distribution of areas of difficulty in the DI data (Figure 7) align with those observed in the SDAC, for example, seeing, hearing, and moving difficulties become more prevalent as age increases, whereas learning and communication disabilities are more commonly reported in younger age groups. This alignment suggests data collected via the DI questions are reflecting the natural progression of disability types across different life stages.

Additionally, the DI data revealed higher rates of disability and related need for assistance among individuals with behavioral flags, family violence flags, and high-risk flags, compared to those without these flags. For example, our data align with known population data which indicates that women living with disability are nearly twice as likely as women without disability to have experienced violence by an intimate partner over a 12-month period (ABS, 2021).

These findings reinforce the importance of considering intersectionality and the compounded effects of multiple vulnerabilities when delivering health care services. Behavioural flags are often used after an adverse experience or event has already occurred within the hospital setting. Providing the opportunity for patients to report their disability status and care needs before coming to hospital can better prepare health services to proactively provide the right support at the right time and potentially reduce the risk of adverse experience.

4.2 Acceptability of the DI

The acceptability of the DI questions was generally high among patients, carers, and clinicians, indicating a positive reception and a willingness to engage with the process. Patients and carers appreciated the opportunity to communicate their needs and felt that the DI contributed to raising awareness about disability within healthcare settings, promoting inclusion and accessibility.

Quantitative findings from the Theoretical Framework of Acceptability (TFA) survey revealed strong acceptability overall and across individual constructs. This suggests that participants found the DI questions useful, understandable, and relatively easy to complete. Patients who identified as having a disability and needing assistance to access healthcare showed slightly higher overall acceptability scores than the broader patient/carer cohort. They particularly scored higher in Intervention Coherence and Perceived Effectiveness, indicating a clearer understanding of how the DI questions worked and a positive perception of their potential benefits. Among clinicians, Opportunity Cost had a stronger positive

correlation with General Acceptability compared with other constructs, suggesting that clinicians' perception about whether the DI questions are a priority in care delivery influenced overall acceptability in this group. Across all groups, Affective Attitude (how comfortable respondents felt completing the DI questions) scored the lowest (ranging between 3.6/5 for clinicians and 3.8/5 for patients/carers). While still a moderate to strong score, this revealed some room for improvement in how comfortable respondents felt asking and completing the DI questions.

Qualitative findings provided further insights into challenges that could impact the successful implementation and utilisation of the DI questions. Clinicians highlighted the importance of better integration into clinical workflows, provision of sufficient training and support, and addressing concerns about the time and effort required to complete the DI process in busy settings. Patients also raised considerations regarding health service capacity and the ability of staff to use the information effectively to provide the necessary supports.



4.3 Implementation Challenges and Recommendations

The study identified several key challenges in the implementation of the DI questions, providing valuable lessons for future efforts to improve disability identification in healthcare systems.

Workflow Integration	<p>Successful implementation of the DI requires seamless integration into existing clinical workflows. Sites that embedded the DI questions into routine admission processes, such as Austin Health and the RWH, achieved higher completion rates. While the specific processes and mechanisms to achieve this may differ across sites, ensuring that the questions are easily accessible and integrated into daily practice is crucial for sustained adoption.</p>
Training and Support	<p>Clinicians expressed a need for more comprehensive training to feel confident and comfortable in asking the DI questions and using the information effectively. Ongoing education and support are essential to build clinician confidence and ensure consistent utilisation of the DI process. Training should be specific to what the DI is and why it is important, who should complete the DI, and how and when to complete the DI in relation to specific workflows. Training should also encompass how information provided can help inform processes to incorporate adjustments and supports within subsequent provision of care. This training, however, is more likely to be effective when embedded within wider capacity building approaches to improving disability awareness and the importance of equitable access to healthcare.</p>
Balancing Burden and Benefits	<p>While most participants did not find the DI questions burdensome, clinicians highlighted the importance of minimising additional workload and ensuring that the process does not interfere with other clinical priorities (Opportunity Costs). Streamlining the DI process within workflows and providing clear guidelines on its implementation will help mitigate perceived burden.</p>
Consistency and Follow-Through	<p>Concerns about the consistent use of DI information and follow-through on identified needs were raised by both patients and clinicians. Establishing clear protocols for reviewing, acting on and monitoring how DI data is informing care is essential to ensure that the information collected leads to meaningful improvements in patient care. Equally important, is to ensure that patients and carers are clearly informed about why the information is being collected and how it will be used (Refer to the recommended DI question preamble included in Appendix 1).</p>
Customisation and Sensitivity	<p>The study revealed that certain subgroups, such as patients with mental health conditions, chronic pain, and fatigue, may have found the DI questions less applicable to their individual difficulties. Providing examples of the breadth of conditions or impairments (including mental health conditions) that may contribute to activity limitations and participation restrictions in Q1 will further optimise the DI questions. The addition of 'stamina or endurance' to the 'physical' area of difficulty in Q2 broadens its scope to better encompass conditions characterised by fatigue or pain (refer to Appendix 1).</p>

Additional research should be conducted exploring how best to capture more detailed information on support needs and care preferences that could link to the DI Questions and give further context to 'areas of difficulty' identified (for example 'Health Passports'*).

* Health Passports are a document used to collate detailed information about a person's support needs and care preference designed to go with a patient when presenting at a health service, for example Julian's Passport https://www.health.qld.gov.au/_data/assets/pdf_file/0032/858362/3.-Julians-Key-Health-Passport-100gsm-LHC-staple.pdf

4.4 Implications for Policy and Practice

The findings of this study have important implications for policy and practice in disability identification and healthcare provision within the study hospitals and wider jurisdictions:

Standardisation of Disability Data Collection	Developing standardised approaches to disability identification, grounded in frameworks like the ICF and aligned with national surveys like the SDAC, can improve the consistency and comparability of disability data across healthcare systems, as demonstrated in this study. Current advancements in data linkage systems within Australia and the establishment of National Disability Data Asset also provide a potential platform to utilise de-identified hospital administrative data to monitor health outcomes among the Australian population (Fortune et al, 2023).
Co-Design and Stakeholder Engagement	Engaging stakeholders, including individuals with disability, carers and clinicians, in the co-design of disability identification processes, and evaluation of implementation has been a central component of this project. Continuing to ensure that this is prioritised will help ensure that the approaches and responses are relevant, inclusive, and accurately reflect the priorities and diverse experiences of people with disability within healthcare systems.
Leveraging Digital Health Platforms	Utilising patient portals and other digital health platforms can facilitate self-reporting and enhance patient engagement in the DI process. Ensuring accessibility and user-friendliness of these platforms is critical.
Continuous Evaluation and Improvement	Ongoing evaluation of the DI process, including regular feedback from patients, carers, and clinicians, is essential to identify areas for improvement and ensure that the process remains responsive to the needs of individuals with disability. This includes further research to examine how specific cohorts, such as older patients (over 65 years of age), younger cohorts (0 to 2 years), pregnant women with disability, First Nations people and people Culturally and Linguistically Diverse backgrounds, are engaging with the DI questions and process. Future monitoring, evaluation and research should also explore the impact of the DI process on delivery of care, patient experiences and outcomes across diverse patient groups.

In conclusion, the implementation of the DI questions in the Parkville Precinct and Austin Health EMR systems represents a promising step towards improving disability data collection and understanding barriers to healthcare access for individuals with disability. While initial findings are encouraging, addressing the identified challenges, and building on the successes will be crucial for optimising the DI process. This study contributes towards developing a standardised approach to disability identification, emphasising the need for continuous evaluation, stakeholder engagement, and leveraging digital health platforms to enhance the inclusivity of healthcare services and achieve equitable health outcomes for all.

The DI Questions with integrated optimisation (Appendix 1) and accompanying 'Accessible Care Toolkit' are provided as a companion resource to assist with implementation of the recommendations presented in this report.

Appendix 1: The DI Questions

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)

Optional: What condition or conditions (if known) are the main cause of your difficulties?

3 Would you like us to know about any adjustments or assistance needed for appointments or when you come to hospital?

Yes

No

Declined to answer

If yes, please provide further information about the type of adjustments or assistance needed. You can select from the following examples or provide your own:

Finding your way around the health service.

Communication (e.g. Auslan or communication device).

Understanding information (e.g. extra time for questions, information written down).

Decision making and/or consent (e.g. my support person).

Mobility and transfers (e.g. a wheelchair or a hoist).

Personal care (e.g. help with showering or eating).

Sensory or physical environment (e.g. a quiet waiting space or low lighting).

Emotional well-being (e.g. things that keep me calm).

Other (e.g. pressure care, specific equipment, anything else not captured above).

Appendix 2: TFA Online Survey Items

Patient or Carer Online Survey – TFA Constructs

TFA construct	Generic TFA questionnaire items	Guidance notes
Affective Attitude How an individual feels about the intervention	How comfortable did you feel completing the disability question(s)?	<ol style="list-style-type: none"> 1 Very uncomfortable 2 Uncomfortable 3 No opinion 4 Comfortable 5 Very comfortable
Burden The perceived amount of effort required to participate in the intervention	How much effort did it take to complete the disability question(s)?	Reverse scored (as shown) <ol style="list-style-type: none"> 5 No effort at all 4 A little effort 3 No opinion 2 A lot of effort 1 Huge effort
Perceived Effectiveness The extent to which the intervention is perceived to have achieved its objective	Completing the question(s) provided me with opportunity to communicate my care needs, related to a disability or condition (Patient) Completing the question(s) provided me with opportunity to communicate the care needs of [my child / my family member / the patient], related to a disability or condition (Carer)	<ol style="list-style-type: none"> 1 Strongly disagree 2 Disagree 3 No opinion 4 Agree 5 Strongly agree
Intervention Coherence The extent to which the participant understands how the intervention works	It is clear to me how completing the disability question(s) will help the hospital to provide me with better care (Patient) It is clear to me how completing the disability question(s) will help the hospital to provide [my child / my family / the patient] with better care (Carer)	<ol style="list-style-type: none"> 1 Strongly disagree 2 Disagree 3 No opinion 4 Agree 5 Strongly agree
Self-efficacy A participant's confidence that they can perform behaviour(s) required to participate in the intervention	How confident did you feel about providing responses to the disability question(s)	<ol style="list-style-type: none"> 1 Very unconfident 2 Unconfident 3 No opinion 4 Confident 5 Very confident

TFA construct	Generic TFA questionnaire items	Guidance notes
Opportunity Costs The benefits, profits or values that would have to be given up to engage with the intervention	Completing the disability question(s) interfered with my other health care priorities (Patient) Completing the disability question(s) interfered with [my child's / my family member's / the patient's] other health care priorities (Carer)	5 Strongly disagree 4 Disagree 3 No opinion 2 Agree 1 Strongly agree Reverse scored (as shown)
General Acceptability	How acceptable was completing the disability questions to you?	1 Completely unacceptable 2 Unacceptable 3 No opinion 4 Acceptable 5 Completely acceptable The General Acceptability item has been included as in some instances, an overall acceptability item may be useful to allow for researchers to explore which of the individual TFA Constructs influences/drives participants' General Acceptability judgment.

Clinician Online Survey – TFA Constructs

TFA construct	Generic TFA questionnaire items	Guidance notes
Affective Attitude How an individual feels about the intervention	How comfortable did you feel completing the disability question(s)?	1 Very uncomfortable 2 Uncomfortable 3 No opinion 4 Comfortable 5 Very comfortable
Burden The perceived amount of effort required to participate in the intervention	How much effort did it take to complete the disability question(s)?	5 No effort at all 4 A little effort 3 No opinion 2 A lot of effort 1 Huge effort Reverse scored (as shown)
Perceived Effectiveness The extent to which the intervention is perceived to have achieved its objective	Completing the question(s) provided me with useful information about the patients care needs/disability	1 Strongly disagree 2 Disagree 3 No opinion 4 Agree 5 Strongly agree

TFA construct	Generic TFA questionnaire items	Guidance notes
<p>Intervention Coherence</p> <p>The extent to which the participant understands how the intervention works</p>	<p>It is clear to me how the completing the disability question(s) will help [hospital name] to provide the patient with better care</p>	<p>① Strongly disagree ② Disagree ③ No opinion ④ Agree ⑤ Strongly agree</p>
<p>Self-efficacy</p> <p>A participant's confidence that they can perform behaviour(s) required to participate in the intervention</p>	<p>How confident did you feel about asking the disability question(s) of all patients?</p>	<p>① Very unconfident ② Unconfident ③ No opinion ④ Confident ⑤ Very confident</p>
<p>Opportunity Costs</p> <p>The benefits, profits or values that would have to be given up to engage with the intervention</p>	<p>Completing the disability question(s) interfered with my other priorities</p>	<p>⑤ Strongly disagree ④ Disagree ③ No opinion ② Agree ① Strongly agree</p> <p>Reverse scored (as shown)</p>
<p>General Acceptability</p>	<p>How acceptable was completing the disability questions to you?</p>	<p>① Completely unacceptable ② Unacceptable ③ No opinion ④ Acceptable ⑤ Completely acceptable</p> <p>The General Acceptability item has been included as in some instances, an overall acceptability item may be useful to allow for researchers to explore which of the individual TFA Constructs influences/drives participants' General Acceptability judgment.</p>

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