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**RESEARCH** **Open Access**

# A patient self-report disability identifier within health service electronic medical records: evaluation of patient, carer and clinician acceptability

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## Abstract

**Background** A third of the 5.5 million Australians with a disability require adjustments to access healthcare effectively. Ensuring clinicians have timely information about a patient's disability and care needs can support more responsive care. Disability Identifiers—brief question sets—offer a practical way to capture this information. However, their use in healthcare remains limited. To address this, a group of clinicians, consumers and researchers from five tertiary and quaternary health services in Victoria, Australia, co-designed and implemented a patient self-report Disability Identifier within Electronic Medical Record systems. This paper presents an evaluation of the acceptability of this intervention among patients, carers, and clinicians.

**Methods** The Disability Identifier questions were integrated into Electronic Medical Record systems across the five health services in March 2023, with the evaluation period spanning the first nine months of implementation (1st March–30th November 2023). Using a mixed methods convergent parallel design and guided by the Theoretical Framework of Acceptability, we conducted online surveys, interviews, and focus groups with patients, carers, and clinicians. Data analysis explored perspectives and experiences across eight constructs: general acceptability, affective attitude, burden, ethicality, intervention coherence, opportunity costs, self-efficacy, and perceived effectiveness.

**Results** Survey results indicated strong acceptability of the Disability Identifier questions. Interviews with patients and carers reflected generally positive perceptions of the intervention, with many noting that it signalled a commitment by health services to improve care for people with disability. Clinicians emphasised that, with adequate training and resources, this intervention could raise awareness about disability and contribute towards disability-responsive care.

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**Conclusions** Integrating patient self-reported Disability Identifiers into EMR systems marks a critical step toward improving disability-responsive healthcare. Building trust in Disability Identifiers requires clear communication about their purpose, benefits, and role in improving care while also addressing disability awareness and discrimination in healthcare settings. While continuous evaluation of their use and impact on patient experiences and outcomes is recommended, this research lays the foundation for other jurisdictions to adopt a standardized approach to integrating Disability Identifiers into health data systems. Ultimately, effective use of patient self-report Disability Identifiers has the potential to promote more equitable health outcomes for people with disability.

**Keywords** Disability, Disability identifiers, Electronic medical records, Healthcare, Universal access, Health equity, Disability data, Acceptability, Co-design

## Introduction

More than 5.5 million Australians live with disability, representing 21% of the national population [1]. Barriers to healthcare access are often encountered by people with disability and contribute to substantial health inequities experienced by this group [2]. For example, people with disability are more likely to experience and prematurely die from non-communicable (e.g. cardio-vascular disease, cancer, mental illness) and communicable diseases (e.g. Tuberculosis, COVID-19) [2–7]. One in three Australians with disability require adjustments in how care is provided to enable access to healthcare [7]. When this need for assistance or adjustment is not recognised or provided, the health inequities experienced by people with disability are likely to be exacerbated.

Providing clinicians access to timely information about patient disability and care needs has the potential to help address health inequities by enabling disability-responsive healthcare [2, 8]. Identifying and flagging this information early during healthcare interactions, such as at intake or admission, can help clinicians make informed decisions about necessary adjustments required to improve patient care for the individual [9].

Globally, there are very few examples where Disability Identifiers have been integrated within health service administrative or clinical data sets to inform disability-responsive care or monitor health outcomes [10, 11]. The United Kingdom's National Health Service (NHS) collects and analyses disability data through their NHS Digital Disability codes, as well as the Reasonable Adjustment Flag which records a person's needs and adjustments, with this information made available through the NHS Spine [12–14]. The NHS Disability coding includes a variety of data sources, including self-reported disability information through Equality and Diversity Monitoring Forms. The UK has also progressed data linkage capabilities which enables NHS Digital data to be linked with, for example, mortality data collected through the Office of Statistics [15, 16]. Research in the United States is working to implement and evaluate strategies within various healthcare jurisdictions to document disability status and patient accommodation needs within electronic health records to inform care delivery [17–21]. In other settings, disability questions, such as the Washington Group Short Set on Disability - designed for use in population-based surveys - have been piloted within local health service admission processes including in Cambodia [22], Paraguay [23], India & Tanzania [24] and Bangladesh [2, 10, 25].

Within the Australian context, Fortune et al. were engaged by the federal government to undertake work to develop Disability Identifier questions, which have now been included in *My Medicare*: an online voluntary patient registration system within primary health care (general practice) [9, 26]. To our knowledge, however, Australian health service and hospitals are yet to routinely collect data within health administration systems to identify individuals with disability [9].

To address this gap, a team of clinicians, consumers, and researchers from five tertiary and quaternary hospitals in Victoria (Australia's second most populous state) co-designed and integrated a patient self-report Disability Identifier (DI) into their Electronic Medical Record (EMR) systems [27]. The participating health services included the Royal Children's Hospital Melbourne (RCH), the Royal Melbourne Hospital (RMH), the Royal Women's Hospital (RWH), Peter MacCallum Cancer Centre (PMC) and Austin Health. The DI is underpinned by the International Classification of Functioning, Disability, and Health (ICF) which conceptualises disability as a dynamic interaction between health conditions and environmental and personal factors [28]. This framework provides a comprehensive view of disability, emphasising both individual and societal aspects. The ICF provides the foundation for the Australian Bureau of Statistics (ABS) Survey of Disability, Ageing, and Carers (SDAC) as the 'gold standard' for identification of disability within the general Australian population [1].

The co-designed Victorian Hospital DI consists of a set of 3 questions. Question 1 serves as the primary disability identification question, asking patients or their carers about difficulty doing activities, related to a long-term health condition, impairment or disability. Question 2 is intended to capture information about the area of difficulty experienced by patients who have positively responded to question 1. Question 3 is intended to identify if there is a need for assistance or adjustments to access healthcare services [27] (see Supplementary File – Sect. 1).

A mixed-methods evaluation was conducted to examine its implementation and early use, assessing the DI's utility and acceptability over the first nine months following integration (March - November 2023) [19]. During this period, 20,083 patients completed the DI across the five participating health services (see Supplementary File – Sect. 2, Table 1 for details on patient characteristics). This paper focuses specifically on the acceptability of the intervention from the perspectives of patients, carers, and clinicians. Using online surveys, semi-structured interviews, and focus group discussions, we explored experiences of completing the self-report disability questions and factors influencing engagement with the DI. This study addresses the research question: What is the acceptability of the Victorian Hospital DI from the perspectives of patients, carers, and clinicians?

## Methods

### Study design

This evaluation adopted a convergent parallel mixed methods study design, guided by the Theoretical Framework of Acceptability (TFA) [29]. Quantitative data (Online surveys) and qualitative data (interviews and focus group discussions) were collected concurrently and analysed independently. The purpose of this approach was to gain a more comprehensive understanding of the acceptability of the Disability Identifier (DI) intervention by drawing on the strengths of both methodological strands. Integration of both quantitative and qualitative results occurred at the interpretation phase was guided by the TFA as further described below [29].

### The theoretical framework of acceptability

Developed by Sekhon et al, the TFA was specifically developed to enable evaluation of the acceptability of healthcare interventions as perceived and experienced by intervention providers and recipients. It consists of an overarching general acceptability construct alongside seven inter-connected constructs: (i) Affective attitude (how an individual feels about the intervention); (ii) Burden (perceived amount of effort that is required to participate in the intervention); (iii) Ethicality (extent to which the intervention aligns with an individual's value system); (iv) Coherence (extent to which the individual understands the intervention and how it works); (v) Opportunity Costs (extent to which benefits, profits or values must be given up to engage in the intervention); (vi) Self-Efficacy (individual's confidence that they can perform the expected role/behaviours required to participate in the intervention); and (vii) Perceived Effectiveness (degree to which the intervention is perceived as likely to achieve its purpose) [29]. The TFA was used to inform the design and subsequent analysis of the online survey, qualitative interviews and Focus group discussions.

### Ethics statement

Ethics approvals for this multi-site study were obtained by the RCH Human Research Ethics Committee (Project HREC/100979/RCHM2023) and Austin Health's Human Research Ethics (Project HREC 97208/Austin-2023).

### Quantitative strand

#### *Online surveys of patients, carers and clinicians*

**Participant eligibility and recruitment** Eligibility at Parkville health services (RCH, RMH, RWH and PMC) for the patient and carer online survey was determined by retrospective audit of EMR data, including those who had responded (Yes/No/Declined to answer) to the primary DI question (Q1) between 29 th March– 30 th November 2023. Eligible patient and carer survey participants were over 18 years old ($n =$ 10,103). Eligible individuals were invited to complete the survey either via a message to their Parkville patient portal (for active users) or postal letter. Invitations included a link to the survey with an embedded Participant Information Statement clearly stating the voluntary nature of participation, the anonymity of responses, and the use of data for research purposes. Completion and submission of the anonymous survey was taken as implied informed consent, consistent with NHMRC guidelines for low-risk, anonymous research. Eligible Austin Health patients and carers included individuals who had responded Yes to the primary DI question (Q1) between 1 st March – 30 th November 2023 and were over 18 years old ($n =$ 1,785). They were invited to participate via email or text message. In the absence of a response to initial contact, a single reminder was sent to all potential participants via the same contact mode before being considered lost to follow up.

The survey and participant information statement for implied consent was designed to be broadly accessible and inclusive for people with diverse access needs. Features included a simplified visual layout, high-contrast text, text-to-audio functionality, and the option to contact the research team by phone to ask questions or complete the survey verbally if online completion was not possible.

Eligible Parkville Clinicians included those who had completed the DI on or after the 29 th March 2023 ($n =$ 972). They were invited to participate via an email that included the study information and a link to the survey, again outlining that consent was implied by completion. Three reminders were sent. Eligible Austin Health staff included those who had completed a patient admission assessment on or after 1 st March 2023 ($n =$ 2,540). As above, they were invited to participate via email, with two email reminders sent.

**Data collection** Two online surveys were created to assess (i) patient and carer, and (ii) clinician perspectives on and experiences of the DI questions and their use within EMR to inform disability-responsive care. The surveys were created using a generic TFA questionnaire developed for the purpose of adaptation by Sekhon et al. [29] to assess prospective or retrospective acceptability of any healthcare intervention (see Supplementary File – Sect. 3, Tables 2 and 3). 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 FGDs. The online surveys were administered electronically via Research Electronic Data Capture (REDCap) [30].

**Data analysis** Online Survey respondents who did not complete all TFA Constructs questions were excluded from the Survey data analysis. Survey data were analysed by generating scores for each of the TFA constructs examined, as well as generating a single Acceptability score by (i) Computing the total mean score (and confidence intervals) for each of the TFA constructs, and (ii) using the mean score (and confidence intervals) for the General Acceptability item. Higher mean scores indicate stronger acceptability, including for burden and opportunity cost constructs which were inversely rated in the survey (see Supplementary File – Sect. 3, Tables 2 and 3). A linear mixed-effects model was used to examine differences in TFA construct scores across self-reported areas of difficulty. The model included fixed effects for Constructs and General Acceptability (7 levels), Area of Difficulty (7 levels), and their interaction, with a random intercept for each respondent to account for repeated measures. This approach accommodates unbalanced data, accounts for individual differences in baseline ratings, and provides flexibility in handling missing values. The model was estimated using maximum likelihood, and Type III Wald $\chi^2$ tests were used to assess the significance of main effects and interactions. All analyses were conducted in R using the lme4 package. Responses to open-ended questions included in the surveys were analysed using simple thematic analysis and included in the overall synthesis of findings.

### Qualitative strand

#### *Qualitative interviews with patients and carers*

Patient and carer perspectives on and experiences with the DI questions and engaging with the DI process were further explored through semi-structured interviews. Interview questions were designed to elicit participants' reflections across each of the TFA constructs to ensure a comprehensive exploration of the DI acceptability.

**Participant eligibility and recruitment** Potential participants included existing patients and carers who had completed the online survey and provided consent to be contacted to participate in a follow-up interview. The research team sought to identify a representative sample of participants regarding disability, gender, age and health service (noting only patients accessing Parkville health services participated in this component). Potential participants were invited to participate via their preferred mode of contact (i.e. email or text message). Participant Information Statements were sent via email or discussed via telephone. Informed consent was obtained prior to the interview with capacity to provide consent ascertained via seven Easy English true/false questions.

**Data collection** A date and time to conduct the interview via phone or online platforms (e.g., Zoom, Microsoft Teams) were arranged with interested participants. Patients and carers were asked about their understanding of the questions and how they felt about the intervention, the perceived usefulness and burden, and suggestions for improvement. Interviews lasted for between 30 and 60 min.

**Data analysis** Interviews were recorded and transcribed verbatim. Our reflective thematic analysis commenced with familiarisation and immersion by the two members of the research team (AD, MH) leading this component of the analysis. An initial coding framework was developed deductively based on the TFA constructs, with data categorised under the seven TFA Constructs. In conjunction, we allowed space for inductive coding 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. AD and MH independently coded a sample of transcripts and met regularly to reflexively compare interpretations, refine codes, and ensure consistency across the categorisation of codes. These processes helped to enhance trust and minimise bias.

#### *Focus group discussions with clinicians*

FGDs were completed with clinicians at each of the Parkville health services, with the intention to explore the implementation experience from the clinician's perspective.

**Participant eligibility and recruitment** Clinicians who completed the online survey and provided their information to be contacted regarding participation in a focus group discussion were eligible. Recruitment of clinicians was coordinated through site investigators. A purposive sampling approach was undertaken to achieve diversity of experiences across key clinical groups (Allied Health, Nursing and Medical) at each participating site. Potential participants were invited via email and provided with the Participant Information Statement and Consent form.

**Data collection** Discussions were designed to develop an understanding of barriers and facilitators to the adoption of the DI questions and opportunities to improve their use. FGDs were completed via Zoom.

**Data analysis** FGDs were recorded and transcribed verbatim, before being uploaded into NVivo (v14) for analysis. Two researchers independently coded the data (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. Further analysis used a deductive approach, to understand clinician perspectives in context of the TFA. This involved three researchers (NM, JR, IG) organising codes within categories and sub-categories based on the seven constructs within the TFA. Reflexive discussions between the same three researchers occurred to facilitate deeper engagement with the data, and challenge individual interpretations. This led to refinement of codes and categories, representing the clinicians' views about the DI, aligned under the TFA constructs.

### Integration of qualitative and quantitative strands

Integration of findings occurred during the interpretation phase. Team-based interpretation sessions were regularly conducted with team members (JR, AD, NM, MH) leading the online survey data analysis and the qualitative analysis of the interviews and FGDs, allowing us to triangulate and integrate the data and assess the perceived acceptability of the intervention in a structured and theoretically informed way. The team examined convergence and divergence between data sources and refined interpretations within the TFA framework. Further consultation with the wider research group supported deeper contextualisation of the results and helped ensure that interpretations reflected the multidisciplinary and co-design ethos of the project.

## Results

### Participant characteristics and demographics

A combined total of 1,181 patients and 180 carers completed the online TFA survey (Table 1). Table 2 displays the range of self-reported areas of difficulty identified by respondents who completed the survey. A total of 221 clinicians completed the clinician online TFA survey (Table 3). Nine patients and five carers completed the semi-structured interviews. All carers were mothers of

**Table 1** Demographics of patients and carers completing the Online TFA Survey by Hospital*

| | | RCH n (%) | RWH n (%) | PMC n (%) | RMH n (%) | Austin Health 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 (2.7%) | 67 (9.9%) | 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%) |
| Identified as having a 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 to access healthcare?^ | 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 | 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 included in this table (age, gender, hospital, disability, disability type, assistance needed) relates to the patient for whom they provide care

^% show need for assistance as a proportion of total survey respondents positively identifying with a disability (denominator n=715)

**Table 2** Patients represented in the online TFA survey by self-reported area of difficulty

| Area of Difficulty*^ | Seeing | Hearing | Speaking | Learning | Moving | Mood | Other |
|---|---|---|---|---|---|---|---|
| N (%) | 140 (19.4%) | 76 (10.6%) | 146 (20.3%) | 282 (39.2%) | 524 (73.3%) | 335 (46.9%) | 97 (13.6%) |

*Note - The % shown in this table are each 'area of difficulty' as a proportion of total survey respondents identifying an area of difficulty

^Respondents can select more than one area of difficulty so the sum (%) do not equal 100%

**Table 3** Clinician online TFA survey participants by professional group and hospital*

| | | RCH *n* (%) | RWH *n* (%) | PMC *n* (%) | RMH *n* (%) | Austin Health *n* (%) | Total *n* (%) |
|---|---|---|---|---|---|---|---|
| Survey Respondent - Professional Group | 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 4** Demographics of patients represented in the patient and carer semi-structured interviews (*n* = 14)

| | | Number of Patients *n* (%) | Represented by carer |
|---|---|---|---|
| Gender | Male | 3 (21.4) | 2 (14.2) |
| | Female | 11 (78.6) | 3 (21.4) |
| | Gender Diverse | - | 0 |
| Age | 0–17 | 3 (21.4) | 3 (21.4) |
| | 18–30 | 2 (14.2) | 1 (7.1) |
| | 31–45 | 2 (14.2) | 1 (7.1) |
| | 46–64 | 7 (50) | 0 |
| | 65+ | 0 | 0 |
| Self-reported Area of difficulty* | Seeing | 3 (21.4) | 2 (14.3) |
| | Hearing | 0 | 0 |
| | Communication/Speaking | 3 (21.4) | 2 (14.3) |
| | Cognitive/Learning | 8 (57.4) | 4 (28.6) |
| | Physical/Moving | 10 (71.4) | 3 (21.4) |
| | Mood/psychosocial | 5 (35.7) | 0 |
| | Complex/other | 2 (14.3) | 2 (14.3) |
| | Total | 14 (100) | 5 (35.7) |

**Table 5** Focus group discussion participant by professional group (*n* = 28)

| | | Number of participants *n* (%) |
|---|---|---|
| Professional group | Allied Health | 16 (57.1) |
| | Medical/Nursing | 10 (35.7) |
| | Administration | 2 (7.1) |
| | Total | 28 (100%) |

the participants they represented (Table 4). Twenty-eight clinicians took part in FGDs (Table 5).

## Acceptability of disability identifier intervention

Results from the online survey, interviews and FGDs were integrated and are presented below in alignment with the TFA.

### *General acceptability*

General Acceptability reflects the extent to which patients, carers and clinicians felt the intervention – in this case integrating self-reported DI questions within EMR and patient portal - is appropriate, feasible and would contribute towards improved processes and outcomes. Results from the online surveys demonstrated a strong General Acceptability mean score of 4.2 out of five across patients, carers and clinicians. Focusing in on our priority target group of respondents who positively identified as having 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 with a General Acceptability mean score of 4.5 out of five (Table 6).

The survey results showed no significant differences in TFA construct profiles across Area of Difficulty subgroups. The main effect of Area of Difficulty was not statistically significant, $\chi^2(6) = 9.74$, $p = .136$, and there was no evidence of a Construct × Area interaction, $\chi^2(36) = 39.23$, $p = .334$. While the “Other” category had slightly lower overall ratings compared to “Hearing” (b = – 0.336, $p = .009$), this was an isolated effect and not part of a broader pattern of divergence. Strong acceptability scores were observed across different area of difficulty groups for individual TFA Constructs and General Acceptability scores ranged between 4.1 and 4.3 across subgroups (see Supplementary File – Sect. 4, Table 4).

Overall, patients and carers interviewed generally felt positive about the intervention, citing that it demonstrated that these health services were striving to improve services for people with disability. Nonetheless, most expressed concerns about the capacity to effectively utilise the DI to improve care.

> *I wish that more places asked those kind of questions. ... It was positive to feel like people actually cared and were asking such specific questions. But there was also the part of me that was like, I don’t think... that it’s actually going to do any good, you know... who will actually look at the [DI responses]? (Patient interview, P9)*

Clinicians participating in the FGDs also felt the intervention provided an important opportunity to raise awareness about disability and had the potential to enhance disability-responsive care. They recommended refining the DI questions to better capture wider experiences of disability, including neurodivergence and psychosocial disability. Clinicians also noted the need for more purposeful training on disability and how best to integrate the DI questions in their workflow processes. However, clinicians also raised concerns around the burden of additional training and the time required to effectively utilise the DI in EMR.

### *Affective attitude – how an individual feels about the intervention*

Within this construct, the online survey mean scores of 3.8 out of five for patients and carers and 3.6 out of five for clinicians indicate respondents generally felt ‘comfortable’ completing the intervention. While still a moderate to strong score, this construct scored lower compared with other constructs for patients, carers and clinicians. Some survey participants noted that while disability and chronic conditions are complex and difficult to live with, they are comfortable to discuss them or answer questions in relation to them.

> *As difficult as it can sometimes be dealing with both disabilities, I have no difficulty in answering questions about [them]. (Patient survey)*

**Table 6** Individual TFA construct and general acceptability scores*

| | | **All patient & carer Respondents (Mean, CI)** | **Patient & carer priority Sub-Group (Mean, CI)** | **Clinician Respondents (Mean, CI)** |
|---|---|---|---|---|
| TFA Constructs | Opportunity Cost | 4.1 (4.0–4.2) | 4.0 (3.8–4.2) | 3.6 (3.3–3.9) |
| | Intervention Coherence | 3.8 (3.8–3.9) | 4.0 (3.8–4.2) | 4.0 (3.6–4.2) |
| | Perceived Effectiveness | 3.7 (3.6–3.7) | 4.2 (3.9–4.2) | 4.0 (3.7–4.2) |
| | Self-Efficacy | 4.1 (4.0–4.1) | 4.0 (3.8–4.2) | 3.8 (3.6–4.0) |
| | Burden | 4.5 (4.4–4.5) | 4.1 (3.9–4.3) | 4.0 (3.8–4.2) |
| | Affective Attitude | 3.8 (3.7–3.8) | 3.8 (3.6–4.0) | 3.6 (3.3–3.9) |
| General Acceptability | | 4.2 (4.2–4.3) | 4.5 (4.3–4.6) | 4.2 (4.0–4.4) |
| Overall Acceptability (Percentage) | Completely Acceptable | 41.9% | 52.8% | 36.5% |
| | Acceptable | 42.8% | 41.6% | 47.3% |
| | No Opinion | 13.9% | 5.6% | 14.9% |
| | Unacceptable | 0.3% | 0.0% | 1.4% |
| | Completely Unacceptable | 1.2% | 0.0% | 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

^Priority sub-group represents 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(n=89)

Interview participants described feeling positive about having the option to complete the DI questions. The process was highlighted as enabling self-reflection on disability and related needs within the health system, with some prompted to more proactively communicate their needs with clinicians. Subsequent planning with clinicians improved feelings of safety and comfort during engagement with hospital services.

Patients and carers were optimistic the intervention would help enhance disability awareness and clinician understanding of required supports. There was some concern that the information provided would not be consistently utilised by staff, due to heavy workloads and insufficient capacity and resources to provide disability-responsive care. Even so, there was hope that the intervention would lead to better resourcing overtime, contributing to improved patient and carer experiences, 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 agreed that this intervention can enhance awareness and their understanding of patient perspectives on disability. In turn, it can provide a common language for patient and clinician interactions to help identify what reasonable adjustments may improve experiences of care. Clinicians raised concerns that some staff may lack the confidence or willingness to ask the questions.

> *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, S9)*

#### *Burden – the perceived amount of effort that is required to participate in the intervention*

This construct was reverse scored, with a higher mean score indicating lower perceived burden. Online survey results indicate minimal burden with an overall mean score of 4.0 out of five for clinicians and 4.5 out of five for patients and carers. Patients with disability and carers reported a slightly lower score of 4.1 out of five. Qualitative responses revealed perceived burden was related to time, ease and comfort. Patients and carers generally expressed minimal difficulty and low burden completing the DI questions.

> *I thought the questions were pretty simple … I thought they were stock standard questions when you go to the doctor and they ask you "Do you have asthma". Like it just kind of felt like that. Like you were just ticking off boxes. Which is fantastic. (Carer interview, P1)*

A small number of patient and carer interviewees felt some tension with aspects of the questions. They perceived that the intervention would contribute to clinician discomfort and burden, which exacerbated their own experiences of burden. In part, this related to a patient's own level of comfort in responding to the DI questions, with some highlighting that the questions would have felt more burdensome earlier on in their disability journey. Similarly, a few clinicians expressed concerns around not knowing when to ask 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, S3)*

Clinicians, patients and carers felt having the information embedded within the EMR could reduce the burden on patients to repeat their disability information and the burden associated with hospital administration, including when transitioning between hospitals or paediatric to adult services.

> *I think there's huge benefit to having the information and being able to access the information quickly or that it's there and people don't have to retell their stories, and it's them articulating their own experience. Not us imposing kind of more diagnostic criteria or something of their experience. (Clinician FGD, S4)*

However, embedding in the EMR didn't appear to reduce clinician burden. Integrating the DI questions into clinician workflow and the extra time required to ask the questions was a common concern among clinicians, with some expressing the process doubled-up with information collected during a standard subjective examination. There appeared to be less perceived burden when the DI questions were built into bookings and admissions workflows, and when clinicians had more knowledge of and easier access to the DI questions.

> *The booking screen and flow is quite easy to use. (Clinician FGD, S10)*

#### *Ethicality – the extent to which the intervention has good fit with the individual's value system*

As described earlier, Ethicality was not measured in the online surveys but was discussed in the interviews and FGDs. Patients and carers perceived that the intent of implementing the intervention was to improve outcomes for people with disability, which strongly resonated with individuals' value systems. Completing the DI questions was also described as less about individual-level benefit, and more of a way to 'give-back' to the hospital and the disability community in promoting disability awareness and inclusion.

> *I'd love it if there were some changes. ... to help myself and others. ... But like I said, I try to help as much as I can. I mean, if it doesn't benefit me, it's OK. At least all this information ... and get to the bottom of it to help others. ... I didn't really think of myself. (Patient interview, P2)*

Despite this, several patients, carers and clinicians questioned the ethicality of asking for disability-related data when systems, policies and resources are not yet consistently available to provide the supports required to facilitate better care.

> *It's great to have the questions, but if you're not aware, if you don't look at it beforehand or if the intake admin officers are not understanding of the fact that it's there. Or looking at it in advance, 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, S2)*

> *It is important to ask these questions, but this will only improve health care if staff are looking at and using this information. There needs to be better awareness raising in the health workforce about disability and different needs. (Patient Survey)*

In relation to the collection and visibility of information on the EMR, clinicians raised some ethical considerations around the need to protect vulnerable patients and balance the value in having information available with concerns about people who access that information potentially not acting in the person's best interest. While other participants challenged this notion and suggested a need to normalise the conversation and have an openness around disability, rather than hide it due to fears around potential stigma.

> *I would really find it quite offensive seeing someone [a clinician] that will hide it because we think maybe [it will] reflect in a certain way towards you [the patient] ... I think it should be open to all, even if that makes us feel a bit uncomfortable in how we think. (Clinician FGD, S8)*

#### *Intervention coherence – the extent to which participants understand the intervention and how it works*

Patients, carers and clinicians generally described the DI questions as easy to understand. This sentiment was echoed in the online survey results with a mean score of 3.8 out of five among patients and carers and 4.0 out of five for clinicians. Patients with disability and carers of patients with disability demonstrated a mean score 4.0 out of five for intervention coherence.

> *This was great to complete, thanks folks! The wording was succinct to ensure the point, and the questions broad enough to allow flexibility for tailored responses for everyone's needs. (Patient survey)*

Clinicians expressed consistent knowledge on why the questions are being asked and what the intention is behind having the questions included in the EMR. They recognised the additional benefits of the intervention, such as building rapport with patients, providing learning opportunities on the diversity within disability, and improving patient care.

> *Disability is - it's like a good learning opportunity for people that don't know much about disability in particular. And then, yeah, 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, S9)*

Many clinicians understood that the questions are intended to be a patient self-report disability identifier, rather than clinical observation, but expressed that there were challenges to using the questions as intended. Among patients and carers, however, there were differing understandings of why or when the DI questions would be asked, and how they might work. Some recognised they would be routinely asked of all patients, regardless of presentation setting, to improve services. Others felt it was specifically asked of them because they were seen as having disability.

> *I guess it was to find out that I am a person with disability. [To improve] 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, P3)*

> *Why was I asked? … I don't know. Is it because I have disability? … I think it was useful to be asked those questions. (Patient interview, P2)*

Some participants experiencing multiple episodes of healthcare interaction said that similar questions had been asked by staff across different clinical services (e.g. allied health outpatients, in-patient settings). They were not always clear about when, how and the frequency of which the questions should be asked. As such, a small number of participants thought the DI questions were being used by clinicians as an assessment of their mental health, cognition or consistency of responses (i.e. do their responses match what they have responded elsewhere).

> *I don't think they read them at all. Because well, it could be one of two things. It could be that they want to make sure that I'm in my right mind and I remember what I told them. … I think a lot of these questions say the same thing. So, I was a bit, not confused, but curious as to why the same questions were asked so many times in different ways. (Patient interview, P5)*

#### *Opportunity costs – the extent to which benefits, profits or values must be given up to engage in the intervention*

This construct was reverse scored, with a higher mean score indicating lower perceived opportunity cost. Online survey results in relation to opportunity costs revealed a mean score of 4.0 out of five for patients and carers. This aligns with qualitative findings that suggest the opportunity to 'contribute' to benefitting the future healthcare of people with disability, generally outweighed any costs in not individually benefiting from immediate changes in care.

> *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, P14)*

Some patients and carers again perceived that the intervention opportunity costs were more likely to be borne by clinicians. Indeed, the online survey mean score for this construct for clinicians was 3.6/5. All groups associated opportunity costs to perceived burden and intervention coherence. As such, while clinicians expressed that they feel the questions are useful, their use has not been consistently integrated into their own workflow because of time restraints and existing admin burden.

> *I think as a tool it's quite useful within EMR, but again I think it's that admin burden within clinics… Is potentially where it's stumbling. (Clinician FGD, S6)*

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

> *If there was like an easier way just for like a clinician to, you know, one click… And then, you know, they can see some information of how they need to communicate… or you know if there are any special needs. (Clinician FGD, S3)*

#### *Self-efficacy–participant's confidence that they can perform the behaviour(s) required to participate in the intervention*

Patients and carers were asked how confident they felt in providing responses to the DI questions, with an online survey mean score of 4.1 out of five for this construct. Clinicians were asked about their confidence in asking the questions and using the information, resulting in a mean score of 3.8 out of five. Most patients and carers felt confident in their capacity to respond to the DI questions. Differences did emerge, however, in their level of motivation to do so. Lower levels of motivation related to the perception that the questions did not allow them to adequately describe their experiences of disability and care needs, or that information shared would not be utilised by clinicians or contribute to improvements in care.

> *How do you capture those nuances? … Sometimes it's sort of, it's a bit of a frustrating one, because you want to explain the infinite nuances to the condition, but you know, it's not that people don't want to listen, it's perhaps they don't need to have that information to do what they do. (Patient interview, P6)*

Greater confidence was associated with longer periods of time with a disability, progressing to the point whereby some participants wanted to share information and their expertise to help themselves, clinicians and other people with disability accessing healthcare. Anticipated improvements in disability awareness - including through the intervention - amongst clinicians, further facilitated self-efficacy confidence to complete the DI questions.

> *If I was to do this survey a couple of years back... I would have felt uncomfortable. I might have not even partaken. ... A lot of changes have happened, and that's why it made it a bit easier. And if I can ... help you know the situation, people like me as well... I'm more than happy to take part in it.... Even the doctors over the time. Still the same doctors that I'm seeing, but the new ones that have come as well have made it, I feel like a bit easier to break that barrier. (Patient interview, P12)*

Indeed, confidence and self-efficacy was higher for some clinicians than others. Some raised issues around not knowing who is responsible for asking the questions, alongside not having the confidence to know when it may or may not be appropriate on someone's journey, to ask the questions and have conversations about disability and care needs. This confusion was particularly evident when clinicians may have identified a discrepancy in documented diagnosis, a patient's insight into their condition or how they identify with disability, and their subsequent capacity and/or willingness to respond to the questions as anticipated by clinicians.

> *It's not actually that uncommon that patients don't necessarily have insight into what their needs are... They're happy to disclose physical disabilities. I've had quite a few situations where people have been much more cagey [guarded] around psychosocial stuff. Yeah, mental health stuff. Yeah, because of, you know, historical taboo. (Clinician FGD, S5)*

While having pre-planned prompts for initiating the conversation increased confidence for clinicians, several still highlighted the need for improved training and support to equip clinicians with the skills to both engage with the intervention and provide the necessary adjustments in care requested by patients.

> *I have not received adequate education about use of the identifier ... More education should occur. (Clinician survey)*

#### *Perceived effectiveness – the extent to which the intervention is perceived as likely to achieve its purpose*

The online survey asked patients and carers whether completing the DI questions provided them with an opportunity to communicate their care needs, with a mean score of 3.7 out of five indicating general acceptance that it would. For patients with a disability and carers of a patient with a disability, this was the highest scoring construct, with a mean score of 4.2 out of five. Clinicians were asked whether the DI provided them with useful information about patients' disability and care needs, with a mean score of 4.0 out of five reflecting most clinicians agreed with this sentiment.

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 because 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)*
>
> *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)*

More broadly, however, most patients and carers acknowledged it was too early to tell if the intervention had led to improved practice. Yet a previously highlighted the process was still seen as contributing positive change in and of itself.

> *The more that people talk about it, or listen or ask about it, the more the disability doesn't frighten other people. ... I think the more that people can indicate that somebody's got something, the more people may be mindful and more kind ... I think they're really, really important because it, I don't know if this is the right word, but it helps triage your situation. (Patient interview, P8)*

Clinicians highlighted that the language in the screening question itself was well structured, with a focus on function rather than a label.

> *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, S10)*

There were mixed views from clinicians around the DI questions effectiveness in identifying certain disability types. 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 who experienced chronic or persistent fatigue.

> *It's more tailored for physical disability as opposed to the other side … So it's clinical usefulness then is … less essentially, than for physical. They're just, yeah, not tailored to the more invisible disability as such. (Clinician FGD, S7)*

Clinicians also expressed some concerns about the accessibility and flow of questions, limiting patient opportunity to complete all sections. In turn, low usage was a barrier to perceived effectiveness. Clinicians suggested keeping the process simple would help promote its use.

> *Not over complicating the communication process. Keeping it simple and I find when you keep the communication process simple for anything like that, people are more likely to pick it up. (Clinician FGD, S11)*

Regardless, clinicians felt when the information was there, it was considered helpful and viewed as an effective tool.

> *I actually found that quite helpful because it sort of gave a more personal touch to the things they we're having trouble with and the kind of help that they would like. (Clinician FGD, S1)*

Ultimately, patients, carers and clinicians felt that more training on disability, skills to utilise the information, better integration within workflows, and resources to respond accordingly through enhanced disability-responsive care are all required to fully effect the potential of the intervention.

> *Because everybody's so busy … hospitals are so short staffed. That 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, P5)*

## Discussion

In line with international priorities, integration of patient self-reported Disability Identifiers with health service EMR systems represents a significant step towards enhancing disability-responsive healthcare and equitable health outcomes for people with disability [2, 9, 31]. Our evaluation assessing the acceptability of the Victorian Hospital DI provides valuable insights into successes and challenges, as well as implications for future practice and policy development.

### Perceived acceptability and engagement

Patients and carers broadly appreciated the opportunity to provide disability-related information through the DI questions, recognising its potential to enhance disability awareness and accessibility within healthcare services. The DI resonated strongly with individuals' value systems of respect for people with disability and broader community inclusion. However, uncertainty emerged regarding whether the information provided would be meaningfully utilised by hospital staff, particularly in high-pressure settings such as emergency departments and outpatient clinics. Similarly, and aligning with the wider literature, potential tensions emerged relating to the fact that some individuals with disability - particularly less visible disability – may choose not to share disability-related information due to fear of discrimination [11, 32]. To build patient and carer trust to engage with the DI, clear communication about the DI's objectives and benefits is critical. This includes distinguishing its role in current data collection from its evolving potential to further drive more responsive care and outcomes. Arguably even more urgent, is building patient trust in sharing disability-related information, and continual action within healthcare settings to improve disability awareness and address discrimination [2, 31].

How the clinicians feel about the intervention was viewed from the perspective of benefits, concerns and usefulness. Clinicians generally expressed positive attitudes toward the DI, acknowledging its potential to facilitate more responsive care for people with disability. Clinicians, patients and carers were optimistic that the DI would ultimately decrease the burden associated with completing general hospital administration. However, practical challenges such as workflow integration and administrative burden were noted. Embedding the DI seamlessly into existing EMR workflows is crucial to ensuring its sustainability and effectiveness. Less perceived burden was reported by clinicians when the DI questions were built into bookings and admissions workflows. This theme aligns with higher DI completion rates observed in settings where the DI questions were integrated as a mandatory component of nursing admission questions [27].

### Training and awareness

Successful implementation of any intervention relies on clinician engagement, which depends on knowledge, confidence, and adequate resources [20, 24]. A recurrent theme across groups was the need for targeted training to support DI implementation. While some clinicians reported receiving training, others lacked sufficient opportunities to understand the value of the DI, how to integrate it into their practice, and how to initiate meaningful conversations with patients.

A lack of awareness about the DI questions and uncertainty around implementation emerged as barriers. Less perceived burden was observed where there was greater knowledge of the DI questions and how to access them in the EMR. Training should therefore focus on promoting awareness of the DI's objectives, equipping clinicians with the confidence to engage in discussing disability-related topics and offering practical guidance on accessing and using DIs within specific workflows. Training must also improve clinicians understanding of healthcare adjustments and how to utilise DI data to inform adjustments in healthcare delivery [9, 12, 17, 31]. Crucially, clinician training must go further to address the wider competencies needed for disability-inclusive care. This includes strengthening staff capability to understand and respond to different types of disability, particularly intellectual and cognitive disability, where barriers to care are often most acute. Internationally, there are examples of system-wide responses, such as the UK National Health Service's (NHS) mandated training on intellectual disability and autism, which offer a model for large-scale upskilling of the healthcare workforce. In Australia, building similar national training frameworks could support more consistent, rights-based approaches to disability inclusion in healthcare. Concerns regarding training burden must also be managed, potentially through integrating training into existing professional development programs or offering flexible, self-paced learning modules.

### Design and content refinements

Both clinicians and patients identified opportunities to optimise the DI questions to better capture the diversity of disability experiences and ensure inclusivity. Their recommendations highlighted the importance of ensuring DI questions are accessible for people with diverse communication needs (e.g. low vision, low literacy). Patients and carers also highlighted the importance of better capturing experiences related to neurodivergence, psychosocial disabilities, and conditions like chronic fatigue and pain. Clinicians also felt it was important to incorporate mechanisms to document whether questions were completed by the patient or carer directly or with a clinician. These and other changes have been included in the final version of the DI questions (see Supplementary File – Sect. 4).

### Ethical implications

Ethical considerations emerged, particularly regarding the healthcare system's capacity to act on the information collected through the DI. To address this, participants stressed the importance of aligning the implementation of the DI with ongoing efforts to build healthcare system capacity for inclusive care. Patients, carers, and clinicians emphasised that the collection of disability data must be accompanied by adequate knowledge, resources, and policies to provide necessary adjustments and supports. Transparent communication about how the data will be used and demonstrating its impact on patient care are essential for maintaining stakeholder confidence.

Despite these concerns, participants acknowledged that collecting DI data is a critical first step in understanding and responding to the needs of patients with disability. They recognised that the DI data itself has the potential to inform the development of appropriate policies and practices, ultimately guiding health system improvements to better support people with disability.

### Policy and practice implications

Findings from this study align with broader evidence on the potential of Disability Identifiers to drive more inclusive and responsive healthcare systems [9, 17]. Realising this potential requires coordinated efforts involving government, disability stakeholders, and healthcare providers. Key priorities include building capacity to consistently implement, analyse and utilise DI data to evaluate and inform disability-responsive healthcare interventions across settings. The introduction of DIs must also be accompanied by institutional commitment and structural reforms, including policy mandates, clinical governance mechanisms, and funded implementation supports.

Future research should also focus on the effectiveness of DIs to improve care delivery, patient experiences, and outcomes across diverse patient groups. It remains essential to continue to promote co-design approaches to ensure the development and utilisation of DI questions and processes are relevant, inclusive, and reflect the diverse experiences of people with disability within healthcare systems [9].

### Future directions

Longer-term evaluation is required to assess the DI's impact on patient outcomes and system performance. Efforts should focus on linking DI data to outcomes, developing strategies to enhance clinician engagement, and addressing systemic barriers to equitable healthcare [2, 9, 31, 33]. By embedding the DI into routine practice and fostering collaborative partnerships, healthcare systems can take significant steps toward achieving disability-inclusive care.

Future work should also explore how system-level levers such as clinical accreditation standards, mandated training, and national frameworks can be harnessed to embed disability-inclusive practices across services. Implementation science approaches may be particularly useful in identifying strategies to support widespread adoption and sustainability of DIs, particularly in resource-constrained settings.

Opportunities to scale the DI model to other healthcare settings, promoting consistency and comparability of data across regions, should also be explored. Further investigation is also needed to consider the feasibility and usefulness of adapting the DI for patients under 2-years of age.

As with other countries such as the UK, Australia has made significant advancements in data linkage systems, including through the establishment of the National Disability Data Asset, which aims to bring together data from across Australia to better understand and meet the needs of people with disability [16, 34]. In time, the National Disability Data Asset may provide a platform to link hospital-based DI data with broader datasets, providing valuable insights into healthcare access, service utilisation, and outcomes for people with disability.

### Strengths and limitations of the research

This study represents one of the first evaluations of a co-designed, self-reported DI integrated into health service EMRs and patient portals, offering novel insights into its acceptability from multiple perspectives within multiple different hospital settings. The study captured the experiences and perceptions of a broad range of stakeholders, including patients, carers, and clinicians, providing a comprehensive understanding of the DI's acceptability. Additionally, the study was conducted across diverse hospital settings spanning tertiary and quaternary paediatric and adult care, cancer care, and maternity services. Use of an established framework, the TFA, ensured a structured and rigorous approach to evaluating the intervention, whilst combining quantitative surveys with qualitative interviews and focus groups enriched the findings and enabled triangulation of data.

The study focused on acceptability of the DI within the first 9 months of its implementation and did not examine the long-term impact of the DI on patient outcomes, limiting its ability to assess the full potential of the intervention. The findings reflect the early stages of the DI's implementation, and some challenges identified may diminish over time as processes are refined.

While our findings indicate broadly consistent perceptions of DI acceptability across diverse disability types, the study was designed to capture the views of all patients and carers who completed the DI, rather than focusing on any specific sub-group. In addition, many people report difficulties in more than one area, and so comparisons are not between discrete groups of people. Future research should employ more differentiated methods to explore how people with different types of disability engage with the DI and with healthcare services, with particular attention to priority groups who face significant access barriers, such as individuals with intellectual disability or augmentative and alternative communication needs [35].

Survey participants were self-selected, which may introduce bias as those with strong opinions about the DI were more likely to participate. While the study was conducted across five diverse hospital settings using two different EMR systems: Cerner Powerchart (Oracle Cerner, Austin, TX) and Epic Systems (Verona, WI), caution should be taken when generalising findings to other jurisdictions, settings and systems. Finally, while the online survey was completed across all sites, qualitative patient and carer interviews and FGDs were conducted at the Parkville health services only.

## Conclusion

This research paves the way for other jurisdictions seeking to adopt a standardized approach for disability identification. Emphasising continuous evaluation, stakeholder engagement, and leveraging digital health platforms, the DI initiative demonstrates a transformative approach for advancing disability-responsive healthcare and equitable health outcomes for all.

### Abbreviations

| | |
|---|---|
| DI | Disability Identifier |
| EMR | Electronic Medical Records |
| FGD | Focus Group Discussion |
| PMC | Peter MacCallum Cancer Centre |
| RCH | The Royal Children's Hospital Melbourne |
| RMH | The Royal Melbourne Hospital |
| RWH | The Royal Women's Hospital |
| TFA | Theoretical Framework of Acceptability |

## Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12913-025-12974-5.

Supplementary Material 1.

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**Authors' contributions**

JR: Conceptualisation (Lead), Methodology (Lead), Validation, Quantitative and QualitativeAnalysis, Investigation, Writing – original draft (Lead), Project Admin and funding acquisition. AD: Conceptualisation, Methodology, Validation, Qualitative Analysis, Investigation, Writing – original draft. NM: Conceptualisation, Methodology, Software, Validation, Qualitative Analysis, Investigation, Writing – original draft. MH: Methodology, Validation, Qualitative Analysis, Investigation, Writing – original draft. KM: Conceptualisation, Methodology, Validation, Investigation, Resources, Writing – review and editing, Project Admin. KF: Conceptualisation, Software, Validation, Resources, Writing – review and editing. AS: Software, Validation, Investigation, Resources, Writing – review and editing. LM: Conceptualisation, Methodology, Resources, Writing – review and editing, Project Admin. JM: Conceptualisation, Methodology, Resources, Writing – review and editing, Project Admin. RJ: Methodology, Validation, Investigation, Resources, Writing – review and

editing. AS: Methodology, Resources, Writing – review and editing, Project Admin. MG: Methodology, Resources, Writing – review and editing, Project Admin. JM: Quantitative Analysis and data visualisation,, Writing – review and editing. CI: Conceptualisation, Methodology, Resources, Writing – original draft, Supervision.

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**Data availability**
Data and materials is not publicly available in line with Ethics approval.

## Declarations

**Ethics approval and consent to participate**
In accordance with the National Health and Medical Research Council ethics approvals for this multi-site study were obtained by the RCH Human Research Ethics Committee (Project HREC/100979/RCHM2023) and Austin Health's Human Research Ethics (Project HREC 97208/Austin-2023). All participants provided consent to participate. All aspects of the study were conducted in adherence with the Declaration of Helsinki.

**Consent for publication**
Not applicable.

**Competing interests**
The authors declare no competing interests.

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