

The graphic features a dark blue background. In the center, there are two concentric rings. The inner ring is a solid light blue, and the outer ring is a gradient of colors from light blue to orange to yellow. Surrounding these rings is a thick, scalloped border that also follows the same color gradient. The text is centered within the inner ring.

**Accessible
Care Toolkit
Implementation
Guidelines for a
Patient Self-Report
Disability
Identifier (DI)**

Accessible Care Toolkit Implementation Guidelines for a Patient Self-Report Disability Identifier (DI)

Produced in partnership with



Supported by



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More information about the development, testing, refinement, and evaluation of the Disability Identifier (Appendix 1) is available in ‘Implementing Disability Identification in the Electronic Medical Record: Evaluation of Utility and Acceptability’, a research collaboration between the Parkville Precinct Hospitals, Austin Health, Healthy Trajectories – A child and youth disability research hub and The University of Melbourne Disability and Health Unit.

Enquires and feedback

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Instructions on how to use this Guide

This resource is intended as a guide for health service staff on how to use the Disability Identifier (DI) in Electronic Medical Records (EMR). The guidelines can be customised to suit different health services adopting the DI. Appendix 2 provides a space for information specific to your health service, ensuring the guidelines are relevant and targeted to each setting.

Adoption of the DI in EMR

Each health service will have its own unique governance and health information structures. For health services adopting the DI within their EMR, it is important to engage leadership from the outset and ensure key stakeholders are consulted. A good place to start is identifying an executive (senior leadership) sponsor. Implementing the DI and providing healthcare adjustments requires a 'whole health service' approach, involving cross-departmental collaboration. Early on, identify whether you have a Disability Action Plan working group or another disability-focused working group, ideally with consumer membership, that can advise on implementation.

This resource provides general guidance on who should complete the DI questions, as well as when and how they should be completed. However, it should be noted that the DI must be integrated into the specific workflows of the health service where it is being used, such as within inpatient nursing admission questions. Key clinical governance groups involved in these workflows should also be engaged early.

Due to the proprietary nature of some EMR systems, implementation of the disability identifier may need to be tailored to meet system architecture rules (for example: character limits or question cascade logic). You will need to work with your EMR, health information or IT teams to determine the appropriate build for your EMR system.

The DI has been successfully integrated and evaluated in both Epic Systems (Verona, WI) and Cerner Powerchart (Oracle Cerner, Austin, TX). For further information refer to 'Implementing a Patient Self Report Disability Identifier in Electronic Medical Records: Evaluation of Utility and Acceptability' (Rowe et al., 2024).

Disability

What is disability?

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

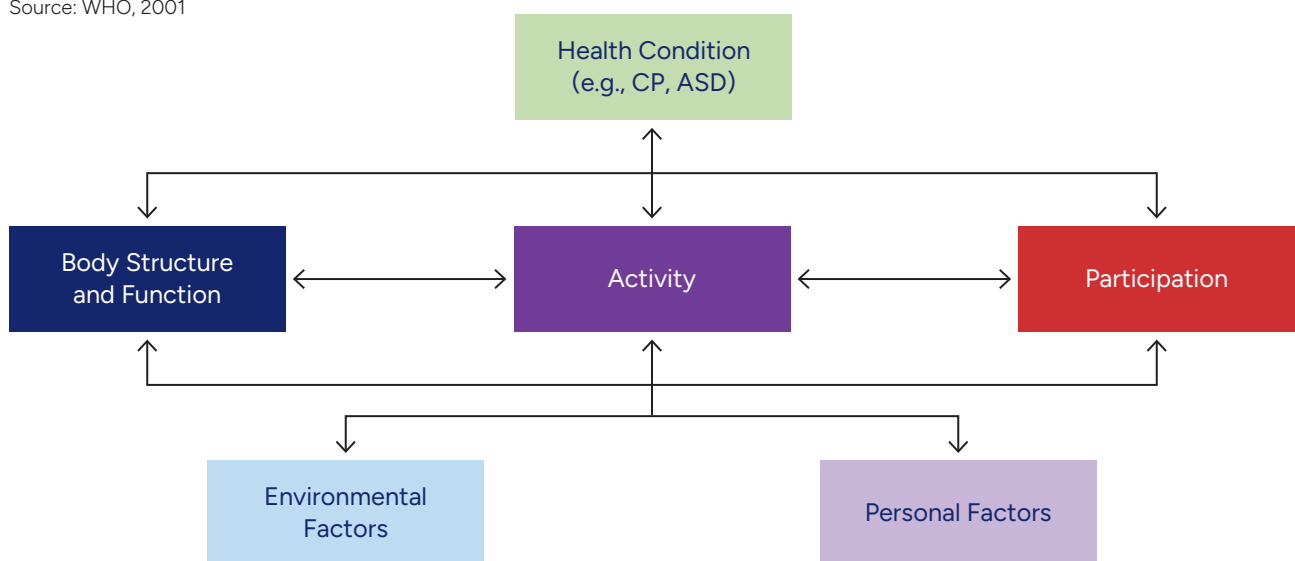
(United Nations Convention on the Rights of Persons with Disability, 2006)

The United Nations Convention on the Rights of Persons with Disability (CRPD) builds on the social model for understanding disability and the related human rights model of disability. This model recognises that disability results from the interaction between a person’s impairment and the physical, attitudinal, communication and social barriers that exist in society. Disability is therefore not a ‘deficit’ within the individual but rather the result of the way society deals with impairment, a characteristic of human diversity. The human rights model goes further to uphold the inherent dignity within human diversity, including all people with disability.

The International Classification of Functioning, Disability and Health (ICF) was developed by the World Health Organization (WHO) and provides a standardised way to measure disability. The ICF conceptualises functioning as a dynamic interaction between a person’s health condition, environmental factors and personal factors. Disability is an umbrella term for impairments, activity limitations and participation restrictions.

Figure 1 International Classification of Functioning, Disability and Health

Source: WHO, 2001



Talking about Disability

There is a variety of language to learn when talking about disability. Language changes quickly as our society evolves. Using inclusive language helps create a safe space for staff and consumers. Some general tips for using inclusive language are:

| | |
|--|---|
| Avoid assumptions | <p>Assumptions can make people feel that it is not okay to express themselves.</p> <p>Remember that not everyone belongs to the same group, uses the same terms, has the same beliefs, and expresses themselves the same way.</p> |
| Respect people's experiences | <p>People with disability are the experts in their experience.</p> |
| Person-first/ Identity-first language | <p>Some people with disability prefer person-first language. This emphasises the right to an identity outside of disability. For example, 'Person with disability' vs 'Sam is disabled'.</p> <p>Some people with disability prefer identity-first language, which puts a person's disability identity first. This recognises disability as a key part of identity, and not separate from the person. This may also be preferred because some conditions may not be recognised as a disability by the people experiencing them. Some conditions may be considered to be a culture. For example, 'Deaf person'. This language is common in the Deaf and Autistic communities.</p> <p>It is important to use the language that a person prefers. If you are not sure what a person prefers, use person-first language until you are sure, or ask someone what they prefer.</p> |
| Use appropriate terminology | <p>See the glossary included on page 16 of this toolkit.</p> |

Disability in Australia

Who has disability?

5.5 million

or about 21.4% of Australian's have disability



Disability increases with age

~3 million

people provide unpaid care for an older person or person with disability in Australia. About one third of these are primary carers.

People with disability are more likely to experience sexual and family violence. They may have more difficulty accessing public transport and have a harder time accessing affordable housing.

People in other typically marginalised groups experience more disability. This could be Aboriginal and Torres Strait Islander peoples and people from the LGBTQIA+ community. When groups overlap like this, it is called intersectionality.

Disability and healthcare

The CRPD recognises that people with disability have the right to 'the enjoyment of the highest attainable standard of health without discrimination on the basis of disability' (United Nations, 2006). Everybody in Australia has the right to access general healthcare including health screening, vaccinations, and family planning.

Overall, people with disability have a higher prevalence of health conditions and are more likely to rate their health as fair or poor compared to the general population. Despite this, they experience more barriers when trying to access healthcare than people without disability.

These barriers can include:

- Buildings and facilities that aren't accessible
- Discrimination from staff
- Information that isn't accessible

Disability specific services

Other public schemes to support people with disability with their healthcare include:

- **The National Disability Insurance Scheme (NDIS):** The NDIS provides funding to people with disability under 65 years old. It includes early intervention for young children who may need extra help in their early years. The funding aims to support people to achieve their individual goals.
- **Home Care Package:** A coordinated package of care for people over 65 years old. It includes 4 levels of funding.

These schemes need an application to become part of them. Sometimes assessments are needed to decide if someone is eligible for funding. Neither of these services include all people with disability in Australia. This means we cannot use data from these services to identify people with disability who access healthcare. The purpose of the DI is not to determine eligibility for these services.

Sometimes the way these services and the public healthcare system interact can be complicated. Refer to the Disability Liaison Officer service if this complication impacts a person's access to healthcare, or length of stay in hospital. Your hospital may also have a Hospital Liaison Officer who can help [Hospital discharge | NDIS](#).

Disability and the law

Australia has ratified the CRPD. This means Australia is obliged to uphold these rights. We do this through a National Disability Strategy and by making laws that protect these rights. In Australia, some of the Acts and agreements that help protect the rights of people with disability are:

- *Disability Discrimination Act 1992* (Cth)
- *Disability Act 2006* (Vic)
- *Equal Opportunity Act 2010* (Vic)
- The National Agreement on Closing the Gap

The Royal Commission into the Violence, Abuse, Neglect and Exploitation of people with Disability (Royal Commission, 2023) has made many recommendations relating to Australian law, policy and services to ensure we meet our obligations under the CRPD. It calls for development and enactment of

the Disability Rights Act, and a review of the National Disability Strategy. The Royal Commission also makes specific recommendations to strengthen healthcare access and navigation, provision of adjustments in healthcare and data collection for people with disability.

In Victoria, the State Disability Plan also helps guide Victorian services on how to be inclusive and uphold the rights of people with disability.

The *Disability Act 2006* (Vic) requires all government services to make a Disability Action Plan to help put into action how each service can be more accessible and inclusive. This includes all public hospitals. Familiarise yourself with your own health service's Disability Action Plan.

The DI initiative is in line with the National, State and hospital disability plans. Figure 2 illustrates the disability policy and legislative landscape for Victorian Health Services.

Figure 2 Disability policy and legislative landscape for Victorian Health Services

| | | | |
|----------------------|--|--|---|
| International | United Nations Convention on the Rights of Persons with Disabilities ↗ | | |
| National | Australia's disability strategy (2021–2031) ↗ | Australian Charter on Healthcare Rights ↗ | Disability Discrimination Act 1992 (Cth) ↗ |
| | The National Safety and Quality Health Service (NSQHS) Standards ↗ | National Roadmap for Improving the Health of People with Intellectual Disability ↗ | Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability ↗ |
| Victorian | Disability Act 2006 (Vic) ↗ | Equal Opportunity Act 2010 (Vic) ↗ | Charter of Human Rights and Responsibilities Act 2006 (Vic) ↗ |
| | Inclusive Victoria: state disability plan (2022–2026) ↗ | | |
| Local | Disability action plans | | |

Identifying Disability in healthcare

Why identify disability?

To begin to address inequitable health outcomes and the barriers that patients with disability experience accessing healthcare, it is critical that we are routinely identifying patients with a disability in admission processes. Collection of this information will help services learn more about how to meet the needs of people with disability in healthcare service delivery.

The CRPD and the Royal Commission (2023) stipulate that we should collect these data.

The DI has been co-designed with people with disability, clinicians and technical experts in disability, disability data and health information systems. It is a way for people with disability to tell healthcare staff what they need.

The DI was designed to enable:

- Improved identification of patients with a disability, via patient self-report.
- Quick access/display of disability information relevant to the delivery of inpatient and outpatient care, via a patient's electronic medical record.
- Timely referral and provision of adjustments to healthcare delivery
- Improved collection of patient data about disability to inform care delivery and for reporting and service planning purposes.

What are the DI Questions?

The DI Questions allow people with disability or their carer to self-report their disability status.

They are 3 questions that ask if a person has difficulty with activities of daily living related to a long-term health condition, impairment or disability. There is an option to ask for adjustments or additional assistance (Refer to Appendix 1).

Once someone has completed the questions, the information should be 'flagged' and visible on a patient's record. This will allow clinicians to see how they can best care for that patient (refer to Appendix 2). This visibility will also decrease duplication of patients answering the same questions in the future.

Who to ask?



All patients accessing our health services should be given the opportunity to answer the DI questions. Most disabilities are not visible, so it is critical that we do not make assumptions. The DI questions have not been evaluated for use in children under the age of 2 years old, therefore further research is recommended before implementation of the DI in this age group.

How to Ask?

The DI is conceptually based on the International Classification of Functioning (ICF). It also aligns with other international and nationally used tools. It's important to use the specific language provided. Appendix 1 includes the full DI Question set along with a preamble to the DI questions.

The DI does not directly ask 'Do you have a disability?'. This is because some people do not identify with the term, or see their condition as a disability, like the Deaf community.

The questions are designed to allow patient (or carer) self-report. This means healthcare staff cannot make assumptions or complete the DI without the person or their carer. This is the best way to make sure our consumer's voices are heard.

It's important to ask the questions in the person's preferred communication style. This might mean using an Auslan or other language interpreter or a communication device. Don't assume the person does not have capacity to answer for themselves. Always ask the person before deferring to a parent or carer.

It is a good idea to ask the questions in a private setting, so the patient or carer feels safe to share. Information collected will be visible to any EMR user. Make sure to only add information that a person willingly shares and consents to being in their record.

When to ask?

The best time to complete the DI with a patient or their carer is before they come to a health service or early in an appointment or admission. Collecting this information early can better inform the care we provide our patients.

The disability identification questions are designed so they can be updated over time. This is because disability and function are not static – they change over a person’s lifetime, and a person’s needs may change too. If you aren’t sure whether to re-ask the questions, think about the following:

- How much time has passed since last answering the questions?
- Has the person had a significant change in their life?
- Has the person’s condition changed or progressed?
- Has the person had a change in their function?

In general, 6 months or more is a good guide for when to re-ask. Incorporating a timestamp to show when the DI was completed will help to determine when to re-ask.

Who should complete the DI?

Remember, disability is everyone’s business. All clinicians should be able to ask the disability identification questions, and to respond to a patient’s needs.

The DI is more likely to be completed when it is:

- Integrated as a standard part of an admission process
- Able to be updated or completed in a subsequent healthcare encounter
- Available for patient self-completion via a patient portal.

Clear guidance on by who, when and how to ask or complete the questions will build confidence in clinicians and healthcare staff to engage with the DI process. Table 1 below provides a summary and can be customised to your specific health service (see example in Appendix 2).

Table 1 DI Implementation Summary (Who, When, How)

| Who? | When? | How?* |
|--|--|-------------------------------------|
| Clinicians and healthcare staff asking the DI questions (Nursing, Allied Health and Medical staff) | <ul style="list-style-type: none"> ● New patient registration ● Scheduling ● Early in an admission/appointment ● At a review or follow up encounter if there has been a change or more than 6 months have passed | Using EMR Integrated Standard Forms |
| Patients and carers self-completion | Any time, as often as needed | EMR integrated Patient Portal |

*When asking the questions, use the language outlined in this toolkit, ask in a private setting and use the patient’s or carer’s preferred communication method.

What happens after the DI is completed?

Once the disability identifier is filled out, it should be prominently visible or 'flagged' in a patient's EMR. For example, located at the top or in the sidebar of the patient's EMR landing page. This could be in the same location as other demographic information (age, gender and primary language). Appendix 2 shows what this may look like on a patient's medical record.

It is everyone's responsibility to check for the DI information captured and to accommodate a person's individual needs. This is referred to as providing adjustments and is one way to uphold the rights of people with disability. Providing adjustments for people with disability is a requirement under the Commonwealth Disability Discrimination Act 1992.

Sometimes people may identify some complex needs. If these are more than a single clinician, ward or clinic could generally manage, you can consider a referral to a service that might be able to help meet that person's needs.

Health services should have a referral guide to help clinicians consider who may be able to help meet a person's needs. For example, if a patient indicates they need an adjustment or additional assistance, there may be a prompt to consider a referral to the Disability Liaison Officer where appropriate.

Health services can also generate reports about the data collected for quality improvement, monitoring patient outcomes for patients with disability and meeting government reporting requirements. For example:

- Which patients currently admitted or scheduled for an upcoming appointment or admission have indicated they have a disability and require adjustment/s or assistance for healthcare access?
- What proportion of patients completing the DI are responding 'yes' to the primary disability identification question (disability prevalence).
- What proportion of patients are indicating a need for adjustments or additional assistance?

Speak to your EMR or health information team about possible reports that you can create from the DI data collected.

What are healthcare adjustments?

'Reasonable accommodation' means "providing necessary and appropriate modifications and adjustments, which do not impose a disproportionate or undue burden, where needed in a particular case"

(UN CRPD, n.d.)

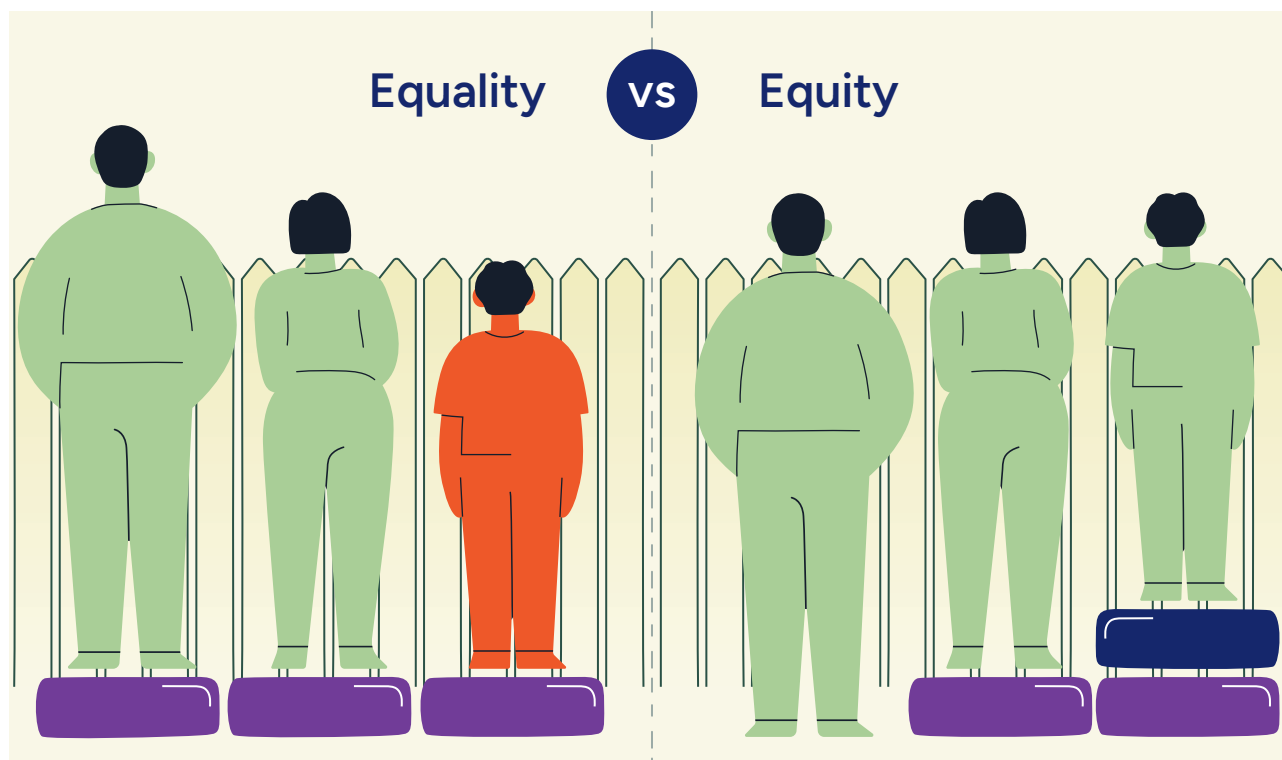
This concept originates from the CRPD, to which Australia is a signatory. As part of this commitment, Australia is obligated to make reasonable accommodations, which have been integrated into national legislation and policy under the term 'reasonable adjustments'. For the purposes of the DI Implementation Guidelines, we refer to these simply as 'adjustments'.

As healthcare service providers, it is our responsibility to make adjustments to ensure that all individuals, including people with disability, can access the healthcare they need. Making these adjustments is a fundamental part of our role as healthcare workers and a crucial way we uphold the human rights of people with disability. These adjustments might involve taking specific actions to overcome barriers that people with disability face when accessing our services. Any healthcare provider caring for a patient with a disability must incorporate these adjustments into their care delivery.

By making healthcare adjustments, we also ensure that we do not discriminate against people with disability, which is essential for meeting our obligations under Australia's anti-discrimination legislation. The Disability Royal Commission has recommended that the requirement to provide adjustments be explicitly recognised in Australian law as a standalone duty.

Adjustments should be anticipatory. This means healthcare staff should plan ahead to make sure barriers are removed before a person attends a service. It is clinicians' responsibility to read the information in the DI once available within a patient's electronic medical record. This will help you to know what adjustments a person might need ahead of time.

Figure 3 Equality vs Equity



Looking at the figure above, adjustments help move our health services from providing a one-size-fits-all approach, to services with equity and inclusion for people with disability. As we learn more about barriers to accessing healthcare through collecting good quality data in partnership with people with disability, we can work towards a fully inclusive health service.

People with disability may need adjustments with:

- the environment
- administrative tasks
- communication

Some examples of health care adjustments might be:

- Making sure you have the right equipment, like a hi-lo bed or a hoist
- Swapping to a room big enough for mobility aids
- Making longer appointments so you can communicate more slowly, or with an interpreter or carer
- Making flexible appointments to suit someone's daily routine

- Having a quiet waiting space available
- Providing information or forms in different ways, like written, oral or digital, or in 'Easy English'
- Including a person's carer or support worker as an expert care partner
- Holding multi-disciplinary team (MDT) meetings early in a person's care to make sure care is coordinated
- Co-ordinating appointments on the same day or grouping together procedures if sedation is required to reduce the number of hospital visits

Some people completing the disability identification questions might not know about possible healthcare adjustments. This could be because of past experiences in healthcare, or because someone might be new to learning about their disability, long term health condition or impairment. If you are helping someone fill out the questions, and they answer yes to the primary disability identification question (Appendix 1), they may need some help to understand what assistance could be available.

Clinical example 1

Sarah is a wheelchair user and regularly attends hospital for outpatient appointments, including scans and small procedures. Sarah has completed the DI, and noted that she needs space for her wheelchair, and access to a hi-lo bed for examinations so she can transfer herself.

When Sarah is booked for her next outpatient appointment, the staff making the booking see Sarah's DI flag, and make sure to book her in a wheelchair-accessible room. They check there is a hi-lo bed. There is no hi-lo bed in the clinic usually, so they arrange one ahead of time.

Clinical example 2

John has an intellectual disability and prefers to come to his hospital appointments with his carer. This helps John feel confident he has understood all the medical information and instructions, because his carer can help to write things down for him and talk about things with him later on. John also likes it when healthcare staff speak slowly and use pictures to help explain things. He likes to ask questions to make sure he understands, so John prefers longer appointment times.

Before booking John's appointment, staff read John's DI information flagged in his medical record. They call to talk about what time of day is good for

an appointment. John is able to choose a time that his carer is available. The staff member books a longer appointment time and offers to phone John two days before to remind him.

During the appointment, John's clinician talks directly to him, speaking slowly and using pictures. The clinician writes down information that will be helpful to remember. The clinician gives John and his carer time to ask all of their questions.

John leaves the appointment feeling he has been heard, and confident he can manage the directions from his clinician.

Clinical example 3

Michael attends the hospital regularly for treatment with his mum Lucy. He has sensory processing difficulties and Lucy has filled out the disability identification questions on his behalf. Lucy noted that the hospital environment is overwhelming for Michael and he requires a quiet space to wait for his appointments, or he can become agitated and distressed. This has previously resulted in a 'Code Grey' response being called, further contributing towards Michael's anxiety coming to hospital.

After reading Michael's DI information, when booking Michael's appointment, his team make sure to co-ordinate with other appointments he has that week, so he only has to come to hospital once. This also helps Michael and Lucy plan for his day.

When he arrives at hospital, the reception staff make Lucy aware of a quiet space they can wait in, and Lucy receives a text when it is time for Michael's treatment. When they can, the reception team bring Michael's appointment forward so he does not have to wait long. Although this is not usual practice, this is an achievable and important adjustment to ensure Michael can access his healthcare while reducing the risk of an adverse experience. It helps Michael feel comfortable at the hospital and increases the chances he will continue to come for his essential treatments.

The treating team also let Michael and Lucy know about other spaces in the hospital that may be useful, like the family space or quiet meditation space.

[Safety and Quality Victoria](#) has some more information on adjustments for people with an Intellectual Disability.

Want to know more?

| | | |
|-------------------------------|---|---|
| Hospital Resources | Disability Liaison Officer program – Better Health Channel ↗ | Information about the Victorian Disability Liaison Officer program |
| General Resources | The Disability Gateway ↗ | Information and services for people with disability to find the support they need |
| | Safety and Quality Standards for people with Intellectual Disability ↗ | Information about how to implement the Standards to support healthcare right for people with intellectual disability |
| | Expression Australia ↗ | Examples of deaf people’s experiences in hospital |
| | Deaf Victoria ↗ | Includes some resources for working with the Deaf community |
| | Carer Gateway ↗ | A resource for carers of people with disability |
| | Amaze ↗ | Includes resources to help create an Autism Inclusive Australia |
| | Summer Foundation ↗ | Information on supporting young people in aged care |
| | Australian Bureau of Statistics ↗ | Current statistics about disability in Australia |
| | The National Disability Insurance Scheme (NDIS) ↗ | What is the NDIS? |
| | Home Care Packages ↗ | What are Home Care Packages? |
| Education and Training | Just Include Me – Inclusive Health Care eLearning – Council for Intellectual Disability (cid.org.au) ↗ | A free online self-paced training for health professionals that aims to shine a light on person-centered care and support health professionals to learn more about resources, tools, and actions to promote inclusion in health care for people with intellectual disability. |
| | Hospital Inclusion for people with Intellectual Disability ↗ | Short education on hospital journeys for people with disability. You can follow the pathway for hospital staff, disability support workers, or families. |

Frequently Asked Questions (FAQs)

Will I offend someone?

If you ask the questions respectfully, and without making assumptions, you should not offend anyone. Asking about disability in the right way helps make people more comfortable to share information. In research that we have conducted on patient and carer experiences completing the DI, participants indicated strong acceptability (including how comfortable they felt) answering the questions.

Let the patient know that just like other information in their medical record, this information is confidential. If someone chooses not to share information, that is okay too.

Use the preamble provided with the DI (see Appendix 1) to help the patient or carer understand why the questions are being asked and how the information will be used.

How much time and effort will it take?

The DI takes a few minutes to fill out. This should save time throughout an admission or encounter and in future encounters.

Taking the time to ask the questions and document the information will help to prepare clinicians for more patient centered care delivery.

What if I don't know what to do with the information?

Utilise this toolkit as a resource to guide appropriate responses to identified patient needs. There are also some resource links provided on page 14 that will help you know what to do with the information. If you are still unsure, try speaking with your hospital's Disability Liaison Officer.

Can I use this tool as an assessment or triage tool?

No, this is not a clinical assessment or triage tool and should not replace other processes for determining treatment or clinical care.

This is a patient self-report tool, much like collecting other demographic information.

There may be situations where you suspect a person has a disability but the patient answers no or declines to answer the questions. As a patient self-reporting tool, it is important to affirm a patient's responses to the DI and only document what the patient (or their carer where appropriate) reports.

How long is 'long-term'?

Long term is anything lasting or expected to last longer than 6 months. This is aligned with other disability identification approaches in Australia, including the national Survey on Disability, Aging and Carers (SDAC).

What if my service can't make a requested healthcare adjustment?

If identified adjustments cannot be met because the resources aren't available, please let the consumer know, and encourage discussions with the Consumer Liaison team or equivalent.

Always consider a referral to a team that may be able to help or consult, like the Disability Liaison Officer service.

Remember it is our responsibility under law as healthcare workers to make adjustments to ensure the care that we provide is inclusive and equitable.

Ensure that patients, carers and clinicians understand the purpose of the DI. The DI questions are not a way to directly increase or determine eligibility for services (e.g. NDIS, complex care coordination or specialist healthcare services). We also cannot guarantee that we can accommodate all requests for assistance.

The preamble included in the DI will help to guide patient and carer expectations (Appendix 1).

Could the DI lead to more stigma for people with disability?

The DI and information provided should enhance respectful care for people with disability, when used as guided. In fact, research that we conducted found that patients and carers felt that the DI questions and process contributed to raising awareness about disability within healthcare settings, promoting inclusion and accessibility.

Please use this toolkit as a resource to increase awareness about the DI, the rights of patients with disability and the obligations of healthcare providers.

Glossary

Ableism

Ableism is discrimination or prejudice against people with disability. Ableism can be built into the systems we use, or it can be present in interactions between people.

Some examples of ableism are:

- Assuming a person with disability has less value in society
- Assuming a person with disability leads an unhappy life
- Actively excluding someone with disability from an event

Accessibility

If something is accessible, it is usable and meaningful to as many people as possible.

Victoria adopts the principle of Universal Design in all public buildings and spaces. This means designing spaces and services that are accessible to as many people as possible and is inclusive of age, gender, ability and any other social characteristics.

Some examples of things that may make our hospital environment less accessible are:

- Stairs
- Narrow doorways
- Small text fonts
- Complex language
- Not using interpreters
- Discriminatory staff

Disability

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

(CRPD, 2006)

When talking about disability, avoid using euphemisms unless that is a person’s preference. Some examples of euphemisms are ‘diffability’ and ‘differently abled’.

Remember not to use a person’s disability to position them as a ‘hero’ or ‘victim’.

Use person first language in the first instance (i.e. Person with disability) unless the person or group preferences identity first language (i.e. Disabled Person).

Some ways to talk about disability, and some things to avoid:

| Don't Use | Use this instead |
|---|---|
| Disabled bathroom | Accessible bathroom |
| Wheelchair bound | – Person who uses a wheelchair – Wheelchair user |
| Suffers from/afflicted by | ‘... has a chronic health condition’ |
| Intellectually challenged/mentally disabled | ‘...has an intellectual/cognitive disability’ |

Intersectionality

Intersectionality recognises that systems and structures can lead to overlapping forms of discrimination.

In the same way that people with disability experience more barriers to participating in everyday life, so do some other groups. For example, Aboriginal and Torres Strait islander peoples, and the LGBTIQIA+ community. We also know that women with disabilities experience higher rates of intimate partner or family violence compared to women without disabilities. It is important to recognise how these groups intersect, and how barriers can be compounded.

For more information on supporting Aboriginal and Torres Strait Islander peoples at your hospital, speak with your Aboriginal Liaison Officer. Speak to your hospital's Social Work team for support and assistance in relation to gender based violence.

The Royal Commission into the Violence, Abuse, Neglect and Exploitation (2023) considers intersectionality throughout its report, and this is a good way to learn more.

Lived Experience

A person with Lived Experience is someone who has personal experience as a person with disability, or a person caring for someone with disability. People with Lived Experience offer a unique and important perspective on healthcare and access for people with disability.

Representation

Representation is the idea that we should represent all people in society in our workplaces, systems, and media. This is important to make sure everybody's voice is heard and is the best way to make sure we build a society that is accessible for everyone.

Symbols

There are many symbols used to represent the disability community, or to denote a space that is accessible. Not all of the symbols are universally recognised or endorsed. None of the symbols represent all people with disability. Some of the symbols that you may see are summarised below.



International Symbol of Access (ISA)

The International Symbol of access was developed in 1968 following a competition by the organisation now known as Rehabilitation International. It was designed to be simple, practical, and easily identified from a distance and is endorsed by the International Organisation of Standardisation (Lazarte, 2013). While this symbol is widely recognised, it has been criticised for not being inclusive of non-visible disabilities and contributing to misunderstandings of accessibility and disability.

In Australia, this symbol is used to indicate spaces that are accessible (e.g. toilets, pathways, doorways) or to indicate that a space is reserved for a person with disability (e.g. parking space, seats on public transport).



Modified Symbol of Access

The Modified Symbol of Access is the result of a design activism project that aimed to increase conversations about disability in public spaces (Accessible Icon, n.d.). It denotes a wheelchair user with more human like features, who is actively and independently moving their wheelchair. The aim is to symbolise that people with disability are not passive in their lives.

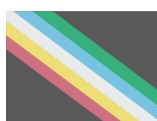
This symbol is in use regularly in certain states in the USA but has not been endorsed by the International Organisation of Standardisation. It has received praise for including a more positive representation of people with disability. It has been criticised for not representing all people with disability

**Symbols
(continued)****Web Accessibility Icon**

While the history of this symbol is difficult to clarify, it appears it was created by Apple, and designed to indicate ease of access for web pages and other hardware and software. It was initially called the Universal Access logo and has been since adopted by many companies (such as Monsido, UserWay and AccessiBe) selling accessibility widget's that can be used on any webpage to add or build accessible options. This has become increasingly used and recognisable across the web. The symbol developed by the UN department of Public Information in New York uses a similar icon of a person connected with a circle.

**Disability Flag**

This flag was designed in 2017 to represent all people with disability. It has been presented to the United Nations and has been used on the International day of People with Disability.

**Disability Pride Flag**

This flag was designed in 2019 by disabled woman Ann McGill. It represents the Disability Pride movement. It was initially created with a 'lightning bolt' design, but was updated in 2021 to be visually safe. This flag is in the public domain.

**Hidden Sunflower**

This Hidden Sunflower symbol represents invisible disabilities (HD Sunflower, 2023). It was launched in 2016 and is used in many public spaces for people to voluntarily identify that they have a hidden disability. A person with a hidden disability could choose to wear a lanyard with a sunflower or present a card with a sunflower. It is a way for that person to discreetly indicate that they may have additional needs, like requiring more time or space. The sunflower was chosen as it represents happiness and strength.

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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.

Preamble to the
DI Questions

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

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

Primary Disability
Identification
question

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

Areas of
difficulty

- Mood, managing emotions, socialising or managing behaviours
- Other (anything not captured above)

[Yellow text input box]

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

[Yellow text input box]

Areas of difficulty

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.

[Yellow text input box]

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

[Yellow text input box]

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

[Yellow text input box]

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

[Yellow text input box]

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

[Yellow text input box]

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

[Yellow text input box]

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

[Yellow text input box]

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

[Yellow text input box]

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

[Yellow text input box]

Need for assistance

Appendix 2: The DI at your health service

Instructions

The below is an example resource and should be used for reference only.

To customise this resource for your health service:

- Download the Word document using the following link: [Accessible Care Toolkit DI at your service](#)
- Replace the *italicised example* text in the Word document with information specific to your health service's integration of the DI.

Health Services are required to have a Disability Action Plan to guide staff towards more inclusive healthcare delivery.

Our Disability Action Plan can be found here:

e.g. [The Royal Women's Hospital Disability Action Plan](#)

The DI Implementation – who, when and how?

The following table outlines who can complete the DI, along with when and how the DI should be completed at your health service:

| Who? | When? | How?* |
|--------------------------------------|--------------------------------------|-----------------------------------|
| e.g. Nursing staff on admitting ward | e.g. New patient admission – bedside | e.g. Nursing Admission Form – EMR |
| | | |
| | | |

*When asking the DI questions, use the language outlined in the DI Implementation Guidelines and ask in a private environment with the patient or carers preferred communication method.

The DI in a patients EMR

This section outlines where and how to access the DI in a patients EMR. Once completed, information collected with the DI questions should be available for all staff to see on the patient's record.

Accessing the DI for Clinicians

The following is an example from the Parkville precinct hospital's Epic EMR system.

Open the patient's record.

Nursing

- Click on the Admissions tab
- The DI questions are located within the standard nursing admission navigator and workflow

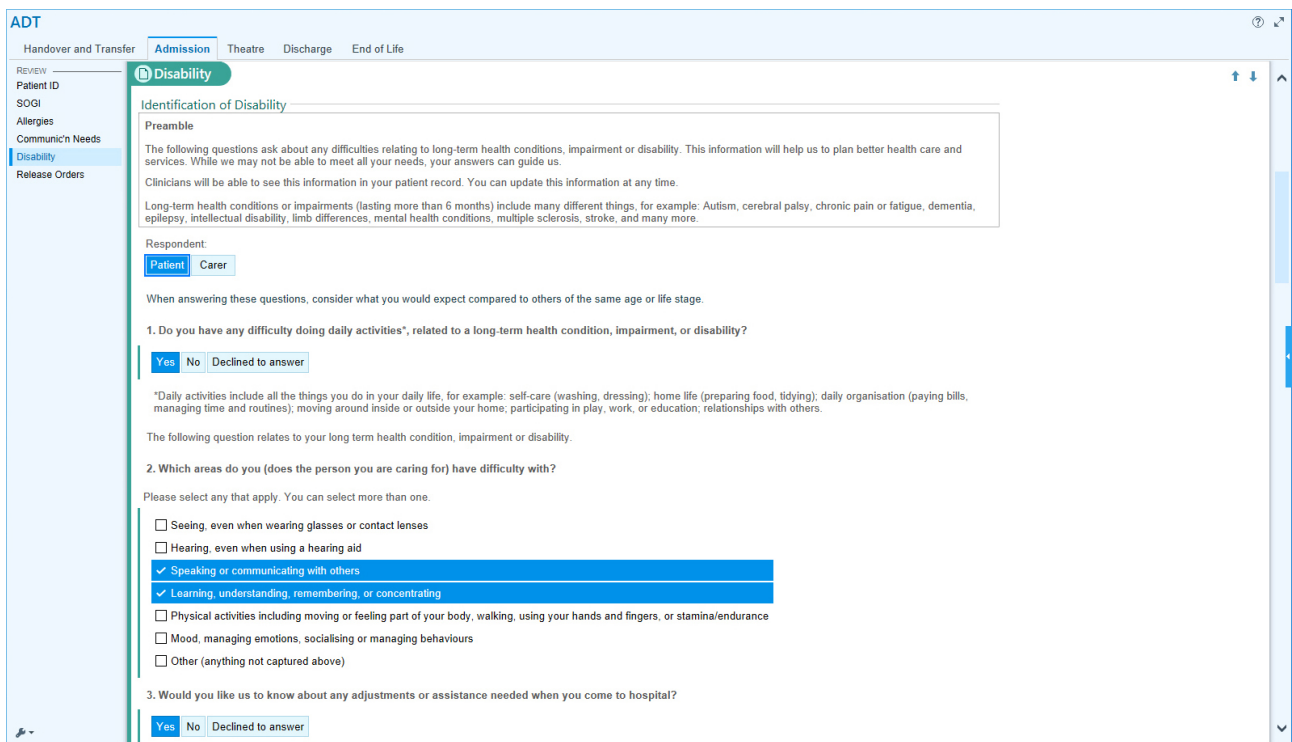


Image taken as a screen shot from Parkville EMR © 2024 Epic Systems Corporation.

The following is an example from Austin Health Cerner EMR System.

Nursing

- Open Care Compass
- Select Admission Assessment from patients activity list
- The DI questions are located within the Admission Assessment form.

General Info

Disability Identifier & DLO Referral

Advance Care Di

Allergies & Sensiti

Social History

Problem List

Communication &

Belongings

Patient Safety

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.

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

Do you/ (does the patient you are caring for) have any difficulty doing daily activities, related to a long-term health condition, impairment, or disability?

Yes No Patient/Carer declined to answer REF TEXT

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

Which areas do you/ (the patient you are caring for) have difficulty with? Please select any that apply. You can select more than one.

| | |
|--|---|
| <input type="checkbox"/> Seeing, even when wearing glasses or contact lenses | <input type="checkbox"/> Mood, managing emotions, socialising or managing behaviours |
| <input checked="" type="checkbox"/> Hearing, even when using a hearing aid | <input type="checkbox"/> Physical activities including moving or feeling part of your body, walking, using your hands and fingers |
| <input type="checkbox"/> Speaking or communicating with others | <input type="checkbox"/> Other physical activities including stamina/endurance |
| <input type="checkbox"/> Learning, understanding, remembering or concentrating | <input type="checkbox"/> Other. |

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

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

Yes - Referral to DLO 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)

Further information

Image taken as a screenshot from Austin Health © Cerner Millennium Oracle Health

Using the DI on the Patient Portal

The following is an example from the Parkville precinct hospital's Epic MyChart® patient portal.

The DI questions sit in the Questionnaires section and are always available for every patient.

Responses completed in the Patient Portal are immediately visible in the EMR for staff to see. They do not require a clinician to validate the responses.

If you are helping a patient find the DI on the Patient Portal:

- 1 Login to the app
- 2 Find the 'Menu'
- 3 Scroll to 'Questionnaires'
- 4 Open the 'Identification of Disability' tab

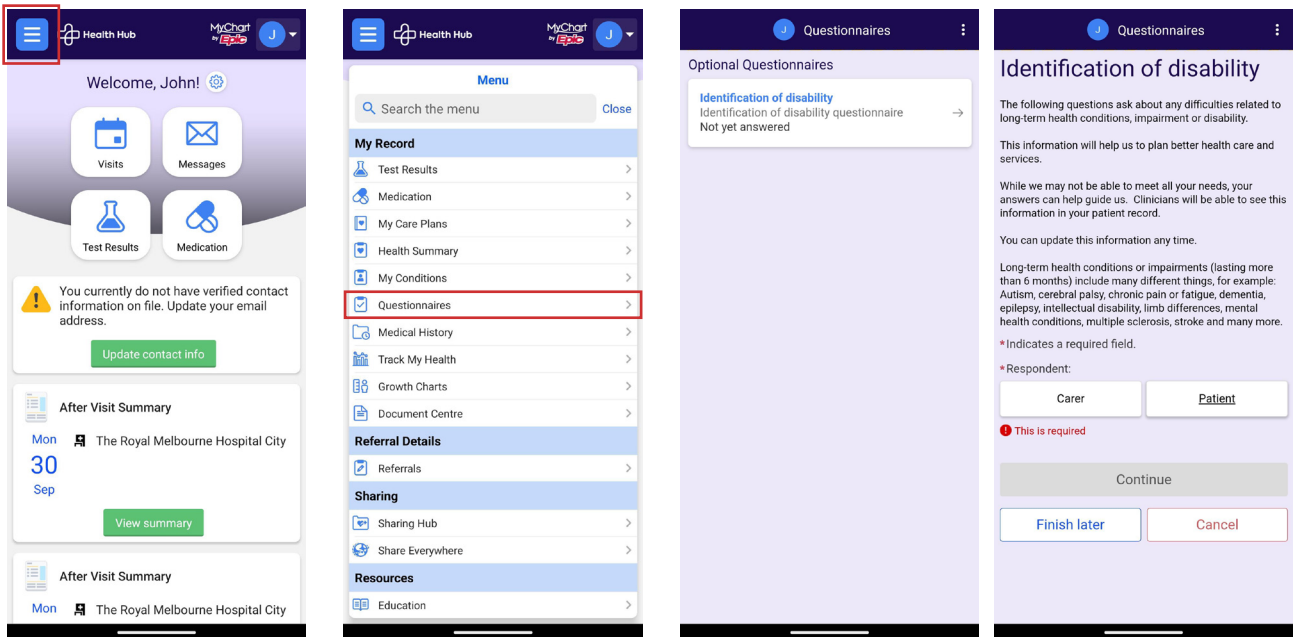


Image taken as a screenshot from MyChart®, a registered trademark of Epic Systems Corporation.

Viewing the DI information once collected

Information collected from the DI should be clearly displayed or 'flagged' in the patient's medical record (for example at the top or in the sidebar of the landing page). This could be in the same location as other demographic information (age, gender and primary language).

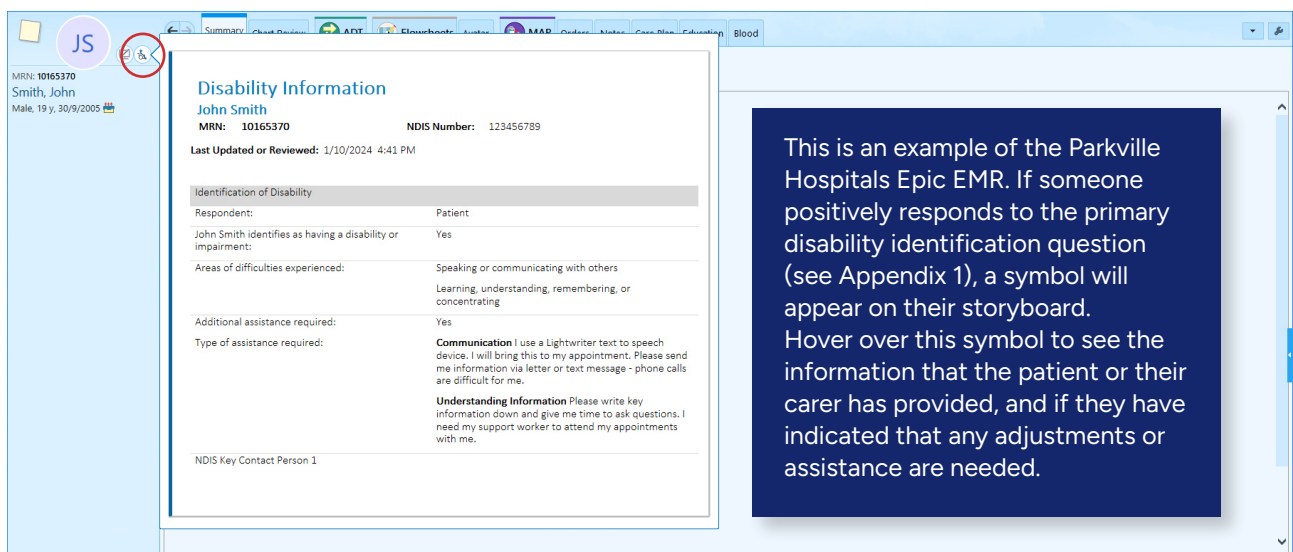


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