Developing self-report disability questions for a voluntary patient registration form for general practice in Australia

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Abstract

Objective: This article reports on research undertaken to develop self-report disability questions for a patient registration form that may be implemented in general practices across Australia as part of a voluntary patient registration program.

Methods: There were four research components: rapid review of approaches for capturing disability information; expert informant interviews (n=19); stakeholder consultation via virtual focus groups (n=65); and online survey (n=35). Findings from each component informed development of materials for subsequent components in an iterative research process.

Results: Three disability questions were developed: two alternative questions for identifying disability, conceptually aligned with the operational definition of disability in Australia's national disability survey; one question to determine the patient's disability group/s.

Conclusions: Knowledge and perspectives from a variety of sources informed the development of self-report questions to identify patients with disability. Implementing these questions represents an opportunity to test new ways of capturing disability information suited to mainstream service provision contexts. It will be essential to evaluate the quality of the data produced during the initial period of implementation.

Implications for Public Health: The collection of self-report patient disability information within general practice, using standard and conceptually-sound questions, has the potential to support improved provision of health care to patients with disability.

Keywords: disability, disability identification, administrative data, general practice, primary health care

Introduction

Population-level data are essential for understanding social, economic and health outcomes for the whole population, and for different population subgroups. Data sources that allow disaggregation by demographic characteristics (e.g. age, gender) and identification of population groups of interest (e.g. people with disability or people from different cultural backgrounds) can be used to identify inequalities and to inform policies aiming to reduce inequalities.

At a population level, people with disability experience poorer health outcomes than people without disability and encounter barriers to accessing health services.[1–7] In Australia, general practice is a critical first point of contact within the health system. Here, we use "general practice" as an encompassing term which includes Aboriginal Community Controlled Health Services. Data on access to and quality of care delivered through general practices to people with disability are limited—there is no nationally consistent primary care dataset,[8] and no national health services administrative datasets include disability identification.[9]

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Policy context and the need for improved disability data

Under the United Nations Convention on the Rights of Persons with Disabilities (CRPD), Australia is obliged to collect statistical and research data to help formulate policies, to assess implementation of the Convention and to identify and address barriers faced by people with disability in exercising their rights (Article 31).[10] The Australian Bureau of Statistics (ABS) conducts several surveys that include disability identification questions. The ABS Survey of Disability, Ageing and Carers (SDAC) is the standard for estimating disability prevalence and the richest source of national data on people with disability.[11]

Policy developments over recent years have led to growing recognition of the need to improve disability data. Australia's National Disability Insurance Scheme (NDIS) has highlighted the need for better disability identification in administrative data sources to understand interactions between the NDIS and mainstream service systems such as health and education, including patterns of service use and outcomes for people with disability.[12] The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability has brought a sharp focus to inequalities and rights violations experienced by people with disability and to shortcomings in available data.[13]

Australia's Disability Strategy 2021–2031 is the overarching framework guiding policy for people with disability.[14] It includes an outcomes framework, and a commitment to regularly report data "to ensure accountability and build the evidence base for making informed decisions." Other recent policy initiatives, such as Australia's disability employment strategy, "Employ My Ability"[15] and the National Roadmap for Improving the Health of People with Intellectual Disability,[16] also include commitments to regular data reporting from administrative data sources.

Work is underway to develop a National Disability Data Asset, comprising linked data from multiple state, territory and national administrative sources. This will greatly increase the ability to analyse data by disability status.[17] However, to provide insights into service use and outcomes for the whole population of people with disability, it will be necessary to have a robust and consistent basis for identifying individuals with disability, beyond the subset of people identified by their contact with disability-specific programs or payments. Given the central role of general practice within Australia's health system, and the high proportion of the population who access general practice services, capturing self-report disability identification in general practice administrative data could be a way to achieve this.[8]

Capturing data on people with disability accessing general practice services

Australia's Primary Health Care 10 Year Plan 2022–2032 proposes introducing a system of voluntary patient registration (VPR) for general practice, including Aboriginal Community Controlled Health Services. Under VPR, "eligible people who have an ongoing relationship with their participating general practice will be eligible to register with the practice and nominate their usual GP."[18(p.14)] The intention of VPR is to help strengthen the relationship between a patient and their general practitioner (GP), support continuity of care, and assist general practices to improve how they meet the health needs of their registered patient population. In future, it is envisaged that "payments linked to VPR will be incentivising quality primary health care, including preventive care, and better health outcomes".[18(p.33)] VPR will provide an important opportunity to improve data on the quality of care delivered to diverse population groups, including people with disability.

The Australian Government Department of Health (DoH) commissioned research to develop questions for use on the proposed VPR patient registration form to identify patients with disability. The disability question/s would be optional—that is, a person may register for VPR but choose not to complete the disability question/s.

The purpose of the research reported in this paper was to develop self-report disability questions suitable for use on the VPR form. We describe the research undertaken and how the findings informed development of a set of disability questions presented to DoH for possible use on the VPR form.

Methods

Research design

The research was conducted within a restricted timeframe (July to November 2021) to meet a specific policy need. We adopted a rapid qualitative approach to optimise the gathering and synthesising of relevant information and knowledge within the time available.[19,20] The research design comprised four components: rapid review of approaches for capturing disability information; expert informant interviews; virtual focus groups; and online survey. Below, we describe the methods and key findings from each of these components. Findings from each component informed the development of materials for subsequent components and together informed development of the disability questions for possible use on the VPR form.

The research team comprised: five academics with (collectively) research expertise in disability, primary health care, disability data development, health classifications and statistical data, and qualitative approaches; two research assistants with lived experience of disability and disability research and advocacy expertise.

The conceptual approach was guided by two key international instruments: the International Classification of Functioning, Disability and Health (ICF) and the CRPD. The ICF provides a common language and conceptual basis for the description and measurement of disability, and conceptualises a person's level of functioning as a dynamic interaction between their health conditions, environmental and personal factors.[21,22]

The project team and DoH agreed that it would be desirable for disability questions used in the VPR form to align conceptually with approaches used to identify disability in key Australian population data sources, particularly the SDAC, Australia's national disability survey. This would enable aggregate VPR disability data to be related to population data to inform policy (e.g. for program targeting and evaluation).

Ethical approval for the focus groups and online survey was obtained from the University of Sydney Human Research Ethics Committee (project number 2021/526).

Rapid review

The purpose of the rapid review was to understand how self-report disability information is currently captured in Australian data sources and to identify approaches used in Australia or other countries that could potentially inform development of self-report disability questions for use in the VPR context. The review was conducted over 3 weeks in July and August 2021. It comprised a targeted literature review focusing on questions used to identify people with disability in administrative data and a search of statistical agency websites in Australia and similar countries for information on self-report disability questions in national surveys and administrative data collections. Detailed methods of the rapid review are reported in Supplementary File 1.

Key findings from the rapid review

In Australia, several approaches for capturing self-report disability information in surveys or administrative data collections were identified (Table 1). All identify disability based on restrictions (or difficulty participating) in daily activities associated with a long-term health condition. The three approaches used in national surveys ask about daily activity restrictions in relation to a list of 17 conditions, impairments and activity limitations.[11,23,24] Respondents' answers to survey questions about particular impairments, activity limitations and health conditions are used to determine their membership of six "disability groups"[4]: sensory; intellectual; physical; psychosocial; head injury, stroke or acquired brain injury; other.

The Standardised Disability Flag[25] and the question developed for use in a public sector employee data collection[26] use a list of life areas aligned with ICF Activities and Participation domains. The Short Disability Flag[27] and Australian Census module[28] ask only about limitations with self-care, mobility or communication; these approaches align with the narrower concept of "severe or profound core activity limitation" used in the SDAC.[11]

Internationally, varied approaches are used for identifying disability in surveys and censuses. For example, the dominant approaches used in Canada, New Zealand, and the USA are based on asking respondents whether they have difficulties in relation to a short list of activities (e.g. hearing; seeing; remembering, concentrating or making decisions; walking or climbing stairs; dressing or bathing; doing errands alone). A set of questions for documenting disability status in electronic health records has been piloted in the USA—six questions about difficulty with selected activities and one asking about need for assistance or accommodations when accessing health care.[29] No other questions for use in administrative data collections were found.

Australian research analysing data on support needs of people accessing disability services found that needs in one subset of ICF Activities and Participation domains could not be used to predict values in another subset.[30] Thus, questions based on lists of selected life domains are likely to under-identify disability.[30,31] For this reason, the research team decided that approaches based on asking about difficulties or restrictions in relation to a short list of activities not spanning all ICF Activities and Participation domains would not be considered further in developing disability identification questions for the VPR form.

Expert informant interviews

During August to October 2021, following the rapid review, a direct approach was used to seek input from relevant experts identified through the professional networks of members of the research team. Input was provided in the context of discussion between the experts and members of the research team (NF and GL), via phone, videoconference or e-mail. Expert informants were provided with background information about VPR and the purpose of the research. Questions were targeted to the informants' areas of expertise.

Table 1: Australian approaches for capturing self-report disability information, as identified in rapid review, 2021.

Administrative data collections	
Standardised Disability Flag[25] Comprises: • activity and participation need for assistance cluster; • education participation restriction flag; • employment participation restriction flag.	Developed for capturing service user disability information in administrative data collections. The activity and participation need for assistance cluster asks "For each of the following activities, do you need help/supervision, have difficulty, or use aids/equipment or medications?"; there are four response options for each of eight activity areas aligned with International Classification of Functioning, Disability and Health (ICF) Activities and Participation domains. Lead-in to question refers to "a long-term health condition or disability that restricts your everyday activities." The education and employment participation restriction flags ask about whether a long-term health condition or disability affects participation in education or work (respectively).
Short Disability Flag[27]	A shortened version of the activity and participation need for assistance cluster component of the Standardised Disability Flag has been used since 2013 in the Specialist Homelessness Services Collection for informing assessment of clients' needs. Presented as a matrix, with four response options for each of three activity areas listed (self-care, mobility and communication).
Disability question developed for use in public sector employee data collection[26]	Single question recently developed for use in a survey of public sector employees (not yet implemented). It asks about "difficulty participating" in any of nine life areas aligned with ICF Activities and Participation domains. Development was informed by focus group consultations and piloting.
National population surveys and the Australian Census	
The Australian Bureau of Statistics Survey of Disability, Ageing and Carers (SDAC)[11]	Australia's national disability survey and "gold standard" for disability prevalence estimation. The operational definition of disability in SDAC is "any limitation, restriction or impairment which restricts everyday activities and has lasted, or is likely to last, for at least six months." Disability status is determined based on responses to numerous questions about restrictions in daily activities associated with 17 conditions, impairments and activity limitations.
ABS "Short Disability Module" used in national household surveys[23]	Identifies disability in a way consistent with the SDAC approach, based on the list of 17 conditions, impairments and activity limitations used in SDAC; the module comprises 16 questions. Used in multiple population surveys.
Australian Census module on "Core Activity Need for Assistance"[28]	Four-question module that identifies people who need help or supervision with self-care, mobility or communication, because of a long-term health condition or disability lasting six months or more. This is equivalent to people identified as having "severe or profound core activity limitation" in SDAC.
The Household, Income and Labour Dynamics in Australia Survey disability question[24]	Single question asking about any long-term health condition, impairment or disability that restricts everyday activities, with reference to a showcard displaying the list of 17 conditions, impairments and activity limitations used in SDAC.

Detailed notes were taken, then summarised and provided to key informants for correction and approval. The research team used the summaries to inform subsequent stages of the project. The summaries were coded using the coding structure developed for the focus group data (below), and input from these two project components was considered together in developing the proposed disability questions and advice for implementation.

Key messages from expert informants

Input was received from 19 individuals, including data experts, academics whose work focuses on people with disability, clinicians with expertise in disability, and disability policy advocates. Key messages are presented here as dot points only, due to space constraints.

- The questions should capture information that is relevant to the person and the GP practice and can support the provision of better health services.
- The questions should be designed to serve the purpose/s for which the data are being captured and to produce the output data required.
- Design of disability question/s requires first being clear about what population of people with disability the questions should capture, for example, is it all people with disability (as identified in the national disability survey), or people with disability who experience barriers to accessing health care?
- The purpose/s for which the data are needed should guide choice of appropriate concepts to underpin the disability question/s.[32] For example, is it more relevant to ask about “difficulty” the person experiences or “need for support”? Whichever concept is selected, the relevant threshold for identifying a person as having disability must be determined.
- It should be possible to relate the disability data captured in the VPR form to other important datasets, including the national disability survey, to better understand service use pathways and outcomes for people with disability.
- Simple questions are more effective; long questions should be broken into parts. The lead-in to a question should not include multiple components, as respondents typically focus their attention on the last part of the lead-in. Plain English expression is important.
- Lists exceeding 8 to 10 categories (e.g. for life areas or disability groups) should be avoided; people will not read all the categories in a long list.
- The question “Do you have a disability” captures how a person identifies and would not be appropriate if the purpose is to understand the person’s functioning and related needs.
- There should be careful consideration of wording. Use of language in a way that labels a person with disability (e.g. “deaf,” “autistic”) can be particularly problematic within First Nations communities, as such language can convey a negative message.

Focus groups

Virtual focus groups followed the expert informant input and were held in September and October 2021. A purposive approach to recruitment was taken to achieve coverage across the following stakeholder groups: Disabled People's Organisations (DPOs—organisations controlled by people with disability) and Disability Representative Organisations (DROs—organisations that represent the interests of and advocate for people with disability); healthcare consumer organisations; Primary Health Networks (PHNs—independent organisations funded by the federal Government to coordinate primary health care in their region), and both clinical and non-clinical general practice staff. Contact details for organisations approached were obtained from publicly available lists.

Before each focus group, participants received background information about VPR and a list of focus group discussion points (see Supplementary File 2).The discussion points document included three lists of categories that might be used as a basis for asking about disability: health conditions, impairments and activity limitations (e.g. shortness of breath, chronic or recurring pain, hearing problems); life areas (e.g. social and community life, self-care); and disability groups (e.g. physical, intellectual). Participants were asked which of these would be best to include on the VPR form. While participants were directed to comment on existing Australian approaches for capturing self-report disability information, informed by the rapid review findings, there was opportunity to critique these approaches and to suggest and discuss alternatives. Focus groups, each lasting 1 hour, were conducted via online videoconference.[36] Each group was co-facilitated by two members of the research team, including one team member with lived experience of disability. Live captioning was provided for most focus groups. Focus groups were audio recorded with the permission of participants and written transcripts were produced. Participants were given the option for an individual interview rather than a focus group if they preferred.

Two focus groups lasting 1.5 hours were conducted to obtain input from participants with intellectual disability; Easy English versions of all consultation materials were provided. These groups, hosted by DPOs with co-facilitation by members of the research team, were not recorded.

Using the focus group discussion points as an organising framework, focus group facilitators synthesised participant input drawing on the transcript, audio recording, and notes taken during the discussion. One team member (NF) used established thematic analysis techniques[33,34] to code and analyse input from all focus groups and interviews. All team members involved in collecting focus group data participated in a series of analysis and interpretation sessions to ensure validity of the qualitative analysis.

Key findings from focus groups

Sixteen focus groups (with between two and six participants) and four interviews were held. Of the 65 participants, 33 (51%) were recruited through DPOs, DROs and healthcare consumer organisations and 32 (49%) through health workforce organisations. Of participants recruited through health workforce organisations, 15 (47%) had a primarily clinical role (including 10 GPs) and 17 (53%) had a primarily non-clinical role. Participants recruited through DPOs and DROs spanned organisations representing people with sensory disabilities (blind, deaf, deafblind), intellectual disability, and acquired brain injury, women with disability, and carers. We did not ask participants to disclose personal information concerning disability, gender, age, First Nations identity, or cultural or linguistic background. Rather, our aim was to achieve diverse input by recruiting through organisations representing a broad range of perspectives.

Often similar views were expressed by participants in both consumer and health workforce groups; as no strong contrasts in perspective were evident, the following summary does not distinguish between them. Detailed results are presented in Supplementary File 3.

Views expressed about the wording of disability questions for the VPR form included.

- Disability questions should be clear and straightforward, with plain English wording, avoiding technical or clinical terms (e.g. "mobility", "psychosocial").
- Questions should be worded so that people can relate what is being asked to their own experience, including people from different cultural backgrounds.
- Experience of disability can be variable over time; disability questions should be worded with this in mind.
- People might have different interpretations of terms such as disability or impairment; terms should be defined.
- Some people do not see themselves as having disability, so some groups of patients might be under-represented if the question asks directly about disability (e.g. people with brain injury, people with mental health conditions, parents of child with a developmental delay).
- Question wording should avoid ableist, negative or causal language that implies that restrictions in participation are due to a person's impairment.
- A timeframe should be specified, for example, "for at least 6 months", to distinguish disability from restrictions accompanying acute health issues.

Table 2 presents a summary of participants' views about each of the three lists of categories presented as possible ways of asking about disability. Positive and negative views were expressed about the lists of life areas and disability groups but only negative views about the list of health conditions, impairments and activity limitations.

Online survey

Focus group participants were subsequently invited to complete an online survey (see Supplementary File 4) and indicate their preferred question or combination of questions for identifying disability. The three disability questions presented in the survey were developed by the research team informed by the rapid review, expert input, and findings from the focus groups. They were as follows:

- Option 1: "Because of a long-term health condition or disability, lasting or expected to last 6 months or longer, do you experience any difficulty or restriction that affects your participation in work, education, social and community life, or doing daily activities?" Responses: Yes/No/Prefer not to say.
- Option 2: "In everyday life, do you have difficulty participating in any of the following, related to a long-term health condition or impairment?" Responses: Yes/No for each of three life areas: "Daily activities such as:…," Activities of independent living, such as:…, "Activities of work, education and community living, such as:…"
- Option 3: "Do you have any of the following disabilities?" Responses: tick-box for the following disability groups (can tick more than one category): Sensory; Intellectual; Physical; Psychosocial; Head injury, stroke or acquired brain injury; Other.

Options 1 and 2 both ask about difficulties/restrictions in life areas, with Option 2 an expanded version of Option 1. Option 3 is based on the disability group categories used for reporting Australian national disability survey data.[4] Due to lack of support for an option based on the list of health conditions, impairments and activity limitations used

Table 2: Views expressed by focus group participants about the lists of categories presented as possible ways of asking about disability (categorised as positive and negative comments), 2021.

Category list	Positive comments	Negative comments
Health conditions, impairments, and activity limitations[a]	*(None provided)*	• The categories are very "medical" and may not resonate with people in terms of how their disability affects them day to day • People might think of health conditions in terms of their medical history • This approach is too broad: "almost anyone could put their hand up for that" • This kind of information is best obtained during a clinical consultation
Life areas[a]	• Could pick up people who don't identify as having disability • Would indicate to the doctor what the person feels they struggle with and could inform the care or services offered • Doctors are less likely to already have this information, so it is potentially more useful • Easy to relate to for people filling in the form • Aligns with the "social model" of disability and would help shift thinking away from a medicalised and stigmatising view of disability towards a whole-person approach	• Could pick up a "motley group" not necessarily with disability • The list lacks a category about impacts on a person's psychosocial and mental health/wellbeing
Disability groups[a]	• Could provide information useful for targeting programs/interventions • Could point to accessibility issues the person may experience • These groups are well recognised within the disability community and some people identify according to disability group (e.g. physical, sensory) • Would yield categorised data output readily usable by general practices and government	• Disability group alone is not enough; also need information about the person's needs or the barriers they experience • Incorrect assumptions may be made based on disability group • May not pick up people who have not been diagnosed with a disability or who don't identify as having disability • People may interpret the categories differently, or not know what category their disability fits into • Disability groups may be seen as "labelling" and could cause offence to some

[a] See Supplementary File 2 for categories presented to focus group participants.

for identifying disability in the national disability survey (see Table 2), this option was not presented.

Respondents were asked to express their preference for Options 1, 2 or 3 alone, Options 1 and 3 together, or Options 2 and 3 together.

Data were analysed to determine the percentage of respondents who supported each of the choices presented. Input provided in free text comments was summarised for each of the choices.

Online survey results

Of 35 online survey responses, 13 were from healthcare consumers (representatives from DPOs, DROs and healthcare consumer organisations) and 22 from health workforce participants.

There was greatest support for including both Option 2 (life areas question) and Option 3 (disability groups question) on the VPR form, with 31% of respondents preferring this. Support was lowest for Option 3 alone (11%) and Options 1 and 3 together (14%). For health workforce respondents, 23% preferred each of Option 1 alone, Option 2 alone, and Options 2 and 3 together. Of consumer respondents, 46% preferred use of Options 2 and 3 together and 31% preferred Option 2 alone.

Comments provided by respondents in favour of Option 1 noted brevity and lack of detailed information requested as desirable features. Option 2 (life areas) received several positive comments about being easy to understand and the relevance of information about functioning in everyday activities. There were also several comments about the length and complexity of this question as a potential problem. For Option 3 (disability groups), several respondents noted that the question is clear and straightforward and would provide information that is useful for GP practices. Others queried whether people would understand terms like “intellectual” and “psychosocial”, and how different interpretations of the disability group categories could impact the resulting data. The several positive comments concerning use of Options 2 and 3 together emphasised the value of having more comprehensive information about “type” of disability and how the person is affected in their daily life, both for GPs and to inform the development or targeting of programs.

Developing disability questions for the VPR form: bringing it all together

Regular research team meetings throughout the project were used to discuss and synthesise emerging findings and decide on disability question approaches to present in focus group materials and subsequently in the online survey. In the final phase of the project, findings from all four research components were discussed to inform development of disability questions deemed suitable for use on the VPR form. This involved balancing different desired features, for example, concise expression versus the benefit of defining terms used.

Results

Three questions were proposed to DoH (Box 1). The questions were based closely on those included in the online survey, with minor modifications to wording and presentation, for example, simplifying descriptions of the three life area categories in Question 2. Questions 1 and 2 are alternative questions for identifying whether a patient has disability, and Question 3 is to determine the patient’s disability group/s.

Discussion

Disability questions proposed for use on the VPR form

Drawing together knowledge and perspectives from a variety of sources informed the development of self-report disability questions suitable for use on a proposed VPR patient registration form.

The final decision about the disability question/s included on the VPR form rests with DoH. Our view is that the data output and disability information provided by each question must be a primary consideration. The data output for question 1 would be three categories: “Yes”, “No”, and “Prefer not to say.” For question 2, the data output would be “Yes” or “No” for difficulty participating in each of the three broad groups of life areas, a “yes” for one or more of which would be taken to indicate that the person has disability.

Questions 1 and 2 are disability identification questions that are conceptually aligned with the operational definition of disability in the SDAC, which is “any limitation, restriction or impairment which restricts everyday activities and has lasted, or is likely to last, for at least six months.”[11,23] They are also aligned with the ICF.[21] Question 1 asks about difficulties or restrictions affecting participation in work, education, social and community life, or doing daily activities; together with the footnoted definition of “daily activities”, this covers all ICF Activities and Participation domains. Question 2 is based on a disability question developed for use in a public sector employee data collection,[26] modified by collapsing the nine life areas used in that question into three groups. This grouping of ICF-aligned life areas has previously been used in Australia for reporting data on the support needs of clients of disability services.[35] Question 2 is an expanded version of question 1; the more detailed information would enable differentiation of patients who have difficulty in one or more of the three life area categories (daily activities, activities of independent living, or activities of work, education or community living).

The data output for question 3 would be a positive response to one or more disability groups. The disability groups are based on those used for reporting data from the SDAC,[4,23] where groups are derived based on responses to the list of 17 conditions, impairments and activity limitations used for disability identification in the survey; respondents are not asked directly about whether they identify with these groups. Question 3 is designed to be used only in combination with question 1 or question 2, and to be answered only if there is a positive response to the disability identification question.

Recommendations for implementation of the disability questions

The advice provided to DoH emphasised that evaluation should be undertaken to inform ongoing refinements. This should include (i) evaluation of the quality of the data produced by the disability questions; (ii) evaluation of the experiences of patients filling out the VPR form and of GP practices implementing the form. The evaluation should be informed by people with disability (and their representative organisations) and data specialists, with sufficient time and resources allocated to allow this. The validity of the proposed disability questions in a general practice context has not been tested and validation studies should be included in the implementation plan. In particular, such studies should look at how these questions work in practice for First Nations people and people from culturally and

Box 1. Disability questions proposed for use on the VPR form

Question 1

Do you experience any difficulty or restriction that affects your participation in work, education, social and community life, or doing daily activities*, related to a long-term health condition or impairment?

- Yes
- No
- Prefer not to say* Daily activities include washing, dressing, eating, moving around the house or outside the home, communicating with others, making decisions, learning new things, preparing meals, managing daily routine, caring for children or others, coping with stress.

Question 2 ☐ Yes ☐ No

In everyday life, do you have difficulty participating in any of the following, related to a long-term health condition or impairment? ☐ Yes ☐ No

- Daily activities, such as:— washing, dressing ☐ Yes ☐ No
  - — walking, handling or lifting objects
  - — speaking, using communication devices
- Activities of independent living, such as:— shopping, cooking, caring for others
  - — making decisions, handling stress
  - — learning, solving problems
  - — relationships with people
- Activities of work, education and community living, such as:— social and community life
  - — work, education or training

Question 3

The categories below are disability groups based on underlying health conditions and on impairments, activity limitations and participation restrictions.

Which of the following best describes your disabilities? (Please tick the box next to any that apply—you can tick more than one box)

- Sensory (e.g. sight, hearing, speech)
- Intellectual (e.g. difficulty learning or understanding)
- Physical (e.g. breathing difficulties, chronic or recurrent pain, blackouts or seizures, incomplete use of limbs)
- Psychosocial (e.g. nervous or emotional conditions, social or behavioural difficulties)
- Head injury, stroke or acquired brain injury
- Other

linguistically diverse backgrounds, and across the full range of disability experience. Further, accessible, Easy English versions of the questions presented above should be developed and tested prior to implementation.

Before consideration of using aggregated disability data captured via the VPR form, advice should be sought from data specialists and from people with disability and their representative organisations about the intended data use. These processes should be inclusive of all people with disability, including people with disabling mental health conditions and people with disability who are not connected with representative organisations.

Strengths and limitations of the research

A key strength of this research was the active involvement of people with disability as members of the project team who co-facilitated the focus groups, guided development of focus group materials and methods, and had input into the analysis and interpretation of focus group data. The research benefited from expert input from disability data experts at the Australian Institute of Health and Welfare, ABS and authors of a recent study reporting on development of disability-related questions for administrative datasets.[26] An additional strength was the considerable knowledge of Australian population and administrative data sources relevant to disability held by members of the project team.

The tight timeframe for this project, and pressures associated with COVID-19 (including lockdowns in some parts of Australia during the consultation period), meant that some stakeholders approached were not able to provide input. Consequently, some important groups of stakeholders were under-represented in the consultation, notably Aboriginal and Torres Strait Islander consumer and health workforce representatives and people from culturally and linguistically diverse backgrounds. People with mental health issues, people with little or no speech and young people were among those groups under-represented or not represented in the consultation.

Conclusion

Data are essential for informing improvements to policy and practice to ensure people with disability enjoy the highest attainable standard of health without discrimination on the basis of disability.[10] The collection of self-report patient disability information within general practice, using standard and conceptually sound questions, has the potential to support improved provision of health care to patients with disability.

In addition, inclusion of disability questions on the proposed VPR form developed through this research is an opportunity to test new ways of capturing disability information suited to mainstream service provision contexts. This is timely, given current data initiatives in Australia including a commitment to regular reporting against the outcomes framework for Australia’s Disability Strategy 2021-2031 and work to develop a National Disability Data Asset.

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Conflicts of interest

The authors have stated they have no conflicts of interest.

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Appendix A Supplementary data

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