

An accessible survey method: Increasing the participation of people with a disability in large sample social research

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Abstract

The 1 in 4 Poll project seeks to increase understanding of the views and needs of people with a disability by developing an accessible survey method. It is being conducted by Deakin University in partnership with the Victorian disability service provider, Scope. To address this goal, the 1 in 4 Poll method has focused on three key strategies: an accessible Internet-based survey; use of an assisted and proxy report; and a 'standard' and Easy English version of the survey. A bespoke online survey design seeks to overcome the limitations in accessibility of available online survey tools. Positive evaluative comments, from respondents across a wide-range of disabilities, suggests that the combination of the three major strategies used in the 1 in 4 Poll has resulted in a valuable and accessible method of large scale surveying of people with a disability.

Introduction

People with a disability represent a significant proportion of the Australian population with approximately one in five Australians reporting a disability (Australian Bureau of Statistics 2003 ^[14]). Additionally, there are more than 2.5 million Australians who are carers (Cummins; Hughes et al. 2007 ^[15]). Together, people with a disability and their carers constitute more than 1 in 4 of all Australians. The 1 in 4 Poll project is being conducted by Deakin University in partnership with the Victorian disability service provider, Scope. The project aim is to develop an accessible research method for obtaining the views of people with a disability across Australia on a range of issues that are of importance to them. In doing so, the goal is to increase understanding of the views and needs of people with a disability and to increase their capacity to influence social and political processes. Central to this aim is to develop an accessible survey method that enables people with a wide range of disabilities, including intellectual disabilities and complex communication needs, to participate in polls and surveys.

This paper commences by outlining the importance of obtaining the views of people with a disability as part of social and democratic participation. The barriers to their inclusion in research, as a mode of participation, are discussed along with established strategies for overcoming these. This is followed by an outline of the 1 in 4 Poll method and an evaluation of this based on feedback from survey participants.

The importance of obtaining the views of people with a disability

People with a disability and their carers constitute one of the most marginalised groups in Australia despite their relatively high proportion of the overall population (National People with Disabilities and Carer Council 2009 ^[16]). Evidence suggests that the number of Australians with a disability is increasing (Australian Institute of Health and Welfare 2006 ^[17], 2007 ^[18]) and, given Australia's ageing population, this trend is likely to continue. Despite growing numbers, people with a disability and their carers continue to struggle to give voice to the issues and concerns they face. They are often excluded from participation in political dialogues and democratic processes, and hence decision making processes that greatly affect them. This exclusion is highlighted in a recent Australia-wide consultation of people with a disability and their carers:

'People with disabilities may be present in our community, but too few are actually part of it ... They struggle to be noticed, they struggle to be seen, they struggle to have their voices heard' (National People with Disabilities and Carer Council 2009 ^[16]: 16).

In contemporary democratic society, the notion that all citizens have equal opportunity to express their views and opinions is a fundamental principle underlying human rights and anti-discrimination legislation (Berry et al. 2006 ^[19]). This principle is currently enshrined in the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (United Nations 2006 ^[20]) which was ratified by the Australian Federal Government on 17 July 2008.

One means of enhancing the socio-political capacity of people with a disability is through research and, in particular, via the use of large-scale surveys which provide an opportunity for citizens to report on their life experiences and opinions. Many such large-scale surveys often exclude people with disability either deliberately or through methodological design that does not allow for the ways in which certain people with disability communicate, or to allow for the physical barriers that may inhibit survey completion (Parsons et al. 2001 [21]; Lloyd et al. 2006 [22]; Carlsson et al. 2007 [23]; Kroll 2011 [24]). The notion of an accessible design has not been applied meaningfully to research and social surveys thereby excluding many people with a disability. As Parsons et al (2001 [21]) argue, '(t)here is little attention given in the academic survey literature (and most probably, in common survey practice) to how many 'standard' procedures serve systematically to exclude persons with disabilities from research of the general population?' (2001 [21]: 180).

Including people with a disability in surveys provides information for research, policy making, and advocacy (Keer 2007 [25]: xi). Yet 'if people are systematically excluded from research participation, their needs, experiences, perspectives are rendered invisible' which skews the evidence base therefore affecting evidence-based practice (Kroll 2011 [24]: 67). As Kroll states, this exclusion of people with a disability 'may bias the choice of outcomes, the effectiveness of evaluation of rehabilitation interventions, and ultimately the adoption of 'best practices' and intervention guidelines?' (Kroll 2011 [24]: 67). Thus, researchers, service providers and governments remain uninformed about the experiences and views of people with a disability who are unable to participate easily and effectively in self-report activities.

Research Methods and their limitations

Overcoming barriers to inclusion in research

Researchers need to incorporate adaptations and supports in their data collection procedures based on the assumption that perspectives of people with a disability, including those with cognitive impairments, are 'credible and valuable?' (Mactavish et al. 2000 [26]: 217). Parsons et al (2001 [21]) argue that ethical guidelines relating to the conduct of human research also require researchers to take account of the special needs of vulnerable groups. Failure to make these accommodations, that is, to implement strategies to overcome exclusions related to impairments, can be understood as a breach of human research ethics as well as a breach of human rights (Office of the Commissioner for Human Rights 2010 [27]).

A central idea flowing from this is the right of people with a disability (whether physical or cognitive) to self-report, or communicate directly, about their own views and experience. There is now a growing body of literature that reports on barriers to self-reporting for people with a disability as well as the research method design strategies that can be employed to overcome these issues. This is a complex and growing area of study. The following discussion, though not exhaustive, seeks to outline common themes in the literature as a background to the 1 in 4 Poll method, focusing on data collection issues and strategies.

Strategies to maximise self-report of people with a disability

Barriers to inclusion in research for people with intellectual or cognitive disabilities

There is now a sizeable body of literature that deals with barriers to inclusion in research for people with intellectual or cognitive disabilities. Common barriers are reported to be cognitive issues such as lack of a concrete frame of reference, difficulty with abstract concepts, difficulty with temporal concepts, limited literacy and vocabulary, communication barriers including unresponsiveness and inarticulateness, limited attention span, and fatigue (Booth & Booth 1996 [28]; Paterson & Scott-Findlay 2002 [29]; Whitehurst 2006 [30]; Carlsson et al. 2007 [23]). The format and presentation of research questions and information can also act as barriers to the meaningful participation of people with cognitive impairments (Rodgers & Namaganda 2005 [31]).

A key strategy to overcome these barriers discussed in the literature is the use of various enhancements such as visual aids, symbols, tapes/videos, simple words and clear questions, and story technique (Owens 2007 [32]; Kroll 2011 [24]; Parsons et al. 2001 [21]). There is a significant set of literature (see Kroll 2011 [24] citing a range of research) that deals with the use of visual and pictorial enhancements for assisting the communication of people with intellectual disabilities (including literature related to augmentative and alternative communication (AAC)). For example, Kroll (2011 [24]) highlights the use of visual scaling and the Talking Mats technique.

Ruddick and Oliver (2005 [33]) place the emphasis on the design of question format, noting that 'when questions are carefully constructed, people with intellectual disabilities have ' been shown to provide valid information about their subjective psychological and emotional states?' (2005: 144). In addition, Kroll (2011) argues that prior testing of material and presentation is required to ensure its cognitive match to respondents.

Overall, researchers argue that the data collection design needs to be undertaken with a clear understanding of the preferred communicative modes and optimal communication environments of respondents (Whitehurst 2006 [30]; Owens 2007 [32]).

Barriers to inclusion for people with complex communication needs

Barriers to inclusion in research for people with a wide range of speech impairments and complex communication needs, sometimes linked to intellectual disability, are varied. Kroll (2011 [24]) identifies the need to provide sufficient time for answer formulation, as well as specifically enabling the use of augmentative and alternative communication modes which may additionally require appropriate seating and lighting for use. Similarly, data collection and recording methods need to be matched to the, possibly multiple, communication modes in use, including written, audio and video data collection techniques (Kroll 2011 [24]).

A range of studies report the importance of recognising the role of communication partners - usually personal assistants, carers or family members - in facilitating and interpreting communication (Kroll 2011 [24]; Cambridge & Forrester-Jones 2003 [34]; Owens 2007 [32]). Other studies have focused on strategies for enabling the participation of those with very limited levels of spoken language. Cambridge and Forrester-Jones (2003 [34]) report on the effective use of individualised communication approaches involving a variable mix of signs and symbols already in everyday use that reflect the vocabulary used by the person that was relevant to the study topic, supplemented by the use of photographs.

Barriers to inclusion for people with physical and sensory disabilities

People with a broad range of physical and motor impairments can be excluded from research for a variety of reasons. In some cases, people have difficulty accessing research data collection sites (eg interview venues), or answering the door to an interviewer (for example in household surveying) (Parsons et al 2001 [21]). Data collection methods (including the use of various instruments) can be inaccessible for people with physical disabilities (Kroll 2011 [24]). For example, various motor impairments contribute to an inability to respond in particular formats such as providing answers in writing (Kroll 2011 [24]).

For people who are deaf or hearing impaired, face to face interviews pose a particular problem, though provision of text is a strategy that addresses this for those who have this literacy. The use of telephone typewriter or textphone (TTY) can be a strategy for phone interviewing, though Parsons et al (2001 [21]) conclude that the variety of TTY types with different character and word limits makes it difficult to design questions to suit this breadth of variation. The use of sign language is also not straightforward, given there is no written form, and questions may not translate directly (Parsons et al 2001 [21]), nor are scales easily translatable or validated in this form (Kroll 2011 [24]). For people with hearing impairments, a common problem is that questions may not be heard (Kroll 2011 [24]).

Visual impairments frequently affect respondents' ability to read questions and respond (Parsons et al 2001). [21] One method of addressing such difficulties is to provide large print versions (Parsons et al 2001 [21]) as well as ensuring surveys are available in different formats - for example, some visual impairments render black print on a white page illegible. The use of high contrast text fonts and colours is suggested by Parsons et al (2001 [21]), along with the use of Braille translation of survey material, as well as audio opportunities to hear the question and to record answers.

Assisted self-report

While the strategies discussed above identify ways to design data collection to enable the self-reporting by many people with disabilities, new understandings of 'self-report' also need to be part of an accessible research design. In particular, self-report needs to be understood as both an independent task, as well as an assisted or supported one. A documented strategy of supporting the rights of people with a disability is the provision of support to participate, within an understanding that autonomous action can encompass dependence on such support without compromising autonomy (see for example Davidson 2007 [35]). This notion has found some application within accessible research design for people with physical as well as intellectual disabilities, and it is argued that assisted response is 'superior to response entirely by another person, and ' to no response?' (Kaye 2007 [36], 123). Kaye argues that people with disability, who have difficulty answering survey questions, need to be allowed an assisted response 'in which the person responds with help from a family member or caregiver?' (Kaye 2007 [36], 105). He further argues that assisted response is a preferred method to proxy as it relies on direct answers from the respondent

rather than assumptions made by a proxy. A number of studies have shown that assisted response can include a range of types of assistance, and that it increases the response rate of people with a disability (Layton et al. 2010 [37]; Kaye 2007 [36]; Kroll 2011 [24] citing Young and Chesson 2006 [38]).

Proxy report

While self-report is the ideal, the nature of impairment can however act as an insurmountable barrier to self-report for some people with a disability, particularly those with severe to profound intellectual disability, and those with informal levels of communication. To date, the dominant strategy to include this group is that of proxy report. There are differing perspectives as to whether the use of proxies is deemed better than not obtaining any information at all (Parsons et al 2001 [21]). Proxies may have a different perspective on the value of the research compared to the person with a disability and may act as a 'gatekeeper' (Carlsson et al 2007 [23]). Also a proxy may provide more information based on their own experiences rather than the experience of the person with a disability (Ison 2009). Generally, proxies are regarded as more accurate when it comes to objective information about the person whose views are being sought but may be less accurate when it comes to subjective ideas and opinions or sensitive information (Hendershot 2004 [39]; Kroll 2011 [24]; Parsons et al 2001 [21]; Watson 2012 [40]).

Parsons et al (2001 [21]) note that the advocacy community advise that 'researchers should always assume that the respondent can answer for himself or herself, even if the assistance of special technology or a translator is required' and that most people with disabilities don't want others answering for them (Parsons et al. 2001 [21], 175).

Selecting appropriate large-scale survey methods

The above barriers apply to a range of research methods including large scale data collection. There are a variety of methods possible for large sampling that have been used to obtain the views of people with a disability. They include telephone surveying, paper-based surveys, email and Internet-based surveying. All of these have strengths in terms of accessibility and gathering of reliable data, but also limitations. There is a small amount of literature that specifically addresses the inclusion of people with a disability, and the barriers and strategies used for each of these methods. Issues relating to household surveying by phone and door-to-door have been examined by Parsons et al (2001 [21]) and Kroll (2011 [24]). Paper-based surveying has also been explored by Parsons et al (2001 [21]) and Stalker, Gilliard & Downs (1999 [41]). The use of email as a mode of surveying has recently been explored by Egan et al (2006) [42] and Ison (2009 [43]). These studies highlight many of the issues and strategies discussed above, and apply them to these particular modes of data collection. For the purposes of the 1 in 4 Poll project, the use of Internet-based surveying was of most interest and appeared to have the potential to overcome, through effective design strategies, many of the barriers inherent in other methods. A short overview of issues - including design - in the use of Internet-based surveying for people with disabilities is presented below.

Appropriate Internet-based survey design for people with a disability

One of the strengths of Internet-based research is the potential to reach across geographical boundaries and to reach hidden or difficult-to-reach populations (Cook et al. 2007 [44]; Wright 2005 [45]). It is argued that the medium may encourage more honest answers to personal and sensitive questions (Eckhardt & Anastas 2007 [46]) by providing a degree of anonymity and confidentiality that surpasses other approaches such as face-to-face interviews or even mail surveys (Cook et al 2007 [44]; Wright 2005 [45]), though such anonymity may also negatively affect validity (Wright 2005 [45]). Technological solutions made available by Internet-based surveying also include specific adaptations or assistive technology designed to address physical, sensory and communication impairments.

However, as with all survey methods, there are barriers as well as enablers regarding accessibility. Various concerns about the value of Internet-based surveys include the inability to calculate response rates, the possibility of multiple responses from the same respondent, the 'digital divide' (with many people excluded from computer or web-access), and literacy levels that may make using such a survey method problematic (Davies et al. 2001 [47]; Blair 2006 [48]; Eckhardt & Anastas 2007 [46]). McKenzie (2007 [49]) noted that while many people experience difficulties navigating around sites, the annoyance experienced is likely to be multiplied for people with learning difficulties 'to the extent that it may present an insurmountable obstacle' (McKenzie 2007 [49], 19). A study by Vaccaro, Hart, Whyte & Buchhofer (2007 [50]) noted a number of difficulties experienced by people with a disability including forgetting procedures or passwords, 'going in circles', taking a long time to find things, difficulty in understanding content, difficulty in identifying appropriate keywords, not being able to find the right answers to questions, and losing focus and patience (Vaccaro et al. 2007 [50], 91).

For visually impaired users, Murphy, Kuber, McAllister, Strain, Yu (2008 [51]) reported on a survey carried out by the U.K. Disability Rights Commission that highlighted barriers regarding the failings of assistive technologies and inadequate presentation of web sites. Web pages are often difficult to interpret when using assistive aids such as text-to-speech synthesizers and Braille output devices. In addition, some assistive devices inadequately handle graphics, moving images, frames, tables, use of scripting languages and streaming audio and video. Similar barriers were revealed by the findings from the European Internet Accessibility Observatory Project (Craven 2005 [52]). Murphy et al (2008 [51]) found that current assistive technologies are inadequate in providing access to information due to navigational constraints, and that complex page structures are confusing for the visually impaired.

This discussion highlights the key element of accessibility or 'usability' where respondents can perform the tasks they wish to (Abascal & Nicolle 2005 [53]). It is therefore important to consider an accessible interface to perform the tasks associated with a survey on the Internet which needs to be designed with consideration of the 'physical, perceptual, and intellectual characteristics of the end-user population' (Davies et al 2001 [47], 109).

Overall, it would appear that the Internet has the potential to increase the inclusion of people with disabilities in the social and political world though any survey design needs to consider a variety of barriers to 'usability'. As Zubai-Ruggieri highlights: 'The use of the Internet gives people power to express themselves, have a voice' (Zubai-Ruggieri 2007 [54], 210).

The 1 in 4 Poll method

The 1 in 4 Poll project aims to develop a method of surveying adults with a wide diversity of disabilities across Australia. As the 1 in 4 Poll survey was intended to be offered for completion to a large and diverse population, the researchers focused on a limited set of design strategies that aimed to address some, though not all, of the barriers to participation discussed above.

Overall, the project team focused on three major data collection design strategies. First, the survey was designed to foster maximum participation through allowing both assisted and proxy reports. Second, researchers focused on developing an accessible Internet-based survey method, supplemented by more traditional hard copy dissemination and completion strategies. Finally, researchers developed several versions of the survey instrument, including a 'standard' English format (though with attention paid to clear language and formatting), as well as an Easy English format that utilised plain or simple language, large font, was in color and used visual or pictorial symbols as supports to written language (see for example guidelines and suggestions in Finlay and Lyons 2001 [55]). The research strategies are explained below and were approved by Deakin University's and Scope's Human Research Ethics Committees.

Assisted and proxy report

The emphasis for the 1 in 4 Poll was on self-report. However, it was recognised that despite all efforts to improve accessibility for people with a disability to self-report, some people may prefer or require assistance to complete, while others may be unable to participate except via a proxy. It was decided that providing a variety of methods to respond 'i.e. self-report, with assistance, or by proxy' was a key component of accessibility. Survey design included explicit instruction, at numerous points, that advised that both assisted response and proxy response was to be from the 'person with a disability's view point'.

It was hoped that this explicit instruction would reinforce the notion of self-report, even where differing levels of assistance were provided. While this may not address concerns regarding the validity of response where proxies answer subjective questions (as previously discussed), it was deemed an important strategy to enable participation of a group of people who would otherwise be excluded. However, it should be noted that there are no mechanisms within this iteration of the survey to test the reliability of assisted or proxy response.

Accessible Internet-based survey

Researchers for the 1 in 4 Poll opted for an Internet-based survey as the most appropriate method for large-scale sampling. As the previous discussion on Internet-based surveying showed, this method has limitations of its own. However, researchers for the 1 in 4 Poll have attempted to address some of the pertinent barriers associated with an Internet-based

survey method as will be discussed below.

To begin constructing the 1 in 4 Poll web site there was the question of whether to use one of the range of online survey programs that are available, or whether to develop one for the purposes of the project. Given the key criteria was accessibility, consideration was given to evaluating the accessibility of the available online survey programs. A comparative effectiveness analysis of multiple online survey programs was undertaken by utilising International Guidelines for Web accessibility - principally Web Content Accessibility Guidelines (WCAG) and US Rehabilitation Act Section 508 standards. WCAG version 1 is a series of technical and design guidelines to minimise user difficulties for people with a disability accessing the web, while part of US Section 508 contains 16 compliance points for online accessibility for people with a disability (for more information see Gottliebson, Layton, Wilson 2010 [56]). Eleven popular online survey tools were evaluated against the key guidelines for their effectiveness. Only one - 'Only a Survey?' - had no accessibility problems though it had an inflexible layout and limited options for question types. The other programs examined had varying degrees of accessibility problems. In all, the comparative effectiveness process did not yield an identifiable tool to ensure adequate accessibility for people with a disability (Gottliebson et al 2010 [56]).

In order to maximise accessibility for people with a disability, a bespoke survey was commissioned and evaluated. Strict conformance to all WCAG guidelines resulted in a simple design with initial testing finding that it conformed to all the assessment criteria, making it more accessible than any of the generic survey engines (Gottliebson et al 2010 [56]). The model included key features such as simple layout with an absence of unnecessary design features, high contrast and larger sized font, vertical formatting for scales and item choices where possible, the use of radio buttons rather than a mouse-operated sliding scale, among other features required by the accessibility guidelines (see those described by Gottliebson et al 2010 [56], 405). This bespoke model was initially used in an unrelated research project, an online survey of adults with a disability in Victoria, and was accessed by a diverse group of people with a disability (n=100) (Layton et al 2010 [37]). Given this tested level of accessibility, the bespoke online survey model was subsequently adopted for the 1 in 4 Poll. It should be noted that this model was a step below that recommended by Gottliebson et al (2010 [56], 408), in that it made compromises to offer a single accessible format, rather than 'an adaptative approach' where the web server was able to automatically adapt the offered layout to suit user needs. This approach was beyond the scope of the 1 in 4 Poll project.

It should be noted that researchers also made available hard copies of the survey instrument. This mixed-mode approach, which offers an alternative method of response (Parsons, Baum, Johnson 2000 [57]), was an attempt to accommodate potentially eligible respondents who may not otherwise be able to participate.

How did we go?

Completion rates

The first 1 in 4 Poll survey was based on the topic of social inclusion and was available for completion online between October 2010 and September 2011 at www.1in4pollaustralia.com [58]. Over this time 1340 attempts were made to complete the survey with 761 respondents doing so successfully. Respondents included those with a wide range of disabilities, including physical (24% of respondents), intellectual (15%), neurological (18%), sensory (9%), psychiatric (6%) and others. Of these, thirty six respondents completed the poll in hard copy rather than online and mailed in their responses. Overall, the data shows that respondents from all disability types, successfully utilised the online format of the survey.

Data was gathered in regard to the mode of completion, including levels of assisted and proxy response. Of the 761 completions, 67% completed the survey independently, 16% completed with assistance, while 17% were completed by proxy. A range of disability types utilised assisted response including those with intellectual disabilities (comprising approximately 37% of those using assisted response), physical (18% of assisted response), sensory (8%), and psychiatric disabilities (5%).

Data was also gathered as to the number of people using the Easy English version as opposed to the Standard English version. By far the most popular version was the Standard English which was completed by 85% of respondents. Overall 117 (15%) respondents used the Easy English version. Of these, the majority identified intellectual disability as their primary disability (35%), while those with physical (14%), sensory (9%) and speech related (3%) disabilities, among other disability types, also comprised the user group of this version. Of those who completed independently, 10% used the Easy English version, while just under half (44%) of those who completed with assistance used the Easy English version. Of those surveys completed by proxy, 10% were the Easy English version. Overall, this appears to indicate that while the standard version was favored by the majority, many respondents took advantage of the opportunity to complete the survey using an Easy English version, particularly when a person with disability was completing with assistance. Arguably this indicates that providing a more accessible Easy English version enables people to complete it who may not otherwise have been able to. What the numbers don't tell us is whether people found either version inaccessible and therefore did not complete it.

Respondent Feedback

An important aspect of the development of an accessible data collection method for people with a disability is the evaluation of its effectiveness. To this end, a number of evaluative questions were included in the 1 in 4 Poll survey.

In order to gauge the user-friendliness of the 1 in 4 Poll, respondents were asked 'to what extent did you find the survey easy to understand and fill out?'. Overall the results were highly positive. On a scale ranging from 'hard to use?' (0) to 'easy to use?' (10), 50% of the respondents rated the poll as 10. Of the two versions, the mean response for the Standard English version was 8.83 (out of 10) and 8.11 for the Easy English version. Data was analysed to identify results for users according to their identified impairment. The lowest user-friendliness rating was recorded by people with intellectual disability whose mean response for user-friendliness (combined for both versions) was 7.67, while those with vision impairment provided a mean rating of 8.05.

Respondents were also asked to suggest any improvements to the survey. Many responses related to the content area of social inclusion. Ninety three (93) of the 146 comments received related specifically to the overall user-friendliness of the survey (see table 1).

Comments and Suggestions	Total Number of Individual Mentions	Summary of Respondents' Remarks
Approval of survey accessibility	40	<ul style="list-style-type: none"> • Easy and quick to use/complete • Simple format • Very accessible with a screen reader
Layout difficulties	11	<ul style="list-style-type: none"> • Make circles to click in bigger • Had to scroll across screen to read the full question • Too many pages/information to scroll through before starting survey
Language comprehension / ambiguous	8	<ul style="list-style-type: none"> • Complex preliminary text • Questions ambiguous ? could be more specific
Technical difficulties	7	<ul style="list-style-type: none"> • 'Save?' and 'continue?' options sometimes failed • Timed out and didn't save
Auslan required	5	<ul style="list-style-type: none"> • Provide an Auslan version of the survey
Audio required	4	<ul style="list-style-type: none"> • Easier to use if audio option (in relation to people who don't use/have screen reader software but may have intellectual disability)
More pictures	3	<ul style="list-style-type: none"> • More pictures to help understand
Clearer instructions	3	<ul style="list-style-type: none"> • Too wordy
Dislike scale	2	<ul style="list-style-type: none"> • Don't like 1-10 • Scaling complex
General comments	10	<ul style="list-style-type: none"> • Needs meter to tell how far through the survey you are • Briefer survey • More reassurance regarding confidentiality

Table 1 - Survey respondents' comments and suggestions in relation to survey accessibility

Of the 93 responses, 40 people indicated in their comments that the survey was easy to use. Eleven people indicated a variety of layout concerns, eight people noted that the wording was unclear or ambiguous, while seven people experienced some form of technical difficulty. While numbers were small, other key suggestions included the need for an Auslan option (5 people), and audio options (4), particularly related to people with an intellectual disability rather than vision impairment. Overall, these comments suggest respondents found the survey relatively easy to use though a number of respondents have identified specific issues that need to be considered. It is possible that those who found fault with the method and didn't find it accessible, may not have been able to adequately record their views hence the bias towards the overall positive appraisal from those who were able to successfully complete the survey.

Conclusion

The 1 in 4 Poll survey method is an attempt to develop reasonable accommodations to research methods to enable the participation of people with a disability. The challenge in designing an accessible data collection approach is to overcome communication, physical and cognitive barriers, and to design a method whereby respondents can understand the questions, communicate according to their preferred method, and access the data collection instrument with minimal inconvenience. To address this challenge, the 1 in 4 Poll method has focused on three key strategies: a focus on self reporting supported by assisted and proxy report; an accessible Internet-based survey; and two versions of the survey instrument, including 'standard' and Easy English versions. These strategies attempted to draw on and incorporate, where possible, many of those already identified in the research literature regarding appropriate research methods for people with a disability.

The bespoke design sought to overcome the limitations in accessibility of available online survey tools by ensuring adherence to WCAG guidelines. This, along with the number and diversity of the respondent group with their strongly positive evaluative comments, suggests that the combination of the three major strategies used in the 1 in 4 Poll has resulted in a valuable and accessible method of large scale surveying of people with a disability. Caution though needs to be applied in final conclusions of method effectiveness given the overall positive bias from those who successfully completed the survey. However, these findings highlight it is possible to enable the participation of people with disability in research and that it is the responsibility of researchers to make necessary accommodations.

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