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Final Report

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for the

Australian Stroke Survivor and Carer Needs Assessment Survey

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Project Contributors

Project conceptualisation and protocol production
Cadilhac D A[1,2]
Naylor R[3]
Kilkenny M[1,2]
Moloczij N[2]
McKenzie J[3]
Andrew N[1]

Project coordination
Andrew N[1]
McKenzie J[3]

Ethics document preparation
Andrew N[1]
Reyneke M[1]

Data analysis
Andrew N[1]
Kilkenny M[1,2]
Purvis T[1,2]

Report compilation and editing
Andrew N[1]
Cadilhac D[1,2]
Naylor R[3]
Kilkenny M[1,2]
Purvis T[1,2]

Project Supervision
Cadilhac D A[1,2]
Naylor R[3]

Affiliations of investigators and project staff
[1]Translational Public Health Unit, Stroke and Ageing Research Centre, Monash University
[2]Florey Institute of Neurosciences and Mental Health
[3]National Stroke Foundation

The report has been prepared on behalf of the National Stroke Foundation Advisory group.

Dr Andrew Baird: Brighton Medical Clinic

Ms Carol Burns: Fraser Coast Health Service District

Professor Lin Perry: Prince of Wales Hospital/University of Technology Sydney

Ms Patricia Morgan: Osborne Park Hospital

Ms Tracy Butler: Consumer

Mr Colin Oxenford: Consumer

Ms Carolyn Prunster: Consumer

Any direct reference to this work must be appropriately acknowledged. Enquires should be directed to Associate Professor Dominique Cadilhac, Translational Public Health Unit, Stroke & Ageing Research Centre, Monash University.

Contact details for information about this report:

Translational Public Health Unit
Stroke & Ageing Research Centre
Department of Medicine, Monash Medical Centre
Southern Clinical School, Monash University
Level 1/43-51 Kanooka Grove
Clayton VIC 3168

Phone: +61 9594 7583 email: Dominique.Cadilhac@monash.edu

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Abbreviations

ABS	Australian Bureau of Statistics
ACT	Australian Capital Territory
ADLs	Activities of daily living
ARIA	Accessibility/Remoteness Index for Australia
HREC	Human Research Ethics Committee
ICD-10	International Classification of Disease 10th revision
NSW	New South Wales
Q1 Q3	Quartile 1, Quartile 3
UK	United Kingdom

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Summary

Introduction

Stroke is a chronic condition which often requires ongoing support and management. However, it is unclear how to best support stroke survivors in their long-term recovery including everyday living and community participation. In order to develop appropriate community services, support strategies and programs, more information about what ‘needs’ are not being met is required from a survivor and carer perspective.

In 2011 the Stroke Survivor and Carer Needs Assessment Survey was developed by the National Stroke Foundation (NSF) in partnership with the Stroke and Ageing Research Centre (STARC) - Monash University and the Stroke Division of the Florey Institute of Neurosciences and Mental Health under the guidance of an Advisory group. The Advisory group consisted of representatives from the partner organisations and representatives from general practice, stroke research and consumers. The survey was designed to ascertain the needs of community dwelling Australian stroke survivors and their carers after the acute phase of the event (e.g. more than one year post-stroke). The stroke survivor section of the survey was adapted from a similar survey used in the United Kingdom.

Stroke survivors were asked about the extent to which their needs were being met across six domains. These domains were: health; everyday living; work; leisure; family/friends and support; and finances. They were also asked about the extent to which having a stroke had impacted on various aspects of their lives and whether or not they were able to access services and support groups. Carers were asked about the impact that taking on a carer role had on various aspects of their lives and whether or not they were able to access appropriate support services.

A pragmatic multifaceted sampling strategy involving both direct and indirect recruitment methods was used to ensure that a nationally representative sample of up to 1,000 survivors was obtained. In addition, informal caregivers of these stroke survivor respondents were invited to answer additional questions specific to their carer role and the extent to which their own needs were being met. Qualitative and quantitative data were collected. The final survey was pilot tested and endorsed for use in Australia by the Advisory group. Ethics approval was granted by Monash University Human Ethics Committee (HREC) and the HREC responsible for each of the hospitals that participated in the project.

Major findings

Over 1,000 stroke survivors and carers participated in the survey. Of these 765 were stroke survivors and 387 were carers. The majority of participants were recruited through hospitals (38%) and identified using ICD10 stroke discharge codes and the Australian Stroke Clinical Registry (AuSCR) (25%). Participants were recruited from all States and Territories in Australia.

Stroke Survivors

Ninety-six percent (N=731) of all respondents reported having needs. Of these 84% reported one or more need that was not fully met across the six domains measured in the survey. The median number of needs reported by participants as being not fully met was 4 of 20 (Quartile 1, Quartile 3 (Q1, Q3): 1, 9). A greater proportion of young stroke survivors (< 65 years of age) and those with substantial disability reported having needs that were not fully met.

Health needs were the most common type of need with 84% reporting health needs that were not fully met. Within the category of health, needs in the areas of concentration, cognition, memory, fatigue and emotions were the least likely to be met. For those with needs in these areas, 75-80% reported that their needs were not fully met. These issues also affected other aspects of stroke survivor's lives with 35% reporting that emotional or concentration issues impacted on their ability to use public transport.

Many participants reported having needs related to returning to leisure activities and returning to work that were not being fully met. Over half of all stroke survivors reported experiencing moderate to extreme changes in their leisure activities and two out of three participants who required assistance returning to leisure activities reported that their needs in this area were not fully met. Three out of four stroke survivors that were working prior to their stroke reported changes in their work situation, with over half reporting that these changes were moderate to extreme. Two thirds of those that needed assistance returning to work reported that their work needs were not fully met. Almost half of all stroke survivors reported moderate to extreme changes in their use of or ability to use transport following stroke

Relationships were also significantly affected by stroke. Moderate to extreme changes in spousal relationships (34%), family relationships (23%) and relationships with friends and people outside the family (31%) were reported by stroke survivors. Many stroke survivors also reported needing assistance with emotional support beyond that provided by family and friends. One in two stroke survivors who reported having need of emotional support reported that their support needs were not fully met. Almost two out of three reported an increase in costs as a result of having a stroke and one in three reported a loss of income.

Caregivers

Most carers (87%) lived with the stroke survivors and the majority, three out of four, were women. Around half reported having experienced moderate to extreme changes in their work and leisure activities since taking on a carer role. Many reported having difficulty accessing local health services and approximately one out of four of those that needed respite care, were unable to access it. Approximately one in five carers reported that they needed more social support.

Implications

This is the first time this type of survey has been done in such a large and diverse number of Australian stroke survivors, one or more years following a stroke. This survey is also unique in that it also includes the caregivers viewpoint. The results presented in this report highlight that a great deal of work is required to improve the degree to which the needs of stroke survivors and their carers are being met in Australia. These data have also provided evidence that our current health systems and community services are not sufficiently meeting many of the needs considered to be most important to stroke survivors and their carers.

Further investigation is needed to identify the factors that facilitate or create barriers related to service access. From this type of information it may be possible to start to address factors within the control of service providers to ensure needs for living with stroke can be more adequately met. Evaluations to assess the effectiveness of existing services related to the common areas of needs that were not being met and identified in this survey, are needed and innovative evidence-based solutions should be sought to address gaps in service provision related to these needs. In particular further investigation is required into how to best address the non-physical consequences of stroke such as return to leisure activities or cognitive problems.

Additional efforts need to be applied to investigating how best to address the needs of groups of stroke survivors with the greatest levels of need. Notably addressing the needs of younger stroke survivors and those with greater levels of disability should be prioritised.

The results of this research have the potential to greatly benefit the broader stroke community and will be used by the NSF to help develop evidence based policy, programs, and strategies aimed at better supporting stroke survivors and their carers in Australia. This is an important first step to improving the lives of the large number of Australians that are living with the consequences of stroke.

Introduction

Background

In Australia, about 50,000 people suffer a stroke each year (1) and approximately 420,000 Australians are living after having had a stroke (1). Nearly 90% of Australian stroke survivors live at home (2). Stroke is a leading cause of long-term adult disability in Australia with about 65% of survivors dependent on others to help them with activities of everyday living (1). Over 60% of people with prevalent stroke are aged 65 years or older (3).

Stroke is a heterogeneous condition the consequences of which are complex and diverse, and not just limited to physical losses (4). Many stroke survivors are at risk of developing depression (5) and report low levels of emotional well-being at one to five years post-stroke (6). In Australia, overall quality of life two and five years after stroke has been reported by many stroke survivors as poor (7, 8). Many stroke survivors also experience activity limitation, restricted social participation and psychological issues such as anxiety and depression many years after their stroke (6, 9).

The needs of stroke survivors also vary based on age, gender and location. Younger Australian stroke survivors have been reported to have more needs compared to elderly stroke survivors, especially in regards to psychosocial issues. Issues related to finances, family roles and work are also particularly prominent within this group (10). International research also provides evidence that women experience poorer long-term outcomes and are less likely to have their needs met than men (11). Where a person lives and geographic access to services and support networks is also likely to impact on the degree to which stroke survivor needs are met (12). The needs of stroke survivors are also likely to vary between countries due to cultural, geographic and health system differences. It is therefore important to obtain an Australian perspective on this topic.

Previous work exploring the needs and attitudes of community dwelling stroke survivors in Australia have been restricted to small locally based studies with an emphasis on qualitative analyses. Nevertheless most of the available literature suggests that although stroke survivors are often still experiencing functional difficulties many years post-stroke, longer term needs are often a consequence of survivors struggling to come to terms with their new condition and with aspects related to integrating back into the community (12). In particular, mood changes such as depression, anxiety and frustration were frequently reported and were often associated with loss of independence, inability to resume previously enjoyed activities and an inability to fulfil previous roles (10, 13-15). Stroke survivors have also reported that the Australian health system is not responsive to the changing needs of stroke survivors and that there is no long-term reassessment of their needs by allied health staff (16). In another small study (n=20) it was reported that 78% of stroke survivors felt that discussing their needs and those of their family with a stroke team was worth researching and 94% felt that this was likely to positively impact on survivor outcomes (17).

The importance of social support through family and informal care givers in meeting the needs of stroke survivors, especially with regards to social participation and overcoming activity restrictions (12, 13) has been highlighted in a number of studies. The use of informal supports such as family and friends has been reported by Australian survivors of stroke as invaluable and a key component in their recovery (14, 18). However, this can be at a significant personal and financial cost to caregivers. Carers of stroke survivors, in Australia also report large levels of needs that are not being adequately met (19) especially with regards to their social lives, tiredness and their own distress at the stroke survivor's condition. Carers have reported experiencing considerable burden and reduced health related quality of life at six to twelve months after taking on a carer role (20). They also reported feeling unsupported, were concerned about the uncertainty of their role and reported difficulties accessing appropriate services (18, 21, 22).

Despite the recognised need to support stroke survivors and their carers living in the community, there is little research in this area and limited understanding of how this may be achieved. The authors of recent literature reviews have concluded that research in this area ***lacks a systematic approach*** to problem identification, ***has a poor evidence base*** and is ***not underpinned by sound theoretical concepts*** (23-25). Within the Australian context there has been very little exploration of the needs of stroke survivors beyond the early discharge period and evidence gaps exist regarding how best to address the long-term needs of stroke survivors and their carers.

The "Walk in our shoes" report

In 2007, in response to this evidence gap, the NSF commissioned a research report entitled "Walk in our shoes". The aim of this report was to assess how stroke had impacted on the lives of stroke survivors and carers, the level of support needed, their assessment of stroke support and barriers and enablers to accessing appropriate services (26). The results included the experience of 104 stroke survivors and 76 carers recruited through advertisements, general practitioners and state based stroke organisations. The surveys and interviews provided evidence that many stroke survivors continued to have problems with memory, mobility, communication and pain. Disability impacted on all aspects of their life including relationships, their ability to work, finances, mood and social life. About 95% of stroke survivors reported that they had yet to make a full recovery and over a third required at least some help with daily activities. Many carers reported a sense of frustration and isolation and two-thirds admitted to having being depressed at times since becoming a carer. The results from "Walk in our shoes" were consistent with the published research with stroke survivors reporting that the more persistent problems were those centred around their ability to cope with the consequences of stroke.

The results obtained from this report were used to inform the NSF support strategy which aimed to prioritise the needs of survivors and carers in the context of current available programs and to guide future program development. Although this report included detailed information obtained from in depth interviews, the small sample size and recruitment methods used meant that the results were not necessarily representative of the Australian population.

The United Kingdom (UK) Stroke Survivor Needs Survey

In 2010, UK Stroke Association released a report which was used to describe the extent to which the long-term unmet needs of community dwelling stroke survivors were being met (27). The extent to which the needs of 799 community dwelling stroke survivors, recruited via UK general practitioners (national sample) or population-based registers (registers) were reported. The national sample contained predominantly older stroke survivors (mean 70 years) with the majority of stroke survivors being three to four years post-stroke (45%), whereas the registry sample contained younger survivors (mean 66.3 years) and were predominantly one to two years post-stroke (42%). Fifty-four percent wanted more information about stroke. Of those respondents who experienced problems, the proportion reporting that their needs were not fully met were for: emotional issues (73%); mobility (68%); falls (68%); pain (49%); concentration (80%) and incontinence (21%). The results of this report highlighted that within the UK system many needs in long-term stroke survivors were not being adequately met. However, this survey only measured the extent to which needs were being met across the domains of health and did not contain information from the perspective of carers.

The Australian Stroke Survivor and Carer Needs Assessment Survey

In Australia, comprehensive national data on stroke survivor needs is limited. Previous research has been based on small samples and the “Walk in our shoes” research did not represent the full range of survivors based on individual and hospital characteristics (26)

In 2011 the NSF funded a survey similar to the one undertaken in the UK (27) in order to ascertain the needs of Australian stroke survivors and their families after the first year of the event. The NSF obtained permission to use the UK survey and adapted it to the Australian context with input from an expert Advisory group. A carers survey was also developed and added to the questionnaire.

The definition of ‘unmet need’ for the purpose of this survey was considered ***‘something or help from someone that would help you to overcome some of the effects of your stroke and resulting difficulties’ (28)***

The Stroke Survivor and Carer Needs Assessment Survey was developed by the NSF in partnership with the STARC - Monash University and the Stroke Division of the Florey Institute of Neurosciences and Mental Health under the guidance of an Advisory group. The Advisory group consisted of representatives from the partner organisations and representatives from general practice, stroke research and consumers.

Aims of the NSF Stroke Survivor and Carer Needs Assessment Survey

The aims of the NSF Stroke Survivor Needs Assessment Survey project were:

- To estimate the levels of long-term unmet needs (minimum one year post-stroke) from the perspectives of community dwelling **stroke survivors** in Australia

- To identify the greatest areas of unmet needs so that policy, programs and strategies can be developed to address unmet needs of **stroke survivors**
- To estimate the levels of unmet needs from the perspectives of **carers of stroke survivors** in Australia
- To identify the greatest areas of unmet needs so that policy, programs and strategies can be developed to address unmet needs of **carers of stroke survivors**

Methods

Survey design and development

The survey is based on the UK Stroke Survivors Needs Survey (27). Quantitative data were collected using closed questions with different scales of response. For example respondents were asked whether a particular need was fully met, partially met, unmet or not applicable (see Appendix A). Open-ended questions were included to provide respondents with the opportunity to submit additional information on how their needs could be better addressed and to ensure that all of the main areas associated with their needs were covered. Demographic variables and questions regarding their current health status related to stroke were added. Many of the non-health questions were redesigned so the extent to which needs across a variety of domains (not just health) were being met could be quantified. For example participants were asked about the extent to which their work and leisure needs were being met. Other questions were adapted for the Australian context. A carers survey was added with an additional 21 questions (see Appendix A), to allow caregivers to answer additional questions specific to their carer role and their own needs. The UK survey contained 43 questions whereas the final Australian version contained 78 questions, 58 survivor questions and 20 carer questions.

The survey was pilot tested to ensure valid and reliable data were collected. Pilot testing of the survey was undertaken with a sample of volunteers from the NSF StrokeConnect group which is a NSF membership program for stroke survivors and carers. Both an online version and a paper based version were pilot tested and a feedback questionnaire was used to obtain constructive suggestions on the readability, ease of use and suggestions for improvement. The pilot testing resulted in minor changes in the formatting and wording of several questions. Feedback and final endorsement of the survey was provided by the Advisory group.

Survey content

The survey included four sections which are explained in detail below:

Section A: Stroke survivors eligibility criteria

The first section of the Stroke Survivors Survey included questions to determine whether the participant was eligible. Refer to page 15 for inclusion criteria.

Section B: Needs survey of stroke survivors

The Australian Stroke Survivors Survey included questions on the following factors:

- ***Health information and needs*** such as blood pressure, dietary advice, help with prevention of falls, bladder or bowel problems, treatment of pain, fatigue, emotional and concentration problems, speaking, reading, sight difficulties and decision making
- ***Everyday living needs*** such as personal care, home help, additional aids, adaptations to home, transport and travel, getting back to driving and travelling on public transport
- ***Work and leisure needs*** such as changes in hours or type of work or study since stroke and changes in leisure activities post-stroke
- ***Family, friends and support group needs*** such as changes in relationships with partner/ spouse and need for advice on sexual relationships since stroke
- ***Financial needs*** such as loss of income, increases in expenses, whether survivors currently receive Centrelink benefits and if they would like advice on how to manage money after stroke
- ***Other needs:*** the final question asks the participant if there were any other needs that had not been covered in the survey

At the end of each section the participant was asked if they had reported that they did not get enough help for any issue covered to describe what type of help, support or service would have been useful.

Section C: Demographic information from stroke survivors

This section asked participants about some basic demographic and stroke outcome information:

- Demographic information such as: gender, age, postcode, years since stroke, ethnicity, level of physical disability; and
- Two validated questions to assess outcome after stroke (29)
    - Do you need help from anybody with everyday activities? (yes / no)
    - Has the stroke left you with any problems? (yes / no)

Section D: Carer's Needs Survey

The carer survey appeared as a separate removable section to allow for confidential completion and submission by carers and included questions on:

- Demographic information such as: gender, age, current living arrangements, relationship to stroke survivor
- Changes in work and leisure activities since becoming a carer for a stroke survivor

- Financial information such as loss of income, increases in expenses and whether they received Centrelink benefits
- Changes in social/family relationships whether they wanted advice on sexual relationships and access to support groups
- Their experience using and accessing Community Health Services, respite care and whether or not they felt that they were receiving sufficient social support.

A complete copy of the questionnaire in provided in Appendix A

Recruitment and data collection

To accommodate the needs of stroke survivors the survey was offered in a variety of formats and since not all stroke survivors may be able to complete the survey independently, proxy responses from informal caregivers was also sought. Informal caregivers were also invited to answer additional questions specific to their carer role and the extent to which their own needs were being met.

Inclusion Criteria

In order to be eligible to participate in the survey, stroke survivors needed to be:

- aged 18 years and over
- independently living in the community (or assisted by informal carers). This was because the purpose of the survey was to collect information to inform the development of community based services and strategies
- have a clinical diagnosis of stroke and have had their first stroke at least one year ago
- be able to complete a questionnaire (with or without appropriate informal support) within the project timeframe. For participants for whom English was a second language, family or a support person could assist with completing the questionnaire

Survey completion options

Stroke survivors and/or their informal carers had the following options to complete the survey:

1. **Online** via a link to a SurveyMonkey webpage (http://www.surveymonkey.com). SurveyMonkey is an on-line survey and questionnaire tool that could be accessed by the stroke survivor easily on the web. The on-line format of the questionnaire was designed by STARC staff at Monash University to ensure valid and accurate data were entered using this tool and the variables were compatible with the other forms of data capture.

2. **Paper-based** survey which was sent to stroke survivors by mail or on request. This paper-based form was designed using Teleform software (http://www.cardiff.com/products/teleform/). This allowed the completed form to be electronically scanned.

3. **Telephone**: An option to complete the survey via the telephone was also made available. Participants could call the NSF Stroke Line (1800 787 653), which is a toll free number, where an appointment could be made with a STARC staff member to complete a survey over the telephone. A STARC staff member, with a clinical background and previous experience administering telephone interviews, performed all of the interviews.

Sampling methods

A multi-faceted sampling strategy was used to assist in recruiting a national sample of stroke survivors. The sampling design was cross-sectional and non-randomised. The main objective was to obtain a sample of up to 1,000 stroke survivors and as many carers as possible, across the spectrum of stroke for Australia using pragmatic and non-coercive approaches. Both direct and indirect methods of recruitment were used. Table 1 provides a summary and further details for each proposed recruitment approach.

Table 1 Direct sources of recruitment

Source of recruitment	Target audience (number of stroke patients and time since stroke)	Target audience (gender & age)	Target audience (location)
StrokeConnect group*	N=611 51% recent strokes (since 2007)	49% male 60% aged 60 years or more	50% live WA & 60% capital cities
StrokeConnect on-line forum*	N=300 Recent strokes (since 2007)	10% aged 60 years or more	-
AuSCR (N= 13 hospitals) Recent strokes (since June 2009)	2010 Annual Report: 1482 patients with follow-up data and 543 (37%) agreed to be contacted about future research projects	Of those who agreed to contacted: 62 % male Mean age 69 years	28% Victoria, 21% QLD, 28% NSW, 24% WA
Purposeful sample of hospitals	Hospitals who participated in the Clinical audits in 2009	53% male ; Median age 77 years	89% urban hospitals

* There is minimal overlap of members between the Stroke Connect and Stroke Connect Forum. Less than 10 people are members of both groups. A maximum of 20% of participants will be recruited from these two sources.

Direct recruitment strategies

The Australian Clinical Stroke Registry (AuSCR)

The AuSCR collects data from participating hospitals to monitor and improve the quality of acute stroke care (http://www.auscr.com.au/). This on-line tool is used by clinicians to collect data on all eligible patients admitted with acute stroke. As part of the three-month follow-up, a question is asked “Would you be willing to be contacted in the future to hear about possible stroke research projects that you may be eligible for?” AuSCR registrants who elected to be part of further research studies were identified to participate in this survey. At the time of the survey 13 hospitals were contributing data to AuSCR.

Prior to recruitment using this method, an application was submitted to the AuSCR Research Task group and the AuSCR Management Committee to obtain approval to contact the eligible stroke survivors for this project.

Eligible participants were sent a questionnaire pack containing, a survivor and a carer questionnaire, an invitation letter, a participant information sheet explaining the purpose of the study and two reply paid envelopes, one for the survivor and one for the carer. AuSCR staff sent the survey packs to potential participants (only those who agreed to be contacted about research projects) on behalf of the researchers so that no identifying information was given to the project staff.

StrokeConnect

StrokeConnect is a NSF membership program for stroke survivors and carers. StrokeConnect provides members with access to NSF programs and information about the stroke recovery journey. NSF communication with StrokeConnect members is based on a paper-based newsletter which can also be accessed on-line from the NSF website. Members of StrokeConnect are recruited directly by staff in participating hospitals on behalf of the NSF. StrokeConnect was established in November 2007 and has over 800 members. The members include 730 stroke survivors, 87 carers, 3 allied health and 36 other individuals. Half of the members are from Western Australia followed by 15% from Victoria, 14% New South Wales (NSW) and 10% from South Australia. The majority of the members are from capital cities (60%) and regional cities or large towns (23%). The age breakdown of StrokeConnect members showed that the older age groups are the main members with 55% aged 70 or more years. Members who joined between November 2009 and end of 2010 (n=360) were sent an invitation letter asking them to participate and a copy of the questionnaire by mail. One month later a reminder follow-up letter was sent to all eligible members and regular reminders and the SurveyMonkey web address were posted in the StrokeConnect newsletters.

StrokeConnect On-line Forum

The StrokeConnect On-line Forum (http://www.strokefoundation.com.au/strokeconnect/index_main.php) is an internet forum that provides a place for people to build connections with others who have been affected by stroke. This forum was established in November 2009 and has around 300 members that have signed up from the general public. On-line members are predominantly younger stroke survivors with 63% aged between 18 and 59 years. There is minimal overlap of members between the StrokeConnect and StrokeConnect On-Line Forum. Less than 10 people are members of both groups. An email invitation to participate in the survey, including a link to the SurveyMonkey website was sent to all members of the StrokeConnect On-Line Forum.

A maximum of 20% of participants were allowed to be recruited from StrokeConnect and StrokeConnect online forum, since the needs of this group may vary compared to participants recruited from other sources.

Hospital Recruitment Strategy

All hospitals that completed the NSF National Stroke Audit Acute Services Organisational Survey and were not participating in AuSCR were sent an e-mail seeking their expression of interest to participate in the Australian Stroke Survivor and Carer Needs Survey. From 177 invitation letters distributed to eligible hospitals, we received expressions of interest from 33 hospitals from all states and territories except the Australian Capital Territory (ACT). These hospitals represent a mix of regional, urban and remote hospitals. From these we selected 20 hospitals to participate in the project. Our primary aim when selecting hospitals for participation was to include hospitals that would enable us to obtain information from a geographically diverse range of stroke survivors living in the community. Hospitals that serviced areas and populations not accessed through AuSCR and the NSF StrokeConnect and StrokeConnect On-Line Forum were given preference for inclusion.

A method was developed to select appropriate sites in locations that would ensure a range of survey respondents from across the country with access to different levels of services. The first step in this process was to map the hospitals, including those covered by AuSCR to location (see Table 2). The second step was to then select the minimum number of hospitals needed to fulfil these criteria based on 1) location; and 2) the likely number of patients with stroke per year (Table 3) while ensuring appropriate urban and rural coverage.

To achieve representation from all States and Territories the following steps were taken (Table 2):

1. Data from the Australian Bureau of Statistics (ABS) was used to calculate the proportion of the Australian population residing in each state. For the purpose of this analysis we included the ACT as part of NSW
2. Using State level ABS data the proportion of the population living in the capital city of each state was calculated
3. The numbers that we expect to recruit using both AuSCR and selected hospitals was calculated based on an assumed response rate of 50% for AuSCR and 25% for hospitals
4. The minimum number of participants that would be recruited from the capital city and rural areas for each state, taking into account numbers likely to be obtained through AuSCR registrants was calculated and the number or questionnaires that each hospital needed to send out, based on hospital size and location was calculated (Table 3). Hospitals were asked to select patients across as many years as was needed to achieve their target sample
5. When specifically selecting hospitals, where possible the aim was, to recruit hospitals that provided a representative coverage of each major city and each regional area. In situations where we had multiple hospitals within a region, such as North Eastern NSW, we used a computer generated program, Intercooled stata 12.0 for Windows (Stata Corporation, 2008) to randomly select one hospital for that region

Table 2: Stroke admissions for each state for metropolitan, regional and rural hospitals.

State	N*	Stroke admissions / year, median (Q1,Q3)*		
		Metropolitan	Regional	Rural
NSW (inc ACT)	9045	282 (189, 364)	110 (80, 160)	20 (10,30)
Victoria	7111	482 (220, 600)	118 (78, 148)	28 (9,65)
Queensland	4396	175 (120, 250)	102 (50,197)	29 (20,37)
South Australia	2103	361 (200, 465)	Not applicable	8 (3, 16)
Western Australia	2120	250 (146, 384)	62 (34,83)	10 (6,20)
Tasmania	653	102 (388, 197)	200 (200,200)	65 (65, 65)
Northern Territory	196	140 (140,140)	56 (56,56)	Not applicable

Q1: 25th percentile; Q3: 75th percentile

*Unpublished data from the NSF National Stroke Audit Acute Services Organisational Survey

Table 3: Recruitment strategy

State	Population[1] n (%)	Reside capital city %[1]	Anticipated sample, AuSCR and Audit[2,3] n	AuSCR anticipate sample[2] n (%rural)	AUDIT anticipated minimum sample[3] Urban n	AUDIT anticipated minimum sample [3] Rural n	Number of hospitals included[7] n
NSW (inc ACT)	7.7M (34)	4.6M (60)	272	67 (36)	114	91	2 Metro 4 Rural
Victoria	5.6M (25)	4.1M (73)	200	77 (0)	69	54	1 Metro 4 Rural
Queensland	4.6M (20)	2.1M (46)	160	88 (0)	0	72	1 Rural 1 Metro*
South Australia	1.7M (8)	1.2M (71)	56	0	41	15	1 Metro 2 Rural
Western Australia	2.3M (10)	1.7M (74)	80	68 (0)	0	21	1 Rural
Tasmania	0.5M (2)	0.2M (40)	16	0	7	9	1 Metro 1 Rural
Northern Territory	0.2M (1)	0.1M (50)	8	0	0	8	1 Rural

M:Million; AuSCR: Australian Clinical Stroke Registry; AUDIT: Hospitals involved in the National Stroke Foundation 2011 audit and not part of AUSCR; *Only 1 rural Queensland hospital volunteered

[1] Australian Bureau of Statistics. Year Book Australia, 2012 Canberra2012 [updated 3 December 2012]

[2] Lannin NA, Cadilhac D, Anderson C, Hata J, Lim J, Levi C, Faux S, Price C, Donnan G, Middleton S on behalf of the AuSCR Consortium. The Australian Stroke Clinical Registry Annual Report 2011. The George Institute for Global Health and National Stroke Research Institute; August 2012, Report No 3, pages 44

[3] Unpublished data from the NSF National Stroke Audit Acute Services Organisational Survey

Once hospitals were selected, ethics approval was sought for each of the participating hospitals. Hospitals were then asked to identify eligible participants based on the International Classification of Disease 10th revision (ICD-10) codes in Table 4 using medical records information, or where available their own local stroke register. Questionnaire packs, with a covering letter from the hospital staff, were sent to eligible participants by the hospital. As with AuSCR, this procedure meant that no identifiable information was given to the survey researchers.

Table 4: ICD10 stroke discharge codes for selection of patients to include in survey

ICD-10 code	ICD-10 description and specific codes
I61	Intra cerebral Haemorrhage (I61.0-I61.9)
I62	Other non-traumatic intra cerebral haemorrhage (I62.9)
I63	Cerebral Infarction (I63.0, I63.1, I63.2, I63.3, I63.4, I63.5, I63.6, I63.8, I63.9)
I64	Stroke, not specified as haemorrhage or infarction

Northern Territory Recruitment Strategy for Indigenous Stroke Survivors

Indigenous Australians make up about 3% of the Australian population and are 1.5 times more likely to be admitted to hospital with a stroke than non-Indigenous Australians (30). As part of this project we were interested in learning about the experiences of Indigenous Australians as well as non-Indigenous Australians.

Staff from Alice Springs Hospital agreed to participate in the hospital recruitment strategy but felt that it would be difficult to recruit Indigenous stroke survivors using the standard recruitment strategy. Instead the following method was used to recruit Indigenous stroke survivors:

1. Indigenous status, language group and gender of eligible stroke survivors were identified from the hospitals internal stroke register
2. An appropriate interpreter from the Aboriginal Support Services Unit contacted the eligible participant by telephone
3. Verbal consent was obtained and if the stroke survivor wished to participate, an appointment was made for the interpreter to perform a face to face interview with the stroke survivor
4. Written consent was obtained at the interview
5. Where possible the stroke survivors carer was also interviewed
6. No personal identifying data was sent to the project research staff

In-direct recruitment strategies

The indirect method of recruitment entailed advertisements in relevant publications (e.g.: journals, newsletters); and advertising via the NSF website and other stroke organisations (i.e. Stroke Society Australasia) and support groups throughout Australia. Referrals were also obtained from health professionals, researchers or friends of stroke survivors through these various mechanisms.

The indirect sources for recruitment included:

- ***NSF website***: during the recruitment phase there was a link from the website to encourage people to complete a survey online or call the NSF specific ‘1800’ number to organise a telephone interview or to have a paper based survey sent to them for completion

- ***NSF email signature*** had a banner for a specified period to promote awareness and encourage participation with a link to the online survey or instructions on how to access a paper-based survey

- ***Stroke Support Groups***: an invitation to participate was sent to 80 stroke support groups registered on the NSF website. Support groups were asked to inform their members of the survey and provide them with the appropriate website link and NSF contact details if they wished to complete the survey

- ***The South Australian Rural Stroke Project***: One of the lead researchers of the South Australian Rural Stroke Project approached the NSF and volunteered to send out surveys to participants enrolled in the South Australian Rural Stroke Project. This resulted in 70 surveys being distributed to participants in this project

- ***Snowballing***: Stroke survivors that participated were encouraged to forward on information/emails to other known stroke survivors (snowballing). There was also a link on the on-line survey where the participant, if they knew of another stroke survivor who might complete the survey, could email them this link.

- ***2012 publicity opportunities***: e.g. the 2012 Australasian Stroke Society of Australia conference and NSF stroke forums.

Data processing and analysis

Data processing

The completed Teleform formatted (paper-based) questionnaires were returned to the NSF using reply paid envelopes. These were then forwarded onto the staff within the Stroke Division of the Florey Institute of Neurosciences and Mental Health where they were scanned, cleaned and submitted into a secure Access database (Access 2007, Microsoft Corporation). Inbuilt logic checks in the databases were implemented to ensure valid data were submitted into the database.

The on-line survey database was downloaded and submitted directly into a secure stata database by the Monash University staff. Prior to analysis, data from both databases were coded and merged into a single dataset. The final dataset was verified and cleaned for any errors prior to final analysis.

Definition of variables

Demographic variables were recoded for analysis. Age was categorised as <65 or 65 years and over, time since stroke was categorised as one to two years or three or more years. Postcodes were used to determine the State in which residents lived. For this report, data from the ACT was included in the NSW data. Postcodes were also mapped to the Accessibility/Remoteness Index for Australia (ARIA) (31) to provide a measure of geographic remoteness. ARIA is used to calculate remoteness as accessibility to 201 service centres based on road distance to provide a geographic approach to remoteness. Each postcode is given an ARIA value which is grouped into five categories: (1) Major Cities; (2) Inner Regional; (3) Outer Regional; (4) Remote; and (5) Very Remote. Category one applies to areas with relatively unrestricted accessibility to a wide range of goods and services and opportunities for social interactions. Category 2 applies to areas with some restrictions to accessibility for some goods and services and opportunities for social interaction. Categories three to five range from significantly restricted to very little accessibility of goods, services and opportunities for social interaction (31). For this report, categories three, four and five were combined and defined as remote, in order to provide sufficient sub-group numbers for analysis.

When calculating levels of need the responses “I did not want help” and “I did not have any problems with” were combined to indicate that the participant did not have a need in that area. When calculating proportions the denominator included only those with needs in the area being described. A need was defined as being “not fully met” if it was reported as either unmet or partially met. For the purposes of this report proportions were calculated for those whose needs were not fully met.

In order to summarise the different categories of need, 13 questions on health needs (questions 9-21; Appendix A) were combined to define the extent to which health needs were being met, three questions on everyday living needs (questions 24-26; Appendix A) were combined to define the extent to which everyday living needs were being met, question 33 was used to define the extent to which work needs were being met, question 35 was used to define the extent to which leisure needs were being met, question 40 to define the extent to which support needs were being met and question 46 to define the extent to which financial assistance needs were being met.

Two specific questions relating to dependency and reported problems that have been shown to have good face and construct validity against common HRQoL measures such as the Euroqol and the SF-36 were used as a measure of outcome (29). Needing help with activities of daily living (ADLs) was used to define level of disability for sub-group analyses.

Although the aim was to recruit stroke survivors who were one or more years post-stroke, some stroke survivors that were less than 12-months post-stroke completed the survey. We decided to include these respondents, provided that they were six or more months post-stroke and residing in the community, as the majority of functional improvement occurs in the first three to six months post-stroke (32).

Data analysis

Data was exported from the Access (Microsoft Corporation, 2007) database for the paper-based surveys and SurveyMonkey for the surveys completed on-line. These databases were transferred using Stat/Transfer (Circle Systems Inc 2007) and merged together in Intercooled stata 12.0 for Windows (Stata Corporation, 2008). These data were then analysed using computer programmes including stata and Excel (Microsoft Corporation, 2007).

The survey data collection forms included simple six-point Likert scales or categorical options to obtain the information on the needs of stroke survivor (Appendix A). Descriptive statistics were used to describe categorical data e.g. n/N and proportions. The Chi-squared statistical test for differences in proportions was used to compare groups and the Wilcoxon Mann–Whitney Rank Sum test was used to compare continuous variables. A p-value of <0.05 was considered to be statistically significant. Where data were missing for a question these data were excluded from the analysis for individual questions (that is, only valid responses were included).

The qualitative free text data were subjected to thematic analysis. A coding tree outlining the major themes and subthemes was developed and used to systematically code and then analyse the text responses. The coding was verified independently by two researchers to ensure the interpretation and meaning of the data was maintained. The findings of the text responses were then triangulated with results of the survey data. Triangulation is the combination of at least two or more theoretical perspectives, methodological approaches, data sources, investigators, or data analysis methods. The intent of using triangulation is to decrease, negate, or counterbalance the deficiency of a single strategy, thereby increasing the ability to interpret the findings (33). In this study, triangulation provided a broader and more comprehensive means to fully explore the areas of need identified by stroke survivors and carers.

Ethics Approvals

Overall ethics approval for this project was granted by Monash University Human Research Ethics Committee (HREC), approval number CF11/2579 – 2011001510. Individual ethics approval was also granted from the HREC responsible for each of the hospitals that participated in the project. In total eight ethics applications and 18 site specific applications were approved for hospital participation.

Stroke Survivor Results

Response rates

Over 1,000 survivors and carers completed the survey. Of these 765 were survivors and 387 were carers. A total of 3495 paper based questionnaires that were sent out through the various recruitment strategies (Table 5) Table 5and of these 616 (18%) were returned. Forty five were excluded as they did not meet the eligibility criteria and four were excluded as they were returned without any valid responses. Table 5 shows the differences in response rates for the different recruitment strategies. It was not possible to determine the response rate for online recruitment strategies.

Staff from 20 hospitals agreed to participate in the project. One hospital was withdrawn from the project due to the primary staff member involved in the project leaving and another hospital was not able to participate due to delays in their local governance unit approving their site specific ethics application. The hospital recruitment strategy was responsible for the greatest number of responses 291 (38%) followed by AuSCR 189 (25%). Only 18% of participants were known to have been recruited through the direct NSF recruitment strategies.

Table 5 Survey response rate from different recruitment strategies

Recruitment strategy	Questionnaires sent out n (%)	Questionnaires returned n (%)	Online response n (%)	Response rate
Paper based/including telephone				
StrokeConnect	360 (10)	92 (16)	43 (22)	38%
AuSCR	602 (17)	183 (32)	6 (3)	31%
Hospital	1700 (49)	279 (49)	12 (6)	17%
Other*	833 (24)	13 (2)	4 (2)	2%
Online				
Website	N/A	N/A	92 (46)	N/A
Email signature	N/A	N/A	12 (6)	N/A
Advertisements	N/A	N/A	5 (2)	N/A
Word of mouth	N/A	N/A	13 (7)	N/A
Support group	N/A	N/A	11 (6)	N/A
Total	**3,495**	**567**	**198**	

AuSCR: Australian Stroke Clinical registry, *Other includes rural stroke project, stroke support groups, professional publicity opportunities etc

Both qualitative and quantitative data were collected. The purpose of the qualitative data was to provide broader and more comprehensive interpretation of the quantitative data. These data enabled a fuller exploration of the areas of need and other aspects not covered by the structured survey questions. Many respondents chose not to complete these additional free text questions. The percentage of overall valid responses for each question varied and ranged from 5% for the question relating to “what assistance would support relationships with family and friends”, to 28% for reasons as to why survivors did not attend a support group.

Survey representation and construct validity

Representation from all of the States and Territories in Australia was achieved (Figure 1). Percentage representation of respondents was similar to the percentage population distribution by State (Table 6). Consistent with the population distribution in Australia, the majority of survey participants (66%) resided in capital cities. The majority (62%) resided in major cities (ARIA category one) with unrestricted geographic access to services. Not all capital cities are classified as ARIA category one e.g. Hobart. Approximately one quarter

(26%) resided in inner regional areas (ARIA category two) with some restricted access to services and 13% resided in outer regional or remote areas (ARIA categories three to five).

Respondents were significantly younger than the general stroke population. The median age was 68 years, (Q1, Q3: 59-77) compared to 77 years for the Australian stroke population (2). However, a similar proportion of survey participants were male (62%) compared to the general stroke population and a similar proportion of participants (40%) reported needing assistance with ADLs compared to the general Australian stroke population (2).

Only 12% of respondents reported that they had other needs not fully covered by the survey, indicating that the survey was well designed and captured the needs considered to be most important by stroke survivors.

Table 6 Breakdown of population and respondents by State

State	Population n (%)*	Reside capital city n (%)*	Responded to survey n (%)	Respondents residing in capital city n (%)
NSW (inc ACT)	7.7M (34)	4.6M (60)	207 (30)	115 (56)
Victoria	5.6M (25)	4.1M (73)	158 (23)	111 (70)
Queensland	4.6M (20)	2.1M (46)	100(14)	69 (69)
South Australia	1.7M (8)	1.2M (71)	78 (11)	47 (60)
Western Australia	2.3M (10)	1.7M (74)	108 (16)	75 (69)
Tasmania#	0.5M (2)	0.2M (40)	35 (5)	14 (40)
Northern Territory	0.2M (1)	0.1M (50)	5 (1)	0 (0)
Total	**22.6M (100)**	**14.0M (62)**	**691 (100)**	**431 (66)**

M: million; ACT: Australian Capital Territory; NSW: New South Wales,*Data obtained from the Australian Bureau of Statistics (34), # Hobart is in ARIA category two

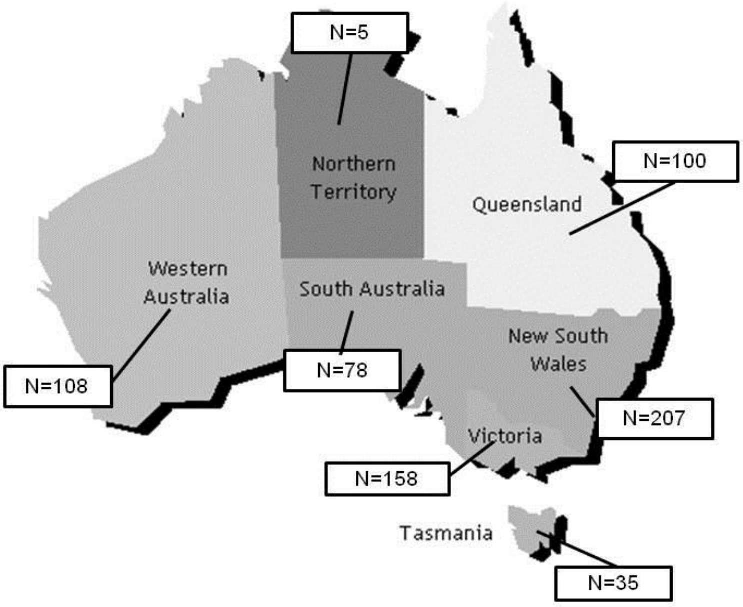


Figure 1 Distribution of respondents who provided postcodes (N=691)

Stroke survivor characteristics

The majority of the participants were male (Table 7) and the median age was 68 years (Q1, Q3: 59-77 years). The median time since stroke was two years (Q1, Q3: 2-4) with the majority being one to two years post-stroke. Almost half still required assistance with activities of daily living and three quarters (73%) said that they were still experiencing problems as a result of their stroke. The majority of participants were born in Australia (73%) and (14%) were born in non-English speaking countries. Only 12 participants (2%) identified themselves as being of Aboriginal or Torres Strait Islander descent. This is less than the national representation of 3%.

Table 7 Respondent characteristics

	Online n (%)	Paper based n (%)	All N
Total	198	567	765
Age*			
<65	104 (38)	167 (62)	271
65-74	38 (18)	177 (82)	215
75+	20 (9)	198 (91)	218
Gender*			
Male	94 (21)	351 (79)	445
Female	68 (25)	201 (75)	269
Time since stroke†			
1-2years	90 (22)	311 (78)	401
3+ years	65 (24)	205 (76)	270
Location†			
Major city	105 (25)	312 (75)	417
Inner regional	36 (21)	137 (79)	173
Outer regional	15 (17)	72 (83)	87
ADL assistance*			
No	76 (18)	347 (82)	423
Yes	85 (30)	195 (70)	280

ADL: activities of daily living, *<10% missing data †10-<15% missing data

Overview of the extent to which stroke survivors needs were being met

Ninety-six percent (n=734) of all participants (N=765) reported having needs. Of those that reported having needs (N=731), 84% (n=614) had needs that were not fully met. Health needs were least likely to be fully met, followed by leisure needs and work needs. For those with needs the median number of needs not fully met was four (Q1, Q3: 1, 9). Figure 2 represents the proportion of participants whose needs were not fully met for each of the main categories. Additional details can be found in Table 8

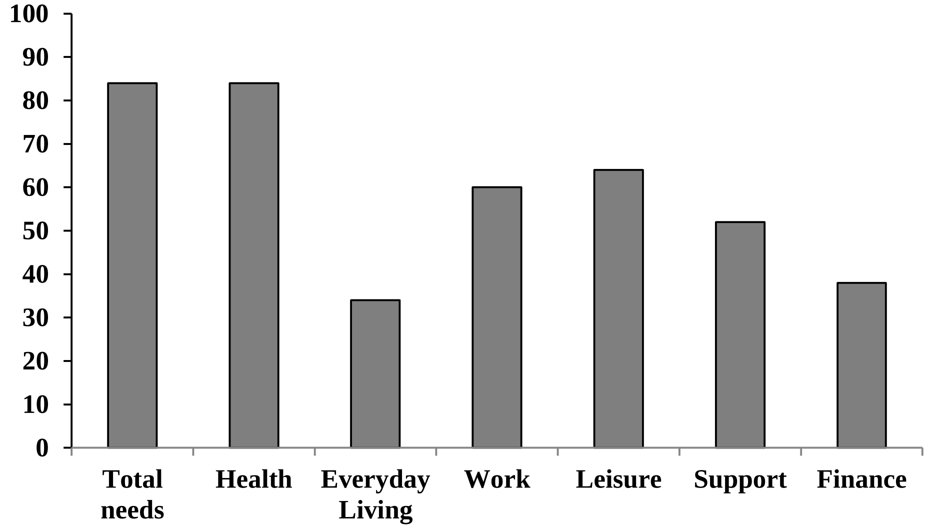


Figure 2 Percentage of participants with needs, whose needs were not fully met

Table 8 Participants with fully met and not fully met needs as a proportion of those with needs in that area

	Total with needs (N)	Need was fully met n (%)	Need was not fully met (%)
Health	708	115 (16)	593 (84)
Everyday living	521	346 (66)	175 (34)
Work	171	69 (40)	102 (60)
Leisure	368	131 (36)	237 (64)
Support	420	202 (48)	218 (52)
Finance	301	188 (62)	113 (38)
All Needs	730	119 (16)	611 (84)

Section 1: Stroke survivors health needs

Information needs

Most of the respondents (80%) reported receiving enough information about their stroke such as what is a stroke, why it happened and how to avoid having another one. A similar number (81%) reported having sufficient advice about how to improve their diet. Those that would have liked more information felt that more information regarding the cause of the stroke and the particular area of the brain affected, as well as secondary prevention management, including diet, lifestyle changes and medication would be useful. Many thought that having more of this information provided earlier after the initial stroke would be beneficial. Additional information on recognising the signs and symptoms of stroke, longer term recovery and prognosis, including further rehabilitation options, and educational materials on mood and emotional changes were also highlighted.

Blood pressure checks

Almost all respondents (99%) reported having had their blood pressure checked in the previous 12-months. For those that did not have their blood pressure checked, common reasons included that they did not like going to the doctor, or if they went to their doctor it didn't get checked.

Table 9. Proportion of all respondents reporting health problems and the extent to which their needs were being met

	Total (N)	Did not have the problem n (%)	Did not want help n (%)	Need was fully met n (%)	Need was not fully met
Mobility	749	177 (24)	17 (2)	300 (40)	255 (34)
Falls	749	238 (32)	20 (3)	265 (35)	226 (30)
Incontinence	746	335 (45)	33 (4)	182 (24)	196 (26)
Pain	748	323 (43)	17 (2)	187 (25)	221 (30)
Swallowing	746	425 (57)	19 (3)	170 (23)	132 (18)
Fatigue	743	167 (22)	77 (10)	124 (17)	375 (51)
Emotions	740	236 (32)	69 (9)	118 (16)	317 (43)
Concentration	733	240 (33)	62 (8)	93 (13)	338 (46)
Memory	734	234 (32)	67 (9)	101 (14)	332 (45)
Speech	738	320 (43)	36 (5)	159 (22)	223 (30)
Cognition	742	285 (38)	47 (6)	104 (14)	306 (41)
Reading	740	399 (54)	57 (8)	87 (12)	197 (27)
Vision	736	367 (50)	34 (5)	119 (16)	216 (29)

Health needs

Participants reported the extent to which 13 different health needs were being met. Responses are shown in Table 9. The most common health problems reported by participants were mobility problems (76%) and psychosocial problems such as fatigue (78%), emotional (68%), memory (68%) and concentration problems (67%). Psychosocial needs refer to those needs related to social and psychological function rather than physical function. Between 75-78% of participants with specific needs, reported that their needs related to concentration, memory, cognition, fatigue and emotions were not fully met. In general participants' physical needs were more likely to have been met. However, approximately half of those with physical needs still reported that these needs were not fully met (Table 10).

Table 10 Participants with fully met and not fully met health needs as a proportion of those with needs in that area

	Total with needs (N)	Need was fully met n (%)	Need was not fully met (%)
Mobility	555	300 (54)	255 (46)
Falls	491	265 (54)	226 (46)
Incontinence	378	182 (48)	196 (52)
Pain	408	187 (46)	221 (54)
Swallowing	302	170 (56)	132 (44)
Fatigue	499	124 (25)	375 (75)
Emotions	435	118 (27)	317 (73)
Concentration	431	93 (22)	338 (78)
Memory	433	101 (23)	332(77)
Speech	382	159 (42)	223 (58)
Cognition	410	104 (25)	306 (75)
Reading	284	87 (31)	197 (69)
Vision	335	119 (36)	216 (64)

Involvement in decisions about healthcare

Participants were asked about whether or not they had been involved as much as they would have liked to have been in decisions about their healthcare. Almost half (48%) reported that they had been sufficiently involved in their care and treatment decisions (Table 11).

Table 11 Involvement in decisions about treatment and care

Response	Number (%)
Yes, definitely	356 (48)
Yes, to some extent	153 (21)
No, but I would have liked to	51 (7)
No, but I do not mind	36 (5)
Don’t know/Can’t say	28 (4)
Did not have any medical care or treatment	114 (15)

Participants were also asked to comment further on what type of help or service would have been useful to help address any health needs that were not being fully met. Some of the main suggestions included improving access to therapy for physical problems, both in hospital based rehabilitation and community settings, and more assistance with reading and writing difficulties. Respondents felt that additional support and treatment for psychological issues including concentration, memory, fatigue and depression, and more regular medical and allied health follow up would also be beneficial. Although not directly asked, there were respondents who stated they were unaware of what assistance was actually available to address these needs.

Section 2: Stroke survivors everyday living needs

Home assistance

Participants were asked if they had received enough help with personal care, home care and maintenance and home adaptations. Of the 363 participants that needed help with personal care 16% reported that they were either not receiving enough or not receiving any help.

For help around the house, 34% of the 390 participants that needed help around the house reported that they were either not receiving any help or not receiving enough help.

Of the 404 participants that needed adaptations made to their home, 19% reported not having enough or any adaptations made. Only 2% of those needing adaptations reported that they needed assistance looking into options for moving to another home.

Table 12. Responses to everyday living needs

Response	Personal care n (%)	Home help n (%)	Home adaptations n (%)
Yes, all the help I needed	281 (38)	206 (28)	321 (44)
Yes, some but not enough	40 (5)	59 (8)	51 (7)
No, but I would have liked to	19 (3)	74 (10)	32 (4)*
I did not need this service	371 (51)	339 (47)	331 (45)
I was already receiving this type of help	23 (3)	51 (7)	N/A
Total (N)	734	729	735

*includes those who need help to move house

Travel and use of transport

Participants were asked if their use of transport and travel had changed because of their stroke, why this had changed and if they had received enough information and help with their transport use. Transport use had changed for 60% of participants and almost half (44%) reported moderate to extreme changes in their use of transport. Of those that reported a change, 57% said that it was due to physical reasons, 11% because of emotional reasons, 24% because of physical and emotional reasons and 8% due to other reasons (

Figure **3**). The qualitative responses revealed that some of the ‘other’ reasons reported included a loss of confidence in their ability to use public transport, ongoing fatigue, and issues related to concentration and memory deficits. Many respondents reported that an increased burden was placed on family and friends due to changes in their transport needs.

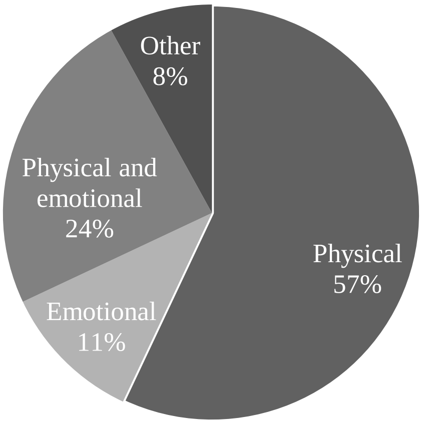


Figure 3 Reasons for changes in transport use.
Denominator only includes those that reported a change in transport use

Most (72%) reported receiving enough advice about driving or getting a disabled parking permit. Of the 366 participants that reported needing public transport advice after stroke, 53% reported that they had received no advice or not enough advice about transport use. From the qualitative responses, respondents reported that additional information on their eligibility and the process for applying for taxi vouchers, and determining any concessions they may be eligible for would be helpful. Identifying services that were available in their local area that could help with transport, especially to and from appointments, and the practicalities of travelling on public transport i.e. booking a taxi, or purchasing tickets on buses or trains were also reported as areas of need.

Participants were also asked to comment further on what other type of help or service would assist them with their everyday living needs. Responses commonly included assistance with house cleaning and domestic duties, shopping, and outdoor home maintenance. Respondents also stated that having accessible transport, and respite for carers or increased help with carer needs would improve everyday living requirements.

Section 3: Stroke survivors work and leisure needs

Of the stroke survivors who were working prior to their stroke (n=431) about three in four (71%) reported a change in their work activities since their stroke and 57% reported that the change was moderate to extreme. Of those that needed help returning to work (n=171), 40% reported that they received all the help they needed and 60% reported that they did not receive any or enough help returning to work (Figure 4). The qualitative responses provided evidence that those survivors who had returned to some form of work identified different needs and assistance to address these needs compared to those who had not returned to work or study. For example, further advice regarding what jobs would be suitable with their current capabilities, practical assistance finding work, and retraining were the issues identified for those looking to enter the workforce again. For those who had returned to work, the types of assistance that participants felt would be useful included additional information on return to work programs that would integrate them back into the workforce and assisted them to deal with the demands of work i.e. fatigue and deadlines, as well as information on any financial assistance that may be available.

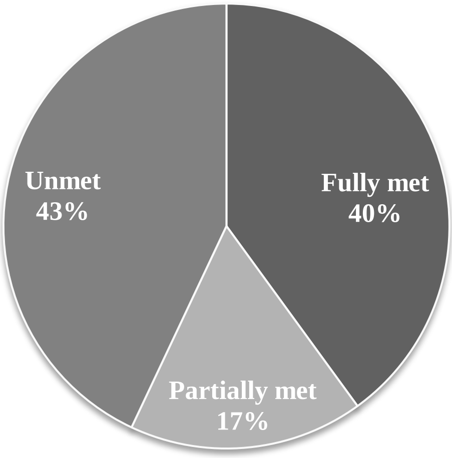


Figure 4 Unmet work needs for those needing assistance returning to work

Almost 80% of participants reported that their leisure activities had changed since their stroke with over half (53%) reporting that this change was moderate to extreme. Of the 368 participants that needed assistance returning to leisure activities, 36% reported that they received all the help that they needed and 64% reported that they did not receive enough help returning to leisure activities (Figure 5). Participants stated that further information about what leisure activities were available and appropriate to their needs would be useful. The respondents who travelled felt that additional advice about means of travel and accommodation which included disabled facilities would have been valuable.

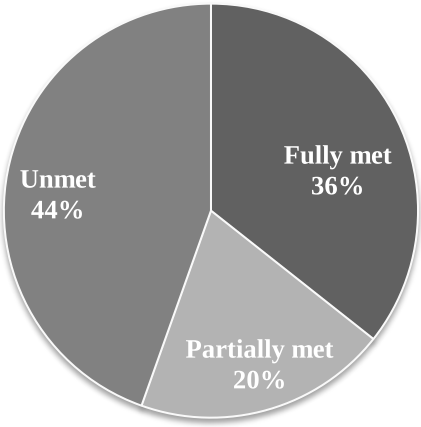


Figure 5 Unmet leisure needs for those needing assistance returning to leisure activities

Section 4: Stroke survivors family, friends and support group needs

Of the 569 participants that had a partner or spouse, 57% reported that their stroke had a negative impact on their relationship and 34% reported that this change was moderate to extreme. Of those for whom it was applicable, 18% reported that they would like advice or information about sexual relations.

Almost half (43%) reported that their relationship with family members had changed since their stroke with almost a quarter (23%) reporting a moderate to extreme change. Over half (51%) reported a change in relationships with people other than family with almost one third (31%) reporting a moderate to extreme change.

Almost two thirds 420 (61%) of participants felt that they needed “external” emotional support, outside of family and friends. Of these 52% reported that they were either not getting enough or not getting any external support (Figure 6).

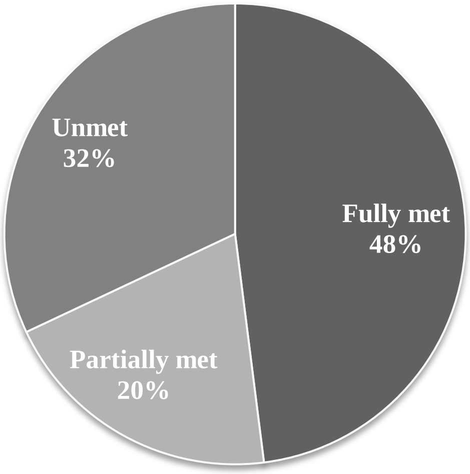
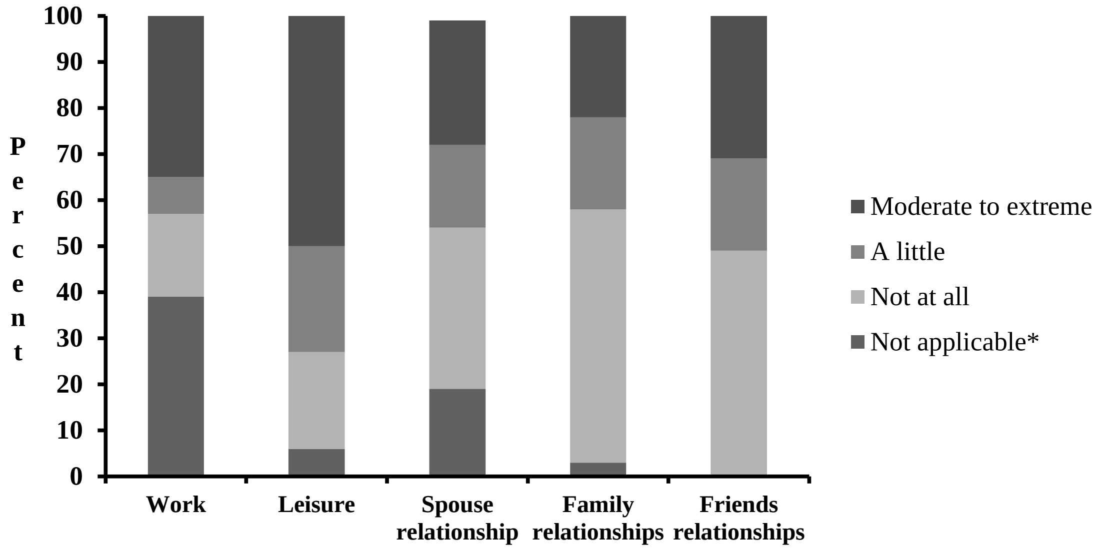


Figure 6 Unmet support needs for those that needed external emotional support

Over one quarter (26%) of participants had attended a support group for people who had experienced a stroke. Eleven percent reported that they would have liked to have attended a support group and 24% said that they were not aware of a local support group. Over one third (39%) reported that they did not want to attend a support group.

When asked to further clarify why they had not attended a support group, there were various reasons reported. Some respondents stated that there was not a support group in their local area, which led to difficulties in accessibility. Others felt that their stroke was only mild and they didn't see a need for it, or that their family and friends provided enough support. Several respondents reported that they didn't want to talk about their problems with others as they were private people. Financial costs associated with attending a support group were also reported as a limiting factor.

Participants were asked to elaborate about other things that they felt would assist with relationships with family and friends using free text responses. The common theme that arose was that by having more information and education material available for family and friends they could better understand the effects and changes after stroke. It was reported that additional support and assistance for family who are carers would also assist with improving relationships with family and friends. Respondents also stated that having an improved understanding and possible strategies for coping with their own emotional and psychological changes, and further assistance in managing communication deficits would assist in fostering these relationships. The need for support groups, with a focus on the needs of younger stroke survivors was also highlighted from the qualitative responses.



**Not applicable means that this category did not apply to them e.g. they were not working prior to their stroke or they did not have a partner or spouse. Other categories refer to the degree of change since having a stroke.*

Figure 7 Impact of stroke on activities and relationships

Section 5: Stroke survivors financial needs

Over one third (36%) of respondents reported a loss in income since having their stroke and almost two in three (60%) reported experiencing an increase in expenses. Almost half (48%) were receiving some form of benefit. Of the remaining participants, 37% were not receiving benefits because they were not eligible or did not need benefits, 11% were not receiving benefits but felt that they should be or didn't know why they weren't, and 3% were not receiving benefits because they found the system too difficult to negotiate.

Almost half (n=301, 42%) reported needing some form of financial assistance or advice. Thirty percent of all responders who experienced a loss of income reported not getting enough financial advice and 24% of responders who reported increased expenses were not getting enough financial advice. Of the 301 participants who needed advice, 37% reported that they either did not receive any or did not receive enough financial assistance. From the qualitative responses, the types of assistance that participants reported needing included an overall summary of what benefits are available and whether or not they or their family/carers were eligible to receive them, as well as specific financial planning advice. Respondents also stated that further assistance in accessing and completing Centrelink forms would be beneficial.

Other comments

Only 12% of participants reported having other needs not fully covered by the survey. The qualitative free text responses allowed further analysis of responses regarding other needs and additional information reported by participants, which covered various areas.

Respondents reported:
- Wanting improved access to sources of information about what services are available to stroke survivors and their family/carers.
- Being burdened by having to source the information independently
- Wanting additional support for younger stroke survivors, including access to further rehabilitation, services, educational opportunities and support groups that specifically address their needs
- That the financial burden, including the cost of medication, treatments (e.g. botox for limb spasticity), driving tests, doctors' visits and equipment (i.e. modified cars) needed to be addressed and possibly subsidised.
- Additional needs associated with transport, access to services, medical and therapy staff and support groups for those in rural or remote areas.

Proportion of stroke survivors with needs according to sub-groups

Variations observed by state

Variations in the proportions of participants with needs in a particular area who reported that their needs were not fully met varied between States. Participants from Queensland (90%) and Western Australia (88%) reported the greatest levels of health needs that were not fully met. Participants from Victoria (40%) and NSW (34%) reported the greatest levels of living needs that were not fully met. Leisure needs were most likely to be not fully met in NSW (68%) and Western Australia (67%) and work needs were most likely to be not fully met in Western Australia (83%) and Queensland (70%). Support needs were most likely to be not fully met in Queensland (58%) followed by Western Australia (56%) and NSW (56%). The financial needs were most likely to be not fully met in Queensland (42%) and NSW (43%). Overall, Queensland had the greatest proportion of participants that reported their needs, across multiple categories of the survey, to be not fully met (Table 13 and Table 14). Variations in the extent to which health needs were fully met were also observed between states, especially in regards to speech, swallowing and vision needs (Table 14).

Table 13. Levels of needs reported by state, across all domains measured

	n (%)	Health needs N=642[†]	Living needs N=481[†]	Work needs N=158[¥]	Leisure needs N=344[‡]	Support needs N=395[‡]	Financial needs N=288[‡]	All needs N=662
New South Wales N=207	**With need**	191 (93)	148 (73)	47 (24)	103 (51)	111 (54)	72 (36)	199 (96)
	Not fully met	159 (83)	50 (34)	24 (51)	70 (68)	62 (56)	31 (43)	165 (83)
Victoria N=158	**With need**	151 (96)	102 (65)	44 (29)	82 (53)	100 (64)	65 (42)	153 (97)
	Not fully met	125 (83)	41 (40)	25 (57)	53 (65)	47 (47)	23 (35)	132 (86)
Queensland N=100	**With need**	96 (96)	80 (80)	27 (29)	59 (60)	66 (67)	52 (53)	98 (98)
	Not fully met	86 (90)	26 (33)	19 (70)	38 (64)	38 (58)	22 (42)	87 (89)
South Australia N=78	**With need**	68 (87)	47 (61)	12 (16)	32 (43)	41 (55)	37 (49)	72 (92)
	Not fully met	54 (79)	15 (32)	6 (50)	18 (56)	16 (39)	11 (30)	56 (78)
Western Australia N=108	**With need**	101 (94)	78 (72)	18 (19)	52 (50)	61 (58)	52 (49)	103 (95)
	Not fully met	89 (88)	25 (32)	15 (83)	35 (67)	34 (56)	16 (31)	90 (87)
Tasmania N=35	**With need**	30 (86)	23 (66)	8 (26)	15 (45)	14 (42)	9 (26)	32 (91)
	Not fully met	21 (70)	4 (17)	4 (50)	7 (47)	6 (43)	2 (22)	21 (66)
Australia N=686	**With need**	637 (93)	478 (70)	156 (24)	343 (51)	393 (59)	287 (43)	657 (96)
	Not fully met	534 (84)	161 (34)	93 (60)	221 (64)	203 (52)	105 (37)	551 (84)

N for domains: includes only those with a need in that area, [†]≤1% missing data, [‡] ≤5%, [¥] ≤10% missing data. Not fully met = partially met + unmet. In this table only 686 of the 765 respondents were included. 74 were excluded due to missing postcodes and data from the Northern Territory was not included due to low numbers (n=5). New South Wales includes data from the Australian Capital Territory

Table 14 Breakdown of health needs categories by State

	n (%)	Mobility N=506‡	Falls N=447†	Incontinence N=339‡	Pain N=368†	Swallowing* N=273‡	Fatigue N=454‡	Emotions N= 399‡	Concent-ration N= 401‡	Memory N=398‡	Speech* N=351‡	Cognition N=376†	Reading N=258†	Visual problems* N=311‡
New South Wales N=207	**With need**	149 (73)	133 (66)	99 (49)	113 (55)	81 (40)	122 (60)	113 (56)	109 (55)	114 (56)	92 (46)	112 (55)	78 (38)	94 (46)
	Not fully met	71 (48)	60 (45)	52 (53)	63 (56)	36 (44)	86 (70)	81 (72)	86 (79)	89 (78)	53 (58)	81 (72)	52 (67)	58 (62)
Victoria N=158	**With need**	116 (74)	96 (61)	74 (47)	73 (46)	59 (38)	104 (66)	86 (54)	99 (63)	100 (64)	84 (53)	91 (58)	58 (37)	65 (41)
	Not fully met	45 (39)	41 (43)	41 (55)	38 (52)	31 (53)	74 (71)	61 (71)	72 (73)	75 (75)	44 (52)	67 (74)	42 (72)	41 (63)
Queensland N=100	**With need**	82 (82)	71 (71)	55 (55)	67 (68)	46 (46)	79 (79)	72 (72)	72 (73)	70 (71)	61 (62)	63 (64)	44 (44)	55 (56)
	Not fully met	38 (46)	38 (54)	27 (49)	40 (60)	17 (37)	68 (86)	57 (79)	59 (82)	53 (76)	40 (66)	52 (83)	30 (68)	41 (75)
South Australia N=78	**With need**	53 (69)	48 (62)	39 (51)	34 (44)	29 (38)	45 (59)	40 (52)	35 (46)	32 (43)	38 (49)	35 (45)	23 (30)	30 (40)
	Not fully met	23 (43)	22 (46)	25 (64)	20 (59)	16 (55)	35 (78)	28 (70)	28 (80)	25 (78)	18 (47)	27 (77)	16 (70)	19 (63)
Western Australia N=108	**With need**	83 (78)	79 (73)	59 (56)	62 (57)	45 (42)	76 (70)	65 (60)	64 (59)	61 (56)	52 (48)	56 (52)	40 (37)	50 (46)
	Not fully met	44 (53)	39 (49)	26 (44)	27 (44)	17 (38)	58 (76)	49 (75)	53 (83)	50 (82)	37 (71)	41 (73)	30 (75)	36 (72)
Tasmania N=35	**With need**	20 (57)	17 (49)	12 (34)	17 (49)	11 (31)	26 (74)	20 (57)	19 (56)	18 (51)	21 (60)	17 (50)	13 (37)	15 (43)
	Not fully met	3 (15)	3 (18)	5 (42)	8 (47)	1 (9)	15 (58)	12 (60)	11 (58)	10 (56)	10 (48)	9 (53)	5 (38)	4 (27)
Total N=686	**With need**	503 (74)	444 (65)	338 (50)	366 (54)	271 (40)	452 (67)	396 (58)	398 (59)	395 (59)	348 (51)	374 (55)	256 (38)	309 (46)
	Not fully met	224 (45)	203 (46)	176 (52)	196 (54)	118 (44)	336 (74)	288 (73)	309 (78)	302 (76)	202 (58)	277 (74)	175 (68)	199 (64)

*Differences are statistically significant $p<0.05$, N for domains: includes only those with a need in that area, † ≤1% missing data, ‡ ≤5% missing data. Not fully met = partially met + unmet.

In this table only 686 of the 765 respondents were included. 74 were excluded due to missing postcodes and data from the Northern Territory was not included due to low numbers (n=5). New South Wales includes data from the Australian Capital Territory

Analyses according to level of remoteness

There were no differences in the proportion of participants reporting leisure needs or support needs that were not fully met based on whether they resided in a major city, an inner regional area or an outer regional area (Table 15). However, a greater proportion of participants residing in cities reported that their needs were not fully met in areas such as, work, finances and everyday living. Stroke survivors residing in inner regional areas were most likely to have their needs met in these areas. (Table 15). Health needs such as speech and swallowing were also least likely to be met in those residing in major cities (Table 16).

Table 15 Levels of needs reported by state location according to remoteness across all domains measured

	n (%)	Health needs N=630†	Living needs* N=470†	Work needs* N=154¥	Leisure needs N=336‡	Support needs N=386‡	Financial needs* N=281‡	All needs N=648
Major city N=417	**With need**	383 (92)	283 (68)	97 (24)	203 (50)	238 (58)	177 (44)	400 (96)
	Not fully met	326 (85)	107 (38)	65 (67)	139 (68)	129 (54)	75 (42)	336 (84)
Inner regional N=173	**With need**	164 (95)	121 (70)	43 (27)	89 (53)	99 (58)	71 (41)	165 (95)
	Not fully met	135 (82)	26 (21)	18 (42)	50 (56)	51 (52)	18 (25)	138 (84)
Outer regional N=87	**With need**	83 (95)	66 (77)	14 (17)	44 (53)	49 (59)	33 (39)	83 (95)
	Not fully met	66 (80)	24 (36)	8 (57)	29 (66)	22 (45)	9 (27)	70 (84)
Total N=677	**With need**	630 (93)	470 (70)	154 (24)	336 (51)	386 (58)	281 (42)	648 (96)
	Not fully met	527 (84)	157 (33)	91 (59)	218 (65)	202 (52)	102 (36)	544 (84)

*Differences are statistically significant $p<0.05$, N for domains: includes only those with a need in that area, † ≤1% missing data, ‡ ≤5% missing data, ¥ <10% missing data. Not fully met = partially met + unmet.

In this table only 677 of the 765 respondents provided sufficient information to be categorised according to their level of remoteness

Table 16 Levels of different health needs reported by location according to remoteness

	n (%)	Mobility N=495‡	Falls N=437†	Incontinence N=330‡	Pain N=360†	Swallowing* N=268‡	Fatigue N=446‡	Emotions N= 392‡	Concentration N= 394‡	Memory N=392‡	Speech* N=343‡	Cognition N=371†	Reading N=254†	Vision N=305‡
Major city N=417	**With need**	311 (75)	265 (64)	200 (49)	216 (52)	160 (39)	270 (65)	242 (59)	231 (56)	230 (56)	212 (51)	230 (56)	146 (35)	165 (40)
	Not fully met	146 (47)	126 (48)	110 (55)	121 (56)	83 (52)	211 (78)	182 (75)	186 (81)	184 (80)	135 (64)	177 (77)	105 (72)	113 (68)
Inner regional N=173	**With need**	119 (70)	109 (64)	77 (45)	94 (54)	67 (39)	116 (68)	94 (55)	106 (62)	106 (62)	82 (48)	90 (53)	68 (40)	92 (53)
	Not fully met	50 (42)	48 (44)	32 (42)	47 (50)	21 (31)	82 (71)	66 (70)	84 (79)	76 (72)	46 (56)	64 (71)	46 (68)	58 (63)
Outer regional N=87	**With need**	65 (76)	63 (73)	53 (62)	50 (58)	41 (48)	60 (70)	56 (64)	57 (66)	56 (67)	49 (56)	51 (59)	40 (47)	48 (56)
	Not fully met	23 (35)	27 (43)	28 (53)	23 (46)	13 (32)	39 (65)	37 (66)	38 (67)	41 (73)	19 (39)	35 (69)	24 (60)	25 (52)
Total N=677	**With need**	495 (74)	437 (65)	330 (49)	360 (54)	268 (40)	446 (67)	392 (59)	394 (59)	392 (59)	343 (51)	371 (55)	254 (38)	305 (46)
	Not fully met	219 (44)	201 (46)	170 (52)	191 (53)	117 (44)	332 (74)	285 (73)	308 (78)	301 (77)	200 (58)	276 (74)	175 (69)	196 (64)

*Differences are statistically significant $p<0.05$, N for domains: includes only those with a need in that area, † ≤1% missing data, ‡ ≤5% missing data. Not fully met = partially met + unmet.

In this table only 677 of the 765 survivor respondents provided sufficient information to be categorised according to their level of remoteness

Analyses by age group

Comparisons were made between those whose needs were fully met and those whose needs were not fully met. The denominator included only those who had needs in the areas reported (Table 17 and Table 18). The survey results have highlighted that the needs of younger stroke survivors (< 65 years) varied compared to those of older (≥ 65 years) stroke survivors. Younger stroke survivors were more likely to report having needs that were not fully met {median seven (Q1, Q3: 2, 11)} compared to older stroke survivors {median four (Q1, Q3: 1, 8)}. A significantly greater proportion of younger stroke survivors reported needs that were not fully met across the domains of health, everyday living, leisure activities, support and finances (Table 17) Younger stroke survivors were more likely to have health needs related to falls, pain, concentration and vision that were not fully met (Table 18).

Analysis by gender

There were few differences between genders. Women reported a median of five needs that were not fully met (Q1, Q3: 1, 10) whereas men reported a median of four (Q1, Q3: 1, 9). However, the difference was not statistically significant. There were no significant differences in the proportion of men and women reporting needs that were not fully met for any of the needs categories (Table 17 and Table 18).

Analysis by time since stroke

Levels and types of needs that were not being fully met also varied according to time since stroke. Those who were three or more years post-stroke reported significantly more needs that were not fully met (median : 6; Q1, Q3: 2, 10) than those who were one to two years post-stroke (median 4; Q1, Q2: 1, 9). A greater proportion also reported that their needs were not being fully met. However, a significantly greater proportion of those who were one to two years post-stroke reported needs that were not fully met related to living needs, leisure needs and financial needs, compared to those who were three or more years post-stroke (Table 17). Those who were 1-2 years post-stroke were also more likely to report health needs related to pain and reading that were not fully met (Table 18).

Analysis by levels of disability

Those with greater levels of disability as indicated by still needing assistance with activities of daily living (ADLs), reported significantly greater levels of needs that were not fully met across multiple categories compared to those that did not need assistance with ADLs. There was a significant difference in the number of needs not fully met between those who needed assistance with ADLs (median 8; Q1, Q3: 3, 12) and those who did not need assistance with ADLs, (median 3; Q1, Q3: 0, 7). In particular participants with greater levels of disability were significantly more likely to report needs that were not fully met related to health, assistance with everyday living, returning to work, returning to leisure activities and emotional support (Table 17). Those with greater levels of disability were more likely to report having health needs that were not fully met in all areas except for incontinence, swallowing and emotions (Table 18).

Table 17 Results of the Subgroup analyses across all domains measured

	n (%)	Health needs† N=708 (93)	Living needs‡ N=521 (68)	Work needs¥ N=171 (22)	Leisure needs¥ N=368 (48)	Support needs¥ N=395 (52)	Financial needs¥ N=301 (39)	All needs† N=730 (95)
Age <65# N=271	***With need***	255 (95)	167 (62)	125 (48)	153 (57)	183 (69)	126 (47)	261 (96)
	Not fully met	224 (88)*	78 (47)*	77 (62)	112 (73)*	116 (63)*	69 (55)*	229 (88)*
Age 65+# N=433	***With need***	398 (92)	322 (75)	39 (10)	195 (47)	219 (52)	165 (39)	413 (95)
	Not fully met	325 (82)*	89 (28)*	21 (54)	114 (58)*	94 (43)*	40 (24)*	338 (82)*
Male# N=445	***With need***	406 (91)	287 (65)	111 (27)	218 (50)	237 (55)	178 (41)	420 (94)
	Not fully met	337 (83)	90 (31)	67 (60)	137 (63)	123 (52)	64 (36)	351 (84)
Female# N=269	***With need***	257 (96)	212 (79)	54 (21)	137 (52)	172 (65)	116 (44)	264 (98)
	Not fully met	220 (86)	79 (37)	31 (57)	93 (68)	89 (52)	45 (39)	224 (85)
1-2 years post-stroke# N=401	***With need***	359 (90)	259 (65)	79 (21)	182 (47)	215 (55)	155 (39)	376 (94)
	Not fully met	293 (82)	97 (37)*	53 (67)	127 (70)*	119 (55)	67 (43)*	306 (81)*
3+ years post-stroke# N=270	***With need***	262 (97)	207 (77)	76 (30)	154 (59)	170 (64)	125 (48)	265 (98)
	Not fully met	229 (87)	58 (28)*	40 (53)	90 (58)*	80 (47)	36 (29)*	233 (88)*
Independent with ADLs# N=423	***With need***	376 (89)	230 (55)	97 (26)	159 (38)	209 (50)	127 (31)	393 (93)
	Not fully met	290 (77)*	61 (27)*	44 (45)*	80 (50)*	88 (42)*	41 (32)	300 (76)*
Not independent with ADLs# N=280	***With need***	276 (99)	261 (94)	67 (26)	191 (71)	196 (73)	165 (61)	280 (100)
	Not fully met	258 (93)*	105 (40)*	53 (79)*	146 (76)*	123 (63)*	66 (40)	265 (95)*

*Differences are statistically significant p<0.005, † ≤1% missing data, ‡ ≤5% missing data, ¥ ≤10% missing data. N for domains: includes only those with a need in that area, %: the percentage of total respondents with that need, ADL: activities of daily living, Not fully met = partially met + unmet. # proportions do not always add up due to missing data

Table 18 Levels of different health needs reported by sub-groups

	n (%)	Mobility N=555†	Falls N=491†	Incontinence N=378†	Pain N=408†	Swallowing N=302†	Fatigue N=499‡	Emotions N=435‡	Concentration N=431‡	Memory N=433‡	Speech N=382‡	Cognition N=410‡	Reading N=284‡	Vision N=335‡
Age <65# N=271	**With need**	191 (72)	166 (62)	116 (43)	151 (57)	107 (40)	200 (74)	183 (68)	178 (67)	167 (63)	141 (53)	159 (59)	110 (41)	120 (45)
	Not fully met	97 (51)	93 (56)*	63 (54)	96 (64)*	44 (41)	159 (80)	142 (78)	152 (85)*	136 (81)	91 (65)	122 (77)	81 (74)	90 (75)*
Age ≥65# N=433	**With need**	324 (75)	290 (67)	231 (54)	222 (52)	169 (39)	260 (61)	224 (52)	226 (53)	236 (55)	215 (50)	222 (52)	150 (35)	193 (45)
	Not fully met	135 (42)	119 (41)*	120 (52)	105 (47)*	78 (46)	186 (72)	158 (71)	164 (73)*	175 (74)	117 (54)	163 (73)	100 (67)	113 (59)*
Male# N=445	**With need**	323 (73)	276 (62)	209 (47)	238 (54)	179 (41)	279 (63)	250 (57)	251 (57)	247 (56)	218 (50)	232 (52)	164 (37)	196 (45)
	Not fully met	145 (45)	130 (47)	103 (49)	123 (52)	81 (45)	203 (73)	185 (74)	195 (78)	183 (74)	129 (59)	175 (75)	113 (69)	128 (65)
Female# N=269	**With need**	199 (76)	186 (70)	143 (55)	144 (54)	103 (39)	190 (72)	164 (62)	158 (60)	162 (62)	145 (55)	154 (58)	102 (38)	122 (46)
	Not fully met	90 (45)	85 (46)	82 (57)	82 (57)	43 (42)	147 (77)	117 (71)	123 (78)	130 (80)	82 (57)	112 (73)	70 (69)	77 (63)
1-2 years post-stroke# N=401	**With need**	266 (67)	231 (58)	172 (43)	199 (50)	142 (36)	247 (62)	217 (55)	220 (56)	214 (54)	186 (47)	205 (52)	143 (36)	165 (42)
	Not fully met	114 (43)	106 (46)	86 (50)	119 (60)*	58 (41)	190 (77)	162 (75)	170 (77)	158 (74)	102 (55)	152 (74)	92 (64)*	108 (65)
3+ years post-stroke# N=270	**With need**	224 (84)	203 (75)	156 (59)	158 (59)	124 (46)	190 (71)	166 (62)	162 (61)	169 (64)	154 (58)	160 (60)	105 (39)	131 (49)
	Not fully met	105 (47)	94 (46)	88 (56)	74 (47)*	58 (47)	141 (74)	122 (73)	132 (81)	136 (80)	97 (63)	121 (76)	80 (76)*	84 (64)
Independent with ADLs# N=423	**With need**	262 (63)	218 (52)	158 (38)	172 (41)	129 (31)	238 (57)	204 (49)	199 (48)	205 (50)	178 (43)	191 (45)	116 (27)	146 (35)
	Not fully met	77 (29)*	76 (35)*	75 (47)	80 (47)*	50 (39)	167 (70)*	145 (71)	143 (72)*	145 (71)*	88 (49)*	133 (70)*	67 (58)*	81 (55)*
Not independent with ADLs# N=280	**With need**	251 (90)	239 (86)	188 (68)	206 (74)	150 (54)	224 (81)	206 (74)	208 (76)	200 (73)	180 (65)	192 (70)	147 (53)	169 (62)
	Not fully met	153 (61)*	135 (56)*	106 (56)	122 (59) *	71 (47)	176 (79)*	154 (75)	173 (83)*	164 (82)*	119 (66)*	151 (79)*	113 (77)*	122 (72)*

*Differences are statistically significant $p<0.05$, N for domains: includes only those with a need in that area, † ≤1% missing data, ‡ ≤5% missing data #proportions do not always add up due to missing data

Not fully met = partially met + unmet

Indigenous stroke survivors

Participants were asked whether or not they were of Aboriginal or Torres Strait Islander descent. Only 12 (2%) participants reported that they were of Aboriginal or Torres Strait Islander descent. Accurate comparisons between Indigenous and non-Indigenous stroke survivors were difficult to make due to small sub group numbers. However, in general all of the Indigenous stroke survivors that participated in the study reported having health needs that were not fully met and twice as many reported having living needs that were not fully met compared to non-Indigenous stroke survivors. Half reported having support needs that were not fully met. All of the Indigenous participants reported that their needs regarding financial advice were being met and there were no differences in regards to the proportion of participants reporting that their leisure needs were not fully met between Indigenous and non-Indigenous participants. The median number of needs that were reported by Indigenous stroke survivors as not fully met was eight (Q1, Q3: 6, 10) compared to five (Q1, Q2: 1, 9) for non-Indigenous stroke survivors.

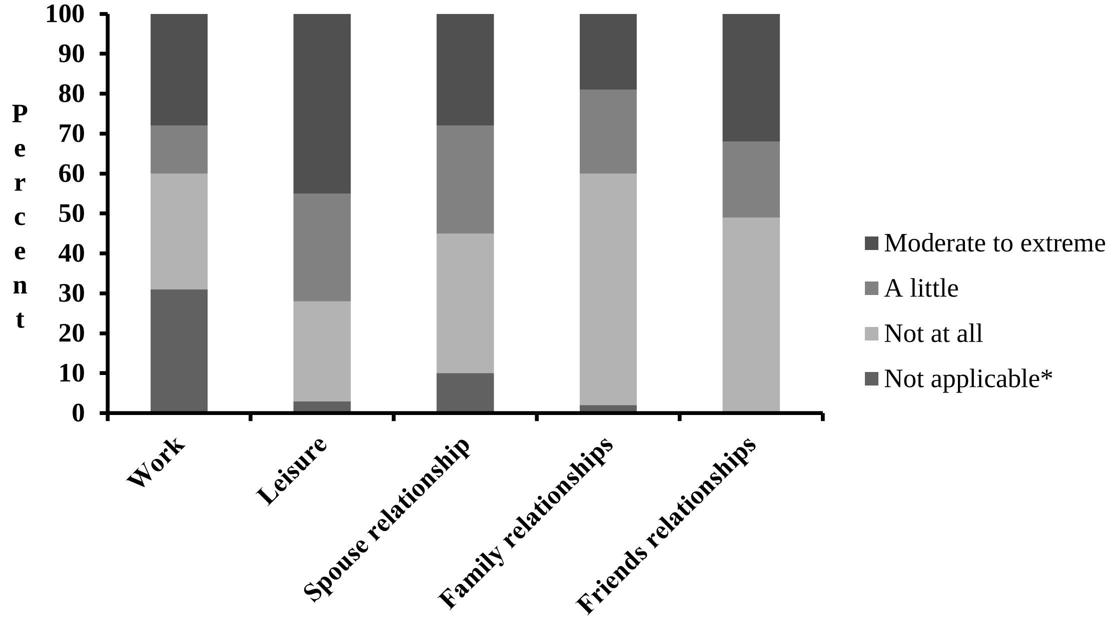
Caregivers results

Caregiver characteristics

The carer survey was completed by 387 participants with the majority (86%) being completed in paper based format. Most carers were female (74%) with a median age of 64 years (Q1, Q3: 55, 72 years). Most (87%) were living with the survivor and most were the spouse or partner of the survivor (76%) with 15% being the child of the survivor. The median number of years that the respondents had been in a carer role was two (Q1, Q3: 2, 5) and only 15% had previously been in a carer role.

Caregiver family, friends and support group needs

Among caregivers that were working prior to taking on a carer role (n=256) 40% reported a moderate to extreme reduction in the amount of work or study that they were able to perform. Of the 364 carers that participated in leisure activities prior to taking on a carer role, almost half (47%) reported a moderate to severe reduction in the number or type of leisure activities that they were able to participate in. Of carers that were the partner or spouse of the stroke survivor (n=336), almost one in three (31%) reported moderate to extreme changes in their relationship. However, only a few (10%) said that they would like some advice or information about sexual relationships with their partner. Many carers also reported moderate to extreme changes in their relationships with other family members (20%) and with other people outside the family such as friends (32%). Despite these large impacts, only one in four (23%) reported attending a carer support group. However, of those that did not attend a support (13%) reported that they would have liked to have attended and 21% were not aware of any support groups.



*Not applicable means that this category did not apply to them e.g. they were not working prior to taking on a carer role or they did not have a partner or spouse. Other categories refer to the degree of change since taking on a carer role.

Figure 8 Impact of stroke on caregiver activities and relationships

Caregiver financial needs

Almost one in three carers reported experiencing a loss of income (28%) since taking on a carer role and half (50%) reported having experienced an increase in personal expenses since taking on a carer role. Half (50%) were able to access carer benefits. However, there were still 11% of carers that either felt that they should be getting benefits or did not know if they should be but were not receiving any benefits.

Caregiver Community Health, respite services and support needs

There was variability in the qualitative responses of carers when asked about their experience of the available Community Health services in their local area. While it was difficult to determine their need for the service, there were carers who reported that they were unaware of Community Health services or had limited experience with them. For those who had accessed the services, the responses were generally positive. However, there were concerns raised about the cost of the service, especially for transportation to and from the centre, and the time limited nature of the service.

Carers were also asked if they had experienced any difficulties accessing Community Health services. The most common difficulty related to locating a community health service, especially in rural or remote locations. Other carers reported that there was often a long wait to access the health services, and inflexible session times also prohibited some survivors attending community health services.

Over half (54%) of the carers reported that they needed to use respite care. Of the 191 who needed respite care approximately one in four (24%) were not able to access it. From the qualitative responses, it was evident that further information on what respite care was available, who to contact and how to go about accessing the service would be beneficial. Respondents also stated that increasing the availability and accessibility of respite positions, especially the short term options, and reducing the cost of respite care would assist to improve access. Overall almost one 1 in five carers (21%) reported that they were not receiving enough social support in their carer role.

Table 19 provides a summary of the main results for stroke survivors and caregivers.

Table 19 Summary of results

Stroke Survivors (n=765)	Caregivers (n=387)
3 in 5 had a moderate to extreme change in work	2 in 5 had a moderate to extreme change in work
1 in 2 had a moderate to extreme change in their leisure activities	1 in 2 had a moderate to extreme change in their leisure activities
1 in 3 had a moderate to extreme change in relationships with their spouse/partner	1 in 3 had a moderate to extreme change in relationships with their spouse/partner
1 in 3 had a moderate to extreme change in relationships with friends	1 in 3 had a moderate to extreme change in relationships with friends
1 in 5 wanted advice on sexual relations	1 in 10 wanted advice on sexual relations
1 in 3 were not getting enough emotional support	1 in 5 were not getting enough emotional support
2 in 3 had an increase in expenses	1 in 2 had an increase in expenses
4 in 5 had health needs that were not fully met	
3 in 4 were not getting enough help with concentration, memory, cognition, fatigue and emotions	
1 in 3 were not getting enough help around the house	
1 in 2 did not receive enough help returning to work	

Discussion

The Australian Stroke Survivors and Carers Needs Assessment survey is the first national survey in Australia to obtain important and detailed information on the self-reported long-term needs of community dwelling stroke survivors and their carers. This survey is an important initial step in developing an evidence based approach towards adequately addressing service provision and program gaps in this area. The results obtained from this survey have highlighted that many stroke survivors have ongoing needs and issues several years after stroke across multiple domains, and that most of these needs are not being adequately addressed.

The pragmatic sampling methods used for this project meant that this survey is not able to accurately provide prevalence data on the needs of Australian stroke survivors. It is likely that patients whose needs were not being fully met were more likely to complete the survey than those whose needs were being fully met. However, these data provide important information on the types of needs that long-term stroke survivors have and the extent to which our governments, health services and health system are meeting those particular needs.

Results from this project highlighted some positive areas in regards to the provision of health care and services. Almost all participants had their blood pressure checked in the 12-months prior to completing the survey and most participants reported receiving enough information about what a stroke was and why it happened. However, in the open ended questions survivors indicated that that they would like more information on recovery and how to access support services, and that families and the community should be better educated about stroke. In general everyday living needs such as those related to personal care and home adaptations were more likely to be met than other types of needs and were being met for the majority of stroke survivors that required these services.

Health needs were the most common category of need not being met. Stroke survivors felt that psychological and cognitive needs such as those related to concentration, memory, cognition, fatigue and emotions were particularly neglected. These results are similar to those reported in the UK study in which higher proportions of not fully met needs were reported in areas such as fatigue, memory and concentration (35). Even though many stroke survivors reported having needs in areas such as mobility or falls prevention, participants felt that these physical needs were more likely to be met than their psychosocial needs. For example, a large proportion of participants reported having mobility needs (82%) and fatigue needs (71%). However, only 25% of those with fatigue problems reported that this need was being fully met compared to 50% of those with mobility needs. This may be because traditional models for stroke rehabilitation have focused on physical losses and assisting the stroke survivor with developing functional independence. Community supports have also traditionally focused on supporting functional independence which is reflected in the lower levels of needs associated with everyday living services.

Evidence suggests that many of the psychological and emotional consequences of stroke continue well beyond discharge from hospital and in many cases do not become apparent until the stroke survivor returns home and integrates back into their local community (23, 36). It is likely that both early and ongoing assessment of psychosocial problems is needed in order to identify those with needs in this area so that evidence based and accessible solutions can be made available to stroke survivors.

Many stroke survivors who required assistance returning to work and leisure activities reported that their needs in these areas were not being met. This is particularly important for maximising social participation for stroke survivors and improving quality of life after stroke. Returning to work and leisure activities are also important for minimising depression and social isolation that can often occur following a stroke (6, 12). It was also apparent from the results that insufficient emotional support was available for a large number of stroke survivors with more than half of those who felt they needed external emotional support, not receiving adequate assistance and only one quarter of stroke survivors attending a support group.

Although it was common for needs to not be fully met amongst all participants, certain sub-groups of stroke survivors were more at risk of not having their needs met than others. Geographically Australia is a large nation with a highly dispersed population. Approximately 60% of the Australian population live in major cities, the other 40% reside in regional or remote areas (34). Although stroke survivors living in more remote areas are likely to need to travel long distances to access services and formal support groups, needs were more likely to not be fully met in those residing in major cities, with those residing in inner regional areas most likely to have their needs fully met. This may be due to larger demands on services in major cities as compared to inner regional areas which still have a range of services available but with a smaller population to service. Another aspect may be the role that local community support may play in meeting the needs of stroke survivors. Previous research in this area has identified social support from family, friends and local community as a key factor in meeting the needs of stroke survivors and facilitating their ability to participate in society (12). This may have contributed to needs in areas such as work, everyday living and finances being fully met for those residing in rural areas as opposed to those residing in major cities.

These results have also highlighted the differences in needs experienced by younger stroke survivors compared to older stroke survivors. The median age of those who suffer a first stroke is about 77 years (2). Consequently young stroke survivors often report feeling unsupported, frustrated and socially isolated and may have additional difficulties associated with negotiating a health system predominantly developed for elderly stroke survivors (10). Young stroke survivors are also left to face many years of ongoing disability and may themselves be carers of young children or elderly parents. They may also be the primary income earner for a number of dependants. Therefore, it is not surprising that a greater proportion of young stroke survivors reported having needs that were not fully met in areas related to emotional support, social participation and finances. Addressing the needs of young stroke survivors are important since the long-term or lifetime costs associated with reduced quality of life can be enormous.

Not surprisingly a greater proportion of those with increased levels of disability reported that their needs were not fully met across most areas. This highlights the need for ongoing care for those with stroke related disabilities. The results of this report also show that the types of needs that are not being fully met can vary with time. A greater proportion of those who were 3 or more years post-stroke reported having more needs that were not fully met than those who were 1-2 years post-stroke. This may be due to increased difficulty in accessing rehabilitation and allied health services beyond the one to two year mark. However, those who were one to two year post-stroke reported increased leisure and financial assistance needs. These differences in needs demonstrate the importance of timing when planning for how best to meet the needs of different groups of stroke survivors.

This survey also captured the extent to which the needs of carers of stroke survivors were being met. It was shown that the impact on carers is significant. Most caregivers reported that work, leisure activities and relationships were heavily impacted on as a consequence of taking on a carer role. This is consistent with previous research in this area (20, 36). Although being a carer can be rewarding and some positive stories emerged from the qualitative data, the personal cost of being an informal carer is rarely acknowledged. It was also highlighted that many carers were unable to access support services such as respite care or support groups and often found it difficult to access services for both themselves and the stroke survivor through their local community health services. Table 20 highlights some of the main areas for intervention based on the results from the survey.

Although a geographically representative sample was obtained not all sub-groups of stroke survivors are adequately represented in this report. Very few participants were not born in Australia and those from non-English speaking backgrounds were poorly represented. Those that participated in the survey were younger than the median age of those that have a first time stroke in Australia (2). However, this may in part be due to younger stroke survivors having better survival following stroke and being more likely to be living in the community. Our sample also has an under-representation of survivors from Aboriginal or Torres Strait Islander descent. As this is a pragmatic sample it is also likely that those who completed the questionnaire were more likely to have needs that were not being fully met than those that did not complete the survey. Consequently, the data are likely to provide an overestimation of the total levels of need that were not being met reported by participants.

Table 20 Summary of major needs and areas for intervention

Stroke Survivors	Caregivers
More support for assisting young stroke survivors (<65 years) to return to work	Improve access to Community Health services
Improved assessment, management and support is needed to address the cognitive and psychological consequences of stroke	Improve access and availability of respite care
More information about disability related public transport use	More social support is needed for carers
More assistance in returning to leisure activities post-stroke is needed.	
More emotional support is needed for stroke survivors	
Financial assistance is needed to help stroke survivors adjust to the increased costs and reduced income associated with having a stroke	

Conclusion

The information contained in this report will assist to identify where, when and how best to optimally support stroke survivors and their carers in the community. This information is essential for planning and prioritising services for stroke survivors and carers from a consumer perspective and is an important first step in developing an evidence based approach to more comprehensive and suitable community based stroke care.

The effectiveness of existing services, in meeting important needs identified in this survey need to be evaluated and innovative solution sought to address gaps in service delivery related to these needs. In particular further investigation is required into how to best address the non-physical consequences of stroke a year or more after stroke. The needs of those who reported the greatest levels of needs that were not being fully met, such as younger stroke survivors, those with greater levels of disability and those from outer rural and remote areas should be prioritised for action.

The results of this research have the potential to greatly benefit the broader stroke community. The National Stroke Foundation are able to use this information to help develop evidence based policy, programs, and strategies aimed at better supporting stroke survivors and their carers in communities across Australia. The results may also be used by participating hospitals or other service providers to develop programmes or processes for addressing the needs of stroke survivors and their carers in the local community and inform the development of local stroke related services. This survey is an important first step in improving the lives of the large number of Australians that are living with the consequences of stroke.

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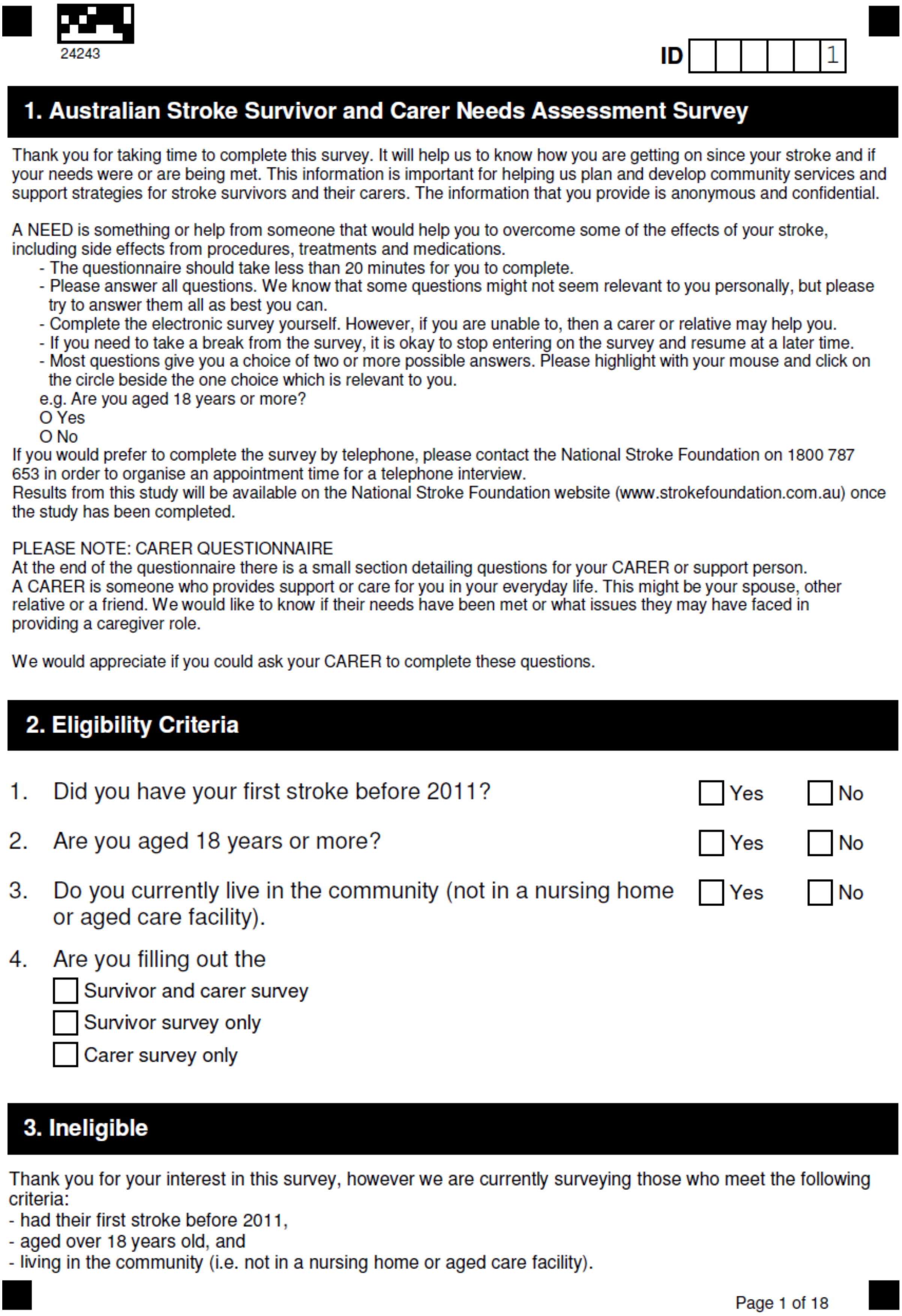
Appendix A: Stroke Survivor and Carer Needs Assessment Survey



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1. Australian Stroke Survivor and Carer Needs Assessment Survey

Thank you for taking time to complete this survey. It will help us to know how you are getting on since your stroke and if your needs were or are being met. This information is important for helping us plan and develop community services and support strategies for stroke survivors and their carers. The information that you provide is anonymous and confidential.

A NEED is something or help from someone that would help you to overcome some of the effects of your stroke, including side effects from procedures, treatments and medications.

- The questionnaire should take less than 20 minutes for you to complete.
- Please answer all questions. We know that some questions might not seem relevant to you personally, but please try to answer them all as best you can.
- Complete the electronic survey yourself. However, if you are unable to, then a carer or relative may help you.
- If you need to take a break from the survey, it is okay to stop entering on the survey and resume at a later time.
- Most questions give you a choice of two or more possible answers. Please highlight with your mouse and click on the circle beside the one choice which is relevant to you.

e.g. Are you aged 18 years or more?
○ Yes
○ No

If you would prefer to complete the survey by telephone, please contact the National Stroke Foundation on 1800 787 653 in order to organise an appointment time for a telephone interview.
Results from this study will be available on the National Stroke Foundation website (www.strokefoundation.com.au) once the study has been completed.

PLEASE NOTE: CARER QUESTIONNAIRE
At the end of the questionnaire there is a small section detailing questions for your CARER or support person.
A CARER is someone who provides support or care for you in your everyday life. This might be your spouse, other relative or a friend. We would like to know if their needs have been met or what issues they may have faced in providing a caregiver role.

We would appreciate if you could ask your CARER to complete these questions.

2. Eligibility Criteria

1. Did you have your first stroke before 2011? ☐ Yes ☐ No
2. Are you aged 18 years or more? ☐ Yes ☐ No
3. Do you currently live in the community (not in a nursing home or aged care facility). ☐ Yes ☐ No
4. Are you filling out the
   ☐ Survivor and carer survey
   ☐ Survivor survey only
   ☐ Carer survey only

3. Ineligible

Thank you for your interest in this survey, however we are currently surveying those who meet the following criteria:
- had their first stroke before 2011,
- aged over 18 years old, and
- living in the community (i.e. not in a nursing home or aged care facility).

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Appendix A: Stroke Survivor and Carer Needs Assessment Survey

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4. Information about Stroke and Stroke Survivors Needs Assessment Survey

Now we would like to ask you some questions about where you found out about the survey and what information you would like to have about stroke.

5. Where did you find out about the Stroke Survivor Needs Assessment Survey?

- ☐ StrokeConnect (online or telephone)
- ☐ AuSCR (Australian Stroke Clinical Registry)
- ☐ Hospital (where stroke survivor was treated)
- ☐ Website (National Stroke Foundation)
- ☐ Email signature (National Stroke Foundation)
- ☐ Advertisements
- ☐ Flyer at General Practitioner Office
- ☐ Other Stroke Support group
- ☐ Friend or relative
- ☐ Other stroke survivor

6. Since your stroke, have you been given enough information about your stroke (e.g. what is a stroke, why it happened and how to avoid having another one). ☐ Yes ☐ No

6a. If no,What type of information would be useful?

5. Your health

Now we would like to ask you some questions about your health and how you are feeling today about your health and wellbeing.

7. In the past 12 months, have you had your blood pressure checked by a health professional (e.g. doctor, nurse)? ☐ Yes ☐ No

7a. If no, why haven't you had your blood pressure checked by a health professional (e.g. doctor, nurse)?

8. Since you stroke, have you had enough advice about how to improve your diet (e.g. alcohol, sugar, fat and salt intakes). ☐ Yes ☐ No

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9. Since your stroke, have you had enough treatment to help improve your mobility (e.g. walking, moving your legs)?
   - ☐ Yes, definitely
   - ☐ Yes, to some extent
   - ☐ No, I did not get enough treatment
   - ☐ I did not want treatment
   - ☐ I did not have any mobility difficulties

10. Since your stroke, have you had enough help to prevent falling?
    - ☐ Yes, definitely
    - ☐ Yes, to some extent
    - ☐ No, I did not get enough help
    - ☐ I did not want help
    - ☐ I did not have problems with falling

11. Since your stroke, have you had enough help with managing any bladder/bowel problems (accidents, constipation, diarrhoea)?
    - ☐ Yes, definitely
    - ☐ Yes, to some extent
    - ☐ No, I did not get enough help
    - ☐ I did not want help
    - ☐ I did not have bladder/bowel problems after my stroke

12. Since your stroke, have you had enough treatment for pain?
    - ☐ Yes, definitely
    - ☐ Yes, to some extent
    - ☐ No, I did not get enough treatment
    - ☐ I did not want treatment
    - ☐ I did not have any pain after my stroke

13. Since your stroke, have you had enough help with managing any swallowing difficulties?
    - ☐ Yes, definitely
    - ☐ Yes, to some extent
    - ☐ No, I did not get enough help
    - ☐ I did not want help
    - ☐ I did not have any swallowing difficulties

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14. Since your stroke, have you had enough help with problems of fatigue (feeling tired all the time)?
   - ☐ Yes, definitely
   - ☐ Yes, to some extent
   - ☐ No, I did not get enough help
   - ☐ I did not want help
   - ☐ I did not have any fatigue problems

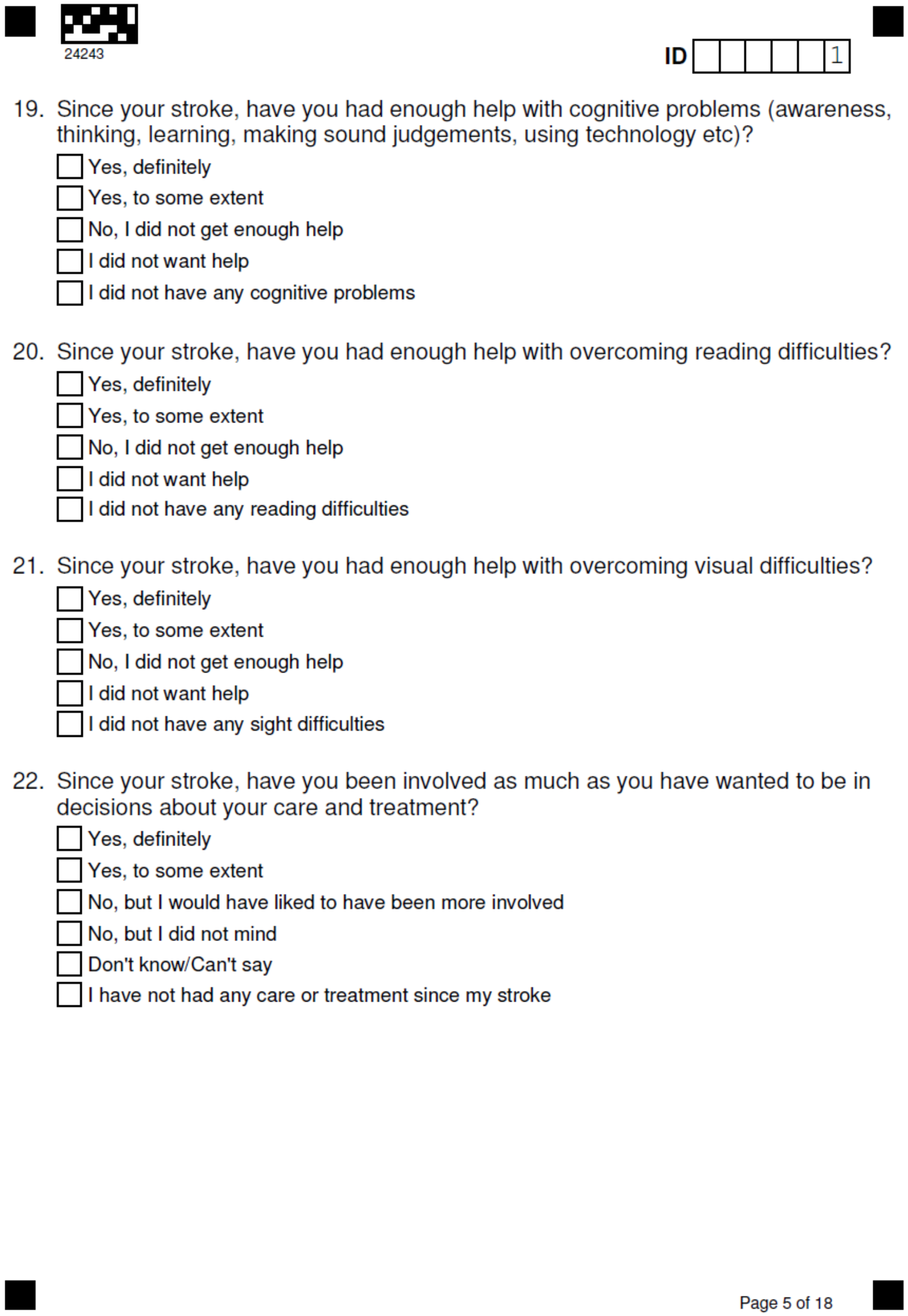
15. Since your stroke, have you had enough help with emotional problems (such as confusion, depression or crying)?
   - ☐ Yes, definitely
   - ☐ Yes, to some extent
   - ☐ No, I did not get enough help
   - ☐ I did not want help
   - ☐ I did not have any emotional problems

16. Since your stroke, have you had enough help with concentration problems?
   - ☐ Yes, definitely
   - ☐ Yes, to some extent
   - ☐ No, I did not get enough help
   - ☐ I did not want help
   - ☐ I did not have any concentration problems

17. Since your stroke, have you had enough help with memory problems?
   - ☐ Yes, definitely
   - ☐ Yes, to some extent
   - ☐ No, I did not get enough help
   - ☐ I did not want help
   - ☐ I did not have any memory problems

18. Since your stroke, have you had enough help with speaking difficulties?
   - ☐ Yes, definitely
   - ☐ Yes, to some extent
   - ☐ No, I did not get enough help
   - ☐ I did not want help
   - ☐ I did not have any speaking difficulties

Appendix A: Stroke Survivor and Carer Needs Assessment Survey



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19. Since your stroke, have you had enough help with cognitive problems (awareness, thinking, learning, making sound judgements, using technology etc)?

☐ Yes, definitely
☐ Yes, to some extent
☐ No, I did not get enough help
☐ I did not want help
☐ I did not have any cognitive problems

20. Since your stroke, have you had enough help with overcoming reading difficulties?

☐ Yes, definitely
☐ Yes, to some extent
☐ No, I did not get enough help
☐ I did not want help
☐ I did not have any reading difficulties

21. Since your stroke, have you had enough help with overcoming visual difficulties?

☐ Yes, definitely
☐ Yes, to some extent
☐ No, I did not get enough help
☐ I did not want help
☐ I did not have any sight difficulties

22. Since your stroke, have you been involved as much as you have wanted to be in decisions about your care and treatment?

☐ Yes, definitely
☐ Yes, to some extent
☐ No, but I would have liked to have been more involved
☐ No, but I did not mind
☐ Don't know/Can't say
☐ I have not had any care or treatment since my stroke

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23. If you did not get enough help for any of the issues covered by these previous questions, what type of help or service would be useful?

6. Everyday living

Now we would like to ask some questions about your needs with regard to everyday living.

24. Since your stroke, have you had enough help with personal care (e.g. help with getting dressed or washed, or dental care)?

☐ Yes, all the help I needed
☐ Yes, some help but not enough
☐ No, but I would have liked it
☐ I did not need this care
☐ I was already receiving this type of help

25. Since your stroke have you had enough help around the house from an external organisation (e.g. help with cooking, cleaning, washing clothes, shopping, ironing, fixing things)?

☐ Yes, all the help I needed
☐ Yes, some help but not enough
☐ No, but I would have liked it
☐ I did not need this service
☐ I was already receiving help around the house

26. Since your stroke, have you had enough adaptations made to your home (e.g. stair lift, grab rails, ramp)?

☐ Yes, all the adaptations I needed
☐ Yes, some but not enough
☐ No, but I would have liked it
☐ No, I did not need home adaptations
☐ I need assistance looking into options for moving to another home

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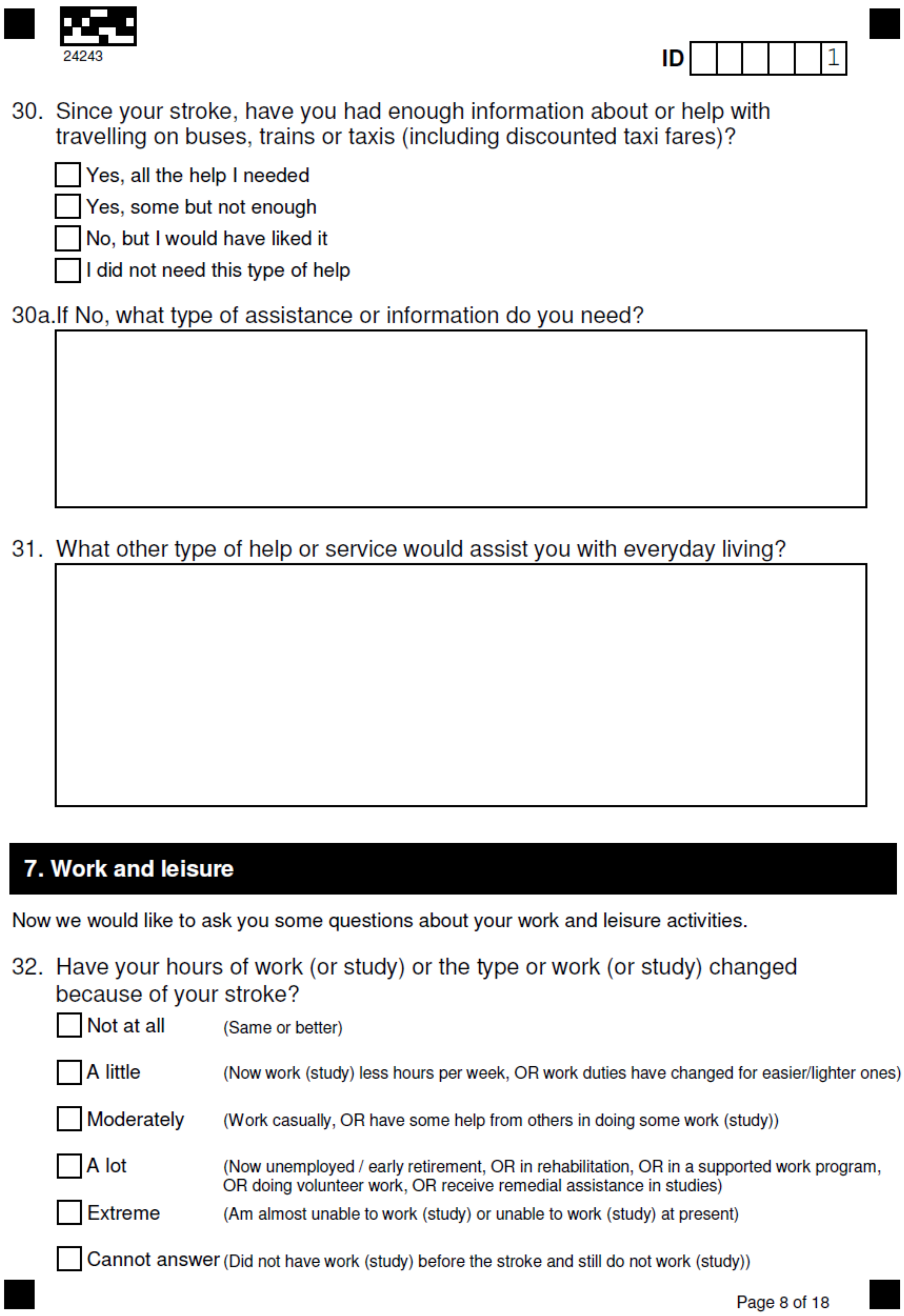
27. Has your use of transport and travel around the community changed because of your stroke?
    - ☐ Not at all
    - ☐ A little
    - ☐ Moderately
    - ☐ A lot
    - ☐ Extreme

28. If your use of transport and travel around the community has changed, is this due to physical or emotional issues?
    - ☐ Physical issues
    - ☐ Emotional/concentration issues (including memory and fatigue)
    - ☐ Both physical and emotional issues
    - ☐ My use of transport has not changed
    - ☐ Other (please specify)

28a. If other please specify

☐

29. Since your stroke, have you had enough help/advice about getting back to driving or getting a disabled parking permit? ☐ Yes ☐ No



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30. Since your stroke, have you had enough information about or help with travelling on buses, trains or taxis (including discounted taxi fares)?

☐ Yes, all the help I needed
☐ Yes, some but not enough
☐ No, but I would have liked it
☐ I did not need this type of help

30a. If No, what type of assistance or information do you need?

31. What other type of help or service would assist you with everyday living?

7. Work and leisure

Now we would like to ask you some questions about your work and leisure activities.

32. Have your hours of work (or study) or the type or work (or study) changed because of your stroke?

☐ Not at all	(Same or better)
☐ A little	(Now work (study) less hours per week, OR work duties have changed for easier/lighter ones)
☐ Moderately	(Work casually, OR have some help from others in doing some work (study))
☐ A lot	(Now unemployed / early retirement, OR in rehabilitation, OR in a supported work program, OR doing volunteer work, OR receive remedial assistance in studies)
☐ Extreme	(Am almost unable to work (study) or unable to work (study) at present)
☐ Cannot answer	(Did not have work (study) before the stroke and still do not work (study))

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33. Since Your stroke, have you had enough assistance returning to work or study or accessing employment (eg. through a Return To Work Program)?
☐ Yes, all the help I needed
☐ Yes, some but not enough
☐ No, but I would have liked it
☐ I did not need this type of help

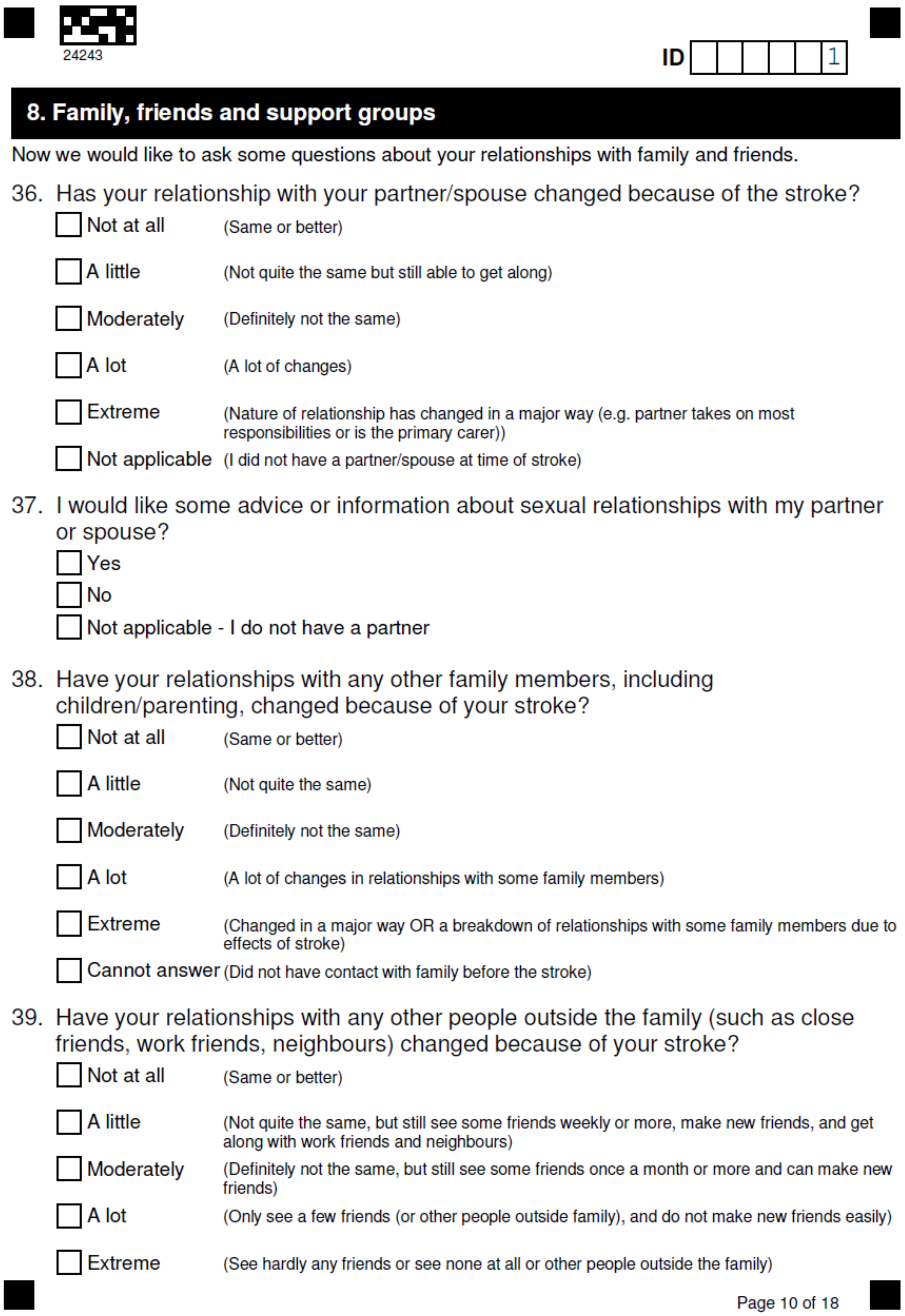
33a. If you did not receive enough help, what type of assistance or information would be useful?

34. Has there been any change in the number or type of leisure activities or interests you participate in because of your stroke?

☐ Not at all	(Same or more, and done as often or more)
☐ A little	(Have most of the same activities and interests, OR have the same activities and interests but do them less often)
☐ Moderately	(Definitely less, but may have developed new activities and interests)
☐ A lot	(Only have some of the leisure activities and interests and have not developed new ones)
☐ Extreme	(Almost none or no leisure activities at present)
☐ Cannot answer	(Did not have leisure activities before the stroke and still do not have leisure activities)

35. Since Your stroke, have you had enough information about or assistance with returning to leisure activities (including holidays and breaks)?
☐ Yes, all the help I needed
☐ Yes, some but not enough
☐ No, but I would have liked it
☐ I did not need this type of help

35a. If you did not get enough help what type of assistance or information would be useful?



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8. Family, friends and support groups

Now we would like to ask some questions about your relationships with family and friends.

36. Has your relationship with your partner/spouse changed because of the stroke?

☐ Not at all	(Same or better)
☐ A little	(Not quite the same but still able to get along)
☐ Moderately	(Definitely not the same)
☐ A lot	(A lot of changes)
☐ Extreme	(Nature of relationship has changed in a major way (e.g. partner takes on most responsibilities or is the primary carer))
☐ Not applicable	(I did not have a partner/spouse at time of stroke)

37. I would like some advice or information about sexual relationships with my partner or spouse?

☐ Yes
☐ No
☐ Not applicable - I do not have a partner

38. Have your relationships with any other family members, including children/parenting, changed because of your stroke?

☐ Not at all	(Same or better)
☐ A little	(Not quite the same)
☐ Moderately	(Definitely not the same)
☐ A lot	(A lot of changes in relationships with some family members)
☐ Extreme	(Changed in a major way OR a breakdown of relationships with some family members due to effects of stroke)
☐ Cannot answer	(Did not have contact with family before the stroke)

39. Have your relationships with any other people outside the family (such as close friends, work friends, neighbours) changed because of your stroke?

☐ Not at all	(Same or better)
☐ A little	(Not quite the same, but still see some friends weekly or more, make new friends, and get along with work friends and neighbours)
☐ Moderately	(Definitely not the same, but still see some friends once a month or more and can make new friends)
☐ A lot	(Only see a few friends (or other people outside family), and do not make new friends easily)
☐ Extreme	(See hardly any friends or see none at all or other people outside the family)

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40. Since your stroke have you had enough external emotional support, outside of family and friends (eg counselling)
    - ☐ Yes, all the support I needed
    - ☐ Yes, some support but not enough
    - ☐ No, but I would have liked it
    - ☐ I did not need external emotional support

41. Have you been to a support group for people who have had a stroke in your local area?
    - ☐ Yes
    - ☐ No, but I would have liked to
    - ☐ No, I did not want to attend a support group
    - ☐ I am not aware of a local support group

41a. If no, why not

42. What other assistance would support your relationships with family and friends?

9. Finances

Now we would like to ask some questions about how your finances have been affected since your stroke.

43. Since having your stroke have you experienced a loss in income? ☐ Yes ☐ No

44. Since having your stroke have you experienced an increase in expenses? ☐ Yes ☐ No

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45. Since your stroke have you received any government benefits (e.g. disability support pension, carer allowance, mobility allowance)?
- ☐ Yes
- ☐ No, but I should have received benefits
- ☐ No, but I do not need any benefits
- ☐ No, I am not eligible for benefits
- ☐ No, because the system was too difficult to negotiate
- ☐ I was already receiving benefits
- ☐ Don't know

46. Since your stroke have you had enough assistance with or information about managing your finances?
- ☐ Yes, all the support I needed
- ☐ Yes, some support but not enough
- ☐ No, but I would have liked it
- ☐ I did not need financial advice or assistance

47. If you need assistance/support for managing your finances or accessing benefits what type of assistance do you need?

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10. Other Comments

48. Do you have any other needs since your stroke which we have not asked you about? ☐ Yes ☐ No

48a. If yes, please write them down here

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11. Information about you

Now we would like to ask you some questions about you, so that we can find out whether different groups of stroke survivors have different needs.

49. Are you male or female? ☐ Male ☐ Female

50. What was your age at your last birthday? ☐☐

51. What is your postcode? ☐☐☐☐

52. How many years ago did you have your first stroke? ☐☐

53. In which country were you born?

☐ Australian	☐ Italy	☐ Scotland	☐ Germany
☐ England	☐ Viet Nam	☐ Philippines	☐ Other (please specify)
☐ New Zealand	☐ India	☐ Greece	

53a. If other, please specify

54. Are you of Aboriginal/Torres Strait Islander origin?
- ☐ Aboriginal but not Torres Strait Islander origin
- ☐ Torres Strait Islander but not Aboriginal origin
- ☐ Both Aboriginal and Torres Strait Islander origin
- ☐ Neither Aboriginal nor Torres Strait Islander origin

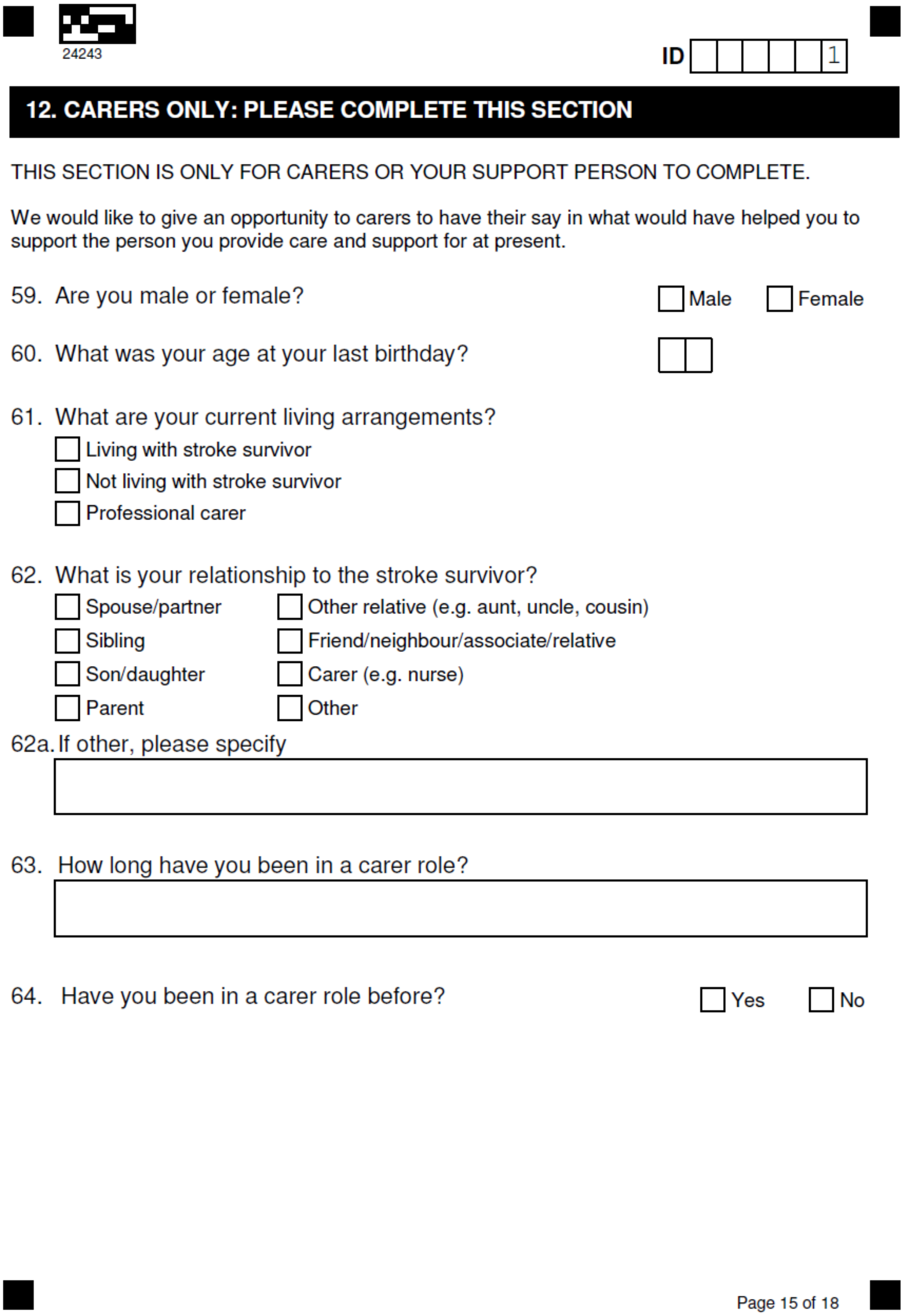
55. What is your current level of physical ability with walking?
- ☐ Able to walk 10 metres and able to walk outside without help
- ☐ Able to walk 10 metres, but unable to walk outside without help
- ☐ Unable to walk 10 metres (or outside)
- ☐ Unknown

56. Do you currently need help from anybody with everyday activities? ☐ Yes ☐ No

57. Has the stroke left you with any problems? ☐ Yes ☐ No

58. Who is completing this survey?
- ☐ Stroke survivor
- ☐ Proxy (son/daughter, friend, relative)
- ☐ Both Proxy and stroke survivor

Appendix A: Stroke Survivor and Carer Needs Assessment Survey



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12. CARERS ONLY: PLEASE COMPLETE THIS SECTION

THIS SECTION IS ONLY FOR CARERS OR YOUR SUPPORT PERSON TO COMPLETE.

We would like to give an opportunity to carers to have their say in what would have helped you to support the person you provide care and support for at present.

59. Are you male or female? ☐ Male ☐ Female

60. What was your age at your last birthday? ☐☐

61. What are your current living arrangements?
    - ☐ Living with stroke survivor
    - ☐ Not living with stroke survivor
    - ☐ Professional carer

62. What is your relationship to the stroke survivor?

☐ Spouse/partner	☐ Other relative (e.g. aunt, uncle, cousin)
☐ Sibling	☐ Friend/neighbour/associate/relative
☐ Son/daughter	☐ Carer (e.g. nurse)
☐ Parent	☐ Other

62a. If other, please specify

63. How long have you been in a carer role?

64. Have you been in a carer role before? ☐ Yes ☐ No

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65. Have your hours of work (or study) or the type or work (or study) changed because of your carer role?

☐ Not at all	(Same or better)
☐ A little	(Now work (study) less hours per week, OR work duties have changed for easier/lighter ones)
☐ Moderately	(Work casually, OR have some help from others in doing some work (study))
☐ A lot	(Am able to work only a little)
☐ Extreme	(Am almost unable to work (study) or unable to work (study) at present)
☐ Cannot answer	(Did not have work (study) before the stroke and still do not work (study))

66. Has there been any change in the number or type of leisure activities or interests you participated in because of your carer role?

☐ Not at all	(Same or more, and done as often or more)
☐ A little	(Have most of the same activities and interests, OR have the same activities and interests but do them less often)
☐ Moderately	(Definitely less, but may have developed new activities and interests)
☐ A lot	(Only have some of the leisure activities and interests and have not developed new ones)
☐ Extreme	(Almost none or no leisure activities at present)
☐ Cannot answer	(Did not have leisure activities before the stroke and still do not have leisure activities)

67. Has your relationship with your partner/spouse changed because of the carer role? (If you are the partner/spouse of the stroke survivor)

☐ Not at all	(Same or better)
☐ A little	(Not quite the same but still able to get along)
☐ Moderately	(Definitely not the same)
☐ A lot	(A lot of changes)
☐ Extreme	(Nature of relationship has changed in a major way)
☐ Not applicable	

68. I would like some advice or information about sexual relationships with my partner or spouse? (If you are the partner/spouse of the stroke survivor)

☐ Yes
☐ No
☐ Not applicable

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69. Have your relationships with any other family members changed because of your carer role?

☐ Not at all	(Same or better)
☐ A little	(Not quite the same)
☐ Moderately	(Definitely not the same)
☐ A lot	(A lot of changes in relationships with some family members)
☐ Extreme	(Changed in a major way OR a breakdown of relationships with some family members due to effects of stroke)
☐ Cannot answer	(Did not have contact with family before the stroke)

70. Have your relationships with any other people outside the family (such as close friends, work friends, neighbours) changed because of your carer role?

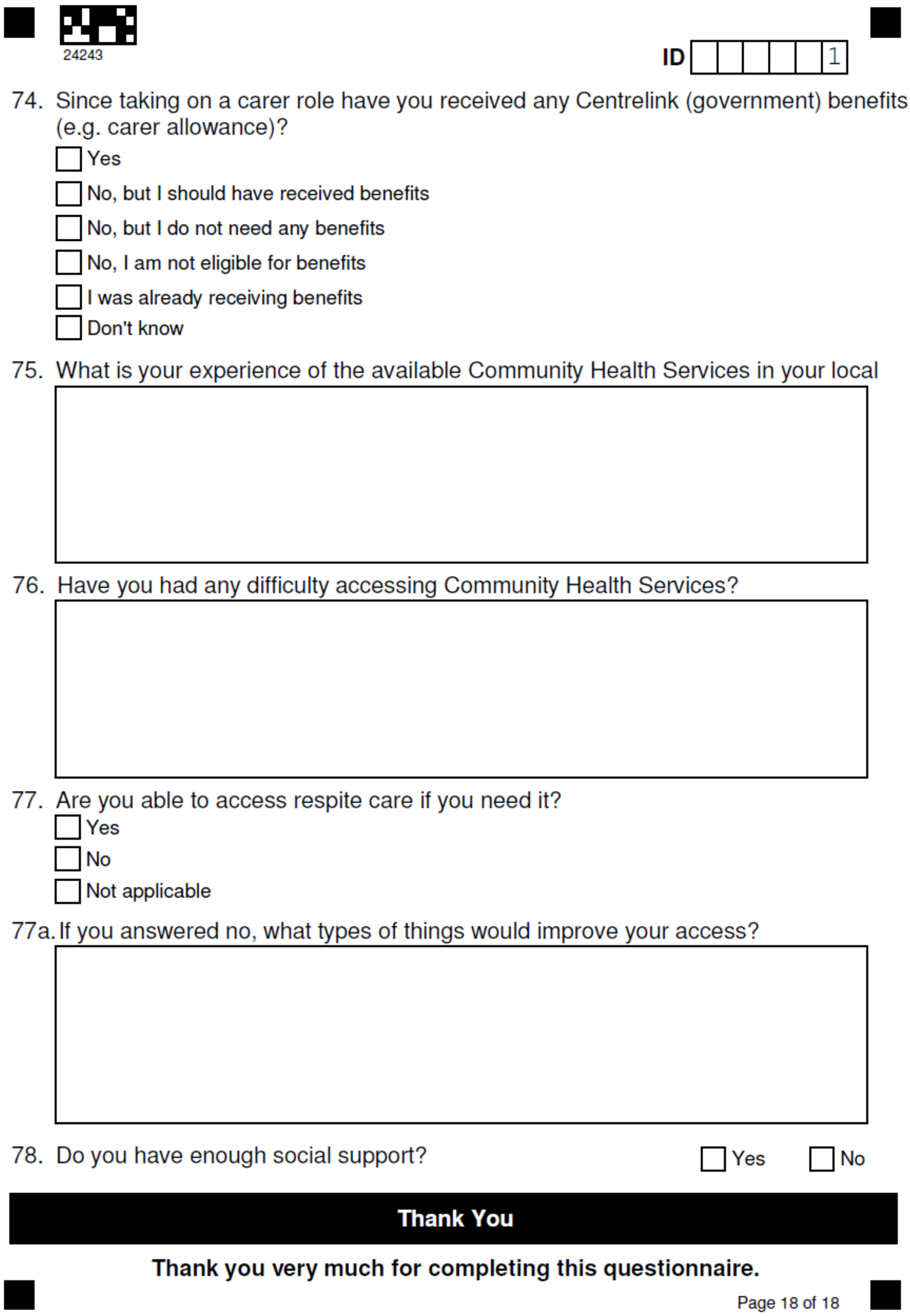
☐ Not at all	(Same or better)
☐ A little	(Not quite the same, but still see some friends weekly or more, make new friends, and get along with work friends and neighbours)
☐ Moderately	(Definitely not the same, but still see some friends once a month or more and can make new friends)
☐ A lot	(Only see a few friends (or other people outside family), and do not make new friends easily)
☐ Extreme	(See hardly any friends or see none at all or other people outside the family)

71. Have you been to a support group for people who are carers of survivors of stroke in your local area?

☐ Yes
☐ No, but I would have liked to
☐ No, I did not want to attend a support group
☐ I am not aware of a local support group

72. Since taking on a carer role having you experienced a loss in income due to reduced hours or changed work circumstances? ☐ Yes ☐ No

73. Since taking on a carer role have you experienced an increase in personal expenses? ☐ Yes ☐ No



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74. Since taking on a carer role have you received any Centrelink (government) benefits (e.g. carer allowance)?
- ☐ Yes
- ☐ No, but I should have received benefits
- ☐ No, but I do not need any benefits
- ☐ No, I am not eligible for benefits
- ☐ I was already receiving benefits
- ☐ Don't know

75. What is your experience of the available Community Health Services in your local

76. Have you had any difficulty accessing Community Health Services?

77. Are you able to access respite care if you need it?
- ☐ Yes
- ☐ No
- ☐ Not applicable

77a. If you answered no, what types of things would improve your access?

78. Do you have enough social support? ☐ Yes ☐ No

Thank You

Thank you very much for completing this questionnaire.

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Appendix B. Participating hospitals

We would like to thank the hospital staff listed below for their support and hard work on the Australian Stroke Survivor and Carer Needs Assessment Project

New South Wales

Westmead Hospital
Pip Galland
Pauline Osborne

Fairfield Hospital
Barbara Chapman
Victoria Knol

Belmont District Hospital
Karen Ruddell
Michael Pollock

Orange Base Hospital
Fiona Ryan

Coffs Harbour Base Hospital
Melissa Christos

Albury Wodonga Health Service – Albury Campus
Vanessa Crosby
Cathy McGlone

Victoria

Northern Hospital
Anne Rodda
Lisa Sanders
Lauren Stewart
Kelly Buhagiar
Talya McDonald
Louise McFarlane

Swan Hill District Hospital
Karina Finch

Bairnsdale Hospital
Susan Perrott

Geelong Hospital
Heather Smith
Peter Gates

Hamilton Hospital
Lisa Livingstone
Jeffrey Slater

Queensland

Prince Charles Hospital
Leah Thomson
Jane Mikli

South Australia

The Queen Elizabeth Hospital
Lizzie Dodd
Jim Jannes

Flinders Medical Centre
Michelle Bronca
Andrew Lee

Whyalla Hospital
Tracy Paterson

Tasmania

Royal Hobart Hospital
Helen Castley

Launceston General Hospital
Annette Viney

Western Australia

Geraldton Hospital
Di Franklin

Northern Territory

Alice Springs Hospital
Karen Harris