**Systematic Review:**

Factors associated with return to work after stroke: A qualitative meta-synthesis

**National Survey of Stroke Survivors 2014/15:**

Exploring the factors related to return to work after stroke

**Focus Groups and Semi-Structured Interviews with Key Stakeholders:**

Examining the barriers and facilitators with respect to return to work after stroke

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# Executive Summary

## Introduction

In Ireland, approximately 10,000 people experience a stroke each year and it is estimated that there are up to 59,000 stroke survivors living in Ireland, of which 30,000 are living with residual deficits.[[1]](#footnote-1) Although stroke often affects those at or beyond retirement age, about one third of stroke survivors are under 65 years of age.[[2]](#footnote-2) Return to work after stroke is often perceived as a critical marker of recovery and contributes to overall well-being and life satisfaction of survivors.[[3]](#footnote-3) The present study explores the factors facilitating and impeding a return to work following a stroke in an Irish context.

## Aims

This report contains three distinct pieces of research:

* Firstly, a systematic review and qualitative meta-synthesis of the literature was conducted to identify the factors associated with returning to work after stroke from the perspective of stroke survivors.
* Secondly, a national survey of stroke survivors was carried out in order to examine the factors related to returning to work after stroke.
* Thirdly, focus groups and semi-structured interviews with key stakeholders were conducted to explore the facilitators and barriers of returning to work from the perspective of stroke survivors, spouses of stroke survivors, healthcare professionals, representatives of stroke advocacy groups and non-governmental organisations.

## Methods of the Systematic Review

A systematic literature search was conducted in October 2014. Articles were initially screened by title and/or abstract and were included if the study was primarily qualitative in nature, which focused on exploring the factors associated with return to work after stroke, from the perspective of the stroke survivor. Two researchers independently assessed the 15 full text articles.

## Methods of the National Survey

Participants for the survey were stroke survivors primarily recruited through the Volunteer Stroke Scheme clubs, Irish Heart Foundation’s National Stroke Support Group Network, clinical nurse specialists for stroke, other healthcare professionals, the National Rehabilitation Hospital in Dun Laoghaire, Baggot Street Community Hospital, Dublin and non-statutory organisations that provide support services after acquired brain injury. The survey was also advertised online.

A questionnaire exploring the factors related to returning to work after stroke was developed from existing validated questionnaires with the permission of the original authors. Data collection took place between November 2014 and February 2015.

## Methods of the Focus Groups and Semi-Structured Interviews

Sixteen stroke survivor participants were recruited though the Volunteer Stroke Scheme clubs, the Irish Heart Foundation’s National Stroke Support Group Network, Baggot Street Community Hospital, Dublin and the National Rehabilitation Hospital in Dun Laoghaire. Two spouses of stroke survivors were recruited through stroke survivors participating in this study.

Thirty-three participants including multidisciplinary healthcare team members working in stroke, representatives from advocacy organisations for acquired brain injury and policy workers for disability non-governmental organisations were recruited for this study.

Areas of discussion included the barriers and facilitators when returning to work after a stroke, the current supports and services available, and the areas in which the current services could be improved.

## Main findings

### Systematic Review

Two members of the research team independently reviewed 15 qualitative studies included, and identified the following overarching themes:

* The nature of the effects of stroke
* The preparatory environment
* Personal coping strategies and internal challenges
* The meaning of work

### National Survey

* A total of 122 stroke survivors, of which 50% were male, responded to this survey. The median age of respondents was 52 years.
* Eighty-two percent of stroke survivors were working prior to their stroke and sixty-one percent returned to work after their stroke.
* Forty-one percent had resumed some work within six months after their stroke and sixty-four percent had begun to work by one year. Only 32% of those who returned were working fulltime one year after their stroke.
* Of those currently in work, 68% returned to their previous employer and 32% to a different employer.
* Those who felt work was at least somewhat important were more likely to return to work (*p*=0.016).
* Those who returned to work were significantly younger at the time of their stroke (42.4 years versus 52 years) compared to those that did not (*p*<0.001).
* Those currently working report a significant reduction in working hours from a pre-stroke average of 46.6 hours to a post stroke average of 29 hours (*p*<0.001).
* Fifty-nine percent of those currently working report that their household income has decreased post stroke.
* The most common problems limiting ability to work were mental fatigue (84%), physical fatigue (78%) and difficulties thinking (78%).

### Focus Groups and Semi-Structured Interviews

For many, the hidden deficits such as difficulties with memory, fatigue and concentration impacted their ability to return to work. Supportive employers and work colleagues were key to facilitating a return to work. A gradual phased return to work was particularly important in addition to support from colleagues. Return to work can take several years to complete, during which stroke survivors may lose confidence in their ability to re-engage with the workforce. During this time, to maintain financial security, stroke survivors often engage with the social welfare system which is confusing to navigate and that there may be a fear factor in returning to work and thereby losing benefits, which were previously relied upon.

## Conclusions

Return to work after stroke is a complex process which can be facilitated or impeded by organisational, social or personal factors, as well as accessibility to appropriate services.

Communication between healthcare professionals and employers can aid the return to work process for the stroke survivor. Furthermore, environmental workplace adaptations, and adjustments such as a phased working can help facilitate returning to work.

Fatigue, both mental and physical fatigue, has a significant impact on returning to work after stroke.

Education for employers and the general public is key in supporting stroke survivors back to work.

The systematic review, national survey and focus group findings allowed the research team to explore and review the evidence relating to the barriers and facilitators when returning to work after a stroke, the current supports and services available, and the areas in which the current services could be improved. Triangulation of the findings from the three discrete methodologies resulted in a number of overarching findings related to the nature and effects of the stroke; the preparatory environment for return to work after stroke; personal coping strategies for the individual and the meaning of work.

# 1. Introduction

## 1.1 Context of Research

Stroke is a leading cause of death and disability worldwide and it is estimated that cerebrovascular diseases account for up to five per cent of total healthcare expenditure in a number of countries.[[4]](#footnote-4) In Ireland, approximately 10,000 people experience a stroke each year and it is estimated that there are up to 59,000 stroke survivors living in Ireland, of which 30,000 are living with residual deficits.[[5]](#footnote-5) Return to work after stroke is often perceived as a critical marker of recovery and contributes to overall well-being and life satisfaction of survivors.[[6]](#footnote-6)

Although stroke often affects those at or beyond retirement age, about one third of stroke survivors are under 65 years of age.[[7]](#footnote-7) Many young stroke survivors would like to return to work provided they are able and their working environment would support them to do so.[[8]](#footnote-8) Employment is an important means of how an individual measures his or her place in society. Many studies have reported that stroke survivors who return to work exhibit higher levels of subjective well-being and satisfaction after stroke.[[9]](#footnote-9)

A number of factors have been identified with facilitating a return to work. These include younger age, the importance of returning to work, family and healthcare support and employer flexibility.[[10]](#footnote-10) Barriers to employment for stroke survivors include older age, engaging in manual or highly physically demanding jobs, difficulties communicating, type of stroke and employers’ attitudes.[[11]](#footnote-11)

To enhance the employment outcomes of individuals who experience a stroke it is essential to understand the factors that determine return to work and retention. A previous national survey of stroke survivors in Ireland found that only 23% of those under the age of 66 worked in a full or part-time capacity after their stroke.[[12]](#footnote-12) However, there is no research regarding the factors that facilitate or act as a barrier when returning to work after stroke in an Irish context. One national report did find that people with a disability were two and a half times less likely to have a job than those without a disability.[[13]](#footnote-13) It is widely acknowledged that the healthcare community is lacking information and knowledge in the area of work rehabilitation of stroke survivors. As such, this report explores the factors that facilitate or act as barriers to returning to work after stroke, thereby helping to understand and enhance the functional and employment outcomes of stroke survivors.

## 1.2 Background

This report contains three distinct pieces of research:

* Firstly, a systematic review and qualitative meta-synthesis of the literature exploring the factors associated with returning to work after stroke from the perspective of stroke survivors.
* Secondly, a national return to work survey of stroke survivors exploring the factors related to returning to work after stroke in the Republic of Ireland.
* Thirdly, focus groups and semi-structured interviews with key stakeholders regarding the facilitators and barriers to returning to work from the perspective of stroke survivors and their spouses, healthcare professionals, and representatives of stroke advocacy groups and non-governmental organisations.

## 1.3 Return to Work Following Stroke

Returning to work after stroke has been identified as a significant rehabilitation goal following stroke as it provides a sense of social identity and is associated with improved self-esteem and life satisfaction.[[14]](#footnote-14) Return to work also serves to facilitate independent living for younger people with stroke and decrease the economic burden on society.[[15]](#footnote-15) A systematic review by Daniel and colleagues examined the social consequences of stroke in people of working age.[[16]](#footnote-16) Of the 78 studies included in the review, 70 studies focused on employment after stroke using return to work as a proxy for recovery or rehabilitation outcome. Rates of return to work in the included studies ranged from 0-100%.[[17]](#footnote-17) However, the authors reported that the overall rate of return to work could not be reliably estimated due to significant heterogeneity between studies with respect to study design, definitions of the population of interest, data collection methods employed and definitions of ‘return to work’. Other authors have also highlighted variation in the term ‘return to work’.[[18]](#footnote-18) Some studies only include competitive full-time employment and others consider part-time work, volunteer work and/or homemaking in the definition.

A number of recent studies have examined predictors of return to work after stroke.[[19]](#footnote-19) Initial stroke severity has consistently been identified as the most robust predictor of return to work. Other factors associated with non-return to work include female gender, age >50 years, self-employment and those employed as unskilled workers.[[20]](#footnote-20) Alternatively, factors predictive of successful reintegration in the workplace include employer flexibility, social benefits, and support from family or co-workers.[[21]](#footnote-21) A recent review of six single-arm cohort studies examined the impact of vocational rehabilitation programmes on return to work rates post stroke. The authors concluded that there was insufficient evidence to support or refute the use of such programmes to facilitate return to work due to the lack of high-quality trials in the area.[[22]](#footnote-22) Qualitative studies have also investigated participants’ experiences and views of returning to work after stroke but no systematic review has summarised the totality of evidence from the perspective of the individual with stroke. As such, there is a need to systematically review the factors associated with return to work after stroke so that appropriate interventions can be designed and implemented to optimise return to work after stroke.

## 1.4 Brief Methodology of Systematic Review

The aim of this systematic review is to examine barriers and facilitators relating to return to work after stroke from the perspective of people with stroke through the process of a qualitative meta-synthesis. Please see Appendix 1 for a more detailed background of the methodology and thematic analysis. This comprised three discrete steps:

1. Selecting relevant papers for inclusion.
2. Critical appraisal and data extraction.
3. Analysis and synthesis of findings.

A systematic literature search was conducted in October 2014 and included the following search engines: MEDLINE, PubMed, EMBASE, Cochrane Library, PsycINFO, EBSCO, CINAHL and SCOPUS. The searches included but were not limited to the following keywords and MeSH terms: employ OR employment OR work OR labour force OR occupation OR workplace OR corporate OR employment OR employ OR vocation AND stroke OR cerebrovascular disorders OR haemorrhage.

Articles were initially screened by title and/or abstract and were included if the study was primarily qualitative in nature, which focused on exploring the factors associated with return to work after stroke, from the perspective of the stroke survivor. We assessed the methodological quality of included papers using criteria described by the Critical Appraisal Skills Programme (CASP).[[23]](#footnote-23) Two researchers (RG and CB) independently critically appraised each individual study and discrepancies were managed by consensus. A third independent reviewer (FH) assessed quality where consensus was not reached. Two researchers (MW and CB) independently reviewed the findings and interpretations from each primary research study, and a thematic analysis was performed and presented.

## 1.5 Brief Methodology of National Survey

The aim of the national survey was to explore the factors related to returning to work after stroke from the stroke survivors’ perspective. Ethical approval for the study was granted by the Royal College of Surgeons in Ireland’s Research Ethics Committee, the Health Service Executive’s Research Ethics Committee and the National Rehabilitation Hospital’s Research Ethics Committee.

Participants for the survey were stroke survivors primarily recruited though the Volunteer Stroke Scheme clubs and the Irish Heart Foundation’s National Stroke Support Group Network. In regions that did not have an active stroke support group the clinical nurse specialist for stroke in the area and other healthcare professionals were contacted and asked to invite eligible individuals to participate. Participants were recruited through the National Rehabilitation Hospital in Dun Laoghaire and Baggot Street Community Hospital, Dublin. Additional participants were also recruited through non-statutory organisations such as Headway Ireland, Acquired Brain Injury Ireland and Brain Rehabilitation Ireland. The survey was advertised online through the Irish Heart Foundation Stroke website ([www.stroke.ie](http://www.stroke.ie)), the Headway Ireland website ([www.headway.ie](http://www.headway.ie)), the Acquired Brain Injury Ireland website ([www.abiireland.ie](http://www.abiireland.ie)) and the Brain Rehabilitation Ireland website ([www.briireland.ie](http://www.briireland.ie)).

The inclusion criteria for this study were as follows:

* Aged over 18 years
* Be able to communicate
* Be able to give informed consent
* Have an Abbreviated Mental Test Score (AMTS) > 6[[24]](#footnote-24)
* Be living in your own home within the local community

Using existing validated questionnaires with the permission of the original authors, a questionnaire was developed to assess respondents’ own experiences of returning to work after the onset of stroke. Most of the questions and the general format of the questionnaire were based on the UK Work after Stroke Survey and the US Return to Work after Stroke Survey.[[25]](#footnote-25) Two volunteers with experience of returning to work after a stroke piloted and reviewed a preliminary version of the questionnaire. Changes were made to the questionnaire based on the feedback received in October 2014. The questions covered the following areas:

* Work history
* Effects of the stroke
* Current work situation
* Employer support
* Finance
* Facilitators and barriers to returning to work

One member of the research team (FH) made initial contact with the stroke group coordinators and explained the study to them. Co-ordinators then identified eligible members within their groups and informed them about the study. Eligible volunteers were given the option of completing the survey face-to-face with the assistance of the stroke support group co-ordinator, completing the survey independently and returning it by post or completing the survey online. Pre-paid addressed envelopes were provided to participants wishing to avail of the postal option. The purpose of the study and the procedure was explained fully to all potential participants. They were provided with an information leaflet and the researcher’s contact details. They were encouraged to ask questions to clarify points that remained unclear. Researchers asked participants to sign a form volunteering informed consent if they were happy that they understood the study procedure and wished to continue. Participants were also made aware that they could withdraw from the study at any time, without giving a reason. Please see Appendix 2 for a more detailed background methodology of this national return to work survey.

## 1.6 Brief Methodology of Focus Groups and Semi-Structured Interviews

The aim of the focus groups in this report were to examine the facilitators and barriers to returning to work after stroke from the perspectives of stroke survivors and their spouses, healthcare professionals, representatives of stroke advocacy groups and non-governmental organisations.

Ethical approval for the study was granted by the Royal College of Surgeons in Ireland’s Research Ethics Committee, the Health Service Executive’s Research Ethics Committee and the National Rehabilitation Hospital’s Research Ethics Committee.

Stroke survivor participants were recruited though the Volunteer Stroke Scheme clubs, the Irish Heart Foundation’s National Stroke Support Group Network, Baggot Street Community Hospital, Dublin and the National Rehabilitation Hospital in Dun Laoghaire. For those that were interested in participating in this study, focus groups were the primary method of data collection. However, for those that could not attend the focus groups organised, semi-structured interviews and detailed email correspondence were utilised.

Similar to the national survey, the inclusion criteria for stroke survivors were as follows:

* Aged over 18 years
* Be able to communicate
* Be able to give informed consent
* Have an Abbreviated Mental Test Score (AMTS) > 6
* Be living in your own home within the local community

Spouses of stroke survivors were recruited through stroke survivors that took part in the study. Members of the multi-disciplinary team working with stroke patients (occupational therapy, physiotherapy, psychology, speech and language therapy, social work and consultant physician), representatives from advocacy organisations providing support for acquired brain injury and policy workers in non-governmental organisations were recruited to this study.

Once the study had been explained to participants and they were satisfied that any questions were answered, written informed consent was provided. Open questions explored during focus groups and semi-structured interviews included the current supports available to return to work after stroke, the facilitators and barriers to returning to work after stroke, the current services available and the ways in which the current services could be improved.

All focus groups and semi-structured interviews, were recorded and transcribed. Each transcript was then analysed independently by the researchers (FH, CB) and coded into primary themes and subthemes based on an overarching framework developed from the systematic review.

Please see Appendix 3 for a more detailed methodology of the focus groups and semi-structured interviews conducted during this study.

As the merit for the use of a range of methodologies has become more widely accepted in health services research, the appreciation of the value of using different or mixed methods needs to be accompanied by recognition of the pragmatic implications of how those methods are to be brought into relationship with each other in a particular study.[[26]](#footnote-26) The potential for ‘knowing more’ about a phenomenon through the use of different research methods in a study is often discussed under the umbrella of ‘triangulation’. Triangulation or the examination of the same concept through two different approaches involves the support of one set of findings with another in anticipation that the two sets of evidence with triangulate or converge on a single outcome.[[27]](#footnote-27) In essence, once a finding has been confirmed by two independent processes, the uncertainty of its interpretation is reduced, thus providing a more accurate description of the phenomenon. The systematic review, national survey and focus group findings allowed the research team to explore and review the evidence relating to the barriers and facilitators when returning to work after a stroke, the current supports and services available, and the areas in which the current services could be improved.

# 2. Systematic Review: Factors Associated With Return To Work After Stroke: A Qualitative Meta-Synthesis

## 2.1 Description of Studies

### Identifying published papers relevant to the focus of the study

The initial search string yielded 13,396 articles, of which 1,519 were excluded on the basis of duplication and 1,905 were removed due to year of publication (<1994). The remaining 9,972 were screened based on title and/or abstract and 9,891 were excluded. Two reviewers (RG and CB) independently assessed the full-text of the remaining 81 articles. Sixty-seven articles were subsequently excluded as the focus of the research question/population of interest was not relevant to this synthesis topic. The reference lists of the 14 remaining articles were searched and one subsequent study was included.[[28]](#footnote-28) Therefore, 15 articles were included in the final review.[[29]](#footnote-29) Figure 2.1 describes the flow of studies in the review.

### Descriptive characteristics of the studies included

The descriptive characteristics of the included studies are presented in Table 2.1. Studies included between one[[30]](#footnote-30) and 43 participants[[31]](#footnote-31) (median 12 participants) with a total number of 215 participants across all studies. Participants’ ages ranged from 20 to 85 years. The most common methodology employed was “grounded theory”.[[32]](#footnote-32) Other methodologies used included “naturalistic methodologies”[[33]](#footnote-33), “critical interpretivist approach”[[34]](#footnote-34) and “phenomenology”.[[35]](#footnote-35) Some studies did not describe the methodology but rather the method of analysis used; “framework analysis”,[[36]](#footnote-36) “content analysis approach”,[[37]](#footnote-37) “nominal group technique”,[[38]](#footnote-38) “narrative analysis”[[39]](#footnote-39) and “constant comparative analysis”.[[40]](#footnote-40) Two studies used mixed methodology, and were included as the qualitative results were presented independently.[[41]](#footnote-41) For participants, the time since first stroke at interview ranged from 7 days[[42]](#footnote-42) to 11 years.[[43]](#footnote-43) Two studies conducted follow-up interviews up to 12 months after the initial interview,[[44]](#footnote-44) while one study followed participants for 18 months[[45]](#footnote-45) and another study followed the participant for 3 years after the initial interview.[[46]](#footnote-46) The post-stroke working status of participants that were interviewed was described in most studies,[[47]](#footnote-47) and ranged from 11%[[48]](#footnote-48) to 100%.[[49]](#footnote-49) These methodologies are appropriate and widely-used in qualitative research of this kind. For an explanation of these methodologies please see the glossary in Appendix 4.



**Figure 2.1 Flow diagram of studies included in the review**

**Table 2.1 Descriptive characteristics of studies included in the review**

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
|  | **Author(s)** | **Participant description (n, sex, age)** | **Time since stroke at 1st interview** | **Other interviews** | **Interview Setting** | **Work Status** | **Qualitative Methodology** |
| 1 | Alaszewski et al. (2007) | N=43M=28 F=15Age 30-59  | <3 months | Every 5 months up to 18 months post stroke | Unclear | N=18 (42%)working at the time of the study | Naturalistic Methodologies |
| 2 | Corr and Wilmer (2003) | N=6M=4 F=2Age 39-62  | 10-132 months(mean 90 months) | None | Neutral meeting place | N=3(50%)working at the time of the study | Mixed Methods |
| 3 | Culler et al. (2011) | N=10M=3 F=7Age <60a | N=5 <5 yearsN=3 6-10 yearsN=1 >10 years | None | Unclear | N=10(100%) working at the time of the study | Mixed Methods |
| 4 | Erikson et al. (2010) | N=7M=4 F=3Age 42-61  | <1 month | 1, 3, 6 and 12 months post stroke | Home, work, interviewers’ workplaces, or rehabilitation setting | Unclear | Grounded Theory  |
| 5 | Flinn and Stube (2010) | N=18M=3 F=15Age unclear | Unclear | None | Public building in local community | Unclear | Not described |
| 6 | Garcia et al. (2000) | N=14M=10 F=4Age 31-60 | 1-10 years(median 2.5 years) | None | Unclear | N=5(36%)working at the time of the study | Not described |
| 7 | Gilworth et al. (2009) | N=13M=7 F=6Age 24-64 | 3 months-8 years | None | Unclear | N=7(54%) working at the time of the study | Not described |
| 8 | Gustafsson and Turpin (2012) | N=1F=1Age 32a | 3 years | Email conversation up to 6 years post-stroke | Email based | N=1(100%)working at the time of the studyb | Not described |
| 9 | Hartke et al. (2011) | N=12M=8 F=4Age 31-67 | Mean 4.5 years | None | “Nearly all” in a hospital setting | N=8(67%) working at the time of the study | Modified Grounded Theory  |
| 10 | Koch et al. (2005) | N=12M=10 F=2Age (mean 61) | >6 months | None | Participant home (N=10)University campus (N=2) | N=4(33%) working at the time of the study | Grounded Theory  |
| 11 | Lock et al. (2005) | N=37M=24 F=13Age >20 | 6 weeks-32 years | None | Stroke support centre meeting room | N=11(30%) working at the time of the study | Not described |
| 12 | Medin et al. (2006) | N=6Sex unclearAge 30-65 | ~ 3 years | None | Informants’ home (N=5)Interviewer’s home (N=1) | Unclear | Empirical Phenomenology |
| 13 | Robison et al. (2009) | N=19cM=11 F=8Age 53-85a | 7-39 days post discharge (median 16 days) | 12 months post-stroke | Participants home (N=19) | N=2(11%) working at the time of the studyd | Not described |
| 14 | Vestling et al. (2013) | N=12M=8 F=4Age 43-61 | 2-25 months post stroke | None | Unclear | N=12(100%) working at the time of the studye | Not described |
| 15 | Wolfenden and Grace (2012) | N=5F=5Age 35-45  | 1-9 years post stroke | None | Unclear | N=4(80%) working at the time of the study | Critical Interpretivist  |
| aAge at the time of strokebEmployed and unemployed during the course of studycInitial sample of 20 participants, however, one participant died within follow-up at 12 monthsdReturned to work at follow-up at 12 monthseReturn to work included both those who returned to paid work and those who returned to vocational training |

### Quality appraisal of the studies

A summary of the methodological quality assessment of each study according to the CASP criteria is contained in Table 2.2. The overall methodological quality of the studies was good. The majority of studies provided a clear description of the recruitment strategy, the data collection procedure, as well as a clear presentation and discussion on the findings of the study. However, only five of the fifteen studies demonstrated evidence that the relationship between the researcher and the participants was adequately considered.[[50]](#footnote-50) Two studies reported that the researchers had previously met with participants, however this relationship was not as a treating therapist.[[51]](#footnote-51) One study reported that researchers met the participant when data had already been collected.[[52]](#footnote-52) A further study reported that researchers aimed to take a neutral stance on the desirability of returning to work post stroke to allow stroke survivors vocalise their views.[[53]](#footnote-53) A further study acknowledged that the views of the researcher may have influenced the conclusions drawn from the data.[[54]](#footnote-54)

Most of the studies did not discuss the number of individuals approached and the number of individuals who refused to take part during the recruitment process. As such, ascertaining the level of selection bias is difficult. Only two studies discussed the number of participants that refused to take part and the reasons given,[[55]](#footnote-55) while one study reported that it was not possible to follow the number of individuals approached over the course of recruitment.[[56]](#footnote-56) Additionally, only three studies adequately addressed issues with data saturation.[[57]](#footnote-57) Ten of the fifteen studies reported receiving ethical approval to conduct their research,[[58]](#footnote-58) while thirteen studies explicitly stated that informed consent was necessary to participate in the study.[[59]](#footnote-59) The setting of interviews was described in eight studies.[[60]](#footnote-60)

**Table 2.2 Methodological quality of studies**

|  |  |
| --- | --- |
| **Authors** | **CASP Questionnaire** |
|  | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| Alaszewski et al. (2007) | Yes | Yes | Yes | Yes | Yes | Unclear | Yes | Yes | Yes | Unclear |
| Corr and Wilmer (2003) | Yes | Yes | Yes | Yes | Unclear | Unclear | Yes | Unclear | Yes | Unclear |
| Culler et al. (2011) | Yes | Yes | Yes | Yes | Unclear | Unclear | Unclear | Unclear | Yes | Clear |
| Erikson et al. (2010) | Yes | Yes | Yes | Yes | Yes | Unclear | Yes | Yes | Yes | Clear |
| Flinn and Stube (2010) | Yes | Yes | Yes | Yes | Unclear | Yes | Yes | Yes | Yes | Clear |
| Garcia et al. (2000) | Yes | Yes | Yes | Yes | Unclear | Unclear | Unclear | Yes | Yes | Clear |
| Gilworth et al. (2009) | Yes | Yes | Yes | Yes | Unclear | Unclear | Yes | Yes | Yes | Clear |
| Gustafsson and Turpin (2012) | Yes | Yes | Unclear | Yes | Unclear | Yes | Unclear | Yes | Yes | Clear |
| Hartke et al. (2011) | Yes | Yes | Yes | Yes | Yes | Unclear | Yes | Yes | Yes | Clear |
| Koch et al. (2005) | Yes | Yes | Yes | Yes | Unclear | Yes | Unclear | Yes | Yes | Clear |
| Lock et al. (2005) | Yes | Yes | Yes | Yes | Unclear | Yes | Unclear | Yes | Yes | Clear |
| Medin et al. (2006) | Yes | Yes | Yes | Yes | Unclear | Unclear | Unclear | Yes | Yes | Clear |
| Robison et al. (2009) | Yes | Yes | Unclear | Yes | Unclear | Unclear | Unclear | Yes | Yes | Clear |
| Vestling et al. (2013) | Yes | Yes | Yes | Yes | Unclear | Yes | Yes | Yes | Yes | Clear |
| Wolfenden and Grace (2012) | Yes | Yes | Yes | Yes | Unclear | Unclear | Yes | Unclear | Yes | Clear |
| **CASP Key** |
| CASP Key:1. Was there a clear statement of the aims of the research?
2. Is a qualitative methodology appropriate?
3. Was the research design appropriate to address the aims of research?
4. Was the recruitment strategy appropriate to the aims of the research?
5. Was the data collected in a way that addressed the research issue?
6. Has the relationship between researcher and participants been adequately considered?
7. Have ethical considerations been taken into consideration?
8. Was the data analysis sufficiently rigorous?
9. Is there a clear statement of findings?
10. How valuable is the research?
 |

## 2.2 Synthesis of the Identified Themes

Each study was analysed by the research team and key themes were identified. Two members of the research team (CB and MW) independently reviewed and discussed the overarching themes identified from the included studies. Themes and subthemes identified as part of this meta-synthesis are presented in Table 2.3 with evidence from the original texts. These themes are: the nature of the effects of stroke, the preparatory environment, personal coping strategies and internal challenges and the meaning of work.

**Table 2.3 Process of thematic analysis**

|  |  |
| --- | --- |
| **Category** Subthemes | **Selected examples from primary studies** |
| **The Nature of the Effects of Stroke** | * “Cognitive–perceptual changes were also frequently mentioned as presenting barriers to the resumption of employment” (Koch et al., 2005)
* “…difficulties in using a hand, fatigue, speech or memory problems… a barrier to work…” (Alaszewski et al., 2007)
* “…respondents reported… having loss of function in an arm and leg, being clumsier (drops objects), having to be careful walking, needing to walk with a brace, having “spotty” balance…” (Culler et al., 2011)
* “…talked about persistent symptoms in relation to ability to perform at work” (Gilworth et al., 2009)
* “Difficulties with memory, processing information, speech and language, vision, walking, using the dominant hand and the effects of fatigue were all reported as barriers to employment” (Lock et al., 2005)
 |
| **The Preparatory Environment**  |  |
| The healthcare context | * “…perceived barriers to employment stemming from within the rehabilitation system… in several cases beginning with admission to unsuitable wards and misdiagnosis of their condition” (Lock et al., 2005)
* “Some professional groups (such as occupational therapists (OTs) were identified as being proactive regarding rehabilitation for work…” (Lock et al., 2005)
* “Rehabilitation limitations were sometimes attributed to services not being geared towards younger people” (Lock et al., 2005)
* “…participants did not receive professional rehabilitative assistance in negotiating this process; they relied on understanding employers” (Wolfenden and Grace, 2012)
* “…participants described tests conducted at the rehabilitation clinic and not linked to actual workplace demands as irrelevant and artificial” (Erikson et al., 2010)
* “Very rarely, if at all, did health-care professionals prepare the participants or their families for the potential for post stroke fatigue and its occupationally challenging consequences” (Flinn and Stube, 2009)
 |
| The bridge between the clinical and employment spheres | * “…participants bemoaned the widespread lack of awareness of stroke in younger people, reflected in poor service provision and general ignorance about the impairments that stroke leaves behind…” (Lock et al., 2005)
* “Some interviewees felt resentful that they had not been fully involved in discussions with their employer and the health care team about the decision they would not be able to return to work…” (Gilworth et al., 2009)
* “…choosing to disclose that you are a stroke survivor has the potential to change how you are perceived socially within the workplace and it may again lead to misconceptions and misunderstandings… not disclosing may make it difficult to explain why you are having difficulties” (Gustafsson and Turpin, 2012)
* “It was clear some interviewees were not sure when to go back to work and specifically were not given clear advice, or did not agree with the advice given by their General Practitioner or consultant” (Corr and Wilmer, 2003)
* “…informants’ comments revealed that if a support person had been appointed in advance it would have been a great help” (Vestling et al., 2013)
 |
| The workplace context | * “…simple adjustments within the work place had been effective at facilitating return to work… support from the employer for a phased return to work where working hours gradually build and/ or with the opportunity to work lighter duties” (Gilworth et al., 2009)
* “Employers’ negative attitudes, inflexibility and failure to implement adaptations to the stroke survivors’ work role, hours or equipment were perceived as barriers” (Lock et al., 2005)“
* “Stroke survivors who had successfully returned to work made particular note of how inviting the work place was to their return” (Hartke et al., 2011)
* “…co-workers were experienced as significant in a successful and sustainable return to work” (Medin et al., 2006)
* “Organisations were frequently viewed as threatening or oppositional, setting up road blocks to needed resources” (Hartke et al., 2011)
* “Participants who ran their own small businesses found their colleagues particularly supportive” (Alaszewski et al., 2007)
 |
| **Personal Coping Strategies and Internal Challenges** | * “…informants experienced their return to work as a gradual process in which they increased their work ability and workload step-by-step, and they found themselves acting as motors in this process” (Medin et al., 2006)
* “Individual creativity was also important for developing active techniques for adaptation and problem solving… such as trying to find out in advance when and which problems might appear, and then find a solution” (Vestling et al., 2013)
* “Individuals who were not working at the time of their stroke tended to assume that their stroke was an additional barrier to work and that possible employers would not recognise their potential” (Alaszewski et al., 2007)
* “…persons with aphasia… involved the use of a third person to prepare information prior to communicating with clients or other outside speakers” (Garcia et al., 2000)
* “…coping strategies as they applied to returning to work were evident … such as resilience, problem solving, risk taking, and stress management to maintain health” (Hartke et al., 2011)
 |
| **The Meaning of Work** | * “…individuals perceived stress as a causative factor in stroke and that work caused stress… could act as a barrier to return to work” (Alaszewski et al., 2007)
* “…felt that they had to get back to work, since work was and is an important part of their lives” (Medin et al., 2006)
* “Being able to return to work was seen as proof of their recovery…” (Medin et al., 2006)
* “…when considering employment, people appeared motivated by… the opportunity for interaction with others” (Robison et al., 2009)
 |

### Nature of the effects of stroke

Participants in the included studies discussed the nature of the effects of stroke and how it affected their ability to work, thus acting as a barrier to return to work. *“Most participants indicated that their ability to perform tasks related to their job position was compromised”*.[[61]](#footnote-61) These were often quite visible physical effects such as difficulties in arm function, mobility and balance. *“Hand paresis was frequently identified as a physical barrier to return to work… but spasticity and general locomotion were also noteworthy, particularly in more physically demanding work…”.*[[62]](#footnote-62)

However, the invisible effects such as fatigue, memory deficits, word-finding and cognitive impairments were also reported as a barrier when returning to work. *“…fatigue, mild word-finding problems and processing issues could not be easily seen or understood by others”*.[[63]](#footnote-63)

For participants, the ambiguity regarding the course of their recovery and the level to which they would regain functional abilities led to difficulties for those planning when to return to work and those seeking new employment. *“The uncertainty of recovery was particularly impeding for those looking to find a new job after their stroke”*.[[64]](#footnote-64)

### Preparatory environment

It emerged from analysis of the studies that elements of the preparatory environment from the initial healthcare context to the workplace setting could serve as barriers or facilitators to return to work post stroke. Three subthemes with this broader theme were identified including the healthcare context, the bridge between the clinical and employment spheres and the workplace context.

#### Healthcare context

Some studies reported that the rehabilitation system, was perceived as a barrier to return to work following stroke. Participants reported barriers early in the pathway such as admission to an unsuitable ward and misdiagnosis of illness, but also a sense of rehabilitation aimed at achieving a minimum functional level which was insufficient for workplace return.[[65]](#footnote-65) Within the health system, access to therapy services and return to work clearance was seen as a key role of the physician.[[66]](#footnote-66) However, access to these services was often difficult to obtain.[[67]](#footnote-67)

Healthcare professionals, such as the occupational therapist, were often regarded as being proactive for rehabilitation and facilitating return to work.[[68]](#footnote-68) *“Other health care professionals, such as various rehabilitation therapists, often endorsed the importance of work, provided a reality check on readiness, and were a source of motivation”*.[[69]](#footnote-69) Communication and cooperation between these healthcare professionals was reported as being very helpful during their rehabilitation.[[70]](#footnote-70) Furthermore, participants described vocational rehabilitation as being of *“critical importance”*,[[71]](#footnote-71) and being inspired by familiar places such as the workplace to engage in the rehabilitation process.[[72]](#footnote-72) On the contrary, *“the rehabilitation was described as including activities such as weaving and modelling clay, which were experienced as quite meaningless and not adapted to their needs or their age”*.[[73]](#footnote-73)

#### The bridge between the clinical and employment spheres

In transitioning from the rehabilitation setting to the workplace environment, participants reported a number of factors which acted as facilitators and barriers for returning to employment post stroke. The communication and cooperation between healthcare professionals and employers was identified as a facilitator for both access to services and a return to work. *“Liaison between rehabilitation professionals and employers was seen as an important factor in enabling people to access appropriate services and to eventually return to work”*.[[74]](#footnote-74) However, there were feelings of resentment when this communication did not involve the participant.[[75]](#footnote-75)

For some, there was uncertainty regarding the disclosure of having a stroke to employers. Although the declaration of having a stroke may have helped to facilitate adaptations and allow others to understand workplace difficulties from the perspective of the person with stroke, there was also the possibility that a participant may be perceived differently in this environment.[[76]](#footnote-76) For these individuals, the issue of worker rights featured. *“There was often a sense that she perceived she was going into battle to ensure that her rights as a stroke survivor and worker were being upheld”*.[[77]](#footnote-77)

While some participants described that earning money motivated their return to work, others articulated that the fear of losing benefits as an income was *“a disincentive to returning to full-time employment”*.[[78]](#footnote-78) In addition, the benefits system as a whole was seen as a complex system which was difficult to engage with following stroke. *“The benefits system was seen as being unfair, discriminatory and inaccessible to people with the reading, writing and/or comprehension difficulties associated with stroke”*.[[79]](#footnote-79)

The timing of a return to work following stroke was an issue, particularly in circumstances where there was a lack of clear advice provided by healthcare professionals or a disagreement with the advice given.[[80]](#footnote-80) As a result, stroke survivors would either return to work prematurely or would delay their return to focus on recovery, *“…survivors would delay returning to work to focus on recovery from such deficits, or they would underestimate the impact of these deficits on their performance and prematurely attempt a full return”*.[[81]](#footnote-81) In addition, participants felt that there was a lack of awareness of stroke and the resulting impairments especially in younger stroke survivors. This was particularly evident in service provision deficits.[[82]](#footnote-82) It was suggested in several studies that a support person to aid employer negotiations, provide support and concrete information was a facilitator to returning to work.[[83]](#footnote-83)

#### Workplace context

It emerged from many studies that workplace accommodations and attitudes impacted on return to work post stroke. “*The main factors associated with employer agencies were sick leave arrangements, adaptations and attitudes, all of which could act as enablers and barriers to work after stroke*”.[[84]](#footnote-84) For some participants, accommodations such as a phased return to work with reduced hours and lighter duties initially, helped to facilitate this process.[[85]](#footnote-85) For others, adaptations of the physical work environment or equipment acted as a facilitator.[[86]](#footnote-86) The support of work colleagues and supervisors in the working environment was expressed by participants as a facilitator to return to work.[[87]](#footnote-87) Interestingly, while those that were self-employed found work colleagues to be very supportive, those that worked for larger organisations found that the work environment lacked support at times, “*some experienced this environment as unsupportive… for participants who had worked for larger or public sector organisations*…”.[[88]](#footnote-88)

### Personal coping strategies and internal challenges

Following a stroke, participants identified internal challenges that they faced and strategies that they used in relation to dealing with the issue of return to work. The journey to return to work was often frustrating, and feelings of fear and anxiety were mentioned both for participants considering a return to work and those that returned several years previously. *“Fear that failure to perform adequately at work could result in a demotion and salary reduction also served as a disincentive”*.[[89]](#footnote-89) While some participants avoided challenging activities that, prior to the stroke were automatic, others found personal traits of resilience and determination were key to their recovery and subsequent return to work. *“Some felt it was determination that had aided recovery, and therefore, ability to get back to work”*.[[90]](#footnote-90) Insight into ones limitations following stroke was also recognised as an important factor in the return to work process. *“The survivors’ perception of their ability and readiness to return to work was evident in their willingness to accept limitations imposed by the stroke and their sense of confidence to re-enter the daily work world with them”*.[[91]](#footnote-91) However, this acknowledgement was sometimes challenged by the expectations of others. *“Other individuals within their social environments seem to want this level of pre-stroke participation as well, creating fairly high (and sometimes unsafe) expectations for the participants…”*.[[92]](#footnote-92)

As limitations were accepted by participants, a number of coping strategies were employed to help facilitate the return to work process. For some, individual creativity and taking the initiative was required in order to pre-empt problems that may occur and find a solution accordingly.[[93]](#footnote-93) Concentrating on one issue at a time, the use of memory notes and audio cues were also utilised to facilitate return to work. For others, their faith, organisation skills, and relaxation techniques were key facilitators in returning to work, *“…survivors identified several positive coping strategies, such as relying on their religious faith, celebrating small improvements in their recovery, being organised, practicing positive problem solving, using relaxation techniques, and developing good communication skills”*.[[94]](#footnote-94) A degree of self-reflection on the success of participants’ efforts in returning to work was also evident in some studies with psychological well-being enhanced by this success.[[95]](#footnote-95)

### The meaning of work

The meaning attached to work was an important factor for participants when deciding whether to return to work following stroke. For many participants, work was a valued activity, an important element of their life, and an integral part of their identity. *“Work was thought of as a means for personal development and feelings of pride of one’s own performance”*.[[96]](#footnote-96) For some, returning to work was regarded as a proof of recovery and a way of putting the stroke into the past in order to move on with their life.[[97]](#footnote-97) For others, a resumption of work challenged the individual’s pre-stroke work identity and *“…transition from a productive member of the work team to one who was perceived in a negative way was difficult to reconcile”*.[[98]](#footnote-98)

For individuals considering early retirement, there was a sense of being a burden both to family and society.[[99]](#footnote-99)

Perceptions of stress as a causative factor of their stroke often caused participants to reappraise their lifestyle and the part that work played in it. *“Despite the strong desire to return to work, most interviewees re-evaluated their work/life balance in view of their experience of work stress and stroke…”*.[[100]](#footnote-100) In addition, family and friends would often reappraise their expectations and support for work due to their concern for the stroke survivors’ health. *“…support from family and friends in their efforts to recover… for returning to work could be ambivalent as it conflicted with their concern for the survivor’s well-being”*.[[101]](#footnote-101)

The need to earn money and the potential loss of income were frequently mentioned as important motivators for returning to work.[[102]](#footnote-102) However, for some participants post stroke, there was ambivalence towards earning money, *“…informants showed an ambivalent attitude; the money was thought of as handy and necessary… but at the same time also thought of as being of less importance”*.[[103]](#footnote-103) As well as highlighting the financial benefits of return to work, the role of work as a social outlet and as an opportunity to interact and meet people was also an important factor for participants when contemplating a return to work.[[104]](#footnote-104) However for some, social integration in the work environment following a stroke could prove difficult and lead to anguish. *“…there was unmistakable joy when she felt that she was ‘fitting in’... there was also an equal amount of distress when it was not going well”*.[[105]](#footnote-105) For participants returning to work, voluntary work was viewed as a valued activity,[[106]](#footnote-106) which was often used as a transition to part-time or full-time engagement in work.[[107]](#footnote-107)

## 2.3 Discussion

### Statement of principal findings

This review summarises the totality of evidence relating to factors that impact on return to work from the perspective of the person with stroke. Four overarching themes were identified to summarise the findings from these qualitative studies including the nature of the effects of stroke, the preparatory environment, personal coping strategies and internal challenges and the meaning of work.

### Findings in the context of other studies

Participants of the studies included in this review discussed the nature of the effects of stroke as a barrier to returning to work after stroke. This theme has been found in previous qualitative reviews exploring the wider experiences of stroke survivors regarding physical activity post stroke and community re-integration post stroke.[[108]](#footnote-108) This has also been reflected in a systematic review of quantitative research which found that the severity of the stroke was a predictor of returning to work after stroke, with physical, social and psychological disabilities as a result of stroke being themes identified in the literature reviewed.[[109]](#footnote-109)

With respect to the theme focusing on the preparatory environment for return to work, quantitative research has found that occupational and vocational therapies offer significant benefits to stroke survivors in returning to work.[[110]](#footnote-110) Furthermore, Lawrence, (2010) also found a degree of frustration in stroke survivors when involved in rehabilitation lacking an active engagement on their part.[[111]](#footnote-111)

The transition from the healthcare context to the workplace can be difficult for stroke survivors. In keeping with the findings from the current review, Lawrence (2010) also reports that following the initial eagerness to return home, there is often a realisation from stroke survivors of the true impact of stroke. This is echoed in quantitative literature with variable rates of return to work within six months following stroke but also a second peak of return to work at twelve to eighteen months.[[112]](#footnote-112) In the present review, younger stroke survivors identified that there was a lack of awareness of stroke in their age group.

For many participants, the accommodations made and the support offered acted as both a barrier and facilitator to their return to work. This often included adaptations to the working environment, flexible working hours and lighter duties. These findings mirror previous quantitative research which found an association between the level of support offered and a higher rate of return to work following stroke.[[113]](#footnote-113)

Another theme identified in this review was personal coping strategies and internal challenges. Feelings of frustration, fear and anxiety were not uncommon for stroke survivors when contemplating a return to work, and we concluded that internal traits of resilience and determination were helpful to overcome these emotions. Accepting limitations was found to be an important strategy as it enables the use of coping strategies to facilitate a return to work post stroke. This theme is not unique to return to work, however, and was found in previous qualitative research examining wider stroke recovery.[[114]](#footnote-114)

A further theme identified in this review was the meaning attached to work. For some, returning to work was identified as proof of recovery and a way of moving forward. This was similar to Lawrence (2010) who found that returning to work marked a return to normality for stroke survivors. Although it was found that the means to earn money and potential loss of income were motivators for returning to work, this review also found that stroke survivors often reappraise their work/life balance, prioritise certain goals and adopt a different role.

### Clinical and policy implications

There are a number of clinical and policy implications for healthcare professionals and the broader stroke services community as a result of this review. There is a requirement for access to dedicated stroke units in the acute phase so that the management of these patients is optimised. The findings from this review support the argument that return to work should be addressed throughout the rehabilitation phase, and that healthcare professionals have a significant role to play in this regard.

Following a period of dedicated inpatient rehabilitation, there is a need to integrate community support services to optimise return to work among these stroke survivors. Suggestions arising from this review include a dedicated community stroke support liaison officer to facilitate the transition between the hospital and community environment. Furthermore, education is necessary in the community and the workplace to ensure that family, friends and employers are aware of the impairments, activity limitations and participation restrictions of the stroke survivor.

In the workplace, there is a need for flexibility and creativity to adequately support and encourage return to work. Incentives such as reduced or flexible working hours, re-visitation of work tasks and peer support all serve to facilitate the transition to the workplace.

### Strengths and weaknesses of this review

This systematic review synthesised the totality of evidence in relation to the barriers and facilitators to return to work faced by individuals with stroke. We identified 15 unique studies that explored issues around return to work using a comprehensive and robust methodology. However, our findings should be interpreted in the context of the study limitations. While the methodological quality of the studies was good overall, the application of a critical appraisal tool highlighted some weaknesses, particularly regarding the internal validity of the studies. While the use of a checklist in qualitative research is debatable, we have employed it to assist with the comparison between the studies. Furthermore, the generalisability of the findings is limited by the lack of standardisation of services for individuals with stroke on a local, national and international level. Finally, it must be acknowledged that the conclusions drawn from this review may have been influenced by the professional background of the authors.

### Areas for further research

Future research should explore issues around return to work from the perspective of other stakeholders including employers, service providers and family/carers using a mixed methods approach. The findings gleaned from such studies will serve to inform the development of multi-faceted interventions to target the barriers to return to work highlighted in this review. These interventions should be developed in liaison with the different stakeholders to ensure optimal outputs. Finally, factors identified as facilitators of return to work should be explored more fully to ensure that efforts are made to integrate these through transitions of care for the stroke survivor.

# 3. National Return to Work Survey of Stroke Survivors 2014/2015

## 3.1 Survey Characteristics

Data were collected between November 2014 and February 2015 in the form of paper and online survey responses. This report will present the findings based on 58 online responses and 64 paper responses received.

## 3.2 Data Analysis

Categorical data were coded and entered into a Microsoft Excel spread sheet. Continuous data were entered in numerical format. All quantitative data were analysed using STATA version 13.1. Descriptive analysis was carried out. Frequencies were presented and tabulated across relevant variables. Mean and standard deviations were calculated for normally distributed continuous variables, while median and interquartile ranges (IQR)[[115]](#footnote-115) were calculated for non-parametric variables. Statistical tests were performed at the 95% confidence level. A priori subgroup analysis was performed. Pre and post-stroke working hours were compared using a paired t-test. An independent t-test was used to compare age at stroke for those that did and did not return to work. Associations between gender, geographical location, employment support and the importance of return to work, respectively, and those that did and did not return to work were also investigated using univariable logistic regression.

All open responses were transcribed. Additional responses provided throughout the questionnaire were analysed as a whole. Negative, positive and neutral experiences were grouped and then coded into themes. Responses to the questions "If you worked since your stroke, what helped most?" and "If you tried to return to work or have worked since your stroke, what were the biggest challenges?" were analysed independently. Relevant individual quotations were selected to support statements and where it was felt that the qualitative meaning of the response was lost in coding.

### Characteristics of respondents

One hundred and twenty-two stroke survivors (50% male) responded to this survey. The median age of participants was 52 years (IQR=21 years). The median time since their stroke was 3 years and 2 months, (IQR=4 years and 4 months). Twenty-one respondents experienced multiple strokes. Respondents' median age at the time of their stroke was 49 years (IQR=23 years). It is a well-educated sample with 73% having achieved at least the Leaving Certificate equivalent, and 23% having completed a postgraduate qualification. The geographical distribution is largely representative of the national spread with 35% of respondents from Dublin, 49% from a rural area and 16% from another urban area.[[116]](#footnote-116) Nineteen percent of respondents reported living alone, with the remainder living with family or their spouse. As can be seen in Table 3.1, 58% percent of respondents currently mobilise independently without an aid, 29% mobilise with a small aid including a stick and/or a brace, while 13% require a walker or wheelchair. The majority of respondents reported experiencing numerous effects from their stroke. The most commonly reported effects were difficulties with thinking (76%), physical fatigue (73%) and arm function (68%). Figure 3.1 shows the proportion of respondents who experienced each problem.

**Table 3.1 Respondent Characteristics (n = 122)**

|  |  |
| --- | --- |
|  | Number or respondents (%) |
| Gender Male Female Not specified | (50%)(48%)(2%) |
| Experienced multiple strokes | (17%) |
| Education  Completed the Leaving certificate Completed postgraduate qualification | (73%)(23%) |
| Geographical distribution Dublin A rural area Another urban area | (35%)(49%)(16%)  |
| Mobility Independently without an aid With a small aid (stick and/or brace) Require a walker or wheelchair | (58%)(29%)(13%) |
| Working prior to their stroke | (82%) |
| Previous work sector Public sector Private work  Self-employed | (38%)(44%)(16%) |
| Stroke effects Difficulty thinking Physical fatigue Difficulties using arm Mental fatigue Difficulties with mobility Emotional difficulties Communication difficulties | (76%)(73%)(68%)(65%)(64%)(56%)(47%) |

Figure 3.1 Problems experienced after stroke

### Return to work

Eighty-two percent of respondents worked before their stroke. Of those who worked prior to their stroke 61% returned to work, and 50% are currently working. Of those that were working previously, 71 respondents attributed a great deal of importance to returning to work, 13 felt it was somewhat important, 6 felt it was a little important and 5 felt it was not at all important. It was found that those who felt work was at least somewhat important were more likely to return to work (*p*=0.016).

Those who returned to work had a mean age of 42 years (SD[[117]](#footnote-117)=11.6) at the time of their stroke. This made them significantly younger at the time of stroke, on average 9.5 years younger (95% CI[[118]](#footnote-118) -14.16, -4.92) than those who did not return. Table 3.2 presents differences in the demographic characteristics of respondents by their return to work status.

Table 3.2 Respondent characteristics by return to work status

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Work status** | **Not before stroke (n=22)** | **Not since stroke****(n=39)** | **Since stroke but not now (n=11)** | **Currently working****(n=50)** |
| Male (%) | 73% | 50% | 46% | 44% |
| Current Age (median years) | 64 | 58 | 48 | 46 |
| Age at stroke (median years) | 63 | 51 | 36 | 42 |
| Third level degree qualification (%) | 14% | 32% | 9% | 52% |

The geographical spread of the population in this study is largely representative of the national population. In this study, 55% of those that returned to work described living in an urban area, whereas 45% reported living in a rural area. There was, however, no association found between geographical area and likelihood of return to work (*p*=0.215).

Of those that returned to work 44% were male and 56% were female, however, there was no association found between gender and return to work (*p*=0.568).

Prior to their stroke, 38% of those working (n=100) were employed in the public sector, 44% in the private sector and 16% were self-employed. They worked an average of 44 hours a week (SD 23 hours).

Of those currently working (n=50), 48% have recommenced employment for over a year. Of those currently working, 38% are employed in the public sector, 38% are in the private sector and 21% are self-employed. Sixty-eight percent of workers (n=34) are working for their previous employer, with eight working in their previous role, seventeen having modified their hours, and the remainder carrying out a different role or multiple activities. Of those currently working, 32% are not working for their previous employer (n=16), with 25% of these reporting that they are in a different job with a different employer (n=4).

There is a significant reduction in the number of hours worked by those who have returned. Of those who returned to work, 30% did not return to fulltime work. Those currently working reported that they now work an average of 29 hours a week (SD=12.6 hours), an average reduction of 17.6 hours (95% CI 9.4-25.9 hours) in comparison to their pre-stroke working levels. This reduction in hours has led to 59% of those who are currently working reporting that their household income has decreased. Return to work for respondents also seems to have been a lengthy process. In terms of time to return to work, 41% had resumed some work within six months after their stroke and 64% had begun to work by one year. Only 32% of those who returned were working fulltime one year after their stroke.

Of the 11 individuals who worked since their stroke but are not currently working, four are doing voluntary work, three are unemployed, one reached retirement age, one retired on medical grounds, one is on sick leave and one is on invalidity pension. Of the 39 individuals who have not worked since their stroke, twelve are on sick leave, twelve have retired on medical grounds, four are unemployed, four are doing voluntary work and the remainder have reached retirement age or are currently studying. Of these 39 individuals, 22 reported that they do not feel fit enough to work, 18 are unable to carry out their previous job, and 6 are unable to drive or use public transport to get to work, while 4 individuals reported being unable to meet the expectations of their employer. Other reasons given for not returning to work include family responsibilities, being retired, financial barriers and being unable to find work.

Respondents reported numerous problems that affect their ability to work. The problems that caused most difficulty for respondents were mental fatigue, physical fatigue and difficulties with thinking, with over 78% of those who experienced these problems finding that they impacted on their work. Figure 3.2 shows how each problem affects respondents' ability to work. The number reporting each difficulty is presented as a percentage of those who experienced that particular deficit after stroke.

Figure 3.2 Problems affecting work after stroke

Some respondents have provided additional descriptions of specific deficits and how they can affect their ability to work, with those who completed the survey online coded as O, and those that completed a paper survey coded as P. In addition, dealing with these deficits has been described to lead to stress and anxiety.

"Communication important part of job but combined with memory, concentration and fatigue very difficult to perform to standard before stroke." (O35)

"My energy and concentration levels plus my ability to do tasks, both in terms of private and public life is greatly diminished." (O49)

"I was right handed but since the stroke I have had to learn to write with my left hand so I am a lot slower taking notes etc., I will get anxious, panicky and frustrated with myself in certain situations - usually it relates to the loss of short and long term memory recall." (O18)

"I have encountered problems, from day to day, in terms of lack of concentration, memory recall, severe lack of energy, not being able to deal with surrounding noise within the office environment. This leads to stress stemming from all of the above." (O49)

“My work was mental/ psychological etc... not physical. I could not register words/ sentences or speak on the phone. I would have been a potential danger or liability.” (P4)

“When under pressure writing and speaking can become a problem.” (O76)

### Support from employers

There was a significant association found between the level of perceived employer support and return to work for stroke survivors (*p*=0.002). Those who returned described a greater level of employer support. Figure 3.3 shows the level of support received from employers reported by respondents, presented according to their return to work status. The most common accommodation reported by respondents was flexible working hours (47% of respondents). Of all respondents, 41% felt more support should have been offered from their employer, 64% felt their employer understood their needs, 22% felt pressure from their employer to return to work and 23% reported experiencing discrimination during job application processes.

Figure 3.3 Level of employer support

Respondents provided additional information to describe both positive and negative experiences of interaction with their employers. Contact was appreciated, especially when there was genuine concern.

"They were genuinely concerned about my wellbeing as opposed to enquiring to ascertain when I would return to work." (O53)

Several respondents reported the distress of receiving no contact from their employer or receiving contact perceived as "demanding", requesting medical certificates or an expected return date.

“I did not receive any contact except to demand a 'sick cert'.” (P7)

“At one point had manager shout at me demanding when will I return.” (O4)

“Felt under pressure to return to work because of phone calls regarding courses and if they would put my name down and cert every week resulting in two hour sitting in GP surgery to get cert, plus the financial strain with regard to cost of the cert.” (P42)

"I send in regular medical certs and I have had no contact. I have called to get information on my options. I was palmed off and told that someone would call me. They never returned my calls." (O14)

One individual reported this causing them to make a poorly timed decision.

"I quit my job due to constant demands of when would I return. I did this at a time I was depressed and still struggling to comprehend what had happened." (O4)

Being allowed to make the decision about retirement in their own time was appreciated. In contrast having the decision to stop work made for them was very difficult for some respondents.

"My employer 'let me go' the day I was released from the hospital - the day I got home. The shock of this was nearly the last straw and very difficult to cope with." (O56)

Respondents described experiences of being "managed out" and having belongings packed up from their desk. For some respondents there was no opportunity to change role or reduce hours.

“My employer terminated my employment effective immediately.” (O56)

A number of respondents described the benefits of gradually returning to fulltime hours over the course of one month to three years. They referred to "phasing", being allowed to take as much time as needed, "easing back into shifts" and being allowed to work at their "own pace".

“I was advised on numerous occasions that I should take as much time as I needed to recover.” (O53)

“They have left the decision to me to return to work when I feel ready.” (P55)

“Being encouraged to work at my own pace and to rest whenever I feel the need.” (O44)

“My immediate superior… recommended that I ease back into the shifts. I did not work for the first half of the early shift and only worked half of the night shift and finished early.” (O49)

Positive words used to describe employers were "helpful", "supportive", "accommodating", “caring” and "understanding". Some respondents valued the understanding that they were a different person after stroke, and one respondent saw their employer's personal experience of living with someone with brain injury as an advantage.

In contrast, when employers did not understand the effects of the stroke it led to challenges for respondents. Some employers overestimated the effects that the stroke had while others did not understand subtle deficits. Respondents reported that some employers did not understand transport difficulties or the time required to recover from stroke.

“It was difficult to make them understand transport difficulties.” (P5)

“Little understanding was given to how long it takes to get over stroke.” (O4)

“Lack of understanding around effects of stroke.” (O63)

Some employers were able to provide particular supports including occupational nurses and doctors and transport to and from work for a limited period. Going back and being accepted by colleagues was an important part of recovery for some.

"Also to feel you are getting back to yourself and returning to the same job is obviously easier, I don't think I could imagine having to start a different job with people I didn't know, being with people who know what's happened was easier in my experience." (O17)

"My return to work and normality was a crucial element in my healing and recovery from my stroke." (O28)

### Available services

Two-thirds of respondents reported receiving more than one service to help with their return to work. Figure 3.4 shows the number of respondents that reported receiving each service.

Figure 3.4 Services received by respondents[[119]](#footnote-119)

Respondents provided additional information to describe both positive and negative experiences of services. Helpful services described include stroke support groups such as Acquired Brain Injury Ireland, Headway, Quest, Employability Ireland, outpatient rehabilitation, the "communication buddy system", stroke nurses, stroke consultants and general practitioners (GPs).

Several respondents described experiencing no support in the community once leaving hospital. They reported feeling "lost" and needing to talk about "fears and concerns". The lack of support for young people and for those outside Dublin was specifically mentioned. The need for counselling and stroke support groups was also highlighted.

“There isn't much advice for a younger stroke person to return to work. What a 30 something hopes to achieve professionally isn't necessarily what an older person post stroke would want to achieve.” (O10)

"I would like to see the development of a community stroke nurse and a physiotherapist and a whole team so I could access the same therapy once I am at home. This is essential." (P8)

Three respondents highlighted the need for information and advice about the need to start slowly when returning to work.

"I was my own worst enemy whilst returning to work - always trying to do more than I should have. Someone should have been guiding me and preventing me from doing that." (O19)

“If I was to give advice to anyone I would really put over the need to start slower when returning to work.” (O10)

Some respondents described the lack of understanding about available services among both healthcare professionals and welfare services.

"I feel a lot of the reason of my lack of success at returning to work long-term after my stroke was due to the fact I didn't know where or who to contact." (O18)

“Felt no one knew what was best for me, when asking consultants what should I do - it was really left up to myself.” (O10)

"The social welfare system is totally disconnected from stroke survivors. A stroke survivor should be allowed keep their disability/ invalidity allowance/ pension to carry out limited real work.” (P6)

“The lack of information I experienced in Social Welfare Office…. was disgraceful.” (O43)

### Facilitators and challenges

#### What helped most?

Forty-three respondents described what had helped their return to work most. Fourteen mentioned work support including patience and understanding, flexibility and workplace adaptations.

“The support from my employer allowing me to return to work gradually to cater for my fatigue…” (O53)

“…the fact that I knew that my job is there, waiting for me and I should not rush to return to work…” (O43)

Eight respondents cited social support including family, friends, neighbours and colleagues.

“Encouragement and understanding from family and friends…” (P42)

Seven respondents described help from health professionals including occupational therapy, speech and language therapy, physiotherapy, doctors, nurses and services such as Acquired Brain Injury Ireland, National Learning Network and Headway Ireland.

“The speech therapy helped a lot in terms of trying to get around the effects of flow of speech and identifying alternative words for conversation in everyday life.” (O49)

“The time in the Stroke Rehab centre was excellent for rehabilitation and for my confidence.” (O68)

“National Learning Network supervised work programme suited to ability... recovered confidence and work schedule.” (P6)

Five individuals described personal factors such as a sense of “personal achievement”, “keeping busy” and “wanting to get back to as 'normal' a life as possible”.

Other facilitators included the "prospect of earning money", using work as a “focus” to take the mind off stroke, “exercise and rehab”.

#### What were the biggest challenges?

Sixty-three respondents described the challenges they experienced while attempting to return to work. Twenty-nine individuals mentioned problems associated with the stroke, most commonly fatigue, but also memory, speech and physical deficits.

“Tiredness – it’s so frustrating. Everyone is tired by Thursday but I have stroke tiredness on top of normal day to day tiredness.” (O10)

“Memory, speech and physical exhaustion were my biggest problems when I returned to work.” (O11)

“My writing and reading are not great. I look well, but I find most people do not understand my difficulties and some are not patient.” (O66)

Fifteen of them described emotional challenges including depression, lack of confidence, fear and feeling isolated.

“Fear I would not be capable of doing the job.” (O41)

“The pressure of work was difficult to manage and sometimes led to emotional/mental strain.” (P23)

Five respondents reported challenges related to their employer.

“Most of the potential employers that I have met with have been sympathetic, but there is a massive lack of knowledge and empathy towards a stroke person.” (O15)

Four reported difficulties with transport due to the loss of driving and difficulties encountered with public transport. Two reported difficulty with accessibility to certain workplaces. Other challenges reported by respondents include financial challenges and difficulty with the completion of work.

##

## 3.3 Discussion

### Statement of principal findings

The results of this national survey provide an insight into the factors associated with returning to work after a stroke. Over half of respondents working prior to their stroke returned to work while only one third of those who returned to work were working fulltime at one year post stroke. For those working at the time of the study, there was a significant reduction in the number of hours worked post stroke with many respondents reporting a reduction in their income. For stroke survivors engaged in the job application process, approximately one in four reported experiencing discrimination.

### Nature and effects of stroke

Mental fatigue, physical fatigue and difficulties thinking were the three most common problems that stroke survivors reported impacted their ability to work. For many, the deficits associated with stroke were the greatest challenge to returning to work. Of those that did not return to work, many reported not feeling fit enough to do so or being unable to carry out their previous job role.

Although gender and geographical location were factors found to have no significant association with return to work, age at the time of stroke and the level of importance attached to returning to work, however, were associated with return to work. Those who returned to work were significantly younger at the time of their stroke compared to those who did not. Also, individuals who felt that returning to work was at least somewhat important were more likely to return to work.

### Preparatory environment

Employer support was also an important issue for many stroke survivors. Although many felt their employer understood their needs following stroke, almost one in four felt pressure from their employer to go back to work. Furthermore, many respondents reported that more support should have been offered, with those who did return to work describing a greater level of employer support. For many, this workplace support was the greatest facilitator for returning to work.

In terms of accessing available services, physiotherapy and occupational therapy were the most commonly availed of services. Two thirds of respondents received more than one service to help with their return to work but several participants reported receiving no professional support in the community once discharged from hospital.

### Findings in the context of other studies

### Nature and effects of stroke

The majority of respondents in this study were working prior to their stroke. As found in the systematic review published in this report, respondents found that the nature of the effects of stroke were a barrier when returning to work. Similar to a previous national survey conducted in the USA, fatigue, both mental and physical, alongside difficulties with thinking were the most common problems that respondents found affected their ability to work.[[120]](#footnote-120) Reasons for not returning to work after stroke included not feeling fit enough, being unable to carry out a previous job role, being unable to drive or use public transport and being unable to meet the expectations of an employer.

For those that did return to work after stroke, this rate of return, at 61%, was found to be higher than the mean rates of 44% (range 17% - 73%) and 45% (range 0% - 100%) found in two previous reviews.[[121]](#footnote-121) However, the methodological differences in reviewed studies with respect to study population, definition of work, follow-up period and study design in both reviews question the reliability of such estimates.

### Preparatory environment

Although a large percentage of respondents returned to work, there was a significant reduction in the number of hours worked, with 30% of respondents reporting that they did not return to fulltime work. This was similar to a previous study examining the sociodemographic differences in return to work after stroke in London, England, which found that of those that returned to work after stroke, 35% did not return to fulltime work.[[122]](#footnote-122) Vestling et al. (2003), however, investigating the indicators for return to work after stroke in Sweden, found that 61% of individuals who had returned to work did not return to fulltime work after stroke. Reflecting the significantly reduced working hours post stroke, over half of respondents currently working in this study reported a decrease in household income.

In addition, the timing of return to work was an important issue for respondents. Forty-one percent of respondents in this study had resumed some work within six months after their stroke. This is similar to previous work by Saeki et al. (1995) who found that stroke survivors tend to return to work during two periods, at six months post stroke, and at twelve to eighteen months post stroke. Lindström et al. (2009) found that 86% of stroke survivors returned to work by one year, which compares to 64% of respondents in this study returning to work in some capacity by one year.

### Factors influencing return to work

Although gender was not associated with return to work in this study, age was found to be a significant factor when returning to work, with those who returned to work being significantly younger at the time of their stroke (42 years) than those who did not return to work (52 years). Interestingly, in their study, Vestling et al. (2003) found that there was no correlation between age at stroke and return to work. Varona et al. (2004), however, when investigating the long term prospects of ischemic stroke in young adults found that being able to return to work was associated with an age lower than 36 years (*p*=0.01). Lindström et al. (2009) found that there was no significant difference in returning to work regarding age groups in their national survey of stroke survivors, though their participants were aged between 18-55 years. Wozniak et al. (1999) found that stroke survivors employed at one year follow up were significantly younger (*p*<0.05) at 52 years compared to those that were not employed at 57 years, while Busch et al. (2009) found that those who returned to work at one year follow up were also significantly younger (*p*=0.01) at 52 years compared to those who did not return to work at 55 years. Furthermore, Busch et al. (2009) found that those aged 55 years and over were particularly less likely to return to work after stroke.

### Meaning of work

In the systematic review published in this report, the meaning attached to work was found to be an important factor for participants when deciding on returning to work following stroke. In this survey, the importance of returning to work was relevant for many stroke survivors when contemplating a return to the workplace. Internationally, Bryan et al. (2002) found that 75% (n=503) of stroke survivors surveyed expressed their desire to return to work after a stroke and Lindström et al. (2009) found that 70% (n=565) of respondents felt it was important to return to work after stroke. In the present study, of those that were working previously, 88% of respondents (n=84) felt it was important or somewhat important to return to work while 16% (n=11) felt it was a little important or not at all important. As such, it was found that those who felt work was at least somewhat important were statistically significantly more likely to return to work (*p*=0.016). Similarly, Lindström et al. (2009) found that those who felt it was important to return to work (n=442) after a stroke were significantly more likely to return to work (*p*<0.001) compared to those who felt it was not important (n=123).

### The workplace context

As well as the importance of work to the individual, similar to the Lindström et al. (2009) findings, the level of support offered, and in the present study, specifically the level of employer support offered, was found to be significant for respondents (*p*=0.002) with those who returned to work describing a greater level of employer support. This employer support often manifested itself in employer accommodations such as flexible working hours. Although over half of respondents felt that their employer understood their needs, many felt that more support should have been offered, while some felt pressure to return to work. Almost one in four respondents described experiencing discrimination during job application processes.

In this survey, although the majority of respondents reported receiving access to more than one service to help return to work, many described experiencing a lack of support in the community once leaving hospital, particularly for younger stroke survivors. This lack of access to advice and information was specifically mentioned by stroke survivors in this survey and has been found in a previous national survey of stroke survivors conducted in Australia.[[123]](#footnote-123)

### Clinical Implications

Return to work rates in this study were found to be quite high. However, when analysed further, it was revealed that many of those who returned to work were not working fulltime one year after their stroke. Post stroke deficits were found to be barriers to returning to work, while personal and organisational factors were found to act as facilitators or barriers.

The meaning of work and importance of returning to work to the individual was associated with a higher return to work rate following stroke. Although for some stroke survivors, returning to work is not an important goal, for many it can have a positive impact on the their psychological wellbeing, and as such, should be facilitated when possible.[[124]](#footnote-124)

One facilitator evident in this survey was the level of employer support post stroke, which was associated with higher return to work. The Irish Stroke Clinical Guidelines in 2010 regarding vocational activities recommend advising stroke survivors and employers of grants available that may facilitate a gradual return to work for the employee or allow the purchasing of equipment to make adjustments and accommodations at the workplace. Such accommodations may help employers to facilitate a return to work both for stroke survivors who are motivated to return to work but also for those who report feeling not fit enough to return to work or those feeling unable to carry out their previous work role.

Furthermore, the age at the time of stroke for the stroke survivor should be considered. This study highlighted that those who were returning to work were significantly younger at the time of their stroke than those who did not. Although more likely to return to work, this cohort of survivors expressed a definite need for access to services and advice that are directed specifically towards the needs of younger stroke survivors. Directing such services at specific groups may also help those older individuals that are not returning to work to re-engage in the workforce.

In addition, access to information and education on workers’ rights post stroke may help those that wish to re-engage in the workforce but report experiencing discrimination during the job application process.

### Strengths and Weaknesses of the Study

A major strength of this study is that the survey used was developed from two previously used surveys, the UK Work after Stroke Survey and the US Return to Work after Stroke Survey.[[125]](#footnote-125) The survey was then adapted to the Irish setting through input from healthcare professionals and stroke advocacy personnel. A preliminary version of the questionnaire was then piloted by two volunteers with experience of returning to work after a stroke and changes were made to the questionnaire based on the feedback received.

It was intended in this study to recruit a sample that was geographically representative of the national spread. This was attempted by recruiting primarily through the Volunteer Stroke Scheme clubs and the Irish Heart Foundation’s National Stroke Support Group Network, non-statutory organisations and contacting the clinical nurse specialist for stroke in regions that did not have an active stroke support group. The survey was also promoted via online websites. As a result, the geographical distribution of respondents is largely representative of the Dublin/non-Dublin spread with 35% of respondents living in Dublin compared to 40% of the population nationally. There were however, more respondents living in rural areas (49%) and less living in another urban area (16%) than the general population of 38% and 22%, respectively.

One element of this study which helped in terms of recruiting participants was access to the survey online via websites such as the Irish Heart Foundation, Headway Ireland, Acquired Brain Injury Ireland and Brain Rehabilitation Ireland. However, a limitation of such access is that it is not known if any individuals completed both the online and paper survey, thereby duplicating results.

This study sample is not a random or nationally representative sample of all individuals who have experienced a stroke in Ireland in the last number of years. For this reason it is likely to exclude both the most isolated stroke survivors, who may have the greatest level of need, and those least affected and those not seeking support after their stroke for return to work issues. Every effort was made to access a sample that was representative of the national geographical spread. In areas where there was no stroke or brain injury support group, health care professionals contacted the research team and acted as gatekeepers and posted questionnaires on our behalf to their clients. Our sample includes more respondents living in Dublin/urban areas (51%) and less in rural areas (49%) than in the general population.

This survey provides an insight into the factors associated with returning to work after stroke and may help to understand the facilitators and barriers in an Irish context, thereby enhancing the functional and employment outcomes of stroke survivors.

# 4. Focus Groups and Semi-Structured Interviews with Key Stakeholders

## 4.1 Focus Group Characteristics

Data were collected between November 2014 and March 2015 in the form of focus groups and semi-structured interviews. This report will present the findings from 10 focus groups, 11 semi-structured interviews and 2 detailed email correspondences.

## 4.2 Data Analysis

All recorded data from focus groups, semi-structured interviews and detailed email analysis were transcribed verbatim. The approach described by Miles and Huberman was adopted for analysis of the transcriptions for stroke survivors and their spouses.[[126]](#footnote-126) All participants were assigned a code to ensure anonymity in the transcript. The transcripts were explored by a process of reading and re-reading. On the first reading, transcripts were read in their entirety to acquire a sense of the whole. On the second reading, using line by line analysis, patterns and themes were identified and listed. Prior to the third reading, the responses from all participants to each question were transferred to Microsoft Excel for further examination. The third reading involved checking the suitability of the coding system and pursuing patterns both consistent and inconsistent with the codes defined. An overarching framework developed during the systematic review was used to describe the primary barriers and facilitators for returning to work after stroke.

A similar process was used to analyse the transcriptions for healthcare professionals, multidisciplinary healthcare team members working in stroke, representatives from advocacy organisations for acquired brain injury and policy workers for disability non-governmental organisations. Through the process of reading and re-reading, the barriers and facilitators to returning to work as well as improvements that could be made to current stroke services were identified.

### Characteristics of respondents

Sixteen stroke survivors, two spouses of stroke survivors and thirty-three members from the multidisciplinary healthcare team and advocacy groups providing support for acquired brain injury participated in focus groups, semi-structured interviews and in two instances provided a detailed email correspondence (Table 4.1).

**Table 4.1 Focus Group Characteristics**

| **Method of Data Collection** | **Number of Participants** | **Professional/Stroke Survivor/Employer** |
| --- | --- | --- |
| First focus group | 5 | Consultant PhysicianClinical Nurse SpecialistPsychologistOccupational TherapistSocial Worker |
| Second focus group | 2 | Social WorkerPsychologist |
| Third focus group | 3 | PhysiotherapistOccupational TherapistSpeech and Language Therapist |
| Fourth focus group | 5 | Two PsychologistsThree Assistant Psychologists |
| Fifth focus group | 2 | Policy Workers at Disability Non-Governmental Organisation |
| Sixth focus group | 6 | Six Stroke Survivors  |
| Seventh focus group | 8 | Six Stroke Survivors Two Stroke Group Facilitators |
| Eight focus group | 2 | Support Line OperatorCommunity Integration Officer  |
| Ninth focus group | 2 | Two Psychologists |
| Tenth focus group  | 2 | Two Stroke Survivors \*One stroke survivor was accompanied by their spouse |
| First semi-structured interview | 1 | Community Integration Officer |
| Second semi-structured interview | 1 | Policy Worker at Disability Non-Governmental Organisation |
| Third semi-structured interview | 1 | Training Officers |
| Fourth semi-structured interview | 1 | Training Officers |
| Fifth semi-structured interview | 1 | Training Officers |
| Sixth semi-structured interview  | 1 | Non-Governmental Organisation Providing Services For People With Disabilities |
| Seventh semi-structured interview | 1 | Occupational Therapist |
| Eight semi-structured interview  | 1 | Spouse of Stroke Survivor |
| Ninth semi-structured interview  | 1 | Spouse of Stroke Survivor |
| Tenth semi-structured interview  | 1 | Stroke Survivor |
| Eleventh semi-structured  | 1 | Stroke Survivor |
| Detailed email correspondence | 2 | Vocational Assessment Service |
| Detailed email correspondence | 1 | Psychologist  |

## 4.3 Identified Themes from Stroke Survivors

An overarching framework developed during the systematic review published in this report was used to describe the primary barriers and facilitators experienced by stroke survivors.

### The Nature of the Effects of Stroke

The type and extent of deficits that are experienced after stroke such as mobility, physical and communication deficits were highlighted as important factors in whether or not individuals return to work.

“I didn’t get back to work, because I have aphasia, it was kind of moderate, yeah, severe – kind of severe, it started off as moderate/severe and obviously with the, the help that I got I got to moderate, but it wasn’t enough,… so I couldn’t go back, I couldn’t go back as, doing that job.” (Focus group 6, participant 5)

For some, the stroke affected their ability to drive and in doing so impacted the ability to work, particularly in rural areas, “I couldn’t drive…so I couldn’t, couldn’t work really” (Focus group 7, participant 2). For one urban dwelling stroke survivor, post stroke balance difficulties prevented a return to cycling to work.

Alongside, the visible effects, for many stroke survivors, hidden deficits such as difficulties with memory impacted their ability to return to work and in one instance, prevented a return to work.

“I’m a joiner by trade but I lost all interest. I wasn’t able to remember how to do it.” (Focus group 7, participant 2)

Another hidden effect of stroke, fatigue was discussed and described as impacting both the ability to work and time outside of work.

“…like when I went back to work in the first place the only way I can describe it is it’s like a rechargeable battery, you know, and the battery is nearly gone down, you just feel absolutely wasted, drained. You’d go home from work and you’d just have to collapse in to bed, you couldn’t do anything at all.” (Focus group 6, participant 3)

While the physical effects of stroke were often recognised, there was a lack of awareness from others of the invisible or hidden effects of stroke, with one individual describing how co-workers “look at me and say we don’t see anything different” (Focus group 6, participant 1). This was echoed by another participant who was unable to return to work.

“…I’d tell most people that I’ve had a stroke and, but they kind of forget about it then after a while and they don’t realise the ongoing problems…” (Focus group 6, participant 5)

### Preparatory Environment

#### The Healthcare Context

For many participants, there was a genuine appreciation and satisfaction with the quality of care received during their hospital stay and community rehabilitation, although the initial hospital experience for one participant was challenging.

“Initially when I went in with the stroke I was being sent home, I was told that ‘ah you’re fine, go back and go to your GP’… I mean I had said yeah, listen, there’s something wrong with me…” (Focus group 6, participant 4)

For many stroke survivors, the relationship with healthcare professionals was a positive one with healthcare professionals providing support and encouragement which facilitated a return to work.

“…she was excellent, just her whole manner was and she just gave me a great confidence and said, you know, listen, you might be feeling crap now but, you know… and it is, it is the encouragement there – and at every stage I got encouragement.” (Focus group 6, participant 4)

Clearance and advice on returning to work was often provided by physicians, occupational or speech and language therapists, depending on the nature of the effects of the stroke. However, the communication between patient and healthcare professional during this process could be improved as stated by one participant.

“And actually it would be helpful to have someone who listens more to the individual. Because like, we have opinions.” (Semi-structured interview participant 10)

Though participants were generally happy with the quality of services, access to such services was described as difficult for some individuals with one stroke survivor feeling that he didn’t receive enough speech and language therapy following his stroke. Another participant attributed the lack of services received as a product of an age divide, with younger stroke patients receiving less services due to “being fine” while those “…sixty-five and over are treated fairly comprehensively” (Focus group 6, participant 1). This participant described their difficulties in accessing physiotherapy.

“…you know, the one weak area in [hospital] was physio – I was there, I was in over Christmas, which didn’t help, but I spent a week trying to see a physiotherapist…” (Focus group 6, participant 1)

As a result of insufficient therapy services, the need to pay for private therapy sessions following discharge from hospital was expressed by two individuals.

A further barrier in the rehabilitation context was the transition from hospital discharge to community rehabilitation services. For one stroke survivors there was both a lack of awareness of community services and lack of willingness to refer to community services, describing it as a “willingly disjointed service” (Focus group 6, participant 1).

#### The Bridge between the Clinical and Employment Spheres

In transitioning from the hospital and community setting to the workplace, a number of factors which acted as barriers and facilitators were mentioned by participants. A number of individuals, including those that returned to work and those that did not, mentioned the importance of financial security post discharge from hospital, “…it was important for me to get the insurance, you know, it was really” (Focus group 6, participant 5). However, on occasion, there was then pressure from insurance companies to return to work.

For some stroke survivors, communication with employers was positive, “…I was told the job was protected and I could come back and do what I was doing...” (Focus group 6, participant 3), whereas for others, negotiations were described as “difficult” and hampered by communication deficits.

When considering a return to employment, and undertaking the job application process, it was mentioned by some individuals that having a disability was seen by employers as a barrier to re-entry.

“…I don’t think they’d like to do that, if you’re in a wheelchair, or if you have a disability. They’re not kind of the employers that would take you on.” (Focus group 7, participant 3)

“…if they’ve a choice between someone who’s had a stroke and someone who hasn’t they’re going to pick the person who hasn’t had a stroke and there’s nothing you can do to get around that…” (Focus group 6, participant 2)

For many stroke survivors, although it was acknowledged that the FAST campaign was highlighting stroke to the general public, it was felt that there was a general lack of information on stroke available to the public.

It was also reported that there was often a lack of information and clarity from health professionals on issues such as the subsequent effects of stroke and factors such as when to return to work, “The thing I find, I’m sick seeing doctors here and there. You ask a question and nobody knows the answer, to the question” (Focus group 7, participant 2). The use of stroke support groups and focus groups organised by non-statutory organisations were mentioned by participants as very positive, both for obtaining information on stroke and gaining confidence within that community.

“…it was from that, the support from within, from people who have experienced it, who can give the confidence to each other…” (Focus group 6, participant 5)

In addition, one participant reported that a liaison officer provided by their workplace helped facilitated their return to work.

“…he’d call out like and he’d come in to the house… and talk to you, you know, about problems you’re having or how, you know, how you’re coping with it and, you know, if he could answer any questions you had…” (Focus group 6, participant 3)

#### The Workplace Context

Re-engaging in the workforce was often facilitated or impeded by the relationship between the stroke survivor and their employer, and the possible accommodations and adjustments made to facilitate a return to work.

“…I knew the manager, I knew him well, and you know, they, they kind of gave great, you know, support and would cover you…” (Focus group 6, participant 4).

For most participants, the accommodations offered were usually reduced hours with a gradual return to work and lighter duties.

“initially they said go back for four hours for the week – so I went back for four hours for this week – and then it was, you know, built up, you know, two days a week, three days a week…” (Focus group 6, participant 4).

In addition to employer support, the support from colleagues was reported as being helpful to a successful return to work, particularly in the initial stages.

“And like I am very blessed, I have wonderful colleagues and they’ve carried me a little bit.” (Semi-structured interview participant 10)

Although employers were often supportive in the return to work process, it was felt that they were often fearful of contributing to the cause of the stroke or potentially causing another stroke.

“…she’s terrified that she might have had something to do with me going out in the first place, you know.” (Focus group 6, participant 6)

However, employer and colleague support was not forthcoming for all stroke survivors. To help secure a job and battle discrimination during the job recruitment process, some chose not to disclose that they previously had a stroke.

“…well I am a very honest person – so it was strange to have to go and basically nobody in work has any idea what happened to me but like there was absolutely no other choice…” (Focus group 6, participant 2)

### Personal Coping Strategies and Internal Challenges

Following a stroke, many survivors reported internal challenges and the strategies that they used to overcome these. For some, there was embarrassment, frustration and anger at issues such as the perceived lack of progress in recovery and the lack of understanding from others including family and friends. In addition, some participants expressed feelings of fear, both when thinking back to the time of their stroke and when looking to the future, with one individual expressing a fear of demotion on returning to work.

When stroke survivors expressed a nervousness or lack of confidence on returning to work and a fear of how they would be perceived, there was a sense that personal traits of resilience and determination tended to help overcome these emotions.

“I think it was me. I was determined to go back and I kept fighting.” (Semi-structured interview participant 10)

“…beforehand what I tried to do is I tried to steel myself as to how people perceived me and – or how people would perceive me in work…” (Focus group 6, participant 4)

For many, there was an awareness of their limitations and an acceptance of change post stroke. For some, this was an acceptance of their inability to meet the requirements of their previous job upon the initial stages of their return to work.

“…there was a considerable amount of responsibility involved and, you know, I had to kind of turn back and say right, listen, in some respects I’m not the same person…” (Focus group 6, participant 4)

Personal coping strategies employed by individuals included adapting to post stroke visual deficits when working at a computer screen and using software to help read out emails at work. For others, regular communication was key to remind their employer of the supports necessary to facilitate their work. However, for some there was a feeling of embarrassment “when things go wrong“, which led to some stroke survivors hiding their difficulties to try fit in at work and maintain a sense of pride.

### The Meaning Attached to Work

For stroke survivors, work was often an important part of their identity. For some, the desire to return to the workplace was due to boredom and being “fed up watching TV”, while for others work provided a means of supporting their financial needs. When contemplating a return to work after stroke, one participant wanted to return to work as soon as possible.

“With me anyway, it would be straight away. Because that’s what you, you’d, you’d be thinking about wouldn’t you. You’d be thinking about wages coming in and when I’ll be able to get back to work and how will I support this and that.” (Focus group 7, participant 2)

For another participant there was a fear that retiring from work early would result in financial difficulties in the future.

“I’d actually applied for the disability pension and I thought Jesus, wait now… and I thought Christ, wait now, I’m going to be pensioned out at this stage.” (Focus group 6, participant 4)

The same participant also described how they re-evaluated their goals following their stroke and realised that promotion was unlikely, and therefore prioritised working to secure their pension.

For those that were unable to return to work, past times and social activities with friends and family occupied the previous role of work.

## 4.4 Factors Highlighted by Spouses of Stroke Survivors

For spouses of stroke survivors interviewed in this study, opinions were expressed on issues including the initial hospital care, community rehabilitation services, the improvements to current services and subsequent return to work for their spouses.

Both participants were very appreciative of the initial hospital care and in particular, the access to information from healthcare professionals.

“I mean he was very impressed with all the services and I was very impressed like even when he was in the hospital I had access to people to answer any of my questions and all the rest…” (Semi-structured interview participant 9)

However, it was felt that for acute hospital services the primary goal was achieving functional independence for the stroke survivor. Once discharged to the community, it was felt that there was a “gap” in services. For one participant, there was a lack of information from healthcare professionals in hospital regarding community stroke services.

“…there wasn’t any advice, certainly not to me and I don’t think to him either, regarding, you know, onward going services in the community.” (Semi-structured interview participant 8)

Once accessed by stroke survivors however, community stroke services were described as “helpful”, “fantastic” and “supportive”. For one participant, the services helped to build confidence and empower the stroke survivor to help themselves.

Following discharge from hospital, participants expressed feelings of concern and fear that another stroke may occur. In addition, on reflection, there was a feeling for one participant that they did not encourage their spouse to “push themselves” enough when at home. This was due to a lack of awareness, and made more difficult by the differing advice from healthcare professionals. The need for clear information to prepare families for the impact of stroke was also expressed.

“…it would maybe be helpful to have a little bit of preparation, just to be aware of the things that might become issues for that individual so that you're a little bit prepared or can make allowances or can, yeah, just sort of pave the way a little bit.” (Semi –structured interview participant 8)

For both participants, supportive employers and work colleagues were key to facilitating a return to work for stroke survivors. This could often involve making employers and co-workers aware of the impact of stroke and the “lingering repercussions” for the stroke survivor. A gradual phased return to work was also mentioned as a particularly important facilitator.

“…I thought they were very good, like they actually made it very easy for him in that it was very much phased over quite a long period of time…” (Semi-structured interview participant 8)

## 4.5 Factors Highlighted by Healthcare Professionals, Members of Advocacy Groups and Non-Governmental Organisations

A number of factors were highlighted which could act as facilitators or barriers for stroke survivors returning to work.

### The Effects of Stroke

The type and extent of deficits that are experienced after stroke were seen as important factors in whether or not individuals return to work. Although physical deficits were mentioned as a barrier in returning to work after stroke, it was expressed that less visible post stroke deficits such as decreased insight, executive function and fatigue may be more difficult to deal with than visible deficits. The reason for this is that less allowance may be made, or symptoms may not be picked up until later on.

"If you go back to work in a wheelchair there's probably people going to make some allowances for you but if you come back in and to all intents and purposes you look like you're ok those hidden deficits, like fatigue, cognitive issues, insight awareness, they will have a major impact." (Focus group 1, participant 4)

For this reason, the rapid discharge of those with mild strokes and those who are successfully thrombolysed was discussed. These individuals may not be referred to rehabilitation services and so hidden deficits may not be picked up. This could lead to difficulties with return to work upon discharge.

“Usually what happens, people go back to work quite soon after a stroke and it doesn’t work out. Because it’s, it’s far too soon, they haven’t come to terms with those invisible sort of consequences.” (Semi-structured interview participant 1)

The insight that the individual has into their deficits is seen as important, and insight itself can be affected by higher-level cognitive deficits. Participants described the challenges of assisting a person with poor insight to return to work after stroke.

“…if working with someone who has impaired self-awareness as well. That’s a real challenge because it’s very difficult to set appropriate rehabilitative goals, when someone doesn’t really understand the difficulties.” (Semi-structured interview participant 1)

It was highlighted by many participants that fatigue has a significant impact on the ability of a stroke survivor when returning to work.

“…fatigue, is a huge problem and I think you know you have got this competing demand, you know, they want to do well at work and yet they are exhausted...” (Focus group 1, participant 3)

### Personal Factors

It was mentioned by many participants that a return to work post stroke can often be a process which takes several years to complete, during which stroke survivors may lose confidence in their ability to re-engage with the workforce.

“I guess a major barrier as well in terms of the client’s perspective is their confidence. It’s just completely gone and they feel that they can’t return to work…” (Focus group 8 participant 1)

During this time, to maintain financial security, stroke survivors often engage with the social welfare system. It was suggested that this system was quite confusing to navigate and that there may be a fear factor in returning to work and thereby losing benefits which were previously relied upon.

“…a huge fear factor of how are they going to cope with returning to work and losing, you know, those travel passes or that medical card which has been so important in terms of getting medication and travelling to and from appointments.” (Focus group 8 participant 1)

Personal motivation was mentioned as an important facilitator when contemplating a return to work. However, for some stroke survivors, there may also be a reappraisal of their work/life balance, and returning to work may not be an appropriate option.

“You may take stock of your situation and realise that other priorities are more important say in your life than getting stuck into work.” (Focus group 1, participant 1)

It was also highlighted that as work can be an integral part of an individual’s identity, adapting their role on returning to work may not be something that some stroke survivors are open to.

“…you see, I suppose you have to remember that for some people their whole identity is their job and then you’re suggesting, go back to your employer, but change your duties and that, that’s not easy for some people.” (Focus group 3, participant 3)

### Organisational Factors

A number of organisational factors such as the level of employer support available to stroke survivors was reported as helping to enable or impede the return to work process.

Adaptations such as a returning to work on a gradual, phased basis with increased flexibility could often facilitate stroke survivors to manage issues such as fatigue while building confidence in their ability to work.

However, during the discussion it was felt that there was a general lack of public awareness regarding stroke which for many employers resulted in an uncertainty on how to accommodate stroke survivors back into the workplace, in some cases being “terrified of what they're taking on” and possibly deeming the individual to be a health and safety risk.

“…there’s not enough kind of media coverage out there, not enough kind of training for employers, not enough awareness about how to work with someone who’s got an acquired brain injury. So employers are very unsure of, of what to do and put a plan in to place.” (Focus group 8, participant 1)

With a lack of advice available for employers when re-integrating a stroke survivor back into the workplace, one participant, working in the community, described how “managers are just really thankful to have someone to speak to… have someone to talk to and feel like they’re not alone”. Alternatively, it can be helpful if there is an occupational health department available to provide advice.

“…an employer having access to an occupational health department. I think that can be very helpful because they have their own in house staff and they’re able to provide advice.” (Focus group 4, participant 2)

The type of job sector was also discussed by participants. For those that were self-employed, it was felt that this could be advantageous given the degree of personal control over the number of hours they could work or the type of tasks they could do, but also challenging if there was a need to return to work too soon. For those returning to the public sector, it was felt that more supports are available compared to those returning to the private sector, although it was noted that this may be changing.

“Those who are in the public service, there is an appreciation within the public service that they will try to accommodate people in a restricted role because they have been loyal to the public service and they have been with them for many years.” (Focus group 1, participant 1)

Although employers can be quite supportive, for stroke survivors unsure of returning to work, there can often be pressure to decide on whether or not to return.

“Whilst on one hand they have a lot of support, there’s also a pressure there for a decision to be made, are you returning, or are you not. So I think there is an inevitable pressure there, at some point, to make a decision, one way or another.” (Focus group 4, participant 2)

The work environment and colleague support can also be a factor. While increasing work demands mean colleagues are often “pushed harder”, it was expressed that for stroke survivors close to retirement, colleagues may be “willing to carry them” until they reach their pensionable age.

### Rehabilitation Services

During discussions on rehabilitation services, issues such as the need to educate employers, work colleagues and the general public on issues such as stroke and disability was highlighted as a significant facilitator for returning to work after stroke.

“…awareness and also a broader awareness of disability and diversity and equality training amongst the employers I think is going to be important to go alongside that as well, that people understand that there’s a lot to be gained from having a diverse work force that’s representative of the world out there.” (Focus group, participant 2)

Education and formal training programmes in the area of work were also suggested for healthcare professionals working in stroke in order to help develop specialist services around the country in the local community setting. The need for a stroke pathway which allows, once discharged, access back to services in a timely fashion when needed was also expressed.

Apart from educating health professionals and employers, early supported discharge was also suggested as a possible facilitator to help stroke survivors return to work after stroke.

“Well that aspect that you are out of the hospital setting where if you can get to the toilet yourself you’re cured whereas if you're at home then there are visiting therapists that are going to discuss with you your real needs in the home situation, one of which may be vocational and you can have a proper discussion with your early ESD[[127]](#footnote-127) team in the home situation because you're in a different environment where you've moved on in your considerations.” (Focus group 1, participant 1)

The development of services within the community may be quite challenging however, as it was reported by several participants that healthcare policy and therefore, funding, tends to be directed more towards the acute hospital setting rather than community services.

“I mean we've never had proper community psychological, social or family supports or Personal Assistants or Rehabiliation Assistants you know they...it was just beginning to trickle down you know, I think our community support structure compared to other countries, a lot of the budgets I think are very hospital based.” (Focus group 1, participant 2)

Funding was also an issue for non-statutory agencies providing support services for stroke survivors, reporting reduced funding and yet increased demand for their services. It was noted that with decreased funding available for stroke survivors, services tended to be geared more towards those with severe post stroke deficits.

“Because the funding is diverted into managing the cases where they’ve a severe level of, of need. And a severe level of difficulty, so you know, the people who have the most potential for going back to work, are the least likely to actually get a service.” (Focus group 4, participant 2)

For one participant working in the community, there was a sense that once discharged from the acute hospital setting, “you’re left out in the community by yourself”. (Semi-structured interview participant 1). This is clearly related to earlier findings in this study relating to the preparatory environment for return to work after stroke, and more specifically the bridge between the clinical and employment setting.

## 4.6 Discussion

### Statement of principal findings

The mobility, physical and communication deficits that are experienced after stroke were seen as important factors in whether or not individuals return to work. Mental fatigue, physical fatigue and difficulties thinking were common problems that stroke survivors reported impacted their ability to work. Transport was also highlighted where stroke affected their ability to drive and in doing so impacted the ability to work, particularly in rural areas. The visible and invisible effects of stroke and brain injury were highlighted, for many, the hidden deficits such as difficulties with memory, fatigue and concentration impacted their ability to return to work. This is particularly relevant in the context of employer and colleague support, where there was a lack of awareness from others of the invisible or hidden effects of stroke.

Clearance and advice to return to work was often provided by physicians, however, the communication between patients and healthcare professionals during this process could be improved. Supportive employers and work colleagues were key to facilitating a return to work. A gradual phased return to work was particularly important. For the majority, communication with employers was positive, whereas for others negotiations were hampered by such issues as communication deficits. The role of a liaison officer was reported to facilitate a return to work. For most participants, the accommodations offered were reduced hours with a gradual return to work and lighter duties. The support from colleagues was reported as being helpful to a successful return to work, particularly in the initial stages. It was felt that there was a general lack of public awareness regarding stroke, which for many employers resulted in an uncertainty on how to accommodate stroke survivors back into the workplace. This highlights the need for resources and training. For those returning to the public sector, it was generally felt that more supports were available compared to those returning to the private sector.

For spouses of stroke survivors it was felt that for acute hospital services the primary goal was achieving functional independence for the stroke survivor. Once discharged to the community, it was felt that there was a “gap” in services.

Return to work can take several years to complete, during which stroke survivors may lose confidence in their ability to re-engage with the workforce. During this time, to maintain financial security, stroke survivors often engage with the social welfare system. This system was described as being quite confusing to navigate. There may also be a fear factor in returning to work resulting in a loss of benefits, which were previously relied upon. Personal motivation was an important facilitator however, for some stroke survivors, there may also be a reappraisal of their work/life balance.

### Findings in the context of other studies

The main findings of this study are largely reflective of both the systematic review and national survey published in this report.

Fatigue for the stroke survivor is a significant barrier for those considering a return to work and for those already returned to work. This was mirrored in the results of the national survey in this report which found that fatigue, both mental and physical, was the most common issue affecting stroke survivors.

This study also found that employer and colleague support played a key role in facilitating or impeding a return to work. This is unsurprising as it was found that in the national survey in this report that those who returned to work described a greater level of the level of support offered. This employer support often manifested itself in employer accommodations such as flexible working hours or a gradual phased return to work. Education for employers and work colleagues was suggested as a means of helping to integrate stroke survivors back into the workplace.

Education and formal training for healthcare professionals was also deemed important in order to provide specialist vocational rehabilitation services for stroke survivors in the local community.

A further finding of this study was that stroke survivors experience a lack of support in the community once leaving hospital. This is not unique to Ireland as a lack of access to advice has also been described in an Australian national survey of stroke survivors.[[128]](#footnote-128)

### Clinical implications

For many, return to work can have a positive impact on their psychological wellbeing, and as such, should be facilitated when possible. One facilitator evident in the focus groups was the level of employer support post stroke, which was associated with higher return to work. The Irish Stroke Clinical Guidelines in 2010 regarding vocational activities recommend advising stroke survivors and employers of grants available that may facilitate a gradual return to work for the employee or allow the purchasing of equipment to make adjustments and accommodations at the workplace. Access to information and education on workers’ rights post stroke may help those that wish to re-engage in the workforce.

### Strengths and Weaknesses

These focus groups and semi-structured interviews provide an insight into the factors associated with returning to work after stroke and may help to understand the facilitators and barriers in an Irish context, thereby enhancing the functional and employment outcomes of stroke survivors.

A particular strength of these focus groups and semi-structured interviews is the recruitment of stroke survivors, spouses of stroke survivors, healthcare professionals and members of advocacy groups and non-governmental organisations, thereby helping to give an overall perspective of the facilitators and barriers to returning to work in an Irish setting.

The focus groups included stroke survivors and their spouses, healthcare professionals, representatives of stroke advocacy groups and non-governmental organisations. Stroke survivor participants were recruited though the Volunteer Stroke Scheme clubs, the Irish Heart Foundation’s National Stroke Support Group Network, Baggot Street Community Hospital, Dublin and the National Rehabilitation Hospital in Dun Laoghaire. The focus group sample is not a random or nationally representative sample of all individuals or professionals.

It must be acknowledged however, that the conclusions drawn from this study may have been influenced by the professional background of the authors.

# 5. Conclusion

Return to work after stroke is a complex process which can be facilitated or impeded by organisational, social or personal factors, as well as accessibility to appropriate services.

For stroke survivors, fatigue, both mental and physical fatigue, has a significant impact on returning to work. Environmental workplace adaptations, and adjustments such as flexible work hours and a gradual phased return to work may help to facilitate this process.

A key support person who can provide advice on stroke, help navigate the services available and negotiate with employers on returning to work can also help facilitate a return to work for stroke survivors.

To help integrate stroke survivors back to work, there is a need for educating the general public and thereby, employers and co-workers, on stroke and the effects of stroke. This could be achieved directly through communication between healthcare professionals and employers or work colleagues. To inform the general public, media campaigns by stroke advocacy groups may be useful.

Further to educating the general public, there is also a need to educate healthcare professionals in the area of return to work in order to develop further specialist services in Ireland in the local community setting. There is also a need for a stroke pathway which allows, once discharged, access back to services in a timely fashion when needed.

In addition, further funding for community services and non-statutory agencies is necessary to meet service demands and provide ongoing support for stroke survivors, their families and employers.

It must be acknowledged that the generalisability of the findings is limited by the limited national representativeness of the study sample and the conclusions drawn may have been influenced by the professional background of the authors.

The systematic review, national survey and focus group components of this study allowed the research team to explore and review the evidence relating to the barriers and facilitators when returning to work after a stroke, the current supports and services available, and the areas in which the current services could be improved. The overarching findings related to the nature and effects of the stroke; the preparatory environment for return to work after stroke; personal coping strategies for the individual and the meaning of work.

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# Appendix 1: Detailed Methodology of Systematic Review

## Study Design

Qualitative research aims to explore and interpret the views, feelings and experiences of a study population.[[129]](#footnote-129) The purpose of a meta-synthesis is to assess, compare and interpret the findings of published qualitative studies with a focus on increasing the understanding of a specific topic of interest. We used previously published descriptions of process to inform the conduct and reporting of our meta-synthesis.[[130]](#footnote-130) We used previously published descriptions of process to inform the conduct and reporting of our meta-synthesis. This comprised three discrete steps: (*i*) selecting relevant papers for inclusion, (*ii*) critical appraisal and data extraction, and (*iii*) analysis and synthesis of findings.

## Identifying Relevant Papers for Inclusion

A systematic literature search was conducted in October 2014 and included the following search engines: Pubmed, EMBASE, Cochrane Library, PsychInfo EBSCO, CINAHL and SCOPUS. The searches included but were not limited to the following keywords and MeSH terms: employ OR employment OR work OR labour force OR occupation OR workplace OR corporate OR employment OR employ OR vocation AND stroke OR cerebrovascular disorders OR haemorrhage. The full search string is available from the authors.

The search was supported by hand searching reference lists of retrieved articles and searching Google scholar. Studies were limited to those published in the past 20 years (1994-October 2014) to ensure that the barriers and facilitators identified reflected contemporary issues related to return to work. Articles were also confined to those published in the English language only, similar to previous research of this nature.[[131]](#footnote-131) Articles were initially screened by title and/or abstract where three screening questions were initially applied to each article:[[132]](#footnote-132)

* Study design - Is the study primarily qualitative in nature, involving both qualitative methods of data collection and analysis? We excluded studies that used a mixed methods study design where the main aim of the study was quantitative.
* Population of interest – Does the study focus on a population of individuals with stroke? Studies that focused on caregivers, family, or employers in isolation were excluded.
* Exposure and outcomes – Does the study explore factors associated with return to work after stroke? Studies that explored related topics such as interventions to improve return to work were excluded.

## Critical Appraisal and Data Extraction

We assessed the methodological quality of included papers using criteria described by the Critical Appraisal Skills Programme (CASP).[[133]](#footnote-133) Two researchers (RG and CB) independently critical appraised each individual study and discrepancies were managed by consensus. A third independent reviewer (FH) assessed quality where consensus was not reached. We also extracted descriptive information from each study including: study design and setting, number and description of participants, and type of analysis reported. A summary of the original findings and interpretations was also created for each included study.

## Analysis and Synthesis of Findings

The synthesis of qualitative research focuses on the interpretation of findings on a selected topic based on published findings rather than individual patient data.[[134]](#footnote-134) In this review, we employed a descriptive meta-synthesis in which unchanged texts of the primary research studies formed the data for analysis and these findings were not deconstructed prior to synthesis. This has been used in previous similar studies.[[135]](#footnote-135) Two researchers (MW and CB) independently reviewed the findings and interpretations from each primary research study. An overarching framework describing the main themes was subsequently developed to illustrate the primary barriers and facilitators associated with return to work after stroke. Each study was then systematically searched to extract any unchanged text that identified barriers and facilitators to return to work using the previously compiled framework. Subthemes were described under the main themes. Direct quotes from participants were not extracted to ensure that findings were representative of patterns emerging from the meta-synthesis of the studies.

**Table A1.1: Evidence of Relevant Themes in Each Study**

|  |  |
| --- | --- |
| **Themes** | **Studies in Which Themes are Evident\*** |
| The Nature of the Effects of Stroke | 1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14 |
| The Preparatory Environment:- The Healthcare Context- The Workplace Context- The Bridge between the Clinical and Employment Spheres | 2, 4, 5, 8, 9, 10, 11, 12, 13, 14, 151, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 152, 3, 6, 7, 8, 9, 10, 11, 12, 14, 15 |
| Personal Coping Strategies and Internal Challenges | 1, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 14, 15 |
| The Meaning of Work | 1, 5, 7, 8, 9, 10, 11, 12, 13, 14, 15 |
| **Study Key** |
| Alaszewski et al., 2007=1 | Garcia et al., 2010=6 | Lock et al., 2010=11 |
| Corr and Wilmer, 2003=2 | Gilworth et al., 2009=7 | Medin et al., 2006=12 |
| Culler et al., 2011=3 | Gustafsson and Turpin, 2012=8 | Robison et al., 2009=13 |
| Erikson et al., 2010=4 | Hartke et al., 2011=9 | Vestling et al., 2013=14 |
| Flinn and Stube, 2009=5 | Koch et al., 2005=10 | Wolfenden and Grace, 2012=15 |

**Table A1.2: Detailed Process of Thematic Analysis**

|  |  |
| --- | --- |
| **Category** Subthemes | **Selected examples from primary studies** |
| **The Nature of the Effects of Stroke** | “Most participants indicated that their ability to perform tasks related to their job position was compromised” (Culler et al.); “…frustration when he visited his workplace and discovered that he could no longer handle routine tasks with his right hand” (Erikson et al.); “There appeared to be gradual realisations that they were going to be unable to return to their jobs…”; “…changes were attributed to either their inability to carry out the essential functions of their positions…” (Koch et al.); “Some stroke survivors reported cognitive/perceptual impairments…” (Culler et al.); “persons with aphasia spoke more specifically of the characteristics of aphasia… referred to the… processing of information” (Garcia et al.); “Impaired ability to concentrate or losing train of thought was similarly cited as one of the symptoms preventing one interviewee from re-training” (Gilworth et al.); “Cognitive impairments that were identified included mental slowness and memory problems…” (Hartke et al.); “Cognitive–perceptual changes were also frequently mentioned as presenting barriers to the resumption of employment” (Koch et al.); “…difficulties in using a hand, fatigue, speech or memory problems… a barrier to work…” (Alaszewski et al.); “Severe disability undoubtedly creates a major barrier to return to work” (Alaszewski et al.); “…the residual problems following his stroke, in particular memory loss and exhaustion, influenced the return experience…” (Corr and Wilmer); “…respondents reported… having loss of function in an arm and leg, being clumsier (drops objects), having to be careful walking, needing to walk with a brace, having “spotty” balance…” (Culler et al.); “When talking about the barriers to returning to work, all 10 stroke respondents complained of physical issues…” (Culler et al.); “…talked about persistent symptoms in relation to ability to perform at work” (Gilworth et al.); “…the ‘hidden’ nature of Robyn’s difficulties... fatigue, mild word-finding problems and processing issues could not be easily seen…” (Gustafsson and Turpin); “Deficits from the stroke itself or subsequent complications, such as falls or seizures, served as barriers to return to work” (Hartke et al.); “Hand paresis was frequently identified as a physical barrier to return to work due to the need for efficiency in typing and computer use…” (Hartke et al.); “Difficulties with memory, processing information, speech and language, vision, walking, using the dominant hand and the effects of fatigue were all reported as barriers to employment” (Lock et al.); “…persons with aphasia spoke more specifically of the characteristics of aphasia… referred to the effect of fatigue and the processing of information…” (Garcia et al.); “Fatigue and weakness were identified as two of the most common barriers to resuming employment…” (Koch et al.); “The uncertainty of recovery was particularly impeding for those looking to find a new job after their stroke” (Hartke et al.) |
| **The Preparatory Environment**  |  |
| The healthcare context | “…perceived barriers to employment stemming from within the rehabilitation system… in several cases beginning with admission to unsuitable wards and misdiagnosis of their condition” (Lock et al.); “…rehabilitation stops when minimal function is regained and is insufficient in duration or scope to prepare people for work after stroke” (Lock et al.); “Rehabilitation limitations were sometimes attributed to services not being geared towards younger people” (Lock et al.); “…the workplace inspired participants to choose training materials and activities that were representative of the challenges that needed to be met to return to work” (Erikson et al.); “Two found accessing occupational therapy support easy” (Corr et al.); “Very rarely, if at all, did health-care professionals prepare the participants or their families for the potential for post stroke fatigue and its occupationally challenging consequences” (Flinn and Stube); “Physicians were often described as the gatekeepers to therapy resources and provided official clearance for readiness to work” (Hartke et al.); “Other health care professionals… often endorsed the importance of work, provided a reality check on readiness, and were a source of motivation” (Hartke et al.); “Professionals’ negativity sometimes actively discouraged consideration of return to work” (Lock et al.); “Some professional groups (such as occupational therapists (OTs)) were identified as being proactive regarding rehabilitation for work…” (Lock et al.); “The occupational therapist was involved in this return to work process and arranged meetings with the workplace, the manager, and in one case also with co-workers” (Medin et al.); “participants did not receive professional rehabilitative assistance in negotiating this process; they relied on understanding employers” (Wolfenden and Grace); “…the vocational rehabilitation started during the medical rehabilitation period…” (Vestling et al.); “…the workplace and the home were familiar places where the meanings participants gave to activities inspired and challenged them to engage more fully in their rehabilitation process” (Erikson et al.); “…some activities at the rehabilitation clinic neither bore relation to their actual prestroke work tasks nor were challenging enough to match the complexity of tasks they needed to return to work” (Erikson et al.); “vocational rehabilitation counseling was… regarded as being of critical importance” (Hartke et al.); “…there were also examples of how participants found activities within the rehabilitation setting that more closely connected to their workplace task demands” (Erikson et al.); “participants described tests conducted at the rehabilitation clinic and not linked to actual workplace demands as irrelevant and artificial” (Erikson et al.); “…very few participants identified factors in the rehabilitation process which acted as enablers of employment” (Lock et al.); “hospital-based rehabilitation aimed primarily at restoring bodily functions and a return to everyday activities, rather than promoting return to work” (Medin et al.) |
| The workplace context | “…simple adjustments within the work place had been effective at facilitating return to work… support from the employer for a phased return to work where working hours gradually build and/ or with the opportunity to work lighter duties” (Gilworth et al.); “There was sense of euphoria when workplaces acknowledged the need for flexibility to accommodate requirements like fatigue and would allow reduced work hours or absences from work when required” (Gustafsson and Turpin); “Work places varied in their degree of flexibility and accommodation” (Hartke et al.); “Employers’ negative attitudes, inflexibility and failure to implement adaptations to the stroke survivors’ work role, hours or equipment were perceived as barriers” (Lock et al.); “…some unemployed… felt strongly that with reasonable adjustments, such as special equipment and employer flexibility, they were capable of holding down a job” (Lock et al.); “…factors associated with employer agencies were sick leave arrangements, adaptations and attitudes, all of which could act as enablers and barriers to work after stroke” (Lock et al.); “…the importance of flexibility in relation to working hours and workload and the merits of being able to arrange a phased return…” (Robison et al.); “…interventions such as technical aids and adaptations of the physical environment at the workplace, were appreciated” (Vestling et al.); “…felt that her superiors at work lacked competence about rehabilitation, or they were not interested” (Medin et al.); “…strategies that addressed the organisations asked that the employers encourage supportive behaviour on the part of colleagues and supervisors” (Garcia et al.); “Stroke survivors who had successfully returned to work made particular note of how inviting the work place was to their return” (Hartke et al.); “…co-workers were experienced as significant in a successful and sustainable return to work” (Medin et al.); “Positive attitudes were frequently seen as stemming from employers having some first-hand or familial experience of stroke” (Lock et al.); “An unstable work environment, characterised by change and downsizing, was experienced as an obstacle with respect to employment” (Medin et al.); “…positive impact on their psychological wellbeing, particularly for those who were able to find meaningful employment consistent with their abilities and interests” (Koch et al.); “…participants who felt that work colleagues or managers were not supportive and did not recognise and support them, found return to work difficult” (Alaszewski et al.) “The main factor that seemed to allow almost all of the stroke survivors to return to work was a supportive employer” (Culler et al.); “there was a recognised need for a supportive workplace and supervisor” (Gustafsson and Turpin); “The availability of genuine support and understanding in relation to employment was important to the participants and their re-establishing identity” (Wolfenden and Grace); “she was overwhelmed by the support and encouragement she received from her work colleagues” (Wolfenden and Grace); “Organisations were frequently viewed as threatening or oppositional, setting up road blocks to needed resources” (Hartke et al.); “…some informants expressed worries that had there been a need for a wheelchair, this would have been a barrier… regarding accessibility at work” (Vestling et al.); “Some experienced this environment as unsupportive… for participants who had worked for larger or public sector organisations, especially if employers required an occupational health check” (Alaszewski et al.); “Participants who ran their own small businesses found their colleagues particularly supportive” (Alaszewski et al.); “A stable work environment that encouraged the individual and made the informant feel safe and secure promoted the return to work process” (Medin et al.) |
| The bridge between the clinical and environment spheres | “…participants bemoaned the widespread lack of awareness of stroke in younger people, reflected in poor service provision and general ignorance about the impairments that stroke leaves behind…” (Lock et al.); “Open communication with supervisors appeared key to proper adjustment” (Hartke et al.); “Liaison between rehabilitation professionals and employers was seen as an important factor in enabling people to access appropriate services and to eventually return to work” (Lock et al.); “….social insurance officers helped as much as they could with communication between the workplace and the informants” (Medin et al.); “Some interviewees felt resentful that they had not been fully involved in discussions with their employer and the health care team about the decision they would not be able to return to work…” (Gilworth et al.); “…choosing to disclose that you are a stroke survivor has the potential to change how you are perceived socially within the workplace and it may again lead to misconceptions and misunderstandings… not disclosing may make it difficult to explain why you are having difficulties” (Gustafsson and Turpin); “…fear of losing benefits was a disincentive to returning to full-time employment” (Culler et al.); “…benefits often offered less money than a survivor would make by working, but the possibility of jeopardizing this guaranteed income by attempting to return to work and failing was a considerable deterrent” (Hartke et al.); “Participants called for help in making the transition from rehabilitation to independence, and for long-term reassessments to provide them with information about their workplace capabilities” (Lock et al.); “It was clear some interviewees were not sure when to go back to work and specifically were not given clear advice, or did not agree with the advice given by their General Practitioner or consultant” (Gilworth et al.); “Whether back at work or not, subjects spoke about the need for more information” (Gilworth et al.); “Younger people may feel less able to ask questions, or may believe that hospital staff expect them to know about the return to work process” (Gilworth et al.); “There was often a sense that she perceived she was going into battle to ensure that her rights as a stroke survivor and worker were being upheld” (Gustafsson and Turpin); “…it was widely felt that many employers and employees are unaware… or that employers can purposefully ignore the legislation” (Lock et al.); “…there was the need for a mentor or support person; a person who would work… to assist her to negotiate the work-based training” (Gustafsson and Turpin); “The involvement of a vocational counselor was viewed as a positive force for support and concrete information, resources, and negotiation with employers” (Hartke et al.); “the informants emphasised the ability of the SI officers to create flexible solutions based upon the informants’ needs” (Medin et al.); “They stressed the importance of talking to a professional” (Medin et al.); “It was also pointed out that a full time personal assistant at work would not have been appreciated but instead thought of as a barrier” (Vestling et al.); “…everybody except the self-employed had by themselves found a person they usually turned to, if or when they experienced any problems” (Vestling et al.); “…informants’ comments revealed that if a support person had been appointed in advance it would have been a great help” (Vestling et al.); “membership of Different Strokes… was seen as having an important role in providing the physical and psychological support for recovery towards work which was unavailable within state-funded rehabilitation services” (Lock et al.); “The benefits system was seen as being unfair, discriminatory and inaccessible to people with the reading, writing and/or comprehension difficulties associated with stroke” (Lock et al.); “…contacts with the social insurance office were also experienced as significant since the personnel were very supportive, helpful and open during the process” (Medin et al.); “…survivors would delay returning to work to focus on recovery from such deficits, or they would underestimate the impact of these deficits on their performance and prematurely attempt a full return” (Hartke et al.) |

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| **Personal Coping Strategies and Internal Challenges** | “The survivors’ perception of their ability and readiness to return to work was evident in their willingness to accept limitations imposed by the stroke and their sense of confidence to re-enter the daily work world with them” (Hartke et al.); “Participants portray the desire and press for occupational role engagement… yet also realising the occupations cannot be performed in the same way as prior to the stroke” (Flinn and Stube); “…informants experienced their return to work as a gradual process in which they increased their work ability and workload step-by-step, and they found themselves acting as motors in this process” (Medin et al.); “The informants expressed pride in their own capacity to take the initiative and in their ability to take action” (Medin et al.); “Individual creativity was also important for developing active techniques for adaptation and problem solving… such as trying to find out in advance when and which problems might appear, and then find a solution” (Vestling et al.); “…some interviewees thought age could be a barrier…” (Gilworth et al.); “Individuals who were not working at the time of their stroke tended to assume that their stroke was an additional barrier to work and that possible employers would not recognise their potential” (Alaszewski et al.); “Some stroke survivors avoided activities that presented challenges…” (Koch et al.); “…persons with aphasia suggested only strategies for themselves in removing obstacles related to quantity… giving only essential information and using alternate methods of communication such as writing, using a keyboard, and using visual cues” (Garcia et al.);“…survivors identified several positive coping strategies, such as relying on their religious faith, celebrating small improvements in their recovery, being organised, practicing positive problem solving, using relaxation techniques, and developing good communication skills” (Hartke et al.); “Some felt it was determination that had aided recovery, and therefore, ability to get back to work” (Gilworth et al.); “Although the outcome of employment changes precipitated by the stroke were positive for some, others encountered situations that led to underemployment, unemployment, and financial constraints” (Koch et al.); “The participants also began to anticipate that they would have difficulties in returning to work” (Erikson et al.); “Other individuals within their social environments seem to want this level of pre-stroke participation as well, creating fairly high (and sometimes unsafe) expectations for the participants…” (Flinn and Stube); “Work was regarded as… a way to do what one was expected to do financially” (Vestling et al.); “Some informants did not experience any pressure to perform and felt this as a relief” (Vestling et al.); “…some expectations or demands would have been appreciated, even if not at the same level as before the stroke” (Vestling et al.); “Fear that failure to perform adequately at work could result in a demotion and salary reduction also served as a disincentive” (Hartke et al.); “…informants now and then had had negative thoughts concerning the return to work process and their new life situation…. especially frequent at the initial stage of the return to work process, but faded with time and when their efforts had been successful” (Vestling et al.); “The constant barriers and the sense of battling on her own often left Robyn feeling discouraged” (Gustafsson and Turpin); “Focus group members recognised that their individual characteristics… influenced their work prospects after stroke” (Lock et al.); “Some focus group members expressed pride in the personal qualities that had enabled them to return to work” (Lock et al.); “Participants’ perceptions of the immediate work environment, especially work colleagues and managers’ understanding of their situation was important” (Alaszewski et al.); “There was a fear that there were people in superior positions who could make important decisions about Robyn and her future, but who did not necessarily have an adequate understanding of her needs or abilities” (Gustafsson and Turpin); “Whereas those who perceived their efforts to be successful were likely to report positive psychological benefits, those who perceived their efforts to be unsuccessful described negative psychological repercussions” (Koch et al.); “…individuals who had developed a strong sense of their own resilience, even their own indestructibility, tended to treat their stroke as another challenge they could and would deal with” (Alaszewski et al.); “All informants identified their families as the prime source of support during the rehabilitation process, and in particular their spouses (or ex-spouses), their children and their parents” (Medin et al.); “For the self-employed a supportive spouse was highly regarded and considered “necessary”” (Vestling et al.); “… strategies suggested by persons with aphasia… included the practising of writing to improve speed, avoidance of difficult situations, the request for help and the planning of tasks to increase efficiency” (Garcia et al.); “…coping strategies as they applied to returning to work were evident … such as resilience, problem solving, risk taking, and stress management to maintain health” (Hartke et al.); “…survivors identified several positive coping strategies, such as relying on their religious faith, celebrating small improvements in their recovery, being organised, practicing positive problem solving, using relaxation techniques, and developing good communication skills” (Hartke et al.); “Concentrating on one issue at a time in order to stay calm and avoid making mistakes was another way to keep away from problems” (Vestling et al.); “The use of checklists and memory notes was also common, as well as the use of audio-signals such as alarm-clocks, to be reminded of the time, or as a means to start getting ready” (Vestling et al.); “Problems could be avoided by for example actively seeking help from family, friends and workmates” (Vestling et al.); “Some participants realised that their decreased abilities would require them to modify their work situation” (Erikson et al.); “…visits to their workplaces provided the participants with opportunities to experience and reflect on their current abilities” (Erikson et al.) |
| **The Meaning of Work** | “…individuals perceived stress as a causative factor in stroke and that work caused stress… could act as a barrier to return to work” (Alaszewski et al.); “Despite the strong desire to return to work, most interviewees re-evaluated their work/life balance in view of their experience of work stress and stroke…” (Hartke et al.); “It was considered important to live a busy life with different activities, sometimes considered more important than work, or at least full time work” (Vestling et al.); “…mixed feelings concerning early retirement… feelings of fear and frustration about having to accept the possibility of being a burden to other people” (Vestling et al.); “…the potential loss of income was an important motivator for returning to work” (Alaszewski et al.); “… when individuals had prior health problems their adjustment to living in reduced circumstances acted as a barrier to returning to work” (Alaszewski et al.); “Work was regarded as a way of earning one’s living” (Vestling et al.); “…informants showed an ambivalent attitude; the money was thought of as handy and necessary… but at the same time also thought of as being of less importance” (Vestling et al.); “…returning to work had a special significance… a way of showing that they were progressing and returning to pre-stroke normality” (Alaszewski et al.); “…transition from a productive member of the work team to one who was perceived in a negative way was difficult to reconcile” (Gustafsson and Turpin); “…survivors who were uncertain of the value of their skills or the direction of their work life were less clear about return” (Hartke et al.); “Individuals who made a rapid return to work clearly articulated the benefits of work and the importance of work in their lives” (Alaszewski et al.); “Individuals who did not return following their stroke also recognised the value of work” (Alaszewski et al.); “A further factor which influenced return to work was individual personality…. participants differed in the relative importance attached to getting back to work” (Gilworth et al.); “being active, useful, and self-sufficient were strong motivators, and work, even in an alternate job, was often seen as the vehicle to fulfilling these aspirations” (Hartke et al.); “…felt that they had to get back to work, since work was and is an important part of their lives” (Medin et al.); “…people appeared motivated by… a basic need for occupation” (Robison et al.); “Work was thought of as a means for personal development and feelings of pride of one’s own performance” (Vestling et al.); “Returning to work was often an explicitly formulated goal by the informants…” (Vestling et al.); “…work seemed to stimulate internal personal aspects such as self-fulfilment…” (Vestling et al.); “…felt isolated during the sick leave and had longed to get back to work” (Vestling et al.); “…some participants, stroke did change the meaning of work and included some undesirable features, in particular stress” (Alaszewski et al.); “…work was mostly thought of as enjoyable and meaningful” (Vestling et al.); “Work was spontaneously thought of and appreciated as something to do…” (Vestling et al.); “A sense of fulfilment through work… was frequently identified when the pre stroke work experience was positive, and work was perceived as critical to self-worth” (Hartke et al.); “Previous experience of serious illness and disability which had resulted in early retirement or incapacity benefit acted as a major barrier to working” (Alaszewski et al.); “Being able to return to work was seen as proof of their recovery…” (Medin et al.); “…support from family and friends in their efforts to recover… for return to work could be ambivalent as it conflicted with their concern for the survivor’s well-being” (Hartke et al.); “…when considering employment, people appeared motivated by… the opportunity for interaction with others” (Robison et al.); “Work was spontaneously thought of and appreciated as… an opportunity to meet people” (Vestling et al.); “…there was unmistakable joy when she felt that she was ‘fitting in’… an equal amount of distress when it was not going well” (Gustafsson and Turpin); “Organisations also served as an opportunity for volunteer work as a transition to temporary, contract, or permanent paid employment” (Hartke et al.); “Despite some suggestion that volunteer roles can be demeaning, they recognised that voluntary work offered certain rewards” (Lock et al.) |

# Appendix 2: Detailed Methodology of National Return To Work Survey of Stroke Survivors 2014/15

## Sampling and Recruitment

Participants for the survey were stroke survivors primarily recruited though the Volunteer Stroke Scheme clubs and the Irish Heart Foundation’s National Stroke Support Group Network. In regions that do not have an active stroke support group the clinical nurse specialist for stroke in the area was contacted and asked to invite eligible individuals to participate. Additional participants were recruited through non-statutory organisations that provide services to individuals with acquired brain injury. These organisations include Headway Ireland, Brain Rehabilitation Ireland and Acquired Brain Injury Ireland. The survey was advertised online through the Irish Heart Foundation Stroke website ([www.stroke.ie](http://www.stroke.ie)), Headway Ireland ([www.headway.ie](http://www.headway.ie)), Brain Rehabilitation Ireland ([www.briireland.ie](http://www.briireland.ie)) and the Acquired Brain Injury Ireland website (www.abiireland.ie).

The Irish Heart Foundation’s National Stroke Support Group Network has links with groups in the Dublin areas of Castleknock, Crumlin, Taney, Whitehall and Tallaght and nationally in Cork city, North Cork County, Kerry, Galway, Ballinasloe, Mayo, Sligo, Wexford, Waterford, Limerick, Tippperary, County Wicklow, Bray and Naas. Each support group has roughly 10-30 active members.

Clinical nurse specialists and other healthcare professionals assisted with recruitment in the absence of Stroke Support Groups in other areas.

The Abbreviated Mental Test briefly assesses cognitive ability. Individuals are asked 10 questions in total. Four of the questions assess orientation to person, time and place. Four questions assess short and long term memory. The remaining questions require individuals to count backwards from twenty and to recognise two familiar people. A score of less than 6 is suggestive of impaired cognition at the time of testing.[[136]](#footnote-136) During this study, the Abbreviated Mental Test was conducted with eligible participants if a significant cognitive impairment was suspected.

Stroke support group co-ordinators assisted eligible participants with completing the survey if necessary, and allowed sufficient time for all participants to understand each question and to respond effectively.

### Inclusion Criteria

Inclusion criteria for this study were as follows:

* Aged over 18 years
* Be able to communicate
* Be able to give informed consent
* Have an Abbreviated Mental Test Score (AMTS) > 6
* Be living in your own home within the local community

### Exclusion Criteria

Participants were excluded from this study if they were:

* Aged less than 18 years of age at the time of testing
* Unable to give consent
* Not residing in their own home

## Research Tools

A questionnaire was developed to assess respondents’ own experiences of returning to work after the onset of stroke. This dealt with the supports available to people to facilitate return to work, and the barriers to returning to work. The questionnaire was developed from existing validated questionnaires with the permission of the original authors. Most of the questions and the general format of the questionnaire were based on the UK Work after Stroke Survey and the US Return to Work after Stroke Survey.[[137]](#footnote-137) Questions were adapted where necessary for the Irish setting.

Two volunteers with experience of returning to work after a stroke piloted and reviewed a preliminary version of the questionnaire. Changes were made to the questionnaire based on the feedback received in October 2014. The number and complexity of questions was reduced. Questions about the pressure of returning to work and the support of employers were added. Boxes were included after key questions to give participants the option of including further details.

There were 33 questions in the final questionnaire. There were 26 closed questions, of which 18 of these questions included boxes to capture further detail. There were also 10 open questions.

The questions covered the following domains:

* Work history
* Effects of the stroke
* Current work situation
* Employer support
* Finance
* Facilitators and barriers to returning to work.

An open-ended question asked what had helped participants’ recovery most since returning home after their stroke. A second open-ended question asked participants’ to identify what were the biggest challenges when returning to work after their stroke.

Demographic information was captured at the end of the questionnaire. This included age, gender and time since first and subsequent strokes. Marital and residential status was also recorded. Location was categorised as Dublin, other urban or rural.

## Fieldwork

A researcher (FH) made initial contact with the stroke group coordinators and explained the study to them. Co-ordinators then identified eligible members within their groups and informed them about the study. Eligible volunteers were given the option of completing the survey face-to-face with the assistance of the stroke support group co-ordinator, completing the survey independently and returning it by post or completing the survey online. Pre-paid addressed envelopes were provided to participants wishing to avail of the postal option. The purpose of the study and the procedure was explained fully to all potential participants. They were provided with an information leaflet and the researcher’s contact details. They were encouraged to ask questions to clarify points that remained unclear. Researchers asked participants to sign a form volunteering informed consent if they were happy that they understood the study procedure and wished to continue. Participants were also made aware that they could withdraw from the study at any time, without giving a reason.

Online responses were recorded using the Survey Monkey application. The link to the online survey was available with the advertisements on the Irish Heart Foundation Stroke website, the Headway Ireland website and both organisations’ social media. A full explanation of the study was detailed on the introduction webpage of the survey. Potential risks and benefits were detailed as well as contact details of the researchers. Participants were required to provide consent before proceeding with the online survey. A large “Withdraw from Survey” option was available throughout the study in the top right hand corner of each page. Participants were given the option of providing contact details for the sole purpose of receiving a copy of the final report. IP addresses were not recorded to protect participants’ anonymity.

Ethical approval was sought and granted for this study by Research Ethics Committee at the Royal College of Surgeons in Ireland, the National Rehabilitation Hospital Dun Laoghaire, and the Health Service Executive.

### Data Analysis

Categorical data were coded and entered into an Excel spread sheet. Continuous data were entered in numerical format. All quantitative data were analysed using STATA statistical software. Descriptive analysis was carried out. Frequencies were presented and compared across relevant variables using crosstabs. Mean and standard deviations were calculated for normally distributed continuous variables, while median and interquartile ranges were calculated for non-parametric variables.

Open responses were transcribed and coded into themes. Relevant individual quotations were selected where it was felt that the qualitative meaning of the response was lost in coding. Where specific details could potentially identify individuals, they are omitted from the quote and the omission is indicated.

# Appendix 3: Detailed Methodology of Focus Groups and Semi-Structured Interviews with Key Stakeholders

## Sampling and Recruitment

Stroke survivor participants were recruited though the Volunteer Stroke Scheme clubs, the Irish Heart Foundation’s National Stroke Support Group Network, Baggot Street Community Hospital, Dublin and the National Rehabilitation Hospital in Dun Laoghaire. For those that were interested in participating in this study, focus groups were the primary method of data collection. However, to facilitate those that could not attend the focus groups organised, semi-structured interviews, and narrative analysis of emails were conducted.

Spouses of stroke survivors were recruited through stroke survivors that took part in the study. Members of the multi-disciplinary team working with stroke patients (occupational therapy, physiotherapy, psychology, speech and language therapy, social worker and consultant neurologist/rehabilitation medicine/occupational health) were recruited.

### Inclusion Criteria

Similar to the national survey, the inclusion criteria for stroke survivors in this study were as follows:

* Aged over 18 years
* Be able to communicate
* Be able to give informed consent
* Have an Abbreviated Mental Test Score (AMTS) > 6
* Be living in your own home within the local community

Members of the multi-disciplinary team working with stroke patients (occupational therapy, physiotherapy, psychology, speech and language therapy, social work and consultant physician), representatives from advocacy organisations providing support for acquired brain injury and policy workers in non-governmental organisations were recruited to this study.

### Exclusion Criteria

Stroke survivor participants were excluded from this study if they were:

* Aged less than 18 years of age at the time of testing
* Unable to give consent
* Not residing in their own home

## Research Tools

The following open questions were explored during each focus group, semi-structured interview with stroke survivors and their spouses.

* How would you describe your experiences of return to work after your stroke?
* How would you describe the support that you received to support your return to work after your stroke?
* How would you describe the barriers that you experienced in relation to your return to work?
* How would you describe the facilitators that you experienced in relation to your return to work?
* How would you describe the current supports available to you for return to work after stroke?
* Who are the service providers/stakeholders perspective in relation to factors that influence return to work after stroke?
* How could the current services be improved?
* What are the current challenges that affect you?
* Are there any other issues which we have not discussed that you would like to mention about your return to work?

For healthcare professionals and members of the advocacy groups working with acquired brain injury, the following open questions were explored:

* How would you describe your experiences of return to work for stroke patients under your care?
* How would you describe the support that they received to support their return to work after stroke?
* How would you describe the barriers that they experienced in relation to their return to work?
* How would you describe the facilitators for return to work after stroke?
* How would you describe the current supports available for return to work after stroke?
* Who are the main service providers in relation to return to work after stroke?
* How could the current services be improved?
* What are the current challenges that affect your patients, your service?
* Are there any other issues which we have not discussed that you would like to mention about return to work after stroke?

## Fieldwork

The researchers made contact with eligible participants directly in the case of healthcare professionals, members of advocacy groups providing support for acquired brain injury, and representatives of non-governmental organisations. To recruit stroke survivors and spouses of stroke survivors, gatekeepers were used.

Interested participants were provided with an information leaflet and the researcher’s contact details. They were encouraged to ask questions to clarify points that remained unclear. Researchers asked participants to sign a form volunteering informed consent if they were happy that they understood the study procedure and wished to continue. Participants were also made aware that they could withdraw from the study at any time, without giving a reason.

Eight focus groups took place on site in a comfortable open room, for example at a stroke support group meeting, and two focus groups took place in the Royal College of Surgeons in Ireland.

Ethical approval for the study was granted by the Royal College of Surgeons in Ireland’s Research Ethics Committee, the Health Service Executive’s Research Ethics Committee and the National Rehabilitation Hospital’s Research Ethics Committee.

### Data Analysis

All recorded data from focus groups, semi-structured interviews and detailed email analysis were transcribed verbatim. The approach described by Miles and Huberman was adopted for analysis of the transcriptions for stroke survivors and their spouses.[[138]](#footnote-138) All participants were assigned a code to ensure anonymity in the transcript. The transcripts were explored by a process of reading and re-reading. On the first reading, transcripts were read in their entirety to acquire a sense of the whole. On the second reading, using line by line analysis, patterns and themes were identified and listed. Prior to the third reading, the responses from all participants to each question were transferred to Microsoft Excel for further examination. The third reading involved checking the suitability of the coding system and pursuing patterns both consistent and inconsistent with the codes defined. An overarching framework developed during the systematic review was used to describe the primary barriers and facilitators for returning to work after stroke.

A similar process was used to analyse the transcriptions for healthcare professionals, multidisciplinary healthcare team members working in stroke, representatives from advocacy organisations for acquired brain injury and policy workers for disability non-governmental organisations. Through the process of reading and re-reading, the barriers and facilitators to returning to work as well as improvements that could be made to current stroke services were identified.

# Appendix 4: Glossary of Terms

| **Term** | **Definition** |
| --- | --- |
| 95% Confidence level | The boundaries within which the true parameter of the population measure will fall in 95% of the sample tested.[[139]](#footnote-139)  |
| A priori | Statistical analysis planned prior to data collection.[[140]](#footnote-140)  |
| Abstract | A brief summary of how research was conducted and the findings from this research  |
| Aphasia | This is a language disorder due to damage to a certain part of the brain. A person may have difficulty with reading, writing, talking or understanding someone when they speak.[[141]](#footnote-141)  |
| Categorical data | Data that are classified into two or more distinct categories, i.e. male or female.[[142]](#footnote-142)  |
| Content analysis | A method of qualitative data analysis that interprets the meaning in the words of written or verbal text through the use of coding to identify themes and patterns in the analysed text.[[143]](#footnote-143)  |
| Continuous data | Data whereby a distinct score is given, i.e. the time taken to complete a task[[144]](#footnote-144)  |
| Credibility | This refers to the plausibility of the research findings and whether they accurately represent the thoughts, views and experiences expressed by the individuals or groups involved.[[145]](#footnote-145)  |

|  |  |
| --- | --- |
| Critical interpretivist methodology | A qualitative research methodology which involves taking a critical view when interpreting the data and recognising that there may be a number of interpretations which could be distorted from the dominant ideology of the setting.[[146]](#footnote-146)  |
| Data saturation | The point at which further data analysis does not generate new themes or add to insights already gained.[[147]](#footnote-147)  |
| Focus group | A means of collecting qualitative or descriptive data through a group discussion usually facilitated by a moderator.[[148]](#footnote-148)  |
| Framework analysis | A method of qualitative data analysis which involves five important steps: familiarization with the data, identifying a thematic framework, indexing, charting and mapping and interpretation.[[149]](#footnote-149)  |
| Grounded theory | A method of qualitative data analysis which aims to generate concepts and theories ‘grounded’ in the data and is based on inductive reasoning.[[150]](#footnote-150)  |
| Interquartile range | The difference between the upper quartile (highest 25% of the data) and lower quartile (lowest 25% of the data).[[151]](#footnote-151)  |
| Latent analysis | A method of qualitative data analysis which aims to make inferences from that which was stated and in essence, identify the hidden meaning behind text.[[152]](#footnote-152)  |
| Mean | The average value, which is calculated by adding all values from a sample and dividing by the number of observations.[[153]](#footnote-153)  |
| Median | The middle value in a group of values, calculated when all values are ranked in order.[[154]](#footnote-154)  |
| Mixed methodology research | When both qualitative and quantitative research methods are used in a study.[[155]](#footnote-155)  |
| Narrative analysis | A method of qualitative data analysis which aims to interpret the main narrative themes behind the data to help understand how these experiences are socially and culturally constructed.[[156]](#footnote-156)  |
| Naturalistic methodology | A qualitative research methodology which studies individuals in their natural setting and aims to interpret phenomena in terms of the meaning individuals bring to them.[[157]](#footnote-157)  |
| Nominal group technique | A qualitative research methodology which aims to create ideas and develop group consensus in a structured format, with the use of rating results or ideas.[[158]](#footnote-158)  |
| Normally distributed | A symmetrical distribution around the central value which implies that the majority of values lie around this centre of this distribution.[[159]](#footnote-159)  |
| P-value | A threshold value, ranging between 0 and 1, for which the results observed may have occurred through chance alone.[[160]](#footnote-160)  |
| Phenomenology | A qualitative methodology which aims to gain insight into a particular view of a certain phenomenon, i.e. patient satisfaction with acute hospital services.[[161]](#footnote-161)  |
| Qualitative research | A form of social inquiry the aim of which is to gain insights and interpret the views, thoughts and experiences of individuals or groups.[[162]](#footnote-162)  |
| Quantitative research | Research which aims to quantify the number of a characteristic or characteristics using mathematical or statistical analysis.[[163]](#footnote-163)  |
| Standard deviation | A measure of the variation or spread of data around the mean value.[[164]](#footnote-164)  |
| Systematic review | An approach to systematically compile similar literature that address a specific research question using a comprehensive search strategy and rigorous appraisal of literature quality.[[165]](#footnote-165)  |
| T-test | A statistical test used to compare the difference between two mean values.[[166]](#footnote-166)  |
| Thematic analysis | This is the process of summarising important information from a transcript into codes, and then attempting to group similar codes into themes.[[167]](#footnote-167)  |
| Triangulation | The process by which data is examined from different perspectives to give a more detailed understanding of the phenomenon being studied in order to validate the findings, i.e. the use of two or more investigators.[[168]](#footnote-168)  |

1. (Irish Heart Foundation) [↑](#footnote-ref-1)
2. (Hartke et al., 2011) [↑](#footnote-ref-2)
3. (Koch et al., 2005, Hartke et al., 2011) [↑](#footnote-ref-3)
4. (Evers et al., 2004, Rossnagel et al., 2005) [↑](#footnote-ref-4)
5. (Irish Heart Foundation) [↑](#footnote-ref-5)
6. (Koch et al., 2005, Hartke et al., 2011) [↑](#footnote-ref-6)
7. (Hartke et al., 2011) [↑](#footnote-ref-7)
8. (Barker, 2006) [↑](#footnote-ref-8)
9. (Niemi et al., 1988, Daniel et al., 2009, Gabriele and Renate, 2009, Kirsh et al., 2009) [↑](#footnote-ref-9)
10. (Lindström et al., 2009, Busch et al., 2009, Varona et al., 2004, Morris, 2011) [↑](#footnote-ref-10)
11. (Busch et al., 2009, Morris, 2011, Culler et al., 2011, Hannerz et al., Hannerz et al., 2011) [↑](#footnote-ref-11)
12. (Walsh et al., 2014) [↑](#footnote-ref-12)
13. (National Disability Authority, 2005) [↑](#footnote-ref-13)
14. (Baldwin and Brusco, 2011, Hannerz et al., 2011) [↑](#footnote-ref-14)
15. (Trygged et al., 2011) [↑](#footnote-ref-15)
16. (Daniel et al., 2009) [↑](#footnote-ref-16)
17. (Daniel et al., 2009) [↑](#footnote-ref-17)
18. (Treger et al., 2007, Baldwin and Brusco, 2011) [↑](#footnote-ref-18)
19. (Treger et al., 2007, Morris, 2011, Hannerz et al., 2011) [↑](#footnote-ref-19)
20. (Hannerz et al., 2011) [↑](#footnote-ref-20)
21. (Daniel et al., 2009) [↑](#footnote-ref-21)
22. (Baldwin and Brusco, 2011) [↑](#footnote-ref-22)
23. (Critical Appraisal Skills Programme, 2011) [↑](#footnote-ref-23)
24. (Hodkinson, 1972) [↑](#footnote-ref-24)
25. (Rehabilitation Institute of Chicago, 2012, Different Strokes, 2014) [↑](#footnote-ref-25)
26. (Moran-Ellis et al 2006) [↑](#footnote-ref-26)
27. (Moran-Ellis et al 2006) [↑](#footnote-ref-27)
28. (Garcia et al., 2000) [↑](#footnote-ref-28)
29. (Garcia et al., 2000, Corr and Wilmer, 2003, Koch et al., 2005, Lock et al., 2005, Medin et al., 2006, Alaszewski et al., 2007, Gilworth et al., 2009, Robison et al., 2009, Erikson et al., 2010, Flinn and Stube, 2010, Culler et al., 2011, Hartke et al., 2011, Gustafsson and Turpin, 2012, Wolfenden and Grace, 2012, Vestling et al., 2013) [↑](#footnote-ref-29)
30. (Gustafsson and Turpin, 2012) [↑](#footnote-ref-30)
31. (Alaszewski et al., 2007) [↑](#footnote-ref-31)
32. (Erikson et al., 2010, Hartke et al., 2011, Koch et al., 2005) [↑](#footnote-ref-32)
33. (Alaszewski et al., 2007) [↑](#footnote-ref-33)
34. (Wolfenden and Grace, 2012) [↑](#footnote-ref-34)
35. (Medin et al., 2006) [↑](#footnote-ref-35)
36. (Lock et al., 2005, Robison et al., 2009) [↑](#footnote-ref-36)
37. (Flinn and Stube, 2010, Vestling et al., 2013) [↑](#footnote-ref-37)
38. (Garcia et al., 2000) [↑](#footnote-ref-38)
39. (Gustafsson and Turpin, 2012) [↑](#footnote-ref-39)
40. (Gilworth et al., 2009) [↑](#footnote-ref-40)
41. (Corr and Wilmer, 2003, Culler et al., 2011) [↑](#footnote-ref-41)
42. (Robison et al., 2009) [↑](#footnote-ref-42)
43. (Corr and Wilmer, 2003) [↑](#footnote-ref-43)
44. (Erikson et al., 2010, Robison et al., 2009) [↑](#footnote-ref-44)
45. (Alaszewski et al., 2007) [↑](#footnote-ref-45)
46. (Gustafsson and Turpin, 2012) [↑](#footnote-ref-46)
47. (Garcia et al., 2000, Corr and Wilmer, 2003, Koch et al., 2005, Lock et al., 2005, Alaszewski et al., 2007, Gilworth et al., 2009, Robison et al., 2009, Culler et al., 2011, Hartke et al., 2011, Gustafsson and Turpin, 2012, Wolfenden and Grace, 2012, Vestling et al., 2013) [↑](#footnote-ref-47)
48. (Robison et al., 2009) [↑](#footnote-ref-48)
49. (Vestling et al., 2013) [↑](#footnote-ref-49)
50. (Flinn and Stube, 2009; Gustafsson and Turpin, 2012; Koch et al., 2005; Lock et al., 2010; Vestling et al., 2013) [↑](#footnote-ref-50)
51. (Flinn and Stube, 2009; Vestling et al., 2013) [↑](#footnote-ref-51)
52. (Gustafsson and Turpin, 2012) [↑](#footnote-ref-52)
53. (Lock et al., 2010) [↑](#footnote-ref-53)
54. (Koch et al., 2005) [↑](#footnote-ref-54)
55. (Medin et al., 2006, Vestling et al., 2013) [↑](#footnote-ref-55)
56. (Alaszewski et al., 2007) [↑](#footnote-ref-56)
57. (Alaszewski et al., 2007, Erikson et al., 2010, Gustafsson and Turpin, 2012) [↑](#footnote-ref-57)
58. (Alaszewski et al., 2007; Corr and Wilmer, 2003; Culler et al., 2011; Erikson et al., 2010; Flinn and Stube, 2009; Gilworth et al., 2009; Hartke et al., 2011; Robison et al., 2009; Vestling et al., 2013; Wolfenden and Grace, 2012) [↑](#footnote-ref-58)
59. (Alaszewski et al., 2007; Corr and Wilmer, 2003; Erikson et al., 2010; Flinn and Stube, 2009; Garcia et al., 2010; Gilworth et al., 2009; Gustafsson and Turpin, 2012; Hartke et al., 2011; Koch et al., 2005; Lock et al., 2010; Medin et al., 2006; Vestling et al., 2013; Wolfenden and Grace, 2012) [↑](#footnote-ref-59)
60. (Erikson et al., 2010, Flinn and Stube, 2009; Gustafsson and Turpin, 2012; Hartke et al., 2011; Koch et al., 2005; Lock et al., 2010; Medin et al., 2006; Robison et al., 2009;) [↑](#footnote-ref-60)
61. (Culler et al., 2011) [↑](#footnote-ref-61)
62. (Hartke et al., 2011) [↑](#footnote-ref-62)
63. (Gustafsson and Turpin, 2012) [↑](#footnote-ref-63)
64. (Hartke et al., 2011) [↑](#footnote-ref-64)
65. (Lock et al., 2005) [↑](#footnote-ref-65)
66. (Hartke et al., 2011) [↑](#footnote-ref-66)
67. (Corr and Wilmer, 2003, Robison et al., 2009, Wolfenden and Grace, 2012) [↑](#footnote-ref-67)
68. (Lock et al., 2005, Hartke et al., 2011) [↑](#footnote-ref-68)
69. (Hartke et al., 2011) [↑](#footnote-ref-69)
70. (Medin et al., 2006) [↑](#footnote-ref-70)
71. (Hartke et al., 2011) [↑](#footnote-ref-71)
72. (Erikson et al., 2010) [↑](#footnote-ref-72)
73. (Medin et al., 2006) [↑](#footnote-ref-73)
74. (Lock et al., 2005) [↑](#footnote-ref-74)
75. (Gilworth et al., 2009) [↑](#footnote-ref-75)
76. (Gustafsson and Turpin, 2012) [↑](#footnote-ref-76)
77. (Gustafsson and Turpin, 2012) [↑](#footnote-ref-77)
78. (Culler et al., 2011) [↑](#footnote-ref-78)
79. (Lock et al., 2005) [↑](#footnote-ref-79)
80. (Gilworth et al., 2009) [↑](#footnote-ref-80)
81. (Hartke et al., 2011) [↑](#footnote-ref-81)
82. (Lock et al., 2005) [↑](#footnote-ref-82)
83. (Gustafsson and Turpin, 2012, Hartke et al., 2011) [↑](#footnote-ref-83)
84. (Lock et al., 2005) [↑](#footnote-ref-84)
85. (Gilworth et al., 2009, Robison et al., 2009) [↑](#footnote-ref-85)
86. (Lock et al., 2005) [↑](#footnote-ref-86)
87. (Medin et al., 2006, Hartke et al., 2011) [↑](#footnote-ref-87)
88. (Alaszewski et al., 2007) [↑](#footnote-ref-88)
89. (Hartke et al., 2011) [↑](#footnote-ref-89)
90. (Gilworth et al., 2009) [↑](#footnote-ref-90)
91. (Hartke et al., 2011) [↑](#footnote-ref-91)
92. (Flinn and Stube, 2010) [↑](#footnote-ref-92)
93. (Vestling et al., 2013) [↑](#footnote-ref-93)
94. (Hartke et al., 2011) [↑](#footnote-ref-94)
95. (Koch et al., 2005, Vestling et al., 2013) [↑](#footnote-ref-95)
96. (Vestling et al., 2013) [↑](#footnote-ref-96)
97. (Medin et al., 2006) [↑](#footnote-ref-97)
98. (Gustafsson and Turpin, 2012) [↑](#footnote-ref-98)
99. (Vestling et al., 2013) [↑](#footnote-ref-99)
100. (Hartke et al., 2011) [↑](#footnote-ref-100)
101. (Hartke et al., 2011) [↑](#footnote-ref-101)
102. (Alaszewski et al., 2007) [↑](#footnote-ref-102)
103. (Vestling et al., 2013) [↑](#footnote-ref-103)
104. (Robison et al., 2009, Vestling et al., 2013) [↑](#footnote-ref-104)
105. (Gustafsson and Turpin, 2012) [↑](#footnote-ref-105)
106. (Lock et al., 2005) [↑](#footnote-ref-106)
107. (Hartke et al., 2011) [↑](#footnote-ref-107)
108. (Lawrence, 2010, Nicholson et al., 2013, Walsh et al., 2014) [↑](#footnote-ref-108)
109. (Harris, 2014) [↑](#footnote-ref-109)
110. (Harris, 2014) [↑](#footnote-ref-110)
111. (Lawrence, 2010) [↑](#footnote-ref-111)
112. (Morris, 2011; Saeki et al., 1995) [↑](#footnote-ref-112)
113. (Lindstrom et al., 2009) [↑](#footnote-ref-113)
114. (Thompson and Ryan, 2008) [↑](#footnote-ref-114)
115. IQR = Interquartile Range [↑](#footnote-ref-115)
116. Central Statistics Office, 2011 [↑](#footnote-ref-116)
117. SD=Standard Deviation [↑](#footnote-ref-117)
118. Confidence Intervals [↑](#footnote-ref-118)
119. OT= Occupational Therapy, SLT=Speech and Language therapy, CLO=Community Liaison Officer, Occ=Occupational, NRH=National Rehabilitation Hospital [↑](#footnote-ref-119)
120. (Rehabilitation Institute of Chicago, 2012) [↑](#footnote-ref-120)
121. (Treger et al., 2007; Daniel et al., 2009) [↑](#footnote-ref-121)
122. (Busch et al., 2009) [↑](#footnote-ref-122)
123. (National Stroke Foundation, 2007) [↑](#footnote-ref-123)
124. (Koch et al., 2005) [↑](#footnote-ref-124)
125. (Rehabilitation Institute of Chicago, 2012, Different Strokes, 2014) [↑](#footnote-ref-125)
126. Miles and Huberman, 1994 [↑](#footnote-ref-126)
127. ESD = Early supported discharge [↑](#footnote-ref-127)
128. (National Stroke Foundation, 2007) [↑](#footnote-ref-128)
129. (Holloway and Wheeler, 2013) [↑](#footnote-ref-129)
130. (Salter et al., 2008, Bondas and Hall, 2007) [↑](#footnote-ref-130)
131. (Reed et al., 2012, Walsh et al., 2014) [↑](#footnote-ref-131)
132. (Campbell et al., 2003, Salter et al., 2008) [↑](#footnote-ref-132)
133. (Collaboration for Qualitative Methodologies, 2011) [↑](#footnote-ref-133)
134. (Campbell et al., 2003, Hammell, 2006, Salter et al., 2008) [↑](#footnote-ref-134)
135. (Salter et al., 2008, Walsh et al., 2014) [↑](#footnote-ref-135)
136. Hodkinson, 1972 [↑](#footnote-ref-136)
137. (Rehabilitation Institute of Chicago, 2012, Different Strokes, 2014) [↑](#footnote-ref-137)
138. Miles and Huberman, 1994 [↑](#footnote-ref-138)
139. (Field, 2013) [↑](#footnote-ref-139)
140. (Hickson, 2013) [↑](#footnote-ref-140)
141. (Barnes et al., 2005) [↑](#footnote-ref-141)
142. (Field, 2013) [↑](#footnote-ref-142)
143. (Houser, 2011) [↑](#footnote-ref-143)
144. (Field, 2013) [↑](#footnote-ref-144)
145. (Pitney and Parker, 2009) [↑](#footnote-ref-145)
146. (DeChesnay, 2005) [↑](#footnote-ref-146)
147. (Sim and Wright, 2000) [↑](#footnote-ref-147)
148. (Sim and Wright, 2000) [↑](#footnote-ref-148)
149. (Gerrish and Lathlean, 2015) [↑](#footnote-ref-149)
150. (Gerrish and Lathlean, 2015) [↑](#footnote-ref-150)
151. (Field, 2013) [↑](#footnote-ref-151)
152. (Waltz et al., 2010) [↑](#footnote-ref-152)
153. (Sim and Wright, 2000) [↑](#footnote-ref-153)
154. (Field, 2013) [↑](#footnote-ref-154)
155. (Hickson, 2013) [↑](#footnote-ref-155)
156. (Holloway and Wheeler, 2013) [↑](#footnote-ref-156)
157. (Goyal, 2010) [↑](#footnote-ref-157)
158. (King and Horrocks, 2010) [↑](#footnote-ref-158)
159. (Field, 2013) [↑](#footnote-ref-159)
160. (Hickson, 2013) [↑](#footnote-ref-160)
161. (Hickson, 2013) [↑](#footnote-ref-161)
162. (Holloway and Wheeler, 2013) [↑](#footnote-ref-162)
163. (McIntosh-Scott et al., 2013) [↑](#footnote-ref-163)
164. (Field, 2013) [↑](#footnote-ref-164)
165. (Melnyk and Fineout-Overholt, 2011) [↑](#footnote-ref-165)
166. (Field, 2013) [↑](#footnote-ref-166)
167. (Dempster, 2011) [↑](#footnote-ref-167)
168. (Holloway and Wheeler, 2013) [↑](#footnote-ref-168)