Performance-based measurement of participation for people with aphasia: Using an iPhone application to measure talking time in everyday life

Caitlin Ellen Brandenburg
Bachelor of Speech Pathology (Hons I)

A thesis submitted for the degree of Doctor of Philosophy at
The University of Queensland in 2015
School of Health and Rehabilitation Sciences
Abstract

People with aphasia often experience reduced participation in life roles as a result of their communication disorder. The aims of this thesis were to 1) develop an iPhone application (CommFit™) which measures talk time and was easily used by people with aphasia, and 2) to use the app to explore talk time as a possible performance based indicator of participation, as a supplement to currently used self-report measures. This thesis used the International Classification of Functioning, Disability and Health (ICF) as a framework for defining participation and structuring the research.

The first (preparatory) phase of this thesis involved reviewing the current state of research in the areas of participation assessment and mobile technology use, in order to inform development of the CommFit™ app. In the first stage of preparation, the concept of participation was reviewed and current self-report measures of participation restriction were crosswalked to ICF categories. Ninety instruments (2,426 items) were coded and of these, 29 instruments contained over 50% participation items. The crosswalk showed that many of the current measures for this population are not participation focused, according to the operational definition of participation developed in this thesis. The Subjective Index of Physical and Social Outcome (SIPSO) emerged from this study as a measure which contained mostly participation content, had been validated with a stroke population, and was appropriate in both format and time required to be used by people with language difficulties. Thus, the SIPSO chosen as the measure of participation for use in the second phase of this research.

The second stage of the preparatory phase consisted of a review of the use of mobile technology by people with aphasia, stroke survivors and elderly people. The review focused on synthesising the literature into a list of technology design features that facilitate technology use for this population. These features were; use of multimodal communication, utilisation of aphasia-friendly text features, large buttons, stable interface, simple navigation and lack of visual clutter. These features were integrated into the design and development of an iPhone app which measured talk time- the CommFit™ app.

The last stage of the preparatory phase involved a small but in depth study investigating the development and accuracy of CommFit™. The iterative process of developing the CommFit™ app to be aphasia-friendly was described in detail. In the accuracy study, the talk time logged by the app was compared to talk time obtained from a continuous recording. Three non-neurologically
impaired participants who recorded their daily talk for a total of 10 hours in different environments. Accuracy of the app was found to be satisfactory at ±4% of the true talking time in ideal or silent environments and ±13% in everyday environments. The end result of the preparatory phase was a valid, usable app for counting talk time.

The second phase of this research explored the use of CommFit™ to count the talk time of people with and without aphasia. The aims of this study were; 1) to explore whether the talk time of people with aphasia was correlated with measures across the three ICF domains- Body Functions and Structures (Western Aphasia Battery-Revised), Activity (Communicative Activities of Daily Living-2) and Participation (SIPSO); 2) to compare the talk time of people with aphasia to a non-aphasic control group of the same age; and 3) to investigate the how talk time varies across weeks and days of the week (e.g. Mondays, Tuesdays). Twelve people with aphasia and seven healthy participants used CommFit™ to count their talk time for 6 hours a day for two weeks.

Results indicated that talk time was moderately correlated with the measure of participation (SIPSO) but not with the other two measures. This indicated that talk time may be an indicator of participation for people with aphasia, but that it did not reflect impairment and activity limitations. The mean talk time of people with aphasia was 2.7 minutes per hour lower than that of the non-aphasic group, but this was not significantly different. Usability results showed that people with aphasia found the iPhone and app very easy to use, however they did experience some difficulties with the headset used in the study. Ten people who consented to participate in the study were able to use CommFit™ independently, and all were able to use it with assistance. Additionally, all participants had positive feedback about the system overall. These results indicated that CommFit™ was a usable indicator of participation for people with aphasia.

The results of this thesis demonstrate that when mobile technology is designed for people with aphasia using the features outlined, it is possible for people with aphasia to use the technology independently. This has positive implications for the use of smart phones and tablets in the rehabilitation of people with aphasia, and supports the notion that people with communication disabilities can participate in the digital world if barriers are minimised. This has positive implications for the future of telehealth and self-management programs for this population. The thesis also provides an early indication that talk time can be used as an indicator of participation for people with aphasia and that it may also be used as a way of gaining quantitative information about level of participation and verbal language use. However, use of talk time as a measure is a new concept, and more investigation is needed both for people with aphasia and other populations.
Declaration by author

This thesis is composed of my original work, and contains no material previously published or written by another person except where due reference has been made in the text. I have clearly stated the contribution by others to jointly-authored works that I have included in my thesis.

I have clearly stated the contribution of others to my thesis as a whole, including statistical assistance, survey design, data analysis, significant technical procedures, professional editorial advice, and any other original research work used or reported in my thesis. The content of my thesis is the result of work I have carried out since the commencement of my research higher degree candidature and does not include a substantial part of work that has been submitted to qualify for the award of any other degree or diploma in any university or other tertiary institution. I have clearly stated which parts of my thesis, if any, have been submitted to qualify for another award.

I acknowledge that an electronic copy of my thesis must be lodged with the University Library and, subject to the policy and procedures of The University of Queensland, the thesis be made available for research and study in accordance with the Copyright Act 1968 unless a period of embargo has been approved by the Dean of the Graduate School.

I acknowledge that copyright of all material contained in my thesis resides with the copyright holder(s) of that material. Where appropriate I have obtained copyright permission from the copyright holder to reproduce material in this thesis.

[Signature]

C Brandenburg
Publications during candidature


Publications included in this thesis


*This paper is included as Chapter 2 of this thesis*

<table>
<thead>
<tr>
<th>Contributor</th>
<th>Statement of contribution</th>
</tr>
</thead>
</table>
| Caitlin Brandenburg (Candidate) | Study design (75%)  
Data collection (100%)  
Statistical analysis (70%)  
Wrote the paper (100%)  |
| Linda Worrall               | Study design (25%)  
Edited the paper (50%)  |
| Amy Rodriguez              | Edited the paper (40%)  |
| Karl Bagraith              | Statistical analysis (30%)  |

*This paper is included as Chapter 3 of this thesis*

<table>
<thead>
<tr>
<th>Contributor</th>
<th>Statement of contribution</th>
</tr>
</thead>
</table>
| Caitlin Brandenburg (Candidate) | Study design (70%)  
|                         | Literature search and synthesis (100%)  
|                         | Wrote the paper (100%)  |
| Linda Worrall          | Study design (10%)  
|                         | Edited the paper (34%)  |
| Amy Rodriguez          | Study design (10%)  
|                         | Edited the paper (33%)  |
| David Copland          | Study design (10%)  
|                         | Edited the paper (33%)  |


*This paper is included as Chapter 4 of this thesis*

<table>
<thead>
<tr>
<th>Contributor</th>
<th>Statement of contribution</th>
</tr>
</thead>
</table>
| Caitlin Brandenburg (Candidate) | Study design (60%)  
|                         | Data collection (100%)  
|                         | Data analysis (100%)  
|                         | Wrote the paper (100%)  |
| Linda Worrall          | Study design (15%)  
|                         | Edited the paper (34%)  |
| Amy Rodriguez          | Study design (15%)  
|                         | Edited the paper (33%)  |
| David Copland          | Study design (10%)  
|                         | Edited the paper (33%)  |

*This paper is included as Chapter 5 of this thesis*

<table>
<thead>
<tr>
<th>Contributor</th>
<th>Statement of contribution</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caitlin Brandenburg (Candidate)</td>
<td>Study design (70%)</td>
</tr>
<tr>
<td></td>
<td>Recruitment (100%)</td>
</tr>
<tr>
<td></td>
<td>Data collection (100%)</td>
</tr>
<tr>
<td></td>
<td>Data analysis and interpretation (70%)</td>
</tr>
<tr>
<td></td>
<td>Wrote the paper (100%)</td>
</tr>
<tr>
<td>Linda Worrall</td>
<td>Study design (10%)</td>
</tr>
<tr>
<td></td>
<td>Data analysis and interpretation (10%)</td>
</tr>
<tr>
<td></td>
<td>Edited the paper (34%)</td>
</tr>
<tr>
<td>Amy Rodriguez</td>
<td>Study design (10%)</td>
</tr>
<tr>
<td></td>
<td>Data analysis and interpretation (10%)</td>
</tr>
<tr>
<td></td>
<td>Edited the paper (33%)</td>
</tr>
<tr>
<td>David Copland</td>
<td>Study design (10%)</td>
</tr>
<tr>
<td></td>
<td>Data analysis and interpretation (10%)</td>
</tr>
<tr>
<td></td>
<td>Edited the paper (33%)</td>
</tr>
</tbody>
</table>


*This paper is included as Chapter 6 of this thesis*

<table>
<thead>
<tr>
<th>Contributor</th>
<th>Statement of contribution</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caitlin Brandenburg (Candidate)</td>
<td>Study design (55%)</td>
</tr>
<tr>
<td></td>
<td>Recruitment (100%)</td>
</tr>
<tr>
<td></td>
<td>Data collection (100%)</td>
</tr>
<tr>
<td></td>
<td>Statistical analysis (75%)</td>
</tr>
<tr>
<td></td>
<td>Data analysis and interpretation (70%)</td>
</tr>
<tr>
<td></td>
<td>Wrote the paper (100%)</td>
</tr>
<tr>
<td>Linda Worrall</td>
<td>Study design (15%)</td>
</tr>
<tr>
<td>Name</td>
<td>Contributions</td>
</tr>
<tr>
<td>-----------------</td>
<td>---------------------------------------------------</td>
</tr>
<tr>
<td>Amy Rodriguez</td>
<td>Study design (15%)</td>
</tr>
<tr>
<td></td>
<td>Data analysis and interpretation (10%)</td>
</tr>
<tr>
<td></td>
<td>Edited the paper (33%)</td>
</tr>
<tr>
<td>David Copland</td>
<td>Study design (15%)</td>
</tr>
<tr>
<td></td>
<td>Statistical analysis (25%)</td>
</tr>
<tr>
<td></td>
<td>Data analysis and interpretation (10%)</td>
</tr>
<tr>
<td></td>
<td>Edited the paper (33%)</td>
</tr>
</tbody>
</table>
Contributions by others to the thesis

The PhD candidate was chiefly responsible for the design of the study, participant recruitment, data collection, data analysis and preparation of manuscripts resulting from the research.

The seminal idea for this project, as well as ethical approval and grant funding was obtained by Professor Linda Worrall and Associate Professor David Copland (NHMRC project grant # 569935) from the University of Queensland. Linda Worrall, David Copland and Dr Amy Rodriguez also had substantial input into the design of the research program, interpretation of results and review of written work. David Copland also conducted some of the statistical analysis outlined in Chapter 6 of this thesis, as denoted in the previous section. Lastly, Dr Karl Bagraith contributed to the statistical analysis of the paper constituting Chapter 2 and Dr Emma Power contributed to the development of CommFit™ outlined in Chapter 4.

To the best of my knowledge and belief, no person who has offered contributions consistent with the above has been excluded as an author. Persons who have contributed to the work but not at a level that constitutes authorship have been acknowledged in the text.

Caitlin Brandenburg    Prof Linda Worrall    Dr Amy Rodriguez    Assoc Prof David Copland
Statement of parts of the thesis contributing to another degree

None.
Acknowledgments

First and foremost, I’d like to acknowledge the time and effort of those who participated in my research. Without their involvement, this work would not have been possible. I found myself continuously humbled by the positivity and generosity of spirit of these individuals, in the face of significant disability. Through listening to these people’s experience of stroke and aphasia, I found the true purpose of my research - to provide better ways of integrating people with aphasia back into lives that are meaningful to them.

I’d like to thank my supervisors, Professor Linda Worrall, Dr Amy Rodriguez and Associate Professor David Copland for their continuous support, time and effort, particularly in these past few months. I count myself lucky to have stumbled upon a group of supervisors who are so dedicated to the field of aphasiology and have such a complimentary range of strengths. I’d especially like to thank Linda, for setting me on this path when I began my honours. I also like to acknowledge Dr Emma Power, who provided essential support in navigating the challenges of developing the CommFit™ app. Lastly, thanks to Mattias Lindgren and the Left Right and Centre app development team, who worked hard to produce a beautiful and functional app for us.

I would also like to thank the Clinical Centre for Research Excellence in Aphasia Rehabilitation and the Communication Disability Centre. My involvement in both groups has had an indelible impact on my development as a disability researcher and professional. In addition, the University of Queensland and the School of Health and Rehabilitation Sciences have provided a supportive and enriching backdrop in which to complete my studies. Also, the financial support of the Australian Postgraduate Award scholarship was essential to my ability to complete my doctoral studies.

I’d also like to acknowledge those close to me for their support. My parents, Shane and Linda, who provided me with the means to pursue my goals, including taking me to speech therapy all those years ago! My sister Kristine, whose relentless dedication to her goals is an inspiration to me. And my partner, Michael, who has been partner to me in the truest sense of the word during my studies.

It is through these people and these experiences I feel that my doctoral studies have developed me not only as a researcher, but as a person, and that is an amazing thing. I feel I have grown closer to being the person I aim to be during this experience.

Finally, I’d like to make special acknowledgements to those that passed during the course of my studies; my beloved dog, Jazz; my father-in-law, Peter Hair; and my grandfather, John Stone. I hope this work honours them.
Keywords

Aphasia, mobile technology, ICF, participation, outcome measurement

Australia and New Zealand Standard Research Classifications (ANZSRC)

110321 Rehabilitation and Therapy (excl. Physiotherapy), 100%

Fields of Research (FoR) Classification

1103 Clinical Sciences, 100%
# Table of Contents

Abstract .................................................................................................................................i
Declaration by author ........................................................................................................ iii
Publications during candidature ....................................................................................... iv
Publications included in this thesis ................................................................................... iv
Contributions by others to the thesis ................................................................................ viii
Statement of parts of the thesis contributing to another degree ........................................ ix
Acknowledgments .............................................................................................................. x
Keywords ............................................................................................................................ xi
Australia and New Zealand Standard Research Classifications (ANZSRC) ......................... xi
Fields of Research (FoR) Classification ........................................................................... xi
Table of Contents ............................................................................................................... xii
List of Tables ....................................................................................................................... xviii
List of Figures ..................................................................................................................... xix
Abbreviations .................................................................................................................... xx

Chapter 1: Introduction ...................................................................................................... 1

1.1 Background and Significance of this Research ............................................................ 1

1.1.1 The Impacts of Aphasia ....................................................................................... 1

1.1.2 The ICF and Aphasia .......................................................................................... 2

1.1.3 Measurement of Participation in Aphasia ............................................................ 3

1.1.4 Use of Talk Time as an Assessment for People with Aphasia ............................... 5

1.2 Aims of the Research ................................................................................................. 6

1.3 Overview of Thesis Structure ..................................................................................... 7

1.3.1 Phase I ................................................................................................................ 7

1.3.2 Phase II ............................................................................................................... 8

1.4 References ................................................................................................................ 10

Chapter 2: Crosswalk of Participation Self-report Measures for Aphasia to the ICF: What Content is Being Measured? ......................................................................................... 14
# Chapter 2: Abstract

2.1 Abstract .......................................................................................................................... 15

2.2 Introduction ...................................................................................................................... 16

2.3 Methods .......................................................................................................................... 19

2.3.1 Instruments .................................................................................................................... 19

2.3.2 Operationalizing Participation .................................................................................... 20

2.3.3 Linking to the ICF ........................................................................................................ 21

2.3.4 Interater Reliability ....................................................................................................... 22

2.4 Results ............................................................................................................................ 23

2.4.1 Identification of Participation Instruments .................................................................... 23

2.4.2 Content of the Participation Instruments ...................................................................... 26

2.4.3 Content of the Secondary ICF Codes ........................................................................... 28

2.4.4 Response Formats ......................................................................................................... 30

2.4.5 Reliability Analysis ....................................................................................................... 31

2.5 Discussion ......................................................................................................................... 32

2.5.1 Participation Instruments ............................................................................................. 32

2.5.2 Participation Content of Instruments ............................................................................ 32

2.5.3 Response Formats ......................................................................................................... 34

2.5.4 Study Limitations ......................................................................................................... 35

2.6 Conclusions .................................................................................................................... 36

2.7 References ...................................................................................................................... 37

# Chapter 3: Mobile Computing Technology and Aphasia: An Integrated Review of Accessibility and Potential Uses

3.1 Abstract .......................................................................................................................... 49

3.2 Introduction ...................................................................................................................... 50

3.3 Mobile Computing and Healthcare .................................................................................. 50

3.4 Barriers to Technology Access for People with Aphasia ................................................. 51

3.4.1 Barriers Related to Health Condition ........................................................................... 52

3.4.2 Barriers Related to Healthcare Services ....................................................................... 52

Chapter 3: Mobile Computing Technology and Aphasia: An Integrated Review of Accessibility and Potential Uses ................................................................................................................. 48
3.4.3 Barriers Related to the Individual ................................................................. 53
3.4.4 Barriers Related to the Nature of Technology .............................................. 53
3.5 Evidence for Accessible Technology .................................................................. 54
  3.5.1 Alternative and Augmentative Communication .............................................. 55
  3.5.2 Computer-based Therapy Programs ............................................................ 55
  3.5.3 Mobile Computer Technology ...................................................................... 56
  3.5.4 Aphasia-friendly Text and Website Guidelines .............................................. 58
  3.5.5 Guidelines for Accessible Mobile Apps for People with Aphasia .................. 59
3.6 Potential Role of Mobile Computing ................................................................. 61
  3.6.1 The Role of Mobile Technology for Participation ........................................ 61
  3.6.2 Functions of Mobile Technology for the Management of Aphasia .............. 62
3.7 Conclusion ........................................................................................................ 66
3.8 References ......................................................................................................... 68

Chapter 4: The Development and Accuracy Testing of CommFit™, an iPhone Application for Individuals with Aphasia ................................................................. 74
  4.1 Abstract ........................................................................................................... 75
  4.2 Introduction ....................................................................................................... 76
    4.2.1 mHealth in Aphasia Rehabilitation ............................................................. 76
    4.2.2 Measuring Talk Time ................................................................................ 77
    4.2.3 Aims ........................................................................................................... 79
  4.3 Development of CommFit™ ............................................................................. 80
    4.3.1 Preliminary Design and Design Goals ....................................................... 80
    4.3.2 Interface Design ....................................................................................... 83
    4.3.3 Function and Navigation ......................................................................... 83
    4.3.4 The CommFit™ App ................................................................................. 84
  4.4 Methods ........................................................................................................... 86
    4.4.1 Participants ................................................................................................ 86
    4.4.2 Equipment ................................................................................................ 86

xiv
Chapter 6: An Exploratory Investigation of the Daily Talk Time of People with Aphasia: Comparison to Non-aphasic Peers and ICF Domains

6.1 Abstract .................................................................................................................. 127
6.2 Introduction ............................................................................................................. 128
  6.2.1 Aims ................................................................................................................... 130
6.3 Methods .................................................................................................................. 131
  6.3.1 Participants ....................................................................................................... 131
  6.3.2 Assessments ....................................................................................................... 133
  6.3.3 Equipment ......................................................................................................... 134
  6.3.4 Data Collection .................................................................................................. 135
6.4 Results .................................................................................................................... 135
  6.4.1 Assessment and Talk Time Results of People with Aphasia ................................. 135
  6.4.2 Correlations Between Assessments and Talk Time of People with Aphasia ........ 137
  6.4.3 Talk time of People with Aphasia Compared with Non-aphasic Controls ........... 139
  6.4.4 Variations in Mean Talk Time Over Days/Weeks ............................................... 140
6.5 Discussion .............................................................................................................. 142
  6.5.1 Relationships Between Talk Time and Each Assessment .................................... 142
  6.5.2 Patterns in the Individual Performance of Participants with Aphasia ................... 144
  6.5.3 Talk Time of Control Participants vs People with Aphasia .................................. 145
  6.5.4 Sampling of Talk Time ...................................................................................... 146
  6.5.5 Talk Time and its Potential Role in Assessment of People with Aphasia .............. 147
  6.5.6 Limitations ......................................................................................................... 148
6.6 Conclusion .............................................................................................................. 149
6.7 References ............................................................................................................ 150

Chapter 7: Conclusions

7.1 Summary of Findings ............................................................................................. 153
7.2 Clinical and Research Implications ...................................................................... 157
7.3 Research Limitations and Ethical Considerations .......................................................... 159

7.5 Conclusion .................................................................................................................. 166

7.6 References .................................................................................................................. 167

Appendix A: Ethics Approval ............................................................................................ 170

Appendix B: Aphasia-Friendly Manual ........................................................................... 171

Appendix C: Interview Schedule ...................................................................................... 175

Appendix D: Feedback scale ............................................................................................ 176
List of Tables

Table 2-1: Proposed division of ICF activity and participation codes ........................................... 21
Table 2-3: Frequency of codes appearing in the participation assessments ................................. 26
Table 2-4: List of primary and secondary codes in the participation assessments ......................... 29
Table 2-5: Response formats of the assessments in order of frequency ...................................... 30
Table 2-6: ICF linkage reliability .................................................................................................. 32
Table 3-1: Summary of possible features of accessible mobile technology for people with aphasia 60
Table 3-2: Categorisation of the functions of smartphone apps designed for people with aphasia... 63
Table 4-1: Comparison of data collection options .......................................................................... 82
Table 4-2: Accuracy results for field test 1 by participant ............................................................... 90
Table 4-3: Accuracy results for field test 1 sorted by environment ................................................ 91
Table 4-4: Accuracy results of field test 2 by participant ............................................................... 92
Table 5-1: Participant characteristics ............................................................................................ 105
Table 5-2: Summary of barriers to using the CommFit™ system, and which participant experienced each of them ........................................................................................................... 111
Table 5-3: Results from usability ratings scale .............................................................................. 117
Table 6-1: Characteristics of participants with aphasia ................................................................. 132
Table 6-2: Characteristics of participants without aphasia ............................................................ 132
Table 6-3: Results for people with aphasia ................................................................................... 136
Table 6-4: Spearman correlations between talk time and each assessment .................................. 139
Table 6-5: Results for non-aphasic controls .................................................................................. 140
List of Figures

Figure 1-1: Illustration of the ICF framework ................................................................. 2
Figure 1-2: Overview of thesis structure ........................................................................ 7
Figure 2-1: Illustration of the ICF coding system ........................................................... 17
Figure 2-2: Inclusion of instruments ................................................................................ 23
Figure 4-1: Illustration of the development process ....................................................... 80
Figure 4-2: Illustration of word document mock up (left) and timing page of pilot app .... 82
Figure 4-3: Flowchart depicting navigation of the CommFit™ app ................................. 83
Figure 4-4: Splash screen ................................................................................................. 85
Figure 4-5: Signup page ................................................................................................ 85
Figure 4-6: Timing screen while timing .......................................................................... 85
Figure 4-7: Sending data ................................................................................................ 85
Figure 4-8: Calibration page ........................................................................................... 85
Figure 4-9: Picture of continuous recorder and lapel mic .............................................. 88
Figure 4-10: Picture of iPhone 4 and BlueTooth headset ............................................... 88
Figure 5-1: iPhone 4 with parts labelled ......................................................................... 107
Figure 5-2: ProPlantronics Voyager Pro+ Bluetooth headset with parts labelled ........... 107
Figure 5-3: Home page .................................................................................................. 109
Figure 5-4: Settings menu .............................................................................................. 109
Figure 5-5: Bluetooth page ............................................................................................ 109
Figure 5-6: CommFit™ app ........................................................................................... 109
Figure 5-7: CommFit™ app while timing ...................................................................... 109
Figure 5-8: Finish timing ............................................................................................... 109
Figure 6-1: iPhone 4 (left) and Plantronics Voyager Pro+ Bluetooth headset ............... 134
Figure 6-2: Boxplot of the average talk times of people with aphasia ............................. 137
Figure 6-3: Talk time vs WAB-R scatter plot ................................................................. 138
Figure 6-4: Talk time vs CADL-2 scatter plot ............................................................... 138
Figure 6-5: Talk time vs SIPSO scatter plot ................................................................. 138
Figure 6-6: Talk time vs SIPSO items 7-9 scatter plot ................................................... 138
Figure 6-7: Bar graph of mean talk time per hour for each day of the week for both groups 141
Figure 6-8: Sample of talk time over the two weeks for PA3 ........................................... 142
### Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>AAA</td>
<td>Australian Aphasia Association</td>
</tr>
<tr>
<td>AAC</td>
<td>Alternative and Augmentative Communication</td>
</tr>
<tr>
<td>AARP</td>
<td>Australian Aphasia Rehabilitation Pathway</td>
</tr>
<tr>
<td>AIHW</td>
<td>Australian Institute of Health and Welfare</td>
</tr>
<tr>
<td>App</td>
<td>Application</td>
</tr>
<tr>
<td>AQ</td>
<td>Aphasia Quotient</td>
</tr>
<tr>
<td>ASHA</td>
<td>American Speech Hearing Association</td>
</tr>
<tr>
<td>CADL-2</td>
<td>Communicative Activities of Daily Living - Second Edition</td>
</tr>
<tr>
<td>CAT</td>
<td>Computer Assisted Treatment</td>
</tr>
<tr>
<td>CF</td>
<td>CommFit&lt;sup&gt;TM&lt;/sup&gt;</td>
</tr>
<tr>
<td>CI</td>
<td>Confidence Interval</td>
</tr>
<tr>
<td>CINAHL</td>
<td>Cumulative Index to Nursing and Allied Health Literature</td>
</tr>
<tr>
<td>COMACT</td>
<td>Communicative Activities Questionnaire</td>
</tr>
<tr>
<td>COT</td>
<td>Computer Only Treatment</td>
</tr>
<tr>
<td>dB</td>
<td>Decibel</td>
</tr>
<tr>
<td>GB</td>
<td>Gigabyte</td>
</tr>
<tr>
<td>GPS</td>
<td>Global Positioning System</td>
</tr>
<tr>
<td>HCI</td>
<td>Human-Computer Interaction</td>
</tr>
<tr>
<td>HP</td>
<td>Healthy Participant</td>
</tr>
<tr>
<td>HSD</td>
<td>Honest Significant Difference</td>
</tr>
<tr>
<td>ICF</td>
<td>International Classification of Functioning, Disability and Health</td>
</tr>
<tr>
<td>ICIDH</td>
<td>International Classification of Impairments, Disabilities and Handicaps</td>
</tr>
<tr>
<td>iOS</td>
<td>iPhone Operating System</td>
</tr>
<tr>
<td>IT</td>
<td>Information Technology</td>
</tr>
<tr>
<td>JPEG</td>
<td>Joint Photographic Experts Group</td>
</tr>
<tr>
<td>LPAA</td>
<td>Life Participation Approach to Aphasia</td>
</tr>
<tr>
<td>LSVT</td>
<td>Lee Silverman Voice Treatment</td>
</tr>
<tr>
<td>Mpo</td>
<td>Months post onset</td>
</tr>
<tr>
<td>PA</td>
<td>Participant with Aphasia</td>
</tr>
<tr>
<td>PC</td>
<td>Personal Computer</td>
</tr>
<tr>
<td>PDA</td>
<td>Personal Digital Assistant</td>
</tr>
<tr>
<td>Ppt</td>
<td>Participant</td>
</tr>
<tr>
<td>SD</td>
<td>Standard Deviation</td>
</tr>
</tbody>
</table>
Chapter 1: Introduction

This chapter provides a brief introduction to the thesis. Section 1.1 will summarise the background and significance of this research, including an introduction to the impact of stroke and aphasia, use of the ICF framework in aphasia rehabilitation, measurement of participation and the potential role of measurement of talk time in aphasia. Section 1.2 outlines the aims of the thesis and section 1.3 provides an overview of the structure of the thesis.

1.1 Background and Significance of this Research

1.1.1 The Impacts of Aphasia

Stroke is the leading cause of disability in Australia, affecting an estimated 1 in 6 men, and 1 in 5 women in their lifetime (Seshadri & Wolf, 2007). Stroke is a leading cause of aphasia, which is a neurogenic communication disorder that can affect all modalities of language, including reading, writing, speaking and understanding spoken language. Aphasia affects around 30% of adults who experience a stroke, and the Australian Aphasia Association estimates that around 80,000 in the country are living with aphasia presently, a number that will only increase as the population ages (AAA, 2011; Engelter et al., 2006; Pederson, Jørgensen, Nakayama, Raaschou & Olsen, 1995). Moreover, aphasia is a chronic condition that will continue to impact the majority of stroke survivors 12 months post onset and beyond (Engelter et al., 2006; Laska, Hellblom, Murray, Kahan & Von Arbin, 2001; Macrae & Douglas, 2008).

As language is a key component of socialisation, aphasia often results in devastating impacts on a person’s psychosocial outcomes following stroke. People who suffer a stroke have poorer quality of life if they have concomitant aphasia, even when other variables such as physical disability are accounted for (Hilari, 2011). Evidence shows that the presence of aphasia results in poor psychosocial well-being, including decreased quality of life (Cruice, Worrall, Hickson & Murison, 2003; Ross & Wertz, 2003), increased incidence of depression (Code & Herrmann, 2003), anxiety (Cahana-Amitay et al., 2011) and social isolation (Brown, Worrall, Davidson & Howe, 2011; Dalemans, de Witte, Wade & van den Heuval, 2010; Holland, 2006). People with aphasia may also be disadvantaged in that they may not have equity of access to health information and health services (Brady, Fredrick & Williams, 2013; Rose, Worrall, McKenna, Hickson & Hoffmann, 2009). Presence of aphasia has negative consequences on individuals with aphasia, their families and society, beyond the consequences of stroke without aphasia.
1.1.2 The ICF and Aphasia

Considering the psychosocial impacts of aphasia, the measurement of these outcomes is an essential component in the rehabilitation of this communication disability. The World Health Organization created a conceptual framework for disability and health which utilises a biopsychosocial model, and includes the societal perspective and its involvement in health conditions (WHO, 2001). This framework originated as the International Classification of Impairments, Disabilities and Handicaps (ICIDH) in 1980, and was updated to the International Classification of Functioning, Disability and Health (ICF) in 2001 (WHO, 2001). The ICF in its current form was designed to bring increased focus to the life functioning aspects of disability, and the effects that contextual factors can have on health outcomes (Ma, Threats & Worrall, 2008). It also improves upon the ICIDH by using neutral terminology, making it applicable to people without and without disabilities and useful for classifying relative strengths for those with disabilities (Ma et al., 2008). The ICF includes three domains of functioning and disability- Body Functions and Structures, Activity and Participation (WHO, 2001). It also includes contextual factors, namely Personal and Environmental Factors (Figure 1-1). The ICF framework has been widely adopted as a framework for aphasia rehabilitation (Ma et al., 2008). This widespread use has resulted in increased interest in measuring participatory outcomes in rehabilitation and highlighted the need for a better understanding of how health conditions impact social participation and the fulfilment of life roles.

Figure 1-1: Illustration of the ICF framework
1.1.3 Measurement of Participation in Aphasia

In light of the centrality of communication to involvement in life roles, participatory outcomes are of particular significance to people with aphasia. The ICF defines participation as ‘involvement in a life situation’ and participation restrictions as ‘problems an individual may experience in involvement in life situations’ (WHO, 2001). The participation domain is not adequately delineated in the classification system and is summarised into the same set of categories as the activity domain. A detailed review of participation and its relationship to activity is discussed in detail in the introduction to Chapter 2 of this thesis (Brandenburg, Worrall, Rodriguez & Bagraith, 2014; Chapter 2).

Improved participation has emerged as a key goal for rehabilitation from the perspective of people with aphasia (Worrall et al., 2011), and intervention efforts such as the Life Participation Approach for Aphasia (LPAA) have focused on improvements in the participation domain (Chapey et al., 2000). People with aphasia have expressed that they want to feel engaged and involved, particularly as a way of contributing to their community, and regaining respect and self-esteem that they feel has been lost as a result of their communication disability (Dalemans et al., 2010). This need is increasingly being recognised in aphasia rehabilitation. Indeed, the Australian Aphasia Rehabilitation Pathway provides this guideline for assessment: ‘All domains of functioning and disability should be assessed’ (AARP, 2014). Accordingly, participatory outcomes should be central to the rehabilitation of people with aphasia.

Despite the importance of measuring participation, two surveys of Australian and New Zealand speech-language pathologists working with stroke and aphasia showed that the majority of assessment tools used were impairment based, such as the Western Aphasia Battery (WAB; Kertesz, 2006) (Verna, Davidson & Rose, 2009; Vogel, Maruff & Morgan, 2010). Some functional assessments made the list of frequently used aphasia assessments, e.g. the Functional Communication Profile (Sarno, 1969) and Inpatient Functional Communication Interview (O’Halloran, Worrall, Toffolo, Code & Hickson, 2004); however, no named assessments were participation-focused. These results have been echoed by international studies (Guo, Togher & Power, 2014; Simmons-Mackie, Threats & Kagan, 2005). It has long been asserted that further attention needs to be given to the participation domain in aphasia research, but this has not yet translated into clinical or research practice (Ross & Wertz, 2003, Ma et al., 2008; Worrall & Hickson, 2008).

The assessment of participation is a continually evolving field. Two qualifiers have been suggested to measure functioning at the level of participation; satisfaction, which is subjective and
internally defined, and *extent*, which is objective and externally observable (AIHW, 2003). Currently, satisfaction with participation for people with aphasia is almost exclusively assessed using questionnaires and rating scales, which ask for ratings of the level of participation and satisfaction (Eadie et al., 2006). Such retrospective self-reports are a popular and time-efficient method of obtaining information about everyday human behaviour (Mehl & Pennebaker, 2003). However, due to the poor delineation of the participation domain, currently available self-report measures often contain items related to impairment, activity limitation, environmental factors and quality of life instead of being purely participation-focused. Chapter 2 of this thesis gives a full review of the measurement of participation using self-report for aphasia rehabilitation, and the limitations of these assessments (Brandenburg et al., 2014; Chapter 2). In the case of people with aphasia, self-report may be particularly problematic, as communication difficulties have the potential to interfere with the understanding of the question and formulation of the response required (Chue, Rose & Swinburn, 2010). A proxy report by a family member or speech-language pathologist may then be used to provide information about the person’s behaviour and feelings. Proxy reports, especially on subjective concepts, are subject to error and misinterpretation (Sprangers & Aaronson, 1992). However, self-reports are the only way of gaining insight into the subjective, lived experience of the individual, a parameter which is valued highly in rehabilitation (Eadie et al., 2006). Thus, self-report of a person’s satisfaction with participatory outcomes is an important measure in aphasia rehabilitation but would benefit from being supplemented with measures of participation extent.

Code (2003) was one of the first to highlight the need to measure the extent of participation using a quantitative perspective of everyday social activity for people with aphasia, in order to enhance understanding of social isolation in people with aphasia, and improve the relevance of social therapies. In the following years, objective quantification of the extent of social participation was given some focus, in the form self-report of hours spent out of the house (Code, 2003) and frequency of communicative and social activities (Cruice, Worrall & Hickson, 2006). However, performance-based measures of participation extent have yet to be developed and used in the rehabilitation of aphasia. This thesis proposes that the quantification of talk time may add to the understanding of the effect of aphasia on social relationships and communicative participation, when used alongside measures of talk quality and satisfaction with participation. Specifically, the program of research investigates the viability of using a smartphone app that counts talk time as a performance-based indicator of participation extent.
1.1.4 Use of Talk Time as an Assessment for People with Aphasia

From the first attempts at studying the language of aphasia in natural environments (Holland, 1982) to the present day, surprisingly little research exists on the nature of authentic everyday communication in this population. Assessment of everyday talk and conversation is not routine clinical practice in speech-language pathology (Simmons-Mackie, Threats & Kagan, 2005). This is despite demands from stakeholders for outcome measurements that reflect a person’s integration into society and quality of life. We currently have an “inability to capture the important but often elusive outcomes of interventions that focus on making a difference to the everyday experience of individuals with aphasia and their families” (Kagan et al., 2008).

Effective assessment is important in rehabilitation as it allows for appropriate diagnosis, prognosis, information giving, research, goal setting, planning of intervention and measurement of the effects of intervention (Coelho, 2005). Assessment tools should be relevant to the person with aphasia and the environmental context in which they communicate, including communication partners (Hersh, 2013). Ecological validity is the degree to which test performance predicts behaviour in real-world settings (Gouvier, Barker & Musso, 2010). Impairment-based assessments in test environments are important for determining a person with aphasia’s capacity, however, may not correlate with real-world performance in the settings in which they live (Gouvier et al., 2010). As such, speech-language pathologists should endeavour to assess communication in real-life settings and with regular communication partners as much as possible (Hersh, 2013; Threats, 2008). Recent advances in technology have made it possible to monitor behaviour continuously in everyday life settings. Thus, there is growing potential for ecologically valid mobile technology-based assessment for people with aphasia, a notion which is discussed in detail in Chapter 3 of this thesis (Brandenburg, Worrall, Rodriguez & Copland, 2013).

There are two ways of establishing ecological validity; veridicality- the correlation between test scores and measures of real-world functioning, and verisimilitude- the degree to which measurement tasks resemble the real-world behaviour (Gouvier et al., 2010). The measurement of talk time of people with aphasia in everyday life has high verisimilitude, as it is the direct measurement of the actual behaviour being investigated. The verbal communication people use in everyday life is highly contextualised and inherently different from that used in the therapy room (Armstrong & Mortensen, 2006; Armstrong & Ferguson, 2010). Communication may be with a number of different communication partners, for many purposes and in many environments. Hence the direct measurement of everyday talk, in terms of both quality and quantity, has high relevance and verisimilitude as compared to traditional language assessments.
Measurement of talk time is also relevant to the self-management of aphasia. As the population ages, more cost-effective methods are sought to address a growing need for services for age-linked conditions like stroke (Jones, Riazi & Norris, 2013). At an individual level, issues of geographical isolation, mobility and individual factors can limit access to face-to-face intervention for some people with language disorders, and there is a need to diversify modes of service delivery (Theodoros, 2012). Self-management underpins the notion of person-centred care, and is linked with improved self-efficacy, autonomy and confidence for stroke survivors (Jones & Riazi, 2010). The Australian Aphasia Rehabilitation Pathway states that people with aphasia should be provided with means to self-manage their condition, and have the right to be provided with their own assessment results (AARP, 2014). However, very few assessment approaches in aphasia and stroke rehabilitation support self-management, and most interventions still rest upon the clinician as the decision maker and holder of knowledge (Jones et al., 2013). Ideally, people with aphasia should be able to monitor their own progress day-to-day, which points to a need for non-traditional assessment practices and the use of technology for delivering real-time data in a manner that does not require feedback from a clinician. This could be achieved through use of technology to give people with aphasia feedback on their amount of talk without regular clinician input.

1.2 Aims of the Research

This research originated from a perceived need for a performance-based indicator of participation for people with aphasia. This thesis will investigate the use of talk time, as obtained by an iPhone application (called CommFit™), as this measure. The aims of this research were to:

1) Investigate the current state of measurement of participation in aphasia rehabilitation.

2) Review the use of mobile technology with people with aphasia, and identify design features which aided usability.

3) Develop a valid and usable mobile tool for the measurement of talk time for people with aphasia.

4) Determine the barriers and facilitators to people with aphasia using this tool.

5) Use this tool to investigate the talk time of people with aphasia as an indicator of participation.
1.3 Overview of Thesis Structure

This doctoral thesis consisted of two phases. Phase I consisted of literature reviews and preliminary development of the CommFit™ app as a measurement tool, and Phase II consisted of the research study that tested the usability of CommFit™ and the measurement of talk time of people with chronic aphasia. The research stages and their relationship with the five thesis chapters are shown in Figure 1-2.

![Phase I -> Phase II diagram]

This thesis has been submitted under The University of Queensland’s definition of a “partial thesis by publication”, and as such each chapter, with the exception of this and the concluding chapter (Chapter 7), has either been published or submitted for publication. Publication details and a brief linking passage have been included at the beginning of each chapter. All chapters that contain work submitted for publication have been formatted to be consistent with style of the thesis with regards to layout, terminology and referencing style. The thesis uses Australian English and adheres to the American Psychological Association (APA) guidelines, 6th edition. Reference is made to the published papers by using both a standard APA in text reference and chapter number (e.g., Brandenburg et al., 2014; Chapter 2).

1.3.1 Phase I

Phase I of the research commenced with two reviews of the literature, which are published in this thesis as Chapters 2 and 3.

Chapter 2 details a review of the current state of participation measurement in aphasia. The definition of participation and its relationship with other ICF domains, particularly activity, was reviewed in depth. Next, all self-report participation measures that could be accessed (111 instruments) were located and transcribed. These items were then crosswalk items to ICF codes as a
way of investigating the content of these measures. This study informed the choice of the Subjective Index of Physical and Social Outcome (SIPSO; Trigg & Wood, 1999) as an assessment measure for the Phase II of the research. It also served as a literature review of the measurement of participation in aphasia, and in rehabilitation in general, and highlighted the current deficiencies in this area. The introduction to Chapter 2 covers the ICF and the concept of participation, especially in how it differs to other ICF concepts and why it is important to aphasia rehabilitation.

Chapter 3 consists of a review of the literature on mobile technology and aphasia and acts as a rationale for use of the smartphone as the measurement tool in this research. It gives an overview of the ways in which mobile technology is currently being used in aphasia rehabilitation and the potential it has for remote, continuous monitoring. This chapter also provides a series of recommendations for the development of mobile technology applications for people with aphasia and other complications of stroke such as visual and fine motor deficits.

Finally, Chapter 4 details the development of the CommFit™ app with commercial app developers and a study confirming the accuracy of the app in logging talk time. The introduction to this chapter expands on the literature review provided in Chapter 3, by reviewing literature available after its publication. The recommendations of Chapter 3 also informed the development of the CommFit™ iPhone application, and this chapter outlines in detail how the app was developed to be aphasia-friendly. This chapter also details a small field study investigating the accuracy of CommFit™ in detecting talk time compared to a continuous recording. Completion of CommFit™ development and evidence of adequate accuracy enabled Phase II of the research.

1.3.2 Phase II

Phase II consisted of a cross sectional study investigating the talk time of people with aphasia and non-aphasic controls. Nineteen people, 12 with aphasia and seven without, participated in the study. This study involved using CommFit™ to time the talk of participants over 2 weeks. The average talk time of the people with aphasia was correlated with measures of impairment (Western Aphasia Battery-Revised), activity limitation (Communicative Activities of Daily Living-2) and participation restriction (Subjective Index of Physical and Social Outcome). The talk time of people with aphasia was also compared to non-aphasic participants. Lastly, the usability of the app was investigated using a ratings scale, semi-structured interviews and field notes.

Chapters 5 and 6 present the results from this cross sectional study of talk time in individuals with aphasia. Chapter 5 describes the usability results from this study for the aphasic
cohort. Chapter 6 reports on the talk time of people with aphasia, comparing it with non-aphasic controls and with measures of impairment, activity limitation and participation restriction.

Chapter 7 concludes the thesis, outlining the findings of the research as a whole, identifying limitations and considering the future directions for the CommFit™ app and the measurement of talk time.
1.4 References


Australian Aphasia Association. (2011). *Supporting people with aphasia and their families* [brochure]. Australia: AAA.


Chapter 2: Crosswalk of Participation Self-report Measures for Aphasia to the ICF: What Content is Being Measured?

This chapter introduces the measurement of participation in aphasia rehabilitation. The introduction to this chapter provides a background on the ICF and its components, with a focus on the Activity and Participation domain. It attempts to define and operationalise participation, and this conceptualisation is used for the remainder of the thesis. The study described in this paper is a crosswalk of participation measures to ICF domains, and constitutes a review of how participation is currently being measured in aphasia rehabilitation. It also identifies the Subjective Index of Participation and Social Outcome (SIPSO) as a suitable measure, in terms of content, to be used in Chapter 6 of this thesis.

This chapter has been published by the peer-reviewed rehabilitation journal, Disability and Rehabilitation, as an advance online publication, awaiting print (Brandenburg, Worrall, Rodriguez & Bagraith, 2014). The content included in this chapter is identical to the published manuscript; however, the formatting has been modified to match the style of this thesis. Thus tables, figures, headings and references may have been altered from the published version to adhere to American Psychological Association stylistic guidelines, 6th edition.
2.1 Abstract

*Purpose:* Community participation is of importance to people with aphasia, who at risk of becoming socially isolated. This study investigates the content of measures of community and social participation for this population by crosswalking items to the ICF. The crosswalk will investigate: 1) to what extent the included assessments assessed participation only, 2) what content appeared most frequently and 3) which response formats were utilised.

*Methods:* Instruments were identified from four systematic reviews and a literature search. One hundred eleven instruments that were self-reported, developed for adults and published in English were identified. Items were linked to ICF domains, and 3rd level categories of the Activities and Participation chapter.

*Results:* Ninety instruments (2,426 items) were included. Of these, 29 instruments contained over 50% participation items. The most frequently included participation categories in this subset were education, paid employment, recreation, socialising, being a carer, relating with friends, family and spouses, volunteer work, managing finances, community life, civic duties, human rights and religion/spirituality. Self-care, mobility and domestic life concepts were also frequently reported. Commonly used response formats were restriction, frequency and satisfaction.

*Conclusions:* Few instruments solely assessed participation according to our operationalisation. This study provides a list of possible measures for use in assessing participation in aphasia and other health conditions.
2.2 Introduction

For people with a chronic health condition such as aphasia, their ability to participate fully in their social lives and community may be impacted. In recent years there has been an increasing focus on outcome measurement of a person's social involvement and fulfilment of valued life roles. This is partially due to the publication of the International Classification of Functioning, Disability and Health (ICF) in 2001 (WHO, 2001), which identified participation in life roles as a distinct construct from daily activities, worthy of its own measurement and intervention. Participation has even been proposed as the ultimate outcome of rehabilitation (Dijkers, 2010), and research in aphasia frequently requires a valid instrument of participation. However, there is still widespread disagreement on what participation is and how it should be measured. This review includes a crosswalk of the items of existing aphasia-related participation instruments onto ICF codes as a way of investigating the content of these measures. It extends on previous efforts in the area as it differentiates between participation and activity codes and thereby explores the construct of participation and how it is being assessed. While participation instruments relevant to aphasia were of interest in this study, participation is a general construct and many generic measures were also included. Accordingly, the results are expected to be applicable to a wide range of health conditions.

The International Classification of Functioning, Disability and Health was developed by the World Health Organisation (WHO) to conceptualise the impact of health conditions on a person’s functioning and health. It has been used as a guiding framework in rehabilitation research and practice, and adoption of the framework carries the expectation to assess and treat at all levels (Eadie et al., 2006; Simmons-Mackie & Kagan, 2007). The ICF includes three domains which interact to create states of functioning or disability; Body Functions and Structures, Activities and Participation, and the contextual factors of environment and personal attributes (WHO, 2001). These domains are made up of 1,454 conceptual categories, each assigned a unique alphanumeric code and arranged in a hierarchical structure. Firstly, a letter denotes the domain, followed by numbers denoting chapter, second third and fourth level categories. Some chapters also contain hyphenated codes which group together second level categories. For example, in chapter 8, Major Life Areas, the third level code ‘d8501- Part-time Employment’ falls under the second level code ‘d850-Remunerative Employment’, which is contained by the category grouping or ‘chunk’ code ‘d840-d859- Work and Employment’ (Figure 2-1).
For people with aphasia, the domain of participation in the ICF is of particular importance. In addition to other impacts of stroke, people with aphasia face further barriers to participation in society, as communication underlies the fulfilment of many roles and relationships (Howe, Worrall & Hickson, 2006). Indeed, a review of people with aphasia’s key goals during rehabilitation revealed that most were linked with the Activities and Participation chapter (Worral et al., 2011). Most of these goals were participation related and included things like engagement in social, leisure and work activities. The ICF framework is also frequently used to structure language assessment and therapy, with the role of participatory outcomes receiving more emphasis in recent years (Cruice, Worrall, Hickson & Murison, 2003; Threats & Worrall, 2004). Hence, it is important that the construct of participation plays a major role in the rehabilitation of aphasia, a need which requires suitable tools for the assessment of participation.

The use of ICF codes as a reference point to compare the content of existing measures of health-status onto ICF terminology has been prioritised by the WHO as a way of implementing the framework into research and practice in rehabilitation (Shulz, 2008). This process is variously referred to as content comparison, crosswalking, mapping or linking in the literature. Content comparisons of outcome measures have been conducted in areas such as cerebral palsy (Schiariti, Fayed, Cieza, Klassen & O'Donnell, 2011), head and neck cancer (Tschiesner, Rogers, Harréus, Berghaus & Cieza, 2008) and stroke (Geyh, Cieza, Kollerits, Grimby & Stucki, 2007). While there have been systematic reviews of participation instruments comparing their content (Eyssen, Steultjens, Dekker & Terwee, 2011; van der Mei, Dijkers & Heerkens, 2011), studies using the ICF to do this have typically included only a few select measures (Noonan et al., 2009; Resnik & Plow, 2009). Each of these studies also defined and operationalized the concept differently.

Even though activity and participation appear to be distinct concepts worthy of assessment in their own right, there is little consensus in the literature about how to delineate the two constructs. These differences can be attributed to the fact that delineating the activity and

<table>
<thead>
<tr>
<th>Domain</th>
<th>Chapter</th>
<th>Chunk</th>
<th>Second level</th>
<th>Third Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Activities and Participation</td>
<td>d8- Major life</td>
<td>d840-d859- Work and employment</td>
<td>d850- Remunerative employment</td>
<td>d8501- Part-time employment</td>
</tr>
</tbody>
</table>
participation categories/codes is not a straightforward task. The ICF combines activity and participation into the same component under the heading 'Activities and Participation', with the task of distinguishing them to be decided by the user. The WHO defines activity as 'the execution of a task or action by an individual', while participation is described as 'involvement in a life situation' (WHO, 2001). These concepts have been criticized in the literature for not being conceptualised to the depth needed, and not being adequately differentiated (Whiteneck & Dijkers, 2009; Worrall et al, 2011). However, some empirical studies have demonstrated that the two concepts are distinct and recommended detailed and separate assessment of each (Ayis et al., 2010; Jette, Haley & Kooyoomjian, 2003; Pollard, Johnston & Dieppe, 2011).

The WHO suggests four options for separating the two concepts. 1) That there is one set of activity and one set of participation codes with no overlap. 2) That there is partial overlap between the two concepts. 3) That the lower level categories are activities and the broader categories and chapter headings are participation. 4) That every category can be both activity and participation based on interpretation. Participation instruments have used a variety of these options to operationalize the construct and develop content (Magasi & Post, 2010). Some authors have stipulated that the concepts described in participation instrument items have to involve two or more people (Eadie et al., 2006; Eyssen et al., 2011). However, this definition excludes items relating to self-care and religion, which may be a source of contention as solitary self-care tasks and religious expression may form a major part of one’s social identity. Content comparisons have designated particular chapters as participation, such as chapters 7-9 (van der Mei et al., 2011), 3-9 (Noonan et al, 2009), or even that all chapters should be included in a participation instrument (Resnik & Plow, 2009). Other authors have argued that the separation between activity and participation is not rational and should be reworked entirely (Nordenfelt, 2003).

As the WHO offers no official position on how to separate the concepts, and the definitions given in the literature are varied, choosing an instrument for clinical or research purposes can be a complex task. There are a plethora of instruments published in this area, and these vary widely in content, item format, method of response and intended respondent. Many instruments that purport to measure participation often include a mixture of activity and participation content, and sometimes include body function, personal, environmental and quality of life items (Perenboom & Chorus, 2003). To complicate matters, instrument items are derived from numerous sources, including users, published literature, past instruments, ICF codes or other frameworks such as the Disability Creation Process (Patrick, 1998). In addition, instruments are designed to be generic or condition specific, as well as self, proxy or clinician reported. Some authors have argued that self-reporting is necessary to gain a full understanding of a person's participation, as only the person
with the health condition is privy to all social encounters in their everyday lives, and able to shed light on internal constructs such as satisfaction and importance of social roles (Eadie et al., 2006). Others have suggested that proxy instruments are a valid alternative to self-report for people with severe cognitive and communicative difficulties, as long as they involve the person with the health condition as much as possible (Dalemans, de Witte, Lemmens, van den Heuvel & Wade, 2008). This study focuses on self-report instruments as the most common way to assess participation (Dijkers, 2010) and includes both generic- and condition-specific measures.

By crosswalking the items of participation self-report instruments to ICF categories, this review aims to determine the content validity of current participation measures, that is, how they cover the chapters of the ICF. This crosswalk will identify which content appears most frequently in participation instruments, as a way of both evaluating the measures themselves, and informing broader inferences about the construct of participation. As current definitions are ill equipped to address the rich and varied items that appear in instruments, an operationalization of participation and separation of the codes is proposed. Response options will also be reported for these instruments, in order to shed some light on how participation is being measured. This review does not examine the psychometric properties of the instruments, such as validity, reliability, feasibility and responsiveness, which are also essential to choosing instruments but beyond the scope of the current study.

2.3 Methods

2.3.1 Instruments

Instruments were identified from five sources; 1) a systematic review of general participation instruments (Eyssen et al., 2011), 2) a clinically focused review of participation instruments for people with aphasia (Dalemans et al., 2008), 3) a review of communicative participation instruments (Eadie et al., 2006), 4) outcome measures of functional communication in the Cochrane review on therapy studies in aphasia (Brady, Kelly, Godwin & Enderby, 2012), and 5) a search of the literature. The abstracts of PsycInfo, Medline and CINAHL were searched for the terms participation and measure/scale/instrument/assessment/questionnaire/tool and stroke/communication by the primary author of this paper. The first review by Eyssen and colleagues was an extensive systematic review completed in 2011 and was expected to identify the majority of participation instruments (Eyssen et al., 2011). The following three reviews were added in order to ensure all aphasia- and communication-focused instruments were included, whilst the literature search was undertaken to identify instruments published after the previous reviews, and any missed measures.
Inclusion criteria were that the instrument was self-report, developed for adults, published in English and that the content was accessible to the researcher. Only one version or iteration of the same instrument was included, with either the most recent or longest version included (for instruments where there was a short form available). This decision was made so that our review of instruments was current and so that the maximum number of items could be included. The focus at this stage of data collection was to identify as many participation-focused instruments as possible. As participation is a general concept which should not be specific to a single health condition, no attempt was made to filter for stroke or aphasia.

2.3.2 Operationalizing Participation

In order to operationalize the concept of participation for this crosswalk, three core characteristics of a participation item were developed by the team. The first characteristic is that a participation item is the summation of a number of activities into a larger societal role or function. An item may therefore include specific activities as examples or components of that role. This characteristic reflects many definitions of participation as more complex than activity, and consisting of multiple activities (Whiteneck & Dijkers, 2009). For example, 'How many times a week do you do the dishes?' is an activity level item, consisting of a single activity, whereas 'How much time do you spend caring for your home? (e.g. dishes, gardening, shopping)' would be a participation level item as it combines a number of activities including washing the dishes.

Leading on from this idea, the second characteristic is that a participation item should be able to be accomplished through a number of methods, unlike activity items which tend not to allow for individual choice. For example, an item about getting around the community would be related to participation, whereas an item about driving a car is more activity-like. This is because a person may be satisfied with their ability to get around even if they are restricted in driving. An item about driving as a means of getting around the community is not widely applicable and depends on person’s individual preference, cultural expectation and environment (including access to a car and roads). A participation item should allow for multiple means of achieving a full score on that item, and participation restriction should not be dictated by impairment or activity level difficulties. This stipulation is based on the underlying principle of parity in the ICF, that the classification should allow comparisons across individuals with different aetiology. This also helps to address the issue raised by Nordenfelt (2003), that the ICF does not take into account a person’s will or desire to do something, as desire to do an activity should not dictate participation restriction in the way that it is defined here.
The final characteristic is that the item should invoke a wider context, referred to in the ICF as the 'societal perspective'. Participation has been described as the fulfilment of personal goals and societal roles (Perenboom & Chorus, 2003). For the purposes of this review, this means that a category must involve other people, community, or is a socially valued role. In traditional conceptualisations of participation, this societal perspective is usually interpreted as involving other people. However this conception of participation would exclude religion, moving around the community, homemaking and some forms of recreation, which are clearly participation related. For this study, the stipulation is that the item must constitute a socially defined role or have concepts related to a wider social context, such as community.

Prior to the crosswalk of instrument items, a set of 500 sample items were discussed in regard to the characteristics described above. This discussion resulted in the proposed division of activity and participation codes shown in Table 2-1. All of the categories in chapters one, two and three, as well as most of chapters four, five and six were classed as activity. Chapters seven, eight and nine, as well as 'd660- Caring for others', were classified as participation. From looking at the kinds of items in the sample set, it was evident that no clear categorisation could be agreed upon for all items linked at chapter level to mobility (d4), self-care (d5) and domestic life (d6). For example, an item linked to d4 might be simply ‘mobility’, or it might be a question about travel for recreation. Therefore the items to be crosswalked to these codes were to be judged independently, based on content and with reference to the three characteristics of a participation item.

Table 2-1: Proposed division of ICF activity and participation codes

<table>
<thead>
<tr>
<th>Activity</th>
<th>Participation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chapter 1: Learning and applying knowledge</td>
<td>Chapter 7: Interpersonal relationships</td>
</tr>
<tr>
<td>Chapter 2: General tasks and demands</td>
<td>Chapter 8: Major life areas</td>
</tr>
<tr>
<td>Chapter 3: Communication</td>
<td>Chapter 9: Community, social and civic life</td>
</tr>
<tr>
<td>Chapter 4: Mobility</td>
<td>d660: Caring for others</td>
</tr>
<tr>
<td>-Except d4: Mobility</td>
<td></td>
</tr>
<tr>
<td>Chapter 5: Self care</td>
<td></td>
</tr>
<tr>
<td>-Except d5: Self care</td>
<td></td>
</tr>
<tr>
<td>Chapter 6: Domestic life</td>
<td></td>
</tr>
<tr>
<td>-Except d6: Domestic life</td>
<td></td>
</tr>
<tr>
<td>-d660: Caring for others</td>
<td></td>
</tr>
<tr>
<td><strong>Combined</strong></td>
<td></td>
</tr>
<tr>
<td>d4: Mobility, d5: Self Care, d6: Domestic Life</td>
<td></td>
</tr>
</tbody>
</table>

2.3.3 Linking to the ICF

Instrument items were coded onto ICF categories by a single rater who had completed ICF training and was familiar with content of the framework. The linking process followed established linking
rules for measures of health status (Cieza et al., 2005). However, contrary to these linking guidelines, meaningful concepts from response formats (e.g. satisfaction) and health conditions (e.g. schizophrenia, aphasia) were not linked as this information was not significant to the aims of the study. Demographic items (e.g. age, gender) and items related to the instrument itself (e.g. evaluating the instrument itself, asking for additional information) were also not linked or included in the item count.

The first step in the linking process was to identify the meaningful concepts in the items as per Cieza and colleagues (2005). These meaningful concepts were then mapped to ICF domains; Activities and Participation (d), Body Functions (bf), Environmental Factors (ef), not defined (nd-quality of life, nd-general health) and not covered (nc). Concepts that were mapped to domains other than Activities and Participation were not coded further, as the detail of these codes was not considered important for the aims of this study. Those linked to the activity and participation domain were then linked to the most precise ICF category, including chapter, second and third level codes, as well as category groupings (e.g., d810-d849). The category groupings, which are not often utilised in crosswalks, were included to retain detail that might be lost otherwise. For example, in chapter 8, an education item that does not specify what level of schooling (high school vocational, etc) would be coded into 'd8- Major Life Areas'. By using 'd810-d849- Education', the fact that the item refers more specifically to education as a major life area is able to be kept.

For items with multiple meaningful concepts, a single primary concept was identified and secondary concepts were coded separately. Identifying major and minor meaningful concepts has been suggested by other authors in order to identify correlations between codes (Noonan et al., 2009). Identifying a single primary concept because an item on an instrument has a single rating; the respondent must think about and rate only one overarching concept for each item. For example, an item with the meaningful concepts of ‘work’, ‘study’ and ‘homemaking’ would have the primary concept of ‘d8-Major Life Areas’, as two of the concepts fall beneath this, even though the third concept, homemaking, falls under the separate category of d6. The response formats from the items were also collated and placed into broad categories, similar to other linking studies (Magasi & Post, 2010).

2.3.4 Interater Reliability

Five hundred instrument items, approximately one fifth of the total items in all reviewed instruments, were assigned for interater reliability. Items were chosen at random using a random number generator. Rating of these items was completed by another researcher with comprehensive knowledge of the ICF and practical experience in crosswalking (Bagraith & Strong, 2013; Bagraith,
Hayes & Strong, 2013). The degree of agreement between the two raters was calculated by means of the kappa statistic, which is a measure of the agreement that exists beyond the amount of that expected by chance alone (Cohen, 1960). Values of kappa generally range from 0 to 1, where a value of 1 would indicate perfect agreement and 0 would indicate no additional agreement beyond what is expected by chance alone. Bootstrapping (via SPSS v21) was used to generate 95% confidence intervals for the kappa statistic.

2.4 Results

![Diagram of inclusion of instruments]

Figure 2-2: Inclusion of instruments

2.4.1 Identification of Participation Instruments

One hundred eleven instruments were identified from the reviews and literature search. As per Figure 2-2, the majority of these were sourced from Review 1 (Eyssen et al., 2011). Of these, 10 were excluded as they were not self-report, two because they were versions of other included instruments, eight because they did not focus on participation or related concepts and one because it could not be located. This left 90 instruments and 2,445 items which were linked to the ICF, a full list of which can be seen in Table 2-2. Due to the large volume of instruments that were identified,
### Table 2-2: List of all included assessments and their abbreviations

<table>
<thead>
<tr>
<th>Assessment</th>
<th>Abbrev.</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Activity Participation Questionnaire</td>
<td>APaQ</td>
<td>Li, Wells, Westhovens &amp; Tugwell, 2009</td>
</tr>
<tr>
<td>Adelaide Activities Profile</td>
<td>AAP</td>
<td>Clark &amp; Bond, 1995</td>
</tr>
<tr>
<td>Affect-Balance Scale</td>
<td>ABS</td>
<td>Bradburn, 1969</td>
</tr>
<tr>
<td>Amputee Medical Rehabilitation Society</td>
<td>AMRS</td>
<td>Gardiner, Faux &amp; Jones, 2002</td>
</tr>
<tr>
<td>Assessment of Life Habits (General Short Form 3.0)</td>
<td>LIFE-H</td>
<td>Noreau, Fougeyrollas &amp; Vincent, 2002</td>
</tr>
<tr>
<td>Assessment of Quality of Life</td>
<td>AQoL</td>
<td>Hawthorne, Richardson &amp; Osborne, 1999</td>
</tr>
<tr>
<td>Australian Community Participation Questionnaire</td>
<td>ACPO*</td>
<td>Berry, Rodgers &amp; Dear, 2007</td>
</tr>
<tr>
<td>Barthel Index</td>
<td>BARTH</td>
<td>Granger, Dewis, Peters, Sherwood &amp; Barrett, 1979</td>
</tr>
<tr>
<td>Brief Cancer Impact Assessment</td>
<td>BCIA*</td>
<td>Alfano et al., 2006</td>
</tr>
<tr>
<td>Burden of Stroke Scale</td>
<td>BOSS</td>
<td>Doyle et al., 2004</td>
</tr>
<tr>
<td>Cambridge Multiple Sclerosis Basic Score</td>
<td>CAMBS</td>
<td>Mumford &amp; Compston, 1993</td>
</tr>
<tr>
<td>Communication Outcome After Stroke Scale</td>
<td>COAST</td>
<td>Long, Hesketh, Paszek, Booth &amp; Bowen, 2008</td>
</tr>
<tr>
<td>Communication Profile for the Hearing Impaired</td>
<td>CPHI</td>
<td>Demorest &amp; Erdman, 1987</td>
</tr>
<tr>
<td>Communicative Activity Log</td>
<td>CAL</td>
<td>Pulvermüller et al., 2001</td>
</tr>
<tr>
<td>Communicative Effectiveness Index</td>
<td>CETI</td>
<td>Lomas et al., 1989</td>
</tr>
<tr>
<td>Community Integration Measure</td>
<td>CIM</td>
<td>McColl, Davies, Carlson, Johnston &amp; Minnes, 2001</td>
</tr>
<tr>
<td>Community Integration Questionnaire</td>
<td>CIQ*</td>
<td>Sander et al., 1999</td>
</tr>
<tr>
<td>Community Participation Indicators</td>
<td>CPI*</td>
<td>Magasi, Hammel, Heinemann, Whiteneck &amp; Bogner, 2009</td>
</tr>
<tr>
<td>Craig Handicap Assessment and Reporting Technique</td>
<td>CHART</td>
<td>Segal &amp; Schall, 1995</td>
</tr>
<tr>
<td>Disabilities of the Arm, Shoulder and Hand</td>
<td>DASH</td>
<td>Jester, Harth, Wind, Germann &amp; Sauerbier, 2005</td>
</tr>
<tr>
<td>Disability Rating Scale</td>
<td>DRS</td>
<td>Hall, Cope &amp; Rappaport, 1985</td>
</tr>
<tr>
<td>Disease Repercussions Profile</td>
<td>DRP*</td>
<td>Taylor, Myers, McNaughton &amp; McPherson, 2001</td>
</tr>
<tr>
<td>Environmental Status Scale</td>
<td>ESS*</td>
<td>Stewart, Kidd &amp; Thompson, 1995</td>
</tr>
<tr>
<td>EuroQuol-5D-S3</td>
<td>EQ</td>
<td>Rabin &amp; de Chiaro, 2001</td>
</tr>
<tr>
<td>Frenchay Activities Index</td>
<td>FAI</td>
<td>Schuling, de Haan, Limburg &amp; Groenier, 1993</td>
</tr>
<tr>
<td>Functional Autonomy Measurement System</td>
<td>SAAF</td>
<td>Herbert, Carrier &amp; Bilodeau, 1988</td>
</tr>
<tr>
<td>Functional Independence Measure</td>
<td>FIM</td>
<td>McPherson, Pentland, Cudmore &amp; Prescott, 1996</td>
</tr>
<tr>
<td>Functional Status Questionnaire</td>
<td>FSQ</td>
<td>Jette et al., 1986</td>
</tr>
<tr>
<td>Functioning Assessment Short Test</td>
<td>FAST*</td>
<td>Rosa et al., 2007</td>
</tr>
<tr>
<td>General Health Questionnaire</td>
<td>GHQ</td>
<td>Tait, French &amp; Hulse, 2003</td>
</tr>
<tr>
<td>Global Assessment of Functioning</td>
<td>GAF</td>
<td>Hilsenroth et al., 2000</td>
</tr>
<tr>
<td>Health Assessment Questionnaire</td>
<td>HAQ</td>
<td>Bruce &amp; Fries, 2003</td>
</tr>
<tr>
<td>Health of the Nation Outcomes Scales</td>
<td>HOMOS</td>
<td>Gigantesco, Picardi, de Girolamo &amp; Morosini, 2007</td>
</tr>
<tr>
<td>Hearing Handicap Index for the Elderly</td>
<td>HHIE</td>
<td>Ventry &amp; Weinstein, 1982</td>
</tr>
<tr>
<td>Hearing Participation Scale</td>
<td>HPS</td>
<td>Hawthorne, Hogan &amp; Hawthorne, 2002</td>
</tr>
<tr>
<td>Household and Leisure Time Activities Questionnaire</td>
<td>HLTA*</td>
<td>Vidrine, Amick, Gritz &amp; Arduino, 2004</td>
</tr>
<tr>
<td>ICF Measure of Participation and Activities Questionaire- screenner</td>
<td>IMPACT-S</td>
<td>Post et al., 2008</td>
</tr>
<tr>
<td>Illness Intrusiveness Ratings Scale</td>
<td>IIRS*</td>
<td>Devins, 2010</td>
</tr>
<tr>
<td>Impact of Vision Impairment Profile</td>
<td>IVI</td>
<td>Hassell, Wei &amp; Keeffe, 2000</td>
</tr>
<tr>
<td>Impact on Participation and Autonomy</td>
<td>IPA*</td>
<td>Cardol, de Haan, de Jong, van den Bos &amp; de Groot, 2001</td>
</tr>
<tr>
<td>Independent Living Skills Survey</td>
<td>ILSS</td>
<td>Wallace, Liberman, Tauber &amp; Wallace, 2000</td>
</tr>
<tr>
<td>Instrument of Home and Community Participation</td>
<td>PAR-PRO*</td>
<td>Ostir et al., 2006</td>
</tr>
<tr>
<td>Inventory of Functional Status</td>
<td>IFS</td>
<td>Thomas-Hawkins, 2005</td>
</tr>
<tr>
<td>Japanese Knee Osteoarthritis Measure</td>
<td>JKOM</td>
<td>Akai et al., 2005</td>
</tr>
<tr>
<td>Keele Assessment of Participation</td>
<td>KAP*</td>
<td>Wilkie, Peat, Thomas, Hooper &amp; Croft, 2005</td>
</tr>
<tr>
<td>Lancashire Quality of Life Profile</td>
<td>LQOLP</td>
<td>Oliver, Huxley, Priebre &amp; Kaiser, 1997</td>
</tr>
<tr>
<td>Leisure Time Satisfaction</td>
<td>LTS</td>
<td>Stevens et al., 2004</td>
</tr>
<tr>
<td>Life Functioning Questionnaire</td>
<td>LFQ*</td>
<td>Altschuler, Mintz &amp; Leight, 2002</td>
</tr>
<tr>
<td>Living with Dysarthria</td>
<td>LwD</td>
<td>Hartelius, Elming, Holm, Lovberg &amp; Nikolaids, 2008</td>
</tr>
<tr>
<td>London Handicap Scale</td>
<td>LHS*</td>
<td>Harwood, Rogers, Dickinson &amp; Ebrahim, 1994</td>
</tr>
<tr>
<td>Mayo-Portland Adaptability Inventory- Participation</td>
<td>MPAI-PI*</td>
<td>Malec, 2004</td>
</tr>
<tr>
<td>Index</td>
<td>Description</td>
<td>Reference</td>
</tr>
<tr>
<td>-------</td>
<td>-------------</td>
<td>-----------</td>
</tr>
<tr>
<td>NHS</td>
<td>Rai, Kiniorns &amp; Burns, 1999</td>
<td></td>
</tr>
<tr>
<td>NEADL</td>
<td>Wu, Chuang, Lin, Lee &amp; Hong, 2011</td>
<td></td>
</tr>
<tr>
<td>NHP</td>
<td>Wiklund, 1990</td>
<td></td>
</tr>
<tr>
<td>OPCS</td>
<td>Wellwood, Dennis &amp; Warlow, 1995</td>
<td></td>
</tr>
<tr>
<td>OHIP</td>
<td>Awad, Al-Shamrany, Locker, Allen &amp; Feine, 2008</td>
<td></td>
</tr>
<tr>
<td>PART-O*</td>
<td>Bogner, Bellon, Kolakowsky-Hayner &amp; Whiteneck, 2013</td>
<td></td>
</tr>
<tr>
<td>PM-PAC*</td>
<td>Gandek, Sinclair, Jette &amp; Ware, 2007</td>
<td></td>
</tr>
<tr>
<td>POPS*</td>
<td>Brown et al., 2004</td>
<td></td>
</tr>
<tr>
<td>PARTS/M*</td>
<td>Gray, Hollingsworth, Stark &amp; Morgan, 2006</td>
<td></td>
</tr>
<tr>
<td>PIPP</td>
<td>Pallant, Misajon, Bennett &amp; Manderson, 2006</td>
<td></td>
</tr>
<tr>
<td>PGWBI</td>
<td>Grossi et al., 2006</td>
<td></td>
</tr>
<tr>
<td>QCL</td>
<td>Paul et al., 2004</td>
<td></td>
</tr>
<tr>
<td>QOLS-S*</td>
<td>Burckhardt &amp; Anderson, 2003</td>
<td></td>
</tr>
<tr>
<td>ROPP*</td>
<td>Sandström &amp; Lundin-Olsson, 2007</td>
<td></td>
</tr>
<tr>
<td>RAP</td>
<td>van Bennekum, Jelles &amp; Lankhorst, 1995</td>
<td></td>
</tr>
<tr>
<td>RNLI*</td>
<td>Wood-Dauphinee, Opzoomer, Williams, Marchand &amp; Spitzer, 1988</td>
<td></td>
</tr>
<tr>
<td>ROT</td>
<td>Merkies, Schmitz, van der Meché &amp; van Doorn, 2000</td>
<td></td>
</tr>
<tr>
<td>SF-36</td>
<td>Jenkinson, Wright &amp; Coulter, 1994</td>
<td></td>
</tr>
<tr>
<td>SFS</td>
<td>Birchwood, Smith, Cochrane, Wotton &amp; Copestake, 1990</td>
<td></td>
</tr>
<tr>
<td>SRPQ*</td>
<td>Gignac et al., 2008</td>
<td></td>
</tr>
<tr>
<td>SSQ</td>
<td>Gatehouse &amp; Noble, 2004</td>
<td></td>
</tr>
<tr>
<td>SAQOL-39</td>
<td>Hilarie, Byng, Lamping &amp; Smith, 2003</td>
<td></td>
</tr>
<tr>
<td>SIS</td>
<td>Duncan et al., 1999</td>
<td></td>
</tr>
<tr>
<td>SA-SIP30</td>
<td>van Straten et al., 1997</td>
<td></td>
</tr>
<tr>
<td>SHE*</td>
<td>O’Donoghue, Duncan &amp; Sander, 1998</td>
<td></td>
</tr>
<tr>
<td>SIPSO*</td>
<td>Kersten, George, Low, Ashburn &amp; McLellan, 2004</td>
<td></td>
</tr>
<tr>
<td>SPRS-2*</td>
<td>Tate et al., 2012</td>
<td></td>
</tr>
<tr>
<td>PS*</td>
<td>Van Brakel &amp; Anderson, 2006</td>
<td></td>
</tr>
<tr>
<td>THQ</td>
<td>Kuk, Tyler, Russell &amp; Jordan, 1990</td>
<td></td>
</tr>
<tr>
<td>USER-P*</td>
<td>Post et al., 2012</td>
<td></td>
</tr>
<tr>
<td>VDA</td>
<td>Cohen &amp; Kimball, 2000</td>
<td></td>
</tr>
<tr>
<td>VAPP</td>
<td>Ma &amp; Yiu, 2001</td>
<td></td>
</tr>
<tr>
<td>VHI</td>
<td>Jacobsen et al., 1997</td>
<td></td>
</tr>
<tr>
<td>VOISS</td>
<td>Deary, Wilson, Carding &amp; MacKenzie, 2003</td>
<td></td>
</tr>
<tr>
<td>VRQOL</td>
<td>Hogikyan &amp; Sethuraman, 1999</td>
<td></td>
</tr>
<tr>
<td>WAQ</td>
<td>Perry, Garrett, Gronley &amp; Mulroy, 1995</td>
<td></td>
</tr>
<tr>
<td>WHODAS</td>
<td>Chisolm, Abrams, McErdle, Wilson &amp; Doyle, 2005</td>
<td></td>
</tr>
<tr>
<td>WHOQOL</td>
<td>Power, Bullinger &amp; Harper, 1999</td>
<td></td>
</tr>
<tr>
<td>WSAS*</td>
<td>Mundt, Marks, Shear &amp; Giest, 2002</td>
<td></td>
</tr>
</tbody>
</table>

* Participation measures (>50% participation items, covering more than 1 ICF chapter)
the measures were further filtered into those that had over 50% participation items and covered more than one ICF chapter. This filtered out instruments that were not assessing participation according to the definition given in this paper, and those that were focused on only one aspect of participation, such as leisure time or work life. Out of the original 90 instruments, 29 had over 50% of their items linked to participation codes, and represented more than one chapter. These are denoted with an asterisk in Table 2-2. These 29 assessments were all either included in Review 1 only (Eyssen et al., 2011), Review 1 and another review, or were identified in the literature search (Figure 2-2).

2.4.2 Content of the Participation Instruments

A frequency count of all codes is summarized in Table 2-3. Codes which fell outside of the Activities and Participation domain were among the most common. Environmental factors (ef), body functions (bf), concepts not covered by the ICF (nc) and quality of life (nd-qol) were represented in 21, 20, 11 and 6 items respectively. Items making general reference to participation (d) were also prevalent at 16 items. Broad chapter heading codes from d5-d9 were represented frequently (10 or more times).

Table 2-3: Frequency of codes appearing in the participation assessments

<table>
<thead>
<tr>
<th>Chapter</th>
<th>2nd Level and Chunk Codes</th>
<th>3rd Level Codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>d1: Learning and Applying Knowledge</td>
<td>d130-d159: Basic learning 2</td>
<td>d175: Solving problems 1</td>
</tr>
<tr>
<td>d2: General Tasks and Demands</td>
<td>d210: Undertaking a single task 1</td>
<td>d230: Carrying out a daily routine 2</td>
</tr>
<tr>
<td>d3: Communication</td>
<td>d330: Speaking 1</td>
<td>d335: Producing nonverbal messages 1</td>
</tr>
<tr>
<td></td>
<td>d345: Writing messages 1</td>
<td>d355: Discussion 3</td>
</tr>
<tr>
<td></td>
<td>d360: Using communications devices and techniques</td>
<td>d3600: Using telecommunication devices 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>d3601: Using writing machines 1</td>
</tr>
<tr>
<td>d4: Mobility</td>
<td>d460: Moving around in different locations 14</td>
<td>d4600: Moving around within the home 7</td>
</tr>
<tr>
<td></td>
<td>d470: Using transportation 3</td>
<td>d4601: Moving around within buildings 2</td>
</tr>
<tr>
<td></td>
<td>d470-d489: Moving around using transportation 4</td>
<td>d4602: Moving around outside buildings 4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>d4702: Using public motorised transportation 2</td>
</tr>
<tr>
<td>Code</td>
<td>Description</td>
<td>Count</td>
</tr>
<tr>
<td>------</td>
<td>--------------------------------------------------</td>
<td>-------</td>
</tr>
<tr>
<td>d5</td>
<td>Self-care</td>
<td></td>
</tr>
<tr>
<td>d510</td>
<td>Washing oneself</td>
<td>1</td>
</tr>
<tr>
<td>d530</td>
<td>Toileting</td>
<td>1</td>
</tr>
<tr>
<td>d540</td>
<td>Dressing</td>
<td>3</td>
</tr>
<tr>
<td>d550</td>
<td>Eating</td>
<td>2</td>
</tr>
<tr>
<td>d570</td>
<td>Looking after one’s health</td>
<td>1</td>
</tr>
<tr>
<td>d4751</td>
<td>Driving motorised vehicles</td>
<td>3</td>
</tr>
<tr>
<td>d5300</td>
<td>Regulating urination</td>
<td>1</td>
</tr>
<tr>
<td>d5301</td>
<td>Regulating defecation</td>
<td>1</td>
</tr>
<tr>
<td>d5701</td>
<td>Managing diet and fitness</td>
<td>7</td>
</tr>
<tr>
<td>d6</td>
<td>Domestic Life</td>
<td></td>
</tr>
<tr>
<td>d610</td>
<td>Acquiring a place to live</td>
<td>1</td>
</tr>
<tr>
<td>d630</td>
<td>Preparing meals</td>
<td>4</td>
</tr>
<tr>
<td>d640</td>
<td>Doing housework</td>
<td>14</td>
</tr>
<tr>
<td>d650</td>
<td>Caring for household objects</td>
<td>3</td>
</tr>
<tr>
<td>d660</td>
<td>Assisting others</td>
<td>17</td>
</tr>
<tr>
<td>d6200</td>
<td>Shopping</td>
<td>9</td>
</tr>
<tr>
<td>d6402</td>
<td>Cleaning living area</td>
<td>1</td>
</tr>
<tr>
<td>d6501</td>
<td>Maintaining dwelling</td>
<td>1</td>
</tr>
<tr>
<td>d6505</td>
<td>Taking care of plants</td>
<td>2</td>
</tr>
<tr>
<td>d7</td>
<td>Interpersonal interactions and relationships</td>
<td></td>
</tr>
<tr>
<td>d730-d779</td>
<td>Particular interpersonal relationships</td>
<td>4</td>
</tr>
<tr>
<td>d710</td>
<td>Basic interpersonal relationships</td>
<td>1</td>
</tr>
<tr>
<td>d730</td>
<td>Relating with strangers</td>
<td>2</td>
</tr>
<tr>
<td>d740</td>
<td>Formal relationships</td>
<td>3</td>
</tr>
<tr>
<td>d750</td>
<td>Informal social relationships</td>
<td>5</td>
</tr>
<tr>
<td>d760</td>
<td>Family relationships</td>
<td>18</td>
</tr>
<tr>
<td>d770</td>
<td>Intimate relationships</td>
<td>13</td>
</tr>
<tr>
<td>d7100</td>
<td>Respect and warmth</td>
<td>3</td>
</tr>
<tr>
<td>d7200</td>
<td>Forming relationships</td>
<td>2</td>
</tr>
<tr>
<td>d7402</td>
<td>Relating with equals</td>
<td>4</td>
</tr>
<tr>
<td>d7500</td>
<td>Friends</td>
<td>15</td>
</tr>
<tr>
<td>d7501</td>
<td>Neighbours</td>
<td>5</td>
</tr>
<tr>
<td>d7502</td>
<td>Acquaintances</td>
<td>2</td>
</tr>
<tr>
<td>d7503</td>
<td>Co-inhabitants</td>
<td>4</td>
</tr>
<tr>
<td>d7701</td>
<td>Spousal relationships</td>
<td>1</td>
</tr>
<tr>
<td>d7702</td>
<td>Sexual relationships</td>
<td>3</td>
</tr>
<tr>
<td>d8</td>
<td>Major life areas</td>
<td></td>
</tr>
<tr>
<td>d810-d839</td>
<td>Education and work and employment</td>
<td>25</td>
</tr>
<tr>
<td>d840-d859</td>
<td>Work and employment</td>
<td>7</td>
</tr>
<tr>
<td>d860</td>
<td>Basic economic transactions</td>
<td>4</td>
</tr>
<tr>
<td>d865</td>
<td>Complex economic transactions</td>
<td>2</td>
</tr>
<tr>
<td>d870</td>
<td>Economic self-sufficiency</td>
<td>2</td>
</tr>
<tr>
<td>d8700</td>
<td>Personal economic resources</td>
<td>14</td>
</tr>
<tr>
<td>d850</td>
<td>Remunerative employment</td>
<td>37</td>
</tr>
<tr>
<td>d855</td>
<td>Non-remunerative employment</td>
<td>13</td>
</tr>
<tr>
<td>d9</td>
<td>Community, Social and Civic Life</td>
<td></td>
</tr>
<tr>
<td>d910</td>
<td>Community life</td>
<td>11</td>
</tr>
<tr>
<td>d920</td>
<td>Recreation and leisure</td>
<td>50</td>
</tr>
<tr>
<td>d930</td>
<td>Religion and spirituality</td>
<td>11</td>
</tr>
<tr>
<td>d940</td>
<td>Human rights</td>
<td>5</td>
</tr>
<tr>
<td>d950</td>
<td>Political life and citizenship</td>
<td>10</td>
</tr>
<tr>
<td>d9101</td>
<td>Formal associations</td>
<td>12</td>
</tr>
<tr>
<td>d9201</td>
<td>Sports</td>
<td>4</td>
</tr>
<tr>
<td>d9204</td>
<td>Hobbies</td>
<td>2</td>
</tr>
<tr>
<td>d9205</td>
<td>Socializing</td>
<td>25</td>
</tr>
<tr>
<td>d9300</td>
<td>Organized religion</td>
<td>3</td>
</tr>
<tr>
<td>d9301</td>
<td>Spirituality</td>
<td>1</td>
</tr>
</tbody>
</table>
The most frequent second, third and chunk level codes in the Activities and Participation domain were recreation (d920), paid employment (d850), education (d810-d839) and socialising (d9205). Second and third level concepts that were represented between 10 and 20 times were moving around in different locations (d460), housework (d640), caring for others (d660), relationships with family, friends and spouses (d760, d7500, d770), volunteer work (d855), personal economic resources (d8700), community life (d910), informal associations (d9101), religion and spirituality (d930) and political life and citizenship (d950). Of these, all were participation codes except for moving around in different locations and housework.

Participation codes that were represented five to 10 times were informal relationships (d750), relationships with neighbours (d7501), work and employment (d840-d859), and human rights (d940). Activity codes seen in five or more items were moving around the home (d4600), managing diet and fitness (d5701) and shopping (d6200). Not defined- quality of life was also represented six times. There were also a plethora of codes which appeared only one to four times, including 31 activity codes and 19 participation codes.

2.4.3 Content of the Secondary ICF Codes

Whilst a single primary code was identified for each item, secondary codes were also recorded and counted. Eighty-four items from the filtered participation instruments (~13%) had secondary codes. Table 2-4 shows which secondary codes were associated with which primary codes, and in how many items this association appeared.
Table 2-4: List of primary and secondary codes in the participation assessments

<table>
<thead>
<tr>
<th>Primary Code</th>
<th>Secondary Codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>d: Activities and participation</td>
<td>d4 1 d660 1 d9202 1 d9204 1 d9405 1</td>
</tr>
<tr>
<td></td>
<td>d5701 1 d850 1</td>
</tr>
<tr>
<td></td>
<td>d6 1 d855 1</td>
</tr>
<tr>
<td></td>
<td>d640 1 d8700 1</td>
</tr>
<tr>
<td></td>
<td>d6505 1 d9201 1</td>
</tr>
<tr>
<td>d230: Carrying out a daily routine</td>
<td>d850 1 d920 1</td>
</tr>
<tr>
<td>d3: Communication</td>
<td>d740 1 d7500 1</td>
</tr>
<tr>
<td>d335: Producing nonverbal messages</td>
<td>d3350 1 d3351 2</td>
</tr>
<tr>
<td>d360: Using communication devices and techniques</td>
<td>d3600 2 d3601 2</td>
</tr>
<tr>
<td>d460: Moving around in different locations</td>
<td>ef 3</td>
</tr>
<tr>
<td>d470-d489: Moving around using transportation</td>
<td>d4701 1 d4751 1</td>
</tr>
<tr>
<td>d5: Self-care</td>
<td>d510 8 d550 4 d630 1</td>
</tr>
<tr>
<td></td>
<td>d5201 1 d570 2</td>
</tr>
<tr>
<td></td>
<td>d530 3 d5701 1</td>
</tr>
<tr>
<td></td>
<td>d540 8 d6200 1</td>
</tr>
<tr>
<td>d6: Domestic life</td>
<td>d6200 3 d6402 2 d6505 1</td>
</tr>
<tr>
<td></td>
<td>d630 2 d650 1</td>
</tr>
<tr>
<td></td>
<td>d640 4 d6503 1</td>
</tr>
<tr>
<td>d6200: Shopping</td>
<td>d430 1</td>
</tr>
<tr>
<td>d650: Caring for household objects</td>
<td>d6501 1 d6505 1</td>
</tr>
<tr>
<td>d660: Assisting others</td>
<td>d7500 1 d760 3</td>
</tr>
<tr>
<td></td>
<td>d7501 1 d7600 3</td>
</tr>
<tr>
<td></td>
<td>d740 1 d7601 1</td>
</tr>
<tr>
<td>d7: Interpersonal interactions and relationships</td>
<td>d760 1 d770 1</td>
</tr>
<tr>
<td>d730-d779: Particular interpersonal relationships</td>
<td>d7500 2 d760 2</td>
</tr>
<tr>
<td>d750: Informal social relationships</td>
<td>d7500 3 d7501 2</td>
</tr>
<tr>
<td></td>
<td>d7501 2 d7502 1</td>
</tr>
<tr>
<td>d7500: Friends</td>
<td>d3600 1 d3601 1</td>
</tr>
<tr>
<td>d760: Family relationships</td>
<td>d3600 1 d7600 1</td>
</tr>
<tr>
<td></td>
<td>d3601 1 d7603 1</td>
</tr>
<tr>
<td>d8: Major life areas</td>
<td>d6 8 d840-d879 10</td>
</tr>
<tr>
<td></td>
<td>d660 1 d855 2</td>
</tr>
<tr>
<td></td>
<td>d810-d839 1 d910 2</td>
</tr>
<tr>
<td>d810-d839: Education</td>
<td>d825 2 d830 1</td>
</tr>
<tr>
<td>d840-d859: Work and employment</td>
<td>d850 6 d855 6</td>
</tr>
<tr>
<td>d9: Community, social and civic life</td>
<td>d910 3 d930 2</td>
</tr>
<tr>
<td></td>
<td>d9205 1 d950 1</td>
</tr>
<tr>
<td>d920: Recreation and leisure</td>
<td>d6505 2 d9201 4</td>
</tr>
<tr>
<td></td>
<td>d7500 1 d9202 2</td>
</tr>
<tr>
<td></td>
<td>d760 1 d9203 2</td>
</tr>
<tr>
<td></td>
<td>d9204 4 d9205 2</td>
</tr>
<tr>
<td>d9201: Sports</td>
<td>d5701 3 d920 1</td>
</tr>
</tbody>
</table>
Most broad categories, i.e. chunk (d810-d849) and chapter level (d5 to d9), were associated with second and third level codes that fell hierarchically beneath them in the ICF. This is consistent with the hierarchical structure of the ICF, as the primary categories are often an overarching concept, and the secondary categories are examples or components of it. For example chapter 5, self-care was associated more than once with the secondary codes washing (d510), toileting (d530), dressing (d540), eating (d550) and looking after one's health (d570). Some chapters were linked with secondary codes which fell outside the chapter, such as chapter 8, major life areas, which was commonly associated with domestic life (d6), education (d810-d839), paid and voluntary employment (d850, d855). More specific second and third level codes were often linked to secondary codes that did not fall underneath them, or even within the same chapter.

2.4.4 Response Formats

The response formats from the 29 participation instruments were summarised into categories and are listed in Table 2-5. Participation restriction was the most common response required of participants, used in 18 instruments. Frequency of engagement in a role was the second most common type of response, included in 13 instruments. This category included both objective frequency (e.g., how many times a week) and subjective (e.g., too little, a lot). Satisfaction was the third most common category, and this also included other emotional concepts such as enjoyment and happiness. The next most frequently represented were the assistance and importance categories which were included in six instruments apiece. Assistance refers to the level of assistance a respondent needed to accomplish a task or role, and importance was a response format whereby respondents were asked to judge how important a role or activity was to them. Other response formats represented were difficulty, desire to change level of participation and customized response formats.

Table 2-5: Response formats of the assessments in order of frequency

<table>
<thead>
<tr>
<th>Category</th>
<th>Assessments</th>
<th>Example Item</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Restriction</strong></td>
<td>BCIA, DRP, ESS, IIRS, HHIE, HLTA, IPA, KAP, LFQ, LHS, MPAI, RNLI, ROPP, SHE, WSAS, PM-PAC, PS, USER-P</td>
<td>ROPP: is involved in recreational activities in the way and when one wants. My participation is 0-4 scale from not restricted to severely restricted (Sandström &amp; Lundin-Olsson, 2007).</td>
</tr>
<tr>
<td><strong>Frequency</strong></td>
<td>ACPQ, CIQ, CPI, HHIE, IHCP, LFQ, PART-O, PARTS/M, PM-PAC, POPS</td>
<td>SIPSO: Since your stroke, how often do you visit friends/others? Most days 4; At least once a week 3; At least once a fortnight 2; Once a month or less 1; Never 0</td>
</tr>
</tbody>
</table>
SHE, SIPSO, USER-P (Kersten, George, Low, Ashburn & McLellan, 2004).

<table>
<thead>
<tr>
<th>Satisfaction &amp; enjoyment</th>
<th>ACPQ, LFQ, PARTS/M, QOLS-S, ROPP, SHE, SIPSO, SPRQ, USER-P</th>
<th>SHE: How happy are you overall with the way you can spend your leisure time? 1-5 scale from very unhappy to very happy (O’Donoghue, Duncan &amp; Sander, 1998).</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assistance</td>
<td>CIQ, ESS, MPAI, PARTS/M, SHE, SIPSO</td>
<td>ESS: Personal assistance required. None- requires constant attendant or care in an institution (Stewart, Kidd &amp; Thompson, 1995).</td>
</tr>
<tr>
<td>Importance</td>
<td>CPI, DRP, PARTS/M, POPS, SPRQ, PS</td>
<td>POPS: How important to your satisfaction with life is working for pay? Most 4; Very 3; Moderate 2; Little 1; Not important 0 (Brown et al., 2004).</td>
</tr>
<tr>
<td>Custom</td>
<td>CIQ, ESS, LFQ, MPAI, PM-PAC</td>
<td>PM-PAC: Which category best describes your current employment situation? Working full time, retired, a homemaker, etc (Gandek, Sinclair, Jette &amp; Ware, 2007).</td>
</tr>
<tr>
<td>Difficulty</td>
<td>FAST, MPAI, SIPSO, SPRS</td>
<td>SIPSO: Since your stroke, how much difficulty do you have moving around all areas of the home? No difficulty at all 4; Slight difficulty 3; Some difficulty 2; A lot of difficulty 1; I cannot move around all areas of the home 0 (Kersten, George, Low, Ashburn &amp; McLellan, 2004).</td>
</tr>
<tr>
<td>Desire to change</td>
<td>ROPP, POPS</td>
<td>ROPP: Has the opportunity to work in the way and when one wants. I want support to change my level of participation Y/N (Sandström &amp; Lundin-Olsson, 2007).</td>
</tr>
</tbody>
</table>

2.4.5 Reliability Analysis

Table 2-6 shows that the inter-rater reliability was acceptable for each level of coding. According to Landis and Koch’s recommended interpretation of kappa values (Landis & Koch, 1977), reliability ranged from almost perfect at .85 (component-level) to moderate at .58 (chunk-level). As expected, reliability was better at the broader levels of comparison. Moreover, the reliability is consistent with that reported elsewhere by the ICF Research Branch when linking similar content to the ICF (Tschiesner et al., 2008).
Table 2-6: ICF linkage reliability

<table>
<thead>
<tr>
<th>Level</th>
<th>Percentage Agreement</th>
<th>Kappa (95% CI)*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Component</td>
<td>92.29</td>
<td>0.85 (0.80;0.89)</td>
</tr>
<tr>
<td>First Level</td>
<td>89.51</td>
<td>0.79 (0.72;0.85)</td>
</tr>
<tr>
<td>Chunk</td>
<td>78.95</td>
<td>0.58 (0.35;0.80)</td>
</tr>
<tr>
<td>Second Level</td>
<td>87.04</td>
<td>0.74 (0.66;0.81)</td>
</tr>
<tr>
<td>Third Level</td>
<td>80.77</td>
<td>0.62 (0.47;0.75)</td>
</tr>
</tbody>
</table>

*Bias-corrected bootstrapped confidence intervals (1000 resamples)

2.5 Discussion

2.5.1 Participation Instruments

Less than a third of the functional/participation instruments found in the literature contained over 50% participation items according to the definition of participation and its operationalisation guidelines outlined in this paper. Only two had only participation items, the Social Role Participation Questionnaire which had 12 items in chapters 7, 8 and 9, and the Work and Social Adjustment Scale, which was a 5 item questionnaire with items in chapters 6, 7, 8 and 9. It is clear from these results that few instruments exist that measure participation exclusively according to our definition. This finding is consistent with the literature, in particular a review by Eyssen and colleagues in which raters judged 25% of 2,426 items of participation assessments as reflecting participation (Eyssen et al., 2011; Magasi & Post, 2010; Perenboom & Chorus, 2003). Almost all the instruments included in this study contained items with primary concepts from body functions, environmental factors, quality of life, activity and concepts not covered by the ICF. This is evidence that instruments that measure participation exclusively are needed, so that this construct can be measured in a valid way. Separate measurement of participation can help identify participation restriction and determine treatment outcomes for this domain. The inclusion of ICF codes outside of the Activities and Participation chapter indicates that, in order to advance participation as a focus of rehabilitation, an agreement needs to be reached on what constitutes a participation instrument.

2.5.2 Participation Content of Instruments

There were a number of participation categories that were represented in almost all instruments—education, paid employment, recreation and socialising. Other frequently represented categories were being a carer, relating with friends, family and spouses, volunteer work, managing finances,
community life, civic duties, human rights and religion/spirituality. Performance in these roles appears to be key to assessing participation, and they were identified across the many populations for which these instruments were designed.

These roles roughly correspond with a review by Eyssen and colleagues which classified definite and possible participation items as social life, work/study, family life, financial, leisure, religion, general participation, sexual, perception, shopping, home, or transport (Eyssen et al., 2011). The final two of these resemble the broader themes of the activity or mixed categories that appeared frequently in the instruments of this crosswalk, which fell under three main conceptual themes- moving around, homemaking and self-care.

The concept of moving around in different locations, and its subset, moving around in the home, were commonly represented in the identified participation instruments. The concept of moving around in the home is usually considered too specific to be participation, however moving around the community has been identified as a potential grey area between activity and participation (Whiteneck & Dijkers, 2009). It is integral to fulfilling many social roles, such as travelling to work, school, to visit relatives and to get out and about in the community. In this way, it is a component of participatory roles, and therefore more activity related. However, people may also travel for pleasure, bringing an element of recreation into the concept, and this kind of travel has been identified as social participation in other studies (Jette et al., 2003). There is also a notion of ‘getting out and about’, wherein there is no particular purpose for the travel. This can be related to involvement in the community and recreation.

The presence of housework and domestic life in participation instruments reflects the sentiments of other authors (Whiteneck & Dijkers, 2009), that home making is a social role deserving of a more direct set of categories, preferably under chapter 8, major life areas. This position is substantiated by the data as domestic life was commonly a secondary code to major life areas, usually paired with work and study. Shopping was also commonly included, despite traditionally being classed as an activity level concept. Shopping is a complicated category as it has links to domestic life, self-care, recreation and economic life, which possibly explains its inclusion here. Perhaps it necessitates a social role in and of itself; the consumer role.

Lastly, self-care and managing one's diet and fitness appeared commonly in the participation instruments. Self-care was a category that was treated as both activity and participation in the data analysis, depending on the content of each item. Its frequent presence in these instruments, and in other studies, supports the duality of this concept (Jette et al., 2003). Caring for oneself can be seen as similar to caring for others, a concept that is commonly considered a participatory role. A
common feature of items in this group was the word 'appearance', which by definition brings in a social aspect to self-care - the idea that one is bathing, dressing and grooming with social motivations, which again brings a participation element into the category. The concepts of self-care and managing one's diet and fitness appear to be more participation related than other self-care categories such as bathing and toileting as they are made up a number of activities and can include a social aspect (Whiteneck & Dijkers, 2009). There is also the notion that caring for one's health is a major role for a person with a health condition. When a person is in recovery or rehabilitation, it could be argued that their main role in life is managing their health, superseding their major life roles of work, school, homemaking or caring for others for a period of time.

Concepts external to the Activities and Participation domain were also common in these instruments. When considering these, it is important to note that the ICF is intended to be dynamic, with each domain interacting with the others to create a state of functioning. For example, Environmental factors and body functions were among the most highly represented, at 20 inclusions each. Environmental factors have a strong conceptual link with participation, and changes to environment are a key way to modify or improve participation (Noonan et al., 2009). It can be surmised that environmental factors have either proven difficult to distinguish from participation items, or that their inclusion was deemed necessary to gain a full picture of participation. Quality of life is also related to participation, but the nature of this link is unclear (Whiteneck & Dijkers, 2009), and two concepts have been shown to overlap in aphasia (Worrall et al., 2011). Concepts not covered by the ICF were also highly represented. Not covered items included concepts like plans for the future and self-determination. As the not covered items were so heterogeneous, it is unclear if their frequency identifies an issue with the scope of the ICF or with the content of the instruments themselves.

2.5.3 Response Formats

There were a number of different types of response formats represented in the participation instruments. There seems to be little agreement between the instruments on how participation should be measured and what information should be collected from respondents. Responses ranged from objective, such as how many people, how much time, how frequently, to the subjective, such as satisfaction or if the respondents perceived they were doing an activity too little or too much. Interestingly, only one instrument, the Australian Community Participation Questionnaire, allows for a subjective judgement of 'too much' involvement in a role. The response metric of assistance was identified in the ICF itself as an important parameter for measuring both activity and participation (WHO, 2001), and participation has been described as having an element of autonomy.
Response formats like satisfaction and restriction are popular ways of measuring participation, while others, like frequency and difficulty, have been associated with the measurement of activity. These forms of response are all used by the listed participation measures, though with different weightings and in different combinations. More unique response metrics included desire to change the level of involvement and the importance of an activity or role. These responses do not measure the concept of participation itself, but rather, given how much or little the respondent participates, how important this is to them and whether they wish to decrease/increase their involvement. There seems to be little agreement on what response type is needed when measuring participation.

This review of the content of participation instruments may assist researchers and clinicians in selecting a targeted measure of participation. However, the data presented here must be considered with psychometric properties, length, intended population and suitability for the individual, health condition and healthcare context. The study provides some empirical evidence that the ICF categories of moving around, homemaking, shopping, self-care and managing diet and fitness are often included in participation-focused instruments. This necessitates a critical discussion on whether these concepts are activity or participation, or whether there exists a grey area between the two. The authors advocate that the concepts of activity and participation need to be delineated for the ICF to be used effectively as a framework for health status measurement. It also shows that development of new instruments must be approached with a clear conceptualisation of participation.

2.5.4 Study Limitations

There are a number of limitations to this study. Firstly, it must be noted that although 90 instruments were included in the study, the list may not be comprehensive. It is also noted that this crosswalk investigated instrument content in ICF terms; it does not report on psychometrics, intended population and other parameters that are integral to choosing outcome measures for research and clinical purposes. The focus of the study was on instruments which assess participation only, and no allowance was made for measures which contained a subscale for participation, as some other studies have done (Eyssen et al., 2011). Lastly, it is to be noted that the process of interpreting the items into meaningful concepts and then mapping them to codes is based on a rater’s culture and experience, and thus subject to bias (Noonan et al., 2009). However, the interrater reliability for this crosswalk was high despite a lack of shared culture and experience between the two raters, although they were both from the same country (Australia).

Despite these limitations, this study is expected to provide a significant contribution to ICF literature. No other study has coded the assessment items to the ICF to the scope and detail of this
crosswalk. Additionally, the three guidelines for participation items, based on theoretical work and practical coding, break new ground and could be utilised in further participation research. Lastly, because the data collection had a communication and aphasia focus, the results are expected to be especially relevant to speech-language pathologists, but also to all rehabilitation professionals.

2.6 Conclusions

It is clear from these results that consensus on what constitutes a participation item is required in order for the ICF to be used successfully as a framework for the development and interpretation of health-status measures. The content of the instruments included in this study fell across many ICF categories, often outside the Activities and Participation chapter. Common codes across all instruments were education, paid employment, recreation, socialising, being a carer, relating with friends, family and spouses, volunteer work, managing finances, community life, civic duties, human rights and religion/spirituality. This study also showed that the concepts of moving around, homemaking, shopping, self-care and managing diet and fitness were commonly included in these participation instruments, and some rationale for why this may be occurring was presented. It is recommended that the points raised in this study be addressed by future studies which seek to define or operationalise participation. The results may also guide researchers and clinicians to choose an appropriate instrument, as participation instruments vary widely on how and what they measure. Ultimately it is hoped that this crosswalk will inform a consensus on measuring this important dimension of the ICF for people with aphasia and other disabilities.
2.7 References


Gigantesco, A., Picardi, A., de Girolamo, G. & Morosini, P. (2007). Discriminant ability and


(SMAF): Description and validation of an instrument for the measurement of handicaps. *Age and Ageing, 17*(5), 293-302. doi: 10.1093/ageing/17.5.293


Worrall, L., Sherratt, S., Rogers, P., Howe, T., Hersh, D., Ferguson, A. & Davidson, B. (2010). What people with aphasia want: Their goals according to the ICF. *Aphasiology, 25*(3), 309-322. doi:
Chapter 3: Mobile Computing Technology and Aphasia: An Integrated Review of Accessibility and Potential Uses

This chapter contains a review of the use of mobile technology in aphasia rehabilitation. It serves as an introduction and background to the field and identifies the rationale for the research approach. As this chapter was published in early 2013, an update to this review is found in the introduction to Chapter 4 of this thesis, covering literature available after publication. This chapter outlines published literature at the time and proposes a series of guidelines for designing mobile technology for people with aphasia. These guidelines were later used in Chapter 4 to inform development of the CommFit™ app.

This chapter was published in *Aphasiology* in April, 2013 (Brandenburg, Worrall, Rodriguez & Copland, 2013). The content included in this chapter is identical to the published manuscript; however, the formatting has been modified to match the style of this thesis. Thus tables, figures, headings and references may have been altered from the published version to adhere to American Psychological Association stylistic guidelines, 6th edition.
3.1 Abstract

*Background*: Recently, the use of mobile computer technology in health management has received attention in research and clinical domains. The role of mobile devices such as smartphones and tablet PCs in the management of aphasia has not yet been thoroughly reviewed in the literature, and research on mobile technology and aphasia is scarce.

*Aims*: The aim of this paper is to review accessibility issues and the potential uses of mobile computing for people with aphasia, with a view to stimulating and guiding further research.

*Main Contribution*: The literature reviewed is synthesised into key design features which may enhance the accessibility of technology for people with aphasia. The importance of access to technology for non-rehabilitative purposes and the potential role of smartphones as a cost-effective, time-efficient and context-sensitive health management tool are outlined. Potential functions of speech pathology applications (apps) are also proposed, with the aim of improving the organisation and direction of research in this area.

*Conclusions*: Improving access to mobile computing technology by people with aphasia has the potential for enhancing both social participation and management of aphasia. It is clear from this review that more research is needed into how accessibility may be improved, as well as on the development of mobile applications that aid management of aphasia.
3.2 Introduction

Mobile technology has a growing place in daily life. People in developed countries are increasingly more likely to make a call on a mobile phone than a landline, check emails on a laptop than a desktop, or play a game on a handheld console than a stationary one. In the past five years, the rapid uptake of handheld computing options such as smartphones and tablet PCs has also received attention in health and disability research. For people with a disability, use of mobile technology offers a unique platform for disability management, but also introduces a new set of accessibility barriers. As yet, little research has focused on how mobile computer technology can be used by people with aphasia. This review integrates both experimental and non-experimental literature on possible barriers to mobile technology use for this population, summarises the literature on improving accessibility through technology design, and proposes the potential uses of this technology in the lives of people with aphasia. Integrative reviews have been identified as a broad type of research review used to investigate a topic of interest rather than a specific research question, and are especially useful when there is little empirical literature available (Whittemore & Knafl, 2005). The overarching aim of this review is to summarise the current research related to mobile computer technology and aphasia and therefore identify areas for continuing research.

3.3 Mobile Computing and Healthcare

Mobile technology is a loosely defined term, usually encompassing any form of wireless and handheld computing device, such as handheld computers, personal digital assistants (PDAs), gaming consoles and smartphones. While some definitions of mobile technology include laptops, the focus of this paper is on smaller, handheld mobile computing devices incorporating touch screens, such as smartphones and tablet PCs. These mobile computing devices feature internet connectivity and a range of sensors, including microphones, GPS and accelerometers and are easily programmable using downloadable applications (apps) available to the public. As such, mobile computing devices have the capacity to act as any number of devices in tandem; a voice recorder, a GPS device, a camera, a personal diary, a computer therapy program, and a social networking device in everyday life environments.

The availability and use of health-related apps for mobile devices has been on the increase. In the final half of 2009, the number of health-related smartphone apps increased from a few hundred to around 7000, with a significant percentage of those targeted for use by trained health professionals (Terry, 2010). Around 3% of these apps were directed towards the management of
chronic disease (Sarasohn-Kahn, 2010). Mobile apps have been successfully marketed for the management of chronic health conditions such as post-traumatic stress disorder (Department of Veterans Affairs, 2011) and skin cancer (Cancer Council Australia, 2012). Furthermore, many studies have demonstrated their successful application including, for example, heart rate monitoring for cardiac patients (Leijdekkers & Gay, 2006), dietary management for diabetics (Arsand, Tufano, Ralston & Hjortdahl, 2008), GPS monitoring for wandering in Alzheimer’s patients (Sposaro, Danielson & Tyson, 2010) and distribution of diagnostic images between health professionals in stroke care (Takao, Murayama, Ishibashi, Karagiozov & Abe, 2012). Morris, Mueller and Jones (2010) shed light on the use of mobile technology by stroke survivors, outlining data from this population from the broader population of the Rehabilitation Engineering Research Center for Wireless Technologies’ (Wireless RERC) 2010 Survey of User Needs. They report that 64% of respondents to this survey identifying as having had a stroke use their wireless device every day and 90% own or have access to a mobile wireless device. Also, 80% considered wireless access to be “very important,” although use tended strongly towards more traditional usage such as making phone calls (Morris et al., 2010). Less than half of stroke respondents reported use of text messaging, contacts, calendar, and camera features, and a third or less reported using internet, email, GPS and emergency services. Notably, less than 10% of stroke survivors reported using wireless mobile devices for mobile health monitoring and downloading apps.

Despite increased use of mobile technology in the management of chronic diseases and stroke, to our knowledge there is no quantitative research on the use of mobile technology by people with aphasia. There are indications that a significant proportion are computer literate; a study by Elman and Larsen (2010) indicates that 58% of 33 participants with aphasia currently use a desktop computer in the home, 79% had used one before their stroke and 82% want to use computers in the future. There is also some evidence that people with aphasia are also utilising mobile computing technology, as using “aphasia” as a search word on iTunes- one of the main marketplaces for mobile apps- returns over one hundred apps targeted to this population. Research into the experiences and perceptions of mobile computer technology by people with aphasia is needed, as continued uptake and successful use of this technology may be affected by the barriers aphasia can impose.

3.4 Barriers to Technology Access for People with Aphasia

Previous research has identified some likely barriers to use of technology (not specifically mobile technology) by people with stroke and aphasia. These include barriers relating to the health
condition, the user, and the nature of the technology itself. Awareness of the specific barriers that may exist in this population is necessary so that accessibility may be improved.

**3.4.1 Barriers Related to Health Condition**

For people with aphasia, language deficits can create a significant barrier to technology use. Egan, Worrall and Oxenham (2004) described the effect of aphasia on training a person to use computer technology. They proposed that difficulty understanding spoken and written language would impede an individual’s ability to understand and apply spoken and written instructions in a training scenario. Furthermore, reduced speaking ability may affect asking questions for clarification, and writing impairments would make note-taking and following instructions difficult (Egan et al., 2004). Difficulties with reading and writing were also predicted to affect an individual’s ability to interact with computer functions using text or typed input. As the language impairment of each person with aphasia is unique, and may include one or a combination of these issues in varying degrees of severity, the barriers to technology use may differ across individuals.

Apart from language deficits, people with aphasia may also experience age- and stroke-related deficits which affect their ability to use technology. Motor deficits resulting from stroke or increased age are likely to cause difficulties with fine motor tasks required to physically interact with mobile devices, such as activating a touch screen or pressing a button. Older adults and people who have experienced a stroke might also experience varying types and degrees of cognitive impairment that affect their ability to learn new skills. Impaired vision is another barrier to using technology. Vision changes that occur with increasing age include presbyopia (inability to focus on close objects), decreased contrast sensitivity and dark/light adaptation and slower recovery from glare (Carter, 1994), such as from a computer screen. These changes have obvious implications for the size of text, graphics and buttons on technology interfaces. In sum, language deficits, combined with other potential stroke- and age-related deficits, create a wide array of issues that need to be considered in technology design targeted for individuals with aphasia.

**3.4.2 Barriers Related to Healthcare Services**

Chen and Bode (2011) interviewed a range of health professionals, including speech-language pathologists, to investigate what factors influence therapists’ decisions to acquire and use new technology devices. Notable barriers were cost, logistical issues, time commitment and services/resources required. However these devices included a large range of technologies including speech generating devices, neuroprostheses for electrical stimulation, interactive metronomes, adaptive keyboards and speech recognition programs, so their relevancy to mobile computing
technology may be limited (Chen & Bode, 2011). As mobile computing devices such as smartphones and tablet PCs are often acquired and owned by the client, it is expected that some of these barriers may be reduced or eliminated for this type of technology. However, unlike devices which are purchased by and kept in clinics, training and supporting the use of mobile technology in day-to-day life is not traditionally seen as part of a clinician’s role. A better understanding is needed of the barriers healthcare services may experience in implementing mobile computing technology in particular, especially in relation to management of aphasia and speech-language pathology services.

3.4.3 Barriers Related to the Individual

The same study suggested that patient characteristics such as motivation, cognition, expectations and family support have been identified as factors for consideration by health professionals when considering using a new technology (Chen & Bode, 2011). Research more specific to aphasia indicates a person’s experience and confidence using technology may also act as barriers to use. It has been suggested that people who used mobile technology before acquiring aphasia may have an advantage if they retain some of the relevant skills and knowledge for computer literacy (McGrenere et al., 2003). Conversely, people who were not computer literate before their stroke may find learning a new set of skills more challenging due to aphasia and related cognitive impairments. Confidence may also be a factor, as a study involving people with aphasia interacting in 3D game worlds found that providing the participants with feedback and reassurance in order to reduce frustration was important to training success (Galliers et al., 2011). It is expected that availability of assistance may be important to encourage technology use by people with aphasia; however, more research is needed in this area.

3.4.4 Barriers Related to the Nature of Technology

In addition, the design and nature of mobile computer technology can act as a barrier to widespread adoption by people with aphasia. Sarasohn-Kahn (2010) outlined several considerations to the uptake of mobile solutions in the healthcare arena, including the fact that smartphones and tablet PCs have physical barriers due to small screen size and the need for effortless use in any number of environments. Privacy and security concerns were also a consideration, as the risk of keeping health-related information on a personal computing device needs to be carefully managed. Password protection is a part of this but competent developers are required who can manage security issues, particularly for apps which communicate with websites and other platforms. Another barrier was that there are a large number of apps available and users may find it difficult to select an app which is relevant to them. Adding to this issue is that apps are usually designed to make a profit for the developer, resulting in many apps being associated with a particular company,
drug or medical device, while fewer apps may be focused on the less profitable aspects of healthcare. The final barrier to adoption of mobile technology by health care consumers was a lack of knowledge about aphasia on the part of the creators. To ensure that an app is effective in influencing the behaviour of the user, some authors suggest that the intended user population be involved in the design, a process known as participatory design (Sarasohn-Kahn, 2010). For computer technology researchers with no knowledge of language disorders and their potential impact, the challenge of creating a protocol that allows people with aphasia to effectively interact with technology may be significant. Indeed, some researchers have indicated that difficulty in communicating thoughts and understanding instructions, as well as the heterogeneity of the user group, were barriers to research involving participants with aphasia (McGrenere et al., 2003). However, development of technology which is accessible despite a range of health conditions and individual factors is indicated, rather than developing the technology and addressing accessibility after the fact. In order to achieve this, the specific design features which have been shown to improve accessibility must first be determined.

3.5 Evidence for Accessible Technology

It has been suggested that there is a “digital divide” that exists between those that are able to access digital technologies and those that cannot, whether as a result of poverty, internet coverage or disability-related access issues (Elman, 2001). Further to this, Elman and Larsen (2010) suggested that the digital divide for people with aphasia may be on the increase, and called for action by aphasiologists to determine how to maximise the accessibility of digital technology for this population. One advantage of mobile computer apps is that they can be adapted for people with disabilities. For example, touch screens allow buttons to be customised, instead of fixed access via keyboard and mouse. Apps can be modified for vision and mobility issues, as there is no set button or font size. The multimedia nature of such devices may also allow programming which utilises sound, picture and video instead of just written text. In order to identify what adaptations might be beneficial for people with aphasia, a literature search was conducted. The abstracts of CINAHL, PsycInfo and Medline databases were searched for the term “aphasia” and the terms “phone,” “tablet,” “mobile,” “technology” or “computer.” Few studies specifically addressed mobile technology and aphasia; however, other areas of technology, such as Alternative and Augmentative Communication (AAC; Moffatt, 2004) and computer programs may indicate what features may enhance usability for people with aphasia. The most relevant aspects of this literature are now summarised.
3.5.1 Alternative and Augmentative Communication

The most established form of computer technology used in the management of language disorders is AAC technology. High-tech AAC devices aim to supplement or replace impaired spoken language in everyday life. Use of AAC by people with aphasia is relatively low, and most high-tech devices have been designed with other populations in mind (Linebarger, Romania, Fink, Bartlett & Schwartz, 2008), such as individuals with amyotrophic lateral sclerosis, traumatic brain injury and multiple sclerosis (van de Sandt-Koenderman, 2004). Nevertheless, a small number of high-tech AAC devices have been developed specifically for people with more severe forms of aphasia (Aftonomos, Steele, Appelbaum & Harris, 2001; Daeman et al., 2007; van de Sandt-Koenderman, Wiegers & Hardy, 2005). A review of AAC usage by people with severe aphasia concluded that although some studies show communication improvements in controlled environments, use of AAC failed to generalise to everyday use (Jacobs, Drew, Ogletree & Pierce, 2004). It is unclear whether this was a result of usability issues or because the participants did not find the devices useful for supplementing communication. However, some exceptions exist. The Talksbac AAC system, developed with input from people with aphasia and their carers, generated some useful information on features that may maximise usability (Waller, Dennis, Brodie & Cairns, 1998), which included less information on the screen, removal of prediction algorithms, and substitution of the word “more” with up/down arrows (Waller & Newall, 1997). These results suggest that simple design, a static interface and use of different modes such as symbols/pictures may be important when designing technology for people with aphasia.

3.5.2 Computer-based Therapy Programs

Another key way in which computer technology has been used in the management of aphasia is the delivery of treatment via computer. Computerised aphasia treatment is intended to be therapeutic and improve residual language skills, unlike AAC. Computer therapy is a cost-effective and resource-efficient way of delivering speech-language pathology services. It is now used in a wide range of settings and has become the focus of a significant amount of research (van de Sandt-Koenderman, 2011). Currently available computer programs for people with aphasia are designed to provide practice of varied communication skills for up to several hours a day without the presence of a speech-language pathologist. Researchers at City University created GeST, a computer program for people with aphasia with the aim to elicit and practise use of gesture (Roper, Marshall, Cocks, Galliers & Wilson, 2012). They utilised a separate, simplified keyboard so that all tasks were completed using six buttons; On, OK, Home, Left, Right, and Off, with no mouse. The project also included the creation of a 3D game world to practise gesture in context (i.e., gesturing for an
umbrella when it started raining in the game world; Galliers et al., 2011). This program serves as an example of fixed computer technology that has been modified for usability in order to deliver therapy to people with aphasia for independent practice. However, few other therapy programs in the literature address issues of design for independent use of these types of programs. Consequently, their use is dependent on the presence of therapy assistants or carers to set up and run the program. However, several studies have investigated the use of computer aphasia therapy programs independently following an initial teaching phase and have shown that people with mild to moderate aphasia are almost always successful (Fink, Brecher, Schwartz & Robey, 2002; Laganaro, Pietro & Schnider, 2006; Pederson, Vinter & Olsen, 2001; Ramsberger & Marie, 2007). Despite these promising reports, many of the articles fail to describe what design features allowed for successful use and what features resulted in difficulty or failure to become independent.

In addition to therapy programs, other computer applications have been developed by researchers in the field of Human-Computer Interaction (HCI) to enhance computer accessibility. These applications include multimedia dictionaries for looking up words online (Ma, 2010), digital photo sharing apps for conversational support (Koppenol, Mahmud, & Martens, 2010), email composition support (Mahmud & Martens, 2011), and topic lists to support video chatting (Yasuda, Nemoto, Takenaka, Mitachi & Kuwabara, 2007). However, development does not usually include considerations for people with aphasia. Instead, developers often use proxies (e.g., speech-language pathologists) or make assumptions about what will be accessible based on descriptions of aphasic impairments.

### 3.5.3 Mobile Computer Technology

A handful of studies in which modern mobile computing software has been created and evaluated for use by people with aphasia do exist. Although the literature is small, these studies provide valuable information on designing usable mobile technology for people with aphasia. It is to be noted that there are examples of software being created for early mobile devices before 2000, although these will not be covered here due to the vast differences in the technologies being utilised (Aftonomos, Steele & Wertz, 1997; Colby, Christinaz, Parkison, Graham & Karpf, 1981).

Moffatt (2004) described the experience of a single participant with aphasia using a handheld trimodal dictionary on the IPAQ, a small mobile computer. The researchers noted that the participant found extensive scrolling difficult, needed shallow hierarchies for navigation (kept at a two-tree level), considered the buttons to be too small/too close together (5mm× 5 mm), had difficulty with the language/words used, and identified navigation as the biggest barrier to using the device, although specific reasons for this were unclear. Another participant using a commercial
daily planner app on the same device suggested that the small size of the keyboard and buttons were the biggest barrier to use (Moffatt, 2004).

Allen, McGrenere, and Purves (2008) created PhotoTalk, a mobile app for small mobile computers, to assist people with aphasia to independently organise their photographs with the aim of supporting conversation. The researchers used a participatory design method wherein two speech-language pathologists experienced in aphasia helped to design the app. It was stated that the app “could not contain menus and could only use limited text” (p. 8) to maximise usability for the user. The app was then subjected to an informal usability study in which five participants with aphasia used PhotoTalk with a researcher for an hour and then provided feedback. Lastly, field studies evaluating the use of PhotoTalk were conducted for a period of one month to seven weeks. Quantitative usage data were collected using a tracking system within the app, and semi-structured interviews were conducted. Results suggested that participants were able to use the app independently and were using it most days of the month-long study.

In the same year, Benjamin, Harris, Moncrief, Ramsberger and Lewis (2008) created a mobile web app called “Banga” (now called BangaTen) for delivery of traditional computerised naming therapy. Intended to promote independent practice, this app was initially developed and later updated based on consultation with a single person with aphasia and informal correspondence from aphasiologists (Hagood et al., 2010). However, no specific design guidelines were included in the publications arising from the development of the app.

Greig, Harper, Hirst, Howe, and Davidson (2008) conducted a qualitative study on the barriers and facilitators to mobile phone use for people with aphasia; however, the study focused specifically on making/receiving calls and text messages. Barriers that are relevant to mobile technology use for broader functionality were the size of the screen and buttons (too small), options that were only available in pictorial form, one button having many functions, too many options available on the display, and too many steps required to complete a task. Interestingly, too many features on a phone was also listed as a barrier, despite this also being identified as a major advantage of mobile computing devices. It was noted that effective training and support was a facilitator, and hence it is possible that with adequate support multiple features may not be seen as a barrier.

Although not specific to aphasia, bigger buttons, bigger text, and bigger screens were also common suggestions when stroke respondents were asked what would make their wireless devices easier to use on the Wireless RERC’s (2010) survey. Other suggestions included text-to-speech
recognition, a screen which was more readable outdoors, support for learning to use the device, and better audio and translation services (Morris et al., 2010).

3.5.4 Aphasia-friendly Text and Website Guidelines

Although research into the accessibility of computer technology for people with aphasia is sparse, guidelines for aphasia-friendly text, mainly designed for dissemination of health information, have been shown to increase comprehension of print-based text for people with aphasia (Rose, Worrall & McKenna, 2003). The accessibility criteria for this study were based mainly on aphasia-friendly text principles, which include simple language, short sentences, large print, san serif fonts, use of bullet points, headings and key words in bold, large amounts of text-free space, and using pictures to support the meaning of text (Brennan, Worrall & McKenna, 2005; Rose, Worrall, Hickson & Hoffman, 2011). Other guidelines for aphasia-friendly documents also include using colour to enhance meaning, using simple borders to section information, and ensuring that the style of the document and pictures are consistent throughout (Herbert, Haw, Brown, Gregory & Brumfitt, 2012). Although aphasia-friendly text principles have been used to judge the accessibility of educational websites for people with aphasia (Ghidella, Murray, Smart, McKenna & Worrall, 2005), their applicability to screen-based text has not been investigated. Differences between print- and screen-based text have been shown to have an effect on reading comprehension for the general population. Factors contributing to these differences include the distance between text and reader, angle that characters are viewed from, size and shape of characters, number of characters per line, words per page, amount of spacing between characters and lines of text, extent of margins, and interference from reflections (Muter & Maurutto, 1991). Other criterion related to screen content for aphasia-friendly formatting were more computer-specific, including positive polarity (dark text on a light background) and lack of visual distracters (such as advertisements; Singh, 2000).

Aspects of computer use that do not have print-based correlates, such as navigation, stability of page (page stays the same until an action is performed by the user), and pop up error messages, may prove more of a challenge when designing for individuals with aphasia. Ghidella et al. (2005) included technical stability and the inclusion of a site map for navigation as criterion for accessibility, as indicated by Singh (2000), who predicted that such aspects would be important for people with aphasia using computers.

There are a number of accessibility guidelines specific to web and computer design, however adaptations for cognitive and language disabilities are relatively underrepresented. As yet, research is lacking on how these issues may affect accessibility for people with aphasia.
3.5.5 Guidelines for Accessible Mobile Apps for People with Aphasia

It has been suggested that designing usable mobile technology for people with a disability may not be a case of a single ideal design, but rather flexibility and customisation of design for an array of accessibility needs and preferences (Morris et al., 2010). Use of participatory design methodology has been suggested as one way to maximise the accessibility of computing technology. However, as mentioned previously, even in the subset of people with aphasia, deficits and accessibility needs vary considerably. The challenge for health and disability researchers is determining what aspects of design will be useful for people with aphasia (Elman, 2001). Features which have been identified from the literature to improve the accessibility of mobile technology for people with aphasia include multimodal representation, aphasia-friendly text, large buttons, static interface (layout does not change unexpectedly), simple navigation, and overall visual simplicity. These features, shown in Table 3-1 below, are intended to provide a basis for continuing research in this area.
Table 3-1: Summary of possible features of accessible mobile technology for people with aphasia

<table>
<thead>
<tr>
<th>Guideline</th>
<th>Description</th>
<th>Source/s*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Multimodal</td>
<td>Text should be supplemented by pictures, symbols or spoken word where possible, in order to capitalise on a person with aphasia’s strongest language mode.</td>
<td>Waller &amp; Newall, 1997&lt;br&gt;Brennan, Worrall &amp; McKenna, 2005&lt;br&gt;Allen, McGrenere &amp; Purves, 2008&lt;br&gt;Greig, Harper, Hirst, Howe &amp; Davidson, 2008</td>
</tr>
<tr>
<td>Aphasia-friendly text</td>
<td>Where text is used, aphasia-friendly language principles should be applied, including large text, simple font, adequate use of spacing, simple words and short sentences. It is also suggested that a dark font on a light background is more readable.</td>
<td>Brennan, Worrall &amp; McKenna, 2005&lt;br&gt;Singh, 2000&lt;br&gt;Morris, Meuller &amp; Jones, 2010</td>
</tr>
<tr>
<td>Large buttons</td>
<td>The size of the 'buttons' on touch screens should be maximised to aid accessibility.</td>
<td>Moffat, 2004&lt;br&gt;Greig, Harper, Hirst, Howe &amp; Davidson, 2008&lt;br&gt;Morris, Meuller &amp; Jones, 2010</td>
</tr>
<tr>
<td>Stable interface</td>
<td>The user interface should be stable, and contents of the screen should be predictable, i.e., not change order on the screen using prediction algorithms or contain popups.</td>
<td>Waller &amp; Newall, 1997&lt;br&gt;Singh, 2000</td>
</tr>
<tr>
<td>Simple navigation</td>
<td>Tab navigation is recommended, as options stay within vision at all times, bypassing the need for memory or complex processing. Menu navigation should be kept to a two tree hierarchy. Pages that need scrolling should be minimised.</td>
<td>Moffat, 2004&lt;br&gt;Allen, McGrenere &amp; Purves, 2008&lt;br&gt;Greig, Harper, Hirst, Howe &amp; Davidson, 2008</td>
</tr>
<tr>
<td>Visual simplicity</td>
<td>Overall, apps for people with aphasia should be simple. Busy backgrounds or graphics should be kept to a minimum.</td>
<td>Waller &amp; Newall, 1997&lt;br&gt;Singh, 2000</td>
</tr>
</tbody>
</table>
3.6 Potential Role of Mobile Computing

Recently, Holland, Weinberg and Dittelma (2012, p. 229) proposed that there are two roles of apps in the lives of people with aphasia, as “impairment-focused practice devices” or as “ways to enhance communication and participation in society”. This review takes a similar view, proposing that there are two main roles for mobile technology in this population; firstly, to support accomplishment of everyday tasks to enhance participation, and secondly as a speech-language pathology service delivery tool in the management of aphasia. Both of these uses will be expanded to provide a conceptual basis for future research.

3.6.1 The Role of Mobile Technology for Participation

The growing popularity of internet use for everyday activities such as banking, shopping, and health management puts those who cannot access or use digital technology, such as people with aphasia, at risk of experiencing reduced participation in life roles. For example, it is becoming increasingly common for access to a computer connected to the internet being essential to completing education and employment tasks. There is growing support for the concept that participation in the digital world is becoming as important as participation in the physical world (Elman, 2001). For instance, previously people with disabilities advocated for the right to physically access shops, and today they face a similar fight for the right to access online shopping. In this review, the concept has been termed “digital participation.”

In the World Health Organization’s (WHO) International Classification of Functioning, Disability and Health (ICF), participation is defined as “involvement in life roles,” whereas activities are “tasks executed by an individual” (WHO, 2001, p. 12). Chapters of Activities and Participation listed in the ICF include communication, mobility, domestic life, interpersonal relationships, and major life areas (work, school and economic life). Technology appears in Environmental Factors in reference to assistive devices and in activities/participation under communicating with others by computer or phone. Technology may be comparable to the representation of communication in the ICF; something that is in itself an activity but which underlies many aspects of participation. For example, apps like Facebook, Skype and email may help support interpersonal relationships, grocery store apps help maintain domestic life, banking apps support involvement in economic life and calendar apps remind users of social, health, work and school commitments. These are mostly apps for the general public; however, there are some which support participation designed for people with aphasia. For example, the Aphasia Corner app (http://aphasiacorner.com/app) provides an aphasia-friendly daily news service that is aimed at increasing the community involvement of people with aphasia. This parallel between technology
and communication in everyday life implies that use of technology is worthy of being addressed in treatment. McCall (2012) discusses the notion of teaching a person with aphasia to use technology as a form of treatment, and their ability to use the technology faster and easier as treatment effects. Aphasiologists have begun to describe the clinical applications of computers for psychosocial support, as well as practical steps for implementing these in clinical scenarios (Berarducci, Kilov, Kovesy, Faux & Mozer, 2012; Golashesky, 2008; Holland et al., 2012; McCall, 2012).

Many apps which can be used to enable life participation are intended for the general population. Users of these apps include not just the aphasic population, but also healthy users and users with a range of other health conditions and disabilities, such that the design principles for developing accessible technology specifically for people with aphasia may not be as applicable. This is where the concept of universal design comes into play. Universal design is the concept of design which is accessible to all potential users, whether by one design for all, such as dropped kerbs on street corners which allow wheelchairs, prams and bikes easy access, or by providing different options for different users, such as providing both stairs and elevators in public buildings (Elman, 2001; Morris et al., 2010). Historically, many of the guidelines for universal design tend to focus on physical and sensory issues, whereas barriers created by cognitive and language deficits such as aphasia are harder to conceptualise and overcome, and as a result are sometimes neglected. The focus for aphasiologists may be to devise and advocate adaptations and support that will be useful to people with aphasia.

3.6.2 Functions of Mobile Technology for the Management of Aphasia

Mobile computing has the unique potential to deliver a range of functions to manage a person’s aphasia in their natural environment, such as providing therapy or education. Identifying how mobile technology can support effective management of aphasia is important to both evaluating current uses and developing new ones. Releasing apps as an end product of research programs may also be an effective method of knowledge transfer and exchange; translating research findings into a format that is accessible to the general public. There are over 150 smartphone and tablet PC apps currently available in iTunes using the search term “speech therapy,” and new apps become available weekly. However, many apps are created without significant research or published literature to guide their development, so speech-language pathologists must be selective in their recommendations. Mobile computer apps can be categorised according to disorder (autism, aphasia) or population (school-age, adult) which can be useful to clinicians. However, using this system, many apps will be suitable for a number of categories, or categories may contain too many apps to be practically useful. Table 3-2 below summarises a proposed categorisation system for types of
app according to function. This system was developed by looking at apps which appear in the iTunes store under the search terms “speech pathology,” “speech therapy” and “aphasia,” and then grouping them according to their core function.

The categories that emerged from this process were comparable to the categories created by Katz (2010), who classified use of computers in aphasia into three categories: (1) AAC, where programs are used to supplement or replace natural speech; (2) Computer Assisted Treatment (CAT), where the computer is used with both client and clinician for the purposes of presenting stimuli, storing responses and scoring summaries; and (3) Computer Only Treatment (COT), where the program design allows for independent practice by the person with aphasia. The function-based categories of apps outlined here reflect this to some degree. The proposed categorisation system includes “AAC,” “Therapy” (akin to COT), and categories similar to CAT, which include “Stimulus Presentation,” “Behaviour Tracking,” and “Clinician Tools.” Educational and Environment or Biofeedback are additional categories.

Table 3-2: Categorisation of the functions of smartphone apps designed for people with aphasia

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
<th>Traditional Equivalent</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Alternative and Augmentative Communication</strong></td>
<td>Supplement or take the places of user’s speech to communicate</td>
<td>Low tech AAC systems, Speech generating devices</td>
<td>SmallTalk Aphasia, Expressive, Locabulary Disfluency Index Counter, Clinician’s Assistant</td>
</tr>
<tr>
<td>Clinician Tools</td>
<td>Intended user is clinician, these tools help with caseload management and therapy tasks.</td>
<td>Calculator, Diary, Progress Notes</td>
<td>YackerTracker 1.0</td>
</tr>
<tr>
<td>Behaviour Tracking</td>
<td>Require user to enter information about their behaviour and represents back to them. No analysis of information.</td>
<td>Tallies, Assessment scoring sheets</td>
<td></td>
</tr>
<tr>
<td>Stimulus Presentation</td>
<td>Give stimulus with expectation of action from the user. Can include tracking component where judgement of success/completion is made by user and entered.</td>
<td>Flashcards, pictures, mouth movements</td>
<td>Quick Artic, Speech Trainer 3D, ABA flashcard series, Naming TherAppy.</td>
</tr>
<tr>
<td>Therapy</td>
<td>Contain all the elements of traditional therapy; stimulus, way of response and feedback. Judgement of success/completion in made within the app.</td>
<td>Clinician, Computer Therapy</td>
<td>Comprehension TherAppy</td>
</tr>
<tr>
<td>Education</td>
<td>Give information to the user with the purpose of imparting knowledge. Requires no response or expectation of action from the user.</td>
<td>Pamphlets, training materials</td>
<td>iSpeech, Geek SLP</td>
</tr>
<tr>
<td>Environmental/Biofeedback</td>
<td>Use sensors to gather information about the user or environment, and provides a visual representation.</td>
<td>Sound level meters</td>
<td>VoiceMeter</td>
</tr>
</tbody>
</table>
3.6.2.1 AAC apps

AAC apps are among the most common apps which appear under the search terms “speech therapy” and “speech pathology.” These apps are similar to AAC devices, as they serve to augment or replace human speech as a means of communication. Apps in this category can be as simple as digital drawing pads to write and draw and photography apps for conversation support to those functioning as speech-generating devices such as SmallTalk Aphasia, Expressive, Locabulary and Proloquo2go. The uptake and benefits of different forms of AAC is the focus of a large body of research, increasingly addressing the issue of mobile technology AAC applications.

3.6.2.2 Therapy

Therapy apps use all the elements of traditional therapy whereby the stimuli presentation, user’s response, and the analysis of response and feedback are app-mediated. As such, therapy apps have the potential to replace clinician contact or computer therapy, and thus require the same level of evaluation for accessibility and effectiveness. This type of app is currently rare, and apps available are mainly for therapy to aid comprehension, as the mode of response lends itself to this type of use (e.g., touch response). For example the Comprehension TherAppy app functions as a therapy app; stimulus, touch response and feedback are all contained within the app, making it suitable for home practice. Verbal responses remain an issue for the creation of therapy apps for verbal expression, but there is a potential to use automatic speech recognition as this technology improves (Varley, 2011). The use of mobile computers as a tool to deliver therapy may have important implications for therapy principles that derive from neuroplasticity research, including the opportunity for increased quantity and frequency of treatment and incorporation of therapy in relevant behavioural contexts (Burns, 2008; Pulvermuller & Berthier, 2008). For example, delivering targeted therapy at greater frequency (“use it or lose it,” “intensity matters,” “repetition matters”) and in everyday life contexts (“salience matters”) can extend these neuroplasticity principles that Kleim and Jones (2008) have identified as important to neurorehabilitation. Use of mobile technology has the potential to be an extension of how computer therapy programs are used by people with aphasia, being more mobile, usable and integrated in their daily life activities.

3.6.2.3 Stimulus presentation

Stimulus apps were the second most populous category of apps under the search terms used. These apps provide therapy stimuli similar to flashcard and picture stimuli traditionally used by clinicians. These can include a tracking component, with the distinction from “therapy” apps being that the judgement of success or completion is made by the user, not automatically within the app.
Therefore a secondary person, either a carer or a clinician, is needed to use the app, since independent practice with feedback is not feasible. Flashcard type apps targeted for aphasia therapy include Quick Artic, ABA flashcard series, and Naming TherAppy. There are also apps which utilise video stimuli, such as Speech Tutor, which displays animations of articulatory placements, and the VAST therapy series, which uses real-life video stimuli. Video stimulus may also be useful as stimulus for verbs, adjectives, sentences and longer stories. A particular advantage of using mobile technology to present stimulus is that there is an opportunity for people with aphasia to use the camera to take their own pictures and videos to create personally relevant and contextualised therapy materials (McCann & Greig, 2012). Like clinician tools, stimulus apps can greatly increase the efficiency of therapy delivery, and can also aid home practice.

3.6.2.4 Behaviour tracking

Trackers are apps used by the client or carer in everyday life to track behaviours. Judgement of the occurrence of a behaviour is carried out by the user and entered into the mobile device, rather than being automated. The clinical equivalent of this category of apps are take-home assessments or tracking sheets, such as use of a tally sheet to track word-finding difficulties. Use of handheld computers for tracking behaviour has the advantage of mobility and easy accessibility, as it is expected the user will have the device on hand at the time of behaviour. As yet there are few apps in this category targeted specifically to speech pathology or aphasia. However, there are a plethora of apps which may be customised for this purpose, such as Daily Tracker, which has a number of response formats including checklist, numbers, stars and a five point scale of emotion, from sad to happy. This technology can be easily adapted to document a range of information for clinical and research purposes, such as sampling a conversation, and noting instances of word-finding difficulty. Mobile computing technology allows for constant tracking of user behaviour within their everyday environment, without the need for a researcher or clinician to be present. These developments address an increasing focus on capturing real-life outcomes that are meaningful to the everyday functioning of people with aphasia, rather than what occurs in a clinic (Kagan et al., 2008). Tracking behaviours can be a starting point to deliver timely feedback and support to people with aphasia.

3.6.2.5 Clinician tools

Clinician tools are intended to be used exclusively by a clinician in order to aid diagnosis or assessment. Currently available apps in this category include Clinician’s Assistant, which allows the clinician to enter client characteristics and receive information on aphasia type. Another example in this category which has not been utilised for people with aphasia are calculation apps, such as
Disfluency Index Counter, which helps calculate per cent syllables stuttered. This category also includes a wide array of organisational apps which are not specific to speech-language pathology or even health, such as diary and calendar apps. Clinician tools have the potential to maximise the ease and efficiency of speech-language pathology practice.

3.6.2.6 Educational

The primary role of educational apps is to provide information to the user. They are the digital equivalents of brochures or information sheets for client education. These apps have the potential to provide multimedia information, including pictures and sounds, much like information compact discs. Apps can be interactive, allowing the user to choose the information they would like to receive, and may include quiz components on information learned. Information provision for people with aphasia, their carers, and the wider community is a vital area of research, and mobile computers have the potential to disseminate customised information on a multimedia platform.

3.6.2.7 Environmental or biofeedback

Environmental or biofeedback apps utilise the phone’s sensors to provide real-time feedback. These have the potential for self-management of aphasia or for generalisation of language tasks to everyday life. A current example in speech-language pathology is the use of sound-level meters, like VoiceMeter, which feeds back the volume of environmental noise and the speaker’s voice. Mobile devices have the particular advantage of being integrated into people’s everyday lives, allowing natural and unobtrusive data collection using the phone’s sensors (audio input, GPS, camera, accelerometer) that does not require a separate piece of technology (Raento, Oulasvirta, & Eagle, 2009).

3.7 Conclusion

Mobile computing devices provide a promising avenue for use in delivery of speech-language pathology services for people with aphasia. However, the research evidence in its current state is lacking. Although information on the number and type of apps targeted to people with aphasia on iTunes is available, little is known about the actual usage of these apps. This article proposes a research agenda for aphasiologists in four main areas; investigating the use of mobile technology by people with aphasia, maximising the accessibility of mobile technology for this population, development of new apps with a wide variety of functions, and evaluation of currently existing apps, particularly those with assessments and therapy functionality. Timely and applicable research is needed to investigate methods of maximising accessibility for people with aphasia, as well as
how this technology can be used to optimise life participation for people with aphasia and the management of aphasia. Embracing the additional functions of mobile technology such as tracking and feedback into app development will require new skills for speech-language pathologists and people with aphasia alike. This rapidly changing research and development area will provide boundless opportunities to expand the reach of speech-language pathologists in aphasia rehabilitation.
3.8 References


Chapter 4: The Development and Accuracy Testing of CommFit™, an iPhone Application for Individuals with Aphasia

This chapter details the development and accuracy testing of the CommFit™ app. The introduction to this chapter reviews literature on mobile technology and aphasia which became available after Chapter 3 was published. The process of developing CommFit™ is outlined in detail to assist other researchers and individuals who are developing apps for people with aphasia. Development followed the guidelines for mobile technology outlined in Chapter 3. Next, a small accuracy study is described, in which the talk time logged by CommFit™ is compared to actual talk time. This chapter represents the end of Phase I of the research-development of a usable, accurate app to be investigated in Phase II of the doctoral research, outlined in the subsequent chapters.

This chapter has been published by the peer-reviewed journal, Aphasiology, as an advance online publication, awaiting print (Brandenburg, Worrall, Power, Copland & Rodriguez, 2015). The content included in this chapter is identical to the published manuscript; however, the formatting has been modified to match the style of this thesis. Thus tables, figures, headings and references may have been altered from the published version to adhere to American Psychological Association stylistic guidelines, 6th edition.
4.1 Abstract

**Background:** There has been an increasing amount of focus on measuring the ICF concept of participation in the rehabilitation of people with aphasia. The amount of time that people with aphasia talk has the potential to be used as an indicator of participation for this population. However in order to measure talk time, an accurate, portable and usable biofeedback tool is required. This paper details the development and accuracy testing of the CommFit™ iPhone application which, paired with a BlueTooth headset, times the talk of the user.

**Aims:** The aim of development of CommFit™ was to maximise the likelihood that the app would be usable by people with stroke and aphasia. Accordingly, aphasia-friendly text principles and other features of accessibility were integrated into the design, which is described in detail in this paper. The purpose of this study was to investigate the accuracy of CommFit™ in quantifying talk time in everyday environments in a small number of healthy adults.

**Methods & Procedures:** Participants were three healthy individuals, who each wore the CommFit™ app with BlueTooth headset and a continuous voice recorder for a total of 10 hours in their everyday lives. Talk time registered by the app was compared to the amount of talk time manually calculated from the continuous voice recording to obtain its relative accuracy.

**Outcomes & Results:** CommFit™ measured talk time within ±4% of the actual talk time in an ideal environment with no background noise, and ±13% in everyday environments when a calibration procedure was used.

**Conclusions:** CommFit™ is an app that was developed to be aphasia-friendly and accessible. The accuracy results suggest that the app with headset is a usable and valid indicator of talking time for people with aphasia. Testing will be carried out with the target population to further confirm the usability of the app and its role as an indicator of participation.
4.2 Introduction

The accessibility of modern technology for people with disabilities is an increasing social concern, both for their participation in society and access to increasingly techno-centric modes of rehabilitation (Dobransky & Hargittai, 2006). Barriers for people with language and cognitive disorders can be more difficult to surmount than motor or sensory impairments, especially for technology developers unfamiliar with the field of disability (Moffat, 2004). Mobile phones and other portable devices are a major component of remote health monitoring, or mHealth, and research on the use of mobile technologies in this context has emerged in the past decade (Fiordelli, Diviani & Shulz, 2013; Zhang & Sawchuck, 2013). This paper outlines the development and accuracy testing of CommFit™, an iPhone app designed to count the talk time of people with aphasia as a way of assessing their social participation.

4.2.1 mHealth in Aphasia Rehabilitation

The use of mobile technology such as smart phones in health is known as mHealth, and is a developing area in aphasia rehabilitation (Brandenburg, Worrall, Rodriguez & Copland, 2013; Chapter 3). While there have been a number of reviews and recommendations in the literature over the past few years (Holland, Weinberg & Dittelman, 2012; McCall, 2012), empirical research on the use of this technology with the aphasic population is only just beginning to emerge (Brandenburg, Worrall, Rodriguez, Copland & Power, 2012; Kiran, Roches, Balachandran & Ascenso, 2014; Kurland, Wilkins & Stokes, 2014). Studies have shown that the use of smartphone and tablet apps can result in therapeutic gains for people with aphasia (Brandenburg et al., 2013; Chapter 3). However, this literature is largely focused on describing/evaluating the therapeutic effectiveness of the apps rather than the design and development process. This study details the development of CommFit™ from the beginning stages, in order to describe the process of developing an app for people with aphasia, and highlight the unique issues involved.

A key part of developing apps for people with a disability is the involvement of the target population in the design. This process, known as participatory design, has been previously used with people with aphasia (Moffatt, 2004). The participatory approach requires involvement of the target users (or proxies) early in the design process, in order to increase the acceptability of the technology in the future (Moffat, McGrenere, Purves & Klawe, 2004). For the present research, the aims and features of the CommFit™ app were predetermined, and hence this type of participatory approach was inappropriate. Instead, the app was developed with reference to literature on usability
for older adults, people with aphasia, and people with other disabilities (Brandenburg et al., 2012) and will be tested post hoc by people with aphasia.

### 4.2.2 Measuring Talk Time

Recent developments in mobile computing have allowed for remote and automated monitoring of chronic health conditions (Raento, Oulasvirta & Eagle, 2009). This advance has the potential to improve the independence and self-management of people with stroke and aphasia as they can receive biofeedback in real time. Although other fields have made attempts at real-time monitoring of vocalisations (Warren, 2008), the quantification of talk time using technology is one feedback option that has not, to the authors’ knowledge, been explored in aphasia.

Quantifying how much a person talks has traditionally been achieved through indirect measurement methods such as self-report or diary (Hillman, Heaton, Masaki, Zeitels & Cheyne, 2006). Indirect methods of quantifying talk time involve asking a person to take note of the type and duration of talking activities they engage in. The quantity of talk is usually measured in hours or blocks of time, and does not account for the extent the individual was actually engaged in spoken communication during that time (Code, 2003). Self-report methods also require a user to be aware of their own behaviour and able to remember to log it regularly and accurately - a stipulation that excludes many people with language or cognitive disorders.

Although self-report measures have been the primary method of collecting information about how people communicate in their everyday life, more direct methods of recording have also been used. Continuous digital recorders, from which sound files are manually replayed and analysed, have been used to gain information on a person’s communication in everyday life (Baken & Orlikoff, 2000; Ingram, Bunta & Ingram, 2004). Continuous recording tools are limited in that all noise in the environment is recorded, not just the speaker. For the purposes of quantifying speech, the process of manually analysing a continuous recording is time-consuming. Voice activated recorders have also been used to collect speech samples in everyday life (Mehl, Pennebaker, Crow, Dabbs & Price, 2001). These are recorders that only begin recording when a sound of a predetermined decibel level is detected, and cease when the sound falls below that threshold. This means that only louder sounds are recorded, and some of the background noise and silence is not logged. However the specificity of such commercial devices in identifying the human voice in everyday environments is unreported.

Within the last decade, several research groups have sought to develop mobile devices that would obtain quantitative measures of voice use in everyday life (Cheyne, Hanson, Genereux,
Stevens & Hillman, 2003; Hillman et al., 2006; Popolo, Svec & Titze, 2005). These mobile devices utilise miniature accelerometers to measure the vibration of the vocal chords. They are used to quantify ‘time dose’ (the time in seconds the vocal cords spend vibrating) while allowing the user to be ambulatory (Cheyne et al., 2003). Accelerometers have the advantages of being relatively mobile and able to bypass the privacy issues associated with recording speech but not being highly susceptible to environmental noise (Mehta, Zanartu, Feng, Cheyne & Hillman, 2012). Several of these devices have been made commercially available; the Ambulatory Phonation Monitor (KayPENTAX), Vocalog Vocal Activity Monitor (Griffin Laboratories) and Voxlog (Sonvox), but they remain expensive due to high development costs and specialised circuitry (Mehta et al., 2012).

A mobile device called the LENA Pro has also been developed as a professional tool to collect information on child language. This device records speech continuously for up to 16 hours and provides some automatic analysis, such as conversational turns, estimated words spoken, number of child vocalisations and classification of environmental sounds (speech, television, silence) (LENA Foundation, Boulder, Colorado). The analysis is calibrated to children’s voices and is not highly applicable to adults with aphasia as analysis of conversation is based on a child-adult dyad. In addition, the LENA Pro is not designed to provide feedback back to the user throughout the day, but rather as a clinicians’ tool which must be plugged into a computer and analysed using LENA software following the recording period. Therefore another tool for quantifying talk of adults with aphasia is required.

Recently, developers of the Ambulatory Phonation Monitor have developed a smartphone-based system, with the advantages of being less expensive, able to access professional level support/upgrades and greater familiarity of the smartphone platform to general users (Mehta et al., 2012). However this product is not yet available commercially. Smartphone apps that work like voice activated recorders are an alternative option for recording talking. These applications also allow the decibel threshold that activates the device to be easily changed and calibrated to each user, unlike most voice activated recorders. They are also able to connect wirelessly with BlueTooth microphones, unlike their digital recorder counterparts, which usually require wired microphones. In addition, smartphones are easily programmable and integrate with other functions, such as alerts, email, databases and websites. Smartphones have been identified as a useful tool for recording voice, as they are cost-effective, have flexible programming, are easy to use, provide mobile, unobtrusive data collection and are increasingly available (Raento et al., 2009). However, for people with aphasia, the layout and navigation of the smartphone and its apps can be overly complex. As such, an iPhone app that is specifically tailored to the needs of people with aphasia is

78
required. CommFit™ is an iPhone app that has been developed specifically for the purpose of recording talking time in people with aphasia.

For a measure of talk time to be effective, it must demonstrate relative accuracy in different everyday environments. Research in the field of voice recognition equipment indicates that different environmental factors such as background noise and presence of other speakers may compromise the accuracy of voice recording and detection (Juang, 1991). For systems that use a microphone, the distance between the speaker’s mouth and the microphone in particular can degrade the acoustic signal and overall recording quality of these devices (Omologo, Svaizer & Matassoni, 1998). Studies identified specific everyday scenarios as problematic for recording equipment, such as mealtime recording (Lindstrom, Ren, Li & Waye, 2009), and car environments (Hernando, Nadeu & Marino, 1997). Recording equipment that is used to quantify talk in everyday life should therefore be capable of maintaining accuracy in the different environments the average user may be expected to encounter, indicating the need for field testing in a variety of everyday activities.

CommFit™ does not require absolute accuracy for its intended purpose. Its use will be similar to a pedometer for language- a gross indicator of an underlying construct, in this case, social participation. Research has shown that standard pedometer accuracy is ±10% actual steps taken in ideal or standardized environments (e.g. treadmill walking at moderate speed) (Crouter, Schneider, Karabulut & Bassett, 2003). In more difficult environments, such as walking on different surfaces or at slow speeds, pedometers are more inaccurate (Basset et al., 1996; Leicht & Crowther, 2007). Despite this, pedometers have been shown to be useful as physical activity biofeedback tools, as, even when taking into account a 10-20% error, they are still more accurate than self-reported estimates (Basset et al., 1996). Within 20% accuracy was accepted as a general standard for the accuracy of the CommFit™ system in measuring talk time in everyday environments, as the app is intended to act as a ‘language pedometer’- a gross biofeedback tool that counts talk time.

4.2.3 Aims

This paper will begin by describing the development and features of CommFit™. It then outlines an exploratory study investigating CommFit™’s accuracy in quantifying talk time. The overarching aim of this study was to create an aphasia-friendly iPhone app for people with aphasia, for use in future research projects.
4.3 Development of CommFit™

The development of CommFit™ involved two teams; a team of aphasia researchers with no prior experience in app development, and a team of commercial web developers and graphic designers with no knowledge of aphasia or developing technology for special populations. Development was an ongoing cyclical process that involved numerous mock-ups of the app, with communication between the teams on each version (Figure 4-1). This team-based approach required taking full advantage of the expertise and skills of each group, with open and timely communication between members. The development of the app was divided into two sequential phases. The first phase, the focus of the present study, was the development of the assessment/biofeedback component of the app; counting and displaying talk time. The second phase included the development of intervention components, which will be reported elsewhere.

![Figure 4-1: Illustration of the development process](image)

4.3.1 Preliminary Design and Design Goals

Preliminary design involved four components; education, formulating of design goals, deciding the type of data to be collected and choosing a BlueTooth headset. Before beginning development, the research team met with the app development team and provided education and resources relating to aphasia, how aphasia might affect the use of mobile technology, and available research on aphasia and technology. Education for professionals outside the field of speech-language pathology is necessary, as research has shown that public awareness of the condition is poor (Flynn, Cumberland & Marshall, 2009; Simmons-Mackie, Code, Armstrong, Stiegler & Elman, 2002). As well as written information, the developers were shown videos of people with aphasia to demonstrate practically the kinds of deficits experienced by this population. This was an informal process and the app developers asked questions and clarified information as needed. This education process was
important in ensuring the app would be designed to be usable for this population and aligned with the aims of the research.

Following this, the aims of the research project and function of the proposed app were outlined. This preliminary discussion between both teams informed the general direction of the project. The first step of this stage was to identify the operating system the smartphone app would be developed for, the iPhone Operating System (iOS) by Apple or an Android platform. At that time of development (in 2011), phones operating on an Android platform were becoming increasingly popular, however iPhones remained the most popular smartphone operating system (O’Dell, 2010). One of the main advantages for developing with Android was the open source code and minimally restrictive licensing which would have allowed for easy modification and distribution of software. However, Android-based phones can vary in quality and design, while Apple hardware is known for consistently high quality design (Jacob, 2011). In addition, there were more concerns about the security of Android platforms, as an open platform design leaves it more vulnerable to malware (Messmer, 2012). As usability, security and popularity were identified as key considerations for the project, iOS was chosen, meaning that iPhones would be used.

The second stage of preliminary development was to formalise the functionality of the app. Seven prioritised design goals were developed, consistent with the usual development process in technology design (Raento, Oulasvirta, Petit & Toivonen, 2005). According to our design goals, the app was required to:

1. Accurately quantify the user’s talking time
2. Be as unobtrusive and mobile as possible
3. Be able to collect data continuously over the period of a day
4. Provide maximum usability for people with aphasia, without compromising design goals 1, 2 and 3
5. Present data on talking time to the user in a clear and motivating way, with evident implications for behavioural change.
6. Record data in a secure way, protecting privacy
7. Provide avenues for the user to share their data with researchers in a way that does not violate design goal 6.

The type of data collected by the app was another critical decision made in this step. Two options were possible: a) a sound file containing the voice recordings, and b) a display of the recording time (without the audio). Table 4-1 shows a comparison of the advantages and disadvantages of each
method. Ultimately, option b was chosen because it most closely achieved design goal 1 (quantify talk time) without compromising design goal 6.

Table 4-1: Comparison of data collection options

<table>
<thead>
<tr>
<th>Data Transfer</th>
<th>Accuracy</th>
<th>Other Data</th>
<th>Language sample</th>
<th>Privacy</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Recording</td>
<td>Able to email</td>
<td>Basic proportion</td>
<td>A language sample would require another recording device to be used</td>
<td>No privacy issues</td>
</tr>
<tr>
<td>of Audio</td>
<td>data</td>
<td>comparison</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recording</td>
<td>Files too large to</td>
<td>Able to calculate</td>
<td>CommFit™ records language sample</td>
<td>Privacy issues for other speakers</td>
</tr>
<tr>
<td>of Audio</td>
<td>email</td>
<td>specificity and</td>
<td></td>
<td>recorded</td>
</tr>
<tr>
<td></td>
<td></td>
<td>sensitivity as well as proportion</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The final step in the preliminary stage of development was to identify the type of BlueTooth headset to be used. As there was no formal research published on commercially available headsets, the choice was based on online reviews from trusted technology websites (Dolcourt & Bennett, 2013; Lee, 2010; Lendino, 2010), as well as consultation with the manufacturers. The battery life and audio quality of the headsets were the main technical specifications considered. The Plantronics Voyager Pro + was chosen because of the quality of these particular specifications.

Figure 4-2: Illustration of word document mock up (left) and timing page of pilot app
4.3.2 Interface Design

The visual interface (how the pages of the app appear) was then developed. In order to address design goal 4, the principles of aphasia-friendly app designs from Chapter 3 (Brandenburg et al., 2013) were implemented. These included multimodal representation (use of colours and icons), aphasia-friendly text, large buttons, static interface (layout does not change unexpectedly), simple navigation and overall visual simplicity.

Visual interface development started with simple Microsoft Word mockups made by the research team to illustrate the desired look of the app for the developers. The initial mockups were translated into JPEG mockups in line with traditional app layout by the developer. The process involved in finalising the visual interface was lengthy; a cycle of JPEG prototypes and research team input was repeated three to four times for each page before completion. An example of an early mockup by the research team compared to a later formal JPEG mockup is shown in Figure 4-2.

4.3.3 Function and Navigation

The next step in the process was to develop the navigation of the app. This was visualized by using a flowchart, showing different buttons and where they would navigate to (Figure 4-3). The navigation was further operationalised by the team using a Microsoft Powerpoint mockup with the ‘action buttons’ functioning as links. This process allowed the team to practically experience the navigation of the app, and work out any issues with the navigation and flow of the app while simulating its use. The function of the app at this point was then imagined through a written summary of the function of each page of a specification document put together by the app developers. The agreed to specification document then became the common source document for further development of the app.

![Figure 4-3: Flowchart depicting navigation of the CommFit™ app](image-url)
4.3.4 The CommFit™ App

The next stage of the development process involved the app developers coding the specification document into a working app. Once a functioning app was built, both teams informally tested CommFit™ for bugs and practical issues. The cyclical process was the repeated, with constant feedback between members of the two teams. The app was revised several times until both teams were satisfied with the pilot version.

Screenshots of all the pages of the assessment component of the pilot CommFit™ app are shown below. The app starts with a ‘splash screen’ on start-up that orientates the user to the app (Figure 4-4). When users first download the app, there is a login page where they are required to enter a username and password. After the first login, the account automatically stays logged in and this page is not seen again (Figure 4-5). There is an option available to logout and login with a different user on the settings page (not shown). There is no home page, instead the app opens to the Timer page (Figure 4-2). This page has a large green button in the centre with a white triangle to start timing, and tabs for Results and Settings pages at the bottom. Once the green button is tapped, it turns red and displays a white square (see Figure 4-6). Usually, while collecting talk time data, no time is shown so as not to influence the user’s behaviour. When the red stop timing button is tapped after finishing timing, a final popup-style screen appears, allowing the user to send data, continue timing or discard the data. Tapping *finish and send* sends the data to a website (www.commfit.org.au), or saves it to the phone if internet is not available (Figure 4-7).

As well as the Timer page described above, there is a Settings tab with a number of options, including calibrate audio. The Settings tab is designed to be used by the clinician or researcher, hence aphasia-friendly principles were not applied. The *display timer* option is a simple on/off slider that determines whether the numerical talk time is displayed when timing. The ‘*calibrate audio*’ option navigates to another page (Figure 4-8), where a minimum and maximum threshold is able to be set for timing. This page also includes a counter to help set the threshold and a reset button to set the counter back to zero.
Figure 4-4: Splash screen  
Figure 4-5: Signup page  
Figure 4-6: Timing screen while timing  
Figure 4-7: Sending data  
Figure 4-8: Calibration page
4.4 Methods

Following the development of CommFit™, the app was tested for its accuracy in logging talk time. The purpose of this phase was to study three cases in depth with a particular emphasis on the accuracy of the CommFit™ system in different environments rather than a representative sample. Future studies will explore the generalizability of the findings. Three data collection periods were conducted- a laboratory test and two field tests- which will be reported separately in sections 4.5, 4.6 and 4.7 respectively.

4.4.1 Participants

Three volunteers with no history of speech or language disorders were recruited for this exploratory study. The participants, labelled Participants A, B and C, were all female, had over 16 years of education and were 55, 36 and 24 years of age, respectively. Volunteers were members of the research team, since CommFit™ was in its early developmental phase and not suitable to be tested by others. The potential for bias has been addressed in the discussion.

4.4.2 Equipment

A continuous recorder with lapel microphone and a smartphone with BlueTooth microphone were used for data collection. The continuous digital voice recorder used was the Sony IC recorder, model ICD-UX512F, which has 2GB of memory storage. It has been suggested that a high quality microphone, close to the speakers mouth, can minimise the effects of unwanted environmental noise and reverberation (Baken & Orlikoff, 2000; Parsa, Jamison & Pretty, 2001). Accordingly, the continuous recorder was used with a lapel microphone (Sennheiser N287 basic lapel microphone), which was attached to clothing near the collarbone (Figure 4-9).

The CommFit™ app was used with the participants’ own iPhones, either model 3GS or 4. The Bluetooth headset chosen was the Plantronics Voyager Pro+, which sits in the ear with a small boom microphone extending towards the mouth (Figure 4-10).

4.4.3 Data Analysis

The recordings from the continuous recorder were uploaded to GoldWave (Ingram et al., 2004), a free digital editing program that displays sound files with a visual waveform graphic. True talking time was calculated by manually segmenting the recording obtained from the continuous digital recorder by the first author (CB). During segmentation, vocalizations that served no social function, such as coughing or throat clearing, were deleted. All vocalizations that served a communicative
function, such as talking, interjections indicating hesitancy, and noises indicating assent were retained. The sound file was reviewed a second time by CB to confirm that only vocalisations with a communicative function were included. The duration of this file became the true talking time and the length of the original recording the total recording duration. The talk time logged by CommFit™ was the estimated talking time. The accuracy of the estimated talking time was calculated by dividing the estimated talking time by the true talking time obtained with the continuous recorder. The process of manually segmenting the file for analysis took approximately 150 hours in total- 50 hours for each participant’s 10 hours of timing.
Figure 4-9: Picture of continuous recorder and lapel mic

Figure 4-10: Picture of iPhone 4 and BlueTooth headset
4.5 Laboratory Test

4.5.1 Data Collection

Before main data collection, a laboratory test was conducted to determine the accuracy of the app in ideal conditions. For this test, Participant A recorded for one hour in a silent room, reading text from a novel. Before beginning the sample, the iPhone application was paired with the Bluetooth headset. The participant’s voice was calibrated by setting the decibel threshold to the level at which the participant’s voice activated the recording but not background noise. To begin and finish each time sample, both CommFit™ and the continuous recorder were turned on and off simultaneously.

4.5.2 Results

Analysis revealed that CommFit™ overestimating talk time by 4% over the hour with no background noise. This suggests that CommFit™ is highly accurate in a controlled, quiet environment, and consistent with the gold standard of within 10% accuracy.

4.6 Field Test 1

4.6.1 Data Collection

For the first field test each Participants A, B and C collected a time sample of 6-7 hours in their everyday environments. The same procedure was followed, and each participant used CommFit™ as well as the continuous recorder during their normal daily activities. For this preliminary study, the decibel threshold of CommFit™ was set for each participant using an informal procedure, where the app was set at a level that was judged to be appropriate while the participant was speaking. Participants were instructed not to change their normal vocal behaviour during data collection, and were asked to make note of the environments they recorded in. Recording a participant’s interactions in everyday life and interactions has implications for the privacy of other people in the environment, especially those recorded incidentally (Feiner, 1999; Raento et al., 2009). For that reason, participants were required to inform conversational partners of the use of recording equipment and purpose for recording. If verbal consent was not obtained, participants were required to turn off the recording equipment before continuing the interaction (Feiner, 1999).

4.6.2 Results

The results of the first field test are summarized in Table 4-2, with hours listed in chronological order. Analysis indicated that CommFit™ overestimated the talk time for each participant; Participant A by 66%, Participant B by 62% and Participant C by 8%. In addition, CommFit™
overestimated in every environment sampled (see Table 4-2).

Table 4-2: Accuracy results for field test 1 by participant

<table>
<thead>
<tr>
<th>Ppt</th>
<th>Hour</th>
<th>Environment*</th>
<th>GoldWave (secs)</th>
<th>CommFit (secs)</th>
<th>Percent Accuracy (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>A1</td>
<td>Group meeting</td>
<td>974</td>
<td>1632</td>
<td>168</td>
</tr>
<tr>
<td>A2</td>
<td>Group meeting</td>
<td>1529</td>
<td>1879</td>
<td>123</td>
<td></td>
</tr>
<tr>
<td>A3</td>
<td>Group meeting</td>
<td>927</td>
<td>1244</td>
<td>134</td>
<td></td>
</tr>
<tr>
<td>A4</td>
<td>Walk outside, meeting 2 people</td>
<td>2333</td>
<td>4104</td>
<td>176</td>
<td></td>
</tr>
<tr>
<td>A5</td>
<td>Skype group meeting</td>
<td>404</td>
<td>1364</td>
<td>338</td>
<td></td>
</tr>
<tr>
<td>A6</td>
<td>Quiet computer work</td>
<td>20</td>
<td>59</td>
<td>295</td>
<td></td>
</tr>
<tr>
<td></td>
<td>A Total</td>
<td></td>
<td>6187</td>
<td>10279</td>
<td>166</td>
</tr>
<tr>
<td>B</td>
<td>B1</td>
<td>Walking outside (windy), bus, busy cafe</td>
<td>424</td>
<td>835</td>
<td>197</td>
</tr>
<tr>
<td>B2</td>
<td>Group meeting, quiet computer work</td>
<td>637</td>
<td>847</td>
<td>133</td>
<td></td>
</tr>
<tr>
<td>B3</td>
<td>Group meeting, lunch conversation</td>
<td>834</td>
<td>935</td>
<td>112</td>
<td></td>
</tr>
<tr>
<td>B4</td>
<td>Quiet computer work and phone call</td>
<td>101</td>
<td>652</td>
<td>646</td>
<td></td>
</tr>
<tr>
<td>B5</td>
<td>Quiet computer work, brief conversation</td>
<td>109</td>
<td>235</td>
<td>216</td>
<td></td>
</tr>
<tr>
<td>B6</td>
<td>Quiet computer work</td>
<td>69</td>
<td>135</td>
<td>196</td>
<td></td>
</tr>
<tr>
<td>B7</td>
<td>Quiet computer work, brief conversation</td>
<td>283</td>
<td>342</td>
<td>121</td>
<td></td>
</tr>
<tr>
<td></td>
<td>B Total</td>
<td></td>
<td>2457</td>
<td>3981</td>
<td>162</td>
</tr>
<tr>
<td>C</td>
<td>C1</td>
<td>Car with radio</td>
<td>25</td>
<td>30</td>
<td>120</td>
</tr>
<tr>
<td>C2</td>
<td>TV/conversation</td>
<td>940</td>
<td>1010</td>
<td>107</td>
<td></td>
</tr>
<tr>
<td>C3</td>
<td>TV/conversation</td>
<td>1090</td>
<td>1170</td>
<td>107</td>
<td></td>
</tr>
<tr>
<td>C4</td>
<td>TV</td>
<td>53</td>
<td>64</td>
<td>121</td>
<td></td>
</tr>
<tr>
<td>C5</td>
<td>TV</td>
<td>150</td>
<td>163</td>
<td>109</td>
<td></td>
</tr>
<tr>
<td>C6</td>
<td>Driving with radio</td>
<td>108</td>
<td>128</td>
<td>119</td>
<td></td>
</tr>
<tr>
<td></td>
<td>C Total</td>
<td></td>
<td>2366</td>
<td>2565</td>
<td>108</td>
</tr>
</tbody>
</table>

*Use of italics denotes environments which were sampled for a smaller proportion of that hour

Results were then categorised into seven broader environment categories; group meetings of two or more, skype group meeting, quiet computer use, driving with radio, watching television, watching television while conversing, and outside environments, which included cafes, public transport and walking outside (see Table 4-3). The results were sorted into these environment categories to reveal whether the type of environmental noise may be a contributing factor. Table 4-3 shows the hours included in that category and total proportion accurately detected for each. The Skype call, quiet computer work, outside environments and group meetings had the largest amount of overestimation, while television watching, television with conversation and driving with radio resulted in a lesser amount of overestimation.
Table 4-3: Accuracy results for field test 1 sorted by environment

<table>
<thead>
<tr>
<th>Type of environment</th>
<th>Hours Sampled</th>
<th>GoldWave (secs)</th>
<th>CommFit (secs)</th>
<th>Percent Accuracy (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Watching TV with conversation</td>
<td>C2, C3</td>
<td>2030</td>
<td>2180</td>
<td>107</td>
</tr>
<tr>
<td>TV watching</td>
<td>C4, C5</td>
<td>203</td>
<td>227</td>
<td>112</td>
</tr>
<tr>
<td>Driving with radio</td>
<td>C1, C6</td>
<td>133</td>
<td>158</td>
<td>119</td>
</tr>
<tr>
<td>Group meeting (2+ people)</td>
<td>A1, A2, A3, B2, B3</td>
<td>4901</td>
<td>6537</td>
<td>133</td>
</tr>
<tr>
<td>Outside environments (crowds, cafes, public transport, walking)</td>
<td>A4, B1</td>
<td>2757</td>
<td>4938</td>
<td>179</td>
</tr>
<tr>
<td>Quiet computer use</td>
<td>A6, B4, B5, B6, B7</td>
<td>582</td>
<td>1423</td>
<td>245</td>
</tr>
<tr>
<td>Skype group meeting</td>
<td>A5</td>
<td>404</td>
<td>1364</td>
<td>338</td>
</tr>
</tbody>
</table>

4.7 Field Test 2

4.7.1 Data Collection

As the results of the first field test were not ideal, a second field test was completed to determine if calibration or use of a dedicated iPhone would improve accuracy. A formalised calibration procedure was added to identify the optimal recording level and improve the accuracy of CommFit™. The procedure included:

1. Sustained /m/ for 10 seconds
2. /mu/, /ma/, /mi/ pitch steps
3. Reading of the rainbow passage (Fairbanks, 1960)
4. Reading of the rainbow passage with background noise generated by a computer playing a video at a consistent volume
5. Short conversation (~60 seconds)

This procedure allowed the decibel setting of CommFit™ to be personalized for each user, allowing for the presence of background noise. Participants also used a dedicated iPhone which was not used for any other purpose (i.e., phone calls, text, email, internet) and recorded for three hours each. This was introduced to avoid potential interruption of timing by incoming calls, texts and other apps.

4.7.1 Results

The results from the second field test, with the additional calibration procedure, are shown in Table 4-4. The accuracy of CommFit™ was within 13% for each person. All were recorded in
environments that included quiet computer work, conversation and outdoor environments. Only two environments sampled over 20%, one which was an hour where there was only 20 seconds of talking.

**Table 4-4: Accuracy results of field test 2 by participant**

<table>
<thead>
<tr>
<th>Ppt</th>
<th>Hour</th>
<th>GoldWave (secs)</th>
<th>CommFit (secs)</th>
<th>Percent Accurate (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>1</td>
<td>1046</td>
<td>1175</td>
<td>112</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>818</td>
<td>730</td>
<td>89</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>1049</td>
<td>844</td>
<td>80</td>
</tr>
<tr>
<td>A Total</td>
<td></td>
<td><strong>2913</strong></td>
<td><strong>2749</strong></td>
<td><strong>94</strong></td>
</tr>
<tr>
<td>B</td>
<td>1</td>
<td>280</td>
<td>274</td>
<td>98</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>1063</td>
<td>1295</td>
<td>122</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>650</td>
<td>692</td>
<td>106</td>
</tr>
<tr>
<td>B Total</td>
<td></td>
<td><strong>1993</strong></td>
<td><strong>2251</strong></td>
<td><strong>113</strong></td>
</tr>
<tr>
<td>C</td>
<td>1</td>
<td>449</td>
<td>535</td>
<td>119</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>777</td>
<td>767</td>
<td>99</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>20</td>
<td>0.4</td>
<td>200</td>
</tr>
<tr>
<td>C Total</td>
<td></td>
<td><strong>1246</strong></td>
<td><strong>1342</strong></td>
<td><strong>108</strong></td>
</tr>
</tbody>
</table>

**4.8 Discussion**

This study investigated the accuracy of CommFit™ in detecting true talking time in both laboratory and field tests. The results from the laboratory test indicated that the app is highly accurate in environments with no background noise. However, CommFit™ is intended to be used in everyday environments where background noise will be present. When testing in everyday environments without using a standardised calibration procedure, CommFit™ was markedly overestimating talk times. The breakdown of results by participant in Table 4-3 shows that Participant C was considerably more accurate than the other two participants, even though similar environments were sampled. The large difference between participants seemed to indicate that CommFit™ accuracy is dependent on the dB setting, the voice of the speaker, or the iPhone used.

The breakdown of results by environment demonstrated incongruent results. For example, the most overestimated environments were a Skype meeting and quiet computer work, which might be unexpected and indicates that background noise may not be the cause of this inaccuracy. It is hypothesized the reduced accuracy in these conditions may be due to technical malfunction or differences between the headsets or iPhones used by the participants, given the marked differences in these two environments. To address these issues, a second field test was completed that included standardisation of the equipment. A uniform dB calibration process and a dedicated iPhone resulted
in much greater accuracy. With the exception of one hour, all times for all participants were within the goal of 20% accuracy, with an average of ±13% of the actual talk time.

However, due to the time-intensiveness of data analysis, recordings were limited to a sample of three neurotypical females, who were less than 60 years of age and were native English speakers. An epidemiological study in Melbourne, Australia found that stroke was more likely to occur in males, with a mean age of 74.6 years (Thrift et al., 2009), meaning that the sampled population did not reflect the typical stroke patient. However, accuracy results are expected to be similar in people with aphasia without concomitant issues, although acoustic features will be different for those with hypophonia and dysarthria. Ideally, CommFit™ will be tested with people with aphasia, including male speakers, and other populations before widespread release. Also, there was a potential for bias as the participants were members of the research team. Consequently, participants were familiar with the app and were able to check the accuracy of timing throughout the day. As such, there is a possibility that participants could have changed their behaviour or the environments to ensure accuracy. However, the researchers understood the purpose of the study was to determine if some environments were more accurate than others, and carried on with their daily activities without changing their behaviour, with the iPhone kept in their pocket out of sight. Additionally, no inter-judge analysis of the recordings was done, meaning that inter-judge reliability for actual talk time was not determined.

These results show that CommFit™ is sufficiently accurate to be used as a gross measure of the underlying construct of social participation and language use. In order to maximise the accuracy of CommFit™, it is suggested that the calibration procedure outlined in this study be employed, and that dedicated iPhones be used. It is also advisable that particularly noisy environments be avoided or not included in data analysis. When following these conditions, the CommFit™ app with BlueTooth headset may be useful as a biofeedback measure for people with aphasia to evaluate their current talking behaviour. As a form of biofeedback, accuracy is important, however 100% accuracy was not expected. The true value of this type of measure is to provide a gross indicator of everyday talking.

The CommFit™ app will be used in future studies to investigate the role of talk time in aphasia rehabilitation. Firstly, the usability of CommFit™ for people with stroke and aphasia will be established, and the app redesigned as needed. As talk time has never been investigated in this population, the average talk time of people with aphasia will be determined, as well as whether this differs to non-aphasic controls. As touched upon in this study, talk time is intended to be an indicator of participation for this population, and this will be explored. Future studies will also
focus on changing talk time behaviour—whether people with aphasia are able to increase their talk time and if this has positive effects on participation and/or language recovery. Lastly, CommFit™ needs further development before being made available commercially to outside researchers and clinicians.

4.9 Conclusion

Use of the CommFit™ smartphone application may be a useful way of timing the talk of people with aphasia. This exploratory accuracy study shows that with a uniform calibration procedure and use of a dedicated iPhone, the accuracy can be within 13% for everyday environments, and within 4% in a controlled environment with minimal background noise, in a small sample of neurotypical adults. Its use as a pedometer-like, wearable device for estimating talk time in adults is indicated, suggesting potential utility in people with language disorders. In the future, CommFit™’s usability for people with aphasia will be explored. Future studies will also investigate the degree of relationship between talk time and measures of participation, as well as the ability of people with aphasia to increase their talk time.
4.10 References


Griffin Laboratories, Vocalog Vocal Activity Monitor


KayPENTAX. Ambulatory Phonation Monitor


Sonvox, Voxlog


Chapter 5: Usability Testing of CommFit™, an iPhone Application for Individuals with Aphasia

The outcome of Phase I of this thesis was the development of a usable app (CommFit™) to count talk time in people with aphasia, as outlined in Chapter 4. In Phase II, the CommFit™ app was tested by people with aphasia and non-aphasic controls. The results of this investigation are described in the next two chapters. This chapter details the usability results by describing the barriers and facilitators to using CommFit™ experienced by 12 participants with aphasia.

This manuscript is in preparation for publication in a peer-reviewed journal. The content included in this chapter is identical to the manuscript; however, the formatting has been modified to match the style of this thesis. Thus tables, figures, headings and references may have been altered from the published version to adhere to American Psychological Association stylistic guidelines, 6th edition.
5.1 Abstract

Background: The use of mobile technology in aphasia rehabilitation is an emerging area of research. CommFit™ is an iPhone application which was developed according to aphasia-friendly guidelines to measure the talk time of people with aphasia. Presently, the usability of CommFit™ for people with aphasia has not been investigated, and there is little research on the barriers and facilitators to using mobile technology for this population.

Aims: The aim of this study was to describe the barriers and facilitators experienced by people with aphasia while using CommFit™.

Methods & Procedures: 12 people with aphasia used the CommFit™ system-app, iPhone and BlueTooth headset, to measure their talking time for 14 days. The Western Aphasia Battery-Revised Aphasia Quotient was used to determine aphasia severity. During the initial training session and data collection period, field notes were taken on the use of the app by participants. At the end of the data collection period, participants completed a usability rating scale and participated in semi-structured interviews on the barriers and facilitators to using the CommFit™ system.

Outcomes & Results: Field notes and data from semi-structured interviews identified eight barriers; physical and language impairments related to stroke, other physical barriers not related to stroke, time constraints, unfamiliarity with technology, social attitudes, design of the technology and technology malfunction. Facilitators included support from researchers, support from other people, app design and use of the manual. On the usability rating scale, steps involving the headset were rated as less usable than other steps involved in using the CommFit™ system. However, all steps had mean scores indicating that they were 'easy to use' or 'very easy to use'. Spearman correlations indicated that there was no significant relationship between usability ratings and aphasia severity. However there was a significant negative correlation between age and usability rating of 'pairing the headset' (r=-0.8173, p= 0.013).

Conclusions: The results of this study identified barriers to using mobile technology, many of which were not connected to the participants' stroke-related impairments. It also identified several facilitators which should be capitalised on when using mobile technology with this population. Lastly, results indicated that the BlueTooth headset was not a highly usable component of the CommFit™ system, especially for older users. This needs to be addressed in future research.
5.2 Introduction

Barriers to the accessibility of digital technology for people with disabilities is an increasing social concern. Over the past few years, mobile devices have become a popular way of engaging with the digital world, with research showing that approximately 68% of American adults connect to the internet using smartphones or tablet computers (Pew Research Center, 2014). The popularity of these devices for use in health has spawned its own field, mHealth, which capitalises on the ubiquity, ease of programming and all day monitoring that mobile devices provide (Fiordelli, Diviani & Shulz, 2013). For people with aphasia, mobile technology has the potential to provide unique rehabilitation options, enabling increased treatment intensity and saliency, cost-effective service delivery and improved options for self-management of the condition (Brandenburg, Worrall, Rodriguez & Copland, 2013; Chapter 3). However, there has been little research into the barriers and facilitators to the use of mobile touch screen devices, such as tablet PCs or smartphones, for people with aphasia. Barriers to technology use for people with language disorders are generally given less attention than motor or sensory impairments, as they are less tangible, especially for technology developers unfamiliar with the field of disability (Elman & Larsen, 2010). Thus, people with aphasia are at risk of exclusion from use of mobile technology that has the potential to improve their life participation and healthcare delivery.

Mobile applications (apps) have become increasingly popular with people with aphasia and those who work with them, but formal research in this area lags behind this trend. As increasingly more people with aphasia use apps, there is a need for evidence-based appraisal of their usability and therapeutic effectiveness for this population. Recently, several organizations (e.g., National Stroke Association, The ASHA Leader, The Tavistock Trust for Aphasia) have attempted to fulfil this need by publishing lists of aphasia apps with informal appraisals. However, formal research on the use of mobile technology with the aphasic population is only just beginning to emerge. Studies so far have shown that the use of tablet apps can result in therapeutic gains for people with aphasia (Des Roches, Balachandran, Ascenso, Tripodis & Kiran, 2014; Kurland, Wilkins & Stokes, 2014). The majority of this research literature has focused on therapeutic effect rather than usability.

However, there are some recently published studies that comment upon or explicitly address barriers and facilitators to the use of mobile technology. Kurland, Wilkins and Stokes (2014) conducted a study on the use of an iPad-based aphasia therapy app for home practice and made note of some usability issues. The training process, number of training hours required and assistance needed were noted for each participant. The authors found that, although only one participant had prior experience with iPads, most were able to operate the iPad independently with less than two
hours of training (Kurland et al., 2014). However, one participant was never able to reach independent proficiency, mostly due to inexperience with the technology and disinterest in completing the study, while another withdrew due to personal issues and time constraints. Researchers also experienced difficulty using the technology. For example, one participant was given the wrong stimulus due to a technical error. Other problems included participants accidently changing the volume, forgetting steps, deleting stimulus items, or having difficulty physically executing some steps which was mainly experienced by participants with hemiparesis. Researchers noted that they were often contacted to troubleshoot these types of issues. Despite this, participants were mostly satisfied with the program, and reported experiencing increased ease of use as the project continued.

Szabo and Dittelman (2014) described the use of iPad apps at the Adler Aphasia Center and detailed some of the challenges faced by participants. The authors noted that the people with aphasia were mostly elderly, and thus had limited exposure and confidence with technology, although this trend is changing (Pew Research Centre, 2014). Most participants needed ongoing support to use the iPads, and the need for support was related to level of technology exposure, severity of aphasia, and fine motor capabilities. People with aphasia needed ongoing support from health professionals, volunteers, family and friends; however, support was needed less as they became more familiar with the technology. With regards to the iPads themselves, the authors said that the design of some apps and web pages was problematic because they were not developed with people with aphasia in mind. Specifically, they noted that precision with the touch screen, highlighting text and inconsistent placement of accessibility features were problematic. Time limitations and lack of technically trained staff at the Center to update and troubleshoot the devices were a barrier, and so they hired an outside Information Technology consultant agency to assist. However, most people with aphasia were satisfied with the Adler Aphasia Center’s iPad program, with a mean rating of 4 on a scale of 1 to 5 (with 5 being very satisfied). Authors reported that most members used their devices daily for a wide range of purposes, including accessing news, social networking, entertainment, and practising communication skills.

Routhier, Bier and Macoir (2014) investigated the therapeutic effect and satisfaction with a tablet-based therapy for verb anomia for two participants with aphasia. Following the therapy period, participants were asked to complete a questionnaire which included eight items concerning ease of use of the tablet, and seven on satisfaction with the technical aspects of the program. The former included items about starting the tablet, starting the app, switching screens, closing the app and recharging the tablet. Almost all of the ratings were scored 4 and 5, with a score of 5 indicating it was ‘very easy’ to use. Participants also rated the technical aspects as a 4 or 5, indicating that they
were satisfied or very satisfied. Technical aspects rated included clarity of display, clarity of videos, screen dimensions, weight, finger-controls, reliability and using the tablet for treatment. However, researchers observed that both participants had difficulty learning to use the touch screen in the first session and needed input from the researchers. Participants also reported that they continued to have some difficulty with using the touch screen during home sessions. There was no information regarding whether or not the participants had previous experience using mobile or computer technology.

Miller, Buhr, Johnson and Hoepner (2013) developed AphasiaWeb, a social network for people with aphasia, available as an app for tablet devices. AphasiaWeb was specifically designed to be aphasia-friendly, and this was achieved by involving people with aphasia in the design process, known as participatory design. Development also followed general accessibility principles, such as topical organization and an uncrowded layout (Miller et al., 2013). The authors field tested the application with two regional aphasia groups and collected informal qualitative information about the app’s usability. The authors reported that most participants were satisfied with the app but did not describe usability issues in detail, other than noting one participant would forget where to access certain features of the app.

Other papers have discussed usability of mobile technology with people with aphasia by describing practical experience with using mobile devices in different settings. Holland, Weinberg and Dittelman (2012) provided general guidelines for choosing and introducing apps to clients based on their experiences with the technology programs at the Adler Aphasia Center and Carondelet Aphasia Program. The authors identified hemiplegia and lack of consistency in the design of apps as possible barriers, and stressed the importance of involving family and caregivers in the use of mobile technology. Similarly, McCall (2012) proposed steps to success when using both standard and mobile technology with people with aphasia, based on cases at the Snyder Centre for Aphasia Life Enhancement. The authors recommended that ample time and support needs to be dedicated to people with aphasia when they are learning to use technology. This mainly involved training of family members and others to support use and provide prompting where necessary. The author also noted that previous experience with technology did not seem to be a major barrier for technology use when compared to stroke-related impairments like aphasia and hemiplegia. Lastly, Ramsberger and Messamer (2014) provided suggestions for incorporating apps into therapy by outlining a series of case studies. They suggested that the sensory, motor, and cognitive capabilities of the person with aphasia should be taken into consideration when choosing apps. In terms of usability, the authors noted that popup ads could be problematic, and that apps which required swiping posed a difficulty for some participants with motor impairments.
Presently, published research on the usability of mobile technology for people with aphasia has been largely in the form of commentary, reviews or informal reporting of participant’s comments. Usability has not been investigated in an empirical manner, using a standardized training program and collecting both qualitative and quantitative information from participants with aphasia. Additionally, the usability of mobile apps which have been designed based on published guidelines for people with aphasia has not been investigated.

Our team (Brandenburg et al., 2013; Chapter 3) have synthesized available literature on use of mobile technology for people with aphasia, stroke and the elderly into accessibility guidelines. These guidelines proposed that apps should use aphasia-friendly text formatting, large buttons, stable interface, simple navigation and layout and use of multimodal methods of communicating where possible, such as colours, pictures and spoken word (Brandenburg et al., 2013; Chapter 3). We applied these guidelines to the development of CommFit™, an iPhone app which is designed to count the talk time of people of aphasia as a way of assessing their social participation (Brandenburg, Worrall, Power, Copland & Rodriguez, 2015; Chapter 4). Following this, a study was conducted which investigated the talk time of people with aphasia, as measured by the CommFit™ application (Brandenburg, Worrall, Rodriguez & Copland, under review; Chapter 6). This paper will focus on the barriers and facilitators to the use of CommFit™ as identified by the usability information collected during that study.

5.2.1 Aims

The aim of this part of the study was to investigate the barriers and facilitators experienced by people with aphasia using CommFit™.

5.3 Methods

5.3.1 Participants

The study targeted people with chronic, nonfluent post-stroke aphasia who were community dwelling. Recruitment sources included the Communication Research Registry (www.crregistry.org.au), the Ageing Mind Initiative 50+ Registry (www.uq.edu.au/ami/50-plus-registry) and community contacts. Inclusion criteria were that they had been diagnosed with aphasia following a stroke, and had the ability to use the app or had adequate home assistance to use the app. Exclusionary criteria were fluent aphasia, bilateral hearing aids and any other major sensory, motor or cognitive impairment that would affect use of the app. These criteria were evaluated by a speech pathologist and researcher.
A total of 18 people with aphasia consented to take part in a two-week study. Six participants dropped out, three due to health issues, one because of the time demands of the study, and two due to a combination of difficulty using the device (both only had use of one hand), time constraints and other health issues that made it difficult to complete the study. Usability information was collected, with consent, from these participants until they were unable to continue and this information is integrated into the results.

Twelve people with aphasia (7 males, 5 females) participated in the whole two weeks of the study. The characteristics of these participants are shown in Table 5-1. They ranged in age from 32 to 71 years, with a mean of 56.2. Aphasia severity was determined using the Western Aphasia Battery-2 Aphasia Quotient (Kertesz, 2006). Aphasia Quotients ranged from 24.4 to 95.3, with an average of 78.1. Participants were a mean of 3 years 2 months post onset (range 1 year 1 month – 5 years 11 months). Participants reported a range of experience using technology, from people who had never used anything beyond a basic mobile phone, to people who used iPhone and iPads for their daily communication. Participants were classified as experienced if they regularly used a touchscreen smartphone or tablet (not necessarily an iPhone). Participants were classified as minimally experienced if they used a button input phone only, or owned a tablet or smartphone but were not confident using it independently. Half of the participants with aphasia completed the study in Brisbane (n=6), where the researchers were located, and half (n=6) completed the research interstate in Melbourne or Sydney. All participants with aphasia identified as Australians. Eight participants wore glasses, and none wore hearing aids.

Table 5-1: Participant characteristics

<table>
<thead>
<tr>
<th>Participant</th>
<th>Gender</th>
<th>Age</th>
<th>TPO*</th>
<th>WAB-R AQ</th>
<th>Aphasia Severity</th>
<th>Technology Experience</th>
<th>Hemi-paresis</th>
<th>Glasses</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>F</td>
<td>32</td>
<td>4y 3m</td>
<td>95.3</td>
<td>Mild</td>
<td>E</td>
<td>Y</td>
<td></td>
</tr>
<tr>
<td>P2</td>
<td>M</td>
<td>42</td>
<td>2y 2m</td>
<td>79.5</td>
<td>Mild</td>
<td>E</td>
<td></td>
<td></td>
</tr>
<tr>
<td>P3</td>
<td>F</td>
<td>47</td>
<td>1y 1m</td>
<td>85</td>
<td>Mild</td>
<td>E</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>P4</td>
<td>F</td>
<td>50</td>
<td>3y 5m</td>
<td>94.4</td>
<td>Mild</td>
<td>E</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>P5</td>
<td>M</td>
<td>53</td>
<td>2y 3m</td>
<td>63.5</td>
<td>Moderate</td>
<td>E</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>P6</td>
<td>F</td>
<td>56</td>
<td>1y 9m</td>
<td>65.7</td>
<td>Moderate</td>
<td>E</td>
<td>Y</td>
<td></td>
</tr>
<tr>
<td>P7</td>
<td>M</td>
<td>59</td>
<td>3y</td>
<td>75.9</td>
<td>Moderate</td>
<td>E</td>
<td></td>
<td>Y</td>
</tr>
<tr>
<td>P8</td>
<td>M</td>
<td>62</td>
<td>1y 1m</td>
<td>85.2</td>
<td>Mild</td>
<td>E</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>P9</td>
<td>M</td>
<td>63</td>
<td>7y 5m</td>
<td>92.2</td>
<td>Mild</td>
<td>M</td>
<td></td>
<td></td>
</tr>
<tr>
<td>P10</td>
<td>M</td>
<td>69</td>
<td>5y 11m</td>
<td>83.9</td>
<td>Mild</td>
<td>M</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>P11</td>
<td>F</td>
<td>70</td>
<td>2y 5m</td>
<td>92.7</td>
<td>Mild</td>
<td>M</td>
<td>Y</td>
<td></td>
</tr>
<tr>
<td>P12</td>
<td>M</td>
<td>71</td>
<td>3y 5m</td>
<td>24.4</td>
<td>Very Severe</td>
<td>M</td>
<td>Y</td>
<td>Y</td>
</tr>
</tbody>
</table>

| Mean        | 56.2   | 3y 2m | 78.1
| SD          | 11.5   | 2y 10m | 19.1

*TPO= Time post onset; M=Minimal mobile technology experience; E=Experienced with mobile technology
5.3.2 Data Collection

Participants received approximately 60 minutes of training on how to use the iPhone and app, with participants needing a minimum of 20 minutes and a maximum of 90 minutes. This training was given by a speech-language pathology researcher experienced with the app. To ensure the training for each participant was comprehensive and consistent, a training manual was developed (see Appendix B. The researcher first described the function of the app, then demonstrated the whole process from turning the iPhone on to turning it off. The participant was then required to demonstrate the process, with the researcher assisting where needed. Caregivers were encouraged to attend, and were involved in the training process as much as possible. If needed, the participant undertook a two-day trial using CommFit™ and another session was conducted in which any problems with usability were addressed. Extensive notes were taken by researchers during the training sessions.

The person with aphasia then used the app for a total of 84 hours. Participants were encouraged to achieve this by using CommFit™ daily for six hours over two weeks, although many participants postponed timing due to health issues, personal commitments, holidays/events or simply forgetting to record. They were given a hard copy of the aphasia-friendly version of the training manual describing how to use each page of the app. The manual followed the aphasia-friendly text formatting guidelines by using simple words, short sentences, large sans serif font, bolding of key words, headings, bullet points, a contents page, headings, borders and meaning-related colours, pictures and icons to accompany text (Rose, Worrall, Hickson & Hoffman, 2011). Investigators also documented observations from all calls, emails and face-to-face communication in informal field notes.

At the end of the recording period, participants who were able to attend a face-to-face session (n=6) completed a semi-structured interview that further probed their experiences using the app. The interview schedule is attached as an appendix (Appendix C). The remaining participants, who lived interstate and were not able to participate in person, provided informal feedback via phone calls and email. In addition, all participants were asked to complete a rating scale in which they rated the app from very easy to use (0) to very hard (4) (Appendix D). They were also required to note the type of assistance needed for each stage (i.e., assistance from another person, use of the training manual). Qualitative data on usability came from the semi-structured interviews, observations during training, field notes and other communications during the trial period such as phone calls and emails.
5.3.3 Equipment and Procedure

Participants used an iPhone 4 and Plantronics Voyager Pro Plus Bluetooth headset in the study. These are shown with parts labelled in Figures 5-1 and 5-2. The procedure for using this equipment to record talk is outlined in the seven steps below:

1) Turn on the iPhone by pressing and holding the power button for 3 seconds (Figure 5-1). Users then open the home screen by using the slide to unlock slider in Figure 5-1. For the study, the home screen contained only the CommFit™ and the Settings apps to simplify the display (Figure 5-3). The phones were also set so that they did not automatically go into sleep mode.

![Image of iPhone 4 with parts labelled](image)

*Figure 5-1: iPhone 4 with parts labelled*

![Image of ProPlantronics Voyager Pro+ Bluetooth headset with parts labelled](image)

*Figure 5-2: ProPlantronics Voyager Pro+ Bluetooth headset with parts labelled*
2) Connect the iPhone and the Bluetooth Headset by tapping the Settings icon (Figure 5-3), then Bluetooth (Figure 5-4). On the Bluetooth page, the slider must be set to On (Figure 5-5). Users then press and hold the power button on the headset until they see a blue flash, a red flash, then blue/red flashes in quick succession (Figure 5-2). The headset is not ready to be paired until it is flashing blue and red. Users then tap the dialogue PROPlantronics on the screen and wait for Not Connected to change to Connected (Figure 5-5). The two devices are now connected.

3) Start the CommFit™ app by pressing the home button to return to the home page and then tapping the blue CommFit™ icon to start the app (Figure 5-3). The first time CommFit™ is opened, it shows a login/signup page, but for the study all apps were already logged in. This means that the app opens on the timing page shown in Figure 5-6.

4) Start recording talk time by tapping the large green button with a white triangle to start timing, which turns red and displays a white square (Figure 5-7). Users then press the power button once to put the iPhone in sleep mode so they can put it in their pocket, etc while timing.

5) Stop recording and send data. At the end of the timing period, users press the home button to open the timing page. When the red Stop timing button is tapped, it shows the final popup-style screen, allowing users to send data, continue timing or discard the data (Figure 5-8). Tapping Finish and send sends the data to the website or saves it to the phone if internet is not available.

6) Turn off the iPhone by pressing and holding down the power button and using the power slider (Figure 5-1).

7) Charge devices. Both the iPhone and the headset need to be charged using wall chargers for approximately 2 hours before the next timing session.
Figure 5-3: Home page

Figure 5-4: Settings menu

Figure 5-5: Bluetooth page

Figure 5-6: CommFit™ app

Figure 5-7: CommFit™ app while timing

Figure 5-8: Finish timing
5.3.4 Data Analysis

Interviews were transcribed and interview transcripts, field notes and communications such as phone calls and emails, were collected for each participant. Qualitative data were analysed using qualitative content analysis based on the protocol outlined by Graneheim and Lundman (2004). Data were initially divided into three clear content areas- barriers, facilitators, and comments and notes not related to usability. Data not related to usability were not analysed further. Remaining data were then divided into meaning units, which are defined as ‘words, sentences or paragraphs containing aspects related to each other through their content and context’ and then condensed (Granheim & Lundman, 2004). These condensed codes were then grouped into related categories. The World Health Organization’s International Classification of Functioning, Disability and Health (ICF) provided a framework to describe the factors which impacted on use of the technology (WHO, 2001).

5.4 Results

5.4.1 Themes from Interviews, Observations, Field Notes and Communications

Qualitative data on usability came from semi-structured interviews, observations during training, field notes and other communications during the trial period such as phone calls and emails. These data were logged with as much detail as possible and a file was kept for each of the 12 participants. These files were analysed and a number of barriers and facilitators were identified. Barriers fell into three ICF domain categories; Body Functions and Structures (physical and language impairments related to stroke, other physical barriers not related to stroke), Personal Factors (time constraints, unfamiliarity with technology) and Environmental Factors (social attitudes, design of the technology, technology malfunction). Facilitators were all related to the ICF domain of Environmental Factors, and fell into four categories- support from researchers, support from other people, app design and use of the manual. A summary of these barriers, and the participants who experienced them, is provided in Table 5-2.
Table 5-2: Summary of barriers to using the CommFit™ system, and which participant experienced each of them

<table>
<thead>
<tr>
<th>Barrier</th>
<th>Participants experienced</th>
<th>No.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Body functions and structures</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical impairments related to stroke</td>
<td>P1* P2 P3* P4 P5 P6* P7* P8* P9 P10* P11 P12</td>
<td>6</td>
</tr>
<tr>
<td>Language impairments related to stroke (aphasia)</td>
<td>√ √ √ √ √ √ √</td>
<td>5</td>
</tr>
<tr>
<td>Other physical difficulties</td>
<td>√ √ √</td>
<td>3</td>
</tr>
<tr>
<td><strong>Environmental factors</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Design of technology</td>
<td>√ √ √ √ √ √ √ √ √ √</td>
<td>5</td>
</tr>
<tr>
<td>Technology malfunction</td>
<td>√ √ √ √ √ √ √ √</td>
<td>7</td>
</tr>
<tr>
<td>Unexpected functions of technology</td>
<td>√ √ √ √ √ √ √ √</td>
<td>2</td>
</tr>
<tr>
<td>Social attitudes</td>
<td>√ √ √ √ √ √ √ √</td>
<td>1</td>
</tr>
<tr>
<td><strong>Personal factors</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unfamiliarity with technology</td>
<td>√ √ √ √ √ √ √ √</td>
<td>5</td>
</tr>
<tr>
<td>Time constraints</td>
<td>√ √ √ √ √ √ √ √</td>
<td>4</td>
</tr>
<tr>
<td><strong>Other</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Loss of or damage to technology</td>
<td>√ √ √ √ √ √ √ √</td>
<td>3</td>
</tr>
<tr>
<td><strong>Facilitator</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Environmental factors</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Use of manual</td>
<td>√ √ √ √ √ √ √ √ √ √ √ √ √</td>
<td>12</td>
</tr>
<tr>
<td>Support from the researcher</td>
<td>√ √ √ √ √ √ √ √ √ √ √ √ √</td>
<td>12</td>
</tr>
<tr>
<td>Support from other people</td>
<td>√ √ √ √ √ √ √ √ √ √ √</td>
<td>7</td>
</tr>
<tr>
<td>App design</td>
<td>√ √ √ √ √ √ √ √</td>
<td>6</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>5 6 4 6 10 7 5 6 9 5 7 8</td>
<td></td>
</tr>
</tbody>
</table>

* Out of state participants
5.4.1.1 Barriers

*Physical impairments related to stroke*

Participants found physical impairments related to their stroke, such as hemiparesis, hemiplegia and fine motor difficulties, to be a barrier to using the technology. Presence of hemiplegia was a factor in the two people with aphasia discontinuing the study. In particular, participants with use of only one hand were observed to find it difficult to place the headsets onto their ears and connect the chargers into the devices. Both chargers need to be pushed in with a degree of force, and it was difficult for these participants to leverage the device against something and push the charger in with a single hand. In training, it was observed that many participants were not able to hold down the headset power button for long enough for the indicator to flash blue/red. Participants noted it was difficult to hold the button due to the degree of force and time needed, but most became used to the process during the course of training. In addition, putting the headset on was difficult for P8, who was wheelchair bound and had poor fine motor skills. This participant needed to use a different, larger headset which went over the head so that she could complete the study.

The iPhones’ touch screen posed some difficulty for those with poor fine motor difficulty, usually combined with unfamiliarity with touch screen devices. This was most evident in training and was noted in researcher observations. Participants had difficulty using the on/off slider shown in Figure 5-2, as they had to put their finger in the right place, use appropriate pressure and not remove the finger until the slider was in the correct position. The participants as a whole found tapping the screen easier, but some also found this difficult in the training stage. The most common problem noted by the researcher was tapping above or below *Bluetooth* in the *Settings* menu (Figure 5-5). Some participants did this more than three times before tapping the correct place on the screen. Participants were also observed to hold down the *Settings* and *CommFit™* app buttons for too long (Figure 5-4), activating the iPhone’s ‘jiggle mode’, which can only be exited by pressing the home button. Lastly, some participants held down the iPhones’ power button for too long when putting it into sleep mode, prompting the phone to go to the power off screen (Figure 5-2). When these incidents occurred, the participants were confused and surprised that the expected result was not obtained. Most participants, except those very familiar with the iPad/iPhone, needed help to fix these errors. These issues seemed to resolve with practice since no participant mentioned problems with the touch screen or buttons in their final interviews.

*Presence of aphasia*
Language barriers were not a major barrier to usability for the participants. Most steps involved in using CommFit™ did not require reading comprehension, and even if text was used, for example in the Settings menu, it could be matched with the word shape and position in the manual. Language mostly came into play in training and troubleshooting. In training, some participants found it difficult to follow instructions, or ask questions when they ran into difficulty. Troubleshooting technology issues over the phone with participants was often difficult. Researchers noted that it was difficult to determine what the problem was when the technology was not in front of them, and participants often struggled to describe the problem in enough detail due to their language impairments. As a result, troubleshooting was often done with spouses, or required a face-to-face session.

Physical barriers not related to stroke

Some participants also experienced physical barriers to using the technology that were not associated with their stroke. P2 found the headset uncomfortable to wear for too long on one ear, and would alleviate this by switching ears halfway through the timing session. This was not mentioned by any other participant; however, it was experienced by one researcher during the development of CommFit™. P4 experienced difficulty keeping the headset on as she had unusually small ears, but she was able to wear a headband to keep the headset on during data collection. Lastly, it was observed by researchers in the training phase that participants who wore glasses sometimes found the headset difficult to put on. Most had to remove their glasses, then place the headset on before replacing the glasses. P9 identified this as a barrier to using the CommFit™ system in his final interview.

Design of the technology

At times, the design of the technology was a barrier to its use. P9 commented on the headset, saying that it was 'hard to tell if it's off or on', as it did not visually distinguish between the two states using the indicator light. This was observed to be a problem for other participants in the training phase. He also noted that the headset’s BlueTooth would go out of range sometimes when he left the iPhone in his house and walked around. Some participants also mentioned that they needed to take the headset off in certain environments, for example P5 took it off for visits to the hospital. This participant also said that when answering the phone he would often forget he was wearing the headset and put it to his ear, knocking the headset out of place.

Technology malfunction
Malfunction of the Bluetooth device was the most frequently reported barrier to using the CommFit™ system. P12’s spouse described an issue where the headset would say in his ear ‘power down’ and would turn off. This happened on two occasions, and the headset would not work for the remainder of that day. The manufacturer was unable to provide troubleshooting advice regarding this issue, as it had not been previously reported by other users. P10 experienced an issue where the Bluetooth was not recognised by the iPhone, and would stay in search mode but the device would not appear on the list in Figure 5-6. This problem was fixed by programming the iPhone to forget the device and pairing again. This problem did recur, but the participant and his spouse were able to complete the process of forgetting the device with assistance from researchers over the phone. Participants 5 and 11 also experienced an issue with the headset disconnecting at random times. P11 said of the issue ‘I don't have an issue using it, it's easy, except when it does that (disconnects). It kept doing that at the beginning...I didn't know how to fix it’. It was noted that problems occurred in the three final participants, suggesting that an update to the iPhone Operating System (iOS) may have caused the error. It was unlikely the error was due to the individual headset as each of these participants used a different headset, and replacement headsets were tried with the phones. Another issue with technology malfunction occurred when a participant notified researchers that the headset was unable to be charged. The headset was replaced by the researchers as the cause of the malfunction was unable to be determined.

**Unexpected functions of the technology**

Participants were observed to have significant difficulty when confronted with unfamiliar or unexpected functions of the technology. For example, some time into the study, a popup asking to login to iTunes appeared on the iPhone home screen of P5. His spouse stated, ‘We knew it was for iTunes and just pressed ignore, but it kept coming back every morning’, and implied that this was annoying. Researchers adjusted the settings so this did not recur. There was also an issue for researchers when an iOS update changed the appearance of the layout. A new manual with updated pictures needed to be produced, and participants who were midway through the study were confused by the change, especially as some steps outlined in the manual were different. Lastly, P2 contacted researchers as the name of the BlueTooth device was slightly different from the name in the manual, and he was unsure of what to do. He was given a new manual with the name inserted.

**Social attitudes**

Social attitudes in reaction to the technology were also mentioned as a barrier by one participant. P9 stated that he did not like to wear the headset to the shops, so he would stop the app when he needed to go out. This seemed to be because of a perceived social stigma of wearing a visible
medical/Bluetooth device. He stated that people had asked him about the device, and this made him uncomfortable. Many of the other participants had also been asked what the headset was, and most related that they were happy to share that they were in a research study, and the device was recording their talk time. For example, P11 said ‘I don’t have a problem with people seeing me wearing it...I actually don’t think about it at all while I’m wearing it’.

Unfamiliarity with the technology

Participants unfamiliarity with the technology was another contributor to difficulties. During data collection, two participants accidentally logged out of the CommFit™ app and were unable to log back in or understand what had occurred. One participant, who later dropped out of the study, had logged out and was unsure how it had happened, the other, P11, was logged out by a third party who did not understand how the app worked. The first participant was able to troubleshoot this issue over the phone, but the second participant was unable to adequately describe the issue with the app and required a visit from the researcher. Also, one of the participants accidently turned the BlueTooth slider to ‘off’ (Figure 5-6) and was not able to troubleshoot this independently. He was unable to describe the issue over the phone, necessitating an in-person visit. It is suspected that unfamiliarity with technology may also have contributed to physical difficulties using the touch screen, which were described earlier. Of the five participants who experienced difficulties relating to unfamiliarity with technology, four were identified as being inexperienced with technology (Table 5-1).

Time constraints

Lack of time to complete the study was a major factor in some of the participants dropping out of the study, and a source of difficulty for other participants. The CommFit™ app needed to be used every day and turned on and off at the beginning and end of the recording period. For some participants who were slower at using the technology due to more severe aphasia, physical impairments, or unfamiliarity with the technology, turning CommFit™ on and off was a time demand. However, the majority of participants did not find the process time consuming. One participant stated in his interview that it was ‘hard to remember...some days you forget’. Two participants suggested integrating some sort of reminder system into the app. Some participants reported that they remembered to time every day by making notes in diaries or calendars.

Damage to or loss of technology
Some participants experienced accidental damage to or loss of the headset which disrupted their participation in the study. One participant lost the headset, one was eaten by a dog, and one had pushed the charger in too far and the charging port had broken. Due to its small size and fragility, such incidents are expected. This is especially true as the participants were asked to wear the headsets going about their everyday lives, including leaving the home, where a headset can easily be lost or damaged by accident.

5.4.1.2 Facilitators

Use of the manual

Participants were observed to rely on the manual significantly in training and in their home. Most participants related that they used the manual only the first few days; however, some used it throughout the two weeks. One participant commented that it was ‘very good, very helpful’. Feedback on the manual was highly positive, and in the post study interviews some participants compared it favourably to standard technology manuals.

Support from researchers

Due to the technical and usability issues described above, all participants needed to contact researchers for technical support at some time during the study. Support was mainly provided over the phone and via email, often with a family member instead of the person with aphasia. Researchers noted that it was difficult to troubleshoot technology remotely, as the problem could not be seen. The onus was on the user to communicate the exact problem and its cause adequately, and this was very difficult for some people with aphasia. As a result, home visits were sometimes needed. Without support from researchers during the course of the study, many participants would not have been unable to complete it.

Support from spouses and others

Spouses were also a major source of support for many participants. For around half the participants, spouses attended the training session, helped the person with aphasia with the app, and were involved in troubleshooting. For some participants, particularly P5 and P12, participation in the study would have been impossible without spousal support. Also, a few participants mentioned asking adult children for help using the app. Two participants sought support from health professionals, P11 from her occupational therapist, and P1 from her home carers.

Design of the technology
Various features of the design of the iPhone and app appeared to be facilitators for some participants. Some participants relied on colour more than text. For example, P5 memorised the process of using the CommFit™ app as- ‘(tap) red, blue, then blue’. Although the touch screen was a barrier in some ways, participants found it useful that they could see the colour, icon and text of the selection each time. The one-to-one mapping of button with function was a facilitator, different from non-touchscreen technology where one button may have many functions. When asked about the design of the CommFit™ app, participants noted its simplicity as a facilitator. They also found the large buttons easy to tap, compared to the iPhone Settings where buttons were sometimes small and close together. One participant said of the app “This part is simple, easy. Tap this then this then this, Done.”.

5.4.2 Results from Usability Ratings Scales

Eight of the participants were able to complete ratings scales on the usability of the app. Some interstate participants (n=4) were unable to complete this independently. Results from the remaining eight participants are shown in Table 5-3. It is evident that the steps involving the headset (wearing the headset, pairing the headset) scored slightly lower than other steps with means of 3.1 and 3 out of a possible 4 respectively. Recharging the headset and phone scored a mean of 3.4/4. All other components had means above 3.5 and the mean for overall usability was 3.4/4.

Table 5-3: Results from usability ratings scale

<table>
<thead>
<tr>
<th></th>
<th>Wearing the headset</th>
<th>Turning on the iPhone</th>
<th>Pairing the headset</th>
<th>Starting CommFit</th>
<th>Stopping CommFit</th>
<th>Turning off the iPhone</th>
<th>Recharging</th>
<th>Overall</th>
</tr>
</thead>
<tbody>
<tr>
<td>P2</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>P3</td>
<td>3</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>P4</td>
<td>2.5</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>3.5</td>
<td></td>
</tr>
<tr>
<td>P5</td>
<td>3</td>
<td>4</td>
<td>2.5</td>
<td>3</td>
<td>2</td>
<td>4</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>P7</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>P9</td>
<td>2.5</td>
<td>4</td>
<td>2</td>
<td>4</td>
<td>3.5</td>
<td>3</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>P11</td>
<td>2</td>
<td>4</td>
<td>2.5</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>3</td>
<td>3.5</td>
</tr>
<tr>
<td>P12</td>
<td>4</td>
<td>2</td>
<td>1</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>3.1</td>
<td>3.8</td>
<td>3</td>
<td>3.9</td>
<td>3.7</td>
<td>3.9</td>
<td>3.4</td>
<td>3.4</td>
</tr>
</tbody>
</table>
The relationship of each section’s rating with age and aphasia severity (WAB-R Aphasia Quotient) was tested using Spearman correlations. There was a high negative correlation between rating of pairing the headset and age, which was statistically significant ($r = -0.8173$, $p = 0.01323$) (Hinkle, Wiersma & Jurs, 2003). This means that as the age of the participant increased, the usability rating decreased (i.e. the headset was rated as harder to use). There was also a moderate negative correlation between overall usability score and age, which approached significance ($r = -0.69183$, $p = 0.0573$), such that the older the participants were, the less likely they were to rate the overall usability of the CommFit™ system as easy to use. There were no statistically significant results when comparing usability ratings and aphasia severity.

5.5 Discussion

The aim of this study was to identify the barriers and facilitators to use of the CommFit™ system for people with aphasia. The study identified 10 broad barriers and four facilitators. Barriers were related to Body Functions and Structures, Environmental Factors and Personal Factors, while facilitators were Environmental Factors. The findings of this study are relevant to both the CommFit™ system (the iPhone, app and headset) specifically, and for the development and use of mobile technology for people with aphasia in general.

Impairments related to stroke were among the most frequently reported barriers to using the CommFit™ system. Interestingly, language difficulties did not overtly affect use of the technology itself, but rather the process of training and troubleshooting. Statistical analysis showed that aphasia severity (WAB AQ) was not related to the usability ratings of the participants in this small sample study. However, there were few participants with moderate to severe aphasia, and WAB scores were not sufficiently varied to make a definitive statement on this issue. Nevertheless, results did indicate that people with more severe aphasia in this limited sample were able to use mobile technology that was specifically designed for them, when appropriate aphasia-friendly support was available. The study also found that face-to-face interaction is essential to training and troubleshooting technology with participants with aphasia. Accordingly, studies on mobile technology which seek to include people with aphasia should allow for extra face-to-face training and troubleshooting sessions for these individuals. People with aphasia are at risk of being excluded from stroke research, as their inclusion is seen as too difficult, costly or time consuming (Brady, Frederick & Williams, 2013). This study demonstrates that language difficulties should not preclude people with aphasia from participating in technology studies, as language difficulties affected usability less than other factors such as age, physical impairments and familiarity with technology. There is some evidence that video chat applications like Skype can be used to reduce
the need for in-person visits (Kuwabara, Hayashi, Uesato, Umadome & Takenaka 2009) which may reduce the time and cost of utilising technology in aphasia rehabilitation.

Physical impairments related to stroke, especially hemiplegia, were a major barrier to the use of the CommFit™ system. This is consistent with the findings of many of the other studies (Holland et al., 2012; Kurland et al., 2014; McCall, 2012). However, while hemiplegia was a source of difficulty for participants in this study, and a factor in some participants discontinuing the study, some participants with hemiplegia completed the study with little difficulty. These participants found ways of working around their difficulty, such as anchoring devices and using one hand to push the chargers in, or getting assistance from friends, family and carers. Although individuals who have hemiplegia and hemiparesis may have more difficulty using mobile technology, this study showed that they are not precluded from use based on this impairment alone. While researchers and clinicians should recognize that presence of hemiplegia may cause difficulty using mobile technology, factors specific to the individual and the technological device will ultimately determine their ability to access it. Another reported physical barrier was fine motor impairment, particularly when using the touchscreen. Previous studies have identified learning to use the touchscreen, especially using the swiping motion, as a source of difficulty for people with aphasia (Ramsberger & Messamer, 2014; Routhier et al., 2014). However, it is to be noted that the touch screen was more a facilitator than a barrier in this study, as it allowed for large buttons, with supporting colour and text. Some authors have suggested the use of gaming apps to familiarise users with the tapping and swiping motions required for the touchscreen before introducing them to more complex use (Ramsberger & Messamer, 2014; Szabo & Dittelman, 2014). It is suggested that this idea is explored as part of the training program in future studies.

Other frequently reported barriers were related to technology itself. Unfortunately, the headset used in the study malfunctioned for a number of participants, and the cause of this was unable to be determined. In addition, unfamiliar messages or popups were a source of concern for users, as reported in other studies (Ramsberger & Messamer, 2014). Something as simple as a different name for the Bluetooth device or an iTunes reminder popup can confuse a participant and affect usability. Technology is not always stable or able to be controlled by the researchers, especially when using commercially available technology. However, researchers and clinicians should endeavour to be as familiar as possible with their technology to understand what unexpected functions might occur so that these issues can be anticipated and prevented where possible. For example, in this study the autolock function was disabled on the iPhones so that participants who took longer to operate the phone did not get unexpectedly locked out. Unfortunately, technology malfunction and unexpected functions are not entirely avoidable, but could be minimised by having
more technical expertise in the research team in future studies. The speech pathology researchers involved in the study were often ill-equipped to deal with complex technical issues (e.g. app modifications, coding bugs, complex troubleshooting). CommFit™ was initially developed by IT professionals, but no allowance was made to engage them in ongoing support during the research program, which proved to be problematic. Other studies have reported difficulty with technology malfunctions and the need for staff competent in technology use to support health researchers in such cases (Kurland et al., 2014; Szabo & Dittelman, 2014). This study also illustrated that there is a need to involve people who are competent in both technology and disability in this kind of research.

Facilitators to using the CommFit™ system included support from researchers, family and other health professionals and use of the manual. Need for support from researchers was noted by every participant in the study, and is commonly mentioned in other technology studies with people with aphasia (Kurland et al., 2014; Szabo & Dittelman, 2014). Support from family and friends is also a common theme in the literature, especially the need for training of caregivers (Holland et al., 2012; McCall, 2012; Szabo & Dittelman, 2014). Support from others was vital to the use of CommFit™ by people with aphasia in this study, and many participants would not have been able to complete, or even start, the study without it. This also has implications for the self-management of aphasia using mobile technology. The results of this study suggest that many individuals in this population cannot manage using mobile technology independently, and will need initial training and some form of ongoing support for effective use. Participants with aphasia also found use of the manual to be a facilitator to using CommFit™. Aphasia-friendly manuals have been used in some studies on technology use by people with aphasia to good effect (Greig, Harper, Hirst, Howe & Davidson, 2008; Elman, 2001); however, many studies on mobile technology do not report upon the written support given to participants. This study highlights the importance of providing an aphasia-friendly manual to people with aphasia using mobile technology. Furthermore, the results of this study will be used to develop a troubleshooting section for the CommFit™ manual, to reduce the amount of in-person support required for future research and use.

The results of this study have implications for the further development and use of the CommFit™ system, both in research and clinically. The majority of participants in the study (n=10) were able to learn to use the app independently within one hour-long session, similar to the training time reported by other studies (Kurland et al., 2014). The iPhone and app were rated as highly usable by participants with aphasia, and their design was observed to be a facilitator to use. The aphasia-friendly technology design of CommFit™ contributed to this, as participants commented on the use of colours, large buttons and overall simplicity of the app (Brandenburg et al., 2015;
Chapter 4). As Participant 11 stated ‘The app is a great resource, I think there needs to be more technology for us (people with aphasia) and I think this one was very easy to use’. The results of this study are promising for the use of the CommFit™ app in future research, and as a measure of talk time in people with aphasia.

However, the Bluetooth headset which was used with the app received low scores on the ratings scale and was the most frequent source of technology malfunction. The headset also seemed to be a source of difficulty for those with stroke-related physical impairments or who were unfamiliar with using technology. This was likely because the headset was not designed for accessibility with its small buttons which were complicated to operate. These issues are not specific to the Plantronics headset used in the study, as most commercial Bluetooth headsets are similar in design and operation. In the future, research into the use of CommFit™ will focus on a different, more usable input device to overcome this issue of headset usability.

The findings of the study also have implications for the use of mobile technology, especially apps, by people with aphasia. Results indicated that although most participants were able to learn to use the app independently (n=10), some participants struggled to learn to use the app. Two continued the study but were unable to use the app totally independently, relying on spouse or family support. Other studies have noted that some participants were never able to reach independence, even with increased training time and support (Kurland et al., 2014). It is suggested that people with aphasia should be given as much support as needed to use technology, but it should be acknowledged that independence is not possible for all, especially for those with severe physical, cognitive and language impairments. The results also demonstrate that the protocol for developing CommFit™ for people with aphasia was successful, as the app was rated as highly usable. This suggests that this protocol should be applied to other apps developed for stroke survivors (Brandenburg et al., 2015; Chapter 4). Moreover, in the interest of universal design, technology developers should endeavour to include these accessibility features in any mobile apps.

The barriers and facilitators noted in the study show that when designing and using technology with people with aphasia, more than their just their language difficulties, or even stroke-related impairments, must be taken into account. It was age that most related to ratings of usability. Researchers and clinicians should be prepared for technology malfunction and unexpected functions to impact upon usability, and be prepared to troubleshoot these issues in person. They should also take into account other barriers which may impact use, including time, inexperience with technology and other impairments of the individual, such as wearing glasses or hearing aids. In order to make mobile technology as usable as possible, people with aphasia should be provided with
aphasia-friendly manuals. They should also be given continual support from researchers and clinicians, and be encouraged to bring spouses and other support persons to training sessions. This study gave as much support as needed to participants, and the decision on whether to participate was ultimately left up to them. It remains unclear whether the participants who chose to exit the study would have been able to participate with more in-home support, and whether there is a level of support that is unreasonable to expect (e.g. spouse helping to put the headset on and take it off every day). It is likely that use of apps like CommFit™ will, by their nature, exclude some users, regardless of environmental supports.

5.5.1 Limitations

The results of this study are limited in that only the CommFit™ app and iPhone Settings were accessed on the iPhone. It is unclear how applicable some of the barriers and facilitators listed in the results are to other apps. Barriers related to the Bluetooth headset may also have been specific to the Plantronics Voyager Pro+ headset.

The sample of participants was also limited. For example, no individuals with fluent type aphasias were included in the study, as they were excluded from the larger talk time study in which the usability results were collected (Brandenburg, Worrall, Rodriguez & Copland, 2015; Chapter 6). It is anticipated that training and troubleshooting may have been more difficult for participants with fluent aphasia due to comprehension deficits. Secondly, the majority of people included in the study had prior experience with mobile technology and had mild aphasia (n=8). Participants self-selected for the study, so it is not surprising that people who were more confident in their ability to complete the study volunteered. It is possible that independent use of mobile technology would be more difficult for people with little experience and more severe aphasia, as it was for P12, whose spouse completed most study-related tasks for him. Future studies into technology should endeavour to recruit people with little experience with technology and more severe aphasia.

It is also noted that this study was a part of a larger study investigating talk time. Thus, participants were given as much assistance as possible to complete the two-week study using the app. As a result, true independence using the CommFit™ system was unable to be determined. Finally, no formal assessments of cognitive or motor deficits were administered. However, motor deficits in particular were found to be a barrier to use of the technology, especially hemiparesis. It would be useful to formally assess the fine motor and motor control skills of individuals with aphasia to determine the contribution of these to difficulties using CommFit™. It would also be useful to gain a picture of how deficits in cognitive skills such as sequencing, problem solving and
executive functioning alone impact the use of apps like CommFit™. This indicates a need to investigate the use of CommFit™ in a stroke population who do not have aphasia.

5.6 Conclusion

It is clear from the results that the CommFit™ app and iPhone are appropriate for use by people with aphasia, regardless of their other impairments or experience with mobile technology. However, the BlueTooth headset was problematic, both due to technical malfunction and motor impairments. Future studies into CommFit™ will investigate the use of other input devices. Additionally, the results of this study were a positive indication that people with aphasia are able to use mobile technology in their everyday life; however, the level of success is highly individualised. Some older people with more severe language, cognitive and physical difficulties may need more support when using mobile technology. The use of mobile technology by people with aphasia should be further explored, as it has the potential to promote self-management, home practice and life participation for this population.
5.7 References


Pew Research Center, 2014


Chapter 6: An Exploratory Investigation of the Daily Talk Time of People with Aphasia: Comparison to Non-aphasic Peers and ICF Domains

Chapter 5 described the results of the Phase II study which pertained to usability of CommFit™ by people with aphasia. This chapter describes the talk time results of this study, including both participants with aphasia and non-aphasic controls. It is an exploratory investigation into talk time as a measure and potential indicator of participation. This chapter represents the crux of the doctoral research and investigates a number of factors, including mean talk time per hour, differences between the talk time of people with and without aphasia, correlations with measures of ICF domains and the variability of talk time across weeks and days of the week.

This chapter is in preparation for publication. The content included in this chapter is identical to the submitted manuscript; however, the formatting has been modified to match the style of this thesis. Thus tables, figures, headings, references and the abstract may have been altered from the published version to adhere to American Psychological Association stylistic guidelines, 6th edition.
6.1 Abstract

*Aims*: This paper presents an exploratory investigation of the talk time of people with aphasia. Aims were to compare the talk time of people with aphasia with non-aphasic peers; with measures of impairment, activity, and participation; and investigate the variability of talk time over weeks and days of the week.

*Methods and Procedures*: Twelve people with post-stroke aphasia and seven non-aphasic controls measured their talk time using the CommFit™ app for six hours a day for 14 days.

*Outcomes and Results*: People with aphasia talked for a mean of 4.5 min/hr and non-aphasic controls 7.2 min/hr, which was not a significant difference (p= 0.056). Talk time of people with aphasia was not significantly correlated with WAB-R AQ or CADL-2 scores, but a moderate-high positive relationships between talk time and SIPSO scores was found (r= .648, p= 0.015). Talk time was not significantly different between the first and second weeks of recording for either group, and days of the week were not significantly different except for Saturdays, in which talk time was higher.

*Conclusions*: This study provides some preliminary data on talk time in people with aphasia. Results suggest that talk time is an indicator of participation restriction, but not impairment or activity limitation for this population.
6.2 Introduction

Since the publication of the International Classification of Functioning, Disability and Health (ICF) by the World Health Organization in 2001 (WHO, 2001), rehabilitation services have increasingly focused on the impact of a health condition on all facets of a person's life. For speech-language pathologists working with people with aphasia, participation has been identified as a key goal from the perspective of their clientele (Worrall, Sherratt, Rogers, Howe, Hersh, Ferguson & Davidson, 2010). However, the measurement of participation has not received significant focus in current practice in aphasia rehabilitation (Kagan et al., 2008). This research investigates the use of daily talk time as a performance-based indicator of participation for people with aphasia, intended as a novel adjunct to traditional pen and paper self-report assessment.

The ICF envisages functioning and disability as an interaction between health conditions and contextual factors. It includes the three domains of Body Functions and Structures, Activities and Participation, Environmental and Personal Factors. In the framework, Activities and Participation are defined as separate constructs - activity as 'the execution of a task or action by an individual' and participation as 'involvement in a life situation'. However, the constructs are combined into the same domain under the joint heading Activities and Participation and occupy the same set of codes (e.g. d6200-shopping, d920-recreation; WHO, 2001). This lack of differentiation has been noted in the literature, and controversy exists over what constitutes participation versus activity (Dijkers, 2010). For the purposes of this study, participation will be defined as the fulfilment of valued life roles, with activities being components of those life roles (Whiteneck & Dijkers, 2009). Thus, participation includes roles such as being a carer, engaging in work life, family relationships, recreation, religion/spirituality and care of the home (Brandenburg, Worrall, Rodriguez & Bagraith, 2014; Chapter 2). Activity, on the other hand, includes specific actions that might form part of these roles, like catching a bus, having a conversation and washing dishes. It has been noted that there is a need for more focus on the participation domain in speech-language pathology, coinciding with a change in the therapist’s perceived role in rehabilitation (Worrall & Hickson, 2008). As social approaches such as the Life Participation Approach to Aphasia (LPAA; Chapey et al., 2000) rise in popularity, the need for appropriate measurement of participatory outcomes comes into focus.

Participation is currently primarily assessed using self-report measures, which usually focus on concepts like satisfaction and restriction. These assessments are often classed as ‘functional communication’, and include a mix of content from different ICF domains, particularly participation, activity, environmental factors and quality of life (Brandenburg et al., 2014; Chapter 2).
In addition, cognitive and language impairments, such as those present after stroke, can be a barrier to experiential self-reporting, especially for people with severe aphasia (Davidson & Worrall, 2000, p. 39). This often results in the need to use proxy reporting by relatives or therapists, which can be inaccurate when reporting on subjective experience (Sprangers & Aaronson, 1992). These factors lead to assessment of participation restriction often being overlooked or combined with other concepts under the banner of functional communication (Vogel, Maruff & Morgan, 2010). Assessment of patient experience is an important parameter to measure, especially in terms of satisfaction with participatory outcomes, in order for speech-language pathologists to gauge restriction, plan therapy and measure outcomes. However, this kind of assessment does not allow for easy comparison of actual performance in life roles between people or groups. Measurement of the self-reported experience of participation would benefit from being supplemented by performance-based measurement—i.e. logging of an individual’s actual behaviours, and comparing to subjective experience.

Some instruments have attempted to add rigour to self-report measures by asking the participant to describe the frequency which they participate in various life roles (Code, 2003; Cruice, Worrall & Hickson, 2006). This approach is reliant on the person's recall and interpretation of their own behaviour which may not be reliable given cognitive impairments associated with stroke. Code (2003) investigated the quantity of social activity of 38 people with chronic aphasia using the Social Networks with Aphasia Profile (SNAP). This measure was a diary-based self-report method that required the user to record hours spent out of the house (Code, 2003). Results showed that the individuals with aphasia spent an average of 20 hours out of the house per week, however this varied considerably from person to person (1.5–60 hours). The concept of hours spent out of the house was also related to a number of variables using multiple regression, and severity of aphasia accounted for the most variance (Code, 2003). Notably, age also had a significant impact, while gender had no impact on hours spent out of the house. Although the SNAP had no reliability or validity data, Code argued that no other objective measure was available at the time. It is also noted that the SNAP does not account for participation and socialisation in the home, which is important especially for those with mobility issues. Code also suggested that future research on the quantity of social activity of people with aphasia should include a comparison to healthy controls.

In another study, Cruice, Worrall and Hickson (2006) developed the Social Activities Checklist (SOCACT) to quantify the social lives of people with aphasia, and found that people with aphasia participated in less social activities than their peers. This study also found that over half the participants with aphasia wanted to be doing more social activities, regardless of how many they were currently engaging in (Cruice et al., 2006). These kinds of quantitative self-report measures
provide important information about the social lives of people with aphasia; however, additional information could be gained by the use of more performance-based measures.

In response to the need for performance-based measures of participation, we developed CommFit™, an iPhone application that records talking time (Brandenburg, Worrall, Power, Copland & Rodriguez, 2015; Chapter 4). Talk time is intended to be a gross indicator, rather than a direct measure, of participation. The idea for this measure was based on the use of steps logged by a pedometer as a gross indicator of the underlying construct of physical fitness. Similarly, talk time as measured by CommFit™ may be an indicator of communicative fitness (i.e., participation). In both cases, the indicator is not perfect. Physical activity recorded by a pedometer does not include other exercise such as swimming or lifting weights. Similarly, talk time does not include other forms of communication like writing and reading. Additionally, these measures do not provide an indication of difficulty or quality; some forms of steps are more difficult, such as going up stairs, just as some forms of communication are harder, such as having an in depth discussion versus making a statement. However, pedometers have remained an enduringly useful and popular indicator of fitness, with new generation pedometers being built to interface with smart devices (e.g. FitBit®) (Bravata et al., 2007). The popularity of the pedometer seems to be due to its all day monitoring, ease of use, and form of biofeedback that is easy for the average user to interpret (Bravata et al., 2007). CommFit™ was designed to capitalise on these features. It should be noted that talk time as a measure of participation quantity should be considered along with measures of talk quality and satisfaction with participation when considering individual outcomes.

6.2.1 Aims

The overarching aim of this study was to explore the use of talk time as an indicator of participation for people with aphasia. Talk time was expected to correlate most strongly with participatory outcomes. Communication is central to many life roles, such as work, relationships, recreation and education. It was hypothesized that people who are more actively participating in these life roles would have a higher talk time than those who do not. However, there was a possibility talk time could correlate with impairment and activity limitations, as these ICF concepts are all interrelated and could conceivably influence talking (Ma, Threats & Worrall, 2008). Accordingly, the study’s first aim was to explore whether the talk time of people with aphasia is correlated with measures across the three ICF domains- Body Functions and Structures, Activity and Participation. The second aim was to compare the talk time of people with aphasia to a non-aphasic control group of the same age, to determine whether people with aphasia talked less than those without. Due to the communication difficulties and social isolation frequently experienced by people with aphasia, it
was expected that they would have a lower talk time than their peers. The final aim of this study was to investigate how talk time varies across weeks and days of the week (e.g. Monday, Tuesday) to determine whether a full two weeks of monitoring is required for a representative sample. This study used a cross-sectional design, assessing impairment, activity limitation and participation restriction of the person with aphasia at one point in time, and comparing it to their mean talk time.

6.3 Methods

6.3.1 Participants

Participants with chronic aphasia were targeted and recruitment sources included the Communication Research Registry (www.crregistry.org.au) and community contacts. Inclusion criteria for people with aphasia were that they had been diagnosed with aphasia following a stroke and had the ability to use the CommFit™ app at home either independently or with assistance. Their ability to use the app with or without assistance at home was determined in the first session. Exclusionary criteria were diagnosis of fluent aphasia, bilateral hearing aids and any other major sensory, motor or cognitive impairment that would affect using the app. Participants without aphasia were recruited through the Ageing Mind Initiative 50+ Registry (www.uq.edu.au/ami/50-plus-registry) and community contacts. Healthy individuals were eligible for participation if they were community dwelling and had no history of language difficulties, stroke or major disability. By using the 50+ registry, older adults were targeted, as people who experience a stroke tend to be in this age group, however no other attempt was made to recruit by age. A total of 18 people with aphasia and eight non-aphasic adults consented to take part in the study. Seven people dropped out, three due to health issues, two because of the time demands of the study, and two due to a combination of difficulty using the device (both only had use of one hand), time constraints and other health issues that made it difficult to complete the study. All participants were informed of the time commitment involved in the study but ran into issues after consenting that forced them to withdraw.

Twelve people with aphasia and seven non-aphasic controls (n= 19) completed the study. Half of the participants with aphasia completed the study in Brisbane (n=6), where the researchers were located, and half (n=6) completed the research interstate in Melbourne or Sydney. All control participants were located in Brisbane. Participants with aphasia ranged in age, time post onset, aphasia severity and experience using technology, from people who had never used anything beyond a basic mobile phone, to people who used iPhone and iPads for their daily communication. Table 6-1 shows the demographics for this group, who were seven males and five females with aphasia, with a range of ages and time post stroke.
Table 6-1: Characteristics of participants with aphasia

<table>
<thead>
<tr>
<th>Participant</th>
<th>Gender</th>
<th>Age</th>
<th>TPO*</th>
<th>Hemiplegia</th>
<th>Experience with Technology</th>
</tr>
</thead>
<tbody>
<tr>
<td>PA1</td>
<td>F</td>
<td>32</td>
<td>4y 3m</td>
<td>Y</td>
<td>E</td>
</tr>
<tr>
<td>PA2</td>
<td>M</td>
<td>42</td>
<td>2y 2m</td>
<td>N</td>
<td>E</td>
</tr>
<tr>
<td>PA3</td>
<td>F</td>
<td>47</td>
<td>1y 1m</td>
<td>Y</td>
<td>E</td>
</tr>
<tr>
<td>PA4</td>
<td>F</td>
<td>50</td>
<td>3y 5m</td>
<td>Y</td>
<td>E</td>
</tr>
<tr>
<td>PA5</td>
<td>M</td>
<td>53</td>
<td>2y 3m</td>
<td>Y</td>
<td>E</td>
</tr>
<tr>
<td>PA6</td>
<td>F</td>
<td>56</td>
<td>1y 9m</td>
<td>Y</td>
<td>E</td>
</tr>
<tr>
<td>PA7</td>
<td>M</td>
<td>59</td>
<td>3y</td>
<td>N</td>
<td>E</td>
</tr>
<tr>
<td>PA8</td>
<td>M</td>
<td>62</td>
<td>1y 1m</td>
<td>Y</td>
<td>E</td>
</tr>
<tr>
<td>PA9</td>
<td>M</td>
<td>63</td>
<td>7y 5m</td>
<td>N</td>
<td>M</td>
</tr>
<tr>
<td>PA10</td>
<td>M</td>
<td>69</td>
<td>5y 11m</td>
<td>Y</td>
<td>M</td>
</tr>
<tr>
<td>PA11</td>
<td>F</td>
<td>70</td>
<td>2y 5m</td>
<td>N</td>
<td>M</td>
</tr>
<tr>
<td>PA12</td>
<td>M</td>
<td>71</td>
<td>3y 5m</td>
<td>Y</td>
<td>M</td>
</tr>
</tbody>
</table>

Mean: 56.2  Standard Deviation: 11.5  Range: 32-71

*Time post onset; PA= Participant with aphasia; M=Minimal mobile technology experience; E=Experienced with mobile technology

Table 6-2: Characteristics of participants without aphasia

<table>
<thead>
<tr>
<th>Participant</th>
<th>Gender</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>HP1</td>
<td>M</td>
<td>28</td>
</tr>
<tr>
<td>HP2</td>
<td>F</td>
<td>37</td>
</tr>
<tr>
<td>HP3</td>
<td>F</td>
<td>60</td>
</tr>
<tr>
<td>HP4</td>
<td>M</td>
<td>67</td>
</tr>
<tr>
<td>HP5</td>
<td>F</td>
<td>69</td>
</tr>
<tr>
<td>HP6</td>
<td>F</td>
<td>73</td>
</tr>
<tr>
<td>HP7</td>
<td>M</td>
<td>84</td>
</tr>
</tbody>
</table>

Mean: 59.7  Standard Deviation: 18.6  Range: 28-84

HP= Healthy participant

Table 6-2 shows the demographics for people without aphasia. The control group consisted of three males and four females, with a range of ages from 28 to 84 years. Control participants were not asked about technology experience. Participants were not matched by gender, as previous studies indicate that gender does not significantly influence words spoken per day and hours spent in communication (Code, 2003; Mehl, Vazire, Ramírez-Esparza, Slatcher & Pennebaker, 2007). No statistically significant difference in age was found between participants with aphasia and controls using a 2-sample t-test (p= 0.62).
6.3.2 Assessments

The purpose of assessment was to gauge aphasia severity and determine level of functioning in each domain of the ICF. Participants with aphasia were assessed using the Western Aphasia Battery-Revised (WAB-R; Kertesz, 2007) for impairment, the Communication Activities of Daily Living (CADL-2; Holland, Frattali & Fromm, 1999) for activity limitation and the Subjective Index of Participation and Social Outcome (SIPSO; Kersten, George, Low, Ashburn & McLellan, 2004) for participation restriction.

The WAB-R was chosen to assess the individual’s spoken language, repetition and comprehension of spoken language, as well as give an overall indicator of aphasia severity in the form of the Aphasia Quotient. The WAB-R is an accepted standard for assessment of impairment (Hula, Donovan, Kendall & Gonzalez-Rothi, 2010) and has been used extensively to measure severity of language impairment in people with aphasia (Kertesz, 2007). The test has shown good validity, internal consistency (.91), test retest reliability (.90) and inter-rater reliability (.97) (Kertesz, 2007). No attempt was made to assess written language, as spoken language was considered to be more pertinent to the measurement of talking time.

Assessment of activity may be achieved through direct observation, simulation of real-life activities in a clinical situation or self-report (Davidson & Worrall, 2000). As the focus of this study was everyday communication in real-life scenarios, the performance-based CADL-2 was selected as the measure of activity limitation (Holland, Frattali & Fromm, 1999). Other measures that could have been utilized include self- and proxy-rated instruments such as the ASHA Functional Assessment of Communication Skills or Communication Effectiveness Index. However, the CADL-2 asks participants to demonstrate communication activities they might encounter in their everyday lives, such as going to the shops, visiting a doctor and driving. It is suitable for use with most people with aphasia, as it allows nonverbal responses. This instrument also has proven reliability with adults with neurogenic communication disorders, with an internal consistency coefficient of .93, test-retest reliability at .89 and inter-rater reliability at .99 (Holland et al., 1999). Concurrent, construct and content validity has also been demonstrated for the aphasic population (Holland et al., 1999).

Participation restriction was measured using the SIPSO, a measure of social integration for stroke survivors (Trigg & Wood, 2000). Construct validity, internal reliability and test-retest reliability has been demonstrated for this instrument with the younger stroke population (Kersten et al., 2004). The instrument was designed to be concise, and its short duration and question format means that it is appropriate for self-report by people with mild-moderate aphasia. The questions
were also adapted with a visual analogue scale from 0-4 for this study, with 4 indicating more participation. The majority of items in the SIPSO have also been linked to the ICF concept of participation in a review and crosswalk of participation measures (Brandenburg et al., 2014; Chapter 2). The SIPSO covers ICF categories of d3-communication, d460-moving around in different locations, d4600-moving around within the home, d5-self-care, d540-dressing, d6-domestic life, d6200-shopping, d7-interpersonal relationships, d920-recreation and d9205-socialising (Brandenburg et al., 2014; Trigg & Wood, 2000). Talk time is expected to be more closely linked with the social aspects of participation like communication, relationships and socialising, than with general life roles like moving around and domestic life. In order to investigate the relationship with the more social aspects of participation, items 7 (Since your stroke, how would you describe the amount of communication between you and your friends/associates?), 8 (Since your stroke, how would you describe the amount of communication between you and your friends/associates?) and 9 (Since your stroke, how often do you visit friends/others?) were totalled for separate analysis (Trigg & Wood, 2000).

6.3.3 Equipment

CommFit™ was developed to be aphasia-friendly and easy to use based on guidelines for mobile technology for people with aphasia (Brandenburg, Worrall, Rodriguez & Copland, 2015; Chapter 4). The app has been demonstrated to measure talk time within ±4% of actual talk time in silent environments and 13% in everyday environments (Brandenburg et al., 2015; Chapter 4). Participants used the CommFit™ app with an iPhone 4 and a Plantronics Voyager Pro+ Bluetooth headset (Figure 6-1), with the exception of one participant who was given an over-the-head headset to accommodate fine motor impairments. The iPhones were dedicated for use within the study to ensure accurate and continuous timing and not be interrupted by calls or other apps.

Figure 6-1: iPhone 4 (left) and Plantronics Voyager Pro+ Bluetooth headset
6.3.4 Data Collection

Participants were taught to use CommFit™ by going through the steps in the manual with the researcher. They were then required to demonstrate that they could use the app independently, and a single researcher (CB) rated each step from ‘completely independent’ to ‘was done for them’. If participants were unsuccessful, they were shown again and required to demonstrate a second time to continue in the study. All participants both with and without aphasia were successful in learning to use the app, although people with aphasia usually required more assistance. They were then asked to use CommFit™ to track their talking time for six hours a day for 14 days while going about their everyday lives. This time period of two weeks was chosen so that each day, and a greater variety of potential talking opportunities, was sampled twice, and because previous studies looking at everyday behaviours suggested 10-12 days of data collection for stable and meaningful data (Epstein, 1979). Participants selected the six-hour period at random and were asked not to change their behaviour in any way for the study, other than to avoid recording in loud environments and avoid getting the headset wet. The six hours did not need to be continuous, and the days did not need to be consecutive. Talk time data were sent via internet connection to the CommFit™ website (www.commfit.org.au). Data were also collected on the usability of CommFit™ by people with aphasia using ratings scales and interviews. Usability data will be reported separately (Brandenburg, Worrall, Rodriguez & Copland, under review; Chapter 5).

6.4 Results

6.4.1 Assessment and Talk Time Results of People with Aphasia

Talk times and results on the WAB-R, CADL-2 and SIPSO for participants with aphasia are shown in Table 6-3. WAB-R scores ranged from 24.4 to 95.3 out of 100, with a mean of 78.1/100 (SD=19.1). One participant (PA1) had a WAB-R aphasia quotient of above 93.8, which is used as the cut off for determining aphasic vs unimpaired language functioning (Kertesz, 2007). However, a qualified speech-language pathologist confirmed that this participant was still aphasic due to the presence of errors and word-finding difficulties in conversation, as well as errors in the spontaneous speech and comprehension sections of the WAB-R. This participant was also still receiving speech therapy for her language deficits.

CADL-2 scores ranged from 23 to 99 out of 100 with an average of 88/100 (SD= 20.8). SIPSO scores ranged from 15 to 37 out of 40, with a mean of 25.1 (SD= 6.6). The total scores on items 7, 8 and 9 of the SIPSO ranged from 3 to 9 out of 12, with a mean of 5.4 (SD= 2.3). The range
of talk times was from 1.9 to 12.4 minutes per hour, with a mean of 4.5 min/hr ($SD = 2.8$; 95% CI, 2.6 to 6.3).

**Table 6-3: Results for people with aphasia**

<table>
<thead>
<tr>
<th>Participant</th>
<th>Aphasia Severity</th>
<th>WAB-R Aphasia Quotient</th>
<th>CADL-2 Percentile</th>
<th>SIPSO Score</th>
<th>SIPSO score items 7, 8 &amp; 9</th>
<th>Average Talk Time (min/hr)</th>
</tr>
</thead>
<tbody>
<tr>
<td>PA1</td>
<td>Mild</td>
<td>95.3</td>
<td>96</td>
<td>15</td>
<td>3</td>
<td>2.1</td>
</tr>
<tr>
<td>PA2</td>
<td>Mild</td>
<td>79.5</td>
<td>95</td>
<td>37</td>
<td>9</td>
<td>6.9</td>
</tr>
<tr>
<td>PA3</td>
<td>Mild</td>
<td>85</td>
<td>99</td>
<td>33</td>
<td>7</td>
<td>4</td>
</tr>
<tr>
<td>PA4</td>
<td>Mild</td>
<td>94.4</td>
<td>99</td>
<td>23</td>
<td>4</td>
<td>1.3</td>
</tr>
<tr>
<td>PA5</td>
<td>Moderate</td>
<td>63.5</td>
<td>72</td>
<td>19</td>
<td>3.5</td>
<td>3.3</td>
</tr>
<tr>
<td>PA6</td>
<td>Moderate</td>
<td>65.7</td>
<td>96</td>
<td>25</td>
<td>3</td>
<td>4.4</td>
</tr>
<tr>
<td>PA7</td>
<td>Moderate</td>
<td>75.9</td>
<td>95</td>
<td>25.5</td>
<td>6</td>
<td>2.8</td>
</tr>
<tr>
<td>PA8</td>
<td>Mild</td>
<td>85.2</td>
<td>98</td>
<td>20</td>
<td>3</td>
<td>12.4</td>
</tr>
<tr>
<td>PA9</td>
<td>Mild</td>
<td>92.2</td>
<td>96</td>
<td>33</td>
<td>9</td>
<td>5.5</td>
</tr>
<tr>
<td>PA10</td>
<td>Mild</td>
<td>83.9</td>
<td>94</td>
<td>31</td>
<td>8.5</td>
<td>4.8</td>
</tr>
<tr>
<td>PA11</td>
<td>Mild</td>
<td>92.7</td>
<td>93</td>
<td>19</td>
<td>5</td>
<td>4.1</td>
</tr>
<tr>
<td>PA12</td>
<td>Very Severe</td>
<td>24.4</td>
<td>23</td>
<td>21</td>
<td>4</td>
<td>1.9</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>WAB-R Aphasia Quotient</td>
<td>78.1</td>
<td>19.1</td>
<td>24.4-95.3</td>
</tr>
<tr>
<td>CADL-2 Percentile</td>
<td>88</td>
<td>20.8</td>
<td>23-99</td>
</tr>
<tr>
<td>SIPSO Score</td>
<td>25.1</td>
<td>6.6</td>
<td>15-37</td>
</tr>
<tr>
<td>SIPSO score items 7, 8 &amp; 9</td>
<td>5.4</td>
<td>2.3</td>
<td>3-9</td>
</tr>
<tr>
<td>Average Talk Time (min/hr)</td>
<td>4.5</td>
<td>2.8</td>
<td>1.9-12.4</td>
</tr>
</tbody>
</table>

PA= Participant with aphasia; WAB-R= Western Aphasia Battery Revised; CADL-2= Communicative Activities of Daily Living-2; SIPSO= Subjective Index of Physical and Social Outcome

When graphing the talk time results for the aphasic group as a box plot (Figure 6-2) one clear outlier was evident. This was PA8, who spoke on average 12.4 min/hr, far higher than the next highest talk time at 6.9 minutes, and more than 2.5 standard deviations above the mean, confirming him as an outlier (Miller, 1991). When transferring this participant’s data, there was technical difficulty due to an app update. That is, the app failed to send the data correctly to the website and data needed to be extracted directly by IT support. In addition to this, the participant was living in a house where construction was taking place for some of the study period, and it is possible that this interfered with the accuracy of talk time recorded by the app. Participants were asked to avoid excessively noisy environments as CommFit™ has shown reduced accuracy in such environments, and it is likely that the high talk time of this individual is attributable to measurement inaccuracy (Brandenburg et al., 2015; Chapter 4). This participant’s high talk time could not be attributed to either of these factors with certainty, so the following results will be reported both with and without this outlier. The mean talk time of people with aphasia without PA8 was 3.7 min/hr ($SD = 1.6$).
6.4.2 Correlations Between Assessments and Talk Time of People with Aphasia

The relationship between assessments of each ICF domain and talk time was examined. Figures 6-3 and 6-4 show the scatter plots of WAB-R and CADL-2 scores against talk time. As can be seen in these plots, there is no clear visual relationship between the WAB-R and CADL-2 scores and talk time. However, SIPSO total score and score for the social/communication-related items 7, 8 and 9 plotted against talk time show a positive correlation in Figures 6-5 and 6-6, with a higher talk time correlating with a higher SIPSO score. In these plots, the outlier (PA8) can be clearly identified.
Figure 6-3: Talk time vs WAB-R scatter plot

Figure 6-4: Talk time vs CADL-2 scatter plot

Figure 6-5: Talk time vs SIPSO scatter plot

Figure 6-6: Talk time vs SIPSO items 7-9 scatter plot
These relationships were tested using one-sided Spearman correlations, as shown in Table 6-4. The relationship between the WAB-R aphasia quotient and talk time was not significant with or without the outlier. Analysis of WAB-R scores divided into Spontaneous Speech, Auditory Verbal Comprehension, Repetition and Naming/Word Finding scores also did not reach significance, indicating that level of impairment in any of these areas was not correlated with talking time. Similarly, the relationship between CADL-2 percentile rank and talk time did not reach significance with or without the outlier. These results indicate that there was no relationship between talk time and level of impairment or activity limitation in this cohort.

SIPSO score and talk time showed a stronger but still not significant positive correlation. When this test was repeated without the outlier (PA8) the positive correlation between talk time and SIPSO score became significant at the 0.05 level. These results indicate that participation restriction and talking time were correlated, with a higher SIPSO score (less restriction) predicting a higher mean talk time. The correlation coefficient for this relationship indicates a moderate to high positive correlation (Hinkle, Wiersma & Jurs, 2003).

Table 6-4: Spearman correlations between talk time and each assessment

<table>
<thead>
<tr>
<th></th>
<th>WAB-R</th>
<th>CADL-2</th>
<th>SIPSO</th>
<th>SIPSO 7-9</th>
</tr>
</thead>
<tbody>
<tr>
<td>Talk time</td>
<td>p value</td>
<td>0.491</td>
<td>0.388</td>
<td>0.090</td>
</tr>
<tr>
<td></td>
<td>r</td>
<td>-0.007</td>
<td>0.092</td>
<td>0.414</td>
</tr>
<tr>
<td>Talk time without</td>
<td>p value</td>
<td>0.426</td>
<td>0.468</td>
<td>0.015*</td>
</tr>
<tr>
<td>outlier (PA8)</td>
<td>r</td>
<td>-0.064</td>
<td>-0.028</td>
<td>0.648</td>
</tr>
</tbody>
</table>

*p<0.05

Relationships between each assessment for all 12 participants were also analysed using Spearman correlations. One of these relationships was significant, with a moderate positive correlation between the WAB-R and the CADL-2, r(10)= 0.569, p= 0.027. This indicates that high WAB-R (impairment) scores were associated with high CADL-2 (activity limitation) scores, and vice versa. There was no significant correlation between the SIPSO and either of the two other assessments.

6.4.3 Talk time of People with Aphasia Compared with Non-aphasic Controls

The talk time of participants with aphasia was also compared with talk time for non-aphasic controls. Table 6-5 shows the talk time results for controls. Talk time ranged from 1.6 to 12.9 with a mean of 7.2 (SD= 3.7, 95% CI, 3.5 to 10.9). A Mann Whitney test showed that the mean talk times
of the two groups were not significantly different but approached significance without the outlier (with outlier $p=0.118$; without outlier $p=0.056$).

Table 6-5: Results for non-aphasic controls

<table>
<thead>
<tr>
<th>Participant</th>
<th>Talk Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>HP1</td>
<td>7.8</td>
</tr>
<tr>
<td>HP2</td>
<td>5.6</td>
</tr>
<tr>
<td>HP3</td>
<td>3.3</td>
</tr>
<tr>
<td>HP4</td>
<td>9.4</td>
</tr>
<tr>
<td>HP5</td>
<td>9.8</td>
</tr>
<tr>
<td>HP6</td>
<td>12.9</td>
</tr>
<tr>
<td>HP7</td>
<td>1.6</td>
</tr>
<tr>
<td><strong>Mean</strong></td>
<td><strong>7.2</strong></td>
</tr>
<tr>
<td><strong>SD</strong></td>
<td><strong>3.7</strong></td>
</tr>
</tbody>
</table>

6.4.4 Variations in Mean Talk Time Over Days/Weeks

The study also looked at the pattern and variation of talk time over the two weeks. A paired-samples t-test showed that the first and second week’s average talk time was not statistically significant for either people with aphasia, $t(11)=0.82$, $p=0.440$, or non-aphasic participants, $t(6)=0.28$, $p=0.827$. Figure 6-7 shows a graph of mean talk time per hour for each day of the week for both groups of participants. Graphing the data showed little visual variation across days, except for Saturday which had a higher mean talk time per hour. A one-way between-subjects ANOVA showed a statistically significant difference between days of the week, $F(6,161)=3.91$, $p=0.001$. Post hoc comparisons using the Tukey HSD test indicated that the mean score for Saturdays was significantly different to every other day of the week at the 0.05 level.
Despite these results, researchers observed considerable variation in talk times between weeks and weekdays for some participants. The mean talk times for each day for PA2 are graphed in Figure 6-8 as an example of this variability. The mean talk time per hour for this participant in the first week was 1.5 min/hr, and in the second week was 4.2 min/hr. The graph also shows that although PA2 had similar scores for some days of the week (e.g. Wednesday and Thursday), other days were different (e.g. Monday and Tuesday). This demonstrates that while the difference between weeks was not significant across all participants, for some individual participants considerable variability could be observed.
6.5 Discussion

The aims for this study were to investigate the relationship between talk time and measures of impairment, activity limitation and participation restriction, and to compare the talk time of people with aphasia to non-aphasic controls. Results indicated that there was a moderate to high positive correlation between the participation domain as measured by SIPSO score and talk time. However, there was no significant correlation between talk time and WAB-R score, a measure of language impairment, and CADL-2 score, a measure of communicative activity.

6.5.1 Relationships Between Talk Time and Each Assessment

Talk time did not significantly correlate with the WAB-R aphasia quotient, a widely used measure of impairment and aphasia severity. Indeed, none of the subscores of the WAB-R correlated with talk time, including the verbal language components of Spontaneous Speech and Naming/Word Finding which might be expected to be more related to talk time. However, the study only included one participant with very severe aphasia, with all other participants having a mild or moderate aphasia. People with very severe aphasia often have limited vocabulary and grammatical structures, and need to supplement speech with nonverbal methods of communicating like gesture and drawing (Darrigrand et al., 2011; Papathanasiou, Coppens & Potagas, 2013). Thus, it is possible that if more people with severe aphasia were included in the study and a broader range of performance within
the group, there may have been a stronger correlation between WAB-R scores and talk time. However, it is suggested that language impairment, while a contributor to participation restriction, is just one of many strengths and weaknesses across the ICF which combine to create functioning in this domain.

Our results indicate that the measure of activity limitation, the CADL-2, was not related to talk time. The activity domain can be interpreted to be the components of participation, for example washing dishes and watering plants as activities which contribute to the participation concept of domestic life (Brandenburg, Worrall, Rodriguez & Bagraith, 2014; Chapter 2). In this interpretation, activity limitation might be expected to correlate with talk time, although less so than participation. However, people with aphasia were able to use gesture, writing, pointing and contextual information as well as speech to get their point across, without affecting scoring of the CADL-2. Scores above the 90th percentile were common for most participants (n=10), as expressive language deficits were able to be circumvented with nonverbal communication. This meant that the range of scores was narrow, limiting the interpretability of these results. Future research could investigate the relationship of talk time with other types of communicative activity assessment, possibly including those more sensitive to verbal deficits such as conversational and discourse analysis (Armstrong, Ferguson & Simmons-Mackie, 2013).

As hypothesized, there was a moderate to high positive correlation between the participation domain as measured by SIPSO score and talk time. This was the hypothesized result, as talk time is inherent in most life roles and participatory concepts like maintaining relationships, work, recreation and domestic life. Moreover, the SIPSO is a self-report measure which contains satisfaction questions, and this provides some evidence that quantitative performance and qualitative experiences of participation may be linked. The results also showed that the correlation between talk time and the entire SIPSO, and talk time and the items related to communication, relationships and socialising were similar. This indicates that talk time could be an indicator of both communication-related and general participation. However, this relationship should be interpreted with caution, given that the SIPSO is not an all-inclusive measure of participation and has not been validated with people with aphasia. Future research could investigate whether the correlation is stronger when compared to assessments focused on different aspects of participation, for example communicative and social participation. However, as an exploratory study, these results indicate that talk time has the potential to be used as an indicator of overall participation for people with aphasia.
Our results provide some indication of how ICF domains and talk time interact in different individuals. For example, the CADL-2 and WAB-R results were significantly correlated for the people with aphasia. This relationship was expected, as the activity and impairment domains are interrelated. However, the SIPSO as a measure of participation did not correlate with either the CADL-2 or the WAB-R. Although not an aim of the study, this gives weight to the idea that participatory outcomes after stroke or aphasia, can, and often do, stand independently of impairment and activity level outcomes (Cruice et al., 2006; Kagan et al., 2008). However, the SIPSO is not a perfect nor comprehensive measure of participation for this population. Comparison of WAB-R and CADL-2 scores with other participation measures (particularly measures of communicative participation given the impairment), may yield different results.

6.5.2 Patterns in the Individual Performance of Participants with Aphasia

Individual results showed that some people with mild aphasia experienced marked participation restriction. This phenomenon is most strikingly represented by PA1, who had the highest aphasia quotient but the lowest SIPSO score and the third lowest talk time of the people with aphasia. The low SIPSO score may be explained by the fact that the participant needed a wheelchair for mobility, and that, as a younger person, she held higher expectations for her life, especially in terms of employment, relationships, autonomy and physical abilities at this stage of her life, leading to dissatisfaction. Hence, although her aphasic impairment was mild, she experienced a significant dissatisfaction with her level of participation. A similar pattern of results was displayed by PA11, although she had a slightly higher relative talk time than PA1. This person lived alone and, while not physically disabled, had ongoing health complications as a result of her stroke. These two factors could have led to her dissatisfaction with her level of participation and lack of opportunities to talk and socialise, as well.

On the other hand, the inverse of this pattern was shown by people with more severe aphasia who had comparatively little participation restriction. An example of this was exhibited by PA2, who had mild-moderate aphasia, but a high SIPSO score (37/40) and the second highest talk time. This individual was one of the younger participants, at 42 years of age, and had a young family and no physical disability. He was actively involved with therapy, aphasia research and his wider community. PA12 was another case who had differing levels of impairment and participation. He had the lowest aphasia quotient, but had a SIPSO score of only a few points below the mean. Although this individual was an older person with very severe aphasia, he had little physical impairment, and had a great deal of support and advocacy from his spouse. These two examples give an indication of how and why some people with aphasia can be socially participating and
satisfied despite moderate to severe aphasia. Previous work has identified several overarching themes to successfully living with aphasia, which include; participation, meaningful relationships, support, communication, positivity, independence and autonomy, and succeeding as a journey over time (Brown, Worrall, Davidson & Howe, 2012). Some of these themes are evident in the experiences of these two individuals. In the future, it would be of interest to explicitly log Environmental Factors (health systems, family support), Personal Factors (socioeconomic status, personality) and other related factors when investigating talk time in people with aphasia.

In the past, case studies have identified factors like individuals’ personality, overall health, relationships, support and physical autonomy as important to living successfully with aphasia (Holland, 2006). The patterns found in individual participants in this study provide some evidence that the social isolation that sometimes accompanies aphasia affects people with varying levels of severity of impairment and is not specific to the presence of moderate-severe aphasia or significant communicative activity limitations. The same is true of talk time, which is more correlated with feeling dissatisfied with participation levels than severity of aphasia. Accordingly, it is suggested that the need for rehabilitation and the outcomes of impairment or social approaches to therapy cannot be determined by assessment of one ICF domain alone (Kagan et al., 2008).

6.5.3 Talk Time of Control Participants vs People with Aphasia

Results also showed that talk time between people with aphasia and non-aphasic controls was not significantly different, at 4.5min/hr and 7.2min/hr respectively. This reflects the findings of Cruice and colleagues (2006), who found that aphasic participants engaged in significantly fewer social activities than controls, although in our case results were not statistically significant. However, there was a difference of 2.7 minutes between the two groups’ averages, with the non-aphasic group talking more. These results were not entirely unexpected for two reasons. The first relates to the data; the sample size was small, and even smaller for the control group, and is not entirely representative of the whole population. The second reason is that talk time varied in both groups, and the large standard deviation in talk times meant that there were no statistically significant outliers, despite a result from a non-aphasic person who spoke only 1.6 min/hr (HP7). It may be of note that this participant was the oldest of the non-aphasic cohort. No age-related effect was found in either group, however the range of ages in the control group was limited. Participation, and thus talk time, is expected to vary greatly in any population, due to individual differences in personality and social needs (Code, 2003). For example, in a study of people with aphasia, participants noted that quality and depth of social interaction was more important than quantity (Dalemans, de Witte, Wade & van den Heuval, 2010). This was also shown in the SOCACT study, which found that the
desire of people with aphasia to increase their participation was unrelated to their current level of social activities (Cruice et al., 2006). This supports the idea that comparisons of talk time and quantity of socialisation with non-disabled norms, while potentially useful, should be applied cautiously until further research is completed. Control participants in the study were not tested for participation restriction or satisfaction with their participation for comparison. In a clinical context, we suggest that quantitative data on socialisation, such as daily talk time, always be combined with qualitative data to gain a full picture of a person’s functioning. Future research with a larger participant group could show a significant difference in mean talk times, and should be pursued. It would also be of interest to investigate the talk time of people with stroke who do not have aphasia, in order to examine the role of motor, sensory and cognitive deficits on amount of talk in isolation from language impairment.

6.5.4 Sampling of Talk Time

As talk time is a new type of measure, its variability over time was also explored. This was undertaken in order to determine the length of time and days of the week required for a representative sample. This was important as several participants withdrew because they were unable to complete the two weeks of six hour per day sampling. Also, participants who did complete the study noted that it was time consuming for them. A comparison of talk time by week for both people with aphasia and non-aphasic controls was completed to determine whether sampling for a second week gave enough additional information to be justified. It was found that there was no significant difference between the first and second week of timing for either group, and no differences between days of the week except for Saturday. This stability in talk time is reflected in the results of a study by Mehl and Pennebaker (2003), who found that there was relative objective stability in university students’ social behaviours (e.g. alone, talking to others, reading, eating) over the course of a month. These findings suggest that one week instead of two weeks can be sampled with little effect on the results, as long as the sample includes a Saturday. However it was also noted by researchers that individual results were quite variable, and for some participants the difference between each week of sampling was considerable. This was reflective of Code’s study, which found that people with aphasia ranged from 1.5 to 6 hours spent out of the house (Code, 2003). Higher talk times for Saturdays also did not occur for all participants. This kind of variability was expected, as every individual will participate in different activities each day of the week. Additionally, many of the participants with aphasia were retired, and so a reasonable portion of their recreation and social activities occurred during weekdays. The guideline of sampling for one week including a Saturday could be adopted for future studies measuring talk time, though this standard needs to be investigated further, especially in regards to individual variation.
6.5.5 Talk Time and its Potential Role in Assessment of People with Aphasia

This study acts as a first foray into investigating the duration of everyday talk of people with aphasia. The results revealed that on average participants with aphasia in this study talked around 7.5% of the time recorded, and on average the non-aphasic controls talked 12% of the time recorded. Previously, talk time has been investigated in terms of voice use and misuse using neck attached accelerometer devices (Titze, Svec & Popolo, 2003). One study on voice use by 31 teachers found that their vocal folds were vibrating 23% of the time at work, and 12-13% off work and on weekends (Titze, Hunter & Svec, 2007). This was similar to our results for control participants; however, there is a lack of comparative literature regarding talking time in healthy adults who do not have jobs with high vocal loading. A study with 396 participants found that adults spoke on average around 16,000 words a day (Mehl et al., 2007). Given that most English speaking adults talk an average of 160 to 210 words per minute in conversation (Tauroza & Allison, 1990), and assuming that a waking day is 16 hours, it could be concluded that the participants spoke between 4.8 and 6.3 min/hr. This range falls directly between the mean talk times of people with aphasia and control participants in this study. However, it must be noted that number of hours in the waking day varies, words per minute is a confounded measure as word length varies, and speaking rate varies between speakers and speaking environments (conversation vs. lecture) (Tauroza & Allison, 1990). As noted earlier, a larger scale study on the talking time of healthy individuals would be a valuable contribution to the literature, and provide a norm with which to compare results for other populations like aphasia.

According to the results of this exploratory study, the CommFit™ app has potential to be used as an outcome measure for aphasia rehabilitation. As there is increasing focus on intervention in social participation for people aphasia, CommFit™ could be useful for gauging the effectiveness of such interventions. Clinically, CommFit™ is expected to be used in concert with self, proxy and clinician reported measures, which each serve to give the clinician different information, including qualitative and quantitative aspects. In research, CommFit™ is especially useful as an indicator of participation which allows for objective comparisons of outcomes across individuals and populations. However, use of high talk time as a gauge of positive participation outcomes should be interpreted cautiously, as the measured speech could be errorful or inefficient (Nicholas & Brookshire, 1993). This requires further investigation. Another potential research application is the comparison of talk time to other measures of participation as a way of validating quantitative self-report instruments like the SNAP (Code, 2003) or social activity diaries like the Communicative Activities Checklist (COMACT) and SOCACT (Cruice et al., 2006). It is expected that the use of CommFit™ and measurement of talk time will bring much needed attention to the participation
restrictions experienced by people with aphasia and the importance of addressing this restriction in rehabilitation.

### 6.5.6 Limitations

There were a number of limitations to this study which should be taken into account when considering the results. The first is that there was a small number of participants (n=19), with fewer in the non-aphasic control group. Accordingly, all results are considered to be exploratory in nature. In addition, participation was not measured in the non-aphasic group, so the relationship between talk time and participation is unclear for this population. Future studies could use measures appropriate for healthy adults, such as the SOCACT, to investigate this relationship (Cruice et al., 2006). Interpretation of study results is also limited in that stroke-related cognitive and motor skills were not tested, and hence their impact on talking time and participation is unclear. Future studies in talk time should endeavour to examine these relationships in greater depth, possibly using a stroke cohort who do not have aphasia.

There were also limitations in sampling of talk time. Participants sampled only six hours of their day, potentially missing times when they were more heavily or more lightly engaged in spoken communication. They were also permitted to postpone recording days if necessary. This flexibility was necessary so that data collection was practical and did not significantly disrupt the participants’ lives. It also circumvented battery life limitations. In the future, the aim for CommFit™ should be continuous, non-invasive timing over the course of the day, allowing for more robust data collection.

Lastly, it is acknowledged that participants self-selected to participate in this study, and that those who self-selected may have been more confident in their level of participation and use of technology prior to involvement in the study. The study was also exclusionary in that it was difficult for people with severe cognitive, motor, sensory or language deficits to participate unless they had assistance using the CommFit™ app in their home every day. People who had an involved family member in the home with them most of the day could potentially be more socially involved and talk more than more isolated individuals. Thus, it may be possible that the average talk time reported for this study is actually lower in the general aphasia population. Again, this warrants further investigation with a larger sample size.
6.6 Conclusion

This research showed that in a small sample of people with aphasia, talk time as measured by the CommFit™ app showed a correlation with participation status, and no correlation with impairment or activity limitation. This indicates that talk time, and accordingly the CommFit™ app, have the potential to be used as an outcome measure for aphasia rehabilitation. However, the study was exploratory in nature, and further research is needed in the area of talk time in people with aphasia (broadly) and the use of CommFit™ to measure talk time (specifically).


6.7 References


Chapter 7: Conclusions

This thesis explored the use of talk time, as measured by CommFit™, as an indicator of participation for people with aphasia. This concluding chapter will summarise the major findings from the preceding chapters in Section 7.1 and discuss of the implications of the results on clinical and research practice in Section 7.2. Section 7.3 will identify some limitations of the thesis and outline some directions for further research. Finally, Section 7.4 will provide an overall conclusion to the thesis.

7.1 Summary of Findings

The ultimate aim of this thesis was to investigate the use of talk time, as obtained by an iPhone application called CommFit™, as a performance-based indicator of participation. To achieve this goal, several smaller studies were undertaken to;

1) Investigate the current state of measurement of participation in aphasia rehabilitation (Chapter 2).

2) Review the use of mobile technology with people with aphasia, and identify design features which aided usability (Chapter 3).

3) Develop a valid and usable mobile tool for the measurement of talk time for people with aphasia (Chapter 4).

4) Determine the barriers and facilitators to people with aphasia using this tool (Chapter 5).

5) Use this tool to investigate the talk time of people with aphasia as an indicator of participation (Chapter 6).

Chapter 2 provided a background to the definition and measurement of participation in aphasia rehabilitation. In this chapter, the content of measures of community and social participation for this population was investigated by crosswalking items to International Classification of Functioning, Disability and Health (ICF) categories. Ninety instruments comprising 2,426 items were crosswalked. Of these, 29 instruments contained over 50% participation items and covered more than one ICF chapter. Hence this list of 29 instruments may be used by researchers and clinicians to select assessments that predominantly contain participation items. The most common participation categories in order of decreasing frequency were education; paid employment; recreation; socialising; being a carer; relating with friends, family and spouses; volunteer work; managing
finances; community life; civic duties; human rights and religion/spirituality. These roles were important to the range of populations for which these instruments were designed, including stroke and aphasia, and most are typically classified as participation in the literature (Eyssen et al., 2011). Commonly included non-participation items were self-care, mobility, domestic life, environmental factors, body functions and quality of life. Some instruments included these concepts either because the instruments were created before the ICF or the items were not developed using the ICF as a framework. Many instruments included in the review had a broader ‘functional’ focus, including participation items but not limited to them. In addition, some of these concepts are activity-level according to the guidelines of the review, but are classified as participation-level by other authors (Brandenburg, Worrall, Rodriguez & Bagraith, 2014). With a lack of guidance in the ICF, these concepts may be included in participation focused instruments at the developers’ discretion. The inclusion of non-participation items in instruments based on the ICF points to a need for consensus on the delineation of activity and participation domains in the ICF. The overall finding of the study was that only two instruments (the Social Role Participation Questionnaire and the Work and Social Adjustment Scale) solely assessed participation, and only about one third of the instruments had more than 50% participation items. One of the instruments with over half participation items was the Subjective Index of Physical and Social Outcome, which was designed for stroke survivors. This instrument was chosen as the participation measure for this research due to its appropriateness for the stroke/aphasia population in terms of content, structure, length and psychometric properties.

Chapter 3 reviewed the literature on use of mobile technology, which includes smart phones and tablets in aphasia. The results of the review indicated that there was very little research in the area at the time of the review, although more research has emerged in the last year. As such, newer studies on the use of mobile technology in aphasia rehabilitation were reviewed in the introduction to Chapter 4. The literature reviewed in Chapter 3 found that mobile technology had potential as a cost-effective, time efficient and context-sensitive health management tool for people with aphasia, as well as being useful for non-rehabilitative purposes. A potential categorisation system of the functions of speech pathology applications (apps) was proposed to guide further research. These categories were; alternative and augmentative communication (AAC), therapy, stimulus presentation, behaviour tracking, clinician tools, educational and environmental/biofeedback. The chapter also synthesized the available literature into key design features which may enhance the accessibility of mobile technology for people with stroke and aphasia, taking into account their language, motor and sensory impairments as well as general ease of use. These guidelines can be used by researchers and clinicians to guide the development of usable mobile apps for this population and to assess the usability of already available apps. The guidelines included;
• **Multimodal representation:** Text should be supplemented with use of colour, symbols, icons or spoken word to supplement meaning and provide more cues for people with aphasia.

• **Aphasia-friendly text:** Where text is used, aphasia-friendly principles should be applied, for example sans serif font, large font, bullet points, headings, double spacing, simple words and short sentences.

• **Large buttons:** Large buttons should be used with adequate space in between so they are easier for people with motor difficulties to activate.

• **Stable interface:** The interface should be predictable for the user- content should not change order or design unexpectedly and popups and advertisements should be avoided.

• **Simple navigation:** Shallow level and tab navigation is recommended. The need for scrolling should be minimised.

• **Visual simplicity:** Overall, the app should be visually simple and uncluttered.

Conclusions of the review were that further research is needed to investigate methods of maximising the accessibility of mobile technology to people with aphasia. The findings also indicated that there was a promising body of work into the use of mobile technology in the management of aphasia, but that further research needs to be pursued in this area. It was suggested that future studies look at mobile technology as both a therapeutic tool, and a tool through which to optimise the participation of people with aphasia.

Chapter 4 described the development and accuracy testing of the CommFit™ iPhone application. CommFit™ was designed according to the principles described in Chapter 3 and the development process was described in detail in this chapter (4). Accuracy was calculated from three participants who used the app for 10 hours in different environments. Results showed that CommFit™ measured talk time within ±4% of the actual talk time in an ideal environment with no background noise, and ±13% in everyday environments (e.g., conversation, meetings, driving) when a calibration procedure was used. The results of this study were used to identify parameters for optimal use. The outcome was a usable, accurate app which counts talk time, to be used in the further research described in this thesis. The challenges of app development with a commercial app developer are described in Chapter 4 as a guide for health professionals with no app development experience. Key components to this process for the CommFit™ research team were education and communication between teams, including multiple iterations at each stage of design. This approach
resulted in an app which addressed our goals of design and function exactly, ready to be used by people with aphasia.

The previous chapters of this thesis were preparatory, focusing on investigating the literature, forming hypotheses and developing the CommFit™ app. The final phase of the thesis was an investigation of the use of CommFit™ to measure talk time in people with aphasia and non-aphasic peers. The results of this study are presented in Chapters 5 and 6 of this thesis.

The study presented in Chapter 5 described the usability of the CommFit™ system, as a result of testing 12 people with aphasia who used the app for 14 days. The study identified barriers and facilitators to iPhone, app and headset use through observations, field notes and interviews. Barriers to use were physical impairments related to stroke, language impairments related to stroke (aphasia), other physical difficulties, design of the technology, technology malfunction, unexpected functions of the technology, negative social attitudes, unfamiliarity with technology, time constraints and loss of or damage to technology. Facilitators were use of the hard copy aphasia-friendly manual, assistance from family members and other people, contact with researcher for trouble shooting and the app’s aphasia- and stroke-friendly design. Usability was determined using a rating scale- participants were asked to rate steps involved in using the CommFit™ system from ‘very hard’ to ‘very easy to use’. Overall, the participants with aphasia rated the usability of steps related to the CommFit™ app and iPhone as ‘very easy to use’, and qualitative feedback for these two components was positive. Mean ratings for use of the headset were ‘easy to use’, and some participants rated it quite low on the scale as ‘hard’ or ‘very hard to use’. The headset was also identified as a point of difficulty in interviews, observations and field notes. Its small size made it difficult for those with physical difficulties to operate, and the headset suffered from a number of technical difficulties.

Finally, Chapter 6 presented the results of a pilot investigation of the talk time of people with and without aphasia. Twelve people with aphasia and seven non-aphasic controls used CommFit™ to time their talk for six hours a day for 14 days. For people with aphasia, language impairment was assessed using the Western Aphasia Battery Revised (WAB-R) Aphasia Quotient, communicative activity with the Communicative Activities of Daily Living-2 (CADL-2) and participation with the Subjective Index of Physical and Social Outcome (SIPSO). This study was a first foray into the use of talk time as a measure for people with aphasia, and investigated a number of parameters of talk time. Key findings of this study were that;

- Mean talk time was significantly positively correlated with participation but not with language impairment (expressive or receptive) or activity.
Activity and impairment assessment scores were positively correlated; however, participation was not correlated with either of those domains.

Individual results showed different patterns in performance with some people having high impairment and activity scores but low participation and talk time and vice versa.

The mean talk time of people with aphasia was not significantly different to healthy controls. However, it was almost statistically significant, with people with aphasia talking on average less than their non-aphasic peers.

There was no significant difference between talk times in the first and second week of timing and no differences between days of the week except for Saturday, which had a higher mean talk time.

The overall finding of this thesis was that the CommFit™ app has potential as a usable indicator of participation for people with aphasia.

7.2 Clinical and Research Implications

The research presented in this thesis relates to the investigation of the talk time and use of CommFit™ for people with aphasia. However, the results have broader implications for the use of the ICF and mobile technology in aphasia rehabilitation.

7.2.1 Use of the ICF in Aphasia Rehabilitation

Use of a biopsychosocial model like the ICF in aphasia rehabilitation promotes assessment and therapy in all domains (Simmons-Mackie & Kagan, 2007). The introduction to this thesis highlighted a lack of focus on the participation domain in aphasia rehabilitation. Chapter 2 provided a review and crosswalk of currently used self-report measures, in which it was clear that the current state of assessment of participation is lacking. The content of the assessment instruments included in the study, both aphasia related and more general, illustrated that the participation domain is rarely given specific attention in aphasia rehabilitation assessment, or even rehabilitation assessment in general.

Additionally, this research revealed that for the participants with aphasia, participation restriction as measured by the SIPSO was not correlated with impairment or activity measures. For example, some people with mild aphasia were markedly restricted in their participation while other people with more severe aphasia experienced comparatively little restriction. Traditionally, speech pathologists assess aphasia with impairment level assessments such as the Western Aphasia Battery
and Boston Naming Test and less commonly use activity and participation level questionnaires (Verna, Davidson & Rose, 2009; Vogel, Maruff & Morgan, 2010). However, this may not be adequate as the results have shown that a person with aphasia may be mildly restricted in impairment and activity, but require intervention in the area of participation. Thus, this thesis provided initial evidence that talk time and participation restriction are not necessarily correlated with impairment and activity limitation in people with aphasia, and that there is a need for interventions to move towards an increased focus on participation for this population.

The results of this research also have implications for the revision of the ICF. The activity and participation domains are combined in the ICF into one set of categories, and separation of the two concepts is left to the user. As covered extensively in Chapter 2 there is a lack of agreement on how to separate the two concepts, even amongst experts. The results of this research showed that activity and participation outcomes, as measured by the CADL-2 and SIPSO, were not correlated in the 12 participants with aphasia. This supports previous assertions that activity and participation are separate theoretical concepts, and are deserving of separate assessment and intervention (Ayis et al., 2010; Jette, Haley & Kooyoomjian, 2003; Pollard, Johnston & Dieppe, 2011). The idea that activity and participation domains are distinct dictates a need for consensus on what delineates the two concepts. Users new to the ICF are confronted with two concepts which are purported to be different, but are combined in practice, and this can limit the application of the framework and obscure research into ICF concepts. Therefore, the World Health Organisation must make efforts to move towards a resolution in this matter and revise the ICF accordingly.

7.2.2 Moving Towards Self-management Using Technology

The results of this thesis also have implications for self-management of aphasia using technology. Self-management is increasingly important for aphasia rehabilitation for three reasons. Firstly, it is estimated that around 29% of the Australian population live in regional, remote or very remote areas (Australian Bureau of Statistics, 2013) and this pattern of distributed population is reflected in other parts of the world, such as the United States of America (U.S. Department of Commerce, 2010). Concerns have been raised that there is a lack of speech-language pathology services for these communities (National Rural Health Alliance, 2014). Secondly, an ageing population is putting an increasing demand on speech pathology services. Lastly, advances in the understanding of neural recovery have indicated that therapy should be undertaken intensively, which usually means at least once a day, most days of the week, although no formal standard currently exists (Cherney, Patterson & Raymer, 2011). Thus, there is a need to move away from traditional service models in which speech pathologists see their clients once or twice a week for an hour long session...
in a clinic and into cost effective ways of delivering increased therapy in the home. There is presently a well-established body of research into the utility of telehealth and computer technology for aphasia rehabilitation services (van de Sandt-Koenderman, 2011; Hill, 2008; Theodoros, 2008, 2012). However, research into the role of mHealth (use of mobile technology in health) in this field is only just emerging.

This thesis provides evidence for the use of mobile technology as a viable option for promoting self-management of aphasia. Although the research investigated measurement, the CommFit™ app has a potential therapeutic role in encouraging people with aphasia to increase their talking time. This needs to be investigated further, but this thesis showed that most participants with aphasia were able to independently use the CommFit™ app and iPhone in their everyday lives. Furthermore, they expressed that the app itself was easy to use and were enthusiastic about the use of such apps in their rehabilitation. Some participants were observed to be already using other apps extensively to self-manage their condition. This is indicative that this population is able to use mobile technology independently when it is designed for people with aphasia, and sufficient support is available. Thus, the results are promising for the use of CommFit™, and other mobile technology, in the self-management of aphasia.

7.3 Research Limitations and Ethical Considerations

7.3.1 Research Limitations

This research was intended as a pilot study into the measurement of talk time in individuals with aphasia, providing some preliminary results in areas such as average talk time in people with aphasia vs those without, the relationship between talk time and ICF domains, variability of talk over weeks and days of the week, and usability of the CommFit™ system. As a pilot study, there are some limitations to the interpretation of the results presented in this thesis.

Firstly, the accuracy of the app was only established in three people on the research team, none of whom were typical of the demographics of people with stroke or aphasia, and may have been biased in choosing recording environments. The accuracy was also determined by a single rater and no inter-rater reliability analysis was completed. Accuracy was demonstrated to be low in some environments, which may have skewed the results. The accuracy of CommFit™ needs to be further investigated and improved upon before significant research is attempted in this area.

A major caveat to the interpretation of results is the small number of participants, only 19 in total, with fewer in the control group. Participants were recruited from a small number of sources,
all lived in metropolitan Brisbane, Sydney or Melbourne, tended to be older and the people with aphasia mostly had mild language impairment. In addition, participants were mostly Caucasian, educated and middle class. There was also a high attrition rate for the talk time study, as the time demands of the study were high (three weeks of daily participation including pre and post assessments). It is unknown whether participants who dropped out of the study had a characteristic that may have produced different results. Lastly, talk time was recorded over only six hours per day, the time of which was chosen by the participants. Thus, it is not clear whether those samples were truly representative of their behaviour all day.

As exploratory research, the information collected from participants was limited, which restricts the breadth of analysis of talk time results. For example, in Chapter 5, a formal assessment of cognitive and sensorimotor impairments (e.g. motor sequencing, problem solving, executive functioning) would shed light on the impact of these on using CommFit™, and whether they created more or less of a barrier to use than language impairment. Additionally, collection of quantitative data on time spent by the researcher on training, home visits, phone calls and emails would provide more information about support and resources required for using CommFit™, including economic analysis. In Chapter 6 it would have been of interest to collect more information from participants, especially regarding years in education and rating of perceived talkativeness to determine if these affected the talk times of participants both with and without aphasia. These areas have the potential to be explored in further studies.

### 7.3.2 Ethical Considerations

The involvement of people with language, cognitive and physical disabilities in this research necessitated a considered ethical approach. People with language difficulties are especially vulnerable in research activities as they can have difficulty reading study materials and communicating their needs and wants. Informed consent in particular must be carefully approached for this population.

In order to achieve informed consent, all written materials used in the study were aphasia-friendly. Participants with aphasia received aphasia-friendly information sheets on the study through the Communication Research Registry or their speech pathologist, and contacted researchers if they were interested in being involved. Participants were taken through the requirements of the study with a speech-language pathologist, who was familiar with total communication techniques, and they were invited to bring along supportive individuals if desired. The information sheet and face-to-face information session covered the following points;
• That participation in the study was entirely their choice
• That they were welcome to drop out of the study at any time without compromising the relationship with the registry or university
• That all information they provided us was kept de-identified and in secure, password-protected computers and filing cabinets
• That the research would not cost them any money
• That the research was not of any direct benefit to them and was not a form of therapy
• That they would not be identifiable in any published material resulting from the study
• That they would be able to access their own results after the study is finished

If participants indicated that they understood this information and wanted to participate in the study, they were given an aphasia-friendly consent form for providing informed written consent.

In addition, the use of technology that records speech content potentially raises a number of significant ethical issues (including informed consent of those recorded, electrical transmission of content and rights to confidentiality). These issues were avoided by our selection of an approach that only measures talking time. The app does record speech but deletes this stored data almost instantaneously- as soon as the decibel threshold is determined. Nevertheless, data was kept confidential and securely stored. A different profile/login was used for each participant so they did not have access to each other’s talk time histories. Research team members who participated in the accuracy study did have their speech recorded and listened to, but consented to this and knew the researcher (CB) personally.

7.4 Future Directions for this Research

7.4.1 Future Directions for CommFit™

The CommFit™ app described in this thesis is a prototype, in need of further research and development. In particular, feedback from the participants with aphasia in Chapter 6 of this thesis indicated that the Bluetooth headset was a source of difficulty, both in terms of technical malfunction and usability. It was concluded that other models of Bluetooth headset would likely pose similar problems due to similarity in design. Therefore, future research using the CommFit™ app will seek to identify another suitable input device. Neck-attached portable accelerometers have been used in voice research for measuring vocal cord activity, and would be suitable for the purposes of counting talk time (Cheyne, Hanson, Genereux, Stevens & Hillman, 2003; Hillman et al., 2006; Popolo, Svec & Titze, 2005). One such accelerometer is currently being developed to interface with a smart phone app (Mehta et al., 2012). However, these devices are not yet
commercially available and would need to be developed specifically for the CommFit™ app in collaboration with information technology and engineering professionals. This new input device would need to be further tested with the aphasic population to test its usability. This research is currently underway.

It would also be useful to investigate interest from speech pathologists and people with aphasia in using the CommFit™ system in their rehabilitation. Identifying the characteristics of people with aphasia who are likely to use mobile technology would inform ways of targeting them and determining how they might best be supported. A major question in further development of CommFit™ is whether the target audience should be speech pathologists on behalf of their clients, or people with aphasia living in the community who wish to self-manage their aphasia, or both. This is an important area to investigate both in terms of bridging the research to practice gap and CommFit™’s commercial viability.

After the CommFit™ app has been adequately developed and tested with the aphasic population, the app has the potential to be commercialised. This poses an interesting question on how to distribute the CommFit™ system- as an app available to the public on iTunes, or as a package with the accelerometer, app and access to the commfit.org.au website to be purchased by speech pathologists and distributed to clients. Our research team is currently investigating both options.

As technology continues to develop, there are possibilities for CommFit™ beyond a smart phone app which counts talk time. Future directions for the CommFit™ system could do away with the need for a smart phone altogether, ideally replacing it with a single device that is similar in size to a pedometer. CommFit™ may eventually interface with modern monitoring bracelets like FitBit® or the Up band®, or integrate with other stroke self-management technology (Mawson, Nasr, Parker, Zheng, Davies & Mountain, 2014) to provide talk time as one component of an overall indication of health. It may also be developed into a more sophisticated clinicians’ tool akin to the LENA Pro system (LENA Foundation, Boulder, Colorado). As automated voice recognition and analysis becomes more sophisticated, recording and analysis of speech may also become an option for CommFit™. As addressed in this thesis, assessment of real life communication is much valued but not currently time efficient for speech pathologists, who must record, transcribe and analyse voice recordings manually. Automated speech analysis could be used to analyse vocabulary, grammatical structures and instances of word finding difficulty in people with aphasia, and research is already advancing in this area (Little, Oehmen, Dunn, Hird & Kirsner, 2013). Such analysis could be used to assess large samples of everyday language, and determine generalisation.
of aphasia therapy to everyday communication. It could also be used as a form of augmentative communication or naming therapy, providing online cueing and word suggestions based on semantic and grammatical context. These possibilities and others will be of importance in the coming decades, as mobile health monitoring advances and becomes increasingly employed in this population.

7.4.2 Future Directions in Talk Time Research

Chapter 6 of this thesis described an exploratory study into the talk time of people with aphasia. Talk time has rarely been investigated in the literature for any population, as the technology needed to monitor it effectively has only recently emerged. Accordingly, there is much more to investigate about talk time. For people with aphasia, it would be useful to investigate the environmental and personal factors which determine a person’s talking time and participatory outcome. This research did not assess these areas, and it is likely that personal factors like premorbid talkativeness and extroversion, as well as environmental factors like support of others would impact on talk time. Comparing talk time with measures of language quality would also be valuable to future research, in order to determine whether people with higher talk times aren't simply communicating less efficiently, which could have a negative association with participation. Future research should also explore the relationship of talk time with different forms of participation rather than comparing with just one measure like the SIPSO. This could include measuring participation parameters such as frequency, satisfaction, difficulty and independence, as well as measures of general, social and communicative participation.

It is also of interest to investigate whether people with aphasia can be influenced to change their talking behaviour through biofeedback on talk time. Increasing the talk time of people with aphasia has the potential to improve their language functioning through increased practice. This idea has its roots in theories of neuroplasticity, which posit that increased amount of practice, more frequently, and in relevant contexts supports neural change and functional recovery of language (Pulvermuller & Berthier, 2008). Increasing talk time could also be an indirect way of reducing the social isolation many people with aphasia experience. Research in this area is in its early stages (Rodriguez, 2014; Rodriguez, Power, Worrall, Brandenburg & Copland, 2014). Conversely, people with aphasia who experience press of speech, common in Wernicke’s aphasia, may benefit from talk time biofeedback to help reduce their talking time (Caspari, 2011). Such therapy would need to be carefully mediated so as not to discourage people with press of speech to reduce communication to their detriment.
Measurement of talk time also has the potential to be used in the rehabilitation and management of conditions outside of aphasia. Some examples of populations that may benefit from measurement of talk time include:

- **People with voice disorders**: Measurement of talk time in people with voice disorders is one of the few areas which has already utilised mobile technology to measure talk time. Neck-attached accelerometers have been used in voice research to quantify ‘time dose’—the time in seconds the vocal cords spend vibrating—while allowing the user to be ambulatory (Cheyne et al., 2003). This is of interest to this population as many voice disorders, such as vocal nodules, arise from overuse of voice and subsequent damage to vocal cords. Measurement of talk time has been used to determine the effect of voice use on such disorders, and to encourage behavioural change in these populations.

- **Children with expressive language impairments and their parents.** Children with language impairments, such as autism or specific language impairment, often have a reduced vocabulary and talk less than their peers. Encouraging these children and their parents to talk and interact more has been shown to improve language compared to those who do not, for example in the widely used Hanen It Takes Two to Talk® program (Girolametto, Pearce & Weitzman, 1996). Although there are components to this program other than simply talking more, increased speech is a key goal for both the parent and child. Measurement of talk time could determine to what extent the amount of child and parental speech is associated with expressive language delays, and could be used as a tool to increase interactions. Some research has been done in this field using the LENA Pro, a mobile device which records speech continuously for up to 16 hours and provides some automatic analysis, such as conversational turns, estimated words spoken, number of child vocalisations and classification of environmental sounds (speech, television, silence), and the LENA Foundation has provided normative data for these measures (Gilkerson & Richards, 2008; LENA Foundation, Boulder, Colorado). The system has been used as a tool to identify presence of autism (Xu, Gilkerson, Richards, Yapanel & Gray, 2009), to measure outcomes of a parent intervention program (Weil & Middleton, 2009) and to determine the effects of environmental sounds on children (Christakis et al., 2009). However, talk time has not yet been investigated in depth for this population.
People with Parkinson’s Disease. Parkinson’s disease often affects a person’s vocal function, characterized by dysphonia, reduced pitch range, dysfluencies, reduced loudness and festinating or rushed speech (Sapir, Ramig & Fox, 2008). The Lee Silverman Voice Treatment (LSVT LOUD) is a widely used behavioural treatment which focuses on sensory recalibration to a higher volume, and self awareness/cueing of talking behaviour (Fox, Ebersbach, Ramig & Sapir, 2012). However, like many speech and language treatments, maintenance and generalisation of treatment effects to everyday life is not yet optimal (Fox, Ebersbach, Ramig & Sapir, 2012). Measurement of talk time in tandem with a loudness measure could determine how often people with Parkinson’s Disease are using their loud voice in everyday life and whether this has an impact on maintenance effects. It could also be used as an outcome measure for the LSVT program and similar treatments for this population.

People with mental disorders such as schizophrenia, depression or bipolar disorder. Schizophrenia and bipolar disorder are characterized by the presence of ‘positive’ and ‘negative’ symptoms. ‘Negative’ symptoms of both disorders are characterised by poverty of speech, anhedonia, flat affect, apathy and attentional impairment (Toomey, Faraone, Simpson & Tsuang, 1998). Conversely, press of speech is a commonly experienced ‘positive’ symptom in the manic phase of bipolar disorder, and is sometimes also present in schizophrenia. Similarly, people with mental conditions like depression and social anxiety are more likely to become withdrawn and socially isolated. Measurement of talk time may be useful to investigate the role of decreased socialisation as both a symptom and a contributing factor to depression and social anxiety. It also has the potential to provide greater quantitative insight into these symptoms, and may even be used as an indicator to identify the disorder’s phase in people with schizophrenia or bipolar disorder.

People at risk of being socially isolated. There are various populations at risk of social isolation who cannot be defined by a specific health condition. One example of this is people in nursing homes, who have been shown to experience loneliness to a greater degree than community dwelling older adults (Pinquart & Sorensen, 2001). Measurement of talk time could be a way of investigating social participation in isolated people, and be used as a motivating feedback tool to improve socialisation.
For most of these populations, excessive or inadequate amounts of talking are currently determined clinically through ratings scales, self/proxy report and small scale observations. Research into most of these areas has not yet measured talk time in a quantitative, performance-based way in everyday life. With the rapidly increasing availability of mobile technology, measurement of talk time has become a possibility and is expected to be applied in many different research fields in the coming decade.

7.5 Conclusion

Current research into the use of mobile technology in people with aphasia is only just emerging. This thesis adds to that body of research, as well as introducing talk time as a measure for people with aphasia. The research presented in this thesis represents the beginning of research into talk time as an indicator of participation in people with aphasia, and provides a wide range of preliminary findings on the topic, such as mean talk time per hour, comparison to healthy peers and relationship to ICF domains. It is expected that this work will inspire further exploration of talk time’s potential for both assessment and therapy, and that the CommFit™ system will continue to be developed, evaluated and refined.
7.6 References


Appendix A: Ethics Approval

THE UNIVERSITY OF QUEENSLAND
Institutional Approval Form For Experiments On Humans
Including Behavioural Research

Chief Investigator: Professor Linda Worrall

Project Title: Development Of The Australian Aphasia Rehabilitation Pathway

Supervisor: None

Co-Investigator(s): A/Prof Leanne Togher, A/Prof Alison Ferguson, A/Prof David Copland, Prof Lyndsey Nickels, A/Prof Jacinta Douglas, Prof Beth Armstrong, A/Prof Kirrie Ballard, Dr Bronwyn Davidson, Dr Miranda Rose, Prof Leslie Gonzalez-Rothi, Prof Nina Simmons-Mackie

Department(s): School of Health and Rehabilitation Sciences

Project Number: 2009001850

Granting Agency/Degree: NHMRC

Duration: 31st December 2019

Comments:

Name of responsible Committee:-
Medical Research Ethics Committee
This project complies with the provisions contained in the National Statement on Ethical Conduct in Human Research and complies with the regulations governing experimentation on humans.

Name of Ethics Committee representative:-
Professor Bill Vicenzino
Chairperson
Medical Research Ethics Committee

Date: 26.09.20  Signature: [Signature]
Appendix B: Aphasia-Friendly Manual

CommFit Instruction Manual

Contents
Introduction ...........................................3
Parts .......................................................4
Turning on the iPhone ..............................6
iPhone Home Page .................................7
Connecting the Bluetooth .........................8
Start timing ...........................................11
Turning Off ............................................13
Charging Bluetooth ................................17
Charging iPhone .....................................18

Introduction
CommFit™ is an iPhone app
It counts how much time you talk
It does not record you talking

Using CommFit
To use CommFit, you wear a headset in your ear.
You also start the app on the iPhone
You wear the headset and carry the iPhone in your everyday life.
This manual will tell you how to use CommFit

Parts
This is an iPhone.
This is the power button
This is the touchscreen
This is the home button
This is a BlueTooth headset
This is the indicator light
This is the power button
This is the iPhone charger

This is the BlueTooth headset charger

Turning On the iPhone
Hold down the power button
Let go when you see the apple

Touch the arrow button
Slide your finger to the right

Connecting the BlueTooth
Tap the settings button

Tap BlueTooth

CHECK: The BlueTooth button is green
Bluetooth
Hold down the power button.
It will flash blue, then red, then red/blue
Let go after you see red/blue flashes

Tap PROPIIantronics
Wait

CHECK: Connected appears next to Voyager Pro+
Voyager PRO+ Connected

The BlueTooth is now connected
Press the home button to get back to the home screen

Start Timing
Tap Commfit

Tap the green play button

CHECK: The button turns red
Put the iPhone in sleep
Press the power button

CHECK: The screen goes black

Turning Off
Take the iPhone out of sleep
Press the home button

Touch the arrow and drag it right

Tap the red stop button

Tap Stop timer and send

Tap Finish

Press and hold down the power button

11
12
13
14
Touch the arrow button
Drag your finger to the right

Hold down the power button on the Bluetooth
Let go after the red flash

Charging Bluetooth
Insert black charger into powerpoint
Insert other end into the bottom of the Bluetooth headset
Turn on the powerpoint

CHECK: There is a red light on the Bluetooth

Charge for 2 hours

Charging iPhone
Insert white charger into powerpoint
Insert other end into the bottom of the iPhone
Turn on the iPhone

CHECK: The battery meter appears on screen

Charge for 2 hours
Appendix C: Interview Schedule

1. How did you find using the iPhone and headset?
   Prompts: Did you run into any problems?
   What did you dislike about it?
   Was there anything you liked about it?
   Do you feel comfortable using iPhones now?

2. What did you think about using the app everyday?
   Prompts: Did you think more about how much you were talking?
   Did you change anything about what you did during the day?
   Whereabouts did you use it?
   Did you take it off for anything?
   Did you feel comfortable wearing it in public?
   Did anyone ask about it?

3. Would you use it again?
   Prompts: What if it was part of a therapy to help your aphasia?
   How long would you use it for?
   Could you use it long term?

4. What would you change about it if you could?
Appendix D: Feedback scale

Carrying the iPhone and wearing the headset all the time  
Turning on the iPhone

Pairing the BlueTooth  
Starting timing
Stopping timing and sending

Turning off the iPhone

Recharging

Overall, how hard or easy was CommFit™ to use?