

**Ready to Roll: New Zealand wheelchair users'
preparedness for emergencies**

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Abstract

Background:

People with disabilities are disproportionately affected by emergency situations compared to the general population, with higher mortality rates and increased vulnerability to disrupted infrastructure and services. The 2010-2011 Canterbury earthquakes highlighted issues regarding personal and organisational preparedness for people with disabilities in New Zealand (NZ). The Ready to Roll study investigates issues of emergency preparedness by wheelchair users in NZ, seeks their opinions about a proposed register of vulnerable people for use in emergencies, and also surveys information communication technology (ICT) use patterns amongst this group to determine whether such technology could augment emergency response planning.

Aims:

This study focused on four key questions:

1. What is the current state of emergency preparedness amongst NZ wheelchair users?
2. What are their perceived barriers to emergency preparedness?
3. What is the level of support for, and concerns about, a Disabled Persons Emergency Response Register in this group?
4. What types of ICT, able to support emergency planning and response, are currently being accessed and used by this group?

Methods:

A nationwide survey of adult, community dwelling wheelchair users was conducted using SurveyMonkey™ or a postal questionnaire. Survey questions were developed through a process of engagement with disabled people. A snowball sampling

recruitment method using Disabled Persons Organisations and disability service providers was used to disseminate the survey.

Results:

The key findings from the 101 people who completed the survey revealed less than 30% had an emergency plan and less than 20% were planning for their disability related needs. Personal preparedness barriers identified included the need for assistance from someone else to carry out planning activities (n = 50), lack of disability relevant information (n = 37), limited accessibility to information (n = 24), cost (n = 23), and being unable to stockpile medications (n = 20) or consumables (n = 11). Ninety participants supported the concept of a Disabled Persons Emergency Response Register but fewer (n = 76) thought they would personally participate in such an initiative. The participants of this study reported high levels of internet engagement including internet searches, emails and downloading/installing software (n= 91), online financial transactions (n = 84) and using social media (n = 80). Seventy nine participants were currently smart phone users.

Conclusions

Ready to Roll participants reported much lower levels of personal emergency preparedness and a higher incidence of barriers to preparedness than that reported for the general NZ population, a concerning finding given the increased vulnerability of people with disabilities in emergencies. Findings of this study indicated that adjuncts to assist emergency planners respond to the needs of people with disabilities such as a register system or ICT enabled tools could be useful, well utilised and accessible to this group of participants. However the small scale and limitations of the study produce an inability to generalise findings beyond participants to people with disabilities more broadly. As such, further research into the issues raised by this and previous studies is recommended to improve the personal and organisational emergency preparedness for disabled New Zealanders.

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Personal Statement

I am a New Zealand trained and registered physiotherapist with over 20 years clinical experience. The majority of my career has involved working with people with disabilities, mostly neurological impairments. I currently live and work in Nelson as part of a community rehabilitation team. However, it was in my previous role as a physiotherapist at the Burwood Spinal Unit, where I worked for 13 years, which provided me with the initiative and support to undertake the current project.

As I was living and working in Christchurch at the time of the Canterbury earthquakes, I saw first-hand the physical and social destruction the earthquakes caused, especially for those living with a spinal cord impairment. It was through hearing the stories of clients, friends and colleagues with disabilities that acted as the catalyst for the Burwood Academy of Independent Living, the Department of Orthopaedic Surgery and Musculoskeletal Medicine (University of Otago, Christchurch) and myself to begin looking at the systems in place to assist people with disabilities in emergencies in New Zealand.

I am profoundly grateful to the individuals and organisations that have inspired, supported and funded this project. My wish is that the knowledge gained through this project can be used to improve the emergency preparedness of and for people with disabilities in New Zealand.

Table of Contents

Abstract	iii
Acknowledgements	v
Personal Statement	vi
Table of Contents	vii
List of Tables	xi
List of Figures	xii
List of Abbreviations	xiii
1 Chapter 1: Background and Introduction	1
1.1 People with disabilities in New Zealand	2
1.1.1 The number of New Zealanders affected by disabilities.....	2
1.1.2 Socioeconomic outcomes for people with disabilities in NZ	3
1.1.3 Funding support for people with disabilities in New Zealand	3
1.2 New Zealand: A landscape of risk	4
1.3 Emergency planning and response in New Zealand.....	5
1.4 People with disabilities in emergency situations	7
1.4.1 Morbidity and mortality for people with disabilities in disasters	8
1.5 Personal preparedness of people with disabilities.....	10
1.5.1 Preparedness recommendations for people with disabilities	10
1.5.2 The level of preparedness amongst people with disabilities.....	11
1.6 A recent international example: Hurricane Katrina.....	13
1.7 The Canterbury earthquake series	14
1.8 People with disabilities and the Canterbury earthquakes	15
1.9 The role of Information Communication Technology	18
1.9.1 Geographic Information System mapping	18
1.9.2 Advance warning systems	19
1.9.3 Smart phone applications.....	19
1.9.4 Social media.....	19
1.9.5 Summary of Information Communication Technology’s role	20

1.9.6	Accessibility of Information Communication Technology	20
1.10	Improving outcomes for people with disabilities	22
1.10.1	Changes implemented following Hurricane Katrina.....	22
1.10.2	International initiatives	23
1.10.3	New Zealand initiatives	27
1.11	Including people with disabilities in emergency planning.....	31
1.12	Justification for the current study	33
1.12.1	Previous international surveys	33
1.12.2	The existing NZ research base.....	33
1.12.3	The existing knowledge gap	35
1.12.4	Rationale for choosing wheelchair users as participants.....	36
1.13	Aims of the project.....	36
2	Chapter 2: Research Methods	38
2.1	Methodology.....	38
2.2	Research methods.....	39
2.3	Participants.....	41
2.3.1	Inclusion Criteria	41
2.3.2	Exclusion Criteria.....	42
2.4	Consultation during planning phases.....	43
2.4.1	Consultation with representatives of disabled community	43
2.4.2	Consultation with Māori	44
2.5	Developing the survey tool	44
2.6	Developing the information resources	49
2.7	Pilot Testing.....	49
2.8	Participant recruitment.....	50
2.8.1	Recruitment via Disabled Persons Organisations (DPO's).....	51
2.8.2	Recruitment via health service providers	52
2.9	Ethical Approval	53
2.10	Filling in the questionnaire	53
2.11	Data analysis.....	53
2.12	Funding Support	54
3	Chapter 3 Results	55
3.1	Participant demographics	55
3.1.1	Gender and age.....	55
3.1.2	Ethnicity	56

3.1.3	Impairment and mobility characteristics	56
3.1.4	Geographic location	56
3.2	Emergency preparedness amongst wheelchair users	56
3.2.1	Participants with an emergency response plan	57
3.2.2	Age	58
3.2.3	Mobility impairment: duration and type	59
3.2.4	Ethnicity	60
3.2.5	Living situation.....	60
3.2.6	Previous experience of an emergency	61
3.3	Nature of preparedness.....	61
3.4	Reasons for lack of emergency planning.....	63
3.5	Perceived barriers to emergency planning.....	64
3.6	Disabled Persons Emergency Response Register	65
3.6.1	Preferred method of having information entered.....	66
3.6.2	Privacy and data security concerns	67
3.6.3	Types of information participants are prepared to include.....	68
3.7	Information Communication Technology use	69
3.7.1	Subgroup analysis of postal and online participants	70
3.8	Summary of key findings of the study	71
4	Chapter 4 Discussion	73
4.1	Key findings of the RTR study	73
4.2	The RTR sample.....	74
4.3	Levels of preparedness amongst participants.....	78
4.4	Barriers to preparedness for NZ wheelchair users.....	80
4.4.1	Requirement of help from others	81
4.4.2	Socioeconomic considerations.....	83
4.4.3	Accessibility and disability relevant information	84
4.5	Participant perspectives regarding a proposed register	87
4.5.1	Security of personal information.....	88
4.5.2	Collection and maintenance of personal information	88
4.5.3	Potential issues with vulnerable persons' registers.....	90
4.6	Technology, people with disabilities and emergencies in NZ.....	91
4.7	Strengths of the study	93
4.7.1	Consultation with wheelchair users	93
4.7.2	Consultation with Māori.....	93

4.7.3	Study content.....	94
4.7.4	Use of information video	94
4.7.5	Option for postal or online survey completion	95
4.8	Challenges and limitations of the Ready to Roll study.....	95
4.8.1	Participant recruitment	96
4.8.2	Small sample size	97
4.8.3	Reliance on self-reporting.....	97
4.8.4	Potential bias of participants	98
4.8.5	Lack of a non-disabled comparison group.....	98
4.8.6	Non-validated survey tool.....	99
4.8.7	Limited generalisability of findings	99
4.9	Key learnings to arise from the Ready to Roll project	100
4.10	Recommendations for future research	102
4.11	Summary	103
5	Chapter 5: Conclusion	105
6	References.....	107
7	Appendix A: BACC consultation feedback letter	118
8	Appendix B: Maori consultation letter	119
9	Appendix C: H.E.I. Mahi Ltd letter of support	122
10	Appendix D: The Questionnaire	123
11	Appendix E: List of Disabled Persons’ Organisations email contacts used to assist with potential participant recruitment	133
12	Appendix F: List of healthcare service providers	136
13	Appendix G: Otago Ethics Committee (Health): Letters of approval	137

List of Tables

Table 1.1: The 4R's of emergency management.....	7
Table 2.1: List of questions included in final questionnaire	45
Table 3.1: Demographic characteristics of participants with and without an emergency plan	57
Table 3.2: Association of age with having an emergency plan	59
Table 3.3: Association of mobility impairment duration with having an emergency plan	59
Table 3.4: Association of ethnicity with having an emergency plan	60
Table 3.5: Association of living situation with having an emergency plan	61
Table 3.6: Association of previous experience of a natural disaster with having an emergency plan	61
Table 3.7: Comparison of ICT use patterns between postal and online survey participants	71
Table 3.8: Reported support for potential DPERR and GPS enabled smartphone application by postal and online survey participants	71
Table 4.1: Wheelchair type and age characteristics of RTR sample compared to all NZ wheelchair users.....	75
Table 4.2: Demographic characteristics of RTR sample compared to mobility disabled adults using mobility equipment in NZ	76
Table 4.3: Reasons for not being prepared for the general NZ population and RTR participants.....	81
Table 4.4: Comparison of internet use patterns between RTR participants and the general NZ population	92

List of Figures

Figure 1: Ready to Roll project summary	40
Figure 2: Type(s) of features included in emergency plan amongst participants with an emergency plan	62
Figure 3: Reasons reported for not having an emergency plan amongst those with no plan	63
Figure 4: Emergency preparedness barriers identified by all participants	64
Figure 5: Percentage of participants who support the concept of a DPERR compared to those who would actually participate in a DPERR	65
Figure 6: Concerns about how information is collected and entered in DPERR	67
Figure 7: Concerns about information access and privacy.....	68
Figure 8: Types of information participants were prepared to include on DPERR	69
Figure 9: Use and confidence of participants with internet based applications	70

List of Abbreviations

ACC	Accident Compensation Corporation
BAIL	Burwood Academy of Independent Living
CARD	Collaborating Agencies Responding to Disaster
CDEM	Civil Defence & Emergency Management
DHB	District Health Board
DIEP	Disability Inclusive Emergency Planning
DPERR	Disabled Persons' Emergency Response Register
DPO	Disabled Persons' Organisation
EMIS	Emergency Management Information System
FEMA	Federal Emergency Management Agency
FNSS	Functional Needs Support Service
GIS	Geographic Information System
GP	General Practitioner
GPS	Global Positioning System
ICT	Information Communication Technology
MCDEM	Ministry of Civil Defence & Emergency Management
NGO	Non-Government Organisation
NHI	National Health Index
NZ	New Zealand
ODIC	Office of Disability Integration and Coordination

RCF	Residential Care Facility
RR	Risk Ratio
RSS	Rich Site Summary
RTR	Ready to Roll
SAVE	Systems to Advise of Vulnerable Persons in Emergencies
SCI	Spinal Cord Impairment
SPSS	Statistical Package for the Social Sciences
US	United States
UoO	University of Otago
W/C	Wheelchair

Chapter 1: Background and Introduction

The Ready to Roll (RTR) study investigates emergency preparedness and response for people with disabilities in New Zealand (NZ). The project has arisen from concerns highlighted by people with disabilities following the 2010- 2011 Canterbury earthquakes. In this chapter, the background to the issues which underpin the development to the current project will be discussed.

Firstly, the NZ specific contextual factors are discussed, specifically the number and demographics of the NZ disabled population, the risks posed by NZ's unique geographical features and an overview of NZ's emergency planning and response framework are presented. Next, the role of Information and Communication Technology (ICT) in the emergency planning sector is discussed. Following this, the impact that emergencies have on people with disabilities is discussed using examples from disaster experiences from the United States (US) and NZ. The Hurricane Katrina and Canterbury earthquake experiences are particularly highlighted. This is because the impact of Hurricane Katrina on disabled people has been a catalyst for research and policy changes that may offer insights for the NZ context and second the Canterbury experience was the catalyst for the study. This leads to a discussion of initiatives used for improving the emergency planning and response for people with disabilities. The chapter concludes with a discussion of how the RTR study's research questions contributes to the evidence base by addressing existing knowledge gaps.

Information cited within this chapter comes from a variety of sources including articles published in peer reviewed journals, reports and websites of governmental and non-governmental organisations as well as unpublished grey literature available online. A non-systematic review of the literature published in English language journals was undertaken prior to, and during, the study period using the Web of Science, Ovid, Science Direct, and Scopus databases. Search terms included emergency, disaster, emergency preparedness, disaster preparedness, readiness, disability, wheelchair user, emergency register, information communication technology. In addition, reference lists of identified articles were reviewed for potentially useful articles.

Abstracts of articles thus identified were assessed for relevance to the research questions.

1.1 People with disabilities in New Zealand

1.1.1 The number of New Zealanders affected by disabilities

In 2013 it was reported that people with disabilities represent nearly a quarter (24%) of NZs population with over one million people throughout the country having at least one disability. The number of people with disabilities has increased by four percent since 2001, partly in response to our ageing population. Those over 65 were much more likely to have a disability (59%) than adults under 65 (21%) or children (11%) (Statistics New Zealand, 2014a).

Physical impairment affected 64% of all disabled adults (18% of all New Zealander's aged 15 or over) and was the most common form of disability reported. Amongst those with a physical disability, mobility impairment was the most common, affecting 13% of the total NZ population (557,000 individuals) (Statistics New Zealand, 2014b).

At face value Māori have a similar disability rate (26%) to European New Zealanders (25%) whereas those of Pacific (19%) and Asian (13%) descent have a lower than average disability rate. However, Māori and Pacific people have a younger population age profile than the total population and once this is accounted for, a higher than average rate of disability for Māori and Pacific people is seen (European, 24%; Māori, 32%, Pacific, 26%). Asian people continued to have a lower rate of disability (17%) than other ethnicities even after adjusting for the lower age profile. The median age of people with a disability within each ethnic group shows that disabled European New Zealanders tend to be older than other ethnic groups (European, median age = 57 years; Māori, median age = 40 years; Pacific, median age = 39 years; Asian, median age = 45 years)(Statistics New Zealand, 2014a).

Multiple disabilities are common, with 53% of all disabled people having more than one impairment type. There are differences in the rates that males and females are affected by different impairment types but overall there is no difference in disability rate between genders (Statistics New Zealand, 2014b).

1.1.2 Socioeconomic outcomes for people with disabilities in NZ

People with disabilities in NZ have poorer outcomes across a range of social and economic variables than the non-disabled population (Office for Disability Issues, 2012), (Statistics New Zealand, 2014c). In their briefing paper to the incoming minister, the Office for Disability Issues reports that the three preceding Statistics NZ Disability Surveys (1996, 2001 and 2006) “consistently show poorer life results for disabled people” (p. 13). People with disabilities were more likely to live alone, reside in areas of greater deprivation, to be unemployed and have lower personal and household incomes compared to their non-disabled counterparts (Office for Disability Issues, 2012).

The most recent Statistics NZ *Disability Survey*, conducted in 2013, confirms that people with disabilities in NZ continue to have poorer socio-economic outcomes than the general population. In addition, disabled people were less likely to go out after dark and were more likely to feel vulnerable if they did, were more likely to experience discrimination, less likely to participate in popular leisure activities and more likely to have felt lonely in the past four weeks (Statistics New Zealand, 2014c).

The poor and socially isolated members of a community are at greater risk following emergencies (Gabe, Falk, McCarty, & Mason, 2005; United Nations, n.d.). Thus, the existence of these poorer social and economic outcomes for disabled New Zealanders increases their vulnerability to emergency situations in a way which is separate, and additional to, their disability related issues.

1.1.3 Funding support for people with disabilities in New Zealand

There are two distinct funding systems for people with disabilities in NZ and each funding stream has their distinct criteria, processes and entitlements. With few exceptions, people who sustain a disability as a result of an injury or accident are covered by the Accident Compensation Corporation (ACC). ACC are legislated to fund most treatment expenses, equipment and carer needs required as a result of disability and earnings related compensation (for those working at the time of their injury) equivalent to 80% of the person’s pre-injury income. For those people with a congenital or medically induced disability, funding support comes from the Ministry of

Health for health, equipment and home based support needs while the Ministry of Social Development provides benefits to those who are unable to work as a result of their disability. In general terms, the level of funding and income support provided by ACC appears greater than that provided to those who are not covered by ACC thus producing a disparate, two-tier funding system within in NZ (personal observation based on clinical experience).

1.2 New Zealand: A landscape of risk

NZ is a country shaped by its geology and weather patterns. Sitting on the junction of two continental plates, NZ is a seismically and volcanically active nation while our island geography and mid latitudes location produces weather systems with the potential to produce storm events significant enough to cause damage to property and lives. NZ's geological and ethnological history is littered with examples of events that have produced sudden and dramatic environmental changes. In the times of human habitation, these events have often had destructive social consequences as a result of significant damage to property, livelihoods, social and physical infrastructure (Officials' Committee for Domestic and External Security Coordination, 2007)

The *National Hazardscape Report (2007)* lists 17 natural and manmade hazards which have the potential to trigger an emergency event in NZ. Significant natural hazards include earthquakes, volcanic eruption, tsunami, earthquake or weather induced landslide, floods, coastal hazards, severe winds, snow and wildfires. In addition, there is an increasing potential for man-made emergencies such as infectious disease epidemics, hazardous substance incidents or terrorism (Officials' Committee for Domestic and External Security Coordination, 2007).

Of these 17 hazards, floods are the most common cause of an emergency in NZ (Officials' Committee for Domestic and External Security Coordination, 2007).

However, NZ experiences around 150 earthquakes that are strong enough to be felt with a further ten to fifteen thousand smaller earthquakes being recorded annually. There is also the ever present risk posed by the Alpine fault line which travels over much of the length of the South Island and is one of the most significant onshore fault

lines on earth. Although it has not moved since European settlement, it has the potential to produce a magnitude eight or greater earthquake, strong enough to cause widespread damage to buildings and infrastructure (Officials' Committee for Domestic and External Security Coordination, 2007). In addition NZ has seven active volcanic regions, and our largest city, Auckland, is built on a volcanic field that contains approximately 50 known volcanoes within the wider region (Ministry of Civil Defence & Emergency Management, 2002).

The most significant fatality-producing natural disaster events in NZ to date include the Mt Tarawera volcanic eruption of 1886, killing 153 people, earthquakes in Hawkes Bay in 1931 (256 people killed) (Officials' Committee for Domestic and External Security Coordination, 2007) and Christchurch, 2011 in which 185 people lost their lives.

Given the landscape of risk in which we live, there is a very real potential of a major emergency event striking NZ. Thus the emergency sector's premise that disaster can strike at any time is as apt in NZ as anywhere else in the world. This makes the need for effective preparation and response planning for every member of the community all the more important.

1.3 Emergency planning and response in New Zealand

The Ministry of Civil Defence and Emergency Management (MCDEM) is mandated by the *Civil Defence Emergency Management Act 2002* ("the Act") as the primary organisation responsible for emergency management planning and response in NZ (Ministry of Civil Defence & Emergency Management, 2002). The MCDEM works in close association with local government and territorial authorities in order to assess, plan for and respond to risks at a regional level. Each region in NZ has a regional Civil Defence Emergency Management (CDEM) group covering a single or multiple territorial authorities. It is their responsibility to plan for and respond to local emergencies while MCDEM have the responsibility of managing large scale or national emergencies. The Act allows for the Director of the MCDEM to issue guidelines to

assist organisations responsible for delivering Act related duties to fulfil their requirements (Ministry of Civil Defence & Emergency Management, 2002).

NZ emergency planning measures are based on the “4 R’s” approach (Ministry of Civil Defence & Emergency Management). The 4 R’s refer to the principles of reduction (of hazards), readiness, response and recovery. The 4 R’s approach is prescribed in the Act and is endemic through MCDEM and territorial authority training and policies. Further details of the issues covered by the 4 R’s approach are presented in Table 1.1.

Table 1.1: The 4R's of emergency management

4 R principle	Issues considered
Reduction	Identifying and analysing long-term risks to human life and property from hazards; taking steps to eliminate these risks if practicable, and, if not, reducing the magnitude of their impact and the likelihood of their occurring.
Readiness	Developing operational systems and capabilities before a civil defence emergency happens; including self-help and response programmes for the general public, and specific programmes for emergency services, lifeline utilities and other agencies.
Response	Actions taken immediately before, during or directly after a civil defence emergency to save lives and protect property, and to help communities recover.
Recovery	The coordinated efforts and processes to bring about the immediate, medium-term and long-term holistic regeneration of a community following a civil defence emergency.

Adapted from the Ministry of Civil Defence and Emergency Management (n.d.)

1.4 People with disabilities in emergency situations

While all members of a community are exposed to the risks associated with disasters at similar rates, experience shows that vulnerability to those risks is not shared equally amongst the population. An individual's vulnerability during disasters is influenced by their socio-economic status, their degree of social empowerment and their access to resources that can mitigate risk or assist recovery from emergencies (United Nations, n.d.). Within this context, international experience shows that the elderly and people with disabilities are at greater risk of further disablement, injury or death than the general population in emergency situations (Adams, Kaufman, van Hattum, & Moody, 2011; Bethel, Foreman, & Burke, 2011; Brunkard, Namulanda, & Ratard, 2008; Chou et al., 2004; Doocy, Daniels, Packer, Dick, & Kirsch, 2013; Fujii, 2012; Hogan et al., 2011;

Markwell & Ratard, 2008; Ramirez & Peek-Asa, 2005; United Nations, n.d.; White, Fox, Rooney, & Cahill, 2007).

1.4.1 Morbidity and mortality for people with disabilities in disasters

The reasons that disasters have a greater impact on people with disabilities appear multi-factorial, including (i) inaccessible evacuation transport and shelters, (ii) potential discrimination when accessing scarce resources or services, (iii) a disproportionate impact on people with disabilities resulting from disruption to usual physical, social and environmental support systems and services, and (iv) exclusion from recovery planning and reconstruction efforts which misses an opportunity to create accessible environments and resilient communities for the future (United Nations, n.d.).

Environmental factors play an important role in how people with disabilities are able to participate in their communities. Enders and Brandt (2007) remind us that disability results from the interaction of a person with their environment. While a person may have an impairment of some bodily function, the extent to which this disables them can depend a lot on the environment in which they operate. Thus, people with moderate impairments may be able to function independently, or with minimal disability, in their community given the appropriate equipment and physical and social environment. Conversely those with minimal impairments may have extreme difficulty in their community during emergency situations that affect their environment.

Disasters, by their very nature, significantly disrupt the environment in which all members of a community have to function. Environments can shift from enabling to disabling in a matter of moments. A disaster can be sufficiently disruptive to have a disabling effect upon members of the able-bodied population. It is therefore not surprising that the effects for those with pre-existing impairments would be greater. The loss of usual routines, support networks, equipment, modified housing or transport and civic infrastructure all have the ability to increase the disability of an individual by changing the balance of the person-environment interaction.

People with disabilities are more likely to die as a result of a disaster with mortality rates for disabled persons being up to four times higher than the able-bodied population (Fujii, 2012). Following the Great East Japan Earthquake (2011) and subsequent tsunami, the mortality rate amongst disabled are reported to be at least twice that of the general population. In coastal regions of the Miyagi Prefecture the mortality rate for disabled persons was even higher due to the impaired ability of disabled people to receive and/or respond quickly to tsunami warnings. In this badly affected area, there was a total population mortality rate of 0.8%. In contrast, the mortality rate amongst the disabled population was 3.5%, more than four times higher (Fujii, 2012).

Mortality disparities between the general population and people with disabilities have also been demonstrated in other disasters. While definitions and data collection methods vary amongst published studies, the trend of higher mortality amongst those with disability appears consistent. For example, following the 1999 Taiwan earthquake Chou (2004) identified an odds ratio of death amongst those with a moderate physical disability of 1.7 (95% Confidence Interval [CI] = 1.2 - 2.3) compared with able bodied controls. In a similar case-control comparison between victims of the Hanshin-Awaji earthquake (1995) Osaki and Minowa (2001) found those with physical disability had an odds ratio of death of 1.9 (95% CI = 1 - 3.4) in comparison to able-bodied controls.

In addition to increased mortality, people with disabilities are more likely than the general population to suffer adverse outcomes after an emergency (Gershon, Kraus, Raveis, Sherman, & Kailes, 2013; Morgan et al., 2015; S. R. Phibbs, Woodbury, Williamson, & Good, 2012). For example, people with disabilities are more likely to lose permanent housing or possessions and have an increased risk of financial hardship in the aftermath of an emergency (Gershon et al., 2013). In a survey of over 2000 Christchurch residents (repeated three times between September 2012 and September 2013) those with a disability were amongst those identified as being vulnerable to poorer outcomes. Specifically, people with disabilities were less likely to rate their quality of life or emotional wellbeing positively compared to the general population (Morgan et al., 2015).

1.5 Personal preparedness of people with disabilities

Preparedness is related to the 4 R's principle of readiness as described in section 1.3 and is defined as "the knowledge and capacities developed by governments ... organisations, communities and individuals to effectively anticipate, respond to, and recover from, the impacts of likely, imminent or current hazard events or conditions" (United Nations International Strategy for Disaster Reduction, 2009, p. 21). At an individual level, having adequate household preparedness has been identified as one of the most effective ways to mitigate the risks associated with emergencies (Levac, Toal-sullivan, & O'sullivan, 2012; D. L. Smith & Notaro, 2015) and is a cornerstone of emergency planning (Ministry of Civil Defence & Emergency Management, 2010b). To be prepared for emergencies all members of the community are encouraged to make preparations to be self-sufficient for at least three days following an emergency including stockpiling and maintaining a supply of food, water and other emergency survival items, having a survival plan which includes what to do away from and at home and having a plan for connecting with family or other significant people following an emergency (Levac et al., 2012; Ministry of Civil Defence & Emergency Management, 2010b).

The primary means of raising public awareness about preparedness throughout NZ is the Get Ready Get Thru campaign which, according to the Colmar Brunton (2014) report, is recognised by almost two thirds of New Zealanders. Information specific to people with disabilities is provided on the Get Ready Get Thru website but no other specific educational campaigns targeting this group are known to be in effect (Dunn, Nicholls, Cassidy, & Sinnott, 2012).

1.5.1 Preparedness recommendations for people with disabilities

Emergency preparedness measures in addition to those outlined above are recommended for people with disabilities. Recommendations may include things such as evacuation route planning, stockpiling consumable products and medications, making arrangements with carers and/or support networks and considering alternative options to access essential equipment (Federal Emergency Management Agency, n.d.; Ministry of Civil Defence & Emergency Management, 2010b, n.d.-b;

National Organization on Disability, 2009). In NZ up to an extra 17 emergency preparedness messages for people with disabilities are listed in the *Working From the Same Page* (2010) report produced by MCDEM (Ministry of Civil Defence & Emergency Management, 2010b). Three of these recommendations relate specifically to wheelchair users. The latest readily available public information published by NZ Civil Defence on their website places an emphasis on people with disabilities building a personal support network as well as having a get-away kit, including specialised items in emergency supplies and maintaining at least seven days' supplies of essential medications (Ministry of Civil Defence & Emergency Management, n.d.-b).

1.5.2 The level of preparedness amongst people with disabilities

Several previous studies have identified low levels of personal preparedness amongst people with disabilities (Gershon et al., 2013; National Organization on Disability, 2005; D.L. Smith & Notaro, 2009; D. L. Smith & Notaro, 2015; Wolf-Fordham, Curtin, Maslin, Bandini, & Hamad, 2015). However, the literature regarding the types of emergency preparedness activities undertaken by people with disabilities provides some contradictory findings. There is some research showing that disabled people may be prepared in some aspects of emergency planning at similar rates to the general population but less prepared in other aspects (Bethel et al., 2011; Eisenman et al., 2006; Eisenman et al., 2009; Uscher-Pines et al., 2009). For example, in southern Pennsylvania, Uscher-Pines et al. (2009) conducted a random digit dial telephone survey of 501 adults, a fifth of whom had a member of the household who would require special transportation assistance in an emergency. They identified that disabled or medically unwell people were more likely to have an identified meeting place or shelter, a supply of medications and a get-away kit but were no more likely to have a complete set of household emergency supplies than non-disabled people. In a 2002-2003 telephone based survey of over 1000 Los Angeles residents Eisenman and colleagues (2006) found that those with a disability were more likely to have made an emergency plan for a terrorist threat than non-disabled. However a later survey (2004-2005, n = 2588) using a similar random digit dialling sampling method found no differences in the level of preparedness between disabled and able-bodied people (Eisenman et al., 2009).

On the other hand, other studies have identified lower levels of preparedness amongst disabled people across multiple aspects of emergency preparedness (National Organization on Disability, 2005; D.L. Smith & Notaro, 2009; D. L. Smith & Notaro, 2015). For example, the *Functional Needs of People With Disabilities* (2005) report concluded that 61% of disabled Americans had not made evacuation plans while only 24% had made an emergency plan or preparations specific to their disability (National Organization on Disability, 2005). Using combined data from pre-existing datasets (The Behavioural Risk Factor Surveillance System) including surveys conducted in the United States (US) between 2006 and 2012, Smith and Notaro (2015) found that only about one-third of people with activity limitations (n = 23,172) have an emergency plan. In addition, compared to the general population, those with an activity limitation were more likely to report not being prepared at all and were less likely to have emergency items stockpiled or evacuate if mandated to do so. These results were found to be consistent across the timeframe included in the surveys with “little to no improvement [in preparedness] from 2006 to 2012” (D. L. Smith & Notaro, 2015, p. 411).

The context within which participants are surveyed is often poorly described in previous studies (Bethel et al., 2011; Eisenman et al., 2006; Eisenman et al., 2009; Gershon et al., 2013; National Organization on Disability, 2005; D.L. Smith & Notaro, 2009; D. L. Smith & Notaro, 2015; Uscher-Pines et al., 2009; Wolf-Fordham et al., 2015). There is generally little explanation provided regarding what programmes, initiatives or public messaging is in place to inform or support people with disabilities to increase their personal emergency preparedness. Thus it is difficult to identify if variations in results obtained across various studies are impacted upon by different practices that occur within the various locations that studies take place.

Amongst US spinal cord injured wheelchair users (n = 487) McClure et al. (2011) identified a large gap between the percentage of participants who felt they could safely evacuate their homes compared to the percentage who had actually formulated an evacuation plan. Furthermore, half the participants identified that they would require the assistance of another person to evacuate their home in the event of an emergency and a quarter reported that their intended evacuation relies on assistive

technology. In a qualitative enquiry amongst wheelchair using veterans (n = 19) and staff of veteran affairs hospitals (n = 21) who all had first-hand experience of emergencies, Hogan et al. (2011) provide some insights into systems or practices that could assist with emergency preparation and response. However, the authors do not report on the proportion of wheelchair users who had a personal or household emergency plan.

The issues underlying the poor level of preparedness are not well understood (Riscoe, Schlegelmilch, & Paturas, 2013) (Riscoe et al., 2013) but are likely to include such things as a lack of disability-accessible information, the cost of setting up an emergency survival kit, an inability to stockpile certain consumable items, especially medications, being reliant upon others to assist with making preparations or for some socially isolated disabled individuals, making and maintaining support networks. Owens (2012) identified that other vulnerable groups, namely Non-Asian ethnic minorities and those in low socio-economic groups, were also potentially missing out on the benefits of emergency preparedness public education programmes.

1.6 A recent international example: Hurricane Katrina

On the 29th August 2005 Hurricane Katrina came ashore from the Gulf of Mexico, making landfall on the southern US states of Louisiana and Mississippi. It was to become one of the US's deadliest ever hurricanes producing flooding up to six metres deep over 80% of New Orleans (Markwell & Ratard, 2008). Over 455,000 people were displaced from the Greater New Orleans area (Adams et al., 2011) and up to 1170 people died as a direct result of the hurricane, associated injuries or diseases (Markwell & Ratard, 2008).

The elderly were particularly hard hit with death rates for those 65 or over being up to four times higher than those aged 45-64 (Markwell & Ratard, 2008). Brunkard et al. (2008) identified 971 deaths directly attributable to drowning (40%), injury and trauma (25%) or heart conditions (11%) with 49% of fatalities occurring in the 75+ age group. Adams et al. (2011) identified that those over 60, accounted for 75% of

fatalities despite only representing 15% of the pre-storm population. Nearly half of the elderly residing in affected areas had one or more disability (Gabe et al., 2005).

Hurricane Katrina also highlighted the plight of younger people with disabilities in emergencies. It is difficult to determine the exact number of people with disabilities who died in the aftermath of the hurricane. However, the *The Impact of Hurricanes Katrina and Rita on People With Disabilities* report (2006) states that “it is clear that a disproportionate number of fatalities were people with disabilities” and that “many more people with disabilities under the age of 60 died or were otherwise impacted by the hurricanes” (National Council on Disability, 2006, pp. 3-4). Lack of disability accessible communications, evacuation transport, emergency shelters and interim accommodation were issues identified that have contributed to the disproportionate death and impact rates on people with disabilities (National Council on Disability, 2006), (White, Fox, Rooney, & Cahill, 2007).

These deaths and consequences occurred despite pre-existing legislation (the Americans with Disabilities Act, 1990) intended to eliminate discrimination against people with disabilities and a presidential executive order passed in 2004 which required specific consideration of people with disabilities in emergency planning measures (Markenson, Fuller, & Redlender, 2007).

1.7 The Canterbury earthquake series

The Canterbury earthquake series commenced on the 4th September 2010 with a 7.1 magnitude quake centred near Darfield, 40 kilometres west of Christchurch causing extensive property and infrastructure damage. A further significant, 4.9 magnitude, quake struck the region on the 26th December 2010, causing further damage to buildings and cutting power and water to many homes. This was followed, on the 22nd February 2011, by the most destructive quake of the series. Centred just ten kilometres from the city centre the 6.3 magnitude earthquake was associated with extremely high ground acceleration forces (GNS Science, 2011), causing extensive damage to the central business district, eastern and hill suburbs of Christchurch. The

collapse of two multi-story buildings were responsible for many of the 185 fatalities resulting from that day.

Christchurch went on to endure over 10,000 aftershocks. The city's infrastructure sustained damage significant enough to require years of repair work with an estimated repair cost in excess of 30 billion dollars (Brookie, 2012). Widespread social disruption occurred with many Canterbury residents being temporarily or permanently displaced from their homes as a result of the earthquakes. As the damage to infrastructure and homes was greatest in the poorer eastern suburbs, the effects on the more vulnerable members of the community were magnified.

1.8 People with disabilities and the Canterbury earthquakes

No published data is available to determine the mortality rate amongst disabled persons in the 2011 Christchurch earthquake. While, anecdotally, it does not appear that disabled persons were disproportionately affected in terms of mortality, several reports highlight the significant effects that the earthquakes had on disabled Cantabrians (Brereton, 2012; Morgan et al., 2015; S. Phibbs, Good, Severinsen, Woodbury, & Williamson, 2015; S.R. Phibbs, Good, Severinsen, Woodbury, & Williamson, 2014; S. R. Phibbs et al., 2012).

The emergency response for people with disabilities following the Canterbury earthquakes is characterised by variability. Some people with disabilities had a favourable response while others felt vulnerable, isolated, abandoned, dependent and fearful (Brereton, 2012; S. R. Phibbs et al., 2012). Those individuals with good pre-existing support networks (S. R. Phibbs et al., 2012), an effective emergency plan and kit or those who either proactively sought information themselves or had an effective advocate do this on their behalf (Brereton, 2012) had a more positive response than those who did not.

Mobility within homes or communities severely affected people with disabilities in post-quake Christchurch and was one of the major issues identified by them (Brereton, 2012; Dunn et al., 2012; S. R. Phibbs et al., 2012). For people with mobility impairments, the causes of further disablement following the earthquakes is easily

understood and includes factors such as fallen objects within homes (eg: bookcases, fridges) impeding mobility from room to room; damage to exits (eg: ramps, keyless entry door systems not operating) preventing egress from buildings; severe cracking or lifting of footpaths, flooding and liquefaction restricting mobility within the community and disruption to public transport adding a further barrier to participation within their community or meeting basic needs (eg: shopping) (Dunn et al., 2012).

However, mobility was also restricted for people with other types of disability. For example, vision impaired people found it much more difficult to negotiate the hazards produced by the earthquakes, or the barriers erected around them, while changes to regular routes and bus stop locations (once services resumed) added further problems for the vision impaired and their service animals. Those with intellectual impairment faced different issues but were often still restricted in their ability to mobilise around their communities, predominantly due to difficulties accessing or understanding information about changes to normal transport routes or services (S. R. Phibbs et al., 2012).

Significant issues with emergency welfare shelters, inaccessible temporary toilets, water distribution sites, accessing appropriate information and dealing with staff at organisations who did not have understanding of, or act on, disability related needs have been identified as additional issues faced by people with disabilities in Christchurch following the earthquakes (Brereton, 2012; Dunn et al., 2012; S. R. Phibbs et al., 2012).

Welfare centres set up after an emergency are intended to create an environment in which people displaced from their homes feel safe, seek assistance and have basic needs addressed. Unfortunately, the experiences of disabled people at Christchurch welfare centres tended to mirror the unsatisfactory experiences described following other major disasters around the world (Brereton, 2012; National Council on Disability, 2006; S. R. Phibbs et al., 2012; United Nations, n.d.; White, Fox, Rooney, & Cahill, 2007). The impression of disabled people was that Christchurch welfare centre staff and facilities were generally ill-equipped to address the needs of the disabled community (Brereton, 2012; S. R. Phibbs et al., 2012). A range of issues regarding

welfare centres have been highlighted including inaccessible toilets; insufficient space to mobilise around between beds, belongings etc.; mattresses on the floor that those with mobility issues cannot independently get in or out of; security of self, belongings or medications; inaccessible information and feelings of increased dependence. In at least one case, a disabled person was turned away from a welfare centre as staff felt their needs could not be accommodated, despite not asking the person what their needs were (S. R. Phibbs et al., 2012).

There are examples from the Canterbury earthquakes of individuals or organisations who actively sought to contact disabled people and identify their needs following the earthquakes. When this occurred the individual contacted generally felt well supported (Brereton, 2012; Dunn et al., 2012; S. R. Phibbs et al., 2012). However, the response by agencies overall was considered to be ad-hoc (S. R. Phibbs et al., 2012) with poor coordination of interagency communication (Brereton, 2012). Prior to the earthquakes there was no system in place to record the location and needs of people with disabilities for use in emergency situations (Dunn et al., 2012). John Hamilton, past director of CDEM¹, has also acknowledged that there were lessons to be learnt from CDEM's response to people with disabilities following the quakes (Hamilton, 2012; Ministry of Civil Defence & Emergency Management, 2013a). As a result of the acknowledged lack of coordination between support and response organisations "agencies were initially slow in responding to the specific needs of disabled people, on knowing where people were and who needed help" (Brereton, 2012, p. 10).

One of the apparent difficulties in meeting the needs of people with disabilities following the Canterbury earthquakes was with organisation's inability to access records, held locally, when infrastructure was disrupted or their ability to access buildings was disturbed (Dunn et al., 2012). Potential remediation of these types of issues can be facilitated by various technological advances that are becoming increasingly incorporated into contemporary emergency management practices. As such the following section describes some of the technology enabled advances that

¹ John Hamilton was Director of CDEM during and after the Canterbury earthquakes. He retired in November 2014.

are being used which have the potential to improve the emergency planning and response for people with disabilities.

1.9 The role of Information Communication Technology

Internationally and nationally, Information Communication Technology (ICT) is playing an increasingly important role in the emergency management sector (Federal Emergency Management Agency, 2011; Kapucu, Arslan, & Demiroz, 2010; Mersham, 2010; Ministry of Civil Defence & Emergency Management, 2013b; Troy, Carson, Vanderbeek, & Hutton, 2007). The following section describes some of the most common types of ICT used in modern emergency planning and response, namely Geographic Information System (GIS) mapping, proactive alerting systems, smartphone applications (apps) and social media.

1.9.1 Geographic Information System mapping

GIS mapping is a computer based system that can pull information from numerous sources, identify and then display locations. Information can be layered or filtered on request to display the specific details required. It is a technology that has widespread application within the emergency planning and response sector (Enders & Brandt, 2007; Ministry of Civil Defence & Emergency Management, 2010a). The strength of GIS lies in its analytical ability to source and spatially coordinate information from multiple systems allowing emergency responders to “quickly access and visually display critical information by location” (Enders & Brandt, 2007, p. 224). The use of mobile devices allows responders in the field to relay real time data about critical resources, infrastructure or people back to command centres in order to assist coordination of response efforts.

In NZ GIS mapping technology is incorporated into the Emergency Management Information System (EMIS) which was introduced in 2010. The system gives users the ability to dynamically map the location of variables such as the location of first response units, event sites, and critical infrastructure such as road closures, bridge conditions and hospitals (Ministry of Civil Defence & Emergency Management, 2010a).

1.9.2 Advance warning systems

Proactive, 'advance warning' or 'reverse 911' alerting systems have been established as an alternative (and additional) means of communication from emergency responders to members of the community. The system relies on individuals registering their mobile phone or device with the relevant authority in advance so that they can directly receive warnings about expected or unfolding emergencies. A variety of formats are operational, depending upon the location and authority who has established the system. This type of system is of most use in situations where advance warnings of emergencies are able to be given. As such they are most prevalent in regions where weather related emergencies (eg: hurricanes, tornadoes) are the most common.

1.9.3 Smart phone applications

Smartphone apps have been developed for use by both emergency response personnel and members of the public to assist with planning and response measures. For example, in NZ the EMIS incorporates smartphone features to facilitate information gathering and internal communications within the response sector (Ministry of Civil Defence & Emergency Management, 2010a). In addition, CDEM has apps that are downloadable by the public to improve emergency preparedness and provide some capability for advance warning.

1.9.4 Social media

Social media responses to emergencies come from official and unofficial sources. In NZ CDEM provides official notifications through various social media and ICT platforms including Twitter™, Facebook™, YouTube™ and Rich Site Summary (RSS) feeds. However, the need for official communications to be rigorously formulated prior to dissemination can lead to official messages lagging behind the need that members of the public have for information and guidance during an emergency. In such situations, unofficial social media networks can play an important role in a community's response (Mersham, 2010; Palen, Hiltz, & Liu, 2007).

Unofficial social media networks can potentially provide more rapid information and guidance to citizens about possible or actual emergencies. An example of such an

‘asynchronous disjunction’ between unofficial and official communications is provided by Mersham (2010) who analysed the response to the September 2009 tsunami threat to NZ. During this event official notifications lagged behind unofficial information posted on social media sites. Mersham also notes that social media is increasingly becoming the first point of reference for the public and the mainstream media. While information can be accessed quickly via unofficial social media, there is limited control over accuracy or appropriateness of messaging thus representing significant challenges for authorities (Mersham, 2010; Palen et al., 2007).

A further powerful application of social media is its ability to facilitate local, community driven responses to identified needs. Such responses may be driven independently of official efforts as discussed by Palen et al. (2007) and which were apparent following the Canterbury earthquakes through initiatives such as the Student and Farmy Armies which arose spontaneously and quickly to provide assistance to community identified needs.

1.9.5 Summary of Information Communication Technology’s role

Through a mixture of mediums, provided by a range of existing or spontaneously developed networks, ICT is increasingly becoming part of the emergency management landscape. The reach and speed of access to information enabled by ICT makes it a powerful adjunct to conventional emergency management practices. However, rapid advances in ICT, and especially social media, provides authorities with some additional challenges that require careful consideration and planning.

1.9.6 Accessibility of Information Communication Technology

It is estimated that in 2013, 66% of adult New Zealanders had a laptop computer while 48% had a smartphone. Eighty six percent of smartphone users report daily use of their device, an increase from the previous year (Research New Zealand, 5 March 2013). In addition, social media users in NZ now total some 2.8 million individuals with Facebook™ being the most popular at 1.95 million NZ users (IAB New Zealand, 2014).

The affinity of children for adopting technology is well appreciated in our culture but older adults appear also to be increasingly embracing ICT in their lives. NZs older

adults were early adopters of internet use compared with other countries, having the second highest rate of internet use in 2008 (39%), second only to Canada (Koopman-Boyden & Reid, 2009). Rates have continued to increase, with just under half of the over 65 population being internet users in 2012 (Statistics New Zealand, 2012).

While ICT access and use is generally on the increase in NZ there is evidence to suggest that increased accessibility is not universal and that some portions of society, including people with disabilities, may be missing out on the benefits provided by ICT. Internationally, use of the internet amongst people with disabilities has been shown to be significantly lower than the general population (Cheatham, 2012; Dobransky & Hargittai, 2006; Kaye, 2000; Vicente & Lopez, 2010). Kaye (2000) reported that people with disabilities in the US were only half as likely to have a computer or access to the internet in their homes as non-disabled people.

As previously discussed, people with disabilities in NZ are more likely to be socioeconomically disadvantaged (Office for Disability Issues, 2013; Statistics New Zealand, 2014a), this being one of the factors that has been implicated with poorer rates of personal internet access internationally (Dobransky & Hargittai, 2006; Vicente & Lopez, 2010). However, socioeconomic status is not the only potential barrier for people with disabilities accessing the internet as shown by Vicente and Lopez (2010), who, through a secondary analysis of the European eUser data set, found that “even when controlling for socioeconomic characteristics, people with disabilities are still less likely to use the internet” (Vicente & Lopez, 2010, p. 55). Software or hardware that is expensive or inaccessible to those with a physical or sensory impairment, a need for more knowledge, training or local support services to facilitate connection to ICT devices and the internet have been proposed as additional barriers to people with disabilities adopting digital technologies (Vicente & Lopez, 2010).

There is no literature regarding the use of ICT amongst the NZ disabled population. Thus the applicability of an important component of modern emergency planning and response measures (ICT) to disabled people in NZ is unknown.

1.10 Improving outcomes for people with disabilities

There have been numerous initiatives implemented internationally in response to previously identified shortcomings in the planning, response and outcomes for people with disabilities in emergency situations (Federal Emergency Management Agency, 2015; ParaQuad NSW, 2014; Robinson, Gerber, Eller, & Gall, 2011; Roth, 2010; White, Fox, Rooney, & Cahill, 2007). Similarly, in NZ, the Christchurch earthquakes have increased awareness within CDEM and the wider disability community about the need to improve individual and organisational preparedness to better meet the needs of disabled people (Brereton, 2012; Hamilton, 2012; Ministry of Civil Defence & Emergency Management, 2013a).

In the following sections a summary of some of the key international and NZ initiatives aimed at improving emergency preparedness for and by people with disabilities will be provided. The list of programmes discussed is not intended to be an exhaustive list of all initiatives, rather selected examples will be used to highlight the different types of approaches which are being used. Many of the international initiatives discussed are from the US and have been implemented following Hurricane Katrina. As the US governance environment pertaining to emergency planning for people with disabilities was changed significantly in response to the shortcomings identified after this disaster, this section commences with a summary of the key changes which have facilitated this burgeoning field of work.

1.10.1 Changes implemented following Hurricane Katrina

In response to acknowledged shortcomings in the emergency response following Hurricane Katrina sweeping changes were implemented by the *Post Katrina Emergency Reform Act (2006)*. Amongst these changes were an increased commitment to address the needs of people with disabilities in future emergencies through the appointment of a Disability Coordinator within the Federal Emergency Management Agency (FEMA) (Roth, 2010). As the lead organisation responsible for US emergency planning and response FEMA fulfils a similar role as MCDEM does in NZ.

Since February 2010 there has been a dedicated Office of Disability Integration and Coordination (ODIC) within FEMA. The ODIC vision is for a disability inclusive

approach to emergency planning so that people with disabilities are not seen as separate segment of the population but are considered as an integrated part of the whole community, whose needs are included in all aspects of preparation and response planning (Roth, 2010). ODIC has contributed a disability focus to numerous FEMA policies across a range of emergency planning and response areas and strives to establish collaborative relationships with the many external stakeholders involved in emergency management (Roth, 2010). Through these measures FEMA has taken a lead role in promoting a Disability Inclusive Emergency Planning (DIEP) approach.

In addition, academic and research interest in the area of disability related emergency management has proliferated since the 2005 hurricane season and the subsequent *Nobody Left Behind* project (White, Fox, Rooney, & Rowland, 2007). Prior to Hurricane Katrina little research regarding emergency preparedness and response for people with disabilities had been undertaken (Fox, White, Rooney, & Rowland, 2007) (Rowland, White, Fox, & Rooney, 2007; White, Fox, Rooney, & Rowland, 2007).

So while the impact of Hurricane Katrina on the elderly and people with disabilities was devastating, it has acted as somewhat of a catalyst for change within the US emergency management and research sectors. However, many issues that have been highlighted or initiatives that have been implemented still require further investigation to validate effectiveness and provide evidence for best practice (Rooney & White, 2007), (Rowland et al., 2007), (White, Fox, Rooney, & Rowland, 2007), (Riscoe et al., 2013), (McClure et al., 2011).

1.10.2 International initiatives

There are examples of international initiatives for advancing DIEP occurring at all levels, from central government down to local disability advocacy or service providers. A range of measures have been adopted including regulation/guidelines, preparedness and emergency planning education packages, registries and advance warning alert systems (Christopher and Dana Reeves Foundation, n.d.; Connecticut Developmental Disabilities Network, 2005; Federal Emergency Management Agency, 2010; Kailes, 2011; Kailes & Enders, 2014; Riscoe et al., 2013; Robinson et al., 2011; White, Fox, Rooney, & Cahill, 2007).

1.10.2.1 Regulations

Since 2010, FEMA have adopted a Functional Needs Support Service (FNSS) approach to DIEP (Robinson et al., 2011). The approach was introduced to improve compliance with various US legislative requirements and in recognition that historically those with functional needs were often subject to “disparate treatment and the denial of full and equal services” (Federal Emergency Management Agency, 2010, p. 9). It has coincided with a move away from the term ‘special needs’ which is considered to be so poorly defined that it could potentially account for up to 50% of the US population (Riscoe et al., 2013; Roth, 2010).

The FNSS approach focusses on the functional needs associated with disabilities rather than disability specific directives. It is intended to provide emergency planners and shelter managers with a system to categorise and identify the needs of disabled and other vulnerable individuals. Guidelines are provided to assist planners to accommodate identified needs. The FNSS approach also emphasises the need for, and provides guidance about how to, collaborate with stakeholders to obtain the expertise required to accurately identify and address the functional needs within a community. It acknowledges that such expertise often resides with disabled people themselves and as such they need to be active participants in the emergency planning process (Robinson et al., 2011).

However, following a literature review and interviews with subject matter experts, Riscoe et al. (2013) argues that the FNSS guidelines have a weak evidence base, can cause confusion amongst planners and slow down planning efforts. The authors highlight a particular problem in planning for the needs of people who are normally self-sufficient but are likely to require some extra assistance following an emergency. As this group of individuals are unlikely to be consulted prior to an emergency, allocating resources and predicting their needs is likely to be omitted in planning measures. Further research to fill the knowledge gaps identified, including the development and testing of strategies to more precisely determine the population of people with ‘medical dependency’, the resources they require and obtaining a better understanding of factors underlying personal preparedness for these individuals, is recommended (Riscoe et al., 2013).

1.10.2.2 Personal preparedness education resources and programmes

It is beyond the scope of this discussion to review the numerous resources produced by governmental (central and local) agencies and non-governmental organisations (NGO's) which are designed to improve preparedness of individuals, organisations and communities for disabled people in emergencies. However, it is worth noting that there are a large variety of content and formats available intended to meet the physical and communication needs of many disability types. For example, one resource guide alone (Christopher and Dana Reeves Foundation, n.d.) contains links to 25 different websites devoted to emergency preparedness training for people with disabilities. Numerous resources or programmes originate from North America and are freely available online in the form of written guidelines, checklists, instructional videos (with subtitles or sign language options) and webinars. Some resources are also available in other languages to cater for the needs of ethnic minority groups.

A smaller number of programmes are delivered as group training activities. One such programme, using a peer to peer educational approach, is the Prepare to Prosper programme provided by the Collaborating Agencies Responding to Disaster (CARD) supported by San Francisco Department of Emergency Management. The programme is presented by disabled people in an easily accessible form and has a fear-free, enabling philosophy. In particular, the programme emphasises that being prepared is an everyday activity for people with disabilities as they often need to plan activities, carry supplies and consider contingencies in the course of their everyday lives. Thus, preparing for emergencies is just an extension of an everyday activity (Collaborating Agencies Responding to Disasters, 2015).

A recent Australian collaboration of Bright Sky Australia and ParaQuad has produced an emergency planning checklist for people with disabilities. The tool was developed with spinal cord injured individuals in mind but has potential application across disability types, and with minor modification, in other countries (including NZ) (Jennifer Greenaway, personal communication, 19 Nov 2014).

Despite the prevalence of educational material aimed at improving the preparedness of people with disabilities for emergencies there is limited research which explores its

effectiveness. As such it remains unclear what personal preparedness education approach, if any, is most effective at improving the knowledge and uptake of preparedness activities amongst disabled people.

1.10.2.3 Vulnerable persons registers

Registers have been advocated as part of an effective emergency response for people with disabilities (Enders & Brandt, 2007; Rowland et al., 2007; White, Fox, Rooney, & Rowland, 2007) and are used at a local level in some US and Canadian regions. There are at least 28 such registers used in the U.S alone (Kailes & Enders, 2014) but there is very little detail in the published literature regarding how registers collect, store, maintain and use the information they contain (Dunn et al., 2012; Kailes, 2011; Kailes & Enders, 2014).

Kailes (2011), Kailes and Enders (2014) and Riscoe et al. (2013) warn that the effectiveness of registers has not been adequately demonstrated. The website of Kailes and Enders (2014) contains a comprehensive set of resources and background information regarding registers, including a list of comments supplied by emergency personnel with experience of managing registries on a daily basis or at times of emergency. While the method of selecting which comments are published is not specified, the majority of these comments express reservation about the effectiveness and practicality of registers as seen from the emergency planning stakeholders, thus providing insights into some of the limitations and difficulties associated with the use of vulnerable persons registers. Kailes (2011) further highlights potential concerns about the use of registers relating to expectations inferred by participants that may not be realised in times of disaster, resourcing issues, and loose definitions of purpose, target populations and operational guidelines. Thus, registers, while providing a potentially useful adjunct to a DIEP approach, are not a fix-all solution to the complex issues of enhancing the emergency response to, and by, people with disabilities, and if used need to be carefully planned.

1.10.2.4 Advance warning alerts

A further measure that is adopted by some local emergency response organisations is to use an advance warning notification system to advise vulnerable citizens directly of

evacuation or other emergency notices. In some cases this is referred to as a 'reverse 911' notification sent via text message or other accessible format. The intent of such a system is to ensure that those who may be at risk of missing notifications sent via conventional mass media methods or who may require more time to effect an evacuation are provided with the information they need. However, a system of this sort relies upon vulnerable people being registered for the service, and having access to suitable ICT devices and knowledge, prior to an emergency event occurring which is a potential barrier given the digital divide that may occur for people with disabilities as discussed in section 1.9.6.

1.10.2.5 Summary of international initiatives

The initiatives discussed above, provide some useful models and exemplars of approaches used internationally but cannot be assumed to be applicable to the NZ context without considering our unique risk profile, physical, fiscal and social environments or the needs of disabled people. For example, the issue of evacuation from multi-story residential buildings is a common barrier for people with disabilities in more densely populated urban areas internationally but is likely to be less of an issue for disabled people in NZ where this form of housing is less prevalent. It is also important to consider the existing measures that have been adopted in NZ to meet the needs of people with disabilities in emergencies.

1.10.3 New Zealand initiatives

Similar to the US, NZ has seen an increased focus on DIEP following a natural disaster in which the issues affecting people with disabilities coupled with a sub-optimal response to their needs was highlighted. In this section, examples of some of the measures adopted in NZ since the Canterbury earthquakes will be discussed. First, however, a brief overview of what was in place prior to 2010 is presented.

1.10.3.1 Emergency planning for people with disabilities in NZ prior to 2010

Prior to the September 2010 earthquake CDEM and other emergency services did not have a system in place to identify the location of people with disabilities or their needs to assist emergency response measures (Brereton, 2012; Dunn et al., 2012; S. R. Phibbs et al., 2012). Efforts to contact people with disabilities relied on individuals or

organisations checking existing service users or client lists. Systems were developed 'on the fly' and in some cases efforts were compromised by being unable to access buildings or damaged computer and communication networks (Dunn et al., 2012).

The ACC were able to utilise their claimant detail database to identify individuals who were likely to be most at risk, prioritise, then contact them to check on their wellbeing and needs (Personal communication: ACC case manager, 19th Nov 2014). Because of ACC's infrastructure, the database was accessible nationally therefore much of this work could be undertaken at offices outside of the disaster area. It stands as an example of one of the more successful ad-hoc response measures and provides some potentially useful learnings. Specifically, having a secure national database that can be accessed from outside of the area affected by an emergency can be a potentially useful tool, it allows for personnel, hardware and facilities removed from the damage zone to be utilised and provides a potential model for an emergency response planning tool. ACC's database had advantages over similar ones which were held by carer agencies as it included all serious injury regardless of their need for personal care assistance. Unfortunately, the database was not a full list of all disabled individuals as it did not include those who are not funded by them, thereby missing a significant proportion of the disabled community.

CDEM documents prior to the earthquakes referenced people with disabilities in at least two of its directives to staff. *Mass Evacuation Planning* (2008) and *Working From the Same Page: Consistent Messages From CDEM* (2010) both contain sections that instruct CDEM personnel about issues relating to communicating with and planning for people with disabilities in emergencies (Ministry of Civil Defence & Emergency Management, 2008, 2010b). However, based on available evidence, these directives failed to achieve the desired outcome of a well prepared disabled community and well organised response effort to meet the needs of this community (Brereton, 2012; Dunn et al., 2012; Ministry of Civil Defence & Emergency Management, 2013a; S. R. Phibbs et al., 2012).

1.10.3.2 Regulations/guidelines implemented post 2010

In 2013, there was a noticeable shift in the focus of CDEM documents to being more inclusive in the way they relate to and include people with disabilities in planning measures. The publication of an information series document *Including People With Disabilities* (2013) provided a clear directive to all emergency sector planning personnel that they need to actively engage with and plan for people with disabilities in the course of all planning activities (Ministry of Civil Defence & Emergency Management, 2013a). A subsequent director's guideline regarding public information management provides the requirement and guidelines (albeit general in nature) about communicating with vulnerable portions of the community, specifically including those with disability (Ministry of Civil Defence & Emergency Management, 2013b).

Further impetus to improve NZ's DIEP focus was provided by the latest *Disability Action Plan* produced by the Office of Disability Issues (2014). Priority number seven, of thirteen, is "to improve the responsiveness to disabled people of civil defence and emergency management around New Zealand" (Office for Disability Issues, 2014, p. 7). CDEM is listed as the lead agency responsible for delivering results on this objective but no details regarding measures of success, specific requirements or guidelines are provided.

1.10.3.3 Personal emergency preparedness education resources

The primary information website used by CDEM to the public, Get Ready Get Thru, now contains information specifically for people with sensory and mobility impairments. The information is presented in written, audio and video file format (with sign and eight other language options available) and a *Drop, Cover and Hold* pamphlet specifically for those with a mobility impairment (Civil Defence and Emergency Management, n.d.). In addition, some NGO's and private sector organisations have also produced or updated disability specific preparedness recommendations to the various disabled groups they represent (eg: NZ Foundation for the Blind, Stroke Foundation).

1.10.3.4 Community resources register

In response to the first Canterbury earthquake in September 2010, a group of people from the Selwyn district worked together on a community based initiative to compile

a register of individuals with specific needs, skills or resources that could be utilised in emergency situations. This was a project done in conjunction with, and under the auspices of, the Neighbourhood Watch programme (Dunn et al., 2012). A web-based database was produced which allows for GIS mapping of specific individuals or resources within the community. At the time of the second earthquake the capacity for mobilising and providing assistance was greatly enhanced by using the database (personal communication, David Wilkinson, Neighbourhood Watch Canterbury co-ordinator).

The Neighbourhood Watch initiative in Canterbury is a model which is enabling to people with disabilities. Through the three pronged focus of needs, resources and skills disabled people are able to register their need for potential extra assistance while at the same time listing skills or resources they possess that may be of assistance to others (eg: being an amateur radio enthusiast who could assist with post emergency communications or having a van with a hoist that could be used for transporting other disabled people or heavy equipment).

The developers of the programme were keen to see it extended beyond the Canterbury region via the Neighbourhood Watch network but were limited in their ability to do so due to resourcing. A further limitation of this approach is that it relies on an individual being part of the Neighbourhood Watch programme, a requirement that may be a barrier to widespread uptake for people with disabilities many of whom may be too socially isolated to participate. Thus, while it is a promising and positive initiative that has the ability to greatly enhance the contribution by, and response to, people with disabilities the Canterbury Neighbourhood Watch in its current form is unlikely to represent a viable national solution to the emergency response needs for this population.

1.10.3.5 Other technological adjuncts to emergency response

The use of technology as a tool to improve New Zealanders emergency planning has increased in recent years. Examples of this move include the Red Cross NZ and Auckland Civil Defence which have produced smart phone apps that contain information to assist households to plan for and respond to emergencies. Other apps

recently launched include the capacity for an individual's personal support network to identify their location through the use of Global Positioning System (GPS) co-ordinates (eg: HELP, GPS time tracking). As far as can be determined, at this time, there are no GPS enabled apps in use in NZ that have been developed specifically for people with disabilities.

1.10.3.6 Summary of NZ emergency preparedness initiatives for people with disabilities

In summary, the NZ emergency response sector was not well prepared to meet the needs of disabled people prior to the Canterbury earthquakes but has since made some initial progress towards a more DIEP approach. High level directives within CDEM and the national *Disability Action Plan* provide a mandate for change. However, it does not appear that this mandate has yet produced significant results with regards to meaningful participation of people with disabilities in planning measures or specifically targeted initiatives occurring within CDEM. There are examples of some Disabled Persons' Organisations (DPO's) and Neighbourhood Watch programmes that have some capacity to improve preparedness amongst engaged individuals in selected groups or communities but there remains a lack of centrally coordinated disability specific planning and response measures with no apparent explicit strategy.

1.11 Including people with disabilities in emergency planning

There is widespread agreement amongst national and international researchers, NGO's and leaders of emergency management authorities that people with disabilities must be meaningfully included in emergency planning measures (Brereton, 2012; Castaneda, 2011; Connecticut Developmental Disabilities Network, 2005; Dunn et al., 2012; Hamilton, 2012; Kailes, 2011; Markenson et al., 2007; Ministry of Civil Defence & Emergency Management, 2013a; Owens, 2012; S. R. Phibbs et al., 2012; Roth, 2010; White, Fox, Rooney, & Rowland, 2007).

An example of high level support for including people with disabilities in emergency planning comes from FEMA's director Craig Fugate who states "it is time children, people with disabilities or any other segment of our communities who have traditionally been underserved, to be more fully and consistently integrated into

preparedness and planning efforts at every level of government” (Federal Emergency Management Agency, 2015, p. para 5).

Since establishing the ODIC, FEMA have made some significant gains in their attempts to live up to this mantra, for example, by including a regional disability integration specialist within FEMA regional offices, providing disability specific tools and training to emergency managers, providing more accessible beds for emergency shelters, partnering with nationwide disability rights and independent living organisations to promote their inclusion with planning and response efforts, and hosting two nationwide conferences regarding DIEP practices (Federal Emergency Management Agency, 2015).

Similarly in NZ there is a mandate for including people with disabilities in emergency planning provided by the *Disability Action Plan* (Office for Disability Issues, 2014) and through the director of MCDEM’s information series guide, *Including People With Disabilities*. This guide stipulates that “CDEM personnel are **required** by the Director of CDEM to ensure that all planning, response and recovery arrangements accommodate people with disabilities” (Ministry of Civil Defence & Emergency Management, 2013a, p. 5).

However, unlike the US there is less evidence of specific initiatives or clear guidelines arising from the high level mandate. Therefore the challenge for the NZ emergency management and disability sectors would appear to be to turn the stated intent into meaningful action. There are some meritorious initiatives and models in the international emergency management and disability sectors from which to learn but further understanding of the issues impacting on people with disabilities in NZ is required to inform any future initiatives that may be employed.

NZ has a similar opportunity to learn from the Canterbury earthquake experience as the US did from the 2005 hurricane season. There, the deadly impacts of that disaster for the elderly and disabled acted as a catalyst for a better resourced and coordinated approach to DIEP. The challenge for NZ is to see if we can also learn from these experiences to adopt a truly disability inclusive approach to the unique risk and

demographic profile that exists here. The importance of the issue is heightened when considering that planning for people with disabilities is an issue that impacts on up to a quarter of our population.

1.12 Justification for the current study

1.12.1 Previous international surveys

As discussed in section 1.5.2, a number of previous international studies of emergency preparedness for people with disabilities have used a survey method. Some discrepancies in findings across studies have occurred, potentially due to variation in the types of disability or health status being surveyed and the terminology used to describe the types of emergency planning measures adopted by participants. Most studies have included people with any type of disability (Eisenman et al., 2006; Eisenman et al., 2009; McClure et al., 2011; D.L. Smith & Notaro, 2009; D. L. Smith & Notaro, 2015; Uscher-Pines et al., 2009; White, Fox, Rooney, & Rowland, 2007) with only two previous studies having specifically explored this issue in a wheelchair using population (Hogan et al., 2011; McClure et al., 2011). In addition, only one of these studies included survey data from the most recent seven years (D. L. Smith & Notaro, 2015) with most data being obtained prior to 2008 (Bethel et al., 2011; Eisenman et al., 2006; Eisenman et al., 2009; McClure et al., 2011; D.L. Smith & Notaro, 2009; Uscher-Pines et al., 2009; White, Fox, Rooney, & Rowland, 2007). As a result, the current extent and issues associated with emergency preparedness for wheelchair users remains poorly understood.

1.12.2 The existing NZ research base

There is limited research regarding how people with disabilities in NZ fare in emergencies. There are no published papers in the peer-reviewed or grey literature that quantifies the mortality rate of disabled people during the Canterbury earthquakes. Because existing disability status does not appear in the demographics of those injured or killed at the time of the emergency (Michael Ardagh, Christchurch Hospital Emergency Medicine specialist, personal communication, 22nd November 2013) obtaining accurate morbidity and mortality rates for this group is problematic. The impacts of the earthquakes on disabled Cantabrians has been discussed in the

papers previously mentioned (Brereton, 2012; Dunn et al., 2012; Morgan et al., 2015; S. Phibbs et al., 2015; S.R. Phibbs et al., 2014; S. R. Phibbs et al., 2012).

Tuohy and colleagues (Tuohy, Stephens, & Johnston, 2014; Tuohy & Stephens, 2015; Tuohy, Stephens, & Johnston, 2014) have investigated emergency preparedness amongst older NZ adults, however, the previously discussed study by Phibbs et al. (2012, 2014 and 2015) (see section 1.9), using a mixed method approach, appears to be the only original study to specifically investigate the issues encountered by people with disabilities during an emergency in NZ. They conducted interviews of 15 individuals (12 blind or vision impaired persons and three staff from the Royal NZ Foundation for the Blind) together with quantitative survey results of 25 disabled persons and ten family members to describe the experiences of disabled people following the earthquakes (S. R. Phibbs et al., 2012). They used the findings to make thirty recommendations across a range of areas including: emergency response planning, emergency accommodation and welfare centres, information and communication needs, disaster preparedness planning for disabled people, housing, mobility issues and further support needs.

One of Phibbs et al. (2012) recommendations, also made by Brereton (2012) is that consideration should be given to the establishment of an opt-on emergency response register for disabled people in NZ. The suggestion arose from participants in the study and symposium respectively. CDEM also cite a vulnerable persons register as a potential adjunct to planning measures (Ministry of Civil Defence & Emergency Management, 2010b) but there has been no formal evaluation of the level of support for, or practicality of, implementing such an initiative.

As the issues raised by people with disabilities in the aftermath of the Christchurch earthquakes were mostly related to the principles of organisational and individual preparedness and response (Brereton, 2012; Dunn et al., 2012; S. Phibbs et al., 2015; S.R. Phibbs et al., 2014; S. R. Phibbs et al., 2012), the current study has been developed to further investigate these issues. As far as can be determined, no nationwide NZ study has previously investigated the state of emergency preparedness amongst disabled people or of the factors that may impact on this. Many issues

regarding how prepared people with disabilities are for emergencies, or what barriers they encounter within NZ remain unexplored.

1.12.3 The existing knowledge gap

Based on the available evidence a number of existing knowledge gaps regarding emergency preparedness and planning for people with disabilities in NZ have been identified. Firstly, while international research indicates that people with disabilities tend to be less prepared for emergencies than the general population, the current level of emergency preparedness amongst people with disabilities in NZ is not known. Alongside this, the issues or barriers to personal preparedness that are faced by people with disabilities in NZ has not been investigated. There is a critical need to address this knowledge deficit to inform future disability inclusive planning initiatives.

ICT has become an integral adjunct to emergency planning and response practice but there is a poor understanding of how people with disabilities in NZ access and use this technology. Given international evidence that finds a digital-divide can exist between people with disabilities and the general population it is important to gain a clearer understanding of the ICT access and use patterns of people with disabilities to ensure that they are not excluded from the benefits provided by this rapidly developing emergency management tool.

Vulnerable person's registers for use in emergencies have been advocated both internationally and within NZ. Given that registers of this kind are not without technical and operational difficulties, more research needs to be undertaken to identify if, and how, such a tool could be implemented in NZ. A high priority in this regard is to identify if there is likely to be widespread support for a Disabled Person's Emergency Response Register (DPERR) amongst disabled people, whether they would participate in a DPERR and what concerns they have about it. Phibbs et al. (2012) recommend that a cost-benefit analysis for an opt-on register be undertaken. However, in line with the disability rights ethos of "nothing about us without us" (United Nations, 2004, p. para 1), understanding the end user perspective of a register system is an important first step before proceeding to investigate the technical and operational requirements.

This research project aims to address these identified knowledge gaps within a sub group of the NZ disabled population. For the purposes of this study, wheelchair users have been selected as the participants for this study. The rationale for this decision is presented below.

1.12.4 Rationale for choosing wheelchair users as participants

Wheelchair users were selected as the participants for this study for two reasons. Firstly, wheelchair users are a defined sub group of those with a mobility impairment which is the most common type of disability in NZ (Statistics New Zealand, 2014a). Selecting only wheelchair users maintains a well-defined sample and avoids excessive heterogeneity of participants that could create difficulties with interpreting results, especially given likely sample size challenges.

Secondly, as the level of mobility impairment amongst wheelchair users is at the most severe end of the mobility impairment spectrum, it is reasoned that the majority of issues relating to emergency preparedness affecting mobility disabled individuals will be highlighted by this population. The same cannot necessarily be said if the sample was weighted heavily towards those with less severe mobility impairments, a possibility if broader inclusion criteria were adopted. For example, it is more likely that a wheelchair user will highlight a broader range of mobility impairment related issues regarding emergency preparedness than an individual who uses a walking stick.

However, it is acknowledged that limiting the survey to only wheelchair users incorporates only a small proportion of those with a disability. As such, the range of issues able to be identified and the generalisability of findings from the study is less than if a broader sample of the disabled population was included.

1.13 Aims of the project

The aim of the study was to further the understanding of issues related to emergency preparedness amongst wheelchair users in NZ by identifying their level of personal preparedness, what they perceive as barriers to preparedness, to seek their opinions regarding a proposed DPERR and their ICT use patterns. The title chosen for the project, 'the Ready to Roll survey' was intended to reflect both the concept of

readiness and the nature of the participants (wheelchair users). With the participant considerations and the knowledge gaps discussed above in mind, four key research questions are identified. These questions are:

Amongst wheelchair users in NZ:

1. What is the current state of preparedness for emergencies?
2. What are the perceived barriers to emergency preparedness?
3. What is the level of support for, and concerns about, a Disabled Persons Emergency Response Register?
4. What types of ICT, which could be used to support emergency planning and response, are currently being accessed and used?

Chapter 2: Research Methods

The nature of the research questions (section 1.13) led to a quantitative survey method being selected for this study. Alternative approaches such as interviews or focus groups were considered as a means of obtaining more detailed perspectives of the issues under investigation. However, the requirement for obtaining as broad a representation of opinions as possible, within the constraints of the available resources, meant that a survey was the most appropriate method to achieve the aims of the study. This chapter will discuss the methodological approach and research methods used in this study. The development of the survey tool and participant recruitment processes are also presented.

2.1 Methodology

This research sits within the positivist quantitative paradigm as described by Creswell (2014). The positivist philosophy is deterministic in that it assumes observed outcomes are the result of specific causes and it is these causes that positivist researchers attempt to identify and measure. Positivism has been described as the traditional form of scientific research and as such is more often associated with the quantitative approach than a qualitative one (Creswell, 2014).

Creswell (2014) describes the key assumptions of a positivist approach, as: (i) absolute truth can never be found and it is for this reason that researchers state that they fail to reject a hypothesis rather than proving a hypothesis, (ii) research is a process which involves developing theories, testing them and then accepting, rejecting or refining them, (iii) knowledge is gained through collecting data with instruments completed by participants or through researcher observations, (iv) researchers attempt to develop statements that describe the causal relationships among variables, and (v) being objective is an important feature of good quantitative research, meaning that methods and conclusions are examined for bias. The Ready to Roll (RTR) study uses a survey method and is considered to sit within the positive quantitative paradigm as it incorporates many of the features described above, namely data was gained through

participants completing a questionnaire, a causal relationship between variables was sought and researcher objectivity was maintained throughout the study.

Limitations of the survey method, particularly an online one, were acknowledged in the development of the research methods. Specifically I was aware of issues related to achieving an adequate sample size, potential low response or item completion rates, limited external validity if using a non-probability sampling strategy, having an inability to ask follow-up questions or clarification of responses received (as is possible with interview or focus groups), potential sample bias towards participants who are more engaged with the topic and computer literate, and potential privacy concerns with internet based questionnaires (Ritter & Sue, 2007a; Whitehead, 2007). However, the advantages of a survey method (low cost, broad geographic coverage, ease of collating data for analysis and an ability to maintain participant anonymity) (Ritter & Sue, 2007a) together with consideration of the aims of the study led to the selection of a survey method.

2.2 Research methods

The RTR study is a nationwide survey administered using either the Survey Monkey™ web host or paper-based questionnaire. Participants were able to choose their method of survey completion based on their own preference.

Planning and consultation commenced in July 2013 with survey response collection occurring from the 1st May 2014 until 30th November 2014. An overview of the research process, methods, critical events and timeline is provided in a flowchart (Figure 1).

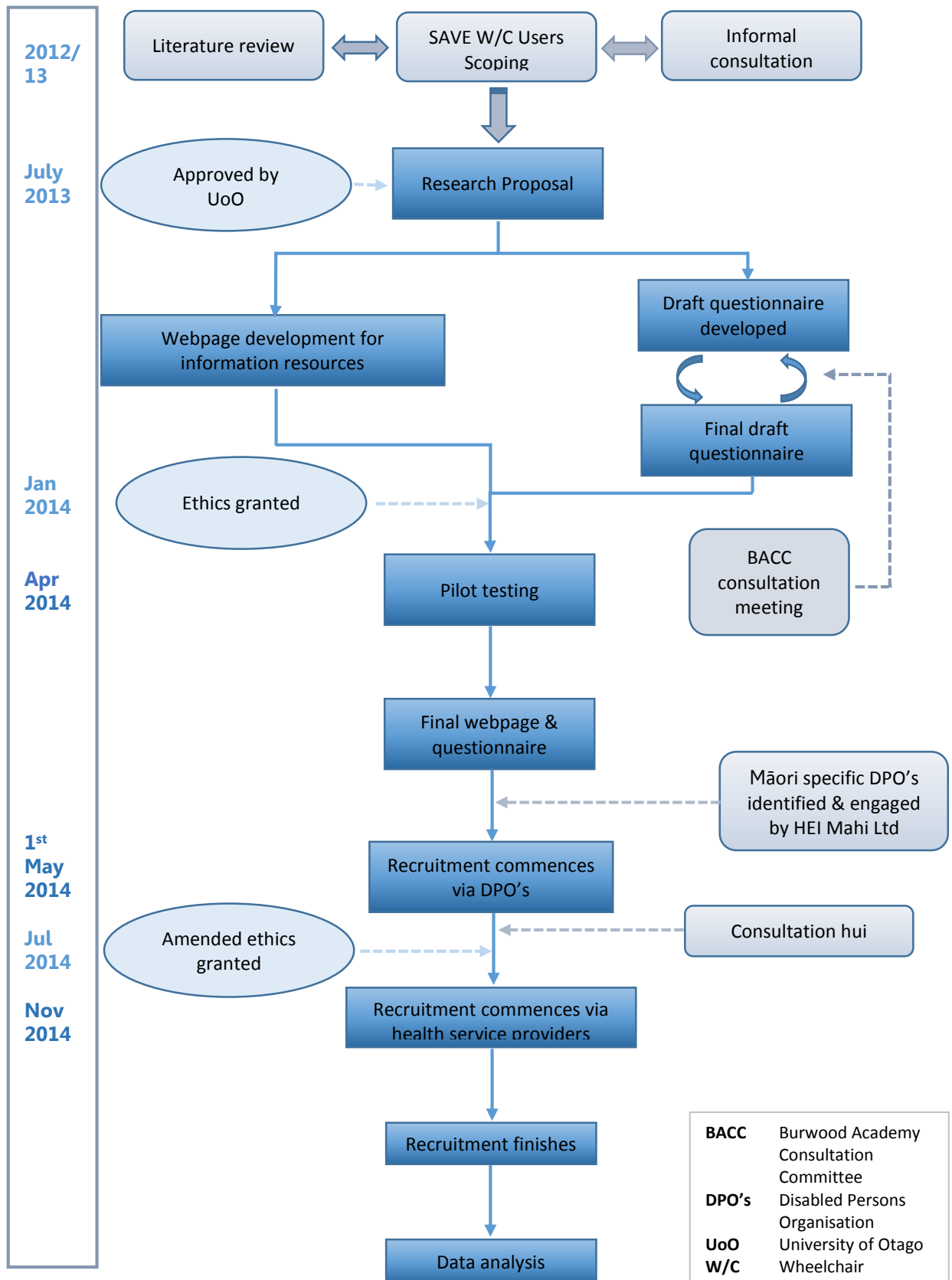


Figure 1: Ready to Roll project summary

2.3 Participants

Wheelchair users, as a subgroup of the disabled population, were the intended participants for this study. The rationale for selecting this group has been discussed in the preceding chapter (section 1.12.4). A biostatistician was consulted prior to ethics committee application to assist with planning and sample size calculations. Based upon the *NZ Household Disability Survey 2006* estimate of 10700 wheelchair users nationwide (Office for Disability Issues, 2013) a sample size of 400 participants was identified. This would allow binomial proportions to be calculated with 95% confidence interval coverage of less than 10%.

2.3.1 Inclusion Criteria

Potential participants were invited to participate in the study if they met the following inclusion criteria:

- 18 years or older
- Using a wheelchair for at least half the time
- Living in the community anywhere in NZ.

Potential participants self-identified as meeting the inclusion criteria. This was a practical decision based on the recruitment strategy used, which did not provide the opportunity to screen potential participants through physical assessment or review of documentation.

The minimum age criteria of 18 years or older was selected primarily for ethical issues involving the ability to provide informed consent. As the primary form of questionnaire response was expected to be via an online survey tool, informed consent forms could not be provided. Consent to participate was indicated at the commencement of the survey itself (see Appendix D) and as such there was no way to confidently assure that those under 18 years had consulted with parents/guardians prior to participating in the study.

There was no upper age limit. During the initial consultation phase, the proposed criteria were presented at three forums, a group of health researchers, a mixed group of health providers, researchers and disabled individuals and finally at a formal end user consultation meeting (explained further in section 2.4.1). At each of these forums, there was discussion about whether to include older adults or not. Some people felt that uptake amongst this older age group for an online survey would be poor and they should therefore be excluded. However, there is evidence that internet use amongst older New Zealanders is increasing (Koopman-Boyden & Reid, 2009). According to Statistics NZ, internet use amongst over 65's is increasing with nearly half of all over 65's (approximately 280,000 individuals) using the internet in 2012. Online banking, shopping and looking up health information were amongst the most common internet functions undertaken (139,000, 137,000 and 135,000 individuals respectively) at some time during 2012. Almost one third of internet using older adults also used the internet for entertainment purposes such as reading online newspapers, books, watching movies or downloading music (Statistics New Zealand, 2012).

For these reasons, I felt that assuming that there would be a poor uptake amongst older adults was presumptive and therefore decided to have no fixed upper age limit for participants. Additionally, including them in the study provides evidence regarding the uptake rate and the ability of older adults to access information in this type of format, which in itself may provide useful insights about how to disseminate information or record the whereabouts of the over 65 age group.

I sought the opinions of wheelchair users throughout NZ as it was considered important to get opinions from people who had, and had not, been involved in the Canterbury earthquakes, even though these events acted as a catalyst to the study.

2.3.2 Exclusion Criteria

Participants were excluded from the study if they were living in residential care facilities (RCF) as they do not face the same issues in emergency situations as those who live in the community. It is expected that RCF staff will be able to provide assistance to residents during and after an emergency. While damage to buildings, infrastructure and disruption to usual care may occur for residents of care facilities,

their location and needs are known. Communication to emergency response services will be facilitated by them being identifiable as a vulnerable facility. This is unlikely to be the case for a disabled individual living in rented or privately owned accommodation within a community. In addition, many RCFs will have emergency response plans in place as part of legislative requirements.

2.4 Consultation during planning phases

Consultation in the planning phases of this study was undertaken to ensure that it was relevant and appropriate for people with disabilities as well as maximising uptake of Māori. The following sections describe the consultation processes used with each of these groups.

2.4.1 Consultation with representatives of disabled community

Informal and formal consultation with representatives of the disabled community took place throughout the project, especially during the planning phase. I considered it important to develop the study in consultation with wheelchair users in order to ensure that it was relevant to them, to comply with the disability rights ethos of “nothing about us without us” (United Nations, 2004, p. para 1) and the previously noted recommendation for disabled people to be involved in all aspects of emergency planning initiatives (section 1.11). Consultation was initially informal, occurring through discussions with disabled people known to me in my role as a health professional.

Formal consultation occurred with the Burwood Academy Consultation Committee (BACC), which comprises of a group of disabled people with an interest and skills in disability and rehabilitation research. They were provided with a summary of the research aims, proposed methods and questionnaire in advance of a consultation meeting that occurred in November 2013. The committee’s recommendations were considered, and where possible implemented, prior to the submission of the ethics application (Appendix A).

2.4.2 Consultation with Māori

I followed the University of Otago ethics application process for consultation with Māori by meeting with the Māori research advisor at the Christchurch School of Medicine in September 2013 (Appendix B). On the recommendation of the Māori research advisor, I further engaged the services of H.E.I. Mahi Ltd, with the aim to maximise the uptake and cultural appropriateness of the study for Māori.

I was cognisant of a potential poor uptake from Māori due to i) an emphasis on online material (advertising, information sheets) and participation, ii) potentially less engagement from Māori with Disabled Person's Organisations (DPO's) through which notification and participation was being requested, and iii) the fact that a non-Māori researcher with no former established networks was conducting the research. H.E.I. Mahi Ltd's role was to advise on culturally appropriate practices and to facilitate networking with a range of regional and national Māori disability groups and communities across NZ (Appendix C). Meetings were held with H.E.I. Mahi Ltd to formulate the participant recruitment strategy.

H.E.I. Mahi Ltd also facilitated a consultation Hui with He Oranga Pounamu of Te Runanga o Ngai Tahu. The consultation Hui was arranged for a time after the commencement of the survey as this was the earliest mutually agreeable time. The Hui provided a forum for me to speak directly to the Canterbury based iwi to advertise the study and address any concerns they had.

2.5 Developing the survey tool

A questionnaire was developed through an iterative process whereby multiple drafts of the questionnaire were developed. Following the guidelines for writing on-line survey questions and designing on-line questionnaires (Ritter & Sue, 2007a, 2007b, 2007d) an initial questionnaire was developed and reviewed for layout, question content and wording together with my supervisors. Amendments were made according to the feedback received prior to entering the questionnaire into a Survey Monkey™ template. The questionnaire contained several questions related to each of

the key research questions to enable a more thorough understanding of the issues. Demographic information was included to assist with the interpretation of findings.

The draft was finalised after being reviewed and piloted by BACC. A list of the questions and response options contained in the final questionnaire is included in Table 2.1 and a copy of the final questionnaire is provided in Appendix D. As recommended by Ritter and Sue (2007) demographic information was included towards the end of the survey. Ethnicity, location and size of town/city was included in the same format used by Statistics NZ.

Table 2.1: List of questions included in final questionnaire

<p>1. I have read the information sheet or watched the information video and agree to take part in the study</p> <ul style="list-style-type: none"> • Yes / No
<p>2. Have you been in a natural disaster (eg: earthquake, flood, severe weather event) that has caused damage to any buildings or infrastructure (eg: power, phone, sewage)?</p> <ul style="list-style-type: none"> • Yes / No
<p>3. Do you currently have an emergency plan?</p> <ul style="list-style-type: none"> • Yes / No
<p>4. Yes, I have an emergency response plan which includes: (select one or more options from the list below)</p> <ul style="list-style-type: none"> • Put aside provisions of food, water and other supplies • Have an evacuation plan • Have a plan with a support network who will check on each other in an emergency • Made arrangements for medications, consumables and carers (if needed) • Other (please specify)
<p>5. No, I don't have an emergency response plan because: (select one or more options from the list below)</p> <ul style="list-style-type: none"> • I've thought about it but not got around to it • I've thought about it but it's not important to me • I've not thought about it • I don't know what to plan for or how to go about it • I can't afford to do it • Other (please specify)
<p>6. What difficulties did you, or might you, come across when making preparations for an emergency? (select one or more options from the list below)</p> <ul style="list-style-type: none"> • None • I need assistance from someone else to help with planning or making physical preparations • Lack of information that is relevant to people with disabilities

- Lack of information that is accessible to people with disabilities
- Unable to stockpile consumables
- Unable to stockpile medications
- Financial. It costs too much to do it
- I am not interested or motivated to do it
- Other (please specify)

7. In an emergency situation, who would you expect to check on you or come to help you?

- No one
- Family / whanau
- Friends
- Neighbours
- Civil Defence
- Police
- Ambulance
- Fire Service
- ACC
- GP
- Carer agency or staff
- Other (please specify)

8. Have you made any formal plans with any of the individuals or organisations above to check on you in the event of an emergency?

- Yes No / Comments

9. Do you think that a voluntary Disabled Persons Emergency Response Register, to assist with emergency planning, preparation and response is a good idea?

- Yes / No
- Unsure
- Comments

10. If one was developed, would you participate in a voluntary Disabled Persons Emergency Response Register?

- Yes / No
- Only if my concerns were adequately addressed
- Don't know
- Comments

11. What type of information would you be prepared to have on a Disabled Persons Emergency Response Register? (select one or more options from the list below)

- Name and contact details
- General type of disability
- Type of assistance potentially required in an emergency
- Equipment requirements
- Transport requirements
- Whether you usually require carers
- Special medicines or medical requirements
- Other (please specify)

<p>12. Please tell us why you wouldn't contribute your personal information to a Disabled Persons Emergency Response Register? (select one or more options from the list below)</p> <ul style="list-style-type: none"> • It's not important to me • Privacy concerns • I already have a good enough emergency plan • I am confident I will get any help I need without having my name on a register • I don't think I will need any extra help • I don't think that having my name on a register will make any difference to the help I receive • Other (please specify)
<p>13. The following questions relate to concerns you might have about how information for a Disabled Persons Emergency Response Register would be collected, stored and used.</p> <p>For each statement below, please tick the circle that best describes how concerned you are about it</p> <ul style="list-style-type: none"> • It would be a hassle for me to add my details and keep them updated • I would be concerned if other people (eg: GP practice, ACC, Ministry of Health) were responsible for entering and updating my details • I am worried about government agencies having access to my personal information • I am worried about other people getting access to my information (e: hackers, unauthorised access, privacy breaches) • I am concerned about who could access the information at the time of an emergency
<p>14. Is there any other comment you would like to make about the development of a Disabled Persons Emergency Response Register?</p>
<p>15. How confident are you with each of the following computer functions?</p> <ul style="list-style-type: none"> • Doing searches on the internet using Google, Internet Explorer, Bing etc. • Sending and receiving emails • Using Facebook, My Space, Twitter etc. • Online banking or bill payments • Downloading and installing software or apps
<p>16. Do you currently use a smartphone, or similar device capable of sending or receiving text/phone/email (eg: iPhone, iPad, Android or Windows phone)?</p> <ul style="list-style-type: none"> • Yes / No / Not sure
<p>17. Would you use a smartphone application (able to be turned on and off by you) that could provide a GPS location of your whereabouts in the event of an emergency?</p> <ul style="list-style-type: none"> • Yes / No / Not sure • Comments
<p>18. Do you currently use a mobile phone that is not a smartphone?</p> <ul style="list-style-type: none"> • Yes / No / Not sure
<p>19. Which option best describes your living situation?</p> <ul style="list-style-type: none"> • Live alone, no carers required • Live alone, carers required

<ul style="list-style-type: none"> • Live with family/whanau, spouse/partner, no other carers required • Live with family/whanau, spouse/partner, carers required • Live with others (flatmates/ boarder etc.), no carers required • Live with others (flatmates/ boarder etc.), carers required • Other (please specify)
<p>20. What type of building is the home you live in?</p> <ul style="list-style-type: none"> • Single storey, stand-alone house • 2 or more storey, stand-alone house • Unit or apartment – single storey • Unit or apartment – part of 2 or more storey building • Single storey house or unit within a complex (eg; retirement village, marae) • Other (please specify)
<p>21. What do you use for mobility most often?</p> <ul style="list-style-type: none"> • Fulltime manual wheelchair • Manual wheelchair, can walk a bit (with or without aids) • Fulltime power wheelchair • Power wheelchair, can walk a bit (with or without aids) • Do not use a wheelchair but have limited mobility • Other (please specify)
<p>22. What is the main reason for your mobility impairment?</p> <ul style="list-style-type: none"> • Stroke • Multiple sclerosis • Traumatic brain injury • Spinal cord injury • Other neurological condition • Amputation • Medical or degenerative condition • Other (please specify)
<p>23. How long have you had a mobility impairment?</p> <ul style="list-style-type: none"> • 5 years OR LESS • 6 - 10 years • 11 – 15 years • 16 – 20 years • MORE THAN 20 years
<p>24. What region of New Zealand do you live in?</p>
<p>25. Do you live in a rural or urban location?</p> <ul style="list-style-type: none"> • Live in a rural area or township • Small town (1,000 – 10,000 people) • Large town (10,000 – 50,000 people) • City (over 50,000 people)
<p>26. What age bracket do you belong to?</p> <ul style="list-style-type: none"> • 18 – 24 years • 25 – 34 years

<ul style="list-style-type: none"> • 35 – 44 years • 45 – 54 years • 55 – 64 years • 65 years or older
<p>27. What gender are you?</p> <ul style="list-style-type: none"> • Male / Female
<p>28. What ethnic group do you belong to?</p>
<p>29. If you have any other comments to make about any of the issues raised in this survey, please include them in the box below</p>

2.6 Developing the information resources

In addition to the required written information sheet, an information video was also produced. The video briefly explained the background to the study, what a DPERR might entail and then followed the same question/answer format used in the written information sheet. The video was written, filmed and edited by myself using freely available software (Windows Movie Maker). By providing the option for potential participants to view a video as well as a written information sheet, I hoped to make the information more accessible to a wide range of individuals.

All the information about the study was uploaded to a dedicated webpage hosted on the Burwood Academy of Independent Living (BAIL) website. The webpage included a brief introduction to the project along with links to the information sheet, information video and Survey Monkey™ questionnaire (www.burwood.org.nz/node/62).

2.7 Pilot Testing

The BACC chair was approached to assist with pilot testing of the process that participants would need to complete. Six wheelchair users from the BACC's wider reference group were selected by the chair and invited to participate in the pilot in April 2014. I had provided a list of six questions that each participant was asked to consider as they navigated through the process of accessing the information and then completing the questionnaire on the Survey Monkey™ website.

The focus of questions at this stage was to explore any issues related to the process rather than seeking detailed feedback about the questionnaire, although pilot group participants were asked about any difficulties they had interpreting, or assigning a response to any of the questions.

Three, of the six people approached, completed the questionnaire on the Survey Monkey™ website but only two responses to the questions were received. As a result of the feedback received, a final comments box was inserted in the questionnaire and the information video was embedded in the webpage as well as being accessible via a hyperlink to YouTube™.

A suggestion was made by one participant to produce a shorter video with actors and professional production, as well as to abbreviate the written information sheet. This was not considered practical to implement as there were no resources available to produce a professional video and the information sheet could not be shortened without omitting information required for ethical approval.

A further request for any additional comments was sent to the pilot test cohort prior to commencing the participant recruitment phase. In particular it was hoped that the person who had completed the survey but not provided any feedback to the questions would add comments. There were no responses to the second approach.

Once the feedback from the pilot testing was incorporated into the webpage, it was promoted on the BAIL website and Facebook™ page. At this time a hyperlink to the webpage, from the BAIL website home page, was activated and the survey become publically accessible.

2.8 Participant recruitment

The RTR study used a snowball sampling recruitment method as described by Ritter and Sue (2007), which usually relies on potential participants being referred by their peers. Ritter and Sue (2007) note that this approach can be effective when the target population is difficult to locate, as is the case with NZ wheelchair users as they come from geographically, diagnostically and socially diverse backgrounds, have more than

one option of funding support and there is no comprehensive pan-disability list of people who use a wheelchair for mobility in NZ. Limitations of the snowball sampling approach are that it produces a non-probability sample, therefore preventing generalising findings to the wider population, and that a homogeneous sample can result (Ritter & Sue, 2007c) as those who act as referrers tend to refer on people who are similar in characteristics to themselves.

For the purposes of this study, the initial approach for participation was made to organisations representing disabled persons. In particular, organisations that advocate for, or provide services to, people with disabilities, especially those with mobility impairments, were approached and requested to promote the study amongst their respective members. This method was selected to achieve as wide a representation of wheelchair users as possible given there is no existing database of wheelchair users in NZ from which to select a randomised sample. Using trusted organisations or individuals to promote the study also provided credibility amongst the target population and was therefore considered advantageous for participant recruitment.

Ultimately, two phases of participant recruitment were used as the first strategy did not achieve the required number of participants after a three month recruitment period. The second phase used a similar sampling framework using health service providers to refer suitable participants to the study. The recruitment method for both phases are described in the following sections.

2.8.1 Recruitment via Disabled Persons Organisations (DPO's)

Participant recruitment via DPO's commenced on the 1st May 2014. An email was sent to 79 individuals within various DPO's throughout NZ. The email contained a brief overview of the research aims, a pre-prepared advertisement for use in publications or notifications, a copy of the written information sheet plus the link to the webpage where further information could be obtained.

DPO's were asked to advise their members about the project via any means they chose (eg: email, newsletters, publications, Facebook™). A snowball sampling method was enabled by requesting them to forward the email and associated content to any

other individuals or organisations that they felt was appropriate. A list of organisations initially contacted is provided in Appendix E.

In addition, H.E.I. Mahi Ltd's contacts within the Māori disability sector were used to improve connections and engagement with Māori. Informal promotion of the project occurred by H.E.I. Mahi Ltd. through a number of discussions with iwi members around the country while they attended various gatherings and Hui.

Formal requests, to assist with participant recruitment were made on the researchers' behalf, directly from H.E.I. Mahi Ltd to the Māori disability community using their established networks. H.E.I. Mahi Ltd used the same advertising and information material as other DPOs. An approach being made directly from one Māori service provider to another was felt to be a more effective way of maximising the participation of Māori, than an approach directly from non-Māori researchers.

Follow up emails to all disability and Māori organisations initially contacted were sent six weeks after the first request.

After three months of recruiting only 60 completed surveys were obtained. At this point, an additional strategy, using health service providers was implemented.

2.8.2 Recruitment via health service providers

A list of health service providers was developed in order to request their assistance with participant recruitment in a similar manner as DPO's. Health service providers contacted included home care / support agencies and allied health professionals working with wheelchair users. The latter were contacted via district health board (DHB) allied health leaders forums and the relevant special interest groups of the respective physiotherapy and occupational therapy professional organisations.

A summary of the study, the assistance requested along with copies of the recruitment advertisement, information sheet, questionnaire and ethics approval letter were sent to all those contacted. Also at this time, H.E.I. Mahi Ltd. were asked to forward this request to any other Māori health providers not already approached.

Health service providers were contacted on the 31/07/14 and asked to continue assisting with recruitment until the end of November 2014. In total, 16 people or organisations were contacted (Appendix F). Additional information for independent ethical review was provided to organisations that requested it (some DHB's and the NZ Occupational Therapy Association).

2.9 Ethical Approval

Initial ethical approval for the study, using participant recruitment via DPO's, was sought and obtained from the University of Otago Human Ethics Committee (Health). Ethics approval was granted on 31st January 2014.

An amended ethics application was required for the second recruitment strategy, using health service providers. This was granted on the 17th July 2014. A copy of the approval letters are included in Appendix G.

2.10 Filling in the questionnaire

Participants were encouraged to complete the survey online via the website link, however, participants were given the option to complete a paper version of the questionnaire if they preferred. Paper questionnaires were obtained either by directly requesting one from me or through copies made by some health service providers. Stamped, self-addressed envelopes were provided for the return of the questionnaires. Paper questionnaires returned were entered onto Survey Monkey™ but I retained the ability to be analyse this data as a separate subgroup.

2.11 Data analysis

All data were exported from the Survey Monkey™ website to an Excel spreadsheet for further analysis using a statistical software management programme (Statistical Package for the Social Sciences, SPSS, Version 22). Descriptive statistical analyses (frequencies, cross-tabulation) were conducted and results are reported as frequencies (n and %). Where appropriate risk ratios were calculated along with 95% confidence intervals and p-values. Statistical significance was set at $p < 0.05$.

Risk ratio, or relative risk, (RR) provides an estimate of how much a given event is likely to occur in one group compared with another (Bowling, 2009). An RR of one indicates that the risk is no greater in either group while an RR of two indicates that the risk of the event occurring in one group is twice that of the other group(s) being compared. The confidence interval (CI) provides an indicator of the degree of accuracy for the RR estimate. Thus a 95% CI range indicates that there is a 95% chance of the true RR being within the range indicated by the upper and lower levels (Liamputtong, 2013). A 95% CI that spans either side of one indicates that the RR is not statistically significant.

2.12 Funding Support

Funding for the project was provided by grants from the Rotary Club of Christchurch, Canterbury Community Trust, Ministry of Social Development, and Canterbury Orthopaedic Services Ltd. The grants provided allowed for the payment of University of Otago fees, a scholarship allowance and sundry expenses. Funding support was acknowledged in all presentations and ethics applications made in association with this project.

Chapter 3 Results

This chapter firstly describes the demographic characteristics of the participants in the study sample. Subsequent sections present the results as they relate to each of the key research questions, namely:

Amongst wheelchair users in NZ:

1. What is the current state of preparedness for emergencies?
2. What are the perceived barriers to emergency preparedness?
3. What is the level of support for, and concerns about, a Disabled Persons Emergency Response Register?
4. What types of ICT, which could be used to support emergency planning and

All percentage figures reported in text and tables throughout this chapter are rounded to the nearest whole number.

3.1 Participant demographics

One hundred and one people completed the survey. Of these, 84 completed their questionnaires online and 17 completed paper forms. The demographic characteristics of participants are discussed below and included in Table 3.1.

3.1.1 Gender and age

A slightly higher number of males (n=51) than females (n=47) completed the survey although three participants did not specify gender. An even spread of age is represented with the exception of the youngest category of 18-24 year olds (n=4). Four of the six age categories had between 16 and 19 participants while the 55-64 year old category had the highest number of participants (n = 25).

3.1.2 Ethnicity

NZ Europeans accounted for 77% (n=77) of participants with 11% (n=11) identifying as NZ Māori and small numbers (n=1-3) of other ethnicities. No Tongans, Niueans or Indians completed the survey (Table 3.1).

3.1.3 Impairment and mobility characteristics

Fifty six participants were fulltime or part time manual wheelchair users while 40 participants used power wheelchairs either full or part time. Half of the participants (n=52) had a mobility impairment as a result of a SCI with the next largest group being those with a neurological impairment from causes other than stroke or multiple sclerosis (n=34). Small numbers of people with stroke, multiple sclerosis, amputation or medical/degenerative conditions completed the survey (n=12). No participants identified traumatic brain injury as the main reason for their mobility impairment (these results are included in Table 3.1).

3.1.4 Geographic location

The largest number of participants resided in the Waikato (n=19), Auckland (n=18), Canterbury (n=14) and Wellington (n=13) regions. No responses were received from the Gisborne, Hawke's Bay or West Coast regions.

3.2 Emergency preparedness amongst wheelchair users

For the purposes of analysing results, preparedness has been determined by responses to questions three (whether or not the participant reports having an emergency plan) and four (what is included in their emergency plan, if they have one) (as detailed in Table 2.1 and Appendix D). Participants who indicated that they had an emergency plan in question three were directed to question four where they were able to select one or more items from a list of common components of an effective emergency plan as discussed in section 1.6 and 1.6.1. Participants who indicated that they had no emergency plan in question three were directed to Question five where they were asked to identify why they didn't have one. All participants (n = 101), whether they had a plan or not, were able to answer question six which asked what difficulties they did, or might, come across while making preparations for an emergency.

3.2.1 Participants with an emergency response plan

Overall, 28 (28%) participants indicated they had a current emergency plan while 73 (72%) did not. Table 3.1 shows the demographic characteristics of participants in relation to whether or not they had an emergency plan. Due to small numbers, some of the categories shown in Table 3.1 were later grouped together for statistical analysis.

When analysing grouped data for age and mobility duration variables there were some statically significant differences observed between participants with a plan and those without a plan. These differences are discussed below (sections 3.2.2 and 3.2.3).

Table 3.1: Demographic characteristics of participants with and without an emergency plan (n = 101)

Demographic variable		Total n (%) ^f	Have current plan n ^y	
			Yes	No
Age category (years)	18-24	4 (4%)	1	3
	25-34	17 (17%)	6	11
	35-44	19 (19%)	5	14
	45-54	17 (17%)	0	17
	55-64	25 (25%)	9	16
	65 or older	16 (16%)	6	10
Gender	Male	51 (50%)	16	35
	Female	47 (47%)	11	36
Ethnicity	NZ European	78 (78%)	21	57
	NZ Māori	11 (11%)	5	6
	Other *	10 (10%)	1	3
	Cook Island Māori	1 (1%)	0	1
	Samoan	1 (1%)	0	1
	Chinese	1 (1%)	0	1
	Tongan	0 (0%)	0	0
	Niuean	0 (0%)	0	0
	Indian	0 (0%)	0	0
Form of mobility used most often	Fulltime manual wheelchair	37 (37%)	9	28
	Fulltime power wheelchair	34 (34%)	10	24
	Manual wheelchair, can walk a bit	19 (19%)	4	15
	Power wheelchair, can walk a bit	6 (6%)	2	4
	Do not use a wheelchair, limited mobility	2 (2%)	2	0

Demographic variable		Total n (%) [‡]	Have current plan n [‡]	
			Yes	No
Duration of mobility impairment	5 years or less	14 (14%)	4	10
	6-10 years	13 (13%)	5	8
	11-15 years	13 (13%)	1	12
	16-20 years	11 (11%)	1	10
	More than 20 years	46 (46%)	16	30
Main reason for mobility impairment	Spinal Cord Injury	52 (52%)	12	39
	Other neurological condition	34 (34%)	12	22
	Multiple sclerosis	6 (6%)	1	5
	Medical or degenerative condition	3 (3%)	1	2
	Amputation	2 (2%)	0	2
	Stroke	1 (1%)	1	0
	Traumatic brain injury	0 (0%)	0	0
Living situation	Live alone, no carers	9 (9%)	5	4
	Live alone, carers	24 (24%)	7	17
	Live with family/whanau/partner, no carers	27 (27%)	4	23
	Live with family/whanau/partner, carers	26 (26%)	8	18
	Live with others (eg: flatmates), no carers	4 (4%)	1	3
	Live with others (eg: flatmates), carers	7 (7%)	2	5
Rural or urban location	Live in rural area/township (< 1,000 people)	13 (13%)	1	12
	Small town (1,000-10,000 people)	12 (12%)	3	9
	Large town (10,000-50,000 people)	18 (18%)	7	11
	City (Over 50,000 people)	55 (55%)	16	39
[‡] Due to missing data (participant non-response), totals may not add to n=101 [‡] Percentage figures rounded to nearest whole number, totals may not sum to 100% *Other: Asian (n = 1); Scottish (n =1); British (n = 1); English (n = 2); NZ'er (n = 3); Other European (n = 1); Not specified (n=1).				

3.2.2 Age

Due to small numbers, the age categories were combined for the purposes of statistical analysis. The resulting three groups will be referred to as the younger (18-34 years), middle (35-54 years) and older (over 55 years) age groups. Table 3.2 presents the RR and CI's associated with having a plan for the three age groups.

Participants in the middle age group were less likely than the other age groups to have an emergency plan. In the case of the older group, this difference is statistically significant ($p < 0.05$). A third of the younger participants, and just over a third (36%) of

the over 55's had an emergency plan while only 14% of those in the middle age group had a plan.

Table 3.2: Association of age with having an emergency plan (n = 101)

	Risk Ratio	95% Confidence Interval Range
35-54 years	(ref)	xx
18-34 years	2.4	0.8, 6.6
Over 55 years	2.6 *	1.0, 6.5
(ref) = Reference group * = Statistically significant, p< 0.05		

3.2.3 Mobility impairment: duration and type

For the statistical analysis of mobility impairment duration the following groups were used: 0-10 years (n=27), 11-20 years (n=24) and more than 20 years (n=46). Table 3.3 presents the RR and CI's associated with having a plan for the three duration of mobility impairment groups.

Those with a mobility impairment for 11-20 years were significantly less likely to have had a plan when compared to the other mobility impairment duration groups. There were no statistically significant demographic differences between those with mobility impairment of 11-20 years duration compared to other groups except that they were more likely to be full time wheelchair users (RR = 2.4, CI range = 1.3, 4.5, p<0.01). The ratio of full time to part time wheelchair use within the 11-20 year duration group was approximately 80:20 compared with approximately 50:50 for the other mobility impairment duration groups

Table 3.3: Association of mobility impairment duration with having an emergency plan (n = 101)

	Risk Ratio	95% Confidence Interval Range
11-20 years duration	(ref)	xx
0-10 years duration	4.0 *	0.95, 16.7
More than 20 years duration	4.1 *	1.0, 16.6
(ref) = Reference group * = Statistically significant, p< 0.05		

There were no other statistically significant differences identified between the demographic variables of participants and the presence or absence of an emergency

plan. However, several trends were observed relating to ethnicity, the participant’s living situation, urban versus rural location and previous emergency exposure of participants. Although the numbers are small, trends based on these demographic characteristics will now be summarised.

3.2.4 Ethnicity

In this sample, Māori as a group reported higher rates of having an emergency plan compared to other ethnicity groups. Although the numbers are small nearly half of those who identified as Māori (5 out of 11) had an emergency plan of some sort. This figure compares to 27% (21 out of 79) of NZ European participants. However, no statistically significant differences were identified in relation to ethnicity when comparing NZ European to Non NZ European or Māori to non-Māori as shown in Table 3.4. Numbers of other ethnicities are too small, mostly individual cases, to identify meaningful trends.

Table 3.4: Association of ethnicity with having an emergency plan (n = 101)

	Risk Ratio	95% Confidence Interval Range
NZ European	(ref)	xx
Non-NZ European	0.8	0.4, 1.7
Māori	(ref)	xx
Non- Māori	1.5	0.7, 3.4
(ref) = Reference group		
* = Statistically significant, p< 0.05		

3.2.5 Living situation

Five out of nine (56%) of participants who live alone with no carers had an emergency plan compared to 25% of those who had any other living situation (n = 89) (Table 3.5). Conversely, 15% of participants living with family/whanau or a partner and not requiring any carers (n=27) reported having a plan compared to 32% of those in any other living situation (n = 71). Only one person out of 13 (8%) living in a rural location or township reported that they had an emergency plan, compared with 25% and 38% for those living in small towns and cities respectively.

Table 3.5: Association of living situation with having an emergency plan (n = 101)

	Risk Ratio	95% Confidence Interval Range
Live alone	(ref)	xx
Live with any other people	1.5	0.8, 2.9
Requires carers	(ref)	xx
Does not require carers	1.2	0.6, 2.3
Live with family/whanāu/partner	(ref)	xx
Live alone or with others (eg flatmates)	0.7	0.3, 1.2
Live alone with no carers	(ref)	xx
All other living situations	2.2	1.1, 4.4
No carers, live with family/whanāu/partner	(ref)	xx
All other living situations	0.5	0.2, 1.2
(ref) = Reference group		
* = Statistically significant, p< 0.05		

3.2.6 Previous experience of an emergency

Thirty percent of those who had been in a natural disaster (14 out of 46) had an emergency plan compared to 26% of those who hadn't previously experienced a natural disaster (14 out of 54). There was no significant difference between the proportion of participants with an emergency plan and those who did not, based on their previous experience of a natural disaster (Table 3.6).

Table 3.6: Association of previous experience of a natural disaster with having an emergency plan (n = 101)

	Risk Ratio	95% Confidence Interval Range
No previous emergency	(ref)	xx
Previous emergency	0.8	0.5, 1.6
(ref) = Reference group		
* = Statistically significant, p< 0.05		

3.3 Nature of preparedness

Amongst the participants who reported having an emergency plan (n = 28), the most common feature was putting aside provisions of food, water and other supplies (n=26)

(see Figure 2). Participants were less likely to have planned for more disability specific issues such as making an evacuation plan (n=18), having a plan with a support network (n=14) and stockpiling medications or other consumables (n=10).

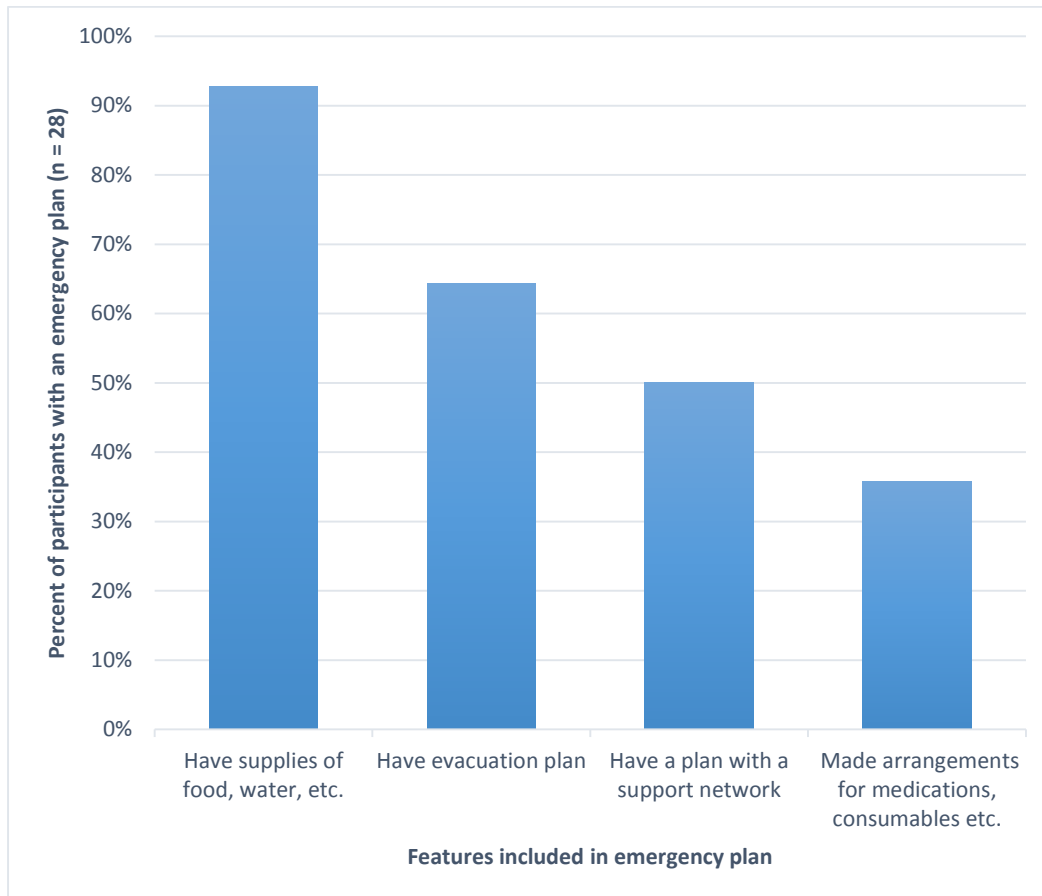


Figure 2: Type(s) of features included in emergency plan amongst participants with an emergency plan (n = 28)

Participants were able to select one or more features included in their emergency plan, totals do not sum to 100%

Emergency plans reported by participants who had previously experienced a natural disaster also included:

- Having a planned route to high ground in the advent of a tsunami (n=1)
- Holding spare medications and supplies at both home and work, as well as participating in regular neighbourhood meetings (n=1)
- Keeping their car fuel tank full (n=1)

- One person noted that they needed to be self-sufficient at home as they did not expect emergency shelters could adequately meet their needs, eg: would not be able to get up and down off mattresses on the floor or access unmodified toilets.

One further participant who had not experienced an emergency situation and lived on the 10th floor of a multi-story building recognised that they would be dependent on others to effect an evacuation but did not note if they had made formal plans.

3.4 Reasons for lack of emergency planning

There were 73 participants who did not have a plan. Amongst the participants with no plan, over half (n = 43, 58%) indicated that they had thought about having a plan but had not yet done anything about it (Figure 3). Twenty four percent of those with no plan in place identified that they didn't know what to plan for (n=17), 14% (n = 10) identified cost as a reason for not implementing an emergency plan while a further 11% of participants (n = 8) had not thought about it at all. Very few participants (6%, n=4) had not taken any action because they didn't consider it important.

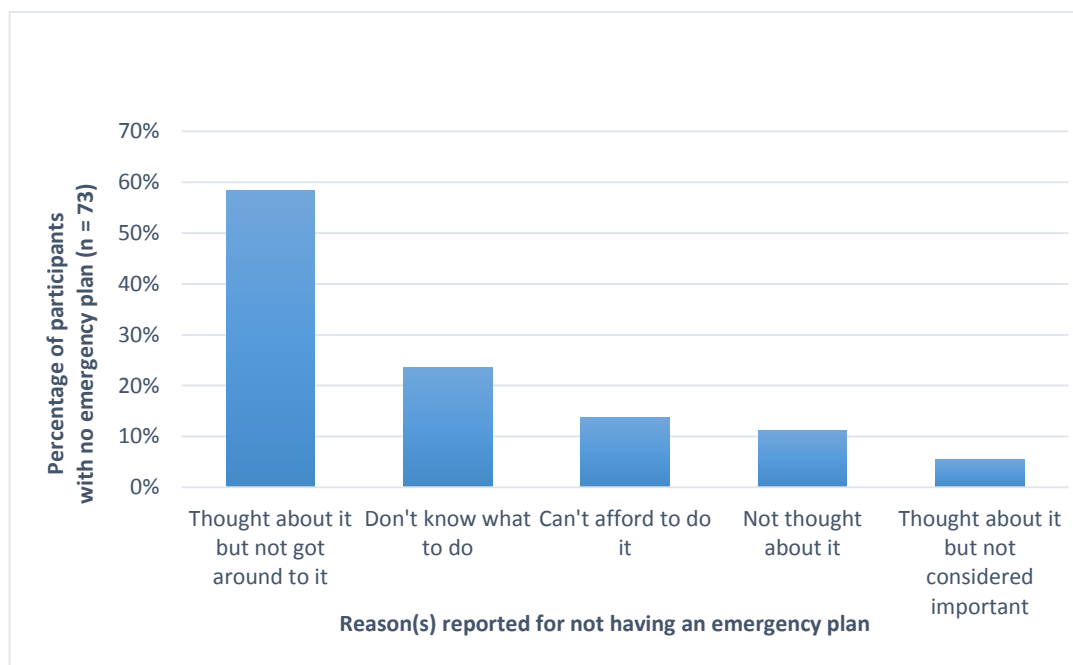


Figure 3: Reasons reported for not having an emergency plan amongst those with no plan (n = 73)

Participants were able to select one or more reasons for not having a plan, totals may not sum to 100%

3.5 Perceived barriers to emergency planning

Amongst all 101 participants, the most common barrier to making preparations experienced or anticipated (based on responses to question 6, as described in section 3.2) was the need for assistance from others for physical preparations or planning (n=50). Other barriers included lack of disability relevant information (n=37), inaccessibility to information (n=24), cost (n=23), and being unable to stockpile medications (n=20) or consumables (n=11) (Figure 4).

Eighteen participants didn't feel there were any barriers for them having an emergency plan. Only five participants indicated that not being interested or motivated to organise an emergency plan as a barrier for them.

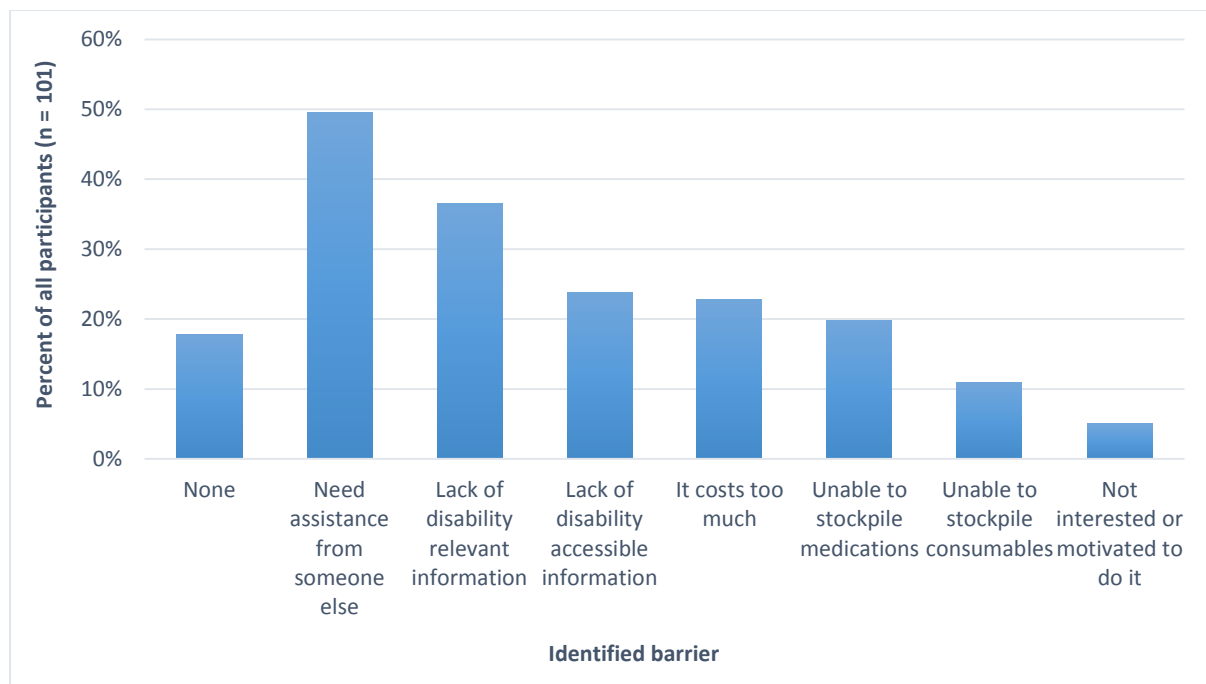


Figure 4: Emergency preparedness barriers identified by all participants (n = 101)

Participants were able to select one or more barriers, totals do not sum to 100%.

Other barriers identified included:

- Difficulty with support network as friends and family are either elderly or disabled (n=1)
- Making a plan for a specific disaster being a challenge (n=1)

- Having no accessible place to stockpile necessities (n=1).

3.6 Disabled Persons Emergency Response Register

Amongst the participants of this study, there was very high level of support for the idea of a DPERR. Ninety of the 99 people who answered this question, thought that a DPERR was a good idea, nine were undecided, while no one opposed it as a concept. A smaller number of participants (n=76) indicated they would participate in a DPERR if it were available. Nineteen participants were either unsure if they would contribute information to a DPERR, or would only do so if they felt their concerns were adequately addressed (Figure 5).

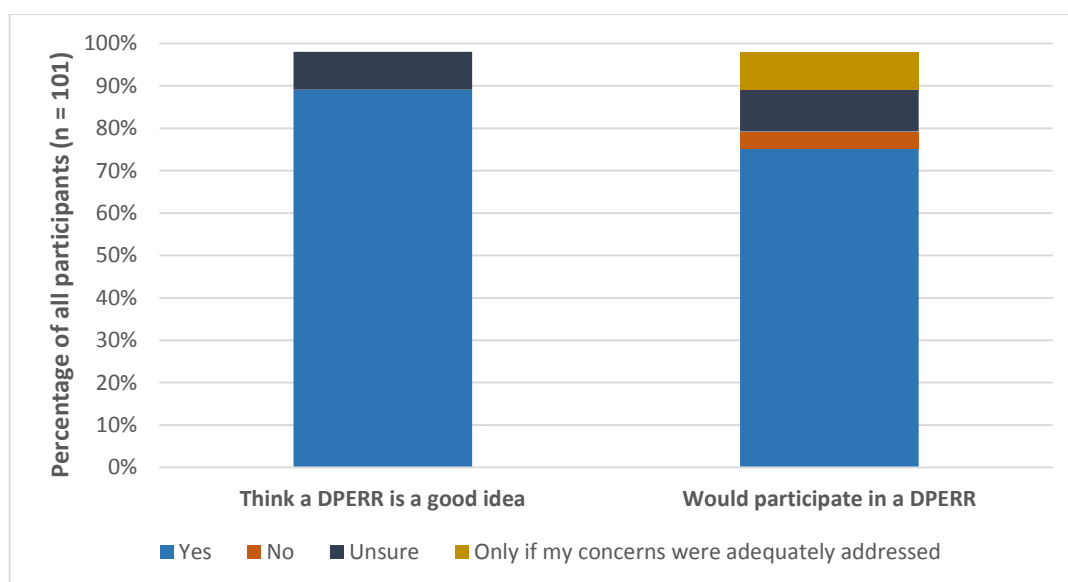


Figure 5: Percentage of participants who support the concept of a DPERR compared to those who would actually participate in a DPERR (n = 101)

Four individuals indicated they would not participate in a DPERR. Reasons included a perception that they either wouldn't need any extra help or that they would get the help they needed without having their name on a register. Further explanation was provided by two individuals who both felt that their personal situation provided them with a good enough support network to manage in an emergency situation but that they could see a benefit for others. Only one of these four individuals reported having a current emergency plan.

Three of the nine people who indicated that they would only participate if their concerns were adequately addressed provided an explanation of this decision. All such comments related to the details of how information was collected, secured and accessed. One participant noted that people with disabilities could be perceived as a vulnerable group who could be taken advantage of if the information fell into the wrong hands.

3.6.1 Preferred method of having information entered

A majority of participants favoured entering and updating personal information themselves as 86% (n=87) had little or no concerns that this would be a hassle for them (Figure 7). Participants who lived with family/whanau or spouse/partner were significantly less likely to be concerned about entering their own details in comparison to those who lived alone or with other non-family people (eg: boarders, flatmates) (RR=3.3, 95% CI =1.1, 6.1, p<0.05). There were no other demographic differences identified between participants who were likely to be concerned about this issue compared to those who weren't.

On the other hand, half the participants were somewhat to very concerned about other people entering details on their behalf (n=48). Nearly a third of all participants (n=31) were quite or very concerned about this issue (Figure 6). Participants who were most likely to be concerned about others entering details on their behalf included: those who have previously experienced an emergency situation compared to those who haven't (RR =1.6, CI = 1.0, 2.3, p<0.05); those who do not need carers compared to those who do (RR =1.6, CI =1.1, 2.4, p<0.05); and Māori compared to non-Māori (RR =1.8, CI =1.3, 2.6, p<0.05).

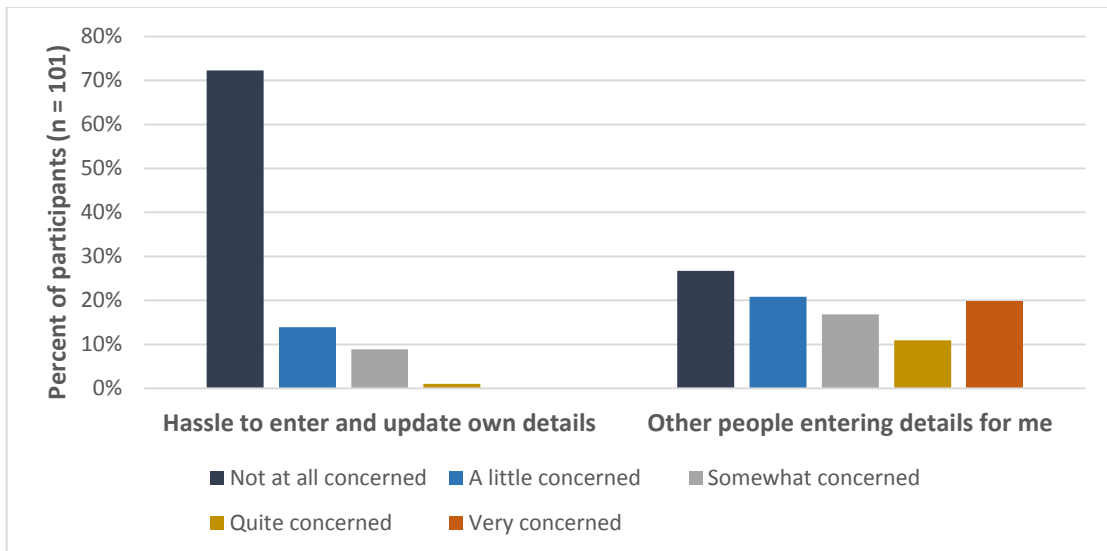


Figure 6: Concerns about how information is collected and entered in DPERR

Two participants provided additional comments indicating that they would be comfortable with other people or organisations entering or updating information on their behalf as long as they had the capacity to edit and affirm details. One further participant suggested using the health passport system as a medium for collecting and updating information for a DPERR.

3.6.2 Privacy and data security concerns

The highest levels of concern were related to security of information from unauthorised access (eg: from hackers) with over half of participants (n=58) being somewhat to very concerned about privacy breaches of this sort (Figure 8). A third of participants (n=35) were quite concerned or very concerned about this issue. Comments provided by participants (n=3) indicate that they would want to know who has access to the information and how it is secured.

Nearly 40% of participants (n=39) were somewhat to very concerned about who would be provided with access to information at the time of an emergency. Thirty six percent (n=36) were somewhat to very concerned about government agencies obtaining access to personal information through a DPERR (Figure 7). Participants who have previously been in an emergency situation, compared to those who haven't, were more likely to be concerned about potential government access to information

through a DPERR (RR =1.8, CI =1.1, 3.2, p <0.05). Participants were less likely to be concerned (little or no concerns) about this issue if they were a full time, compared to part time, wheelchair user (RR =1.8, CI =1.1, 3.1, p<0.05); a power wheelchair user compared to using a manual wheelchair (RR = 2.1, CI =1.0, 4.1, p <0.05); or live with family/whanau or spouse/partner, compared to those who live alone or non-family people (RR =2.0, CI =1.2, 3.5, p<0.01).

Māori participants were significantly more likely to be concerned about both the security of stored information (RR =1.8, CI =1.3, 2.6, p<0.05) and who could access the information during an emergency situation (RR =2.0, CI =1.2, 3.3, p<0.05) than non-Māori.

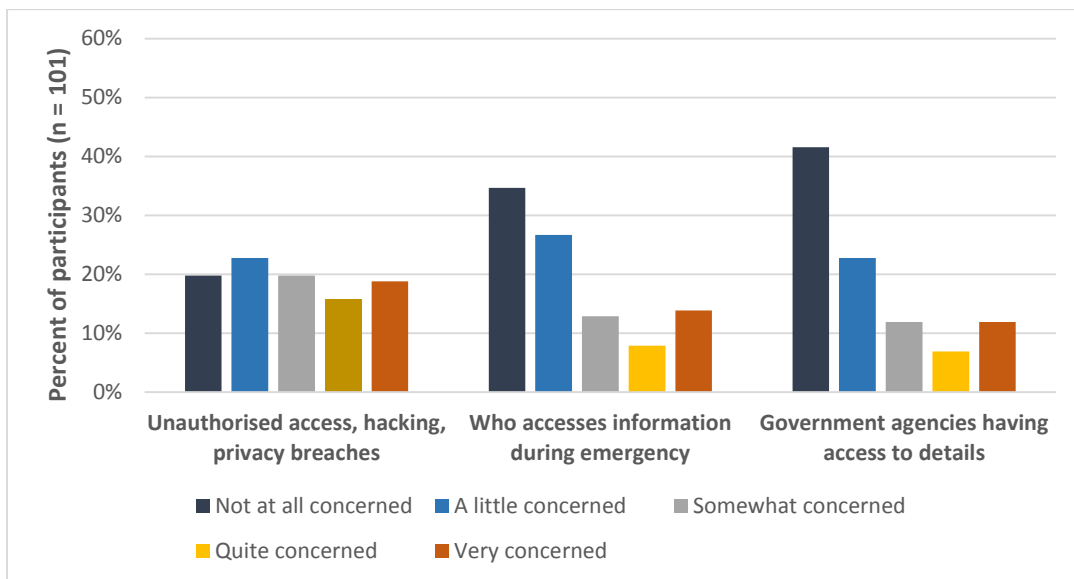


Figure 7: Concerns about information access and privacy

3.6.3 Types of information participants are prepared to include

Participants were more comfortable including personal information of a more general nature on a register. For example, name and contact details (n = 91), general type of disability (n = 91) and type of assistance potentially required (n = 83) were more commonly selected as types of information participants were prepared to include on a DPERR. As information type became more specific to the individual and their usual care, equipment or medical needs, participants were less willing to have this included on a DPERR. This trend is shown in Figure 8. Usual care requirements (n = 64) and

usual medicines or medical needs (n = 61) were the least likely types of information that participants were prepared to include.

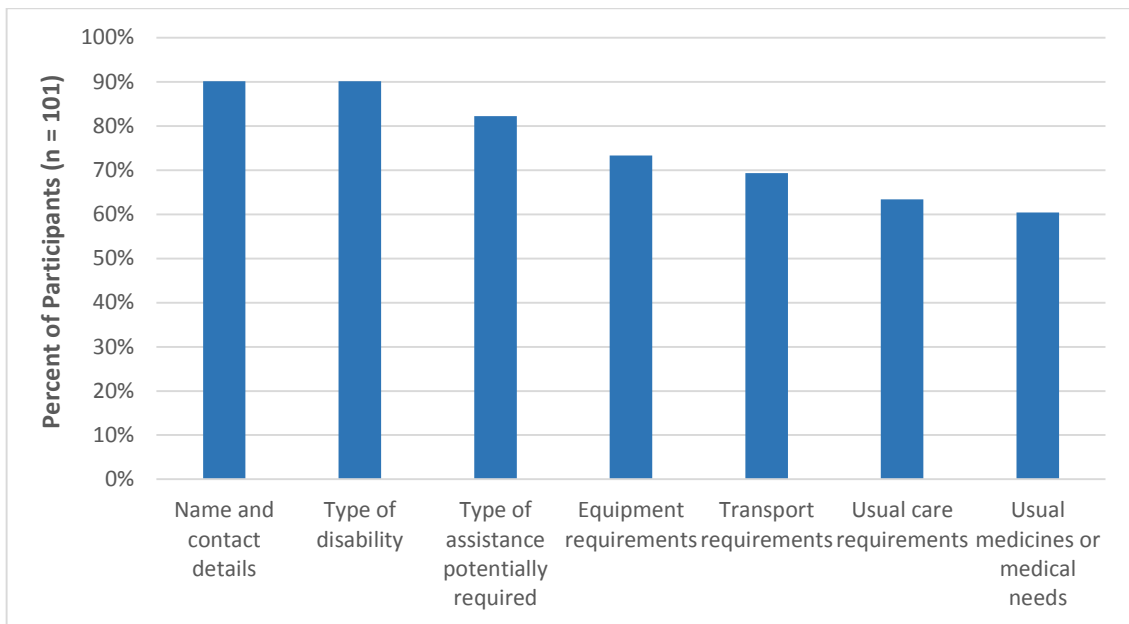


Figure 8: Types of information participants were prepared to include on DPERR (n = 101)

Participants were able to select one or more types of information, totals do not sum to 100%.

3.7 Information Communication Technology use

Participants identified a high level of use of internet based applications with over 90% performing internet searches, sending and receiving emails and downloading and installing software (n=91). Performing online banking or bill payments (n = 84) or using social media (n = 80) were the least likely internet functions to be used.

Participants were most confident with sending and receiving emails (n=80, very confident), internet searches (n=70, very confident), and doing online financial transactions (n=68, very confident). Lower numbers, although still nearly half of the participants, reported very high confidence with using social media (n=47) or downloading and installing software and applications (apps) (n=46) (Figure 9).

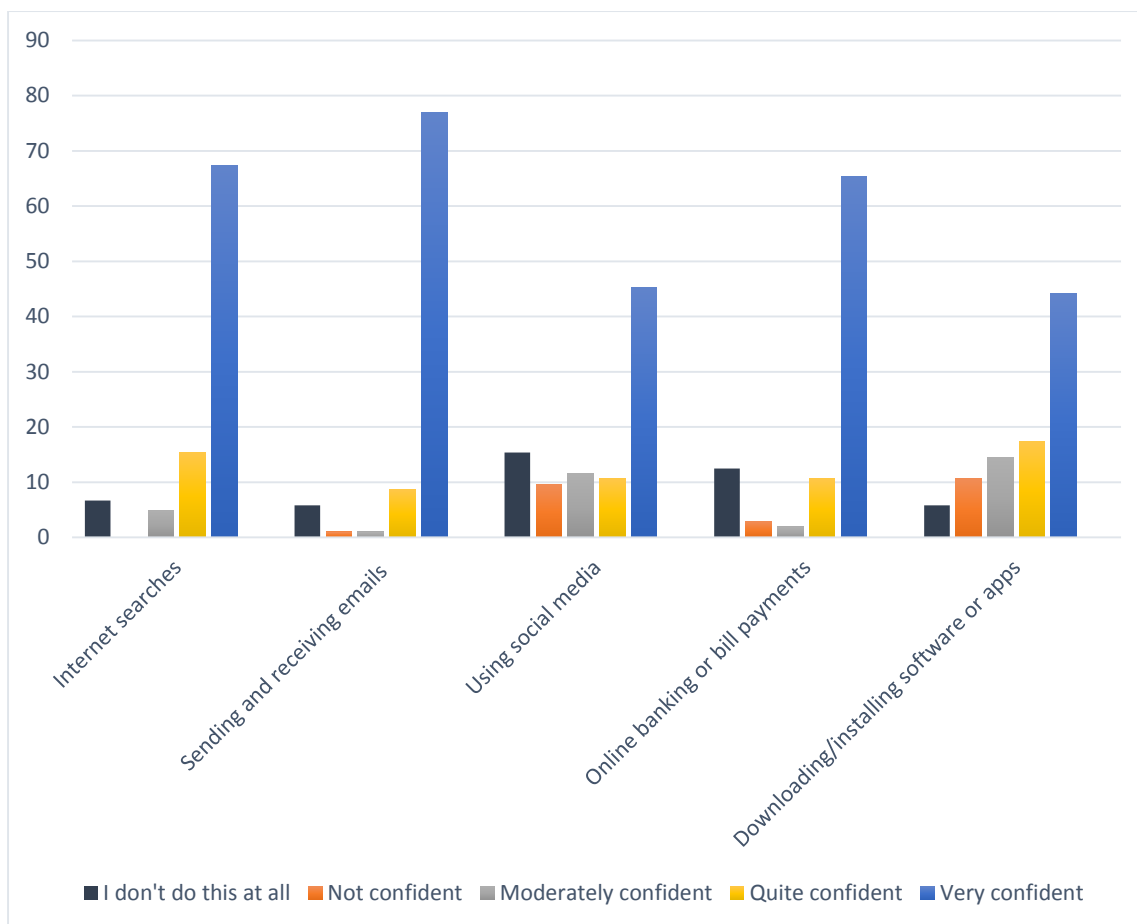


Figure 9: Use and confidence of participants with internet based applications (n = 101)

Seventy eight percent of participants used a smart phone or device capable of sending or receiving text/phone/email (n=79). A further 13% (n=13) used a ‘non-smart’ mobile phone. Over 80% of current smart phone users (n=64) indicated that they would use an application, able to be turned on and off by them, that could provide GPS coordinates of their location in an emergency.

3.7.1 Subgroup analysis of postal and online participants

The majority of participants (83%) completed the survey online which may have contributed to a potential bias in the sample towards those who use the internet. To test this, a subgroup analysis of online versus postal survey participants was performed to look for differences in internet use patterns.

Participants who responded with the online survey option were statistically more likely to use the internet across a range of applications than those who completed the

postal survey (Table 3.8). However, there was no statistically significant difference in the reported use of smartphones between the two groups. There was no significant difference between the groups with respect to the level of support for a DPERR or in the proportions indicating that they would participate in a DPERR or use a smartphone app with GPS locator capacity if either of these technologies was developed.

Table 3.7: Comparison of ICT use patterns between postal and online survey participants (n = 101)

ICT applications used by participants	Postal (n=17)	Online (n=84)	Risk Ratio	95% CI Range * p<0.05
Internet	12	82	1.4	1.0, 1.9 *
Email	13	82	1.3	1.0, 1.7 *
Social media	11	74	1.4	1.0, 2.0 *
Financial transactions	12	76	1.3	0.9, 1.8
Software downloads	12	82	1.3	1.0, 1.7 *
Smartphone user	13	67	0.9	0.3, 2.4

Table 3.8: Reported support for potential DPERR and GPS enabled smartphone application by postal and online survey participants (n = 101)

	Postal (n=17)	Online (n=84)	Risk Ratio	95% CI Range * p<0.05
Think DPERR is a good idea	14	77	0.5	0.1, 1.6
Would participate in a DPERR if developed	12	65	0.8	0.3, 1.8
Would use smartphone with GPS locator app if developed	11	56	0.9	0.5, 1.9

3.8 Summary of key findings of the study

The key findings to have emerged from this study include:

1. Fewer than 30% of participants in this study have an existing emergency plan.
2. 'Prepared' participants were most commonly stockpiling food, water and other supplies in line with general emergency preparedness messages but very few were planning for their disability related needs.

3. Over 80% of participants with no plan in place had thought about it but had not yet moved from thought to action.
4. Half of all participants needed, or would need, help from another person to make preparations and over a third felt there was a lack of information relevant to people with disabilities.
5. There was a high level of support amongst participants for the concept of a DPERR and a majority indicated that they would contribute reasonably detailed personal information but wanted to be able to do this themselves or check its accuracy.
6. Security of personal information stored and who can access it were the major concerns expressed by participants, about a potential DPERR.
7. There was a high level of access, use and confidence with ICT devices and applications amongst study participants. Using social media or online financial transactions were associated with the lowest levels of confidence but were still being used by nearly half the participants.

Chapter 4 Discussion

Emergency preparedness and planning are issues important to all individuals living in NZ and even more important for people with disabilities due to their increased vulnerability during times of disaster. Despite this, there is little research that identifies the level of preparedness amongst disabled New Zealanders (Brereton, 2012; Dunn et al., 2012; S. Phibbs et al., 2015; S.R. Phibbs et al., 2014; S. R. Phibbs et al., 2012). As far as can be determined, the RTR study is the first nationwide study undertaken in NZ to specifically investigate the issue of emergency preparedness amongst a population of disabled people.

In this chapter, the key findings of the RTR study will be discussed in the context of national and international research and practice. Challenges and limitations of the existing study will be outlined. The discussion concludes with six key outcomes which will be presented along with recommendations for future actions or research.

4.1 Key findings of the RTR study

The key findings from the RTR study (listed in section 3.8) indicate that fewer than 30% of RTR participants had an emergency plan of any sort. Those that did have a plan tended to focus most on having a general emergency survival kit but fewer than 20% of all participants had made provision for their disability specific requirements. Over 80% of participants with no plan had thought about it but not yet got around to taking action. For half the participants, the need for assistance from another person to complete planning activities was identified as a barrier to doing so. The participants of this study indicated a high level of support (90%) for the concept of a DPERR although security of data was considered a concern by over half the participants. Finally, the wheelchair users included in this study reported high levels of internet use and confidence.

As the key findings relate to the four research questions they will be discussed under headings reflecting each question's purpose, namely: (i) levels of preparedness amongst wheelchair users in NZ, (ii) barriers to preparedness for NZ wheelchair users, (iii) support for, and issues related to, a proposed DPERR, (iv) the potential role of ICT

in NZ emergency planning and response for people with disabilities. First, in order to contextualise the discussion of the findings of the RTR study within the wider population of interest, the RTR survey sample characteristics will be compared to the known demographic characteristics of the wider NZ wheelchair using population.

4.2 The RTR sample

The *Disability and Formal Supports in NZ in 2006* report (Office for Disability Issues, 2013), which provides the most detailed information available regarding the prevalence and demographic characteristics of mobility impaired persons in NZ², estimates that 10,600 New Zealanders used a wheelchair to assist their mobility in 2006. Thus, while the RTR survey is the largest of its kind yet undertaken in NZ, the number of participants in the study sample still represents under one percent of all wheelchair users. As such the findings of the study cannot be assumed to be representative of all wheelchair users. In this section the known demographic characteristics of wheelchair users in NZ (from the Office for Disability Issues, 2013, report) will be compared to those of the RTR participants in order to determine the representativeness of the study sample.

The RTR sample comprised of 55% manual wheelchair users, 40% power wheelchair users and the remaining 5% either not using a wheelchair or unspecified. This compares to approximately 73% of all NZ wheelchair users using a manual wheelchair with the remaining 27% using a power wheelchair (see Table 4.2) (Office for Disability Issues, 2013). As the RTR sample contains a higher proportion of power wheelchair users than the total NZ wheelchair using population, it appears somewhat skewed towards those with a greater level of mobility impairment.

² The report draws data from the the NZ Disability Survey 2006 and while this was repeated again in 2013, it did not include the same questions regarding use of mobility equipment as the previous survey. As such the 2006 survey provides the most recent information available regarding the demographic characteristics of NZ wheelchair users.

Table 4.1: Wheelchair type and age characteristics of RTR sample compared to all NZ wheelchair users

	W/C users in RTR sample, n (%) ^y			Total NZ W/C users ¹ n (%) ^y		
	Total	< 65	> 65	Total	< 65	>65
W/C users, Total	96	80 (84%)	16 (17%)	10600	Not reported	Not reported
Manual W/C users	56 (58%)	49 (51%)	7 (7%)	7700 (73%)	3600 (34%)	4100 (39%)
Power W/C users	40 (42%)	31 (32%)	9 (9%)	2900 (27%)	Not reported	Not reported

¹ Source: *Disability and formal supports in NZ in 2006* (Office for Disability Issues, 2013)

^y Figures quoted are % of respondents in relation to totals (bold text) of respective studies and may not total to 100% due to rounding.

W/C: Wheelchair

The *Disability and Formal Supports in NZ in 2006* report (Office for Disability Issues, 2013) does not provide further information about demographic characteristics of the NZ wheelchair using population than those contained in Table 4.1 above. As such it is not possible to directly compare the demographic characteristics of the RTR sample to the wider wheelchair using population. However, some further trends may be identified from the demographics of NZ adults with a mobility disability who use any form of mobility equipment as shown in Table 4.2. Based on this information the RTR sample may have a higher proportion of adults under 65 than the total NZ wheelchair using population. The RTR sample has 84% of respondents under 65 while the proportion of mobility disabled adults under 65 years using mobility equipment in NZ is 31% (Table 4.2). In addition, manual wheelchair users account for nearly three quarters of all NZ wheelchair users and more than half of these are over 65 (equating to 39% of all NZ wheelchair users) (Table 4.1). Thus, it is assumed that the RTR sample contains a higher proportion of younger adults (under 65) than the NZ wheelchair using population.

Table 4.2: Demographic characteristics of RTR sample compared to mobility disabled adults using mobility equipment in NZ

	All respondents in RTR sample, n (%) ^y			NZ: Mobility-disabled adults using mobility equipment ¹ n (%) ^y		
	Total	< 65	> 65	Total	< 65	>65
Total	98	82 (84%)	16 (16%)	78300	24000 (31%)	54200 (69%)
NZ European	79 (80%)	67 (68%)	12 (12%)	58000 (74%)	13300 (17%)	44700 (57%)
Māori	11 (11%)	10 (10%)	1 (1%)	8300 (11%)	5100 (7%)	3200 (4%)
Male	51 (52%)	43 (44%)	8 (8%)	31700 (40%)	11300 (14%)	20400 (26%)
Female	47 (48%)	39 (40%)	8 (8%)	46600 (60%)	12800 (16%)	33800 (43%)

¹ Source: *Disability and formal supports in NZ in 2006* (Office for Disability Issues, 2013)
^y Figures quoted are % of respondents in relation to totals (bold text) of respective studies and may not total to 100% due to rounding and other ethnicities not being included in table.

At first, those who identify as Māori in the RTR sample (11%) appears to be under-representative of the general population where they account for 15% (Statistics New Zealand, 2013). Additionally, Māori comprise 23% of all NZ mobility disabled adults living in households (Office for Disability Issues, 2013). However, the definition used for ‘mobility-disability’ in the Office for Disability (2013) report, includes people who have difficulty walking 350 metres without resting, walking up and down stairs, carrying a five kilogram object 10 metres, moving from room to room or standing for more than 20 minutes (Statistics New Zealand, 2007). Many people will meet these criteria for having a mobility disability without necessarily requiring equipment to help them move about (for example due to respiratory or cardiac impairments). For the purposes of comparing the ethnicity characteristics of the RTR sample to the wider NZ population, I consider that the criteria of needing mobility equipment is closer to the RTR sample of wheelchair users than the broader definition of mobility disabled. Therefore, as shown in Table 4.2, there is no difference in the proportion of Māori in

the RTR sample compared to the proportion of Māori in NZ with a mobility disability who use mobility equipment to move around. In both cases this figure is 11%.

The RTR sample has a 50:50 gender ratio compared to a 60:40 ratio (females to males) for the total NZ mobility disabled adult population who use mobility equipment of any sort. The RTR sample has a consistent gender ratio amongst the under and over 65 year age groups. This contrasts with the findings of the Office for Disability Issues (2013) report in which there was approximately a 50:50 split of gender in mobility equipment using adults under 65 but with a shift in the gender ratio, biased towards females (approximately 60:40) in the over 65 age group (Office for Disability Issues, 2013). This is speculated to be a result of females having a longer life expectancy than males in NZ and an increasing incidence of disability with increasing age (Statistics New Zealand, 2014a). The lower proportion of older adults in the RTR sample (only 16% over 65) is likely to be responsible for the observed differences between the two data sets.

In summary, based on the limited information available, the RTR sample varies from the total NZ wheelchair using population by having a higher proportion of power wheelchair users, being younger and having more males. These differences may be a result of the recruitment process relying on DPO's or health professionals to refer potential participants and there may be some bias towards higher levels of engagement or service use by the more physically impaired (power wheelchair users). Additionally, the predominance of information material being made available in electronic format may have favoured access by and uptake of a younger sample of respondents.

These variances of demographics between the RTR sample and the NZ wheelchair using population together with a relatively small sample size imply that the generalisability of results may be limited. Nevertheless, the findings do represent the perspective of a significant number of wheelchair users from across the country and as such provides a voice for their opinions and potentially useful insights for emergency planners, researchers, DPO's and the people they represent.

4.3 Levels of preparedness amongst participants

With less than 30% of RTR participants having stockpiled emergency supplies, the level of engagement with this emergency preparation activity for this study population is much lower than that reported for the general population in NZ. According to the Colmar Brunton (2014) report, commissioned by MCDEM³, and based on a telephone survey of over 1200 NZ residents, 86% of NZ adults reported having emergency survival items set aside. Having emergency survival items is an important aspect of being ready for an emergency but is only part of what is required to be fully prepared. For the general population being fully prepared for emergencies involves having and regularly updating emergency survival items, plus having an emergency survival plan that includes what to do both when, at or away, from home (Colmar Brunton, 2014). In 2014, it was estimated that only 15% of all NZ residents had achieved this level of preparedness although nearly 60% do have a survival plan for home.

Only a small proportion of participants from the RTR study indicated they incorporated disability specific items in their emergency preparations. Approximately 18% of RTR participants reported having an evacuation plan, 14% had a plan with their support network and only 10% had put aside medications or consumable products required as a result of their disability. Even taking in to account methodological and terminology differences between the Colmar Brunton (2014) and RTR surveys, along with the relatively small RTR sample size, there appears to be a stark contrast in preparedness levels between the two groups with the RTR participants being well below that of other New Zealanders.

The low level of preparedness, reported by the RTR participants, is similar to those reported by Phibbs et al. (2014). In that case, prior to the first earthquake 20% (5 out of 25) of survey respondents reported having adequate emergency supplies and 12% (3 of 25) had an emergency plan (S.R. Phibbs et al., 2014). While preparedness improved amongst participants of the Phibbs et al. study following the first

³ MCDEM have commissioned a survey annually since 2006 to assess the effectiveness of the nationwide “Get Ready Get Thru” advertising campaign.

earthquake, both studies highlight potential concerns about the level of emergency preparedness of people with disabilities in NZ.

While previous experience of an emergency situation can act as a catalyst for increasing personal and household emergency preparedness (Colmar Brunton, 2014; Kohn et al., 2012) this was not the case for participants in this study. Participants in this study who had previously been in an emergency situation did not report significantly higher levels of preparedness than those who had not been in an emergency situation. As discussed below, this finding possibly reflects the behaviour of the wider NZ population.

In the two years following the Canterbury earthquakes New Zealanders reported higher levels of preparedness than previously (Colmar Brunton, 2014). Emergency preparedness also increased for the disabled Canterbury participants of the Phibbs et al. study (2014) with a range of preparedness activities being undertaken by participants following the first earthquake in September 2010. Out of 25 participants, only five had stockpiled emergency supplies prior to this first earthquake but this increased to 18 after. Likewise, development of an emergency plan increased from three pre-earthquake, to nine post-earthquake. In addition, following the first earthquake, 18 participants had organised people to telephone, 14 had put together emergency related equipment and 10 had placed important instructions in prominent places. Only three participants had not done anything (S.R. Phibbs et al., 2014).

However, the experience in NZ highlights that the catalytic effect of an emergency event to increase emergency preparedness may not be well maintained. For example, while Canterbury is a region that remains above the national average for being prepared at home, there has been a significant reduction in the number of Cantabrians who are fully prepared compared to previous years (Colmar Brunton, 2014). In addition, the number of New Zealanders who have taken steps to prepare for a disaster in the previous 12 months has had a year on year decline since 2011, the year of the most destructive of the Canterbury earthquakes (Colmar Brunton, 2014). Phibbs et al. (2014) surveyed people as the earthquake events were still ongoing, and showed relatively high levels of emergency preparedness following the first

earthquake. In contrast, the RTR study which was undertaken some three years following the first Canterbury earthquake showed no significant difference in preparedness between participants who had or had not experienced a previous emergency event. The level of preparedness amongst RTR participants reflects those reported in the Phibbs et al. study prior to a disaster.

In summary, the findings of the RTR study indicates that NZ wheelchair users may be much less prepared for emergencies than other New Zealanders. Of particular concern is the very low level of disability specific emergency preparedness measures that have been undertaken by participants in this study. The following section discusses the findings of the RTR study related to barriers encountered to emergency preparedness which may go some way to explaining the preparedness disparity highlighted in this study.

4.4 Barriers to preparedness for NZ wheelchair users

The most common reason for not being prepared amongst the RTR participants was lacking motivation or time. Fifty eight percent of RTR participants with no plan indicated this was the reason for not being prepared compared to 31% of the general NZ population citing the same reason (Colmar Brunton, 2014).

Table 4.3 summarises the frequency which participants in the RTR and Colmar Brunton surveys who were not prepared for emergencies identified the reasons for not being prepared. While terminology and definitions vary between the two surveys, there are higher rates of RTR participants identifying reasons of motivation and not knowing what to prepare for, than the general NZ population.

As discussed in the following section (4.4.1), requiring help from others to make personal emergency preparations was the most commonly cited barrier to preparedness amongst RTR participants but it is not mentioned as a barrier for the general NZ population in the Colmar Brunton (2014) survey. From the information available it is not possible to know if requiring assistance from another person is reported by any respondents of the Colmar Brunton survey. However, if it is, it will be

identified as a barrier for less than 7% of the general NZ population, this being the frequency with which the least commonly identified barrier is reported.

Table 4.3: Reasons for not being prepared for the general NZ population and RTR participants

Reason for not being prepared	NZ (n = 397) [¶]	RTR (n = 73) [‡]
Not got around to it	31%	58%
Cost	14%	10%
Don't know what to prepare	7%	24%
Haven't thought about it	10%	11%
[¶] From Colmar Brunton (2014). Participants who report not being well prepared but consider emergency preparedness to be important. [‡] RTR participants who have no plan		

In the following sections the key barriers to preparedness identified by the RTR study participants will be discussed within the framework of existing research evidence and emergency planning practice.

4.4.1 Requirement of help from others

Setting up and maintaining an emergency supply kit is an activity that involves tasks such as moving and storing bulky or heavy items like containers of canned goods and water that may be more difficult for wheelchair users to manage than the general population. Thus, assistance from another person may be required for a wheelchair user to manage this critical aspect of personal preparedness. Those with mobility impairment are more likely to require external assistance for meeting basic needs, to effect an evacuation or to sustain care requirements in the aftermath of an emergency. As such it is less likely that they will be able to develop an effective plan in isolation from those who will be required to help. The issue is often more problematic due to the additional supplies and measures (eg: ensuring continuation of care givers over the emergency period or planning contingencies for damaged/lost equipment) that may be needed by people with disabilities. Items such as disposable

gloves, catheters, and medications may be required by those with disabilities but may be difficult to stockpile. In the case of medications, this is a particularly difficult task due to the tight controls around some medications (S. R. Phibbs et al., 2012).

For more than half of RTR study participants who did not have a plan, the need for assistance from another person to convert thoughts about getting prepared in to action, was the most commonly reported barrier. Comments provided by four RTR participants provide some insights into this issue. Two participants noted that physical assistance only was required, one of these specifically identified that having no accessible place to stockpile supplies was an issue that they would need assistance with. One participant noted that their closest friends and family were also physically or cognitively impaired creating a further barrier. The remaining participant comment relating to this issue noted that their emergency plan, relied totally on outside assistance and therefore their plan may not work if that support person was injured in an emergency situation.

Phibbs et al. (2014) noted that replenishing supplies after an emergency, may be an issue for people with disabilities. Most of the disabled participants in the Phibbs et al. study needed help to restock supplies between earthquake events in Canterbury due to the disruption to usual infrastructure and services such as public transport, roads and shopping centres. A similar need for additional assistance by people with disabilities following an emergency has also been found in other international studies (Bethel et al., 2011; Brereton, 2012; Castaneda, 2011; Fox et al., 2007; Hogan et al., 2011; Kailes & Enders, 2007; Markenson et al., 2007; Ministry of Civil Defence & Emergency Management, 2013a; National Council on Disability, 2005, 2006). The findings of the RTR study indicate that the need for assistance from others may not be an issue restricted to just the response phase but may be a barrier to NZ wheelchair users making preparations prior to emergencies as well.

It has been suggested that disabled people establish support networks and then discuss and practice their emergency plans with their network (Ministry of Civil Defence & Emergency Management, 2010b, 2013a). However, there is a lack of published papers discussing the types of help people with physical disabilities may

require in order to affect their own personal preparedness planning. Given the paucity of information related to this barrier, further study would be useful to detail the exact nature of the issues involved and possible measures that could be employed to mitigate it.

4.4.2 Socioeconomic considerations

The issue of cost was seen as a barrier by nearly a quarter of all RTR participants (including those with and without a plan), a higher rate than that reported for the general NZ population (Colmar Brunton, 2014). This finding is similar to the findings from Phibbs et al. (2014) who reported cost being the main barrier to accessing emergency supplies. Studies of the general population internationally identified that having a higher income and owning a home are two of the socioeconomic variables associated with a higher likelihood of having emergency supplies stored (Kohn et al., 2012). Amongst people with disabilities, low socioeconomic status has been cited as an additional risk factor to being less prepared (D.L. Smith & Notaro, 2009). Using data from a survey of over 750,000 US citizens, a quarter of whom had a self-reported disability, Smith and Notaro (2009) identified that lower income was associated with being less prepared in both the general and disabled population. Other socioeconomic variables implicated with lower levels of preparedness amongst the disabled respondents in Smith and Notaro's study included being female, non-white, younger than 44, unemployed, uncoupled, less educated and living in an urban area. Income and educational levels was not asked in the RTR survey but have been associated with lower levels of preparedness in other international studies (Eisenman et al., 2006; Eisenman et al., 2009; Kohn et al., 2012; D.L. Smith & Notaro, 2009). Given the findings from studies undertaken in other countries and the poorer socioeconomic outcomes of people with disabilities in NZ (Office for Disability Issues, 2012; Statistics New Zealand, 2014c) it is perhaps not surprising that cost was seen as a barrier to emergency preparedness amongst the RTR participants.

The findings of the RTR study indicate that ethnicity may not be as significant a barrier to emergency preparedness in NZ as Smith and Notaro (2009) found within their US based sample. Within the RTR sample, although the numbers are small, those who identified as Māori reported the highest levels of preparedness. This is in contrast to

previous international studies where the 'white' ethnicity was associated with higher levels of preparedness compared to ethnic minorities such as African American, Latinos and Asians (Eisenman et al., 2009; Kohn et al., 2012; D.L. Smith & Notaro, 2009). However, caution is required when comparing the results from the RTR study with larger international studies due to the small number of RTR participants.

Limited insight into the effect that ethnicity may contribute to emergency preparedness for New Zealanders can be obtained from the Colmar Brunton (2014) survey as ethnicity data is not specifically reported. Kenney and Phibbs (2014) describe Māori cultural practices that may facilitate disaster risk mitigation, recovery and community resilience in a qualitative study with 45 focus group and interview participants. They note that the cultural concept of whakapapa (genealogy) and family (whānau) "provides a stable emergency management infrastructure for Māori" (Kenney & Phibbs, 2014, p. 759) and that marae have for centuries been able to rapidly mobilise support at times of adversity. These factors may potentially contribute to a perception amongst Māori that they have an emergency plan and that this is based more upon the collective preparedness of the iwi (tribe) or whānau than the individual. If this is the case it may go some way to explaining the results from the RTR study in which Māori report higher levels of preparedness than wheelchair users of other ethnicities in NZ. Further research into the cultural values and practices underpinning Māori preparedness, specifically as it relates to people with disabilities, would be useful to better understand this issue.

4.4.3 Accessibility and disability relevant information

While the Civil Defence website contains disability specific information in a range of formats, over a third of RTR participants and nearly half of the participants in the Phibbs et al. (2014) study identified a lack of disability relevant information as a barrier to their personal preparedness. A separate, but related, issue of accessibility of information was identified as a barrier to emergency preparedness by a quarter of RTR participants while 40% of the participants in the Phibbs et al. study disagreed that emergency information was easily accessed.

Differences in the observed rates between the Phibbs et al. (2014) and RTR studies may be related to the nature of disability of the respective study participants, the sampling framework, or the timing of when disability related and accessible information was made available. While the RTR survey only included those who had a mobility impairment requiring the use of a wheelchair, Phibbs et al. included people with different types of disabilities such as vision and hearing impairment. The issues of accessibility for individuals with sensory impairments are likely to be different from those with mobility impairments. The participants in the Phibbs et al. study identified issues of accessing information in the aftermath of the earthquakes when infrastructure was damaged and services were struggling to provide timely and accurate information. These factors may have contributed to the higher rate of participants in Phibbs et al. study identifying information access as a barrier. Additionally, publically available disability related information on the NZ Civil Defence website has been added over time and as such may not have been as readily available for the participants in the Phibbs et al. study at the time they were surveyed.

Having a lack of information available that is relevant to, and accessible by, people with disabilities has been identified by other authors as a barrier to emergency preparedness for people with disabilities (S.R. Phibbs et al., 2014; Priestley & Hemingway, 2007; Spence, Lachlan, Burke, & Seeger, 2007; Sullivan & Häkkinen, 2010). The issues of accessibility and nature of information required, appears to differ for people depending on the type of disability they have. Hence, emergency preparedness information needs to be tailored to suit a range of disability types. It has been recommended that the development and dissemination of information needs to involve disabled people working in partnership with emergency planning and response agencies (Connecticut Developmental Disabilities Network, 2005; Fox et al., 2007; National Organization on Disability, 2005; S. R. Phibbs et al., 2012; Rowland et al., 2007). A similar call for improved access to disability specific information and improved partnerships between disabled persons and MCDEM was made by delegates at the May 2012 *Disability Inclusive Emergency Preparedness and Response Symposium* (Brereton, 2012).

As previously noted, the primary emergency preparedness information source for the NZ public is the Civil Defence *Get Ready Get Thru* (Chapter 1, section 1.5) advertising campaign and associated website. However, in 2014 fewer than 15% of people who saw the television advertisements reported they took the action of visiting the website (Colmar Brunton, 2014). Thus, there appears to be a poor association between those who see the advertising and then view the website (which contains the disability related information in accessible formats). As a result it is possible that many people with disabilities in NZ do not know of the existence of information that could be useful in assisting them to plan for and respond to emergencies.

Internationally, many DPO's take a proactive approach to producing and disseminating personal preparedness information that is intended to meet the needs of the various disability types they represent (chapter 1, section 1.10.2.2). They are often assisted in their efforts by state or national government agencies such as FEMA. A range of pamphlets, websites and other resources are available, many of which contain similar messages (Christopher and Dana Reeves Foundation, n.d.; Federal Emergency Management Agency, n.d.; National Organization on Disability, 2009). However, there are relatively few examples of similar resources produced by NZ DPO's (Dunn et al., 2012).

In NZ the MCDEM *Working From the Same Page: Consistent Messages for CDEM* document, discussed in chapter 1 (section 1.5.1), contains the recommended action messages for the general population and people with disabilities. This document is based on a similar one produced by the American Red Cross in partnership with many US state departments and national organisations (American Red Cross, 2007; Ministry of Civil Defence & Emergency Management, 2010b). As such CDEM uses similar messages for people with disabilities as is used by many of the DPO resources discussed above.

The results from the RTR study show that more participants identified a lack of information relevant to people with disabilities as a barrier to their preparedness rather than a lack of access to this information. However, as NZ's disability specific emergency preparedness information is consistent with international guidelines it

could be argued that the issue of most relevance with regards to emergency preparedness information for disabled New Zealanders may be knowing where to access it rather than it not being relevant. As the RTR study did not include questions about what information participants had accessed, the specific nature of the issues facing people with disabilities with regards to emergency preparedness information remains unclear. Further research into this issue including people with a range of disabilities in NZ is required to address the concerns highlighted by this study and other studies (Brereton, 2012; Dunn et al., 2012; S.R. Phibbs et al., 2014; S. R. Phibbs et al., 2012).

4.5 Participant perspectives regarding a proposed register

In this study 90% of participants indicated support for the concept of a NZ based register for people with disabilities for use in emergencies. Registers of this type have been widely recommended (Enders & Brandt, 2007; Markenson et al., 2007; National Council on Disability, 2006; Rowland et al., 2007; White, Fox, Rooney, & Cahill, 2007) and at face value seem to be a useful tool to assist emergency planners and responders to get help to those who most need it. The high levels of support for the concept reported by the RTR participants arguably provides an incentive to investigate the issue further for use in NZ. However, before embarking on such an investigation it is worth noting the potential problems with registers of this kind, some of which have been identified by RTR participants.

While 90% of RTR participants reported that they thought a DPERR was a good idea, only 76% indicated they would contribute their personal information to a register if one was developed. Some participants felt that with their current level of disability or level of personal support they would be able to manage in an emergency thus not requiring assistance from other sources. However, the majority of participants indicated the concern they had about contributing to a register was related to collection, security and sharing of personal information. Māori were significantly more likely to be concerned about all these aspects of information management than non-Māori. Māori were likely to be concerned about others entering information on their behalf, security of stored information, government access to information held in

a DPERR and who could access the information during an emergency. These concerns are important and require further investigation because they have the potential to influence the success of a DPERR.

Interestingly, participants of this study who had been in a previous emergency (natural disaster) reported higher levels of concern, than those who hadn't, about other people entering information about them on a register and about government agencies gaining access to their personal information through a DPERR. This suggests a level of suspicion which may be due to their previous experiences during or after an emergency. None of the comments received provide any insights into this potential phenomenon and as such is a further line of enquiry that could yield valuable information about the experiences of people with disabilities in emergencies.

4.5.1 Security of personal information

The issue that RTR participants were most concerned about was security of personal information from unauthorised access, hacking or other privacy breaches. Nearly six out of ten participants were concerned about this issue. Providing adequate safeguards to protect personal information is a technical feature built in to numerous registers and as such should not be an unsurmountable obstacle to the development of a DPERR. However, due to the technical nature of ensuring data security, specialist ICT services would be required to set up and maintain the system and this becomes a resourcing and cost issue. Once established, the security features would need to be adequately described to allay the concerns of those who would potentially contribute their information.

4.5.2 Collection and maintenance of personal information

The issue of how information is collected, entered and updated to a register is critical to its ongoing success. In this study participants favoured entering the information themselves as opposed to having others entering it on their behalf. The implication therefore is that an appropriate mechanism for allowing people to do this would need to be incorporated into a NZ DPERR. Unfortunately there is little information available regarding how other registers of this type manage this issue. White et al. (2007), in their summary report of the Nobody Left Behind project notes that registers in use

have common features of being “rooted at the community level” (White, Fox, Rooney, & Cahill, 2007, p. 35), are operated by local emergency management agencies or DPO’s, are available immediately to first responders at the time of an emergency and contain only sufficient information required to affect a response by emergency services.

Any register is only as good as the information it contains, which provides challenges for a system that relies solely on the disabled person to self-enter their details. Firstly, ensuring that those who would benefit most from inclusion on a register do actually get included would be a challenge. For a DPERR to be most effective, finding a way to engage and support the socially isolated, poorer and more marginalised individuals of the disabled community to opt on to the register will be critical as it is these people who appear to be at greatest risk at a time of disaster. The second, ongoing challenge would be ensuring that information is accurate and up to date. If a DPERR were developed that relied solely on people self-entering their information the burden of maintaining this information would fall on the disabled person themselves. On the other hand, the risk of this information being out of date has wide implications. Emergency responders are a critical stakeholder in a register such as a DPERR but could easily lose faith in it if precious time and resources are wasted in an emergency response based on inaccurate information, for example, by checking the whereabouts of a person who is listed at a particular address only to find that they had moved but not updated the register details to reflect this.

Another approach to the collection, and maintenance of data could be to link the register to other databases so that people are prompted to update information at regular intervals. In NZ the use of the National Health Index (NHI) number system acts as a unique identifier that is accessed and updated on most occasions that a person has contact with a health service (eg: GP, pharmacist). As such, it provides the potential for a low burden of maintenance on the disabled person and other system users as it is a task that already forms part of routine processes. A not inconsiderable challenge with this approach is gaining the appropriate consents and technical access to an existing highly controlled database. Alternatively, the burden for maintaining

information could remain with the registrant, but a system of automated prompts via text messaging, emails etc. could be set up to remind them that an update is required.

4.5.3 Potential issues with vulnerable persons' registers

As previously noted, there is very limited published information regarding the operational details and effectiveness of vulnerable persons' registers that are in use overseas (Kailes, 2011). However, there are some potential problems that need careful consideration. June Kailes, a disability policy consultant and author of several articles related to the topic of disabled people in emergencies, summarised the key concerns about registers at the *Getting Real II* symposium in 2011 as: i) they can potentially oversimplify the issues in the minds of disabled people and planners which may lead to complacency on both sides, ii) they can be developed with poor clarity and explicit statements of purpose, iii) they risk increasing dependency of disabled people, iv) they may imply that a level of response will be provided that can't be met, especially with large scale disasters, v) there is often an underestimation of resources required and vi) there is a lack of evidence regarding their effectiveness (Kailes, 2011; Kailes & Enders, 2014).

To mitigate some of the potential problems associated with registers, Kailes (2011) recommends careful consideration of the issues outlined above as well as explicit disclaimers and explanations of what the register can and cannot do. The need for inclusion of disabled people and their representative organisations in developing a register is also emphasised by Kailes, as is a two-way communication system so that the flow of information is not just from the emergency planners down but can accommodate ground up communication. DPO's can play a critical role in facilitating engagement of people in the community who may be otherwise unknown to emergency or other service providers and the two-way flow of communication.

A final consideration regarding vulnerable person's registers is a potential philosophical conflict between their use and the often cited need for people, from all sectors of the community, to be personally prepared for emergencies. A vulnerable person's register could be perceived as undermining the message of personal preparedness incumbent on all members of the community by implying that special

assistance will be forthcoming to those who are on the register. This is a potentially dangerous assumption as the extent of a disaster may overwhelm the abilities of emergency services to respond. Alternatively, there may be an inappropriate response forthcoming which fails to meet the needs of the person with a disability (Kailes, 2011). The challenge, is to balance the benefits that a register may provide with the maintenance and strengthening of personal preparedness of disabled people so that they can be more resilient in emergency situations.

Before implementing a DPERR in NZ other stakeholders such as DPO's, Civil Defence, emergency responders and ICT experts would need to be engaged to determine the feasibility and usefulness of any register system. Existing registers should be examined in more detail particularly focusing on operational details. Liaison with register administrators would be recommended to identify the operational features and systems most appropriate to the NZ context.

4.6 Technology, people with disabilities and emergencies in NZ

Internationally and nationally ICT is becoming an increasingly important consideration for emergency planners and responders (Kapucu et al., 2010; Mersham, 2010; Ministry of Civil Defence & Emergency Management, 2013b; Troy et al., 2007). The use of geographic mapping systems, advance alert warnings, social media, smart phone apps and the internet to rapidly access information from multiple sources all contribute to enhanced abilities to plan for and respond to emergencies, for official agencies and individuals alike.

However, the extent to which people with disabilities in NZ are able to access and benefit from these advances in technologies is unclear as ICT use patterns of the NZ disabled community have not been studied. It is clear from international evidence that a disability technology divide can occur as a result of disability related and personal factors, including socio economic determinants (Kaye, 2000; Vicente & Lopez, 2010). It is understood that disabled people in NZ generally have poorer outcomes across the socio economic variables (Office for Disability Issues, 2012; Statistics New Zealand, 2014c) a significant risk factor for lower levels of access and use of ICT

(Dobransky & Hargittai, 2006; Vicente & Lopez, 2010) but at the present time there is no clear evidence whether this translates to lower ICT use amongst disabled New Zealanders as observed overseas.

The findings of the RTR study show a different trend to the overseas studies as the use of the internet, smart phones, online financial transactions and social media was higher amongst RTR participants than that reported by the general NZ population (Table 4.4). In addition, 78% of RTR participants reported using a smart phone compared to an estimated 60% of the NZ general population (Pullar-Strecker, 2013).

Table 4.4: Comparison of internet use patterns between RTR participants and the general NZ population

	RTR sample	General NZ population (Individuals in 2012)*
Internet use	91%	83%
Online financial transactions	87%	54%
Social media	83%	65%
* Data extracted from tables from <i>Household use of Information Communication Technology: 2012</i> http://www.stats.govt.nz/browse_for_stats/industry_sectors/information_technology_and_communications/HouseholdUseofICT_HOTP2012/Commentary.aspx Downloaded 07.04.15		

While the RTR study is the first to seek clarity of ICT use patterns amongst a group of disabled people in NZ, the limited number and scope of people with disabilities along with a non-randomised recruitment process limits the generalisability of findings to the wider disability population. The majority of RTR participants completed the online version of the survey and were more likely to use internet based applications than those who completed the survey via the postal option (chapter 3, section 3.7.1). Thus there may be a bias in the RTR sample towards those with better access and use of ICT and highlights that the high internet use rate identified in this study cannot be assumed to be representative of NZ wheelchair users in general.

Despite these limitations, the findings of the RTR study show a reasonable level of ICT use and confidence within this group of disabled people. As such, ICT technologies that support emergency preparedness for people with disabilities, as used more extensively overseas, should be explored as a potentially useful adjunct to emergency planning in NZ. There is a clear need for further research into the ICT use patterns of people with disabilities with a particular emphasis on the added benefit such technologies could confer to emergency preparedness and response for this group.

4.7 Strengths of the study

4.7.1 Consultation with wheelchair users

In the spirit of the disability rights philosophy of “nothing about us without us” (United Nations, 2004) the RTR study was developed in consultation with representatives of the people with mobility impairments who are the subjects of the study and amongst the potential end users of a DPERR. Formal consultation occurred in the form of a meeting with the BACC who comprise of a group of disabled people with an interest in disability and rehabilitation research. A mixture of disabilities are represented within the committee or wider reference group. The committee exists “as an initiative to promote consultation between researchers and their populations of interest” (Burwood Academy of Independent Living, 2014). Consultation with, and consideration of the committee’s recommendation, were completed prior to the submission of the ethics application (Appendix A). The consultation undertaken helped to ensure that the study’s content, format and survey wording were appropriate to the intended population. In addition, having the BACC group endorse the project helped increase the credibility of the research amongst the potential participants.

4.7.2 Consultation with Māori

The processes used for consultation with Māori are described in the methods chapter. Meaningful consultation was facilitated through the use of a company (H.E.I. Mahi Ltd.) that has recently been established for this purpose. The RTR study was the first time this approach had been employed by either of the sponsoring institutions (BAIL and the University of Otago) and provides a useful model to support non-Māori

researchers to consult with and engage with members of the Māori community who may otherwise be inaccessible to them.

Consultation with H.E.I. Mahi Ltd. occurred through face to face and phone meetings as well as them reviewing material submitted for ethics review. They provided advice regarding potential recruitment strategies that would best engage Māori and promoted the study at Hui they attended around the country. Overall the use of this approach provided me with a breadth of consultation and reach of access to Māori that I do not feel would have been possible for me otherwise. The involvement of H.E.I. Mahi Ltd may have improved credibility of the study amongst Māori. While it is not possible to determine if H.E.I. Mahi Ltd's involvement actually increased participation of Māori wheelchair users, the study sample does reflect the estimated proportion of Māori with a mobility disability who rely on some form of mobility equipment (as discussed in section 4.2).

4.7.3 Study content

As previously noted, the RTR survey is the first study undertaken in NZ to investigate emergency preparedness amongst wheelchair users. Earlier work (S. Phibbs et al., 2015; S.R. Phibbs et al., 2014; S. R. Phibbs et al., 2012) addressed some of the issues investigated by this study but as far as can be determined, the RTR study is the first time members of the disabled community from around the country have been surveyed regarding their preparedness for emergencies and ICT use patterns. Thus, despite its shortcomings the RTR study contributes to a previously under researched area and provides some useful insights to guide future investigations.

4.7.4 Use of information video

Potential RTR participants were provided the opportunity to read an information sheet about the study or watch a video that contained the same information. Both formats were approved by the University of Otago Human Ethics Committee (Health). The video was hosted on the BAIL webpage that was created especially for the RTR study and could be viewed through a YouTube™ link as well. The information video was used as I was mindful of a potential low health literacy level amongst some portions of the target population and therefore felt that an alternative way of

receiving information about the study was a way of increasing the likelihood of their participation.

The BACC group endorsed the idea of the information video and further suggested that inclusion of a wheelchair user would add authenticity to the project. This suggestion was actively pursued but unfortunately could not be realised as I was unable to find a wheelchair user who was available to participate in filming a video within the required timeframe.

4.7.5 Option for postal or online survey completion

Providing participants with the option of postal or online survey completion was intended to eliminate any barriers that lack of access to the internet may have provided. This was especially important due to the survey's questions regarding use and confidence of ICT amongst wheelchair users. If only one option for completing the survey had been provided there was potential for greater risk of biasing the results one way or the other.

The method of receiving the initial notification of the study may have influenced who and how participants decided to complete the survey. As the recruitment strategy relied on third party organisations to disseminate information about the study, the methods they chose to do this were beyond my control and represents a potential limitation of the snowballing method (as discussed below, section 4.8.1). Thus the proportions of participants who received information via electronic versus non-electronic means is unknown, preventing an effective analysis of this issue. However, differences in ICT use patterns between those who completed the survey online or via post provides some support for the decision to provide both options.

4.8 Challenges and limitations of the Ready to Roll study

The main challenges and limitations of the RTR study were participant recruitment, sample size, self-reporting by participants, potential sample bias, lack of a comparison group, use of a non-validated survey tool and limited generalisability of findings. These limitations are discussed in the following sections.

4.8.1 Participant recruitment

The biggest challenge encountered with the RTR study was associated with participant recruitment. Due to the wide range of causes for mobility impairments that require a person to use a wheelchair there is no way of identifying wheelchair users in NZ. This created a challenge with developing a recruitment strategy due to a lack of a defined population from which to sample. This was the primary reason for selecting a snowball sampling technique using firstly, DPO's and then later, health care providers.

There were limitations of the snowball technique used in this study. Firstly, the snowball sampling method results in a nonprobability sample meaning that the results of this study cannot be generalised to the wider wheelchair using population (Ritter & Sue, 2007c). Secondly, due to the recruitment strategy employed, as the researcher, I had a lack of control over how, and to whom, information about the study was distributed to potential participants. While I attempted to ensure consistent information was distributed through providing pre-prepared advertising and information material, ultimately how this was used was controlled by the individuals or organisations acting as onward referrers. This contributed to a lack of in-depth understanding about the characteristics of those who participated in the study in comparison to those who were eligible but chose not to participate. This in turn limited my ability to assess the representativeness of the RTR sample in comparison to the wider wheelchair using population. Thirdly, the snowball sampling method used was not as successful as hoped for in recruiting participants. Although a good geographical spread of participants was achieved with this approach the target sample size was not achieved. The limitations associated with a small sample size are discussed further in the following section.

Alternative approaches for recruitment were considered in the planning phase but were ruled out for various reasons. A known population, and therefore alternative sampling framework, could have been used from a single disability type. For example, access to both the spinal unit's registers would provide an accurate estimate and contact details for wheelchair users throughout NZ. Using this approach would have allowed for a probability sample using a randomised sampling approach but I did not want to restrict the study to only those with SCI. The reason for this being, that due to

funding sources, there may be significant differences in the level of equipment and personal support provided to SCI individuals compared to other disability types (as discussed in Chapter 1, section 1.1.3). Therefore, restricting the study to just SCI individuals may give a biased outcome that does not reflect the true extent and range of issues affecting the wider wheelchair using population in NZ.

4.8.2 Small sample size

I had originally anticipated that an appropriate sample size for the statistical testing was $n=400$. The sample size that was finally achieved did not meet the sample size target. As a result the study was under powered. While statistical significance could be identified with some of the demographic variables in relation to the issues investigated, the confidence intervals associated with some of these findings indicates a large amount of uncertainty regarding where the true risk may actually lie. In addition, some demographic variables that are actually significant factors may have failed to reach the threshold for statistical significance due to the small sample size.

In retrospect, given the snowball sampling method chosen, I would have included health care providers from the outset of recruitment in order to increase the number of possible onward referrers. An alternative approach that may have worked better would be to potentially work closely with a smaller number of key organisations. For example, CCS Disability Action manage the Mobility Parking Scheme which over 100,000 people with a disability are part of, so partnering more closely with them to disseminate information to people on their database may have been a more effective approach.

4.8.3 Reliance on self-reporting

The RTR study, like others which have attempted to quantify the level of emergency preparedness amongst people with disabilities (Bethel et al., 2011; Eisenman et al., 2006; Eisenman et al., 2009; National Organization on Disability, 2005; D.L. Smith & Notaro, 2009; D. L. Smith & Notaro, 2015; Uscher-Pines et al., 2009) has used a survey method. A limitation of survey based studies is that they rely on the respondent's own perception and reporting of their behaviours. Variations in self-reporting will be influenced by the wording of questions and personal factors and may not be

consistent between individuals within or between studies. As such the possibility of differences in perception between the RTR sample and participants of overseas research or other New Zealanders regarding what being prepared entails cannot be discounted as a confounding variable affecting the comparison between the outcomes of this and previous studies. Additionally, a gap between an individual's perceived and actual level of preparedness may exist. This has been highlighted by international studies amongst the general population (Kohn et al., 2012) as well as wheelchair users (McClure et al., 2011).

4.8.4 Potential bias of participants

Due to the non-randomised snowball sampling method used, there is a potential for bias in the RTR sample towards those who are likely to be interested in the topic. This could potentially produce an overestimation of the level of support for a DPERR as those who are most interested in the topic would possibly look more favourably on this than their peers who are not as motivated by the topic of emergency preparedness. On the other hand, it is possible that this bias could also over-estimate the level of preparedness amongst NZ wheelchair users. In order to eliminate this bias, a sampling approach that did not rely on self-selection would have been required.

4.8.5 Lack of a non-disabled comparison group

The generalisability of the survey findings would have more certainty if a comparison group of non-disabled participants were also included as they have been in several previous US based studies (Bethel et al., 2011; Eisenman et al., 2006; Eisenman et al., 2009; D.L. Smith & Notaro, 2009; D. L. Smith & Notaro, 2015; Uscher-Pines et al., 2009). This would have allowed for direct comparison between wheelchair users and the able bodied population with respect to their level of preparedness, identified barriers and ICT use patterns. In the absence of a control group, extrapolations of these factors have had to be made from other studies which have different sampling strategies, methods and terminology.

4.8.6 Non-validated survey tool

The RTR study used a non-validated, purpose made, questionnaire. The decision to do this was based on the specific research questions, especially those seeking participant's opinions of the proposed DPERR as no existing tool would include questions related to such a specific initiative. The process by which the questionnaire was developed has been described in the methods section. At the time of developing the questionnaire, I was not aware of the Colmar Brunton (2014) report or that this survey had been commissioned annually by CDEM since 2006. I only became aware of the report through a personal communication with the MCDEM that occurred after the survey was completed. The report was provided to me via a link to the appropriate page on the CDEM website. Previous attempts (via phone call and email requests to Civil Defence staff) to identify what research about the general population's preparedness for emergencies had been undertaken in NZ were unsuccessful. If I had been aware of the content of the Colmar Brunton surveys I would have more closely aligned terminology and questions related to emergency preparedness in the RTR questionnaire to those used in the Colmar Brunton surveys. An alternative, validated, tool which could have used for assessing the emergency preparedness of individuals is the Earthquake Readiness Scale as used by Spittal et al (2008). This is a 23 item scale, designed to assess people's earthquake risk mitigation and survival actions. This tool did not include items specific to the questions of the RTR study and would have required significant modification impacting on the integrity of the tool. Further, adding additional questions to this tool would have impacted on participant burden.

4.8.7 Limited generalisability of findings

The cumulative effect of the study's limitations is that there is limited generalisability of findings to the general NZ wheelchair user population. Generalisability to other forms of disability is even more limited, although the findings may have some applicability to those with mobility impairments who do not use a wheelchair. Due to the difference in issues associated with emergency preparedness for people with different disability types it would not be recommended to extrapolate the findings from this study to those with other impairments (eg: sensory or intellectual).

4.9 Key learnings to arise from the Ready to Roll project

The following section amalgamates the results of the RTR study together with the findings from previous research and other published material to create a list of key learnings.

1. International and local experience highlights that people with disabilities are at greater risk of death, injury or further disablement than the general population at times of disaster. Despite this, people with disabilities continue to appear less prepared than their able-bodied peers, thus increasing their vulnerability further. This study has identified a concerning level of preparedness for emergencies amongst its participants with their reported preparation being at much lower levels than those reported for the general NZ population.
2. Wheelchair users in this study have considered the need to make personal emergency plans but the majority have not yet turned this into action. The main reason identified by participants was that they hadn't got around to doing so although there appear to be additional barriers which could impact on their ability to turn thought into action. The most commonly cited additional barrier amongst RTR participants was the need for assistance from another person to implement emergency planning actions. This is an issue that has received little attention in the emergency planning and response literature to date.
3. Disability specific emergency preparedness information is either not being accessed by participants or is being presented in a manner that fails to meet their needs. The content of NZ Civil Defence's disability specific information, which is publically available on their website, appears to be in line with international recommendations and yet over a third of participants in this current study identified a lack of information relevant to people with disabilities as a barrier to their emergency preparedness.
4. NZ has a stated goal of improving disability inclusive emergency planning and response. However, there appears to be a lack of leadership or a cohesive plan of action to achieve this goal. Lessons could be learnt from the US where significant

changes were made to the emergency planning and response networks in the aftermath of the 2005 hurricane season. Central to these changes, with respect to people with disabilities, was a stronger emphasis on emergency planners, responders and community based DPO's collaborating to deliver a range of resources and programmes to support responding agencies and people with disabilities to be better prepared for emergencies. These changes, driven from central government level, have included financial and personnel resourcing aimed at achieving a more disability inclusive focus.

5. The results from the RTR study indicate that a DPERR would have a good level of support from participants provided that people could enter details themselves and be assured that their personal information was stored and used securely. As such a register may be a useful adjunct to improve the response to, and planning for, the needs of people with disabilities in emergencies. However, there are many logistical and operational issues that would need to be addressed before widespread implementation of a register system was considered. Further consultation and research with all stakeholders is required to progress this issue.
6. There is scope within NZ to further utilise a variety of communication mediums, and ICT applications to assist with improving the emergency planning and preparedness for people with disabilities. The disabled participants of this study reported high levels of use and confidence with a range of ICT devices and applications, with use patterns greater than the general NZ population.

Over three quarters of participants indicated that they would use a smartphone application that could provide their real-time GPS location during an emergency situation. Such an application could work within, or sit alongside a register system or other initiatives. An advantage of such an application, is that it could potentially be used within an individual's personal support network for lower level, day-to-day emergencies not just during large scale disasters.

4.10 Recommendations for future research

Several suggestions for future research topics have already been made throughout this chapter. Hence, this section will summarise the potential areas of future research emerging from the study that will help to improve the capability of people with disabilities in NZ to prepare for and respond to emergencies.

1. In order to define the problem and provide an accurate benchmark of progress towards the goal of having a more prepared and resilient disabled community, there is a critical need for better information about the current level of preparedness across the disability spectrum. Ideally, this would occur in a manner that allows for direct comparison between people with disabilities and the general NZ population in order to highlight areas of discrepancy and inform where initiatives may be best directed. As a low cost first step this could be achieved through including disability status amongst the demographic variables collected during the annual MCDEM commissioned national survey of preparedness. Given that people with disabilities account for nearly a quarter of all New Zealanders and there is a stated objective for improving emergency preparedness for disabled people (Ministry of Civil Defence & Emergency Management, 2013a; Office for Disability Issues, 2014) there would appear to be a more than adequate mandate to implement this immediately.
2. The research and emergency planning sectors need to gain a clearer understanding of the facilitators and barriers to preparedness that people with disabilities face in NZ. In particular, the issue of disabled people needing assistance from another person to implement planning measures, which was highlighted in the RTR study needs to be investigated more fully to understand the nature of the issues.
3. To ensure that emergency preparedness information is disability inclusive further research is needed to identify what requirements people with disabilities in NZ have for accessing, processing and acting on such information. As ICT is becoming an important feature of emergency planning and response systems, it is important to understand the degree to which people with disabilities in NZ can access the benefits that arise from this technology. As

such, investigating ICT use patterns within the NZ disability community and the ICT applications which may contribute to improved personal preparedness and organisational planning for the response to people with disabilities in emergencies is also recommended.

4. The level of support for a DPERR expressed by participants in this study indicates that a review of the scope and logistics associated with a register system and how this would link with existing emergency sector technologies may be warranted. Consideration could also be given to how ICT (eg: peer-to-peer text messaging alerts, real-time GPS locator activated via a smart-phone app) could be utilised within an individuals' personal support network to enable a community focussed response to a disabled person at times of emergency.
5. The effect that ethnicity has on personal and household emergency preparedness in the NZ context is a further area that is worthy of investigation, especially the cultural values and practices underpinning emergency preparedness for Māori. The findings of the RTR study also indicate that the possible utilisation of a DPERR may be negatively impacted for Māori and participants who had previously been in an emergency situation due to their significantly greater concerns about how the information a register would contain is managed, stored and shared. It would be useful to understand the nature and causes of these concerns more fully prior to proceeding with a DPERR to ensure that issues raised are adequately addressed.

4.11 Summary

The RTR study has highlighted a concerning disparity between its participants and the general population in NZ with regard to their respective levels of emergency preparedness. The wheelchair users in this study reported much lower levels of preparedness and reported a higher incidence of barriers to getting ready for emergencies than the general population. The findings from the RTR study indicate that adjuncts to emergency planning and response tools such as a DPERR or applications enabled by ICT may have a place and if available would be well utilised by

the study participants. However, the limitations of the RTR study result in a lack of generalisability to wider groups of wheelchair users or those with other types of disability. It is hoped that the issues raised by this study, together with findings from other international and NZ studies, can help increase the research focus within this important but previously under investigated area.

In all research into the issue of emergency preparedness for disabled people it is important to engage, and actively partner, with people with disabilities. Only by doing this will researchers and emergency planners ensure that the outcomes of this activity actually meet the needs of the intended end users and lead to improved resilience and outcomes for people with disabilities in NZ following emergencies. There is need for improved leadership on this issue and development of a cohesive research agenda if the vision outlined in the *Disability Action Plan 2014-2018* of “increasing the responsiveness to disabled people of civil defence and emergency management around New Zealand” (Office for Disability Issues, 2014, p 7) is to be realised.

Chapter 5: Conclusion

International studies and the Canterbury earthquakes have highlighted that people with disabilities can be impacted by emergencies to a greater extent than the general population. However, the findings of the RTR study indicated that participants were generally less prepared for emergencies than is reported by the general population in NZ, thus increasing their vulnerability to emergencies. Study participants reported more barriers to preparedness than is reported for the general population. The major barriers identified were the need for assistance from another person to effect emergency preparations, access to disability specific information, cost and an inability to stockpile disability related consumables, especially medications.

Registers of disabled people living within the community for use by emergency services are used in some overseas locations and have been advocated as a potentially useful adjunct to emergency preparations in NZ. The participants of this study reported a high level of support for the concept but did have concerns about the security and method of entering their personal information. The level of support and concerns about a potential register need to be further investigated amongst a broader range of stakeholders, including people with other disability types, emergency planners, responders and ICT experts to ensure that any initiative to implement a register system in NZ is going to be sustainable and provide tangible benefits.

While lower rates of ICT use by disabled people, often referred to as a digital disability divide have been reported by some authors, this was not evident for the participants of this study amongst whom ICT use was greater than comparable use figures reported for the general NZ population. The RTR participants reported a willingness to consider a potential GPS enabled smart phone application that could be activated at times of emergency and widespread uptake of a range of ICT applications including internet and email use, software download/installation, online financial transactions and social media. Familiarity with all of these ICT applications may facilitate emergency preparedness due to the growing influence that ICT has within the emergency planning sector. As such ICT could potentially become an important tool for planners, DPO's and disabled individuals in order to improve the current state of

preparedness amongst people with disabilities in NZ for emergencies. However, this trend needs to be further explored within the wider disability community to determine the appropriate scope and role of digital technologies for improving disability inclusive emergency planning in NZ.

The RTR study, while small and limited in generalisability, is one of only a few studies to have investigated the issue of emergency preparedness and response for people with disabilities in NZ. The study has highlighted a number of issues that require further investigation in order to confirm and better understand the issues relating to emergency preparedness of and for people with disabilities, particularly given the landscape of risk that exists in NZ. Finally, as people with disabilities comprise nearly one quarter of all New Zealanders it is argued that there is a critical need for a comprehensive plan of further work and research to enable a truly inclusive emergency planning approach to future emergency events in NZ. In order to achieve this outcome it is essential to ensure that government legislation, emergency planners, responders and researchers partner with disabled people to ensure that planning meets the needs of, and improves the outcomes for, disabled New Zealanders in emergency situations.

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Appendix A: BACC consultation feedback letter⁴



C/o - The Burwood Academy of
Independent Living,
Burwood Hospital,
Private Bag 4708
Christchurch,
New Zealand
Email: euconsult@burwood.org.nz
Phone: +64 3 383 8671

20 November 2013

Dear Mr Nicholls,

**Re proposal titled: Development of a system to advise of vulnerable people in emergencies (SAVE):
Wheelchair users: a survey of end users.**

The End User Consultation Committee met with our end-user reference group on November 13th 2013 to discuss your research proposal. The Committee appreciated your willingness to attend and discuss your research with the end-user reference group. Your topic was considered relevant and will no doubt contribute to a greater understanding of how wheelchair users feel about emergency registers in the context of emergencies. The following suggestions are not mandatory and do not replace any issues highlighted by other ethical or cultural consultations that this research has been subject to. The Committee asks that you read the following suggestions in good faith and with an open mind.

Comments & suggestions:

- Suggestions regarding the recruiting of participants for your online survey included circulating information and a link to the survey on the 'connecting people' Facebook page and asking disability organisations to circulate information amongst their networks.
- Your research considers a variety of 'emergency contexts'. The reference group commented that despite some people experiencing earthquake 'burnout', earthquake-related concerns are still very much at the forefront of people's lives, and that your topic is still very important to explore.
- The reference group thought your idea to use an information video was very good, and that you should consider using an end-user, even their family members, in the video as it may create a strong link with potential participants.
- Suggestions to disseminate the results back to participants included:
 - Asking participants to include their email address at the end of the survey if they would like results emailed to them.
 - Including in the survey the name of a website where results may be found once the study is completed.

We wish you every success in your research and ask that you supply the Committee with a copy of the research findings upon completion.

Yours sincerely,
John Bourke, Chair, End User Consultation Committee

⁴ Since the time of meeting, the committee's name has changed from the Burwood Academy of Independent Living End User Consultation Committee to The Burwood Academy Consultation Committee

Appendix B: Maori consultation letter



16 September 2013

Dr Jennifer Dunn
Orthopaedic Surgery and Musculoskeletal Medicine
University of Otago, Christchurch

*Mā te rangahau Hauora e tautoko te whakapiki ake te Hauora Māori.
All health research in Aotearoa New Zealand benefits the Hauora (health and wellbeing)
of tangata whenua.*

Tēna kōe Jenn,

Thank you for taking the time to meet with me at MIHI, at the University of Otago, Christchurch on the 12th September 2013, to discuss your research study titled:

*Development of a System to Advise of Vulnerable People in Emergencies (SAVE):
Wheelchair users: A survey of end users.*

I note that for this research project that you and Dr Debbie Snell are the Principal Investigators. Jason Nicholls, a Master's degree candidate will also be involved. This project considers the development of a national register for vulnerable people, specifically wheelchair users.

I understand that you will also be submitting applications for funding to several bodies, including The Rotary Club of Christchurch, The Canterbury Community Trust, Canterbury Support Fund, the Burwood Academy of Independent Living and Department of Orthopaedics and Musculoskeletal Medicine.

Commentary on Proposed Research Projects

From my discussion with you, I have ascertained that the aim of this project is to examine issues involving the type of information compiled for a national database. In particular how information for a register is collected, stored, accessed and how it is utilised. You will also explore issues surrounding privacy and data security. A nationwide survey of people who use wheelchairs will be recruited for the survey. The goal of this research study is to obtain a good understanding of what the issues/needs are for the intended users and of the proposed national register for use in emergency situations.

Māori Health Gain

In terms of Māori health gain, your research application should highlight the direct benefits for Māori participants who participate in the studies and document the direct health benefits/gains for those individual participants who consent to be part of this research.

Research Office, Department of the Dean
University of Otago, Christchurch
PO Box 4345, Christchurch Mail Centre, Christchurch 8140, New Zealand
Tel +64 3 364 0237 • Fax +64 3 364 1490 • Email research.uoc@otago.ac.nz
www.uoc.otago.ac.nz

This research project could also be strengthened by including a clear epidemiological profile of current rates of Māori who live with a mobility related disability (highlighting current disparities between Māori and non-Māori) nationally, which would provide an appropriate context to the importance of this research topic on future Māori health gain and the contribution of this toward achieving Whānau Ora. The incidence of Māori living with mobility related disability may be higher for Māori and the impact of this greater for whānau.

This study will be looking to survey 200 – 1,000 people and it is anticipated that there will be Māori in this cohort. You indicated consideration will be given to undertaking a sub-analysis using ethnicity. This would help to unmask some distinct diverges between ethnic groups in relation to specific trajectories/issues for Māori in the study.

Consent

Issues regarding informed consent for participants in the study were discussed. Your information sheet should explicitly state that consent is for this study only.

Ethnicity

As your study may involve a number of Māori participants there is a need to acknowledge the issues pertaining to ethnicity and to consider how ethnicity data will be collected for this study. It is therefore recommended that ethnicity data is collected from each participant (in accordance with the MOH guidelines, which involves the use of the Census 2006 question alongside background details, are collected from each participant. Furthermore, if the participant identifies as Māori, but this is not recorded in their records, this should be reflected by informing the clerk and ensuring the participant is correctly recorded as being Māori.

Partnership

I have suggested that you access Ms Mere Hibbs, a Māori Health Manager with longstanding experience, already working with whānau and hapu in your area of research. Mere is also extremely well placed to provide appropriate cultural oversight and guidance to your research project and allow you to consider what cultural aspects or considerations need to be taken into account regarding the incorporation of a Tikanga based framework for this project. With this in mind, it will be necessary to consider in part, funding for anticipated cultural involvement in future based research projects.

Māori health experts like Mere are also well placed within the Māori disability community and may be able to assist in the development and integration of a methodology culturally appropriate for Māori.

Potential Further Support Resources

Further resources that you might want to access to strengthen your responsiveness to Maori within your research are: 1. *HRC's Ngā Pōu Rangahau Hauora Kia Whakapiki Ake Te Hauora Māori 2004-2008*, 2. *The Health Research Strategy to Improve Māori Health and Well Being 2004-2008*. The other reference that is available is 3. *Hauora Māori Standards of Health IV: A Study of the Years 2000-2005* by Bridget Robson and Ricci Harris, Māori Health Research Unit, Wellington School of Medicine, University of Otago, Wellington. All provide Maori specific information on a range of health issues.

The recent publication *Tātau Kahukura: Māori Health Chart Book 2010*, Ministry of Health, 2010 (2nd edition), is an update relating to the socio economic determinants of health, health status and service utilisation of the Māori population. Further references are available from the HRC's *Guidelines for Researchers on Health Research Involving Māori* (page 22), www.hrc.govt.nz

Dissemination of Results

The HRC's Guidelines for Researchers on Health Research Involving Māori, is important in terms of how your research results may contribute to Māori health gain. This should occur not only in an academic forum, but also within the community from where data is drawn. Therefore the findings from this study should be further discussed with relevant Māori stakeholders. I would recommend that you utilise the Māori advisors/supports (in this case Mere Hibbs) to assist you in the dissemination of your research to the appropriate Māori forums. These forums will allow an opportunity for the consideration of Māori community feedback into any discussion going forward.

Ethics

It is a requirement of the ethics approval process, that a final report be submitted when the research is complete. A copy of the report should also be supplied to me at that time, as findings from this project may contribute to the development of future research hypotheses or projects. It is therefore important that appropriate Māori organisations and Māori researchers are aware of your findings.

I wish you well in your research.

Nāku iti nei



Karen Keelan
Māori Research Advisor

Appendix C: H.E.I. Mahi Ltd letter of support



Mr Jason Nicholls
Department of Orthopaedic Surgery and Musculoskeletal Medicine
Email: nicja964@student.otago.ac.nz

18 December 2013

RE: Ready to Roll survey. Wheelchair user's readiness for emergencies and opinions of a proposed Disabled Persons Emergency Response Register

Tēnā koe Jason,

H.E.I. Mahi LTD is pleased to support your research proposal. We look forward to supporting the project to address the cultural and language needs of research participants who identify as Māori.

At our recent face to face discussion we agreed that H.E.I. Mahi LTD, would:

1. Provide culturally responsive advice, guidance and practices tailored to the individual needs of any research participants that self-identify as Māori
2. Carry out written and oral translation services (English-Māori)
3. Act as a liaison between you and a range of regional and national Māori disabilities networks and community groups across Aotearoa New Zealand

We are happy to provide relevant cultural advice and support, in particular; at the scoping phase, during the community engagement phase, and at the survey implementation phase.

We wish you well with your research and look forward to working with you.

Mauri Ora!

Nāku nā
Te Atarua Hibbs
Director

Te Atarua Hibbs
Director
Mobile: +64 (27) 291-8877
Skype: potiki_11

Appendix D: The Questionnaire

Ready to Roll survey: Wheelchair users' readiness
About the survey.
<p>Thanks for showing interest in this survey.</p> <p>If you've made it this far, you have probably already read the information sheet or watched the video that explains what the survey is about, what your participation would involve and what you need to know to make a decision. If you haven't seen either of these, you can still do so now by going to the website at the address below: http://www.burwood.org.nz/projects</p> <p>To continue to the survey click on the "next" button below.</p>
*1. I have read the information sheet or watched the information video and agree to take part in this study.
<p><input type="radio"/> Yes</p> <p><input type="radio"/> No</p>
2. Have you ever been in a natural disaster (eg: earthquake, flood, severe weather event) that has caused damage to any buildings or infrastructure (eg: power, phone, sewage)?
<p><input type="radio"/> Yes</p> <p><input type="radio"/> No</p>
3. Do you currently have an emergency response plan?
<p><input type="radio"/> Yes</p> <p><input type="radio"/> No</p>

Ready to Roll survey: Wheelchair users' readiness

4. Yes, I have an emergency response plan which includes:

Select one or more options from the list below

- Put aside provisions of food, water and other supplies
- Have an evacuation plan
- Have a plan with a support network who will check on each other in an emergency
- Made arrangements for medications, consumables and carers (if needed)

Other (please specify)

5. No, I don't have an emergency response plan because:

Select one or more options from the list below

- I've thought about it but not got around to it
- I've thought about it but it's not important to me
- I've not thought about it
- I don't know what to plan for or how to go about it
- I can't afford to do it

Other (please specify)

Ready to Roll survey: Wheelchair users' readiness

6. What difficulties did you, or might you, come across when making preparations for an emergency?

Select one or more options from the list below

- None
- I need assistance from someone else to help with planning or making physical preparations
- Lack of information that is relevant to people with disabilities
- Lack of information that is accessible to people with disabilities
- Unable to stockpile consumables
- Unable to stockpile medications
- Financial. It costs too much to do it
- I am not interested or motivated to do it

Other (please specify)

7. In an emergency situation, who would you expect to check on you or come to help you?

- No one
- Family / whanau
- Friends
- Neighbours
- Civil defence
- Police
- Ambulance
- Fire Service
- ACC
- GP
- Carer agency or staff

Other (please specify)

Ready to Roll survey: Wheelchair users' readiness

8. Have you made formal plans with any of the individuals or organisations above to check on you in the event of an emergency?

- Yes
- No

Comments:

9. Do you think that a voluntary Disabled Persons Emergency Response Register, to assist with emergency planning, preparation and response is a good idea?

- Yes
- No
- Unsure

Comments:

10. If one was developed, would you participate in a voluntary Disabled Persons Emergency Response Register?

- Yes
- No
- Only if my concerns were adequately addressed
- Don't know

Comments:

Ready to Roll survey: Wheelchair users' readiness

11. What type of personal information would you be prepared to have on a Disabled Persons Emergency Response Register?

Select one or more options from the list below

- Name and contact details (address and phone numbers)
- General type of disability (eg: "mobility impairment, requires wheelchair", "power wheelchair user")
- Type of assistance potentially required in an emergency (eg: "help to get out of building or evacuate", "help to set up home to manage after an emergency")
- Equipment requirements (eg: "needs power for hoist, air mattress etc.")
- Transport requirements (eg: "relies on public transport", "uses van with hoist")
- Whether you usually require carers (eg: "carer visits daily", "24 hour care")
- Special medicine or medical requirements (eg: "needs home oxygen")

Other (please specify)

12. Please tell us why you wouldn't contribute your personal information to a Disabled Persons Emergency Response Register.

Select one or more options from the list below

- It's not important to me
- Privacy concerns
- I already have a good enough emergency plan
- I am confident I will get any help that I need without having my name on a register
- I don't think I will need any extra help
- I don't think that having my name on a register will make any difference to the help I receive

Other (please specify)

Ready to Roll survey: Wheelchair users' readiness

13. The following questions relate to concerns you might have about how information for a Disabled Persons Emergency Response Register would be collected, stored and used.

For each statement below, please tick the circle that best describes how concerned you are about it.

	Not at all concerned	A little concerned	Somewhat concerned	Quite concerned	Very concerned
It would be a hassle for me to add my details and keep them updated	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I would be concerned if other people (eg: GP practice, ACC, Ministry of Health) were responsible for entering and updating my details.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am worried about government agencies having access to my personal information	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am worried about other people getting access to my information (eg: hackers, unauthorised access, privacy breaches)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am concerned about who can access the information at the time of an emergency	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

14. Is there any other comment you would like to make about the development of a Disabled Persons Emergency Response Register?

Ready to Roll survey: Wheelchair users' readiness

15. How confident are you with using the each of the following computer functions?

	I don't do this at all	Not confident	Moderately confident	Quite confident	Very confident
Doing searches on the internet using Google, Internet Explorer, Bing etc.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sending and receiving emails	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Using Facebook, My Space, Twitter etc.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Online banking or bill payments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Downloading and installing software or apps	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

16. Do you currently use a smartphone, or similar device capable of sending or receiving text / phone / email (eg: iPhone, iPad, Android or Windows phone)?

- Yes
- No
- Not sure

17. Would you use a smartphone application (able to be turned on and off by you) that could provide a GPS location of your whereabouts in the event of an emergency?

- Yes
- No
- Not sure

Comments:

18. Do you currently use a mobile phone that is not a smartphone?

- Yes
- No
- Not sure

Ready to Roll survey: Wheelchair users' readiness

19. Which option below best describes your living situation?

- Live alone, no carers required
- Live alone, carers required
- Live with family/whanau, spouse/partner, no other carers required
- Live with family/whanau, spouse/partner, carers required
- Live with others (flatmates / boarder etc.), no carers required
- Live with others (flatmates / boarder etc.), carers required

Other (please specify)

20. What type of building is the home you live in?

- Single storey, stand-alone house
- 2 or more storey, stand-alone house
- Unit or apartment – single storey
- Unit or apartment – part of 2 or more storey building
- Single storey house or unit within a complex (eg: retirement village, marae)

Other (please specify)

21. What do you use for mobility most often?

- Fulltime manual wheelchair
- Manual wheelchair, can walk a bit (with or without aids)
- Fulltime power wheelchair
- Power wheelchair, can walk a bit (with or without aids)
- Do not use a wheelchair but have limited mobility

Other (please specify)

Ready to Roll survey: Wheelchair users' readiness

22. What is the main reason for your mobility impairment?

- Stroke
- Multiple Sclerosis
- Traumatic Brain Injury
- Spinal Cord Injury
- Other neurological condition (eg: Parkinsons disease, Motor Neuron Disease, Muscular Dystrophy)
- Amputation
- Medical or degenerative condition (eg: arthritis, cancer, COPD)

Other (please specify)

23. How long have you had a mobility impairment?

- 5 years OR LESS
- 6 - 10 years
- 11 - 15 years
- 16 - 20 years
- MORE THAN 20 years

24. What region of New Zealand do you live in?

North Island / Te-Ika-a-Mauī

South Island / Te Wai-pounamu

Select your region from
the drop down menus

25. Do you live in a rural or urban area?

- Live in a rural area or township
- Small town (1,000 - 10,000 people)
- Large town (10,000 – 50,000 people)
- City (over 50,000 people)

Ready to Roll survey: Wheelchair users' readiness

26. What age bracket do you belong to?

- 15 - 24 years
- 25 - 34 years
- 35 - 44 years
- 45 - 54 years
- 55 - 64 years
- 65 years or older

27. What gender are you?

- Male
- Female

28. Which ethnic group do you belong to?

Mark the space or spaces which apply to you.

- New Zealand European
- Māori
- Samoan
- Cook Island Maori
- Tongan
- Niuean
- Chinese
- Indian

• Other such as DUTCH, JAPANESE, TOKELAUAN. Please state:

That's the end!

Many thanks for taking the time to complete this questionnaire.

If you wish to make any enquiries about this survey, or receive a copy of the grouped results, please contact Jason Nicholls by email: nicja964@student.otago.ac.nz

Alternatively, if you have any concerns about ethical issues related to this survey please contact Gary Witte (Human Ethics Committee Administrator, phone +64 3 479 8256 or email gary.witte@otago.ac.nz.)

Appendix E: List of Disabled Persons' Organisations email contacts used to assist with potential participant recruitment

Parafed

leesaa@sportnorth.co.nz; paraauckland@xtra.co.nz;
chloew@sportwaikato.org.nz; sophie@parafedbop.co.nz;
jacob.mills@hotmail.co.nz; parafedmanawatu@xtra.co.nz;
parafed.wlg@xtra.co.nz; ksowden@parafedcanterbury.co.nz;
coolcowhans@xtra.co.nz; info@parafedotago.co.nz; dan.ali@xtra.co.nz

The Association of Spinal Concerns (TASC)

info@tasc.org.nz

New Zealand Spinal Trust (NZST)

info@nzspinaltrust.org.nz; akl@nzspinaltrust.org.nz;
debzm@nzspinaltrust.org.nz

CCS Disability Action

mobilityparking@ccsDisabilityAction.org.nz

info@ccsdisabilityaction.org.nz; northland@ccsdisabilityaction.org.nz;
auckland@ccsdisabilityaction.org.nz;
waikato.admin@ccsdisabilityaction.org.nz; bop@ccsdisabilityaction.org.nz;
thb@ccsdisabilityaction.org.nz; manawatu@ccsdisabilityaction.org.nz;
admin.wairarapa@ccsdisabilityaction.org.nz;
ntaranaki@ccsdisabilityaction.org.nz; s&ctaranaki@ccsdisabilityaction.org.nz;
wellington.admin@ccsdisabilityaction.org.nz;
nelson.admin@ccsdisabilityaction.org.nz;
blenheim.admin@ccsdisabilityaction.org.nz;

canterbury@ccsdisabilityaction.org.nz; ashburton@ccsdisabilityaction.org.nz;
rangiora@ccsdisabilityaction.org.nz; greymouth@ccsdisabilityaction.org.nz;
hokitika@ccsdisabilityaction.org.nz; westport@ccsdisabilityaction.org.nz;
kaikoura@ccsdisabilityaction.org.nz;
admin.southcanterbury@ccsdisabilityaction.org.nz;
otago@ccsdisabilityaction.org.nz; admin.waitaki@ccsdisabilityaction.org.nz;
southland@ccsdisabilityaction.org.nz

Stroke Foundation

strokenz@stroke.org.nz national office

northern@stroke.org.nz don.scandrett@stroke.org.nz General manager

midland@stroke.org.nz sheryl.waters@stroke.org.nz Acting gen manager

southern@stroke.org.nz general manager: Neil McIntosh

Disabled Persons Assembly (DPA)

gen@dpa.org.nz

Canterbury and districts

dpachch@cyberxpress.co.nz

Palmerston North & Districts

dpapn@xtra.co.nz

Vaka Tautua

Email enquiry via website <http://www.vakatautua.co.nz/#!contactus/c1oeh>

Brain Injury Association

information@brain-injury.org.nz; canterbury@brain-injury.org.nz;

braininjury@drct.co.nz; liaison@braininjuryhb.co.nz; [\[injury.org.nz\]\(mailto:injury.org.nz\); \[liaison.rotorua@brain-injury.org.nz\]\(mailto:liaison.rotorua@brain-injury.org.nz\); \[134\]\(mailto:liaison.whanganui@brain-</p></div><div data-bbox=\)](mailto:northland@brain-</p></div><div data-bbox=)

injury.org.nz; liaison.headwaybop@brain-injury.org.nz; liaison.cd@brain-injury.org.nz; liaison.gisborne@brain-injury.org.nz; nelson@brain-injury.org.nz; liaison.dunedin@brain-injury.org.nz; liaison.wellington@brain-injury.org.nz; bia.wairarapa@hotmail.com

Muscular Dystrophy Association

National office; info@mda.org.nz;
support@mdn.org.nz; office.mdawgtn@mdn.org.nz; mdacanty@xtra.co.nz

Amputee Federation

janisbourne@xtra.co.nz; amputeeswbop@gmail.com; burnoff@xtra.co.nz;
jon.tracey@xtra.co.nz; jmaher@orcon.net.nz; juanitapenhey@vodafone.co.nz;
claireellenor56@hotmail.com; paul_jesson@clear.net.nz; lrrstan@xtra.co.nz

THINK, The Head Injury Network for Kiwis

admin@THINKNZ.org.nz

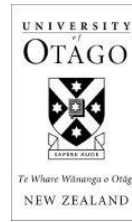
MS Society NZ

info@msnz.org.nz

Appendix F: List of healthcare service providers

- Healthcare of New Zealand
- Geneva Healthcare
- Access
- What Ever it Takes
- Ali's Home Healthcare
- Florence Nightingale
 - Christchurch
 - Blenheim
 - Nelson
- Home and Community Health Association.
- Lavender Blue (P.N. Danneverke and Levin)
- Omahanui Home Care (New Plymouth Wanganui)
- Pacific Homecare (South Auckland)
- Pasifika Integrated Healthcare Limited (Auckland)
- Seating to Go
- Physiotherapy NZ Neurology Special Interest Group
- Physiotherapy NZ DHB Leaders Special Interest Group
- Occupational Therapy NZ Leaders and Managers Special Interest Group
- Occupational Therapy NZ Wheelchairs and seating Special Interest Group
- Auckland Spinal Rehabilitation Unit
- Burwood Spinal Unit

Appendix G: Otago Ethics Committee (Health): Letters of approval



H14/007

Dr J Dunn

Academic Services
Manager, Academic Committees,
Mr Gary Witte

31 January 2014

Orthopaedic Surgery
Dept. of Surgical Sciences
Dunedin School of Medicine

Dear Dr Dunn,

I am again writing to you concerning your proposal entitled “**Ready to Roll survey: Wheelchair users’ readiness for emergencies and opinions of a proposed Disabled Persons Emergency Response Register**”, Ethics Committee reference number **H14/007**.

Thank you for your letter of 30th January addressing the issues raised by the Committee.

The Committee thanks you for confirming that Jason Nicholls is enrolled in the Masters of Health Sciences programme through your department. The Committee further appreciates the clarification in relation to maintaining confidentiality of information noting that Jason Nicholls is already a practising Physiotherapist and as such is bound by the Health Practitioners Competency Assurance Act (HPCA).

Thank you also for attaching the Peer Review conducted by Dr Jonathan Williman.

On the basis of this response, I am pleased to confirm that the proposal now has full ethical approval to proceed.

Approval is for up to three years from the date of this letter. If this project has not been completed within three years from the date of this letter, re-approval must be requested. If the nature, consent, location, procedures or personnel of your approved application change, please advise me in writing.

Yours sincerely,



Mr Gary Witte
Manager, Academic Committees



H14/007

Academic Services
Manager, Academic Committees, Mr Gary Witte

Dr J Dunn

17 July 2014

Orthopaedic Surgery
Dept. of Surgical Sciences
Dunedin School of Medicine

Dear Dr Dunn,

I am again writing to you concerning your proposal entitled "**Ready to Roll survey: Wheelchair users' readiness for emergencies and opinions of a proposed Disabled Persons Emergency Response Register**", Ethics Committee reference number **H14/007**.

Thank you for your request for amendment to use health care and service providers, in addition to Disable Persons Organisation's, to assist with participant recruitment. The service providers will help identify wheelchair users who may meet the inclusion criteria, and will provide information about the study to them. We confirm this amendment is approved.

Your proposal continues to be fully approved by the Human Ethics Committee. If the nature, consent, location, procedures or personnel of your approved application change, please advise me in writing. I hope all goes well for you with your upcoming research. Yours sincerely,

Mr Gary Witte
Manager, Academic Committees
Tel: 479 8256
Email: gary.witte@otago.ac.nz

c.c. Orthopaedic Surgery

