# **RESEARCH Protocol**

## **Summary of Proposed Research**

### **Rationale for Research**

Neurological conditions are common, frequently long-term and disabling, and result in significant individual, whānau/family and societal burden. Scientific advance has resulted in major improvements in acute care and increased survival rates for many people experiencing these conditions. Despite powerful neuroscience and clinical trial evidence indicating potential for improvements to be made over time, the long-term consequences for these populations is enormous and wide-ranging. Our own research, and that of others, highlights that people’s recovery and adaptation is hampered by a system that struggles to deliver clear communication and coordination of care. Our project does not to seek to discover ‘what’ needs to be done as this has been repeatedly shown in previous research. We aim to develop, and put into practice, a workable solution to enhance the system’s ability to meet the health needs of people with long-term neurological conditions.

### **Aims**

We aim to support translation into systems of care: *evidence concerning what people with long-term neurological conditions require to help them maintain health and wellbeing*. We will develop, integrate into practice, and evaluate, a *Living Well Toolkit* to facilitate knowledge exchange for improved quality care for people with long-term neurological conditions. The Toolkit will facilitate information exchange on three key processes linked to better outcomes:

1. Enhancing communication across multiple providers and services
2. Harnessing whanau/family capability for Living Well (self management)
3. Ensuring consideration of care across the lifespan (continuum future focused care)

### **Design and Methods**

We propose a five-phase, mixed-methods design to quality improvement, formulating, incorporating into practice, and evaluating the *Living Well Toolkit.*  We will implement the Living Well Toolkit in six health care settings using a participatory quality improvement design underpinned by the Knowledge-to-Action (KTA) framework. This provides an integrated framework where knowledge creation and knowledge action interact to produce knowledge that is scientifically robust and tailored for knowledge users to enhance optimal uptake. We will investigate outcomes in relation to how the system of care delivers quality of care and patient perceptions of health status, participation, mental health, well-being as well as carer burden. We will examine the acceptability of the Toolkit and service utilisation and associated costs.

Methods used for *Toolkit Development, Piloting and Implementation Protocol Development* are largely qualitative (interviews and focus groups). The Toolkit will then be *implemented* in six primary implementation localities with ongoing monitoring and review. A post-introduction longitudinal cohort study (n=150) will be carried out across the six localities at baseline, three months and 12 months to monitor use and evaluate the Toolkit with regard to quality of care and health outcomes. Finally, roll-out of the Toolkit to other centres will occur in Year Four of the study.

### **Research Impact**

Our study links to multiple research themes noted in the Investment Signal: improving *quality of care; patient centred and integrated care; and workforce capacity and capability.* Delivery is embedded in the study’s design as we introduce a structural change to service delivery for people with long-term neurological conditions (*influencing Performance, Sustainability, Equity and Quality of care and support).* Our study design and user engagement is focused on *Knowledge Translation,* facilitating targeted change in service delivery during the course of the study and informing service design in the future *(Change Orientation)*. The very idea for the work emerged from patient and health/social care professional concerns, as well as those of national agencies (*End user Engagement)*. Our research process involves a wide range of ‘knowledge users’ in developing the project and formulating solutions (*End user Engagement).* Uptake of the results is enhanced by support from the wide range of champions and agents for translation (*Knowledge Transfer)* in our clinical partners in the research, the NGO sector and key policy and funding agencies at both local DHB level and nationally. Our approach and findings could subsequently be applied in different processes and population.

## **Section 2B – Description of Proposed Research**

### **Rationale for Research**

**Our study aims to develop, integrate into practice, and evaluate, a Living Well toolkit to facilitate quality care for people with long-term neurological conditions.**

Recent developments in neuroscience and neurorehabilitation indicate many people with disabling neurological conditions have potential for continued recovery for many years, and the fact that outcomes remain poor for many is anomalous and disappointing.[1] Even if cell damage is irrecoverable, *enhancing* health, wellbeing, participation and *preventing* deterioration/secondary impairments is now known to be possible. Achieving this is crucial for the quality of life of the people concerned and their whānau/family, as well as for the health system, increasingly under pressure and described as unsustainable.[2] We aim to translate into systems of care, evidence concerning what people with long-term neurological conditions require to help them maintain health and well-being. We will work with people with such conditions (including but not limited to stroke, brain injury, multiple sclerosis and Parkinson’s disease); their whānau/family; health and social care providers in the primary and secondary care setting; the NGO sector and community; and funders to introduce into practice a Living Well Toolkit (facilitating information exchange), focusing on three key processes known to impact on health outcomes[3]:

1. Enhancing communication across multiple providers and services
2. Harnessing whānau/family capability for Living Well (supporting self management)
3. Consideration of care across the lifespan (continuum future focused care)

Our approach could subsequently be applied in different processes and populations.

***Why focus on people with long-term neurological conditions?*** Evidence concerning the wide-ranging and devastating effects of neurological conditions is extensive and the individual, societal and economic impacts of these conditions is enormous and, for many, worsening over time. Indeed the World Health Organisation highlights that neurological conditions are the single greatest contributor to the global burden of disease with more than half of the Disability Adjusted Life years (DALYs) in neurological conditions produced by stroke and other cerebrovascular disease.[4] Traumatic Brain Injury (TBI) presents a far greater concern than previously recognised, being predicted to become the 3rd highest contributor to total global disease burden by 2020[5]. This situation is particularly marked in NZ with disproportionate impact of these conditions on Māori, and outcomes for many remaining worse.[6, 7] Our recently completed BIONIC study indicates a 20% higher incidence of TBI in NZ compared to international incidence data, with a particularly high incidence and prevalence in Māori. A similar pattern is emerging in stroke with early data from ARCOS IV indicating a reduction in stroke for those of European descent, but no similar decrease in Māori and other ethnic groups. In addition to the increasing global burden of neurological conditions, the impact on the individual and whānau/family is frequently devastating.[8, 9] Further, impairments inherent in such conditions (such as deficits in communication, cognition, executive and neurobehavioural functioning)[10] are the very skills needed to negotiate the systems of care they will necessarily be exposed to as they live, and try to manage their lives within the context of their condition and its consequences[11].

***Why focus on these three key processes?*** A recent report by a leading researcher in quality improvement John Øvretveit stated a clear rationale for new and operationalised approaches:

‘*Research shows widespread problems in communication, collaboration and lack of support for self-care. Research also shows there are effective changes that can be made, but knowing which changes to make is only part of the solution. What stands between the knowing, and making a real difference for patients, is belief in the value of the change and our ability to make the change, and then working to implement the change.’[3]*

A change in ‘how’ we work with people is clearly needed. Health and social services have long struggled to meet the needs of people with long-term neurological conditions,[4] and a range of our current studies indicate this remains the case with a lack of information about what to expect and what supports might be available and frequently conflicting advice and goals.[12, 13] In addition, there are reports of poor coordination between secondary and primary care with at times no follow up[3, 14-16] and little focus on how people might feasibly enhance their own health and well-being.[17, 18] While acute care pathways for severe injuries are clearly defined[19, 20] and carefully directed by specialised teams (e.g., Stroke Units), transition to post-acute care, community-based rehabilitation and primary care remains problematic despite the promise of various community trials.[3, 21]

In addition to the comprehensive international data identifying these problems,[3] we have undertaken two streams of work informing this submission:

1. Comprehensive quantitative and qualitative data from our studies highlight the nature and extent of difficulties these populations experience and potential responses to ‘fit’ the New Zealand context. Each of these studies (see Table 1) points to the demoralising finding that despite significant knowledge advance, direct translation into practice has not occurred.
2. A series of studies highlighting relatively simple changes in how we listen to and work with patients can improve outcome quality of care [22, 23] and assist people to take charge of their condition resulting in improved health.[24]

*Table 1: Key findings from a series of recent studies undertaken by our team*

|  |  |  |
| --- | --- | --- |
| **Title and funder** | **Key purpose of study** | **Findings of relevance** |
| Quality of care study [25]AUT Contestable Grant | Underpinned NZ’s contribution to a European Framework Grant on QoL & Quality of Care (QoC) | People with long-term conditions want a balance between technical competence and a 'human' approach to care which responds to their circumstances, builds on their strengths and considers how future needs may change.  |
| Vocational Rehabilitation[26]ACC | To inform developments to case management services for ACC  | People perceive a lack of coordination and communication between the different professionals involved in their care. Negotiating the system is difficult and they are considered ‘problem’ clients if they seek information or question the care process. |
| Carers project[27] National Health Committee –MOH | To contribute to MoH Carer’s strategy (How Should we Care for the Carers, Now and into the Future? - Manaaki Tangata[28]  | Many informal carers perceive their perspective as not being taken on board or respected by health and social care professionals. They are keen to see a greater focus on two-way information exchange. Carers are frustrated by being asked about the problems with no action being taken to resolve them.  |
| Living Well Study [17] HRC and MoH | To identify strategies to enhance health and wellbeing for disabled people (specifically focusing on prevention of obesity related disorders)  | Key themes included the need to have individual circumstances/contexts taken into account in planning. People wanted their individual & whānau strengths considered and sharing knowledge with service providers was important to them. Little focus from health and social care professionals on health promotion (e.g., cancer screening, blood pressure monitoring). |
| TBI Experience Study and BIONIC study[29] HRC | To identify the incidence and outcome of TBI with a nested qualitative study of strategies people use for their own recovery and adaptation | The burden of TBI is far greater than previously described, particularly for mild TBI. Many people feel health and social services don’t understand the impact of brain injury nor do they take into account ‘what matters most’ in treatment, management and support. |
| Stroke Experience Study (in progress) HRC | To add depth to the ARCOS IV programme, a longitudinal qualitative study of recovery and adaptation. | Many people with stroke have ongoing but inconsistent input from health and social care professionals over the first year of recovery and find negotiating the system difficult and stressful. |

Outcomes for these people are frequently poorer than they should be and it is now recognised that in part this is due to avoidable and remediable problems: inadequate communication and coordination across health and social care; the absence of acceptable and do-able plans for people to manage their own condition; and a failure to consider the variable and changing nature of health needs.

***Why this approach?*** Working together with people who have long-term conditions, whānau/family, service providers and the NGO sector is essential for translating evidence into action. Drawing on best evidence for effective knowledge translation [30, 31] and incorporating a participatory design[32-35] into quality improvement work will contribute new knowledge from end-users (i.e. the knowledge users themselves) about ‘how’ to deliver evidence-based services and embed that into existing practice. The Health and Disability Commission Health Passport was introduced some time ago (<http://www.hdc.org.nz/about-us/disability/health-passport>) to provide information for health professionals about the activity of daily living needs of disabled people. However, the Health Passport is still not widely used, has not been evaluated, and does not include either a focus on the person and their whānau/family strengths and capabilities, or a focus on providers’ responses to the information shared by the disabled person. In fact, the majority of research concerning patient-held records (PHRs)[36-38] position patients as *passive* holders of a record where their clinical information is located.[39] Although our purpose is quite different and ‘active’, evidence on strategies to enhance the use of PHRs is valuable for informing our approach to the Living Well Toolkit. Importantly for our study, despite a number of limitations to PHRs, and further limitations to research in the field, they are generally well accepted by people with long-term conditions.[39]

A key focus of chronic disease models and related health research.[40] to date has been on changing ‘patient behaviours’ whilst ‘health care practice’ is clearly dependent on the behaviour of health professionals. Our approach acts to support improved responses to key areas of concern to patients and whānau that are known to affect health outcomes. Involvement of key knowledge users in all stages of the project, [41] and incorporating recent findings about what is required to change practice enhances our opportunity to impact on health delivery in the short to medium term. The *organisation of care* is a key technology that influences health outcomes.[42] Our study explicitly addresses three core components of the organisation of any healthcare episode: structure, process and outcome.[43, 44] We will develop a tangible toolkit (*structural* support) aimed at enhancing the core *processes* of care for people with long-term neurological conditions (i.e. communication across multiple providers and services, harnessing whānau/family capability for Living Well, ensuring consideration of care across the lifespan). The implementation of the Toolkit aims to enhance individual and whānau/family health (*outcomes*) and contribute to the *sustainability* of the health service. If successful, quality of care should be improved *during the study.* Commitment and support for the *translational process* within the health and disability sector includes Ministry of Health (MOH), Accident Compensation Corporation (ACC) and Ministry of Social Development (MSD) ensuring *integration* of the Toolkit *more widely* throughout NZ (letters/emails confirming support on file and co-funding offered by ACC).

### **Design and Methods**

***Aim:*** We aim to implement an evidence-based Living Well Toolkit in six health care settings using a participatory approach and drawing on best evidence for effective knowledge translation. We will examine acceptability of the Toolkit, levels of utilisation and associated costs. We will investigate outcomes in relation to how the system of care delivers quality of care and patient perceptions of health status, participation, mental health well-being as well as carer burden.

***Design***: The design of this project is underpinned by the Knowledge-to-Action (KTA) framework proposed by Graham et al,[30]; an integrated framework where knowledge creation and knowledge action interact to produce and synthesise knowledge that is both scientifically robust and tailored for optimal uptake by knowledge users. A participatory approach (involving endusers in the study from initiation through to design and implementation) has been employed in order to ensure that changes are workable for those concerned. The research integrates principles identified by Lewin,[35] emphasising empowerment and participation of the population of interest at all stages of the research. Hallmarks of the approach are that it should be: participatory - through engagement of key stakeholders from the outset; collaborative - through involvement of key stakeholders in the development process of potential strategies for enhancing quality processes; and reflective, with ongoing reflection and modification in response to participant feedback.

**Participants:** Participants are described below for each phase. Our primary participants (knowledge users) are the patients and staff from six clinical settings who have contributed to the development of the protocol. These same settings will be primary locations for the research itself and were selected because they serve the patient population of interest and represent primary care and secondary care, as well as Māori and generic services. Other knowledge users in the process are funders of care and policy makers as outlined below.

***The Living Well Toolkit:*** The Toolkit will be a *structural support* to enhance two-way communication: providing a record of the individual patient and whānau perspectives on the three key processes; supporting those involved in their care/support to consider these processes by including up to date evidence in an accessible format; providing a record of supports and actions of those involved in the person’s care/support. While the exact format of the Toolkit will be informed and refined in response to knowledge users’ feedback, a draft prototype of the Toolkit has been developed building on the knowledge synthesised from our own work and that by others as described above.

*Figure 2 Draft Toolkit – a worked example*

**Page 1: *Client information*** *(to assist professionals to consider what matters most to them in treatment/involvement* and save clients repeating information). As new overall goals/issues emerge, a new page would be added.

|  |  |
| --- | --- |
| Owner | What’s important to me (Overall goal) |
| Katy Harrison | To get back to work and manage my fatigue so it doesn’t stop me from doing what I want to do |
| Date: 10th October 2012 |
| What’s going on for me and my family/ whānau right now: (current issues/progress/concerns): | Comment |
| Fatigue is my biggest issue |   |
| I don’t want my family to worry about me |  |
| Key concerns for the future: |
| My eldest daughter is leaving home for university in January and I will have to rely on my husband for transport more and his job is really busy. |
| Strengths I and my support network have: (Characteristics/achievements/activities) |
| Strengths | Description/comments | Impact on me |
| Determination | I am keen to do what I can to keep healthy | I like to be challenged  |
| Sociable | I like people  | I like social rather than solo activities  |
| Supportive family | They want the best for me | They will do what they can to help |

**Page 2: *Communication information (complete with client)***

|  |
| --- |
| **Service Providers involved in my care:** |
| Name | Role | Client requested information exchange with others? | Signature |
| Jill Smith | Physio | GP / Neurologist / Stroke Foundation | JS |
| Jim Taylor | GP | PT/Neurologist | JT |

**Page 3: *To facilitate active consideration of and response to key issues for people (completed by professionals)***

|  |  |  |
| --- | --- | --- |
| Health/Social Professionals involved | Date  | Note here how treatment/strategy/referral takes account of Pg 1/2 |
| Comment | Signature |
| Jill Smith | 15/11/12 | Explained gradual pacing of activity important for fatigue/referred to gym | JS |
|   |  |  |  |

***Page 4: Health screening / referral (to ensure a focus on future health)***

|  |  |  |
| --- | --- | --- |
| Screening/action for health and wellbeing | Treatment/strategy/referral takes account of Pg 1 | Signature |
| Health and wellbeing  | Advice on activity programme and referred to local gym that has classes Katy thinks she’d like | JS |
| Cancer screening | Not been offered a smear or mammography since her stroke – discussed importance and referred  | JT |

**Page 5: *Evidence for patient/clients and professionals***

* Evidence to support decision making taking into account goals, strengths and future concerns
* Evidence to support consideration of future health with regard to health screening and other referral targeted to population groups
* Link to online version of this information

Initially, the Toolkit will be a paper-based tool, with the capacity to be formatted into alternate formats (e.g. web-based). The Toolkit will be ‘owned’ by individual patients and their whānau/family and as such they can share it with, and seek input from, relevant parties including healthcare providers, community organisations, ACC, Ministry of Social Development (MSD) case managers and others whilst being able to choose with whom they share information.

***Methods:*** Figure 3 provides an overview of the phases across the four year project period.

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***Phase 1 (Toolkit development):*** To ensure the Toolkit is fit for purpose, we will hold focus groups with each key knowledge user group (anticipating 6 groups each with 6-10 people): people living with neurological conditions and their whānau/family, health and social care providers in inpatient, community and NGO settings, and funders of care. Given the high prevalence of neurological conditions and the poor outcomes reported in Māori and Pacific peoples, we will run both a mixed ethnic focus group for patients and whānau as well as one Māori-specific and one Pacific-specific focus group. Individual interviews will be offered to those who prefer and/or for whom it is more logistically viable. This also allows scope for individual interviews to be carried out with key informants where appropriate. A total of ten individual interviews are accounted for in the budget.

*Recruitment and sampling:* People living with neurological conditions and their whānau/family will be recruited via our primary study localities including: Laura Fergusson Rehabilitation, ABI Rehabilitation, Rehab Results, National Hauora Coalition, Counties Manukau DHB and Waitemata DHB with interest from other clinical locations already as well as relevant NGOs (e.g. Headway, MS Society, Stroke Foundation). We will sample for a diversity of people with neurological conditions in terms of time post diagnosis/event, injury/illness severity, ethnicity, age and condition. Providers and representatives from NGOs will be recruited via recruiting localities and sampled for diversity in terms of profession, years of experience and setting. Core funding bodies in NZ have also agreed to take part including ACC, MOH and MSD.

*Procedures:* Focus groups (led by two of the researchers) will explore how best to operationalise support for each key process (communication, self-management, continuum future focused care). Each focus group will have two facilitators – one to facilitate group discussion and one to observe and make notes to capture first impressions and unique aspects of group interaction not easily captured by audio-recordings. Focus groups will be held at a location convenient to group participants, will last approximately 90 minutes and will be audio-recorded and transcribed. Individual interviews will follow a similar structure to focus groups. They will be conducted at a location convenient to the participant in person or via telephone, last approximately 60 minutes and be audio-recorded and transcribed.

*Analysis:* Data will be analysed using content analysis[45] incorporating methods of constant comparison as described by Charmaz[46] to identify categories and themes of importance within and between knowledge user groups. Rigour checks will include independent coding by two members of the research team, team analysis meetings, and Knowledge User Committee involvement in checking interpretation. The Knowledge User Committee will be made up of representatives from key knowledge user groups (e.g. patients, whānau/family, service providers, NGOs, funders). Key findings will be synthesised with existing knowledge (research evidence we have collated and will continue to do throughout the project) to inform the development of a prototype of the Living Well Toolkit.

***Phase 2 (Pilot and Refinement):*** We will pilot the Toolkit in three of our primary study localities (which include inpatient, community/primary care settings, and two dedicated Māori services). The Toolkit will be incorporated into assessment procedures for 6-9 consenting patients. Patient participants will be ≥18 years of age, have a long-term neurological condition (i.e., a disabling neurological condition resulting in long-term health needs); of variable duration on entry to the study (i.e., from recently sustained/diagnosed injury/illness through to those who have lived in the community with their neurological condition for many years). For inpatient participants, we propose the Toolkit be introduced in the two weeks before the planned date of discharge (to allow a focus on this known area of difficulty for patients). For community-based participants, as discharge timeframes are unpredictable, we propose the Toolkit be introduced for consecutive consenting attendees.

*Data collection:* Data concerning the utility of the Toolkit will be collected in semi-structured interviews with the patient and whānau/family, one week after commencing use of the Toolkit and at three months follow-up. Individual patients and their whānau/family will be interviewed together in person at a location convenient to them. Their interview is anticipated to take approximately 60 minutes. In addition, two health professionals or care/support staff involved with the patient participants’ care will be nominated by each participant and interviewed via phone interview; approximately 15-20 minutes per interview at three months and a locality focus group will be run in each locality to explore staff experiences of implementing the Toolkit. All interviews will be recorded and transcribed.

*Analysis:* This will use the same approach as that taken in Phase 1. Findingsfrom the piloting will be synthesised with regard to key strengths, issues or concerns and recommendations, and taken to the Knowledge User Committee to result in the revised Toolkit.

***Phase 3 (Development of Implementation protocol):*** Key informant interviews (n=12) with two key practitioners at each of the six primary localities will take place in this phase. In addition, a focus group at each setting (with key contributors of that service and representatives of services they routinely work with who may interact with patients using the Toolkit). The purpose of these interviews will be to seek feedback regarding the constraints and opportunities for integrating the Toolkit into practice. Key informants may include staff members who will take on a coordination role during implementation, clinical directors, managers, or other key members within the organisation who can provide key information regarding implementation.

*Procedures:* Coordination of interviews will replicate the procedures described above in Phase 1. The main facilitator of this data collection phase will be the implementation coordinator employed to manage the implementation and roll-out process throughout Phases 4 and 5. Interview guides will be developed drawing on the Consolidated Framework for the Advancement of Implementation science (CFAI)[31] which is a comprehensive model synthesising conceptual and empirical evidence from existing implementation science literature. The CFAI identifies five broad domains potentially impacting successful implementation including: the intervention itself, the external and internal context, characteristics of individuals involved and the implementation process. Prompts will be developed to allow an in-depth exploration of each of these domains. Interviews (individual and group) will be recorded, with key points relating to each domain summarised within the interview/group and agreed by participant/s before completion of the session.

*Protocol development:* The findings of this phase will be synthesised and used by an Implementation Committee to inform the development of an implementation protocol for each locality. The Implementation Committee will be made up of the implementation coordinator, principal investigator, an implementation champion from each of the participating localities, as well as a key patient representation from the Knowledge Users Committee. The implementation protocol will account for and respond to the key constraints and opportunities identified by that locality in each of the domains. In essence, while the Toolkit itself will be standardised across locality, the implementation protocol will be tailored to each locality to allow successful uptake of the tool.

***Phase 4 (Implementation and local review):***This will involve staged implementation of the Toolkit in the six primary localities where each locality will embed the Toolkit into practice with the support of the implementation coordinator. As depicted in Figure 3, we will implement the Toolkit in two localities simultaneously followed by a two month monitoring period before initiating implementation in the next two localities and so on. Implementation will follow the protocol developed by the locality in Phase 3. The implementation coordinator will work with each locality’s implementation champion over the two month monitoring period to identify and respond to any issues that may arise in that early implementation period. Information about the Toolkit will be presented at dissemination meetings across a range of health and social services that may interact with patients using the Toolkit.

*Local review:* The implementation coordinator will maintain a log book for each locality to detail activities (e.g., meeting dates and notes), issues that arose and associated strategies, as well as any other information that may streamline subsequent implementation periods (both during the study and in wider implementation). Local case studies will be developed (each site being asked to nominate a case where introduction has been straightforward and one case where it was more difficult). These patient participants and their whānau will be invited to take part in an interview one month after the Toolkit was introduced (estimating a 60 minute interview). With participant consent, two to three professionals who have been involved in their care/support (either within the referring centre or other services the patient has engaged with) will be interviewed by phone concerning their perspective of the Toolkit (15-20 minutes). These case studies will be used to support ongoing training and review.

***Phase 5 (Monitor and extend knowledge use):***Knowledge use in the six primary locations will be monitored by supporting the processes developed for local review above to be integrated into each service. The implementation champion in each locality will work closely with the study team during phase 5 to facilitate on-going use of the Toolkit during this phase (and subsequent to project completion). Monitoring (i.e. audit of adherence to, and complexity of Toolkit use, whether Toolkit use is in keeping with the original intention, and knowledge users’ responsiveness) will be supported by the data collection procedures for the Longitudinal Cohort Study (detailed below).

This phase will also focus on roll-out to other localities (current interest from Burwood Hospital in Christchurch, The Southern Rehabilitation Institute in Christchurch, Rata Rehabilitation in Dunedin, Rehab Plus and Neuro Rehab Results in Auckland). We will develop an implementation protocol for each new locality using the same key informant interviews and focus group process outlined in Phase 3. Our budget includes roll-out support for four additional localities. Implementation will be consistent with the plan outlined above in Phase 4 (i.e., staged implementation of two localities at a time with support from the implementation coordinator over a two month monitoring period), and be informed by lessons learned during the prior phases.

***Evaluation (Longitudinal Cohort Study of Toolkit users)***

In addition to the constant quality improvement approach (involving qualitative and audit data) we describe above, we include a quantitative ‘before and after’ evaluation cohort study with review of Quality of Care, Health Status and health service utilisation at baseline (within two weeks of Toolkit introduction), three and 12 months.

Whilst we have considered multiple evaluation designs, this approach is selected to balance the requirement for monitoring (costs, outcomes, adverse outcomes) with the burden and conflicts measuring 'effectiveness' would impose. The Toolkit intervention is necessarily highly individualised depending on the particular set of providers and services associated with research participants, the particular whānau/family structure and capabilities, and the context of each participant in their life continuum. It is impractical if not impossible [47, 48] to design a control intervention that could mimic or control the time involved in developing the implementation of a Toolkit for each individual and their whānau/family.

Whilst some might suggest the solution to this would be a cluster trial (by recruitment site), we have previously demonstrated that for ‘process redesign’ interventions in NZ, the intra-class correlation coefficient is very high, and there are insufficient recruitment venues in NZ to make this research design useful and practical.[49] We also considered the option of a repeated baseline for rigour, but this is not possible as a key focus for enhancing quality, is around the time of discharge from hospital services, participants for whom change is desirable and likely. We also considered undertaking a dual longitudinal cohort design (i.e. including one historical cohort followed up over 12 months before Toolkit introduction and the second, subsequent to embedding in the services) but the sample size for this would be enormous to cope with case mix adjustment and still liable to confounding. We therefore have prioritised knowledge transfer as the key knowledge advance. We will mitigate bias that could arise by the cohort design by ensuring assessors are independent of the implementation researchers and that assessment as far as practical does not involve knowledge of the particular elements of the Toolkit implementation for each participant.

***Procedures for the Evaluation***

*Sampling:* Twenty-five consecutive, consenting patients admitted to each of the six primary localities (total n=150, sample size calculation below) will be recruited commencing 3 months after introduction of the Toolkit (in Phase 4) to allow embedding of the Toolkit into practice. Patient participants will be ≥18 years, have a long-term neurological condition (as defined on pg 12) of a range of duration.

*Assessment:* Data will be collected by independent assessors at baseline (within two weeks of Toolkit introduction for the individual) and at three, and 12 months. To facilitate recruitment of patient participants, the Toolkit will have a removable front page for participants to indicate approval to be contacted by the research team and sent to the research team.

*Outcome Measures:* We aim to measure the quality of process using the Patient Perception of Rehabilitation Scale (PaPeR)[49] with key outcomes including health and well-being (the SF-36[51] for whom population level data in these groups exists) and participation (Impact on Participation and Autonomy (IPA).[52, 53] We will also include a focus on mental and emotional well-being Hua Oranga, recently validated in a neurological population,[24] and Carer burden on the Zarit Burden Interview.[54] Perceived usefulness of the Toolkit will be evaluated at each time point on a five point Likert Scale (from *Not At All Useful* through to *Extremely Useful*). At 12 months, Extent of use of the Toolkit will be evaluated (once all other assessments are completed to maintain independence of the assessor) with a copy of the Toolkit being made by hand-held scanner and a Likert Scale on examination of its contents (from *No Use* through to *Extensive Use*). In addition, an open ended question on patient views of any perceived impact the Toolkit has had in relation to the three key processes targeted.

*Covariates:* Ethnicity: We will use Question 11 of the (delayed) 2011 New Zealand Census (<http://www.stats.govt.nz/Census/2011-census/2011-census-forms-and-guidenotes.aspx>) and severity of health condition (functional consequences of the condition) using the widely used and well validated AM-PAC [55-57]. Extent of Toolkit use will also be considered as a covariate (using the Likert Scale data). *Service utilisation* and associated costs will be recorded for the longitudinal cohort (for the 12 months after introduction of the Toolkit) by completing a standardised service inventory as used in the BIONIC and ARCOS studies allowing some comparison. Costs (extra time, resources) required by providers and services users to adopt the Toolkit in paper-based form will be reviewed along with estimating costs of alternate Toolkit formats (for example smartphone or web-based).

Data analysis: Data will be used to describe changes in quality of care and health. A mixed linear model will be used to model changes with time for continuous variables. Co-variates of particular interest, which may modify the rate of change with time, include ethnicity and severity of health condition. For analysis of dichotomous variables, we plan generalized linear mixed models using a generalized estimating equations approach.

Our previous research in two settings of neurological rehabilitation identified that the paired standard deviation for two time-separated measurements of the Physical Component Summary (PCS) of the SF-36 is between 7.1 in our study goal setting[49] and 9.5 in our recently completed study of stroke recovery in Maori and Pacific people (the MaPSS study)[24]. The MCID of the PCS of the SF-36 is 4. In order to have 90% power, alpha 5%, using a paired t-test, to detect this difference with the higher SD requires 124 participants, and allowing for 15-20% drop-out gives a target sample size at recruitment of between 145 and 155.

***Summary***

### We aim to develop a workable solution that enhances our capability to meet the health needs of people with long-term neurological conditions, within the timeframe of the project. Enhancing systems of care to deliver better quality services for people with long-term neurological conditions and their whānau/family would alleviate some of the significant burden they currently experience. The project is methodologically innovative in the approach to Toolkit development and the implementation approach. Not only might this enhance health for people with long-term neurological conditions, but our process will provide opportunities for adaptation for other populations and other systems of care.

### **Research Impact**

Our 4 year, participatory designed study will introduce a structural change to service delivery (*influencing Performance, Sustainability, Equity and Quality of care and support)* by introducing a Living Well Toolkit into practice (*Knowledge Translation*). The implementation science approach we are using should produce results even during the very early stages of the work by involving a wide range of knowledge users including patients, whānau/family, health professionals in primary and secondary care and both policy makers and funders.

Better quality care is not a ‘soft’ target for change as it has been linked to reduced costs, [3] which are enormous in neurological conditions. In NZ these are estimated as in excess of $450million yearly in direct costs alone for stroke [58] and conservatively at more than $100 million in TBI, much of that in social rehabilitation costs.[19] The Toolkit, if successfully implemented, should reduce communication failures between patients and practitioners, and between different practitioners (*Knowledge Transfer), a* significant cause of cost in the system.

We have actively worked on uptake and engagement from the start with knowledge users enhancing the opportunity for targeted change within services and future service development *(Change Orientation)*. We are directly focused on identifying how change in the provision of services can be realised *(Change Orientation)* and our process involves a wide range of knowledge users (*End user Engagement)* in the development of the project and formulating solutions. In addition to focusing on *Knowledge Transfer* in introducing the Toolkit itself, we are mindful of the potential for electronic information usage and have therefore initiated links with the National Health Information Technology Plan Shared Care electronic programmes (Janine Bycroft) given that to date, neurological disability has not been identified as a priority area (*Knowledge Transfer*).

Supporters, champions and agents for translation (*Knowledge Transfer)* include our clinical partners in the research: Waitemata DHB, Counties Manakau DHB, the National Hauora Coalition, Acquired Brain Injury Services (ABI LTD) and Laura Fergusson Rehabilitation (LFR), with additional support already confirmed by the Stroke Foundation, the Auckland Brain Injury Association and MS Auckland. We note that this is not merely support for the project but all indicate their willingness to be actively involved in the study.

Interest in the project and its findings, and contribution throughout the project, has been confirmed by sponsors/leaders within the Accident Compensation Corporation (John Wren), Ministry of Health (Christopher Carroll), Ministry of Social Development (David Bratt and Anne Hawker) and the Health and Disability Commission (Elizabeth Finn). Our study links to multiple research themes noted in the Investment Signal in particular improving *quality of care, patient-centred and integrated care, and workforce capacity and capability.* Delivery is embedded in the study’s design and assured given our partnerships with provider networks committed to the project. Opportunities to extend connections during the course of the study are enhanced by the team being based in Auckland, Wellington and Christchurch, and national linkages through the New Zealand Rehabilitation Association.

### **Dissemination of Results**

The research we propose has directly resulted from knowledge user engagement to date both formally (in previous research we have undertaken) and less formally (in the clinical, policy and consultancy work we have been involved in). Our research proposal itself takes a systematic approach to developing knowledge and engaging endusers in the production of that knowledge which further ensures knowledge transfer and change. We have provided evidence of our approach and record and the support from such a wide range of stakeholders, including co-funding as identified below, indicates the value these stakeholders perceive in the project. Much of the dissemination plan is embedded in the protocol itself and our Knowledge User Committee will play a key part in facilitating and guiding appropriate ‘within project’ dissemination and also dissemination to ACC, MoH and MSD.

Finally – knowledge dissemination is integral to the study in so many ways, we also aim to:

* include key findings in our undergraduate and postgraduate teaching programmes (across a range of health professional groupings) to influence future health professionals
* disseminate information in the primary care and rehabilitation communities via newsletter
* present findings at conferences within New Zealand and externally
* produce influential publications in peer reviewed journals

### **Responsiveness to Māori**

Neurological conditions are particularly prevalent for Māori and data about service responsiveness indicates the three factors we are aiming to address are particularly problematic for Māori.[59] Development of this work has drawn on extensive discussions with the National Hauora Coalition (NHC) whose clinical director is co-PI (Harwood). Both Gow and McPherson have been members of NHC’s Oranga ki Tua Service Alliance Leadership Team, working to support NHC to better meet the needs of people with long-term conditions.

In consultation with NHC and others, it has been proposed that the nature of our research intersects with the Whānau Ora approach and as such, could enable positive links between Whānau ora programmes and implementation of national stroke/TBI guidelines and pathways. Our approach explicitly draws on findings from Harwood’s recently completed PhD and aims to be mana enhancing throughout. Our community advisors, Huhana Hickey (Ngati Tahinga) and Charmeyne TeNana-Williams (who works in the sector), have welcomed our approach, contributed to project development and indicated their willingness to facilitate involvement in the study and contribute to the Knowledge Users Committee and the steering group.

Our project addresses each goal of Ngā Pou Rangahau (HRC’s Strategic Plan for Māori Health Research 2010-2015) [60], specifically the third, being to enhance the translation of research into Māori health gain. We have involved Māori researchers, dedicated Māori services and community advisors at each stage of the project and will continue to do this should we be funded. We aim to achieve each of the objectives of our research in a manner that is in keeping with Te Ara Tika. [61]

### **Track Record of the Research Team**

Our interdisciplinary team has an extensive record in research in rehabilitation and community care for people with neurological disorders with team roles identified at the start of this application. There is strong leadership in McPherson and Harwood, and we have both experienced and emerging researchers with expertise in the key areas of the research methodology and the population concerned. Whilst Professor Tony Dowell is not a named investigator (he was away at the time of study registration) he has offerred to be on our advisory committee. This will further assist our connection to primary care given his role academically and in the college. Key skills of the team are:

* Neurorehabilitation, participatory designs, qualitative research, and quality improvement (McPherson, Kayes, Mudge and Kersten)
* Māori health, primary care (Harwood);
* Gerontology, biostatistics (Weatherall);
* Health services research and disability (Payne, Snell and Wilkinson-Meyers) with Wilkinson-Meyers specifically experienced in cost evaluation.
* We have secured the support of a senior health economic advisor (Professor Paul Brown) to mentor emerging researcher Wilkinson-Meyers and our own health economist-in-training who will be employed on the study (Smith).
* Dr Bruce Kent is a health psychologist and stroke survivor who brings both his personal experience of systems of care but also qualitative and quantitative research expertise.

With regard to expertise relating to uptake, the majority of named investigators were selected because in addition to their research credibility, they hold clinical/professional and/or policy leadership roles (facilitating uptake of the research). In particular:

* Harwood is a practising GP;
* Gow and Weatherall are medical practitioners in the hospital setting working with these patients
* Mudge owns and runs a community based neurophysiotherapy practice
* Both Chesters and Gow are leaders within their own DHBs and beyond into national DHB leadership.
* Community providers including ABI Mgt Ltd (Max Cavit CEO, Dr Allison Foster), LFR (Janette Peebles, Rehabilitation Services Manager) and Rehab Plus (Dr Samir Anwar Clinical Director) have also expressed their interest and support for the study and will be involved in all phases.
* McPherson’s longstanding relationship with MoH, MSD and ACC (advising re policy and practice) has been instrumental in gaining their support for the study (and in ACC’s case co-funding). Letters of support from these and other endusers indicate their keeness to be involved in the study and to see a practical tool developed and put into practice that focuses on improving the quality of care for their clients.

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