



ACQUIRED
BRAIN INJURY
IRELAND

Research Prioritisation Exercise

Identifying Our Priority Research Themes 2020- 2024

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In a special way we want to thank our clients and families who made several contributions to the project.

This final report represents the work of the year-long project on setting out our research priorities for the next strategic phase of Acquired Brain Injury Ireland.

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Section 1

Introduction

1.1 Background

Since its foundation, research has been a cornerstone in the development and growth of Acquired Brain Injury Ireland. The organisation has been highly committed to engaging in evidence-based practice and supporting researchers to complete research projects across a range of clinical disciplines in a variety of ways, both internally and externally. Acquired Brain Injury Ireland has strategically committed to engaging and supporting brain injury research and building the brain injury research community in Ireland in its Strategic Plan 2020-2024.

Acquired Brain Injury Ireland operates a Research Ethics Committee (REC) to ensure that the research it supports is meeting the legal requirements and operating to the highest ethical standards. As part of the REC's annual review process in 2019, it was identified that the organisation was at a point in its development where it would benefit significantly from setting out its own research priorities. It was identified that the organisation could play a much more pro-active role in determining the research it supports and by setting priorities for the next strategic phase. As a result, the Research Prioritisation Exercise (RPE) project was developed, a project team put in place and a project plan formed in early 2020.

1.2 Aim and Key Actions of the Project

The aim of the RPE project was to set out the research priorities for Acquired Brain Injury Ireland for the 2020-2024 Strategic Plan using a process-led, iterative approach. A project plan was developed by the project team with the following key elements:

1. Conduct a literature review on other Non-Governmental Organisations (NGOs) and other brain injury organisations doing RPEs, engaging people with acquired brain injury (ABI) in research (Public and Patient Involvement); Scan the literature in this area especially involving people with ABI; Review models of engagement from other RPEs. Literature from the broader health organisation context also considered.
2. Conduct a scoping review of the past (5 years: 2014-2019) research projects engaged in and supported by Acquired Brain Injury Ireland and approved by the REC, to include identifying and quantifying the publications (peer reviewed journals, thesis documents, articles in newsletters) that emerged from these research projects.
3. Engage and consult with key stakeholders internally and externally on the research priorities.
4. Do thematic analysis of findings and engage in a consensus building process.
5. Validate the consensus with key stakeholders (people with ABI and family members).
6. Write report and produce summary.
7. Disseminate findings to all stakeholders.

Section 2

Literature Review on Research Prioritisation Exercises within the context of Acquired Brain Injury Neuro-Rehabilitation Services

2.1 Introduction

Acquired brain injury (ABI) occurs as a result of damage to the brain, which can be caused by a multitude of different incidents such as strokes, tumours, anoxia, hypoxia, toxins, and/or other conditions after birth (Ontario Brain Injury Association, n.d.). Individuals dealing with an ABI often face cognitive, physical, emotional, or behavioural impairments that may result in serious permanent or temporary changes in functioning (Anderson & Catroppa, 2006). There is a growing public awareness of deficits in long-term service provision for people disabled by ABI. Globally estimates suggest that traumatic brain injury (i.e. injury that is caused by an external force) affects 10 million people annually, leading to mortality or hospitalization (Hyder et al, 2007). It represents a major health burden in Western countries, with an annual incidence of up to 1.7 million traumatic brain injuries in the United States alone (Faul, Xu, Wald, & Coronado, 2010). In the UK, brain injuries which result in hospital admission occur in about 270 per 100,000 population per year (Rice-Oxley & Turner-Stokes, 1999).

When the brain is injured, a person's life can be negatively affected, often requiring major life adjustments around the individual's condition. Making those adjustments is critical for recovery and rehabilitation (Lundqvist, Grundstrom, Samuelsson, & Rönnerberg, 2010; Ragnarsson et al, 1999). The provision of neuro-rehabilitation services are pivotal to enable the person with brain injury to address the cognitive, emotional, psychological and physical consequences of their brain injury (Turner-Stokes et al, 2015). The World Health Organisation (WHO) defines neuro-rehabilitation as an interdisciplinary clinical process, outlining that access to the appropriate knowledge, skills and supports is imperative to optimal physical, psychological, social and economic functioning (WHO, 2006). Unlike most other neurological conditions, an ABI is different in that it is non-progressive and, as a result, people can make significant gains when they have access to the appropriate and timely neuro-rehabilitation services (Turner-Stokes et al, 2015; NICE, 2014). Neuro-rehabilitation services are specifically designed for those with neurological conditions who require individualised, goal-focused rehabilitation input (WHO, 2006). A Cochrane Review found that access to earlier and intensive rehabilitation by multi-disciplinary rehabilitation teams improves outcomes (Turner-Stokes et al, 2015; NICE, 2014).

2.2 Neuro-Rehabilitation: An Irish Perspective

In an Irish context, The National Policy and Strategy for the Provision of Neuro-Rehabilitation Services in Ireland 2011-2015 (hereby referred to as the Neuro-rehabilitation Strategy) was published by the Department of Health, along with the Health Service Executive (HSE) in 2011 (Department of Health, 2011). This document aims to provide a single national policy and strategy to inform, guide, and determine neuro-rehabilitation service responses and structures. It also recommended that an implementation framework

be developed to ensure progression of services in line with the Neuro-rehabilitation Strategy. The overall vision of the Neuro-rehabilitation Strategy is for those receiving neuro-rehabilitation supports to be part of the community, and to improve their overall quality of life. The report outlines the importance of service provision locally, on an individual basis, and integrated as part of an adaptable and responsive health system. The National Strategy & Policy for the Provision of Neuro-Rehabilitation Services in Ireland: Implementation Framework (hereto referred to Implementation Framework) was published in 2019, eight years on from the Neuro-rehabilitation Strategy in 2011. It consisted of assessing population needs, mapping existing services, and analysing gaps in terms of service availability in line with best practice (HSE, 2019).

In a recent review of the Implementation Framework, Burke et al (2020) identified that significant key challenges for those with ABIs remain in place, with negative implications for their quality of life. They recommended increased research with regard to the ABI population to support policy development, service planning, and advocacy in terms of making a case for service provision for those with ABI. The inclusion and direct involvement of those with an ABI in policy development, service planning and delivery was also earmarked as imperative to increasing the visibility of those with a brain injury, with the hope of increasing the political priority on the provision and development of neuro-rehabilitation services. Given the limits in terms of funding and resources for research, it is critical to prioritise the many potential research directions that could be pursued to optimise the provision of neuro-rehabilitation services for those with ABI.

The identification of priority areas for research using validated methods is recognised as a good way of ensuring that finite research resources are used with maximal effect (Chalmers, Bracken, & Djulbegovic, 2014; Cuello-Garcia, 2010). An integral element of setting research priorities is to decide who sets the priorities, and what criteria are used to determine them (The Working Group on Priority Setting, 2000). Underlying values and assumptions with regards to Health Problems may vary depending on who is consulted in the process (Lomas, Fulop, Gagnon, Allen, 2003; Bowling, Jacobsen, Southgate, 1993; Sitthi-Amorn, 1995). Inclusion of end users of research (e.g. service-users, clinicians, policy-makers, researchers) helps to ensure that research priorities provide an accurate reflection of the concerns, values and needs of all stakeholders (Lomas, Fulop, Gagnon, Allen, 2003; Institute of Medicine, 2008)

2.3 Research Prioritisation Exercise

Following on from the recommendations of Burke et al (2020) as discussed above, Acquired Brain Injury Ireland conducted an RPE to determine appropriate research areas for the coming years. In line with what is becoming recognised as best practice for conducting RPEs, the organisation used a holistic approach to determine the most appropriate research objectives, including all key stakeholders, with particular emphasis on including the perspectives of service-users and clinicians (Forsythe and Ellis, 2016; Steward and Oliver, 2011; Shippee et al, 2015). Best practice guidelines in health research purport that Patient and Public Involvement (PPI) should be a key component of health organisation research on both methodological and ethical grounds (Wilson, Mathie, Keenan, et al, 2015). This has been adapted by key funding agencies in health research in the United States (Forsythe, Ellis, Edmundson, et al, 2016), Canada (Manafa, Petermann, Mason-Lai, Vandall-Walker,

2018), United Kingdom (INVOLVE, 2012), and in Ireland (Ní Shé, Davies, Blake et al, 2018). The literature review examined the existing literature in terms of conducting RPEs in the context of ABI, and in the broader context of health and clinical care, as a means of informing the RPE undertaken within Acquired Brain Injury Ireland.

As there is a relatively limited number of RPE studies which have been conducted specifically in the field of ABI, firstly we examined the RPE literature within the broader context of health and medical care. A review by Viergever et al (2010) examined the literature on RPEs within the domain of health research. The study sought to analyse the underlying axioms of successful health research prioritisation across varying approaches and summate this into a set of guidelines for conducting RPEs in a health setting. The study produced a checklist of 9 themes which it deemed as imperative to good practice in setting priorities for health research. The 9 key themes consisted of context, use of a comprehensive approach, inclusiveness, information gathering, planning for implementation, criteria, methods for deciding on priorities, evaluation, and transparency. These 9 key themes proved useful to keep in mind as underpinning elements of good quality research prioritisation as we explored different methods which have been used to determine priorities for health research. A study by Mador et al (2016) conducted a review of their own research setting process utilising the 9-item checklist developed by Viergever et al (2010) as the conceptual framework. They demonstrated that the 9-item checklist had utility as a tool for guiding the development of evaluation questions, and enabling the assessment of key constructs related to the design and delivery of research priority setting exercises. While discussing the various methods for research priority setting, it will be important to keep in mind these essential underlying characteristics of a good quality RPE.

One method which has been utilised as a research prioritisation technique is the World Café Methodology. This method consists of a conversational forum designed to effectively engage large groups in discussion around important issues with a view to facilitating meaningful change (Sheridan et al, 2010), and is used, in other contexts, to generate research priorities (Restall et al, 2016). Research examining this conversational method have posited its benefits in terms of promoting interdisciplinary collaboration, fostering innovation and creative thought, and enhancing the relevance of research by engaging end users in discussion about their priorities (Sheridan et al, 2010; MacFarlane et al, 2017). The World Café method involves groups of people discussing a topic of importance to them. Participants change groups, so that they discuss the issue with different people. The method is based on a social constructivist paradigm, whereby knowledge is viewed as socially constructed through interactions with others (Sheridan et al, 2010). Key principles for hosting a World Café discussion are as follows:

- (1) create a hospitable space;
- (2) explore questions that matter;
- (3) encourage everyone's contribution;
- (4) connect diverse people and ideas;
- (5) listen together for insights, patterns, and deeper questions; and
- (6) make collective knowledge visible (Brown, 2002).

The World Café approach was utilised in a recent study by Nalder et al (2018) in a Canadian study which sought to set research priorities for optimising long-term community

integration after brain injury. They reported that the World Café methodology was an effective means of setting research priorities for this population, in particular noting that the breadth of participants and the collegial environment contributed to the identification of a broad perspective on setting future research directions. Given that the study was undertaken with a brain injury population, with a goal of optimising long-term community integration for those with brain injury, it is very much relevant to the current study. MacFarlane et al (2017) used the World Café method as part of a research priority exercise for Primary Care in both Irish and American populations. They reported that the method was a valuable, inclusionary, dynamic method, suitable for participation with community and healthcare stakeholders for research prioritisation with marginalised groups. While this study was not specifically within a brain injury service, it conveys the efficacy of the World Café Methodology within an Irish community and healthcare context, working with marginalised groups. Thus, it is evident that there is a strong rationale to use the World Café methodology with the current study, which is seeking to conduct a research prioritisation exercise for brain injury service development in line with the recommendations outlined by Burke et al (2020). In the current context of Covid-19 restrictions, this approach may not be feasible as it involves a large number of people engaging in contact with each other. This would have to be reviewed in line with public health advice, and a World Café methodology may not be rendered a feasible option at present for logistical reasons.

As outlined previously one of the key recommendations by Burke et al (2020) for future research in the context of ABI was the inclusion of key stakeholders, in particular service-users themselves. Another methodology that has been employed for research priority setting which emphasises the inclusion of key stakeholders is the Global Evidence Mapping (GEM) approach. The 'listening model' developed by Lomas demonstrates the necessity for consultation with stakeholders and places keen emphasis on communication and exchange between decision-makers and the potential users of the research (Lomas et al, 2003). A wider number of research organisations in the context of healthcare have begun to recognise the importance of stakeholder inclusion in determining research priorities and areas for review (The Working Group on Priority Setting, 2000; Oliver et al, 2006; Sassi, 2002). The GEM approach was developed with the specific aim of developing research priorities in those with traumatic brain injury (TBI) and spinal cord injury (SCI). The approach was put forward by the Victorian Transport Action Commission, and was outlined in detail by Bragge et al (2011).

In summary, the approach consists of four steps: the first and second step is to generate and then prioritise research questions; step three involves mapping identified questions to current research, to determine which questions might have already been answered by previous research; and step four involves weighing up research questions and reflecting on the current literature to determine priority research questions. A study by Clavisi et al (2013) examined the efficacy of the GEM approach for determining research priorities for post-acute rehabilitation and long-term care for those with a TBI. They determined that the GEM approach, which was inclusive of many different types of stakeholders and followed a multi-step and multi-method process, was valuable for prioritising research to improve rehabilitation outcomes for those with TBI. The study also determined that the level of representation of key stakeholders could be increased using a combination of methods and a process of linkage and exchange.

2.4 Alternative Methods

Various approaches have been utilised to conduct RPEs in health services outside the remit of ABI. A 2018 New Zealand-based study by Doolan-Noble, Mehta, Waters & Baxter conducted an RPE in the context of aging well research. This study based their RPE design on the 9-item checklist by Viergever et al (2010) discussed above, and thus provides a relevant example of how to actualise a design which incorporates this checklist. This particular study used an innovative design in which ‘roadshows’ or travelling workshops were used to gather input from key stakeholders. These comprised of workshops which facilitated small groups consisting of various stakeholders to discuss research priorities. Five ‘roadshows’ were held in major cities around New Zealand to ensure a wide range of stakeholders from different regions were involved. Key points during small group discussions were recorded on flipcharts, and participants were encouraged to come to an agreement regarding the points documented. A member of each group then presented their flipchart to the larger group, and participants were asked to give 3 votes to the issues which they felt should be prioritised. The prioritised list was then fed back to participants who were asked to identify how they might go about addressing the top 3 prioritised issues, and how they would recognise if their organisation had made an impact. The authors concluded that this method provided an effective means of engaging key stakeholders to jointly develop priorities for research, in a manner in line with the 9-item checklist for RPE (Viergever et al, 2010).

A 2014 UK-wide study by Rowe, Wormald, Cable et al undertook an RPE to determine research priorities in the field of sight loss and vision, through consultations with patients, carers and clinicians. Given that those with sight/vision loss are also a marginalised group, and that it is an area which also lacks a breadth of research (Bourne, Stevens, White et al, 2013), there are certain parallels with ABI. This particular RPE utilised a survey approach. A detailed survey was disseminated to key stakeholders by patient groups, professional bodies, at conferences and through the media, was available for completion online, by post, by phone, and also in alternative formats such as Braille. Upon completion of the survey, this data was then assessed and analysed, and broken into 12 categories based on responses. An interim prioritisation exercise was undertaken to determine shortlists of potential topics for each category. Finally, 12 prioritisation workshops were held (1 for each category), which allowed stakeholders to discuss and debate potential research topics for each category, forming a final list of priorities for each of the 12 categories. The authors reported that this approach was an efficient manner of determining research priorities, and allowed the views of patients, carers, and health professionals to be taken into account equally. The study reported a wide range and comprehensive coverage of topics, and a substantial response. Once again keeping in mind developments regarding the Covid-19 pandemic, and the subsequent social distancing protocols which have been put in place, a survey approach might be a suitable alternative in the current climate.

2.5 Considerations due to Covid-19

In the current global health pandemic as a result of Covid-19, there were a number of implications to be taken into account when deciding which method would be most appropriate for Acquired Brain Injury Ireland’s RPE. Key components of managing Covid-19 have been the restriction of social gatherings, minimising one’s social contacts, and the implementation of physical distancing measures requiring a minimum distance of two

metres between persons. As a result, it was not be appropriate or possible at the time the project was rolled out to conduct an in-person RPE, such as the World Café approach which would require many people to meet and interact in an indoor space. Given the Covid-19 restrictions and to abide with public health guidance for the protection of both staff and participants, we decided that engagement with our stakeholders would incorporate online approaches, including online surveys, tools and video calls to facilitate data collection, consultation and validation.

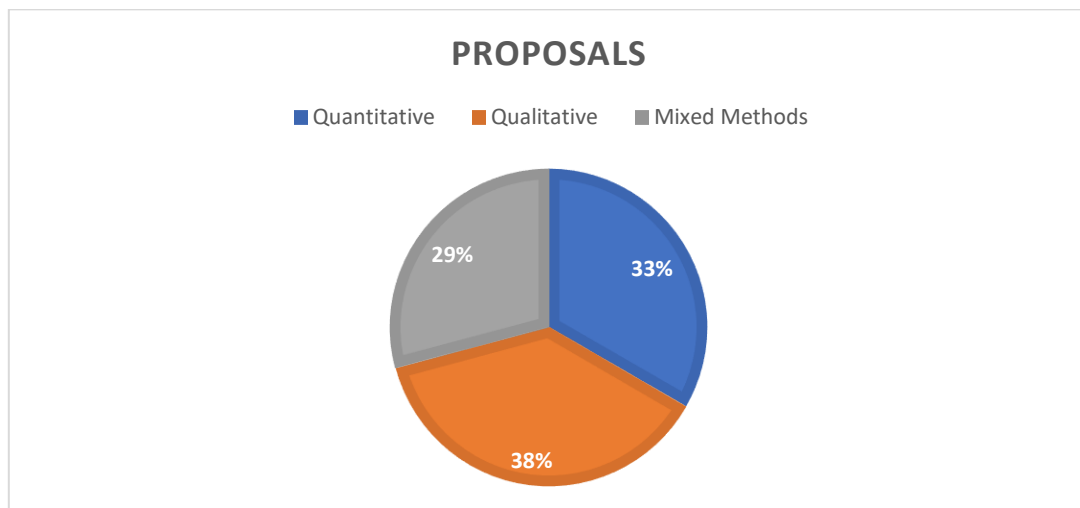
Section 3

Review of Research Projects 2016-2019

3.1 Introduction

A review of Acquired Brain Injury Ireland research studies over the last four years was conducted in order to analyse a number of factors that could inform the research prioritisation planning for the next five years. This included looking at the types of research, the methodologies, the publications, the range of themes and research subjects, and the funding sources.

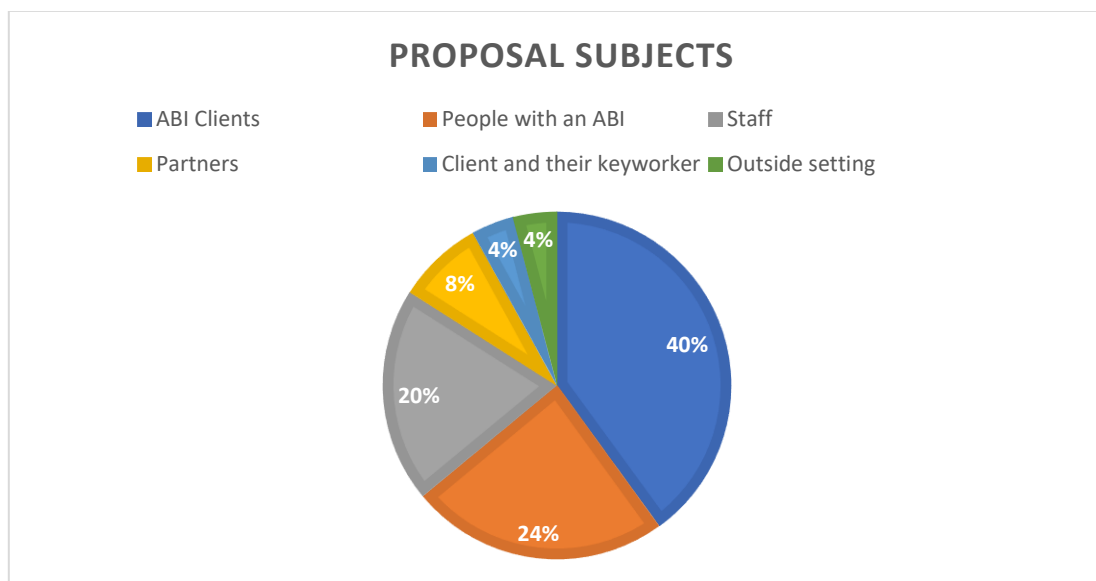
Research methods



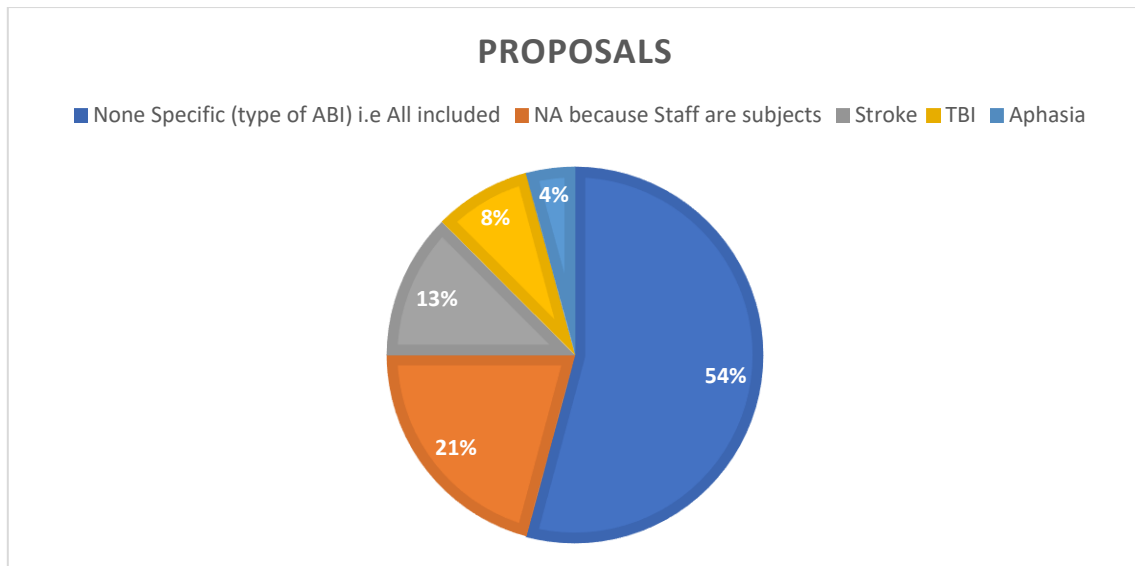
There was a relatively equal mix of type of proposals received (N=24), with Qualitative research representing a slightly higher proportion (38%) compared to Mixed Methods (33%) and Quantitative (29%). This could be understood in the context of the research topics which have tended towards identity, mental well-being and psychological factors. These were approached by researchers in terms of collating lived experiences from participants through interview methods rather than questionnaire completion.



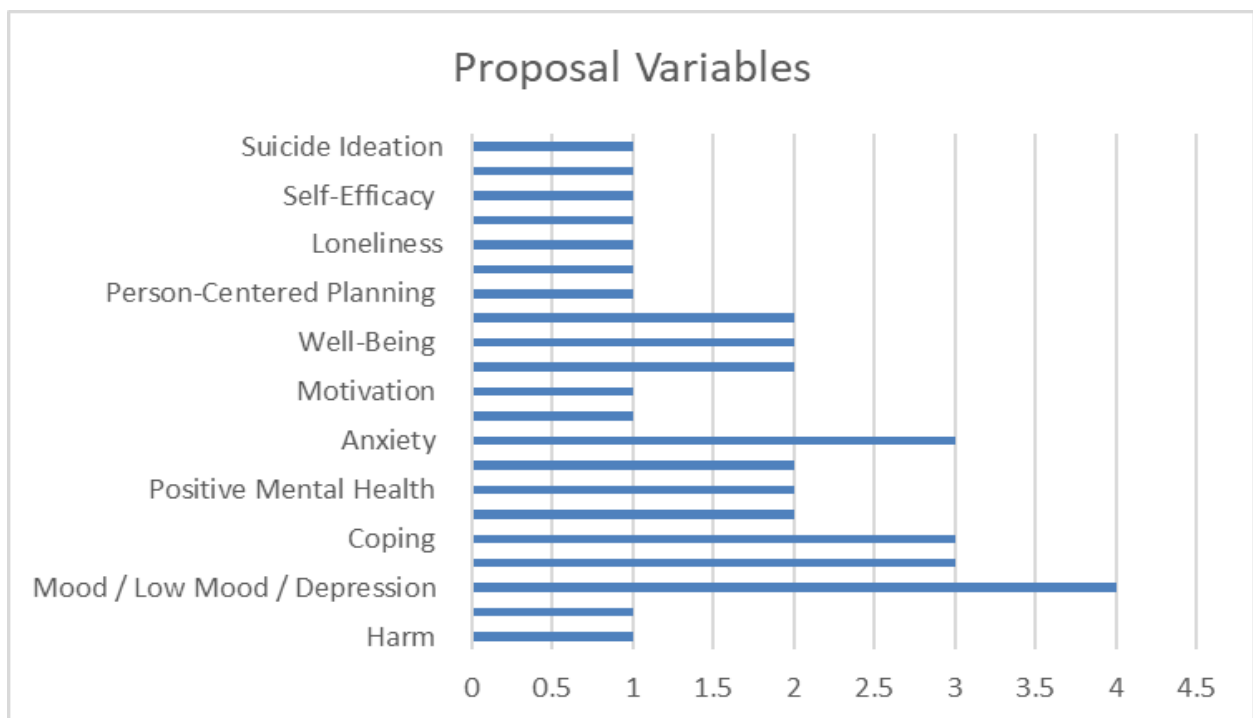
The published research leaned strongly towards Quantitative projects (67%) over Qualitative (16%), with Review studies also represented (17%). We can only surmise the reasons for this, given that more Qualitative research was carried out and there are generally many factors that can influence publication success. Our analysis highlighted that the majority of publications involved use of standardised measurements rather than interviews.



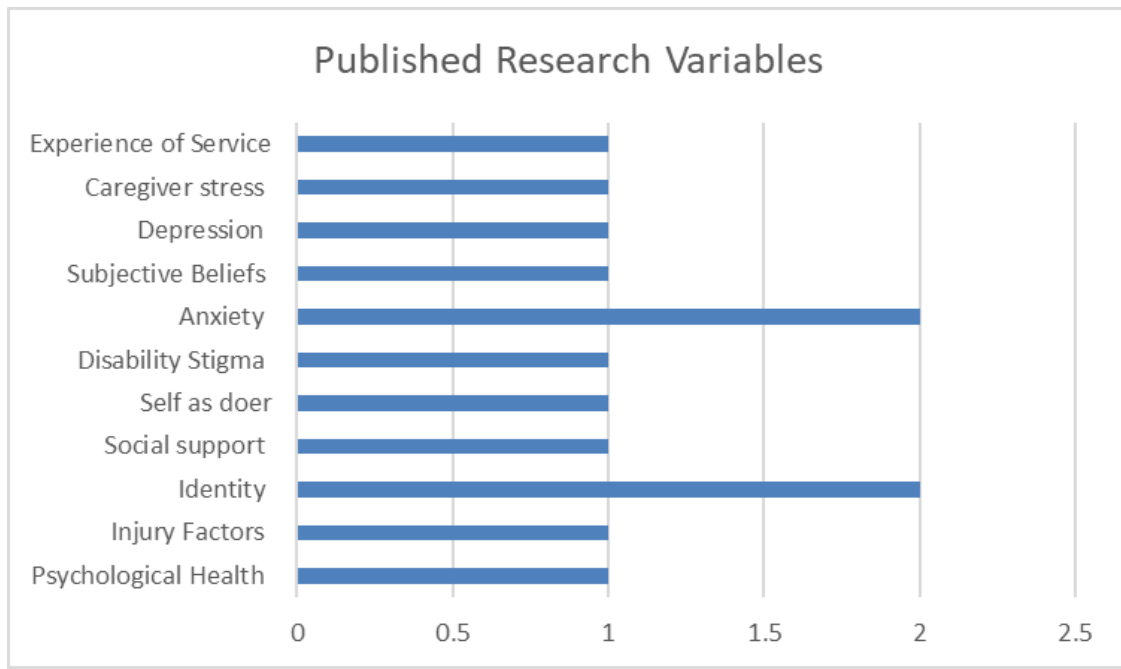
The focus of research participants was mostly on Acquired Brain Injury Ireland clients (40%), with some studies also recruiting from other services. Staff as participants accounted for 20% of the projects and client partners were at 8%. Research studies which had keyworker involvement were also represented (4%), and the outside setting (4%) refers to a nursing home.



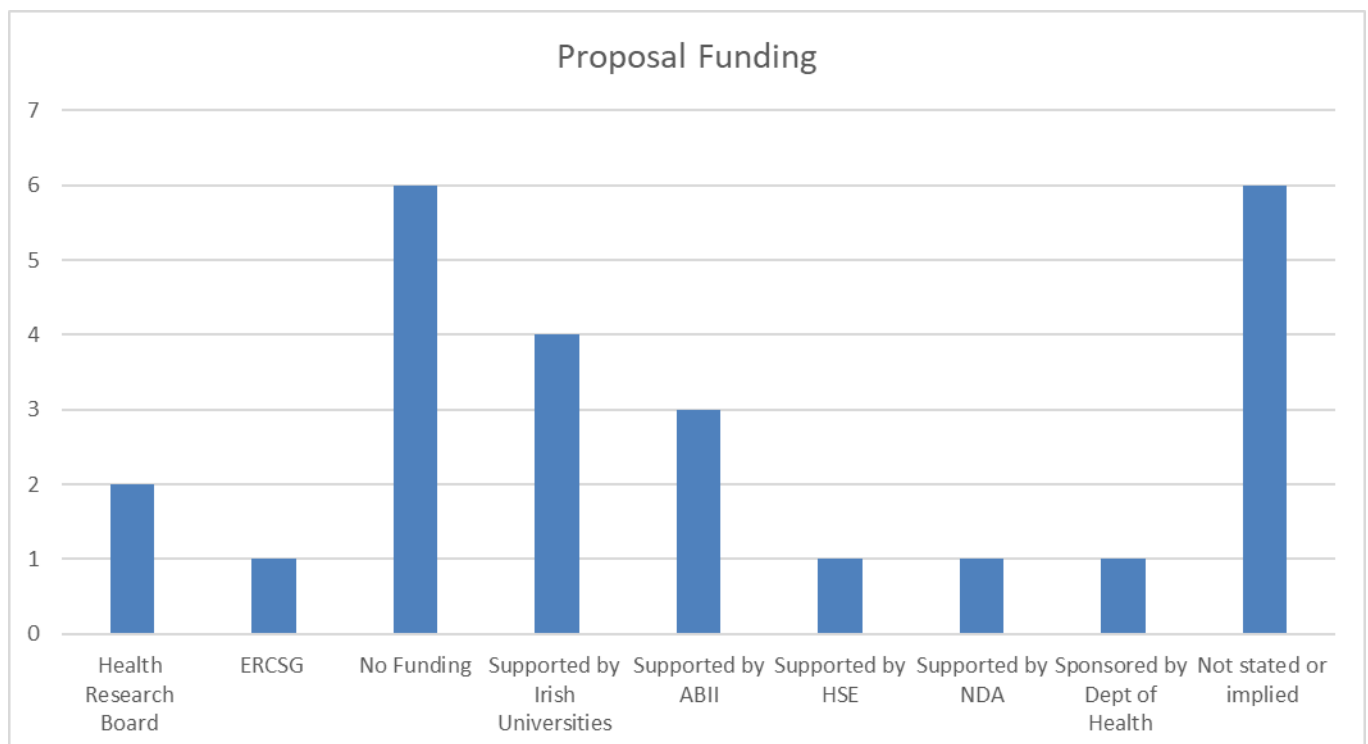
In recent years, the REC has encouraged researchers to be as inclusive as possible with regard to participant criteria, as there had been a previous trend to exclude clients with communication and cognitive difficulties. In the past four years, 54% of proposals included all types of ABI, with specific projects on stroke (13%), TBI (8%) and aphasia (4%).



Proposal variables focused on many psychological themes including mental health, well-being, coping, self-efficacy, and motivation. These themes also highlight that the vast majority of research in the past four years has come through psychology channels.



Publications were highest for variables involving 'identity' and 'anxiety'. This could be attributed to the funding background of these studies, which were intended for publication and dissemination, whereas some other projects were academic thesis requirements.



For the studies where funding was stated, there was a range of groups which have been involved over the past four years including the Health Research Board, European Research

Council, Health Service Executive, the National Disability Authority, Department of Health,
and a number of Irish Universities.

Section 4

Stakeholder Engagement - Analysis of Survey

4.1 Introduction and Methodology

Based on the literature review, the original plan was to host a series of face-to-face meetings (World Café style) across the country with our range of stakeholders to include:

- People with brain injury
- Family members
- Acquired Brain Injury Ireland staff
- Clinicians and allied health professionals working in other settings
- Academics, researchers and students.

However, this plan was reviewed considering public health guidance following the Covid-19 pandemic and a decision was made to move the project online. The RPE team discussed and weighed up the ethical considerations of conducting the exercise during the Covid-19 pandemic, and what impact the concurrent adjustments may have on the equity and parity of data collection among carers, staff, clients and external stakeholders. The team also had an awareness of the dichotomy of maintaining a scientifically evidenced-based approach and having a rational and practical response to the unavoidable limitations that were imposed on the project by conducting such an exercise during a global health pandemic. Discussions also centred on the design of a potential qualitative research element, and practical considerations for conducting this either in person with physical distancing, or via telecommunications software such as Zoom. Following these discussions the team agreed to proceed with the project using a range of technology tools, acknowledging the limitations of the approach, and also reviewing the positive role that technology can play in projects like this by ensuring that they can progress to completion.

4.2 Developing the Questionnaire

Utilising clinical knowledge as well as the literature and scoping reviews as a framework, a questionnaire to examine research priorities amongst key stakeholders was developed. Before large scale circulation, an internal pilot project was run with people with ABI to determine the validity of the questionnaire. Their feedback resulted in amendments to the final version of the questionnaire. Using Survey Monkey software, we distributed the survey of 5 questions via our range of networks both internally and externally. The survey remained open for a month and a total 267 responses were received. This level of response rate superseded our original target of 100-150.

4.3 Questionnaire Findings

This section sets out the details of the findings of the survey question by question.

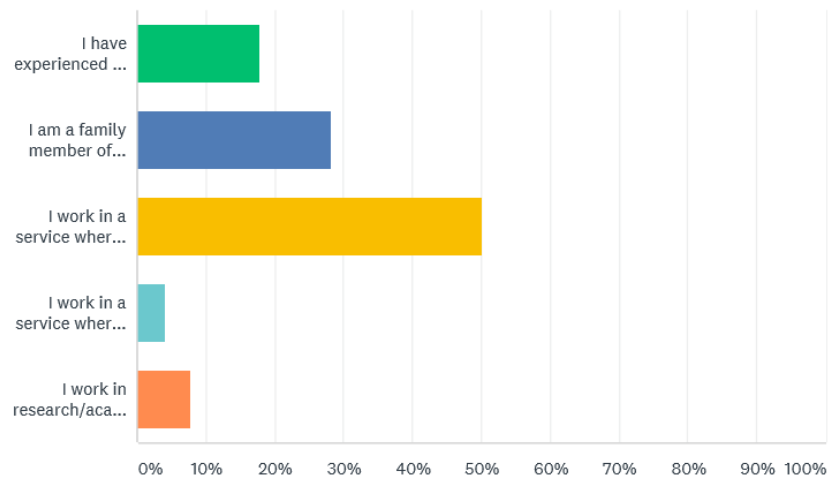
Q1: Profile of survey respondents

The first question of the survey asked the individual completing the survey to identify which demographic group they belonged to from the following categories: 'I have experienced a brain injury'; 'I am a family member of someone who has a brain injury'; 'I work in a service where I meet clients who have experienced brain injuries'; 'I work in a service where I do not normally meet clients who have experienced a brain injury but I would like to know

more about the area'; 'I work in research/academia'. In total 259 respondents completed Q1. The category with the highest response rate was those who work in a brain injury service (N=130, 50.19%), followed by family members of individuals with a brain injury (N=73, 28.19%), and individuals who have experienced a brain injury (N=46, 17.76%). A small majority of respondents worked in the field of academia (N=20, 7.72%), and in services where they did not typically encounter clients who have experienced a brain injury (N=11, 4.25%).

Tell us who you are: Tick one of the boxes below:

Answered: 259 Skipped: 0



Q2: Priority setting by respondents

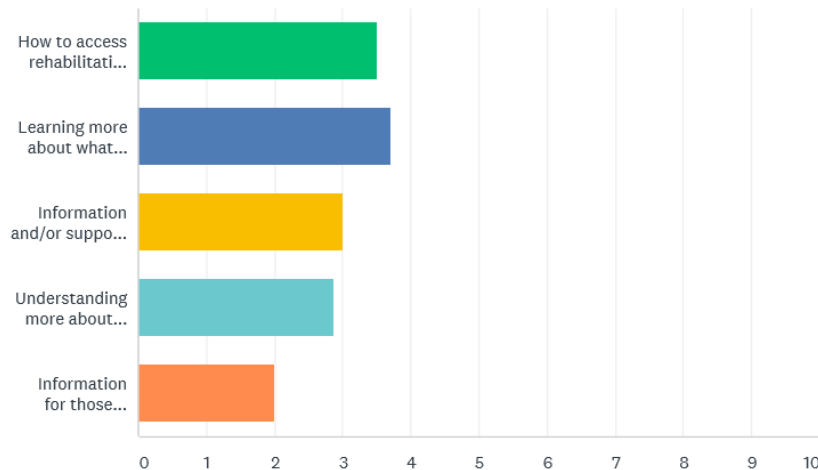
The second question of the survey provided 5 predetermined possible areas for future research, and asked respondents to rate these in order of priority from 1 (highest priority) to 5 (lowest priority). The 5 research areas provided were developed through the pilot test, clinical input, and by identifying existing gaps within the organisation's research profile. The 5 research areas were comprised of the following:

- Access to rehabilitation services after brain injury
- Learning more about what rehabilitation works best
- Information or support for families and friends regarding ABI
- Understanding social issues pertaining to ABI
- Information for those involved in funding ABI services (what to fund and why?)

A total of 257 respondents completed Q2, with a relatively close spread in terms of priority ratings. The research area deemed as the highest priority was 'Learning more about what rehabilitation works best for brain injury' (M=3.71). This was closely followed by 'Access to rehabilitation services after brain injury' (M=3.51). Next was 'Information and support for families and friends following a brain injury' (M=3.01), closely followed by 'Understanding more about social issues pertaining to ABI' (M=2.86). Finally, 'Information for those involved in funding brain injury' was deemed as the least high priority (M= 2.00).

Below is a list of five possible research areas for Acquired Brain Injury Ireland over the next 5 years. Please rate them from 1 to 5 what order of priority you think these should be in. Click on the arrow and numbers 1 to 5 will appear. Click on your choice. 1 = highest priority and 5 = lowest priority

Answered: 257 Skipped: 2



Q3: Areas not included in the priority list

Question 3 asked respondents via an open-ended question if there were any other areas not included in the priority list that they think would be very important for Acquired Brain Injury Ireland to research over the next five years. This included joint projects with other services/teams.

In this section, respondents were given the opportunity to answer in a written format and thus to expand on detail. As with question 2, the focus was areas of importance for Acquired Brain Injury Ireland research over the next five years. 55% of responses reflected the categories in Question 2 in the order of Access, Rehabilitation and Outcomes, Family, Social Issues and Funding.

The new areas identified were (in order of number of comments):

1. Living with an ABI
2. Diagnosis /assessment of ABI presentation and differentiation of diagnosis
3. Public Awareness
4. Employment
5. Residential
6. Child & Adolescent ABI
7. Mental Health
8. Prevalence

Regarding **Access**, pertinent sub-themes emerged which could be categorised into waiting list times, geography, and transition from acute to community services. The need for transport was identified particularly for rural areas. Respondents noted the need for research to examine the “discrepancies in access to services and waiting lists based on

geography". Potential solutions for further investigation were suggested such as "an online network", "audits of existing services, access to these based on geography", and "increasing neuro rehab services all across Ireland to meet needs of the population". There were references to "collaborations" between services for seamless transition of supports from acute to community and the need for "defined clear pathway of care and treatment". It was suggested that information was required both for professionals ("information for GPs and other medical personnel on the hidden impacts of brain injury") and clients/family ("send information home with patients on what services there are out there after a brain injury").

Rehabilitation and outcomes responses focused on multidisciplinary team (MDT) input and long-term outcomes. Comments referenced "Integrated care models", "review of community models of care", "what different types of therapy can improve or aid recovery" and "the value of community involvement". Specific professions were named: Case Management ('Role and impact'); Psychology ('Effectiveness of psychological interventions'); Neuropsychiatry ('Urgent' need); and Speech and Language ('The quantifiable benefits gained from an ABI specific and tailored speech programme'). Tailoring a rehabilitation programme was also reflected in many comments: "What's best to help survivors get back to age appropriate recovery not umbrella one fits all system"; and 'collaboration' between services. 'Advocacy' and 'community integration' were also deemed important. Other specific research topics included 'insight', 'motivation' and 'gender role' factors in the context of analysing rehabilitation outcomes.

Family-focused research was a popular theme. The topic areas ranged from 'education for family members/carers' to examining the 'longer term impact of brain injury on family members and carers'. There was also reference to looking at "how best to support children with a family member with a brain injury". 'Group support/social support' was mentioned and one particular comment stood out, namely "Impact on carers or family members lives: the hidden client?" There was also several references to relationships: "the impact of brain injury on marital and romantic relationships, sexuality."

Social issues can cover a wide range of research topics and this was reflected in the responses which referenced domestic violence, addiction and suicide. The majority of comments in this category related to addiction: "Addiction post brain injury- those that no longer abuse alcohol but show other compulsive behaviours"; "maximizing outcomes for those with prior addiction issues"; and "what effect is alcohol and drug addiction having on those who cannot be supported by our services due to these challenges?".

Funding suggestions included "research on the social return on investment in rehabilitation to show funders and the general public why it so important" and "the economic impact for those of working age, comparisons of effective response in another country such as community response pilot or better service provision".

Living with ABI covered a range of research suggestions from "Learning to live an every day life with an ABI - the ups and downs", "the area of loneliness", "capacity issues", "promoting quality of life and self-management" and the "effects of brain injury as the brain ages". Many of the responses referred to the "long term" impact and "adapting to life post brain injury".

There were numerous comments that were grouped under a research heading of '**Diagnosis/assessment/related ABI presentations/differentiation of diagnosis**'. These included "concussion", "dementia", "brain injury due to rare diseases e.g. Central Nervous System Vasculitis (CNS Vasculitis)" and "disorders of consciousness". Brain injury due to 'Sport/amateur sport' was referenced in some comments. 'Misdiagnosis' and 'unusual effects of brain damage' were also highlighted for further research.

Public Awareness of brain injury garnered many comments in the context of "better awareness and knowledge" and "reduce stigma or mistreatment (i.e. education systems, socialising, political representation)". There was reference to "teach in school the impact of living with an injury". Comments also focused on "what it means in the long term for the person with the injury and their family / friends". There was also reference to the impact of Covid-19 this year: "ensuring society/those working with general public are aware about issues someone with an ABI may have on a daily basis i.e. access to public transport, travel difficulties, grocery shopping (during Covid-19 this may be particularly important - queuing for long periods of time, social distancing, one-way systems, wearing face masks)".

Employment was a popular theme and comments referenced "how brain injury effects access to employment". Respondents noted need for research on "dealing with returning to work for person with injury and their employer" and "the impact of vocational rehabilitation in brain injury in an Irish context". Financial aspects were also included in this theme such as "financial stress on survivors" and "opportunities for work type engagement and the facilitation of this by the rules surrounding social welfare payment entitlements."

The practical aspects of research on **Residential** issues were noted. Comments referred to the need for "independent living facilities" and "moving away from residential settings to proper households". It was suggested that there could be a "joint piece of work with Housing associations" and "step down facility" to support those with more complex needs or vulnerabilities. Another comment noted "the need to increase residential units throughout the country, the importance of multi-disciplinary teams working together to ensure the best possible outcomes....Need more state of the art facilities with clinical supports, transitional units, home care packages". The environment was also highlighted: "does the area they live in meet their needs, i.e. access to outdoor spaces (green spaces), safe spaces to relax and think, suitable access to public transport, suitable equipment at home."

Respondents highlighted the need for further research on **Child & Adolescent ABI**. This included comments on "rehabilitation" for child and adolescents, "inclusion in schooling", "specialist services regarding dual diagnosis". One respondent noted that there is a "service need" for this population.

There was specific reference to **Mental Health** in a number of comments. These referenced the need for a focus on this aspect of ABI and the need for "more mental health services" with specialty in brain injury.

There was also reference to research on **Prevalence**, namely “up to date statistics on prevalence, rate etc of brain injury”.

The volume of comments received in this section underpins the vastness of research topics that can be pursued in brain injury. It was very apparent through analysis of the comments that all stakeholders had a vested interest in research and some topics in particular were very close to respondents’ personal experiences. In order to apply further cohesion in the context of prioritisation of qualitative information, the table below illustrates the themes with the related sub-themes.

Themes	Research focus subthemes
<i>Access</i>	Acute to community Transport Geographical equity Pathway information
<i>Rehab</i>	Models of service MDT roles Collaboration between services Individualised programmes Specific factors impacting on outcomes Long-term effectiveness / best practice
<i>Family/Carers</i>	Education Supporting children Support groups / social support Relationships and sexuality
<i>Social issues</i>	Domestic violence Suicide Addiction
<i>Funding</i>	Economic impact Social return on rehab investment
<i>Living with an ABI</i>	Long-term impact Social access Aging and ABI Quality of life Capacity issues
<i>Diagnosis/assessment/related ABI presentations/differentiation of diagnosis</i>	Concussion Dementia Brain injury due to rare diseases Disorders of consciousness Misdiagnosis
<i>Public Awareness</i>	Inclusion and access Reducing stigma Long-term impact of brain injury Education from school age
<i>Employment</i>	Vocational rehabilitation

	Staff member and employer support Financial aspects
<i>Residential</i>	Transition from residential to more independent settings / step down option Environmental aspects Work with housing associations
<i>Child & Adolescent ABI</i>	Rehab effectiveness Educational support Dual diagnosis
<i>Mental health</i>	Access to specialist mental health
<i>Prevalence</i>	Up-to-date statistics

Q4: Prioritising one research question in the next five years

Survey respondents in Question 4 were asked in an open-ended question to indicate what one research question they want answered in the next five years. There was a very wide variety in the responses which we categorised into 12 themes. These themes covered the following areas: technology; brain injury and later life; impact of ABI; employment and vocational training; support for family carers; role of acute care and the National Rehabilitation Hospital; role of rehabilitation; neuro-rehabilitation policy; services and the pathway; funding for services including value for money; data on ABI and diagnosis. 3 of the 12 themes stood out from the others with the highest number of responses. These were the impact of ABI, the role of rehabilitation and the pathway/services themes.

In response to the ‘impact of ABI’ theme, numerous issues were outlined by the respondents. In general, the responses were related to the impact of brain injury on the person, such as on their relationships, behaviour and mood, and communications. Many questions were raised around the longer-term impact of the brain injury, what does the future hold, families making life-long adjustments, and the stigma and exclusion experienced by people with ABI. One respondent wrote:

“We are saturated with TV programmes that lead you to think that after a brain injury that in time life goes back to normal, but it doesn’t. It is life before and life after. We need to know the lasting impact on survivors and families.”

The ‘role of rehabilitation’ theme also raised a wide range of research questions. Many related to the need to learn more about what rehabilitation interventions deliver the best outcomes for brain injury. Specific services were mentioned including psychology, occupational therapy, and physiotherapy. Related questions about how to motivate the person to engage in rehabilitation (especially for those lacking insight) and when is the best time to start/stop rehabilitation were also raised.

This question from a respondent sums up this theme very well:

“What factors best promote recovery, rehabilitation and progression after a brain injury (including timeframe, strategies, supports, well-being, fatigue management etc...)?”

The third most referenced theme is related to research on services across the pathway. Many respondents refer to the limited services, regional differences and waiting times for services across the pathway. Questions here relate to why ABI services are not as well developed or funded as other specialist services in Ireland, how to navigate the brain injury services in Ireland, and the optimal integrated national pathway and approach to care from the acute hospital to re-integration in the community. One question helps to summarise the large volume of responses in this theme:

“Will brain injury services be more accessible to all parts of Ireland in 5 years’ time?”

Important research questions were raised across the other 9 themes. Of these, 3 themes emerged as the next most populated ones. Employment issues for people with brain injury were highlighted, and questions were included about the opportunities for people with ABI to find employment, and the role of vocational rehabilitation in supporting people to engage in meaningful occupation. Under the theme the role of the National Rehabilitation Hospital (NRH), questions related to why there is a lack of beds in the NRH, why are waiting times so long, and why there are no regional NRH-type beds.

The third theme on ‘funding services/value for money’ (which relates directly to another theme on data on ABI) raised some challenging research questions around how we argue for investment in community rehabilitation services. How are we demonstrating that our services are value for money? There is a need to provide evidence that we are producing better outcomes for people with the investment, and evidence to show how we reduce dependency on services in the longer term with upfront investment. Questions also related to cost-effectiveness of various rehabilitation services. The questions around data relate to this theme and included, for example, “Where is the data on rehabilitation need nationally?” There is an urgent need for data on the number of cases of ABI in Ireland with a breakdown according to gender, age, incidence rates, at-risk groups, untreated ABIs, e.g. in the prison population, and the causes of ABI.

In summary, this question raised a wide variety of response but there are clear issues coming to the fore for our stakeholders.

Q5: Involving people with ABI and family members

Survey respondents were asked in an open-ended question to indicate what could be done to facilitate the involvement of individuals with a brain injury and their families in research, aside from as research participants. In total there were 177 responses for this question, which we categorised into 10 diverse themes. These themes covered the following areas: Education and Training; Accessibility of Research and Advocacy; Family and Carer Support; Social and Peer Connection Opportunities; PPI Approach; ABI Supports; Vocational Opportunities and Employment; Ethics; Access to Services; and Societal Level.

In particular, 3 of the 10 themes were discernible from the others in that they comprised the majority of responses. These were: Family and Carer Support; Social and Peer Connection Opportunities; and PPI Approach. An underlying phenomenon which emerged across the data was a tendency for comments to focus on how supports could be provided,

as opposed to how involvement in research could be facilitated. As a result of this, the theme of 'Access to Services' was the largest of the other 7 themes, and highlighted ideas for access to services including: Improved communication between hospitals and outpatient rehabilitation services; Provision of information; Fundraising and awareness; Expansion of services into more regions; and long-term support for those with a brain injury. This perhaps highlights the necessity for ongoing service development, and may also suggest that the structure of the question could have been reviewed to ensure that it clearly reflects the desired information.

'Family and Carer Support' was one of the strongest themes which emerged when reviewing the data. Generally comments across this theme were quite congruent, and focused on: 'online supports and connection opportunities'; 'in-person family support groups and peer support'; 'provision of information and knowledge for carers and family'; 'wellbeing and mental health of carers'; and 'research on the impact of the family unit due to a brain injury'. There was a general sentiment that carers who were better informed at the initial stage, and who had access to a network of professional and peer supports from an early stage, would be more adequately equipped to deal with the impact of brain injury, and also to engage in research opportunities:

"To support and give families and people living with brain injury the skills and information and opportunities to become their own advocates"

"knowledge for family and carers with encouragement to be aware of and be involved in research from beginning."

'Social and Peer Connection Opportunities' was another theme which was very strongly represented in the data. Once again, comments regarding this theme were relatively consistent, focusing on social groups for those with brain injury to support each other and share knowledge, opportunities for people to meet, engage and collaborate on ideas regarding research (e.g. workshops, forums), using social media to link with peers and empower them to become involved in research, and practical suggestions for involvement in research (data collection, hosting focus groups). A very optimistic and energetic approach towards involvement with research was particularly evident across this theme, with a general sense that bringing people together to support each other, providing them with appropriate information and knowledge regarding brain injury and research methods, and allowing them to work collaboratively on research was the optimal approach. This was conveyed in a number of responses from different participants, two of which you can see below;

"Reaching out to them through social media and other networks to empower them to speak out, attend focus groups, educate them and learn from them."

"Increasing friendship / sense of connection/community: Peer mentor / buddy system where new clients are paired up with clients who have been using the service more often Research assistant work such as data collection (perhaps with assistance from an RA). Assistant moderator roles for focus groups / involvement in

structured interviews. Co-organiser (again, with assistance from an RA if necessary, for example) of social groups outside a clubhouse /day service setting.”

Using a PPI approach to include key stakeholders in research was another theme very strongly represented in the data. There was a noted enthusiasm towards engaging those with a brain injury and their family/carers in research, with most comments touching on similar suggestions. Comments in this section tended to focus on: development of advocacy and empowerment; starting at the local level; input from key stakeholders at the initial stages of research; having key stakeholders involved as active members of the research team; including participation in research design; data collection and analysis; and presentation of research findings.

“Use a PPI approach. Have a panel of experts, individuals with ABI, family members and professionals who act as co-researchers at all stages of the research stage. All get provided with training to conduct research. Opportunity to inform the process. All on an equal footing. Introduced by first name only, not job title.”

“Empowering people/families to use evidence-based advocacy (e.g. highlighting and advocating for translational research, identifying meaningful research questions), involving them in research design (accessibility etc.), involving them in dissemination of findings (e.g. putting findings into practice and figuring out how to do this, almost back to advocacy again), enabling them to lead on advocating for associated social or policy changes.”

Across the other 6 themes, many useful ideas for involving key stakeholders in research were also put forward. The theme of Education and Training focused on the provision of training opportunities for ABI survivors and carers, to provide them with information, and help them to develop the appropriate skills to cope with the impact of brain injury, and work towards rehabilitation goals. Following on from this, another theme focused on increased opportunities and skills training to support those with a brain injury to return to employment or begin other vocational opportunities.

The theme of accessibility and advocacy focused on ways to make research opportunities and the dissemination of research results more widely available to key stakeholders. Suggestions comprised of providing more information to key stakeholders, as well as providing more online and in-person peer support groups to allow key stakeholders to discuss research. One smaller theme looked at whether key stakeholders could be included in the ethics process of research projects, to ensure they have an opportunity to input into research which has been submitted for ethical approval. Another minor theme discussed opportunities for engagement on a more societal level, with a focus on increasing awareness of brain injury among the broader public, collaborating with the media, and creating a platform for greater inclusion of those with a brain injury in wider society.

To summarise, while it is evident that a multitude of different themes were present in the data for this question, it is also clear that several issues were presenting more consistently throughout the data, in particular: Family and Carer Support; Social and Peer Connection

Opportunities; and the use of a PPI Approach. Smaller themes also presented many useful insights and added to the richness of the overall narrative.

Section 5

Building Consensus and Validating our Priority Themes

5.1 Introduction

Following on from the questionnaire analysis, the team engaged in a consensus building exercise to set out the priority themes from the significant levels of data that emerged. This process drew from concepts utilised in the Delphi method (Iqbal & Pison-Young, 2009). The team engaged in further thematic analysis and a distillation of the multiple themes and sub-themes that had emerged in the data. We began by individually creating a set of visuals and charts and then collectively creating a set of charts to agree on the themes using a consensus approach.

5.2 Validating the Consensus

After the consensus building exercise was completed, we had some further one-to-one engagement with clients and family carers, using remote technology to validate the consensus. Application of the triangulation strategy to address validity underpinned this procedure (Carter et al, 2014). In total, we engaged with 6 people, 4 clients and 2 family members. During the engagement, clients and family members were asked to give their overall reflections on the priority themes, identify if something was missing from the priorities, or if something should not be included on the priority list.

From the feedback, the research priorities that we had arrived at through the consensus building was viewed as being accurate, relevant, and inclusive. Nothing was identified as being missing, and nothing was identified that should not be included in the priorities. Many of the respondents highlighted how positive it was to see that people with brain injury and their families were placed at the centre of the process, and that they would be playing an active role in the organisation's research processes.

Some clients and families talked about the lack of access to services and the need for a clear brain injury rehabilitation pathway. They talked about how important it is to improve the experience for the person with brain injury and their family. Many spoke of their difficulties in getting access to timely services and about experiencing waiting lists for all services, including in-patient and community neuro-rehabilitation. Others also spoke of the vital role of public awareness for brain injury and the reality of living life with an ABI.

It is acknowledged that our research has a role in play in producing the evidence around these experiences for people with brain injury and their families. It is also important to identify the broader role of the organisation in engaging in policy advocacy and awareness raising, and to highlight these issues to political, policy and public stakeholders. Our current Strategic Plan lists 'Creating public awareness and influencing public policy' as one of its strategic priorities for 2020-2024. Therefore, while research has a role, it was agreed that the broader strategic priorities of the organisation are critical to bringing about the change that families are seeking.

The feedback also indicated that it is important to make it clear in our communication that all the themes are of equal importance and are closely interlinked. In addition, it was highlighted that communications about the research priorities must be accessible and inclusive, using graphics and pictures alongside the words.

Section 6

Our Research Priorities 2020-2024

6.1 Involving People with Brain Injury and their Families

In setting out our research priorities, there was a recurring theme through all stages of the process: the need to put people with brain injury and their families at the core of our research work. It was identified that this group must play a vital role not only as active research subjects, but that they should influence and be involved with the research project from the design stage right through to the delivery and communication of research results.

Therefore, our research priorities have placed people with ABI and their families at the centre (see Table 1). We are highlighting our commitment to working with people with ABI and their families, our major stakeholders, at every step of the research process. The research projects we support will have to show evidence of their PPI plan, and give assurances to the REC that they involve people with ABI and their families at every stage of their research proposal. The PPI plan will form a crucial element of the research ethics application.

6.1 Priority Research Areas

Having completed all stages of the project, the following four themes have been agreed and approved by the organisation:

Theme 1: Effective rehabilitation.

Theme 2: Access to brain injury services and the rehabilitation pathway.

Theme 3: Impact of brain injury.

Theme 4: Facts and figures.

It is important to note that there is no ranking across the four themes and that they are all interlinked. These themes are now a core part of our research work during this strategic phase of our organisation. In Table 1, below, we highlight the four priority areas and place people with ABI/families at the heart of those priorities.

Under the first theme, **effective rehabilitation**, we want our research to help us improve our knowledge and understanding of what constitutes effective rehabilitation for the person with brain injury. This includes areas of research on the role of the interdisciplinary nature of neuro-rehabilitation; the nature of the expertise and specialist clinical knowledge; developing core outcome sets and improving our understanding of outcome measurement tools; and specific interventions in all the clinical therapy areas including psychology, occupational therapy, social work, physiotherapy, speech and language therapy, and case management.

Under the second theme, **access to brain injury services and the rehabilitation pathway**, we want the research we support to help us to understand how we can improve access to rehabilitation services, and to build a comprehensive understanding of what constitutes an effective rehabilitation pathway in an Irish context. This includes finding ways to address the gaps in rehabilitation services; examining the regional and geographical differences; developing models of service based on need rather than on 'luck' or postcode lottery; the impact of waiting times for services on the rehabilitation outcomes and the reasons for waiting times; the role played by technology (hi-tech and low-tech) in improving access to services; improving our understanding of the range of community services, in particular living arrangements for the long term; and researching the rehabilitation pathway in an Irish context.

The third priority is **the impact of brain injury**. We want our research to tell us more about the impact that having a brain injury has on the individual, their family, and participation in our society in general. This includes areas such as:

Individual impact: mental health, communications, relationships, behaviour; mood; the long-term impact including ageing with an ABI, loneliness and isolation; and quality of life.

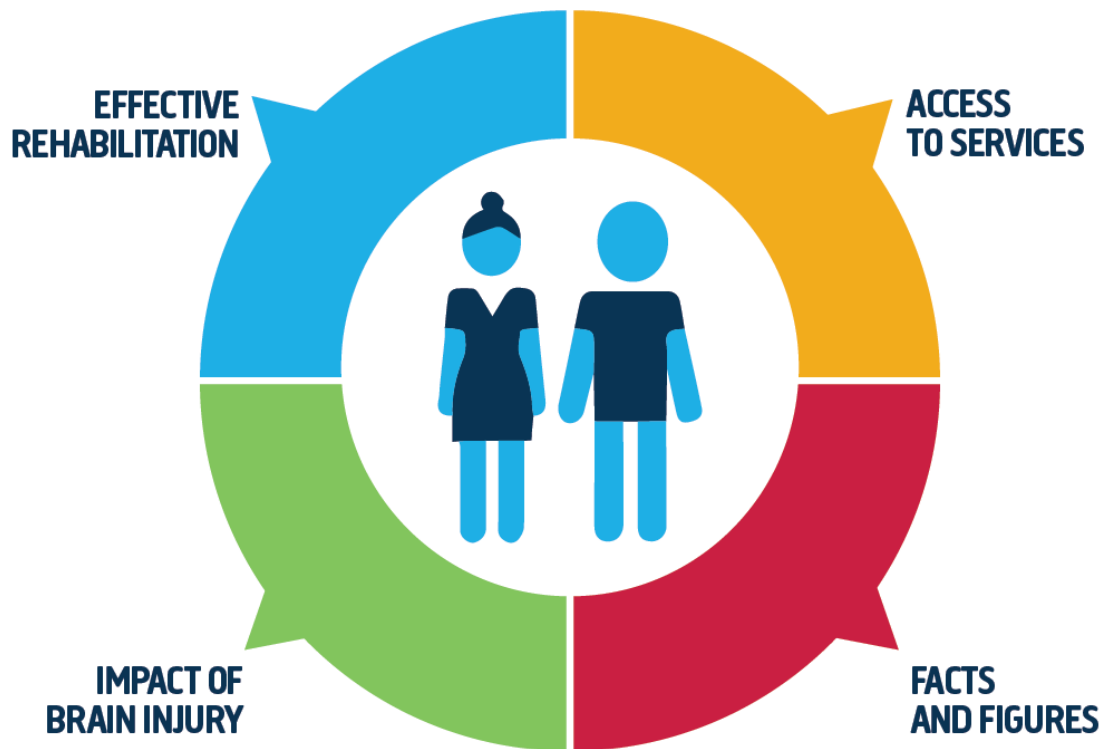
Family impact: examining how to make lifelong adjustments; the need for information, education, training and support; and mental health.

Impact on participation in society: community integration; access to employment opportunities; increased public awareness; transport and housing.

The fourth and final priority focuses on the **facts and figures** around brain injury. We want research to provide data and information on the brain injury population in Ireland, to quantify their needs and make a case for investment in the necessary services across the country. There are currently many gaps in the data on brain injury in Ireland, and we need that data to prove the needs exist. We want to have data that looks at the cost effectiveness of rehabilitation services, as well as value-for-money studies. We need to know how many people there are with brain injury in Ireland, how many people experience a brain injury annually, and what are their rehabilitation needs in quantifiable terms. We need data that helps make the case for greater investment in rehabilitation. We also need data to make the case to government and policy makers to act and invest.

Table 1

RESEARCH PRIORITIES 2020-2024



Putting people with brain injury
AT THE CENTRE OF OUR RESEARCH PRIORITIES

6.3 Final Remarks

The RPE will fundamentally change how Acquired Brain Injury Ireland operates in relation to its research programme for this strategic phase of the organisation. Operationally, the REC will now have to ensure that all research proposals submitted align with the research priorities. The REC will also ensure that the researcher adheres to the PPI requirements. The PPI plan submitted by the researcher will have to make it clear how they are involving and engaging people with ABI and their families in all stages of the research.

Changes will be required on the REC documentation, including new sections in the application form about the PPI and research priorities. Accordingly, updates will also be required to the Guidelines for Researchers document, to reflect the organisation's priorities and best practice in PPI. We have also taken steps to improve the PPI membership on our REC.

During this strategic phase, communication with researchers about our priorities will be key to its success. We will have to make sure that all potential researchers are aware of our priorities and our essential focus on PPI, prior to them developing their proposal. Communications with key stakeholders, including our university partners, will be key.

The RPE serves to highlight our top research priorities to direct our research and organisational strategy. It will also provide opportunities for the organisation to pro-actively pursue research opportunities in our areas of priority, and forge new partnership arrangements with universities and other research agencies and funders.

A review of the research priorities will take place at the end of the strategic phase in 2024.

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