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AUT TRAUMATIC BRAIN
INJURY NETWORK

Collaborative Concussion Outcomes Pilot Project

Evaluation Report

Commencement date: 19/07/2021

Completion date: 31/10/2022

Funder: Accident Compensation Corporation

Executive Summary

Scope and Purpose

The purpose of this project was to develop and test the feasibility of a care pathway delivered using a digital platform (ZEDOC) independent of ACC and the service provider for measuring outcomes within ACC funded concussion services. Those aged under 18 years of age were not included in the pilot.

Methods

Clients were invited to participate in this pilot project if they were; 1) aged 18 and above; 2) who had an accepted ACC claim for a concussion or brain injury; 3) were being treated by ABI within ACC's Concussion Services based in Auckland and Wellington between 19/07/2021and 29/07/2022. Outcome measures were collected up until 29/10/22 to enable complete follow up of all participants who consented into the project.

Prior to, or at their initial appointment, clients were informed by the service provider's administrative staff about the pilot project and were asked if they would like to take part. Clients were then emailed/texted the initial consent and baseline surveys to complete at home prior to their first clinic appointment, or at the clinic (via tablet, kiosk, own device). Throughout the period that the client received concussion services, participants received monthly questionnaires automatically sent by ZEDOC until the client was discharged. The two outcome measures sent to all participants were the EQ-5D-5L that measures health related quality of life and the Brain Injury Screening Tool (BIST) which measures symptom burden. Optional measures of depression (PHQ-9) and anxiety (GAD-7) were additional measures that could be selected by clinicians if relevant to the client.

Results

A total of 256 clients participated in the pilot aged between 11 and 89 years (mean age of 42 years). The majority of responders were female (N=148, 57.8%) and based in Auckland (N=198 77.3%). Just under one in ten participants reported needing support to use the platform. A significant treatment effect from admission to last completed assessment were noted across all subscales of the BIST. EQ-5D responses showed significant improvements on pain/discomfort, usual activities and anxiety depression subscales and overall health rating. There were no significant differences observed for the mobility and self-care subscales (domains where few deficits were observed on admission). There were only a few clients that competed the optional anxiety or depression measures and service evaluation measure meaning no inferences could be made from results.

Summary of Key Learnings

This pilot proved to be valuable in supporting how the digital collection of outcome measures may be achieved. These relate to:

Simplification:

- Make things less complicated. Digital platforms in this context need to be simple and easy to use for both clinicians and clients
- Provide simple explanations for clients. For example, emails from an independent party may have repeated information which can be confusing for clients
- Integrate technology. New platforms need to be integrated into patient management systems to improve clinical utility and aid data interpretation

- Workflow needs to be seamless. Workflow needs to be well thought through from a client perspective, client engagement in the working group may have been helpful

Value and purpose:

- Ensure clinicians and clients see the value of measures. Outcome measures need to be perceived as of benefit to clients and clinically meaningful in order to be adopted
- Determine optimal timing of measures. Timing of outcome measures needs further consideration.

Project management:

- Consideration needs to be given as to how new initiatives are presented and explained to clients when they are not otherwise seen as part of standard treatment. For example, consent forms.
- Strong project management is critical. Need to keep a central record of decisions and justifications to help manage working group membership changes
- Project transitioning is important. Need to close off projects with a discussion around next steps
- Project burden and change fatigue are factors to consider. For example, the need to manage multiple projects within a single organisation to reduce impact on staff.

Limitations

Identifying the limitations of the pilot is likely helpful in supporting future work in the digital collection of outcome measures. Key limitations related to:

- COVID-19 impacts reducing face-to-face contact to socialise the pilot with potential participants; and
- Client participant selection as people suffering from concussion often suffer from symptoms that contributing to data collection via digital methods can be challenging;
- There was no funding available to achieve integration of technology platforms which would have seen ABI's client management system and the ZEDOC platform seamlessly share data; and
- Unique identifiers were not used to enable data matching. This would have also enabled improved analysis of findings including ethnicity data comparisons.

Conclusion

The project was valuable in progressing how digital outcome measures can be collected using a co-design approach.

Overview of project

Initial Aspirations and Background

ABI Rehabilitation NZ Ltd (ABI) was connected to The Clinician via the International Consortium for Health Outcome Measurement (ICHOM). ABI had aspirations to develop a fit-for-purpose, digitized care pathway for collecting outcome measures from clients with concussion. This pathway's purpose was to gather insights on what might work well for clients and to identify any potential barriers. The intention was to test the feasibility of using a digital platform to streamline the data collection and insights generation process.

ACC was introduced to The Clinician separately through discussions around ACC's plans for a national outcomes framework. ACC wanted to ascertain if collecting patient reported health outcome measures (PROMS) could help ACC to understand the Concussion Service from both the client's perspective and in terms of the value of the services it funds. ACC wanted to understand the feasibility and workings behind capturing health outcomes with a provider and third-party technology vendor.

ABI became aware of ACC's interest in working with The Clinician and suggested to ACC a willingness to trial and test a new platform/technology option. ACC was pleased to establish a collaborative, given it was seeking a service provider to support a PROMS project with The Clinician.

Scope and Purpose

The purpose of this project was to configure and test the feasibility of a digital platform (ZEDOC) independent of ACC and the service provider for measuring outcomes within ACC funded concussion services. Those aged <18 years of age were not included in the pilot.

Project Team Roles and Responsibilities

The project team comprised people from a range of organisations to ensure that the necessary expertise was available and that the platform was co-designed to ensure it was technologically sound and met the needs of clients, concussion services and service funders. Representatives from each organisation contributed the following roles in the project;

- *The Clinician* configured and refined the electronic outcome measurement platform (ZEDOC) following team discussions, providing collected data and analysis and sharing learnings from implementing similar value-based care initiatives from around the world throughout the duration of the project.
- *ABI* consented people in its concussion service into the pilot project, coordinated feedback from the clinicians, and provided insights into the needs of clients and concussion services with regard to outcome measurement.
- *Auckland University of Technology* provided expertise in outcome measurement, project design and provided independent evaluation of the project.
- *ACC* funded the components of the project related to configuring and running the digital platform (ZEDOC), ensured the project was linked to ACC strategy and considered potential implementation factors at a system wide level. ABI self-funded its participation in the project.

All parties were involved in regular project meetings, decision making around the format, content and project plan as part of the collaborative nature of the project.

Project Working Group Members

The following people variously contributed to the project over the course of its implementation.

The Clinician	AUT	ACC	ABI Rehabilitation
Helen Hong	Alice Theadom	Sarah Mooney	Christine Howard-Brown
Koray Atalag		Anand Desai	Pauline Penney
Ron Tenenbaum		Chris Crompton	Rachelle Bennett
Howard Hsia		Nic Vipond	Kristen Clarke
Deanna Norgrove		Meagan Stephenson	Michelle Wilkinson
		Wayne Fausett	
		Anthea Clements	

Method

Participants

Participants were invited to participate in this pilot project if they were; 1) aged 18 and above; 2) who had an accepted ACC claim for a concussion or brain injury; 3) were being treated by ABI within ACC's concussion services based in Auckland and Wellington between 19/07/2021 to 29/07/2022. Outcome measures were collected up until 29/10/22 to enable complete follow up of all participants who consented into the project. There were no other exclusions.

Procedure

Prior to, or at their initial appointment, clients were informed by ABI administrative staff about the pilot project and were asked if they would like to take part. Clients were then emailed/texted the initial consent and baseline surveys to complete at home prior to their first ABI clinic appointment, or at the clinic (via tablet, kiosk, own device). Throughout the period that the client received concussion services, participants received monthly questionnaires which were automatically sent by ZEDOC until the client was discharged from the platform. If the treating ABI clinicians determined that there was a need to screen for depression and/or anxiety, they could select on these specific measures on the ZEDOC platform for clients to also receive these measures alongside other outcome measures.

Outcome Measures

Outcome measures were selected following a literature search done by The Clinician research team and selection by way of the best match for testing the independent collection of PROMS. This was a somewhat pragmatic approach that was also influenced by the fact the National Trauma Network collects EQ5D-5L through its registry and the BIST is a validated tool specific to concussion. The add-on depression and anxiety measures were agreed based on the suggestion by The Clinician.

Health Related Quality of Life (EQ-5D-5L)

The EQ5D-5L[1] is a generic measure of the person's health related quality of life. It assesses outcomes across five domains of health: Mobility, Self-care, Usual Activities, Pain/Discomfort and Anxiety/Depression (see Appendix A). The EQ-5D-5L also includes a Visual Analog Scale asking the client to rate how good or bad their health at the point in time on a scale of 0-100, with higher scores indicative of better health. EQ-5D-5L was selected as a widely used generic PROM that is quick to complete, is applicable to a wide range of health conditions and has a New Zealand population value set and has a strong psychometric evidence base.[2]

Symptom Presentation (Brain Injury Screening Tool, BIST)

The BIST[3] was developed to be a brief tool for use on initial presentation after injury to guide health care pathway decision making and to monitor symptoms and recovery over time. The BIST is currently being piloted as a client triage tool within primary care and emergency departments. This offers the advantage that if it was also used as an outcome measure the patient recovery journey could be captured from time of injury until discharge from ACC services. Participants rate the presence and severity of 16 symptom items on a scale of 0-10. There is also an overall impact of injury scale from 0-100. Higher scores are indicative of a higher level or impact of symptoms The BIST has been found to have excellent psychometric properties and contains language that is easy to understand (with a reading age of 6-8 years).[4,5]

Depression (Patient health questionnaire, PHQ-9)

The PHQ-9[6] was an optional measure that clinicians could select if they wanted to include the measure for a specific patient. The PHQ-9 was designed to screen for the presence and severity of depression and to monitor response to treatment. People are asked to rate how often they have experienced indicators of depression such as difficulty sleeping, feeling low or loss of interest in doing things from 0 not at all to 3 nearly every day. Higher scores indicate a higher level of depression. Evidence suggests the measures has good reliability, validity and sensitivity.

Anxiety (Generalised Anxiety Disorder Assessment, GAD-7)

This was another optional measure that clinicians could select to add to the outcome measures that were sent out to participants. The GAD-7[7] was designed to screen for and assess the severity of anxiety. People are asked to state how often that have experienced indicators of anxiety such as feeling nervous, having trouble relaxing or worrying about things on a scale of 0 not at all and 3 nearly every day. There is published research suggesting that the GAD-7 has sound psychometric properties.

Project evolution

The early intention was to integrate the ZEDOC platform with ABI's client management system to supplement the data already collected through the care pathway. However, as the project scope and contract was defined, the short timeframe and ABI budget restrictions meant that integration was not feasible.

Following commencement of the project in July 2021, the project continued throughout the COVID-19 pandemic including periods of significant restrictions such as level 3 and 4 lockdowns. This meant that for periods of time at several points in the project clinicians were not able to see clients in-person.

A number of factors impacted on the focus and goals of the project, as would be expected in a pilot of this nature. Firstly, there were changes in ACC staff, secondly ACC moved towards a test and learn approach, and thirdly ACC shifted its focus to the utility and feasibility of the

EQ-5D-5L in response to internal requirements. Consequently, in early 2022, an additional objective from ACC was to understand the utility of the EQ-5D-5L as a health outcome measure for clients with mild traumatic brain injury (mTBI). This shift allowed the concussion pilot to align with other similar projects to provide additional data for ACC. In January 2022, given the changes in project approach, changes to the underlying structure of the platform were made to respond to feedback from clinicians and clients and to include an updated version of the BIST which had recently been released. A new version of the platform was released in May 2022, where all participants consenting into the pilot following this date were offered the revised platform.

Project Evaluation

Three different evaluation methods were used to elicit learnings from this project.

1. *Quantitative data analysis*. Statistical analysis of the collected data was conducted based on the statistical analysis plan developed at the beginning of the project.

2. *Anonymous qualitative interviews with team members*. Individual project team members were offered the opportunity to talk with an independent researcher about their own personal experience of taking part in this pilot project. This provided an opportunity to provide feedback in an anonymised way to ensure the individual was free to share their opinions without influence from the project team, their employer or concern regarding any other potential implications.

3. *Organisational reflections and learnings from the project.* Given the multiple perspectives of those involved in the project, each party was offered the opportunity to share their reflections and learnings of the project within their own sections of this report.

1. Quantitative data analysis conducted by AUT

Description of the sample

Data was available for a total of N=256 clients as shown in Figure 1. There were 15 clients (6%) who consented but did not enter any self-reported data, two where there were no sociodemographic characteristics provided, and 13 with no outcome measurement data.

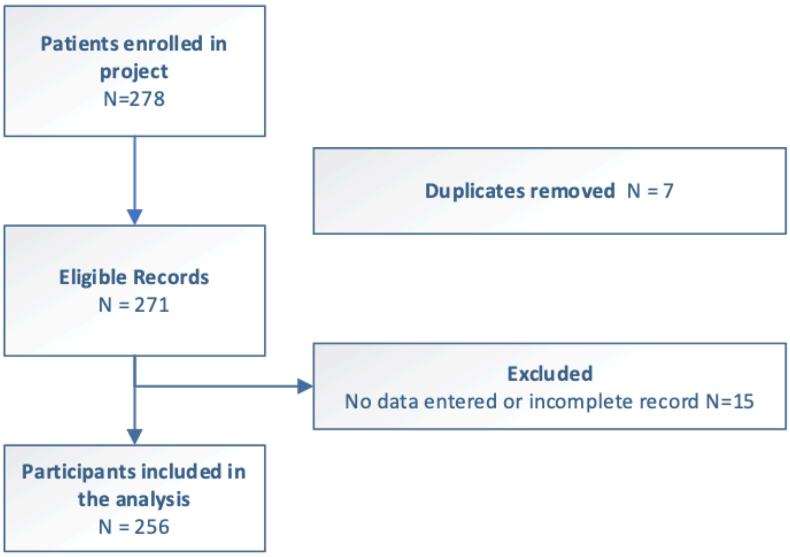

Figure 1. Participant flow diagram

Participants ranged from 11 to 89 years of age, with a mean age of 42 years (SD=17.3). The majority of responders were female (N=148, 57.8%) and based in Auckland (N=198 77.3%).

As data was not linked between the rehabilitation service patient management system and self-reported outcomes in ZEDOC, there was no data available on pre-injury work status, severity of TBI (mild vs moderate) prior TBI history, additional injuries sustained at the time of accident or other medical comorbidities. This precluded completion of some of the planned statistical analysis. Explorations to look at feasibility of linking the datasets and extracting information retrospectively were considered too time consuming and would require an additional budget. For example, it took 10 hours of researcher and ABI staff time to simply link participants between the two datasets. A manual process to review individual records and extract the required information would require a minimum of 30 minutes per participant. There was no funding available to enable completion of this work.

Completion of assessments on the platform

There were 15 people (9%) who reported needing help with completing their assessments on the platform. There were also comments from others that the measures didn't capture some difficulties they were experiencing such as feeling overly emotional, difficulties multi-tasking or ringing in the ears. One participant stated that they wanted to discuss the context and reason the questions were being asked. Another participant noted the impact of additional life stresses on their recovery such as selling their house.

Table 1 outlines the number of self-reported assessments completed at each monthly follow up time point. It was not clear whether the number of assessments completed was due to people no longer choosing to complete the outcome measures or whether they had been discharged from the service pending completion of the outcome measure. The current analysis was not able to establish the number of appointments before discharge due to difficulties in getting discharge dates added to the record. In future studies the discharge date could be used to determine proportion of assessments completed for duration of treatment provided.

Table 1. Number of participants completing each of the assessments at each assessment time point

	Month 1 (on admission)	Month 2	Month 3	Month 4	Month 5	Month 6
BIST	197	118	61	30	16	5
EQ5D	201	112	55	24	15	-
GAD-7	47	29	15	10	5	-
PHQ-9	12	7	2	1	1	-

The aim was to have 256 entries for BIST and EQ-5D-5L, whereas other measures (PHQ-9 and GAD-7) were to be activated based on individual patient relevance. Participants completed on average two assessment time points ranging between 1 and 6 assessments. There were N=79 who only completed one BIST assessment on admission. Males formed only 38.1% of participants who completed a follow up assessment.

Symptom Profile (BIST)

BIST data is only presented for clients completing this outcome measure before it was updated to a new version (change of wording for two items) in May 2022. Participants reported a mean BIST total symptom score of 69.7 (SD 36.0) and mean impact score of 48.7 (SD= 25.3) on admission to the service. Outliers were not removed from the analysis to reflect the full variation of people presenting to concussion services. Those with low total scores reported symptoms including headache and dizziness. There were no significant correlations between age and total symptom or impact scores on the BIST. The BIST median total score on admission (Median = 75.00) which was far higher than the median BIST total score found in the New Zealand general population of N= 23.00 (Shaikh, Tokhi et al. 2022). Scores on the BIST components are shown in Table 2.

Paired samples t-tests were used to make comparisons on each of the BIST component and total symptom and impact scores pre and post service delivery as shown in Table 2. The discharge scores were significantly lower than admission scores across all components and total scores. This indicates that clients improved throughout the duration of the service.

Table 2. BIST Scores on admission and completion of the ABI Rehabilitation Concussion Service for participants with two or more BIST assessments

	On Admission to ABI Rehabilitation			**Final Score**			**Test of Difference for Total Sample**	**95% Confidence Intervals**
	Males Mean (SD) N=88	**Females Mean (SD) N=109**	**Total Mean (SD) N=197**	**Males Mean (SD) N=45**	**Females Mean (SD) N=73**	**Total Mean (SD) N=118**		
BIST Physical Component Score	13.9 (8.6)	19.2 (9.1)	16.8 (9.2)	10.4 (8.8)	13.9 (8.7)	12.6 (8.8)	t = 6.2, p<0.001	3.1-6.0
BIST Vestibular-ocular Component Score	10.4 (8.5)	15.0 (10.0)	12.9 (9.6)	7.2 (8.1)	10.2 (9.8)	9.0 (9.3)	t=6.0, p<0.001	3.1-6.2
BIST Cognitive	16.9 (10.6)	21.6 (11.0)	19.5 (11.0)	10.6 (9.0)	15.6 (11.4)	13.7 (10.8)	t=7.1, p<0.001	4.4-7.7

Component Score								
BIST Total Symptom Score	59.4 (33.2)	78.0 (36.2)	69.7 (36.0)	40.1 (34.1)	55.3 (37.9)	49.5 (37.1)	t=6.8, p<0.001	14.1-25.9
BIST Impact Score	42.9 (25.6)	53.4 (24.1)	48.7 (25.3)	18.9 (20.9)	32.2 (28.9)	27.1 (26.8)	t=9.7, p<0.001	18.6-28.2

Participants who were referred on to Training for Independence or Psychological Service contracts had significantly higher BIST total scores on admission to the service (Mean = 86.6, SD 33.2) than those who were not (Mean=64.8, SD 35.4), t=3.6, p<0.001. Those who were referred to other ACC contracts had significantly higher final total scores (Mean 77.11 SD 37.6) on the BIST than those who were discharged following concussion services (Mean 44.30, SD 27.9). Data was not available to identify if those with high BIST scores on admission, those referred by the hospital or those with moderate injuries had a higher symptom burden or took longer in service. Data on pre-injury employment and return to work was not available within the ZEDOC system. This was a clear limitation of the project.

Whilst individual injury and personal history data were available in the ABI client management system, due to the decision not to link the two systems this information was not available to identify the factors influencing degree of individual change on the four outcome measures e.g., simple vs complex injuries, comorbidities, mood disturbance, time from injury to service, baseline scores, gender and ethnicity using regression analysis.

Health Status (EQ-5D)

The health status rating of participants on a 0-100 VAS scale significantly improved between admission and final scores as shown in Table 3. Additionally, there were significant improvements from admission to final score on the domains of usual activities, pain/discomfort and anxiety/depression. There were no differences in the components of mobility and self-care. This is likely to reflect that 82% and 91% respectively reported no or slight problems in these domains on admission to the service.

Table 3. EQ-5D responses on admission and completion of the ABI Concussion Service for participants with two or more EQ-5D assessments

Dimension	**On Admission N=266**	**On Completion of Concussion service N=150**	**Test of difference**
Mobility N (%)			
No problems	149 (53.8)	100 (36.1)	397.0, p=0.06
Slight Problems	81 (28.2)	35 (12.6)	
Moderate problems	28 (10.1)	15 (5.4)	
Severe problems	7 (2.5)	0 (0.0)	
Unable to walk about	1 (0.4)	0 (0.0)	
Average rating	1.6	1.4	
Self-care N (%)			
No problems	200 (72.2)	127 (45.8)	204.5 p=0.08
Slight problems	52 (18.8)	14 (5.1)	
Moderate problems	14 (5.1)	9 (3.2)	
Severe problems	0 (0.0)	0 (0.0)	

Unable to wash or dress	0 (0.0)	0 (0.0)	
Average rating	1.3	1.2	
Usual Activities N (%)			4736.6 p<0.001
No problems	38 (13.7)	63 (22.7)	
Slight problems	91 (32.9)	43 (15.5)	
Moderate problems	96 (34.7)	36 (13.0)	
Severe problems	29 (10.5)	5 (1.8)	
Unable to do usual activities	12 (4.3)	3 (1.1)	
Average rating	2.6	1.9	
Pain-Discomfort N (%)			3072.0, p<0.001
No pain/discomfort	22 (7.9)	49 (17.7)	
Slight pain/discomfort	126 (45.5)	61 (22.0)	
Moderate pain/discomfort	92 (33.2)	34 (12.3)	
Severe pain/discomfort	25 (9.0)	5 (1.8)	
Extreme pain/discomfort	1 (0.4)	1 (0.4)	
Average rating	2.5	2.0	
Anxiety/depression N (%)			
Not anxious/depressed	89 (32.1)	66 (23.8)	2164.0, p=0.01
Slightly anxious/depressed	95 (34.3)	42 (15.2)	
Moderately anxious/depressed	59 (21.3)	38 (13.7)	
Severely anxious/depressed	19 (6.9)	3 (1.1)	
Extremely anxious/depressed	4 (1.4)	1 (0.4)	
Average rating	2.1	1.9	
VAS 0-100 rating Mean (SD)	63.9 20.4	74.2 (18.3)	T=-8.0 p<0.001

The BIST total symptom score was highly correlated with the BIST impact score (r=0.70). There was a significant but weak correlation with the EQ-5D VAS score (r-0.33) on admission.

Anxiety and Depression Measures (GAD-7 and PHQ-9)

Data are not presented for the GAD-7 or PHQ-9 as too few participants completed these measures (N=41 on admission and N=29 at follow up and N=12 on admission and N=6 at follow up respectively).

Overall evaluation of concussion service

Service evaluation data was only available for N=3 participants. All three would recommend the service to others. Comments included:

> “it was helpful having a one stop shop” (participant 1)
>
> “comprehensive wrap around service, providers talked to each other, so I did not have to keep repeating my story, rehab was tailored to me and they felt invested in my recovery” (participant 2)
>
> “easy effective and great communication” (participant 3)

Overall evaluation of digital platform

Acceptability

The digital care pathway had a lower uptake in males. Scores on the BIST were found to be higher on admission and on final score for females compared to males, however the degree of change between males and females was equivalent. We were unable to determine uptake by ethnicity. There was however good uptake across a very wide range of ages including a number of older adults. About one in ten agreed to take part in the pilot but did not complete the assessments.

Data management

The inability to link data with the patient management system created some significant challenges in monitoring clients during their journey and in conducting this analysis.

Data was extracted using four separate password protected excel databases (two databases each for Auckland and Wellington sites with data using original measures and following refinement of the platform). Merging of these databases was required for analysis.

Unique study IDs (unique identifiers across all sites) were not used so names were needed to identify people in the extraction and to enable datasets to be merged. (Similar numbers were used for the Auckland and Wellington cohorts meaning there were two people with the same study number once merged). This was another limitation of the project.

Ability of measures to detect clinical change

The BIST showed a significant treatment effect from admission to last completed assessment showing sensitivity of the assessment to measure change over time. A change in 10 points on the BIST is considered clinically meaningful change. An average of 20-point change in BIST scores was observed in this data.

The EQ-5D VAS also indicated sensitivity to change over time. However, there was limited ability of the 5 items of the EQ-5D to show a significant difference in scores on the mobility and self-care domains, where there was a degree of impairment indicated on admission. All average changes scores on the 5 items were less than 1.

Approximately 16.4% (n=42) who went on to receive additional services. In these cases, the BIST scores remained high suggesting appropriate rationale to move these clients onto a Training for Independence contract from the concussion service to facilitate recovery.

2. Anonymous qualitative interviews with team members

Ten of the 15 people involved in the operational working group over the course of the study reflected on their experiences of the pilot project. Interviews were conducted by two AUT researchers (Dr Jason Chua and Lara Wilson) independent to the project. Interviewers were audio-recorded, transcribed and de-identified. This enabled reflections to be open and honest. Key areas of reflection on the pilot study identified are presented below illustrated by direct quotes from participants. Overall, it was noted that the positive and negative reflections of the pilot were very consistent across all the interviews. All participants stated that there were valuable learnings from the pilot study and was felt to have been a worthwhile exercise.

> *"The preliminary data is not particularly great, but the learnings for why we got to that and what we could do to improve it is fantastic, so from that perspective, the trial been a success"*

Working style of the group

All those interviewed mentioned how much they valued and had a positive experience of the collaborative approach of the working group. A facilitator to this was how the project had been set up to have a co-design approach based on a clinical need. It was felt that this resulted in all parties seeing value in the work, being equally invested and contributed to high meeting attendance.

> *"Here's the problem, how do we develop a solution to address this problem and that for me made it a really positive experience and everyone was really committed to the project. We had astounding attendance at every meeting throughout the whole duration of the project, which I've never experienced before. I think people went above and beyond because they really valued the aim of the project and they enjoyed the collaborative nature of the project. And even though it didn't always go to plan, there was a collegial atmosphere where we could work through issues and people didn't feel afraid to raise things. So that for me made it really positive."*

A perceived facilitator of the collaborative working group dynamic was that everyone had clear roles and expertise that they brought to the group and that responsibilities were shared.

> *"definitely the, the collaboration, so working with multiple agencies, … all those agencies had similar amounts of input, like, it wasn't really clear that there was one leader, so everyone was contributing as equals… everyone was really confident to speak their mind. There definitely was no kind of hierarchy or status or lack of confidence about contributions being valuable"*

Many participants identified that having the four different parties in the pilot meant that various perspectives were covered and outcomes from the project were optimised.

> *"I think it was just really good having all of the different perspectives to keep the project moving together. It wouldn't have worked if we just had a meeting between [one party] and ourselves, for example, because you needed the whole group there to get the different perspectives."*

Use of the test and learn approach and response to feedback

In addition to the co-design approach to developing the digital care pathway, there was agreement from participants that the ability to test and learn enabled more to be gained from the project than by implementing a fixed solution. The test and learn approach enabled ability to change, to review the changes and to see if further refinements had been effective or an alternative approach needed.

> *"We decided that we would work on a test and learn approach, so anything that wasn't quite working for the ABI team, or the ACC team...and find a way that we could make the project better, so that it was better for the patients who were responding to the questionnaires, or better for the clinicians who are needing to use ZEDOC to collect the outcomes, or better for ACC, when they're actually ingesting the data. So, we collectively, brought up issues every two weeks when we met and then found ways to make changes."*

The willingness of the working group members to connect with and listen to feedback from clinicians within the service was perceived to be a strength of the pilot.

> *"The Clinician team… have been really open to taking on board any kind of feedback or insights that we were able to give them that would make it easier for our clinicians to use it. So that's been really successful.*

However, several participants reflected that engagement with clinical users could have been enhanced throughout duration of the project

> *"Having two cohorts of meetings would be ideal. You have the people who understand the direction, the vision, and how they want to achieve this. So understanding the big picture, point A to point B and the journey, how we're going to get to point B, that's good. Having that is very important. But that needs to diffuse downstream towards the frontline workers. They need to understand… why they're doing these things, what they're trying to achieve as an organization overall and then adapt to that software and then use it."*

Participants described that identified changes in the technology were often able to be fixed quickly and easily, yet others took much longer and were more challenging to navigate and resolve e.g. privacy aspects critical yet took time to resolve.

> "*I would have liked things to have been a bit faster, but in saying that though… some of the changes; that I think required sort of like [technical] changes, which do take time."*

Communication was often reported to be good during the study although several participants noted one occasion where there was a misunderstanding between the working group and the recruitment sites.

> *"We don't know what happened there… Wellington thought that the project had stopped. And so didn't recruit for a month, and so we lost potentially up to 50 clients. So obviously there was a communication breakdown there"*

Ease of use of the platform for clients and clinicians

One of the barriers to clinical utility of the digital platform was that clients sometimes found the system difficult to use.

> *"A lot of people struggled to use the system and a lot of people indicated that they needed help to use the system, more than I expected"*

A further challenge...was the process of obtaining client consent to use their data as part of the pilot study. The process was felt to be too long and complicated affecting patient uptake and interest.

> *"Just reflecting back around consenting clients. I think that the consent process probably got a little bit out of control at one point with additional requirements based on ACC's view, because really, this was really a quality improvement project"*

Another participant stated;

> *"If clients are not able to negotiate the consent process, then some things just won't get followed up. Because hey, it's too hard. And I've got enough hard stuff going on..."*

The ‘who, how and timing’ of being offered to be part of a pilot study was also noted to be an important consideration.

> *“I think it's unfair on administrative staff to be asked to try and explain something to clients who have just had a brain injury, and they're symptomatic, and overwhelmed”*

Participants reflected that another clinical utility issue was regarding the frequency of administration of the outcome measures. Monthly follow up assessments were felt to be too burdensome for participants.

> *“Monthly administration of questionnaires was too frequent, especially when we have patients who are cognitively impaired, photosensitive and prone to headaches, and screen time should be minimized. To implement a digital platform that requires them to look on their phone was a bit difficult”*

A further challenge with the project was that clinicians did not routinely discharge patients from the system at end of treatment, so patients kept getting reminders to fill in outcome measures every month. This was picked up centrally so could be managed to prevent this being perceived badly by patients as part of the pilot but may need to be set up differently in the future.

> *“So I think that in terms of the platform, it might have been better to have a solution around the discharges. Basically, the clinician has been discharging the clients off the off the platform, as they just keep being sent surveys and of course, they just ignored them.*”

The difficulties in use of the system meant that over time, clinical staff stopped engaging with the system.

> *“some staff [clinicians] are very determined to make things work and give it a try and follow the process...and are quite on board with technology, others are not just like, oh, this has just taken me so much longer, It's giving me a headache, my clients don't even want to do it, so why am I doing it?…’ they sort of tried, it didn't work. They got bored. They didn't engage with it anymore”*

However, the clinicians did feedback that having a point of contact to go to with technical queries was found to be valuable.

> *“So it was very helpful to have someone, have a point of contact to problem solve”*

Integrated IT systems

One of the biggest barriers to uptake by clinicians was that the platform was not linked to the client management system and that it was challenging for clinicians to extract clinical information when they needed.

> *“One of the negatives was because it was a completely standalone system. A lot of the clinicians found, they were slightly removed from the client's scores and experiences. And unless they were logging into the platform, before they went and saw the client for the next session, they would be none the wiser what their scores were... It doesn't talk to our client management system. So it doesn't pop up when the clinician logs in. I was really saddened,*

> *but not hugely surprised when I found out that some of the clinicians were not checking the client scores before they went out just because it hadn't been front of mind to log into the separate platform"*

The lack of linkage between the digital platform and the client management system also caused difficulties in looking at the data.

> *"At the start, there was an agreement that we wanted to look at a whole lot of variables like 'Does someone have dual diagnosis? or did they have physical injuries as well? or did they have a history of brain injury?' So we were collecting a lot of that stuff in the background as well and I don't think anyone's pulled that out and had a look at it yet."*

Use of technology to assess outcomes

Participants stated that whilst they embraced exploring how technology could assist with measuring outcomes following brain injury, they added that this brought with it unique challenges in the brain injury population.

> *"People with brain injuries can have reduced screen tolerance. And so asking them to fill in questionnaires online. It's not always a happy marriage."*

Another participant said;

> *"We already know that if you've got a brain injury, you need to limit screen time. Your ability to concentrate and use screens is not necessarily a good thing for you to be doing at length. But we also found that although the setup platform was fantastic, that could be used on a mobile phone, a person with a brain injury going into it and scrolling up through a phone and being asked to rank choices and answers can be really can be really fatiguing. And this likely contributed to some reasons why people didn't participate"*

Choice of outcome measures used

Participants also noted that measuring outcomes is difficult in the context of a brain injury and that getting it right was always going to be challenging. The choice of outcome measures used were described as being a critical component by the majority of participants, although initially this wasn't the main focus of the pilot.

> *"but I think the biggest learning is ...an outcome measure which providers can see as benefiting the client, and the client also sees the benefit for them...It's one of the most important things, because otherwise you're not going to get compliance"*

The choice of one of the outcome measures meant that some clinicians did not see the clinical value of measuring the outcome.

> *"Some of the outcome measures we trialled... they don't really capture what we were wanting. The EQ-5D, really measures people's general health and wellbeing, but that can be affected by so many different things. We had clients who were maybe not progressing, but maybe it was just because they were having a bad time, it didn't have anything to do with the concussion ... so some of those outcome measures that we had originally thought could be useful to capture...weren't that useful."*

Another participant added that the EQ-5D was better at measuring long term changes in health not short-term changes that would be expected in the context of a concussion service.

“The EQ-5D in my view works best when it is a measure taken over time. And so sometimes with short term services, it won't be long enough.”

Two core measures and two optional measures were set up within the digital care pathway. This was to enable clinicians to assign additional measures for anxiety and depression that were relevant to the individual. Participants reflected optional measures were not used by clinicians as anticipated. This was likely due to few people meeting criteria for these measures to be used.

“We had we set-up the platform so that there were core measures to try and keep it simple that would be relevant for every patient coming through the service. ..., very few people used those additional measures”

Influence of the external context on the pilot study

The pilot project did not meet it’s the planned recruitment target of N=1000 patients over the course of 12 months. Participants identified a number of contextual factors that may have influenced this in addition to those raised above.

The COVID-19 pandemic where lockdowns were in place presented a significant challenge. For example, when patients were experiencing challenges in using the system staff were not able to provide the additional support that they normally would if they were seeing people in-person.

“if they could go and see their patients and face to face, we can bring an iPad with you and log into the specific questionnaire with your patient… and you can do it with them. Just right, then and there, that was taken on quite well, but because of COVID they couldn't do it.”

The COVID-19 pandemic also placed an additional burden on clinical staff making it more challenging to implement and test a new system.

“The staff were very good in terms of buy-in but their ability to do this in a COVID environment, was, a factor with the mental fatigue that our own staff experienced”

A further potential reason for a lower uptake of participants was the number of other improvement projects in brain injury that were simultaneously underway. Whilst this enabled clinicians to see how different initiatives may come together in the end, this placed an additional burden on clinicians who were already struggling with managing clinical workloads in the context of the Covid-19 pandemic

“We just felt that our therapists were overloaded with projects and different things and lots of data. So there was a bit of a bit of burnout there really about, let's just streamline the admin tasks and go back to you know, what's absolutely necessary for us to provide a good service”

Change in working group membership over time

There were a number of personnel changes throughout the duration of the project which disrupted the flow of the pilot and meant it was hard for new members to understand the rationales and decisions for why certain aspects of the platform were set up the way they were. Participants who had been on the working group from conception noted that expectations and motivations for the project (scope creep) seemed to shift over time as a result.

"so the motivations for the project changed along the way, and so we did adapt to suit that but how the project was set up initially wasn't what the current project owners envisage the project to be. And so having that more clearly documented as well, would be good to keep everyone on track"

New members coming on board was felt to disrupt the flow of the project. This related to handovers from outgoing to incoming staff which may have meant the understanding of what the pilot was trying to achieve differed.

"though there's been some change from the ACC team, it takes a while to get back into that rhythm when you've got new people coming on board. So I think just having that real stability of the team is another really valuable concept. It also felt like actually, the goalposts had changed a little bit, from the original as well."

Uncertainty about what's next

Several participants raised that they wanted to know what was going to happen next as a result of the pilot, particularly given so much time and effort had been invested into the work. As ACC have a range of outcome projects underway, it was unclear what the next steps were at the completion of the pilot.

"It's like, we've all kind of put lots of love and effort into it, but it's like, you know, how is that going to translate into the future? And, and how, and how will we get the feedback?

Irrespective, a key benefit highlighted from the pilot was that clinical staff were more consistent in their consideration and measurement of key outcomes.

"I think one of the good things that have come out, is we've gotten a lot better at being consistent, and our use of baseline and outcome measures so that's really good."

3. Organisational reflections and learnings from the project

ABI Perspective

Collecting outcome measures as a method to understand the results and changes following a rehabilitation intervention is important to ABI. For this reason, ABI was a highly engaged partner in this project. Using an innovative digital platform for clients to report their progress was an exciting opportunity.

Highlights:

- Project was initiated with clear collaborative intent between all parties
- Using innovative technology
- Client centred approaches
- Test and learn approach

Challenges

- Change in ACC personnel throughout project
- Technology options not interfacing with ABI's Client Management System. This contributed to difficulties engaging ABI clinicians at times. ZEDOC was another separate system for clinicians to log into which they had not embedded as standard process. This also meant the client responses in ZEDOC were not front of mind for the clinician.
- Recruitment approaches – struggling to recruit clients, i.e., those who wanted to participate and then those who could successfully progress through the consent process.
- Feedback from clients – high amount of screen time required and frequency of response requests – clients often withdrew after an initial response due to the nature of the brain injury symptoms they were experiencing (which meant screen time wasn't good for them) and the repetition of the questionnaires (feeling overly bothered by the same questions being repeated and sometimes feeling they had already answered them)
- Pandemic – rehabilitation service delivery changed during this project because of the impact of COVID-19 and multiple lockdowns. Telehealth sessions and using technology became standard and the impact of this was commented on by many clinicians. It also must be acknowledged that the pandemic has had a significant impact on workforce resilience and coping. Many of the clinicians had periods of being unwell, also supporting whānau members and their clients through the pandemic. Many commented they did not have the head space to fully engage with the project.

ABI Clinician Feedback

Project management: ABI is fortunate to have a Service Development Manager who has been engaged in this project from initial stages and has been part of each project meeting and development of project plan, written material, communications, contract review and so on. Many organisations even the same size or larger than ABI do not have this type of role, so it would be difficult for them to commit to this type of project or even implementing a technology platform such as ZEDOC to collect PROMs. Smaller organisations may struggle with resourcing this within their organisation, however, may be delivering high quality rehabilitation services and committed to collecting outcome measures.

Technology: Should ACC decide to suggest a technology platform to collect outcome measures in the future, consideration must be given to the impact on the rehabilitation organisation in time, cost and resourcing to embed this within the organisation. Many organisations may have considered, trialled, or failed fast in this in the past and determined the cost and resourcing too great to absorb as a business cost.

Consideration must be given to how easily and cost effectively a technology platform can integrate with the existing client/patient management systems in order to remove administrative the burden for both administration and clinical team members. Key feedback from clinicians and managers was that if the system does not integrate it loses visibility and just becomes another task to do in an already busy day that has high technology use (remote working, telehealth, internet access, multiple logons for security management).

Multiple logons and password management for different platforms are frustrating and time consuming for the team and they all said have one log on and integration would have made their case load management incorporating the ZEDOC dashboard with outcomes responses far more user friendly and visible. Clinicians want to do clinical work, not admin and so in order for a system to be used well it must be efficient, easy and integrate with the system that holds client notes and where they manage their caseload from.

The ZEDOC platform encouraged clients to report their outcome measures completely separately to the sessions the client was having with their clinician. Client led interventions are desirable, however it was noted there were several downsides to this. These being:

- A disconnect with clinicians not having oversight of notifications being pushed to client and entries responded to by clients. Clinicians had no automatic oversight over the responses the client was entering or even if they were responding or not. They were able to log onto ZEDOC to see if they were completed but as noted above due to the extra steps logging on outside of the client management system, this didn't occur naturally as part of their day-to-day practice. Many clinicians noted they had forgot to check client's responses before they saw the client in the session so felt like they were not using the responses to help lead the rehabilitation session. In contrast when the clinician led the completion of the PROMs, they were able to specifically talk about areas that were either high or low or change from beginning.
- The monthly push notification prompted clients to report on their symptoms – clinicians felt this was far too frequent to be helpful to recovery. Symptom focus is not best practice and was incongruent with the focus on functional improvement.
- Reliability on client led responses when cognitive impairment, fatigue, sensory issues are main impairment from the injury (i.e. TBI). This was another demanding activity for clients who were already struggling with managing day to day tasks during a pandemic. Many could not prioritize this and provided strong feedback that this was a task they did not have the head space, energy or motivation to complete. It is important to acknowledge this going forward for The Clinician and ACC as valuable voice of those clients in this project. The mechanism and timing of reporting was not positive for many clients because of the cognitive demand required.
- Clients may have been unsure why they were being asked the same questions every month.

BIST and EQ-5D

As discussed above, the frequency of the response requests was felt by clinicians to be too often. The clinicians felt the BIST monthly reporting resulted in too much of a focus on symptom reporting. The ABI team across all levels (individual clinicians, managers and project members) felt the EQ-5D is not appropriate for short term conditions (recovery in less than 6 months). It was hard to determine if the responses were due to concussion/TBI injury recovery or were influenced other factors going on for client during the concussion recovery for example – response to COVID-19 Pandemic, economic instability, contracting COVID-19/long COVID, other injuries and so on.

Other Measures

Where ABI clinicians had concerns about the psychological wellbeing of their clients they could access the GAD-7 and PHQ-9 measures. Unfortunately, as the clinicians were not highly engaged with the project, they didn't maximise this opportunity. They clinically knew which clients were struggling and would escalate support (further sessions, psychology input, medical assessment or GP input) but it is unclear if this correlated with any clients who had triggered a response that would result in them being put on the ZEDOC mental health tracks for additional measures.

The Clinician perspective

The Clinician enjoyed the partnership approach taken throughout this pilot between ACC, ABI, AUT and The Clinician. We were able to take away many valuable insights, while getting the opportunity to test-and-learn from new requirements as we endeavoured to improve the implementation for all. Key learnings and insights are outlined below.

(1) Requirements gathering should balance all stakeholder requirements.

The pilot set up was funder/management-driven. Throughout the pilot, we also took on feedback from the platform users (ABI keyworkers and admins). This drove new and often contrasting requirements from the initial set-up. Having an agile approach to project delivery and a highly configurable platform meant we were able to accommodate the changing requirements. We learnt that while possible, some requirements that were particularly related to architectural constraints were much more difficult to change within a live project and this emphasised the importance of balancing the requirements of all key stakeholders from the beginning. For example, in the pilot set-up phase, the requirements were for there to be two projects; one for the Auckland ABI clinic and the other for the Wellington ABI clinic. All keyworkers within the Auckland project would be able to see all Auckland patients and not Wellington patients, while all keyworkers within the Wellington project would be able to see all Wellington patients and not Auckland patients. Throughout the pilot and as keyworkers used the platform, we received feedback that the keyworkers wished to only be able to see their own allocated patients. We made this possible with reconfiguration work but having had this input from the beginning would have benefited the project greatly and had a more positive impact on the keyworkers from the beginning.

(2) Continuity of stakeholder and pilot objectives.

The pilot evaluation objectives were not clearly documented at the beginning of the pilot and were not reflected well enough in the project set-up. The pilot also saw a change in personnel from key stakeholders. Midway through the pilot, there was misalignment between all parties on how the pilot would be evaluated and what the next steps were. As the pilot evaluation plan was re-established between the stakeholders, we were met with a challenge that the initial project set-up was not completely aligned with this evaluation approach. For example, the platform had not been set up to record patient NHI/ACC numbers as a mandatory field, as it wasn't expected of ABI keyworkers to always have this available to them. As the evaluation of the data commenced, while ZEDOC assigned a unique study number for each patient to assist in the data analysis and there were thoughts that in hindsight, it would have been better to collect an NHI/ACC numbers as mandatory or set up the projects to have another common identifier. Obviously, in an integrated solution this wouldn't be a problem as there needs to be a common identifier to match records across the systems. Clear project documentation and more comprehensive agreements on pilot milestones, implementation approach and objectives would make for a more successful pilot. Adopting the test-and-learn approach midway through the pilot proved beneficial for all stakeholders to see how feedback could be incorporated into the platform to improve the user experience, however for a test-and-learn approach to really have impact, this needs to be accounted for from the beginning and contracted so that project resourcing matches the implementation approach. Both The Clinician and ABI provided substantial resources free of charge to accommodate reconfigurations during the test-and-learn phase. But without clear project objective documentation, there wasn’t a clear way for the learnings to be aligned with the final data analysis objectives.

(3) Too many changes for keyworkers can cause poorer adoption.

As this pilot was initially set up to meet funder/management driven requirements, we learnt how this affected adoption by the end-users. Not only was the use of a digital platform new to many of the keyworkers, but the outcomes measures used and the consent processes that arose throughout the project were new. While most users gave feedback that the platform was easy to use, others found that using a laptop for a “pen and paper assessment” was a hassle which highlighted an entrained opposition to technology. We found it was particularly important to spend time educating keyworkers on the benefits of collecting data electronically using the ZEDOC Platform and also providing quick tips (such as bookmarking the ZEDOC Provider Portal tab in their google search bar), to reduce any burden of using technology on those that have a strong preference for pen and paper. Education sessions and 1 pagers proved very useful for this. Keyworkers had also been originally using the paper version of the Rivermead assessment with patients, and as this pilot went live, were required to use new instruments, including the BIST tool. Combining the adoption of completely new tools and processes with the height of the COVID-19 pandemic, we could see how important it was to manage changes in the right way. This again, links back to the importance of including keyworkers in the requirements gathering and set up phase to manage the transition to change in an appropriate way.

(4) Adapting our platform to different user and patient cohorts

We gained valuable feedback from clinicians as they were required to work from home, and this also highlighted the importance of hardware devices for the ABI clinicians when working from home. The devices ABI clinicians used were small tablets/laptops and many clinicians found this difficult to work off when using the ZEDOC Provider Portal. We have since taken on UI feedback to improve usability on various device sizes.

Throughout the project, the benefits of our platform were emphasized for the Concussion cohort (ability to switch to dark mode, change font size), and likewise for the ABI clinicians. We also needed to implement shorter versions of the PROMs questionnaires as prolonged screen time was challenging for the Concussion cohort. We also gathered learnings on the frequency of milestones for this patient cohort, and in future would balance better the need for as much data as possible (driven by the pilot stakeholders), vs the tolerance of patients. We had implemented more frequent milestones to achieve greater data collection but will reduce these next time for the benefit of the patients.

(5) Highlighting the importance of integrating ZEDOC with other systems

As this was a pilot project with limited resources and patient numbers, electronic data exchange between ZEDOC and ABI's client management system was not in scope. However, in almost all projects we run around the world with high patient numbers integrations with the other health information systems (e.g. PAS, EMR, PMS) becomes critical to be able to run these projects at scale and with high user adoption. This is a key learning we consistently get from our many implementations which should inform ACC and other organisations wanting to implement digital health projects for including integrations as a mandatory requirement.

The Clinician Feedback from Key Workers

Our team has also conducted interviews with ABI key workers at the beginning of the project where the general aims and direction of the project was clearer. Although not an independent evaluation we still believe there's value in sharing a summary of our findings which is in alignment with the independent review results. These were conducted and reported on 6/9/2021, 31/8/2-21 and 6/12/2021).

- During COVID, it is appreciated that the PROMs can be collected online rather than on paper.
- There was some hesitance in the beginning due to new technology and new questionnaires as not all key workers are tech-savvy. Some saw it as an added layer of complexity adapting to the electronic platform and continued to use paper forms. One key worker from Wellington worried that clients wouldn't fill out surveys but then client uptake was higher than expected and they found it relatively easy to engage with the platform.
- It saved a large chunk of time which otherwise was spent at the start of the session to understand clients' problems. They also found out that very few clients have filled out surveys but not submitted, or only filled out half of it and on the whole client responses were very good. They also found the approach more environmentally friendly.
- Some clients welcomed the technology, and some found it disruptive. This is dependent on the severity of their concussion.
- Key workers are now able to access client information quickly anytime, anywhere with the internet. They also enjoyed the ability to send out the questionnaires before the appointments.
- Key Workers appreciated the follow-ups are all done automatically without manual intervention. They were able to track previous scores/results easily and use them as part of the appointment/communication positively.
- However, they were not fully informed about the discharge track to send out ABI Experience Survey - there was some knowledge gap.
- The Clinician team was always available for problem solving and training and they were happy that they can reach out to us if they need help.
- On the whole the experience has been positive and the time saving has been really valuable. They also commented that this also gives the patient autonomy to be able to complete the PROMs from the comfort of their home with the help of a family member/caregiver. Having the feedback there gives them a heads-up about a patient before the appointment, particularly for the mental health problems.
- Some clients respond quite early and can look at it before the appointment and take notes. This also acts like a baseline prior to the appointment, so if the client has different symptoms during the appointment, it's useful to have that previous time

point to refer back to and see the change in symptoms between then and during the appointment.

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ACC's perspective

ACC had two objectives for this concussion pilot.

1. Primary objective: Understand the feasibility of capturing health outcomes with a provider and third-party technology vendor.
2. Secondary objective: Understand the utility of the EQ-5D-5L as a health outcome measure for clients who have a mild TBI.

ACC made several key insights into the feasibility of capturing health outcomes from the concussion outcomes trial. Overall, capturing health outcomes is feasible but further consideration of the below insights would need to be accounted for in future projects to ensure maximum participation and value for ACC, providers and clients.

Recruitment and response rates in the pilot were lower than initially expected. This was likely due to number of factors including the overall design as well as external pressures (COVID, staffing) on the provider ABI.

ACC has several key insights into the feasibility of collecting health outcomes.

1. Impact on system requirements and user-experience on data collection.

The trial highlighted the importance of a seamless and administratively simple solution for all stakeholders. Providers reported it was difficult to navigate between two systems to enroll and manage clients on the pilot. Providers also fed back that they found it easier to complete baseline surveys however there were technical difficulties with follow-ups. It was more effortful to complete surveys because systems were not integrated. As a result, many important survey data points, including discharge surveys were not completed. This made it difficult to understand change in health status over time because of the concussion service.

2. EQ-5D-5L shows potential utility as a measure of wellbeing for the concussion cohort but is not entirely suitable.

There was consistent feedback from clinicians that the EQ-5D-5L was not meaningful to them or to the clients. However, results from the surveys did show the EQ-5D-5L was able to detect change in health status overall. Some of the domains (Mobility and Self-Care) had low scores and minimal change, indicating those domains may not be applicable to a client with a mild TBI. This could be expected given the nature of the condition. It is of interest that there were statistically significant improvements in the "Usual Activities" and "Pain Discomfort" domains, showing there may be some utility in using the tool as an overall wellbeing improvement measure.

The EQ-5D-5L scores from the data collected showed improvement in health status over time. Due to low response rates, particularly after 3-4 months, results were less reliable. This can be seen in Figure 3 below with a drop off in later surveys.

There was a significant but weak correlation between the BIST total symptom score with the EQ-5D-5L VAS score (r-0.33) on admission.

To our knowledge, there is no minimal clinically important difference (MCID) known for clients with a mTBI. This makes it difficult to interpret the effect of change in health status for this cohort of clients.

Overall, no significant inferences about the utility of the EQ-5D-5L data can be made from the trial due to lower-than-expected recruitment and response rates. The results are promising but further data is needed to understand utility of EQ-5D-5L for clients with a mTBI.

3. Data Analysis

It is important to identify appropriate data points at the start to ensure data analysis can be robust, consistent and meaningful. Choice of data points must be informed by a clear intention for use of the data- what is the purpose of collection? Data point choice must fit with privacy principles, incorporating privacy by design at the outset. Suitable identifiers must be chosen for ease of data matching.

4. Importance of applying an early continuous improvement focus

The pilot may have benefited from a continuous improvement focus from the outset of the trial. Recruitment and response rates were lower than expected. Changes were made to the trial after eight months to improve help to improve recruitment and consent processes. However, recruitment and response rates (and therefore learning from the trial) may have improved if changes were made earlier.

5. Number of surveys

Surveys were sent monthly to clients. There was feedback from clients that surveying was too frequent and some confusion as to why outcome measures were the same. This may have contributed to the drop off in surveys (See Figure 1 &2). Further consideration is needed to understand what onboarding information clients need and to balance the burden we place on the client to fill out surveys, whilst ensuring sufficient data is collected to inform our objectives.

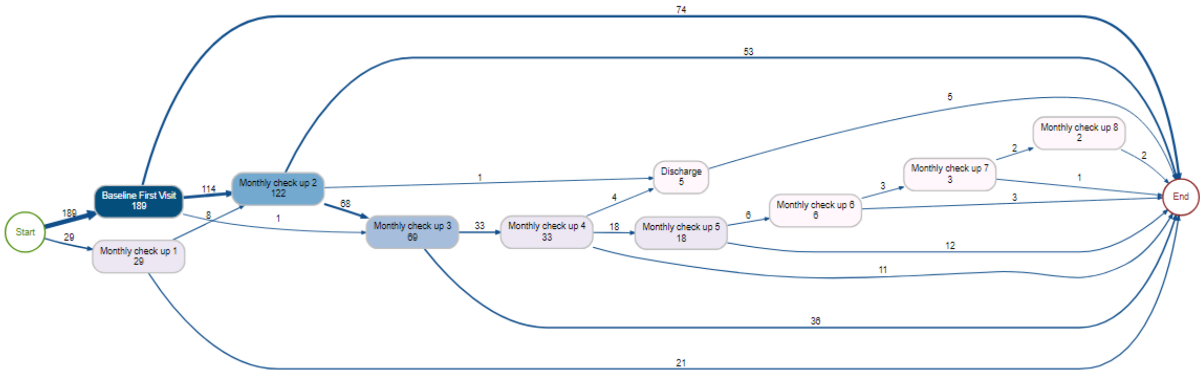

Figure 1: Client Journey (Project 1.0)

This diagram displays the flow of clients for project 1 and the participation rates for monthly check ins for the EQ-5D-5L survey. As seen from the diagram, 189 clients had a “baseline first visit” and 2 clients had up to 8 monthly check ups.

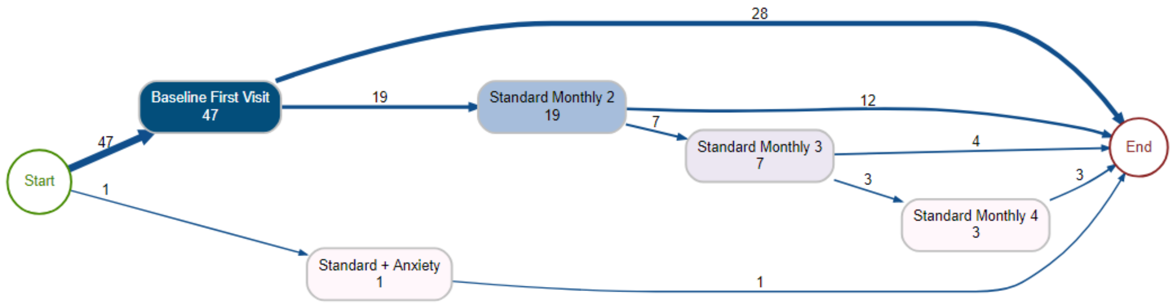

Figure 2: Client Journey (Project 2.0)

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This diagram displays the flow of clients for project 2 and the participation rates for monthly check-ins for the EQ-5D-5L survey. As seen from the diagram, 47 clients had a “baseline first visit” and 3 clients had up to 4 monthly check-ups. There are lower clients counts due to most of the clients being associated with project 1

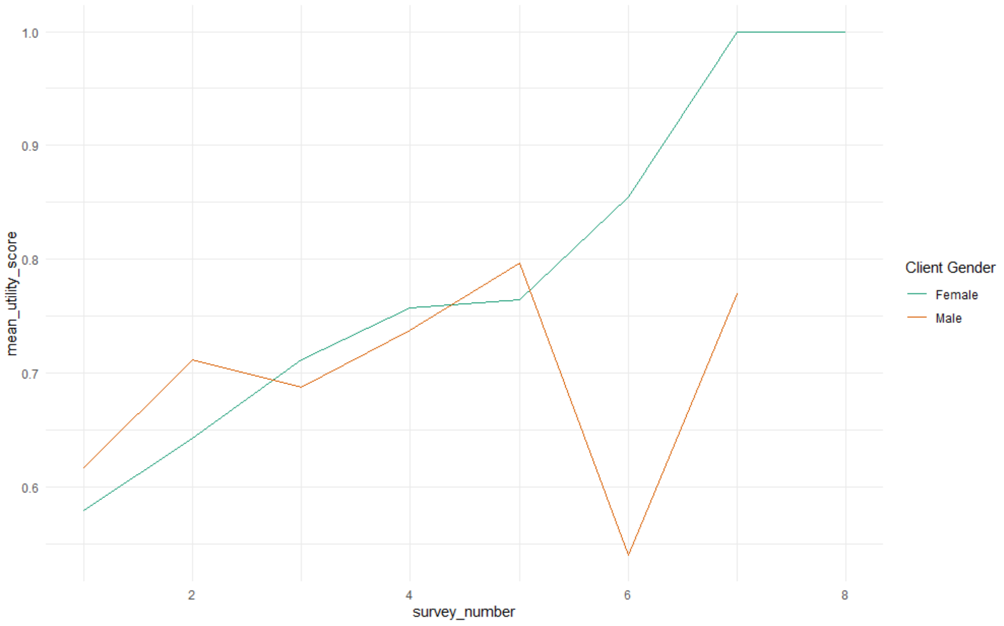

Figure 3: Mean utility score by gender

Figure 3: Project 1 mean utility score by gender over time for EQ-5D-5L responses. This was for clients across both sites (Wellington and Auckland). The 6th survey had a response from 4 females and 2 males. Therefore, the trend differences observed after 5th survey will be influenced significantly by lower sample sizes and not necessarily a reflection of actual gender differences for treatment or recovery.

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