

Understanding the needs of the “miserable minority”

Identifying gaps in the provision of information and support to people experiencing prolonged recovery after concussion and mild traumatic brain injury

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1. Describe the activity undertaken by your organization

Up to 20,000 Australians are hospitalised with a traumatic brain injury (TBI) each year (Helps, Henley & Harrison, 2008). Data suggests that the significant majority (as many as 85%) of this population are diagnosed with a mild traumatic brain injury (mTBI) or concussion. Most individuals with mTBI and concussion make a full and uneventful recovery (Carroll et al, 2004). However, there is a significant minority of people (10-15%) who do not recover within the expected timeframes. This “miserable minority” (an estimated 2,000 - 3,000 Australians every year) experience persistent physical, cognitive and/or behavioural difficulties (Ruff, Camenzuli & Mueller, 1996).

Brain Injury Australia has, through our regular contact with constituents, identified that the needs of the “miserable minority” are poorly addressed. This project aims to:

- Develop a rigorous analysis of the lived experience of people with a prolonged recovery following concussion and mTBI,
- Draw from this analysis and participants’ reflection on their individual experiences, what are the ‘unmet’ needs of people living with concussion and mTBI, and
- Use this new knowledge to guide Brain Injury Australia’s ILC activities.

Prior to the commencement of data collection, ethical approval for this research was obtained from the La Trobe University Human Ethics Committee (approval number: HEC17-086).

Project participants were drawn from: a call in Brain Injury Australia’s regular newsletter to our constituents; our telephone and email consultations; and the AFDO ILC Readiness project survey conducted in July 2017. Participants who registered interest were contacted by Brain Injury Australia with an Information

Statement and contact details for the lead researcher. Brain Injury Australia also offered participants a \$50 groceries voucher in recognition of their contribution.

Participants were asked to complete a brief background survey and participate in a single semi-structured phone interview. Interviews were conducted by phone between September-November 2017, and generally lasted between 30 and 60 minutes. Interviews explored participants' experiences of recovery, including services accessed and found helpful, as well as gaps around information, treatment and supports. The costs of care, lost productivity and quality of life impacts were also explored, as well as barriers to treatment, return-to-work, family/relationship functioning and social participation.

All interviews were digitally recorded with the permission of participants. Recordings were partially transcribed and listened to by the two researchers undertaking the project. Key issues raised by participants were coded to provide common themes.

2. What are the outcomes of the project?

Brain Injury Australia has identified people living with concussion and mTBI as a group for whom well-planned ILC-type activities can make a transformative difference. Comprising a large proportion of our constituents, these people may be invisible as they are either undiagnosed, suffer in silence, or part of a “hard-to-reach” group (or all three). A major barrier to our ILC activities is therefore understanding the unmet needs of this significant “miserable minority” and how best to reach them, and re-engage them with mainstream health and other services.

18 people with lived experience of concussion and mTBI took part in this study. One participant reported their own lived experience as the parent of a young child with mTBI (4 years old). 11 participants were female, and 7 were male. Adult participants ranged in age from 21-61 years. While most participants were from metropolitan areas, six were from rural and regional areas and highlighted the particular and significant challenges for those living outside the major cities. Table 2-1 provides an overview of participant demographic details.

Participants described that they had sustained their injuries through a range of ways, including falls, car and bicycle accidents, sporting accidents and items falling on their heads. Five participants reported that they had sustained more than one injury. All participants reported that they were experiencing at least one ongoing symptom related to their injury. Commonly, these symptoms spanned several domains, and included cognitive, behavioural, physical and psychosocial changes.

Interview data reflected the challenges experienced by participants in accessing timely, specialist and evidence-based information about their injury and appropriate support. Participants’ experiences reflected a clear distinction between those who had been able to successfully navigate the relevant service sectors (medical, health, disability) in order to access the support they required and those who had not been able to do so. This distinction was also evident in participants’ description of the long-term impacts of the injury in many areas of their life.

Table 2.1 Participant Demographic Details (n=18)

		<i>n</i>
Gender	Female	11
	Male	7
Age	>18	1
	18-30	1
	30-45	7
	45-60	7
	60+	2
Injury	Concussion	7
	Mild TBI	11
Location	Metropolitan	12
	Rural	6
Year of most recent injury	2017	5
	2016	5
	2015	1
	2014	3
	2010-2013	2
	>2010	2
Extent of current recovery	<i>Fully recovered</i>	1
	<i>Largely recovered</i>	9
	<i>Halfway recovered</i>	2
	<i>Somewhat recovered</i>	5
	<i>Not recovered</i>	1

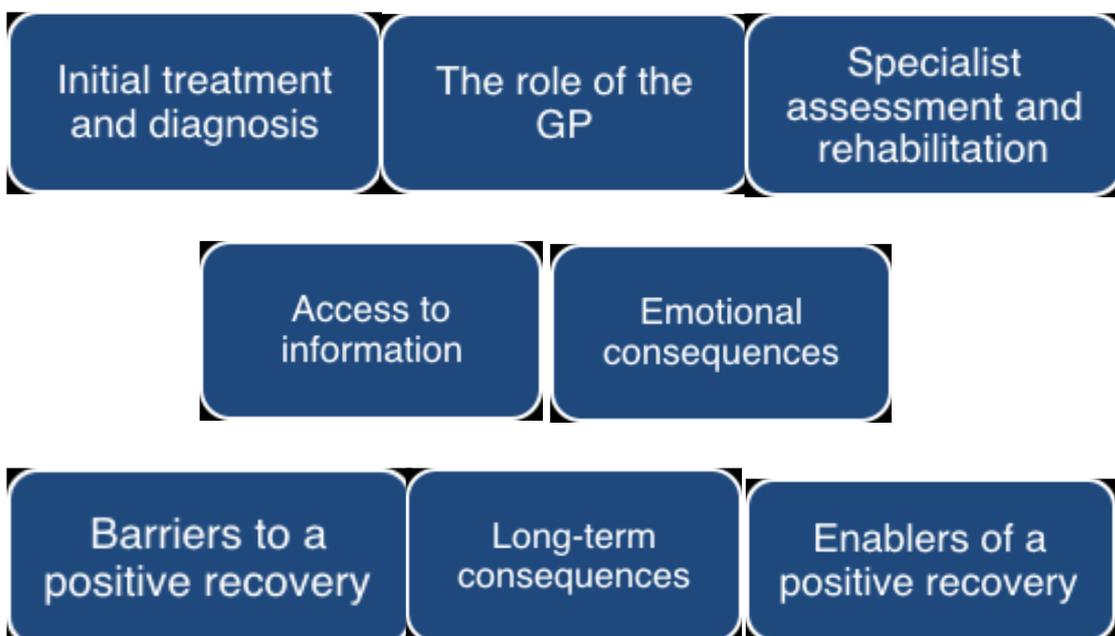
3. What did you learn from the project and how did it relate to the five ILC outcome areas?

This section of the report is divided into two parts. First, the overarching findings from this project are summarised. Next, the findings are applied to the five ILC outcome areas, and include a discussion of the unmet needs of this cohort.

3.1 What did we learn?

The data captured through the interview process coalesced around eight key themes which captured the lived experiences of the participants in this study. These themes represented participants' experiences of early treatment, factors that supported and hindered their recovery, through to the long-term consequences experienced by individuals as a result of their injury. These themes are presented in Figure 3-1 and summarised below.

Figure 3-1. Key themes



Theme One: Initial treatment and diagnosis

All participants sought medical assistance in the days or weeks following injury. Some (12/18) attended an emergency department at a local hospital, others (6/18) initially presented to their general practitioner. A small number of participants (2/18) were satisfied that their treating clinician had identified and diagnosed their injury and provided them with the appropriate treatment, referrals and guidance about management of their injury. For those participants who attended hospital, the most common experience was that, while substantial attention was paid to their physical injuries, there was inadequate assessment of their brain injury. This was particularly the case when there were few signs of injury evident on their brain scan.

The majority of participants who had attended hospital (10/12) felt that they had been discharged too quickly. Some (6/12) reported that they were experiencing confusion and disorientation when they left the hospital. Many described that they had received little advice about what, if any, follow up they needed (10/12). Just over half (7/12) reported that they were unaware that they had sustained a brain injury upon leaving hospital. Many participants (8/12) described

“On the Friday night, my friends were concerned and they took me to emergency. They thought that my pupils were different sizes from each other, and they took me down to emergency but [the staff] rang someone and they said, ‘Oh no, she’s all right. Send her home’.”

“In hindsight, I wish I’d been in [hospital] longer. No-one even spoke to [us] about things like post-epilepsy and things like that. We literally just had to work it out for ourselves that I had a brain injury because everything was different.”

“The [hospital] gave me a sheet of information on concussion. “Read this and don’t drive until you recover and it would probably be a good idea to go see your doctor [in a few days] just to make sure that you’re okay.” It’s taken me more than six months to recover.”

“I was told I was fine to go and would be fine. Although I knew it wasn’t fine. I couldn’t remember anything.”

“I had a horrible experience with an emergency

that they felt they were on their own after leaving hospital and had to try and “work it out” themselves. Given their significant fatigue and cognitive changes, this was often a challenging and frustrating task.

Three participants reported that their practitioners were quick to identify and respond to their injuries and refer them to other practitioners and/or for further testing. The lived experiences of participants highlighted that, where participants were able to be connected to specialist services early, they were able to access treatment and support that assisted a positive recovery.

room doctor who said, “He’s fine. He’s just a baby who has had a sleep or has got a virus or something. And I need to tell you that this is an emergency room for emergency cases.”

“There was no follow up [from the acute hospital]. I actually don’t even think they told me to go to the GP, I just decided it was a good idea to go to the GP.”

“They just basically go, ‘No, no brain bleed, concussion. Time will heal,’ and then you’re out of their system and people are completely lost.”

Theme Two: The role of the GP

The rich data provided by participants highlighted the critical role played by their general practitioners (GPs) over the course of their recovery. Their GP was the initial point of contact after injury for participants, while others saw their GP after discharge from hospital. For all, their interactions with their GP significantly shaped the course of their journey after injury and their interaction with other brain injury and rehabilitation services. Many (12/18) reported their GP was a crucial point of access and referral - they identified and linked them with other services that supported their recovery (such as brain injury rehabilitation services, neurological physiotherapists or psychologists).

However, participants' experiences highlighted that GPs had diverse levels of knowledge about concussion and brain injury which were evident in the way that they engaged with their clients. Several participants (11/18) reported that their GPs appeared to have limited knowledge of concussion or brain injury. This resulted in confusing and sometimes inconsistent advice about what activities (such as driving, working, sports) they should (or should not) engage in, and how long their recovery would

"I did go to the GP the very next day and told them exactly what had happened and they just told me to come back in a week if nothing had changed. You've gone to the place where you think you should be able to get help and that's what they tell you. That was a reoccurring thing for me for quite a few months."

"The GP didn't tell me what to do and what not to do. I look back and that was really bad, and he had no idea."

"Doctors, they're in a tough spot. Trying to treat something when they don't know what it is."

"[My GP] really didn't know enough and I think he just referred me to someone else because he didn't know what to do with the situation, to be honest... they just don't know what to do with [us]."

"My GP was great and it was the combination of him and my physio... the physio said once he'd seen me and everything, he wrote to the GP and said, 'Look, her head's not right,' and the GP started 'skilling himself up', as he put it to me. He said he knew nothing about it but he found out."

take. Generally, in these cases, participants described that their GPs had also advised them “to rest”, often with little explanation of what “rest” meant in practice and how long their period of rest should continue.

“We got a time [to see the GP] immediately... she just ordered another barrage of tests. And then we worked out with her where we could go. Fortunately, she was aware of the brain trauma rehab group [locally]. We got in there.”

Theme Three: Specialist assessment and rehabilitation

Participants' experiences highlighted the importance of access to professionals with specialist knowledge and expertise specific to mTBI and concussion. Specialist practitioners were able to accurately identify and monitor brain injury-related symptoms and design individualised and evidence-based treatment regimes. However, participants' experience illustrated that specialist expertise was not always easy to access. Barriers included the availability of specialist services (particularly outside of major metropolitan areas), prioritisation criteria (which meant that individuals with "mild" injuries were a low priority for services) and the significant financial costs associated with some professionals, particularly for individuals who may have stopped working after the injury.

"I went to the brain injury clinic. I was so happy to be understood. They have a coordinated team. I see them all weekly. They work as a team and problem solve."

"The care and attention and support that I had through that [specialist brain injury] team, the monitoring, the expertise and the competency, I couldn't fault. I really couldn't fault".

"I think... how the system works is you need to tick a certain amount of boxes for them to see you and I didn't tick enough of those boxes. They're only interested in seeing the more [severe] cases."

"[Money] was one of the biggest things with trying to get to the rehab and that in the city..., and even the neurologist was like \$300 a session."

"I had a [neuropsychological] assessment done at some point, and didn't do particularly well. [My counsellor] did say, 'It would be really good to do another one 12 months after the injury,' but we were very broke at the time so I never got it done."

Theme Four: Access to information

Two-thirds of participants reported that they struggled to access information about their injuries and strategies to support their recovery. In the early phase after injury, access to information was hindered by injury-related symptoms (fatigue and difficulty reading/looking at screens meant that participants were unable to search effectively for information themselves) and meant that they were reliant on others to provide them with the information they required. This occurred for some, but not for others. Two participants noted that they were provided with written information about their injuries by the hospital at discharge but this information was not personalised and was not always useful to participants. Where participants were unable to access the information they required, they described that they had worked through the situation through a process of “trial and error” which they felt was less than ideal.

“I would like to be better informed on what’s going on in my head and why and how I can help it. What is out there to help support me?”

“The main thing is just getting information, and understanding what it was that was happening to me... getting an overall [picture] about the symptoms and what’s involved and what to expect. Getting a really clear view on that would have been really helpful because I was blind, I don’t really understand what’s happening to me, and no-one can really tell me.”

“[It would have been helpful to know] what supports can be put in place. The things like reducing your bills, the support through Centrelink. I kind of think GPs should have been able to give that information.”

“It’s really hard to find one convenient place to find all the information.”

“I would’ve liked to have known, “Okay, this is likely the projection your injury will take, the possible consequences.”

“Any kind of objective measures of improvement are good... [and] just explaining what the range of normal is, is good.”

Theme Five: Barriers to a positive recovery

Participants described a range of factors that acted as barriers to a positive recovery, including:

- a lack of knowledge and awareness of concussion (both from health and medical professionals, and among the general public), meaning that their needs were not readily identified or accommodated for,
- being advised that they should just "wait and see" (rather than engage in active treatment) and feeling that their optimal window for treatment had therefore been missed,
- alternatively, not being advised to gradually return to their prior activities and instead prematurely returning to (and struggling with) activities, including employment,
- being involved in legal and insurance processes, in which their individual circumstances and needs felt overlooked, and
- feeling excluded and misunderstood by others.

"I went back [to work] straight away and then I realised that I really shouldn't be there."

"The GP, she was great, but she was saying, "It's just a concussion. You'll be fine in six weeks." And six weeks went, and I'm still not right. Twelve weeks go by, "We'd better get you to a neuropsych[ologist] now," and I'm thinking, "Now? Now you're doing this?" So my first neuropsych appointment was something like four or five months after the injury, and it was only then we realised how serious it was."

"Because it's compensation, they look at it as if you're malingering."

"When I told people I'm not well, I have a head injury or I have concussion, they didn't really understand. They just said, "Oh, well, you look fine. What's wrong with you? You don't look unwell." And I said, "Well, you can't actually see a head injury. I'm not okay. I may look okay but I'm not okay."

"It's not a highly regarded problem in the wider community, in the medical community. Most doctors wouldn't be able to recognise it and even if they did I'm not sure that they are able to give adequate care."

Theme Six: Emotional consequences

Participants described a range of emotions that they experienced over the course of their recovery. A number described a sense of being grateful that their injury was not worse, while acknowledging significant losses that they had experienced. Frequently, participants described that their recovery was *lonely* (reflecting a sense of those around them not understanding their injury) and *frustrating* (in having to seek out answers themselves, often with limited success).

“You lose touch with normal people and their lives. So it can be very lonely.”

“I know I’m not alone and I just wish, I wasn’t so isolated if that makes sense.”

“I’m just sad and frustrated. That gets you down and destroys your motivation to do anything.”

“It was an incredibly frustrating period of time.”

Theme Seven: Enablers of a positive recovery

While participants identified that there were a range of factors that hindered their recovery, they also described factors which had supported a positive recovery. These included:

- Having realistic timeframes for recovery, which allowed participants to think positively about the future and acknowledge positive, incremental changes that were taking place,
- Accepting new limitations and identifying strategies that work for me, often with specialist input to support and monitor such strategies,
- Experiencing recognition and encouragement from others about the significant impact of the injury,
- Connecting with others, particularly others who had been through a similar experience, in order to feel less 'alone', share strategies, and maintain a sense of hope, and
- Feeling and being useful – even where participants were not able to return to their previous, identifying and engaging in alternative meaningful activities was important in maintaining a positive and productive sense of self.

“He said, “12 to 18 months,” and that was difficult information to absorb but it was very helpful to have specific information... It was helpful because it let me start to adapt my mind to that... [to acknowledge] that something really had happened and it was going to be a longer process.”

“Another client and I chatted and enjoyed each other’s company. It’s a different quality sharing your story with another patient as compared to a therapist or general person. The feelings are easier to understand and there’s also a feeling of mutual support, of having something to give, not only to take, needing help.”

“It’s made me appreciate [my partner] a lot more. He was hugely supportive.”

“All my friends and my family were there for me... I had a lot of support and I was very lucky.”

“It helped that everyone was positive about the prognosis. There was light at the end of the tunnel, we just had to go through the tunnel.”

“[The concussion clinic] have done a whole lot of problem-solving, a whole lot of little things that they've done to help me find myself again, to accept, and to give me strategies to live better. I was always crashing, always hitting the wall. It's about pacing. They've explained to me about pacing, pacing, pacing.”

Theme Eight: Long-term consequences

Given the prolonged nature of their recovery, all participants reported that their injury was associated with long-term consequences. The nature and severity of these consequences varied according to the person and the specialist support that they had received. Many described their relationships had changed as result of their injury. For some, the support they had received from someone close to them (generally spouse) during their recovery had strengthened their relationship. However, many described that those around them had provided significant care to them in their recovery (and sometimes continued to do so) and that this had been a cause of concern for them. Several participants (13/18) reported that their broader social relationships had suffered due to their injury. For some, this had continued for several years. In particular, participants described that issues such as fatigue, reduced concentration, and sound/light sensitivity made it difficult to attend social functions and stay connected with friends and extended family. Many (15/18) reported that their fatigue had caused them to withdraw from some or many activities that they had previously enjoyed.

“I really didn’t maintain [my activities in the community] for the most part. I did some bits, but it would be a 10% contribution of what I’d been before.”

“Socially, I can feel myself holding back. Sometimes I’ve just got to observe. There’s enough going on, I can’t find the capacity to participate.”

“It’s even affected my social life. I don’t go out at night much because I just don’t have any energy [once] I finish work.”

“The [insurance company] dispute the impact it’s had on my life. I have no income now, wasn’t planning on this. I am paying for my rehab.”

“[The rehab team] were really conservative with me. Work were really understanding of the situation, so that was another positive. They were incredibly supportive of that staged process...”

“Work held my job – I wanted to go back to

Many participants (15/18) described that the prolonged nature of their recovery from injury had a significant impact financially, related to extended periods away from work, costs associated with treatment and rehabilitation, and the loss of future opportunities. Several participants (11/15) reported that they had experienced significant periods of under/unemployment since their injury, and a number had changed the nature of their employment. Uncertainty about the length and course of their recovery was seen as a challenge for those who negotiated with their employers during their recovery, although there were a small number of participants (3/18) who reported that their employers remained flexible and responsive to their needs in the post injury period.

work. After a year of month-on-month time off work, my [neurologist] said to take another year. I thought, "That means I'll lose my job."

"I really wanted to work but, obviously, the amount I could do was pretty hard to find work for. And the employment agency, when they found out my restrictions, said, 'Oh, you're too disabled. We can't find you work.' And then Centrelink came back and said, 'You're not disabled enough.' They have this criteria and I didn't get enough points."

"I do think that I have a permanent disability, and no-one will ever recognise that. My employer refuses to recognise it as a disability. If I had a permanently mangled leg, they'd say, 'You're disabled,' but this is not considered a disability."

3.2 How do the findings relate to the five ILC outcome areas?

ILC Outcome 1: People with disability are connected and have the information they need to make decisions and choices.

The Lived Experience

The recovery prospects for people who are told they have sustained an mTBI or concussion are not readily predictable. The majority will recover within three months. However, that leaves an estimated 2,000-3,000 Australians each year sustaining an injury that results in more severe and prolonged symptoms. The lived experience of our interviewees, drawn from this prolonged symptom group, reveals a health system that is oriented to the majority outcome – a swift and uneventful recovery. People who experience different outcomes may be treated as outliers or misfits, and clinicians may seek alternative explanations for their symptoms, such as psychological problems, rather than taking their head injury symptoms seriously. Unrecognised, disbelieved and discounted, and with a freshly compromised capacity for information-seeking and self-advocacy, these people are indeed the ‘miserable minority’.

For all interviewees, their lived experience during their recovery period (whether recognized or not) was one of temporary disability. Regrettably, many interviewees experienced a sub-optimal recovery, meaning that there were periods of time where they did not have the information, guidance and support they needed. Some participants are now experiencing permanent disability, in that they report symptoms that are not resolving and in some cases are even worsening.

Our interviewees report a critical lack of information to help them plan and manage their recovery and also to take a realistic approach to their immediate and mid-term arrangements regarding living arrangements, family and work responsibilities, financial and social supports, and community engagement.

Unmet Needs Relevant to ILC Outcome 1

We know from the academic literature that the rate and duration of persistent symptoms following-mTBI can be effectively reduced by a combination of appropriate information, support and self-management. Marshall and colleagues (2015) argue that timely diagnosis and management “improves patient outcomes and reduces the impact of persistent physical, behavioural/emotional and cognitive symptoms” for adults with mTBI (Marshall et al, 2015, referencing: NSW Motor Accident Authority, 2008; Borg et al, 2004; Savola et al, 2003; Ponsford et al, 2002). In a randomised control trial, Mittenberg and colleagues (1996) found that information provision resulted in a 35% reduction in the duration of symptoms following an mTBI.

Our interviewees provided a rich account of the service and information gaps they encountered. The unmet needs of participants relevant to ILC Outcome 1 are described in the previous section and include all of the following themes:

- Theme One – Initial Treatment and Diagnosis
- Theme Two – The Role of the GP
- Theme Three – Specialist Assessment and Rehabilitation
- Theme Four – Access to Information
- Theme Five – Barriers to a Positive Recovery
- Theme Six – Emotional Consequences
- Theme Seven – Enablers of a Positive Recovery
- Theme Eight – Long-term Consequences

How Addressing Unmet Needs Under ILC Outcome 1 Improves the Lived Experience

Interviewees further describe how their lived experience would have been improved by being better connected to advice, guidance, treatment, supports and the related information. They tell us that better information and connection to services and supports would:

- Help them to recover: what to do to promote recovery (and what not to do)
- Help their family/carers to understand what they need during recovery
- Tell them what to expect in a realistic range – timeframes
- Provide them with encouragement and realistic hope
- Provide them with support and legitimacy in dealing with employment, financial issues, expectations of others during recovery
- Give them strategies for maximising their wellbeing during the recovery period without compromising recovery
- Help them to determine their best pathways back to normal activity and when to take each step
- Help them to feel not alone, not malingering, not ‘wrong’
- Give them a GP who understands and supports them, and provides them with guidance and referral where necessary, and celebrates their progress
- Recognise when their disability includes more permanent aspects and helps them navigate to longer-term adjustments, supports and decisions.

ILC Outcome 2: People with disability have the skills and confidence to participate and contribute to the community and protect their rights

The Lived Experience

The majority of interviewees reported limitations in terms of their community participation and protection of their rights. These limitations mostly stemmed from the unmet information needs described under Outcome 1.

All but two of those interviewed reported changing their employment as a result of their injury. For many, this was because their injury caused a prolonged absence from work. For employees, poor understanding of the nature and impact of their injury and likely recovery timeframes meant that they handled decisions around returning to work badly. For employers, inconsistent messages from their employee, coupled with vague and repeated short-term medical certificates, led them to be relatively impatient and unsupportive. In a number of cases, interviewees reported secondary work problems, such as bullying that accompanied their attempts to return to work. Two of these cases resulted in a separate employee claim for Workcover related to bullying-induced stress.

A number of interviewees sustained their brain injury in their workplace, including their journey to or from work. These people reported additional problems in dealing with their insurer. For example, interviewees reported their insurer would interfere with, and in some cases, reduce their access to diagnosis and treatment by mandating which physicians and allied health professionals they should see. A smaller number of this group also reported their symptoms being dismissed and minimised by insurer-compensated clinicians.

Without a consistent message from their GP, both to the employee and in the form of medical certificates provided to the employer, our interviewees were left to provide explanations for their continued absence. Similarly, when they tried to return to work too early, our interviewees reported difficulties, such as making mistakes and having to leave early because of fatigue. It is important to note that the

experience of brain injury-related symptoms may erode a person's capacity to plan and communicate. The majority of our interviewees reported experiences where their rights have not been fully protected.

Our interviewees all expressed a desire to be engaged in meaningful work. For some, a return to work has been achieved. Others have made a number of attempts to return to work but have been unable to maintain employment. Others have found alternative ways to contribute which have been important substitutes for the meaning previously attached to their work. In some cases, these alternative activities have helped form a bridge through the recovery period to post-recovery employment.

Some of our interviewees relied heavily on their work for their day to day financial support. For these people, return to work has been particularly fraught. Lack of financial support has affected their ability to access treatment and to develop the circumstances needed for their recovery. The difficulties experienced in negotiating their injury and recovery with their employer and workplace insurer has extended to their dealings with other sources of financial support, such as Centrelink and State Trustees.

Unmet Needs Relevant to ILC Outcome 2

The unmet needs of participants relevant to ILC Outcome 2 are described in the previous section according to the following themes:

- Theme Two - The Role of the GP
- Theme Three – Specialist Assessment and Rehabilitation
- Theme Five – Barriers to a Positive Recovery
- Theme Seven – Enablers of a Positive Recovery
- Theme Eight – Long-term Consequences

How Addressing Unmet Needs Under ILC Outcome 2 Improves the Lived Experience

Interviewees described how their rights and capacity to participate in the community, including work, could have been improved. They expressed that improved information and policies would:

- Provide clear guidance to their employer/workplace insurer about the nature and impact of prolonged recovery periods following concussion or mTBI
- Help them and their employer/workplace insurer to understand their needs for optimal recovery and take seriously their desire to return to work
- Help them and their employer/workplace insurer design an appropriate return to work plan
- Help them develop alternative activities to aid their recovery and provide them with the benefits of community participation
- Provide a policy framework suited to temporary disability (3-24 months) regarding maintenance of employment, return to work and financial support
- Provide guidance and legal support for cases of unfair treatment.

ILC Outcome 3: People with disability use and benefit from the same mainstream services as everyone else.

The Lived Experience

The majority of interviewees reported limitations in terms of their access to mainstream services. Again, these limitations mostly stemmed from the unmet information needs described under Outcome 1.

The most significant driver of a positive recovery experience was an interviewee's access to a knowledgeable and supportive GP. In these cases, the GP was either the first, or one of the first, to identify the possibility of an extended period of recovery from the person's injury. They informed the person about this clearly, and followed through with monitoring, and as required, referral to specialist treatment and support, typically a brain injury clinic. The GP continued to monitor and encourage their patient through the recovery period.

Another driver of positive recovery was interviewees' access to a specialist brain injury clinic. These clinics provide integrated services, typically including neurologist and/or rehabilitation specialist, neuropsychologist, clinical psychologist, physiotherapist, occupational therapist and speech pathologist.

Significantly, few interviewees reported adequate management of their brain injury in the emergency setting – ambulance and emergency department. Some reported that an underestimation of their injury at this stage 'stayed with them' and continued to thwart their efforts to obtain support and treatment.

Lack of GP knowledge and support was also reported as a significant barrier to a positive recovery. People relied on their GP for referrals, integrated care and support, and for mandatory communications (such as medical certificates). Reasons interviewees gave for lack of GP support included lack of knowledge, anchoring of the hospital assessment, attribution of symptoms to psychological difficulties and conflict of interest where reimbursed by an insurer.

Other barriers to a positive recovery related to the availability and accessibility of suitable services. Brain injury clinics are only located in major cities and, while there have been a few additions in recent years, there are only about 15 across Australia. These clinics deal with injuries of all severities and are hard to access for milder cases, although the success rate for the kinds of treatment and support provided in these cases is high. Those interviewees living in rural and regional areas reported considerable difficulty in accessing specialist services. Symptoms of concussion or mTBI may mean that someone cannot drive and/or experience significant fatigue on long journeys. Additionally, some interviewees reported difficulty in being able to meet the costs of specialist services, including the travel and assistance required to attend. This was particularly the case for those living in rural and regional areas and those with fewer financial resources or ongoing support.

Unmet Needs Relevant to ILC Outcome 3

The unmet needs of participants relevant to ILC Outcome 3 are described in the previous section according to the following themes:

- Theme Two - The Role of the GP
- Theme Three – Specialist Assessment and Rehabilitation
- Theme Five – Barriers to a Positive Recovery
- Theme Seven – Enablers of a Positive Recovery
- Theme Eight – Long-term Consequences

How Addressing Unmet Needs Under ILC Outcome 3 Improves the Lived Experience

Interviewees tell us that improved access to mainstream services, in addition to the information and knowledge-driven service improvements listed under Outcome 1 would:

- Significantly reduce the worry, frustration and misery attached to their injury
- Save time, expense and resources attached to unnecessary tests (e.g. scans)
- Provide them with targeted treatment and supports suited to their specific challenges
- Empower them to 'make the most' of my situation and adapt where necessary.

ILC Outcome 4: People with disability participate in and benefit from the same community activities as everyone else.

The Lived Experience

Many of the unmet needs under ILC Outcome 4 are addressed under Outcome 1 through improved connection and information opportunities. However, a number of interviewees suggested they would value and benefit from some kind of peer support group or network.

All interviewees reported limitations in terms of their participation in community activities during their recovery period. Where this recovery period was less than 12 months, these restrictions have been an accepted component of 'getting better'. However, even in these cases, better information and support during the recovery period (see Outcome 1) could assist people in finding strategies for continued participation and engagement with their families and wider networks.

Those interviewees who found ways to maintain their community activities, or to introduce new ones, reported this as a significant enabler of their positive recovery. Reported benefits included less isolation, greater sense of self-worth, maintenance of family and social networks, and gradual testing and challenging of persistent symptoms.

Some interviewees experienced more extensive and prolonged restrictions to their participation in community activities. The symptoms experienced following concussion or mTBI vary. For some people, for example, difficulties in dealing with noisy environments and problems with balance make it hard to approach many group and social environments. The interviewees who described difficulties as extensive as these also described prolonged recovery periods, in the order of years rather than months. Just as delineating those who experience an extended period of symptoms following a concussion or mTBI from the majority who make a swift and uneventful recovery is important; it is also important to identify those whose injury has resulted in some form of more permanent disability.

As well as receiving advanced guidance on strategies for engaging with community activities, identification of a more permanent disability enables someone to make more long term adjustments to their social arrangements and provides them with additional forms of support, such as an NDIS package, to assist their community participation.

Unmet Needs Relevant to ILC Outcome 4

The unmet needs of participants relevant to ILC Outcome 4 are described in the previous section according to the following themes:

- Theme Five – Barriers to a Positive Recovery
- Theme Seven – Enablers of a Positive Recovery
- Theme Eight – Long-term Consequences

How Addressing Unmet Needs Under ILC Outcome 4 Improves the Lived Experience

Interviewees tell us that being able to participate in community activities will:

- Provide them with incentive and practice to support their recovery
- Increase their sense of belonging
- Benefit their family and networks
- Support their mental health
- Help them to connect, for example, to find future work or volunteering.

ILC Outcome 5: People with disability actively contribute to leading, shaping and influencing their community.

The Lived Experience

For many interviewees, the limitations experienced in community participation described under Outcome 4 translate to barriers to their active involvement in leading, shaping and influencing their community. Many interviewees reported their changed capacity to assist with community-related efforts as not only creating a sense of loss for them, but also creating rifts and discomfort as, similar to employers, community groups failed to appreciate the impact of their injury.

This negative experience born out of misunderstanding, served to isolate some interviewees from those particular groups. For some, the negative experience caused them to withdraw from community activities more generally. However, some interviewees actually developed new activities and forms of community engagement – joining and creating new communities within which they could play a significant role.

More specifically, some interviewees came to realise that they were now a part of the brain injury community. As most people were told, initially, that they either did not have a brain injury or would recover within a few weeks, it took some time for each person to recognise that they were indeed experiencing brain injury. Following that, many have sought connection through Brain Injury Australia and some describe seeking others with similar experiences on Instagram and other social media. This highlights the need for increased opportunities for people with lived experience to be able to provide this feedback. Several participants reported that they were passionate and motivated to help inform the support and information provided to people with concussion and mTBI.

All interviewees reported valuing the opportunity to contribute through these interviews to the future activities of Brain Injury Australia for the benefit of people who sustain similar injuries to their own in the future.

Unmet Needs Relevant to ILC Outcome 5

The unmet needs of participants relevant to ILC Outcome 5 are described in the previous section according to the following themes:

- Theme Five – Barriers to a Positive Recovery
- Theme Seven – Enablers of a Positive Recovery
- Theme Eight – Long-term Consequences

How Addressing Unmet Needs Under ILC Outcome 5 Improves the Lived Experience

Interviewees tell us that being able to actively contribute to leading, shaping and influencing their community will:

- Help them to feel useful and have a sense of purpose in their community
- Provide them with networks and a sense of being valued by their community
- Help them to retain/regain their sense of identity as a leader, shaper and influencer.

And specific to their new brain injury community:

- Help them to ensure others who experience a similar injury have a more positive recovery experience
- Help them contribute to better information, services and supports for people with concussion and mTBI.

4. How has the organisation-specific project contributed to your organisation becoming ILC ready?

Within the larger AFDO-led project, our organisation-specific project has contributed substantially to Brain Injury Australia's 'readiness' for ILC.

We have reinvigorated our dialogue with our constituents and made their voices louder

Brain Injury Australia used the survey component of the AFDO ILC Readiness project to explore our constituents' perceptions of their unmet needs and to invite constituents to self-nominate as interview participants for this individual project. The substantial response to our call (around 40 people with lived experience of concussion and mTBI volunteered to participate) demonstrated the value of this kind of engagement with our constituents and confirmed their enthusiasm to help improve experiences for their community.

By feeding back the results of this project to participants and to the broader Brain Injury Australia community, we are showing our constituents that their voices matter and can influence future directions.

We have demonstrated how we can explore unmet need to inform and provide an evidence base for our ILC activities

The general call, followed by a semi-structured interview approach has been fruitful in providing Brain Injury Australia with rich and authentic accounts of constituents' lived experience of their injury. Through this approach we have been able to explore all ILC-relevant aspects of people's lived experience. By including a range of interview participants, we have been able to build a reasonably comprehensive and objective picture of enablers and barriers to a positive recovery experience. We have also been able to determine indicative proportions of interviewees experiencing, for example, a positive recovery experience or a supportive return to work, versus a delayed and fraught recovery experience and apparent risk of permanent disability.

The approach taken in this organisation-specific project could be replicated to inform other areas of constituent need.

We have developed a more rigorous and definitive account of lived experience of concussion and mTBI in Australia

Brain Injury Australia has been aware, through our work, of the information and service gaps experienced by the 'miserable minority' – those who do not make a swift and uneventful recovery from concussion and mTBI, and may indeed take months or years to recover. For some, it appears that possibly due to delays in appropriate guidance, treatment and support, their disability becomes of a permanent nature. For some, the tendency to minimise 'so-called' mild injuries within the insurance context effectively denies them their rightful entitlements.

The findings of this project will inform our ILC-related activities to improve outcomes for the 'miserable minority' and to design suitable measures of progress.

5. What will you do with the information gained from the activities undertaken by your organisation-specific project?

The rich and generous accounts of Brain Injury Australia's constituents provide a clearer picture of what it means to be in the "miserable minority". While around half (10/18) of those interviewed reported being now largely or fully recovered, the rest continue to experience significant difficulties. For some people living with the consequences of one, or multiple, "mild" injuries, there are a range of factors that, when combined, negatively influence their ability to access the information and services that may support an optimal recovery. Based on the interviews we conducted and feedback provided to Brain Injury Australia, it is evident that these factors may include low levels of community recognition of a disability that cannot be seen, ineligibility and/or deprioritisation of individuals with mild injuries for specialist brain injury rehabilitation services, ongoing questions about the relationship between standard measures of injury severity and resulting disability for individuals in this group, a dearth of evidence-based interventions for individuals with concussion and mTBI, and a tendency to discount the lived experience of those with "mild" injury in the context of insurance or compensation claims.

Brain Injury Australia proposes a number of actions based on the findings of the broader AFDO ILC Readiness project and this organisation-specific project within it. Some of these activities are already underway or committed, while others are under consideration. They are listed below.

Actions underway

- i. Feedback of the project findings to participants and also to the broader Brain Injury Australia community through our newsletter
- ii. Continued effort by Brain Injury Australia, working with NSW Health, on the establishment of specialist concussion clinics throughout the state
- iii. Application (submitted 29th September 2017) for an ILC Readiness Grant for the project "Empowering people with a brain injury - accessible resources to guide

recovery and maximise participation”. Project partners include the University of Melbourne, the Royal Australian College of General Practitioners and Code and Visual. The project will produce new information resources to help people with a brain injury gain confidence in themselves and the support of their GPs as they work together to maximise their prospects for social and community participation

iv. Brain Injury Australia’s facilitation of a national “community of practice” in brain injury for the National Disability Insurance Agency (currently being piloted in Sydney). Its primary purposes are to optimize both needs ascertainment and plan fidelity for National Disability Insurance Scheme (NDIS) participants with an acquired brain injury, including those with “mild” injury

v. Brain Injury Australia’s current leadership of the Acquired Brain Injury and Family Violence Project, a consortium including Monash University, Domestic Violence Victoria, No To Violence incorporating the Men’s Referral Service and the Centre for Excellence in Child and Family Welfare. Funded by the Victorian Department of Health and Human Services, the project responds to recommendation 171 of the Victorian Royal Commission into Family Violence: “The Victorian Government fund research into the prevalence of acquired brain injury among family violence victims and perpetrators.” Victim-survivors of family violence are an example of a “hard to reach” group, some of whom will experience the kinds of longer term consequences of multiple concussions or mTBIs as described in this report.

Actions under consideration

vi. Development of resources to help people with a brain injury that is resulting in temporary disability to navigate their relationship with their employer, insurer (where applicable) and to obtain the financial support, leave and return to work arrangements to which they are entitled. A particular feature to be incorporated addresses the uncertain timeframes attached to recovery from concussion and mTBI

vii. Exploratory development of options for peer support among people experiencing extended duration symptoms following a brain injury

viii. A further survey of Brain Injury Australia's constituents to explore their perceptions of unmet needs and other aspects of their lived experience (not before July 2018).