NASEM TBI Action Collaborative
Patient Engagement
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Project Objective

The Action Collaborative of NASEM's Forum on Traumatic Brain Injury is working to create a model post-acute care system. As a part of that effort, it is conducting consumer research focus groups to qualitatively explore and understand the acute and post-acute care experience of a diverse array of people diagnosed with mild traumatic brain injury. The objective is to gather patient perspectives on the care they received, the care they felt they needed, and the Action Collaborative's proposed aftercare and patient engagement model and tools.

Methodology & Tactics

In Pittsburgh and Milwaukee, we asked focus group research centers to convene four two-hour sessions during the months of March and April, as follows:

- Two groups of eight participants each in Pittsburgh, ages 29-67, on March 20th.
- Two groups of eight participants each in Milwaukee, ages 24-65, on April 17th.

Each of the focus groups was composed of eight people who had been diagnosed by a doctor as having suffered a mild traumatic brain injury (mTBI) within the past year or so. Among the thirty-two, 19 were male and 13 were female, of which 19 were Caucasian, 9 were African American, and 4 were Latino. There was also significant diversity of income, education, personality, injury, severity and duration of symptoms, comorbidities, and more.

The people who came to talk with us about their traumatic brain injuries each had their own story and experience that differed from person to person. Yet, even with this limited sample of respondents, six themes and similarities emerged in terms of what was most helpful and what could have been better in regard to their own response, the treatment they received, and any aftercare.

Summary - Six Primary Themes

1. **Injury Downplayed**—Patients and medical professionals alike seem to have a reflex to downplay or minimize the seriousness and potential repercussions of a mild traumatic brain injury. Primary care physicians, significant others, and caregivers are less susceptible to this reflex to minimize and are more likely to urge action and treatment. Patients often tell themselves and often hear from ER or urgent care staff not to worry because they 'just have a concussion.' Many have difficulty processing persistent symptoms and often assume that they will never get back to normal.

2. **The Brain: Out of Sight, Out of Mind**—The brain and the heart were the two organs ranked by the respondents as the most important. The brain, however, despite this high esteem, remains abstract and untouchable. Contrary to the widespread understanding of the functions, threats, and means to protect the heart and keep it healthy, there was little evidence of any understanding of how to protect, exercise, and facilitate the health and healing of the brain. The plasticity of the brain is a well-kept secret.

3. **Need for Support and Advocacy**—Simply put, when patients had advocates and felt supported, they were more hopeful and engaged in their recovery. Their healing seemed to progress more quickly. If they lived alone, or didn't have support from family, friends, medical professionals, or colleagues, they were less likely to be actively engaged in their recovery. Because confusion, disorientation, and self-doubt often resulted from their injuries, having support and people advocating for them was highly valued by many of the participants. Many—especially men—talked about the stigma of having injured their brains and needing help and time to heal. Many tried to resume work and normal activities while still feeling less than their normal selves. In some cases, medical professionals prevented hasty returns to work, for which patients were grateful. Patients also told us they craved talking to a caring person sympathetic to the challenges they were facing, somebody who could offer some necessary grounding, orientation, and hope for their healing journey.

4. **Fallow Agency**—Many expressed feeling powerless about the challenges their symptoms presented, many of which were not made manifest until after returning home and trying to resume normal activities. Most were discharged or returned home without remembering or having been educated about their injury, and came away without recommendations on how to help facilitate their healing. Many were simply told to take it easy and that they would likely get better in a few days. When symptoms developed and/or persisted, many of the respondents felt like they were on their own trying to educate themselves about brain injuries and many simply did not know what, beyond sitting in the dark, could be done to treat their injury, improve their symptoms or help their brains heal. There was great interest in guidance for what they themselves could do.

5. **Psychological Trauma Untreated**—It is our sense that any effort toward improved post-acute care for traumatic brain injury should start with adopting a better term then 'concussion' that better represents the frequent seriousness of a brain injury. Most all the participants regarded the term 'concussion' to mean that their brain injury was insignificant. We also recognized the need to address the psychological trauma, as well as the physiological trauma. From what many shared, there is psychological trauma - most notably anxiety and depression - in addition to brain injury that was in most cases entirely unaddressed.

6. **The actual proves the possible**—A number of the Pittsburgh participants who were treated at UPMC hospitals reported receiving good acute care and post-acute care. The very best reports we heard about post-acute care and education were from the participants who were recruited to be part of a UPMC study. A model post-acute care system would do well to build on what these patients experienced.

The following is a more detailed account of what we heard from thirty-two people with mTBI.

THE BRAIN

Patients understand that the brain is unquestionably the most important organ in the body, but that is where the understanding often ends.

- The participants overwhelmingly considered the brain as the most important organ in the body—and their mTBI's reinforced this assertion.

> *"The brain is the only thing that makes you you." Pittsburg Male, 44*
>
> *"They can give you a new heart, but they can't give you a new brain." Pittsburgh Female, 53*

- There was a clear consensus that the brain is the most important organ in the body, but the causal relationship between the injury and its sequelae affecting seeing, hearing, walking, balance or mental health (including anxiety, confusion, and depression), was often not clear to those with mTBI.

> *"What's crazy though is if we had not come here today, I never would've made the connection that me forgetting things and me mumbling, you know, I never would've made the connection that that was because of the concussion." Milwaukee Female 49*

- Belief that an injured brain may not heal was common, which was reinforced by the experience many reported of challenging symptoms that persisted many months after the injury.

> *"Don't hurt your brain; you only got one. If you screw your brain up, you're out of luck, you aren't getting better. Don't hurt your brain; you only got one." Milwaukee Male, 49*

Like mental health conditions, the seriousness of a TBI, and many of its symptoms such as anxiety, depression, and anger aren't often recognized because, as one respondent put it, " a TBI is a mostly unseen medical condition."

- Because of the fact that the mTBIs were mostly internal brain injuries without the visible manifestations of other types of injuries (e.g. blunt trauma, broken bones, burns), many found that others had difficulty recognizing the seriousness, or potential seriousness, of the injury. While this is especially true for family members, colleagues, and friends, we also heard similar critiques of medical professionals who sometimes neglected the seriousness of the brain injury, especially in cases where other injuries had occurred.

> *"With brain injuries, it's more ethereal. My shoulder broke, they can see that broken shoulder, 'here's your x-ray'. Your brain, they can scan your brain and not see anything, but you know it's not right." Milwaukee Male, 31*
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> *I did not really know that I had a concussion until [name withheld], a researcher at UPMC for traumatic brain injuries, said that I had a concussion and we'd like you to be in our study." Pittsburgh Female, 35*
>
> *"The doctor's seriousness is what made me realize how serious my head injury was." Pittsburgh Male, 29*

- Some patients had other visible injuries and returned home or to work with a cast, crutches, stitches, bandages, etc. These outward manifestations of a real injury automatically evoked sympathy in others, so the patient's themselves did not have to justify being hurt, absent, and compromised in their abilities. With most of the brain injuries we heard about, however, there were no visible "badges of courage", and the patients (especially men) often downplayed the seriousness of their concussion because, with an invisible injury, symptoms either had to be explained or justified. There is a fear amongst many that their symptoms might be permanent and may simply appear to others as personal inadequacies. This is a stigma particular to a brain injury that many respondents spoke about.

> *"I'm a burden, so I'm not gonna ask for more help. And there's also a bit of a stigma. I'm not gonna go advertising to everybody that I've had a brain injury." Pittsburgh Female 45*
>
> *"I couldn't even speak straight for three months; people thought I was drunk. When you break something or you get punched in the eye, that's something physical people can say "Oh, yeah, that's why." With this, you can't see it and people think it's totally something else." Milwaukee Male, 48*
>
> *"Since nobody can see your injury and you're functioning, nobody really gives a crap." Milwaukee Male, 60*

The word "concussion" isn't descriptive and evokes little in terms of being a brain injury, its seriousness, and the potential consequences.

- Concussion has become a diminutive term that suggests an insignificant injury mostly unworthy of concern. Based on our observation, this is the case culturally and is even used this way by medical professionals. The term "mild traumatic brain injury" gets a patient's attention and conveys the reality that there may be troublesome symptoms, with more than a few days needed for healing. Perhaps most importantly, TBI strikes most as an injury that will require some follow-up and aftercare.

> *"Before, I just thought a concussion was a bruise on the brain; now I see it is a life-long injury." Pittsburgh Male, 29*

"I've had ten diagnosed concussions—that's just diagnosed! My brother was an All-American football player, and my father played semi-pro, so it was called 'getting your bell rung' and we were told to suck it up and and keep moving,"
Pittsburgh Male, 39

I've been to the doctor for broken bones and they'll say, "You need to do this, and this, and this;" it's real thorough. This was not. They were just like, "You're okay. Hurry up and get out of here. You're done." Milwaukee Female, 47

"I wasn't even told I had a concussion. I found out by looking at my paperwork from the ER visit. And then they didn't give me any advice on what to do. I just started looking it up on the Internet. I never had a follow up or anything."
Pittsburgh Female 47

- Because of the cultural norm to discount the significance of a concussion, it was often a partner, family member, or caregiver that insisted on the patient going to the ER, getting a medical evaluation, learning more about the injury, and/or taking steps to address the symptoms.

"My partner, a crazy football fan and sports fan who knows how bad concussions can be, was the best source of information for me. I'm always like, 'I'm just going to push through. I'm going to push through.' I was trying to go to work, and he said, 'Take your black ass home. You have no business sitting in front of the computer.' I never would've thought nausea and vomiting was related to me smacking my head."
Milwaukee Female, 29

CLINICAL CARE

If there are any other injuries, mTBI becomes secondary (at best) for both medical staff and for patients.

- CT scans and MRIs (and perhaps the new blood marker results) that yield a definitive TBI diagnosis help doctors and patients by making an abstract injury more real, factual, physical, and concrete. Patients who were told they had a brain injury or that their brain was bleeding or bruised, seem to have taken their injury more seriously (as did their doctors). These sorts of objective diagnoses validate patients' and caregivers' concerns and prepare them for the symptoms and the challenges and care they may require.

"I remember is waking up in hospital, on the the table, and the doctors said to my wife, 'he's got a brain bleed and a concussion, so we're gonna admit him.' Before we left the hospital, they gave my wife and me detailed instructions about what to do and what not to do. I listened to them and followed their instructions."
Pittsburgh Male, 60

Patients want to see their images or their brains—or at least a brain—to better understand their injuries and how they may be impacted by them.

- Broken bones, burns, and the other comorbidities we heard about were easy for patients to understand in terms of treatment and healing. The brain is unseen and somewhat abstract making a brain injury and sequelae harder to comprehend and take seriously.

> *"Of all the significant injuries that I had including my broken leg, burned hand, and TBI, my brain got the least attention and it continues to be the most chronic and debilitating of all my injuries. They spent the most time treating my burned hand. Pittsburg Male, 29*

> *"I understand that everybody's overworked and understaffed, I get that, but with something like this, I just feel like it should've been taken more seriously. I got more information when I had a baby than when I had a concussion."*
> *Milwaukee Female, 49*

- Unlike many injuries where a doctor will show the patient an image of broken or dislocated bone, tear, ruptured disk, etc. in order to help explain the injury and the required treatment, even the respondents who reported having had scans as part of their diagnosis were rarely shown the images. Most of the participants were interested in an MRI-like image of their brain with an explanation of probable damage so that they can better comprehend and internalize their injury.

> *"It would've made me understand better if they showed me and said, 'Okay, this is what happened, here's what we're looking for, we don't want to see this.' That would definitely have helped." Milwaukee Male, 24*

- Several respondents who had received some sort of imaging were told that the images were "unremarkable" and they weren't expecting or prepared for some of the symptoms that became apparent upon returning home. "Unremarkable" is another term in the medical lexicon, along with "concussion", that minimizes the potential seriousness of a brain injury and should stop being used with patients.

> *"The wording was that the tests were 'unremarkable,' and it wasn't explained what that meant." Milwaukee Male, 56*

> *"I got the feeling that nobody took it really seriously if nothing dramatic showed up on the tests." Milwaukee Female, 32*

- Many patients were met with nonchalance of the medical staff providing the initial diagnosis and treatment, and this unfortunately reinforced the cultural misperception that "concussions" are more often than insignificant injuries and any symptoms they later experience are probably "all in their head."

> *"I think for everybody there's a certain stigma about it. For lack of a better term, it's all in their head. I think people don't take it seriously." Milwaukee Male, 48*

TBI EDUCATION AND DISCHARGE

Discharge is a bad time for conveying information about what the days/weeks ahead may be like.

- Many patients are memory challenged cognitively and situationally. Often, they don't remember what they were given or what they were told. Many only heard (and may have only been told) that their recovery would probably take time, not what they should do or avoid doing. Most reported getting no guidance on sleep, driving, going to work, nutrition, exercise, or that there are treatments to ameliorate many symptoms.

  "They gave me a sheet of paper which I didn't read because I had no idea what was going on." Milwaukee Male, 48

- In most cases, some sort of follow-up or check-in seems crucial in order to make sure that the patients understand the information that may have been given about the diagnosis, symptoms and treatment before being discharged.

  "They sent me on my way, told me to kind of take it easy for a while, to come back in if my headache or my vomiting got worse. I went home, it may have gotten worse or maybe just stayed the same, but I didn't go back." About a month later I was still dealing with constant headaches, some intermittent nausea, and dizziness. Nobody followed up." Milwaukee Female, 38

- The groups in Milwaukee were shown two images, an x-ray of a broken arm, and a color HDFT image of an injured brain. It is our observation that any image of a brain that shows a mTBI will be helpful to patients. The image of the mTBI was impactful and led to lots of questions about the brain, their particular injuries and symptoms, and the healing process. We are not doctors and couldn't answer these questions, but it was clear that an image can instigate opportunities for medical professionals to educate patients.

  "It would've made me understand better if they showed me something and said, 'Okay, this is what happened.'" Milwaukee Male, 24

- There were few reports of being educated on how the brain heals and what promotes brain health. For those patients and their caregivers who had the benefit of some education on this, it was not only an opportunity to learn about the brain, brain health, and mTBI, but it also led to more engagement in proactively trying to facilitate the healing.

  "I had a TBI book, a-couple hundred pages of just people who tell you their stories. And it made me feel better, so I don't feel insane for this." Pittsburgh Female, 39

  "We need more educational materials, like links to YouTube videos, to learn about the healing process. I would definitely want some sort of exercises to help improve short term memory." Pittsburgh Female, 25

FOLLOW-UP CARE

A regular check in after a few days and weeks would be welcomed if the source of the check in was credible and personal.

- The typical instructions given to patients at discharge was to return to the ER if symptoms worsen or last more than a month. Most found this to be too high a bar for follow-up care. Some reported that their PCP later instigated follow-up care.

- Tracking the patients after discharge, and providing guidance (and if necessary, support) are especially important, as many patients reported not knowing the challenges they faced, and help they would require, until getting home.

> *"My doctor told me I might get headaches, to drink water, lay down, and turn the lights off. I had migraine headaches, and I also needed to use a walker and a shower chair we had for our grandparents because I was dealing with balance issues two months after. It wasn't until I got home that I realized how much help I needed."*
> *Pittsburgh Female, 38*

- In Pittsburgh, many of the patients who received acute care at a UPMC hospital reported getting good medical care and good post-acute care. The Pittsburgh respondents who participated in a UPMC study offered reports of great post-acute care.

> *The treatment was spot on, and they didn't rush me. They said, 'This is what you're gonna see, this is what you're gonna feel. You can't drive for a month, you can't work for a month. Here's who we want you to follow up with, and this is when we want you to follow up. You know, they called me to make sure I would follow up and I was gonna make the appointments.*
> *Pittsburgh Male, 60*

A baseline and ongoing cognitive and/or symptom assessment would be very welcomed by most. Getting help tracking their progress toward healing held great appeal.

- Regular check-ins or ways of tracking a patient's progress seem necessary as many of the symptoms of mTBI are not easily identified by some patients as symptoms of their brain injury. Consequently, many lose interest in seeking additional help or in actively working themselves to facilitate further healing. Many of these respondents had lingering symptoms that they had internalized and accepted as their new norm.

> *"I've never even thought about it, I just accepted that this is the new norm."*
> *Milwaukee Male, 24*

> *"What's crazy though is if we had not come here today, I never would've made the connection that me forgetting things and me mumbling was because of the concussion." Milwaukee Female, 47*

Assessment and treatment of psychological trauma seemed an unmet need for most patients.

- In some cases, what caused the injury was traumatic, and in many cases the symptom-related challenges were traumatic. In nearly all cases, psychological trauma was entirely unaddressed.

  "I feel like all of us, all eight of us here, have trauma from this, because we're dealing with this stuff to this day. Short term, what happened at that moment? We were throwing up and were nauseous. The long term is right now, memory issues, depression, remembering things, mumbling, ringing in the ears."
  Milwaukee Male, 24

- Even within this limited sample of patients, one of the most common and debilitating symptoms reported is anxiety. There may be a physiological, neurological, or psychological basis for this based on trauma and/or the particular part of the brain that is injured, but we found that those that didn't have much of a support system seemed most at risk.

  "My concussion was like being underwater. Everything seemed muffled to me, like I was there but I wasn't." Pittsburg Female, 32

  "I just started getting anxiety. I couldn't ignore it." Pittsburgh Female, 53

  I don't know where that anxiety was coming from, I just wanted to get out."
  Milwaukee Male, 56

Personalization, sympathetic listening, and addressing what patients say they need makes post-acute care most effective.

- Any post-acute care, app, or other tools and materials will get more use by patients if they are personalized and speak to the patient's particular injury and symptoms. Most all the respondents were keenly aware when their various interactions with medical professionals were personal and sincere as opposed to when they were being routinely or systematically moved through required medical or insurance protocols as quickly as possible.

  "The information sheets, they're generic, really generic in what they say. It's not specific to your situation." Milwaukee Female, 47

- The power of a connection with somebody who listens and understands can't be overemphasized. The patients who received personalized aftercare from family, friends, and medical professionals seemed to have an advantage in healing more fully and quickly. We learned that often patients with brain injuries can be left feeling lost, disoriented, and anxious. A more empathetic and less procedural connection with others seemed important in helping ground and orient these patients.

  "Sometimes you just want to tell your friend, 'Oh, this is so frustrating, I can't believe I went through this again,' and you just feel that reassurance that somebody's listening to you, you're not alone, you're not by yourself." Milwaukee Male, 49

- Those who had a caregiver seemed to have had a much better recovery experience than those who are alone. Yet, sometimes even those living with family felt alone and expressed interest in ways of getting more information and support. Follow up calls a few days or a week after discharge, or the engagement of a friend or caregiver at discharge would be welcomed by most.

"My friends took care of me. When I was in the hospital, they put together a steak fry for me and sold 450 tickets to it. I think that's a huge reason of why it was such a quick recovery. I had so many people, I had no worries." Pittsburgh Female, 27

"What do people do that don't have the support? Because I couldn't make a phone call to make a doctor's appointment. I couldn't track the conversation even after I was able to make the call." Pittsburgh Female, 65

- We heard repeatedly that communication between doctors and employers was much needed, along with medical guidance/permission for patients to not rush back to work. Another common request was help dealing with health insurance, which can be even more anxiety-inducing or temper-challenging for the cognitively impaired.

"Help me communicate with my work to explain what I can and can't do, my limitations." Milwaukee Female, 25

"My boss kept saying, 'if you could get a letter saying you need off a whole week, I'll pay you.'" Pittsburgh Female, 38

"My whole problem was being forced back to work when I was not well enough to go back to work." Pittsburgh Male, 60

"A dream app would help you with your insurance companies? That would be fantastic." Pittsburgh Female, 32

There is great power in others beyond healthcare professionals.

- There was great interest in fellow mTBI chat groups, survivor video interviews, or other non-hierarchical sources of information and advice. People who have been through similar experiences have a kind of credibility that is different from medical expertise but likely a helpful component to medical care.

"Something pretty easily digestible, like a podcast or a five-minute interviews on YouTube would be great. Milwaukee Male, 48

"At least tell us that this is normal, tell us more stuff that you can do for self-care." Milwaukee Male, 31

"It helps to learn I'm not alone in this and progress is going on with a lot of people, so it's going to happen to me eventually." Milwaukee Female, 47

- We heard enthusiasm about getting reports and advice via books, videos, or podcasts from others in our groups who had TBIs. Most surprisingly, however, the majority of participants in all four groups expressed gratitude for the support, learning, and connection they found in the *focus group* itself. There was an engagement and sincerity in these groups that we have not experienced in the hundreds of focus groups we have moderated over the years. We think that this is because they had an opportunity to share their stories, were listened to, and had the opportunity to learn from and help others.

Honestly, just sitting in here today, you guys have helped me. Pittsburgh Female, 27

I like the support group idea. People who have had a similar experience, who have gone through what you are going through." Pittsburgh Male, 39

"This has been so great, I feel like this session tonight was therapeutic. I wish it wasn't over. Same time next week, guys?" Milwaukee Female, 47

Aftercare that includes an app would be most welcome.

- There are already portals, e.g. My Chart, used by doctors and hospitals that many of the participants are grateful for and already using. Most of the benefits of these apps seem to be mostly logistical and come from scheduling, remembering appointments, and refilling prescriptions. Many complained, however, that they aren't very user-friendly to begin with and a brain injury makes this even more problematic.

"With My Chart, you get your results, but they are not really intended for the layman." Pittsburgh Male, 60

- Many had tried to become more educated and find more information about their injuries through Google and being directed to websites such as WebMD. There was consensus in several of the groups that this kind of research was counterproductive because it left them feeling paranoid, considering worst-case scenarios. Some websites like the CDC and Mayo Clinic were mentioned as being a bit more educational and less likely to stoke their fears. However, none of these sites seemed to encourage optimism because the context they offer isn't personalized and the patients themselves are left trying to figure out where they stand on a continuum of morbidity.

"I wanted age-specific expectations for symptoms and recovery. Most of what I found were for athletes and older adults." Pittsburgh Female, 25

- A baseline and ongoing cognitive and/or symptom assessment would also be very welcomed by most. Getting help tracking their progress in their healing process held great appeal for many. Many wanted an app that does some sort of regular check-in and assessment so that they can track and be reminded of the progress they are making. We think this would help keep the patients stay engaged and optimistic about their progress, and they would be less likely to normalize their symptoms.

"Having [an app] on your phone just to see your progress as you go would be great. I will get really upset when I can't do what I used to, but then thinking back to where I used to be, it's what helps me keep going." Milwaukee Female, 25

"An app would be helpful as a way for [doctors] to check in on you and to give you little reminders of what you should and shouldn't be doing, how to heal your brain, and a way for you to ask questions." Pittsburgh Female, 54

"Keep following up, 'How are you feeling today, what symptoms are you feeling, has this gotten better has it gotten worse?,' until you are healed. I feel that that's a good reassurance." Milwaukee Male, 24

- There was an aversion in most of the groups to any interactions that seemed programmed, robotic and impersonal.

"It has to be somebody real. Personal stuff is important. It has to have the tone and the sympathy. AI can't do that. We've been brushed off so many times."
Milwaukee Male, 24

Noom is a weight loss app, developed by psychologists. It's like a roadmap. It'll give you these little elementary quizzes and then it'll say, 'Oh, you need to do this, this, and that.' There's a coach that'll check in with you every so often and just say, 'Hey, how are you doing?' If you don't go on the app, you'll get a reminder, "Hey, you haven't been in here in a couple days. Are you okay? Are you good?" It's weight loss, so it explains to you why you have the eating habits that you have, why you do the things that you do, which makes it easier for you to not do what you have been doing because you actually get the reasoning behind it. So with this, I think if it says, 'You're forgetting things and this is why, do these puzzles.' That would be huge."
Milwaukee Female, 47

- Patients expressed a desire for recommendations from experts or from people who had recovered from similar injuries regarding what patients can do to help their brains heal.

"Tell us more stuff that you can do for self-care." Milwaukee Male, 49

"I hate doing nothing. Give me things I can do." Milwaukee Male 31

"I hate Brussel sprouts, but if someone said that eating Brussel sprouts would make my brain get back to the way it used to be, I'm like, oh boy!" Milwaukee Male, 48