

Brain Injury Speaks Survey 2: Accessing Primary and Virtual Care

Summary of Qualitative Responses



Survey Overview

In March 2020, we asked members of the *Brain Injury Speaks* Stakeholder Engagement Network three questions about primary care and virtual care. Approximately 25% of the network (122 members) responded to the survey. A fourth, open-ended question was included at the end to provide participants with the opportunity to comment further about their experience with primary care/family doctors and virtual appointments. 75 participants used this open-ended question to describe their experiences.

Summary of Comments

The qualitative findings are presented in three sections: 1) Virtual Care, 2) Primary Care/Family Doctor, and 3) Other. The themes within each section and supporting quotes are described below.

- 1. Virtual Care (n=10).** Two themes emerged: supporting virtual care, and hesitant about virtual care. Most comments were in support of virtual care, as most participants felt that virtual appointments would save time, reduce stress, improve access, and save money. Three participants highlighted the complex nature of brain injury as a barrier to accessing virtual care. One participant expressed that they are not interested in virtual care because of trouble with spending time on screens.

Quote – supporting virtual care: *“Virtual appointments would be valuable given that I have not been able to find a primary care doctor in my city and have to travel to Toronto (a 1.5 hour drive) to see her for anything. During my worst times post-injury I had regular appointments every week. That would be very difficult now.”*

Quote – hesitant about virtual care: *“The virtual appointments with doctors should be in very limited cases. For patients with brain injury, who often cannot express and identify their problem due to cognitive issues, it is very important that a doctor might observe in-person what is going on. Being isolated already, the brain injury patients should choose if they prefer virtual or in-person, but virtual appointments can put them in more isolation that can lead to deeper depression.”*

- 2. Primary care/family doctor (n=38).** Comments about participants’ family doctors ranged widely. Three broad themes emerged: positive experiences with primary care, concerns about primary care, and neutral perceptions. See Table 1 below for a summary of the themes and participant quotes.
- 3. Other (n=27).** Many of the comments centred around accessing services and knowledge of available resources.

Quote: *“The Guidelines for persistent symptoms from concussion are excellent but are not yet familiar to family physicians (FP). I gave a copy to my FP. She referred me to an ABI clinic that made several concrete and useful recommendations but only after a 12 month wait. My FP helped implement many of these recommendations for potential therapies and pharmaceuticals but the wait time meant a wasted year. A compounding problem was additional wait times from ABI referrals (eg another year for an audiology clinic). Other significant issues include: 1) lack of coordination among providers. Coordination defaults to the compromised patient. Paper reports rarely reach other providers files, even with consents. 2) Conflicting recommendations from different*

providers (blind men and the elephant problem – each provider treating a symptom in isolation). 3)
 The busy environment of hospitals and health providers offices which aggravate symptoms.
 Telephone appointments would be much easier.”

Table 1
 Primary Care/Family Doctor –Themes and Participant Quotes

Theme: Positive experiences with primary care	Theme: Neutral Perceptions	Theme: Concerns about primary care
Subthemes	Subthemes	Subthemes
<p>-GP is very supportive and willing to learn/attend extra training about brain injury</p> <p>-GP is thorough and conscientious</p> <p>- GP addresses basic needs and finds the right specialist or service to refer to</p> <p>-GP has been helpful and supportive in doing the associated paperwork</p>	<p>-Family doctor has minimal knowledge about brain injury, but is willing to make appropriate referrals</p> <p>-GP is inexperienced with brain injury care, but I have specialists who provide treatment for me (e.g. physiatrist)</p> <p>-Other rehabilitation professionals (chiropractor or physiotherapist) provide primary care</p>	<p>-Resorting to finding resources and helpful information online or from other sources because family doctor has not been helpful (e.g. GP has never treated anyone with TBI before)</p> <p>-Primary care visits focus on other issues (e.g. diabetes) and do not address underlying brain injury symptoms (e.g. fatigue)</p> <p>-Seeking care from alternate providers (e.g. chiropractors or physiotherapists) because family doctor does not have knowledge about brain injury</p> <p>-Challenges getting appropriate referrals and length of time to make referrals</p> <p>-No support provided for navigating the system/available resources</p>
<p>Quote: <i>Although we attend a clinic setting associated with McMaster University we have always seen the same person. My son's physician is a very caring and patient young man who is interested and highly motivated in dealing with ABI issues. If he does not know the answers he seeks assistance, he listens and guides my son. We have never felt slighted or overlooked, misunderstood or rushed, and an exemplary trusting relationship has developed.</i></p> <p>Quote: <i>I am 'fortunate' that my the sister of my family doctor also has a brain injury/post concussion syndrome as this gave my doctor motivation to learn as much as she could, and also makes her very understanding and supportive of me as her patient.</i></p>	<p>Quote: <i>My family doctor is inexperienced with brain injury and treatment but I luckily have a physiatrist that I see that deals with brain injury treatment. The physiatrist is knowledgeable and continues to be investigate new treatments but he deals mostly with pain and symptom control.</i></p> <p>Quote: <i>My primary care family doctor is very supportive but I had to bring ideas to him for services available to me. He never questioned the symptoms I reported to him, thankfully. But I believe that family doctors should have more information about brain injuries.</i></p>	<p>Quote: <i>My experience is that primary care providers know next to NOTHING about brain injuries, and generally do more harm than good. The ER can tell you if you've got a bleed or an actual crack but not much else. They don't recognize that whiplash is also brain injury and tell you you don't have a brain injury when you do. Basically I know way more than any primary provider. I've had to learn it on my own, and thank god for Facebook groups where I have gotten the most help. I've gotten the most help from several different types of chiropractors who have been actually trained in dealing with brain injuries (unlike primary providers!). The REAL help in dealing with post concussion issues is not paid for by OHIP</i></p>