

## **Understanding the views of people affected by Traumatic Brain Injury on the optimised clinical pathway**

### **Background**

In May 2021, UKABIF facilitated a series of four focus groups with people affected by brain injury to review the draft optimum clinical pathway for traumatic brain injury. Authors of the pathway, including Dr Peter Jenkins and Dr Mike Dilley, alongside The Neurological Alliance, presented the pathway and facilitated the session.

### **Who took part?**

16 people affected by brain injury signed up to take part in the focus groups which were held online.

### **Key findings**

Overall, people with brain injury were broadly supportive of the pathway as presented.

- **Scope of the pathway:** All the groups we consulted with asked that acquired brain injury be included in the pathway, recognising that treatment and support for this group is also subject to significant unwarranted variation
- **Use of remote technology:** A number of participants felt that the role of digital technology, including remote consultations, could perhaps be considered in greater detail in the pathway. Attendees of the focus groups reported mixed experiences of such technology, particularly during the COVID-19 pandemic. All groups felt there might be a place for appropriate use of remote consultations, but this varied from person to person. For example, one member of the focus groups reported good experiences of accessing psychological support remotely, whereas others felt this wouldn't be appropriate as it may be difficult to build a rapport. Concerns about possible digital inequalities were also raised.
- **Role of the third sector:** Multiple attendees highlighted the importance of the voluntary sector in providing peer support, information and advice.
- **Navigating the support available:** A number of suggestions were put forward by attendees that could help people with TBI to navigate the treatment, care and support available to them. For example, one group felt that a directory of appropriate third sector organisations providing information and advice would be invaluable. Every group agreed that a first point of contact and/or case manager are absolutely critical.

- **Possible co-morbidities associated with TBI:** A number of participants felt that co-morbidities associated with TBI, including mental health conditions, could be better captured in the pathway in order to improve coordination and delivery of the support available to manage these. It was also recognised that co-morbidities may vary according to different sociodemographic characteristics.
- **Unwarranted variation in access:** Every group felt their was a 'postcode' lottery of services available, and felt this pathway would be helpful way of levelling up access to support. A number of participants felt that those who experience TBI at a younger age may require more support.
- **Presentation of the document:** Although every group found the pathway useful, particularly after the authors talked through it, participants felt there may be opportunities to simplify the pathway, or design it in such a way that is centred around the individual rather than 'tiers' of service.

### **Barriers to implementing the pathway**

The groups recognised that the pathway as laid out simply does not exist in many areas of the country.

In particular, they felt that knowledge and expertise of the health and care workforce in TBI may be a key barrier to its implementation.

Additionally, there may be opportunities to better support people with TBI and those closest to them to 'self-manage' their condition, but support to do this is not always available/accessible.

Participants felt that the political and public will to improve services may be lacking, and that evidence of the cost-effectiveness of the right services at the right time may help to secure the political will required.

### **Next steps**

The authors of the pathway have taken into account the feedback on the pathway and incorporated this in the final pathway document.

UKABIF and the Neurological Alliance will also work together to assess options to design up the pathway for use by people with neurological conditions.

The final pathway will be published on the NNAG website in 2021.