

Finding the Gaps: The Development of the Brain Injury Unmet Needs Directory

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Background:

The term brain injury covers a wide variety of individual conditions including stroke, hypoxic brain injury and trauma and is a leading cause of morbidity and mortality in the UK and worldwide¹. Traumatic Brain Injuries (TBI) alone result in approximately 1.4 million attendances to A+E in England and Wales each year and is the leading cause of death in the under 40s². Those who do survive moderate or severe injuries often have long-term disability which impacts upon their ability to participate within society, and leads to a considerable carer burden for families and society at large. Even so-called “mild” brain injuries are increasingly being seen as having negative outcomes³.

The NIHR Brain Injury Healthcare Technology Cooperative (HTC) was set up to “Find, Facilitate and Foster” the solving of problems for this patient group through technological solutions. To do this a “Value Chain” (Figure 1) was developed which aims to establish an enabling process of infrastructure to improve the readiness of technology solutions for NHS use. The first step in the value chain is “Find”. In order to “Find” these problems a wide range of activities were undertaken over the course of 5 years in order to develop a “Directory of Unmet Need”.

Aims:

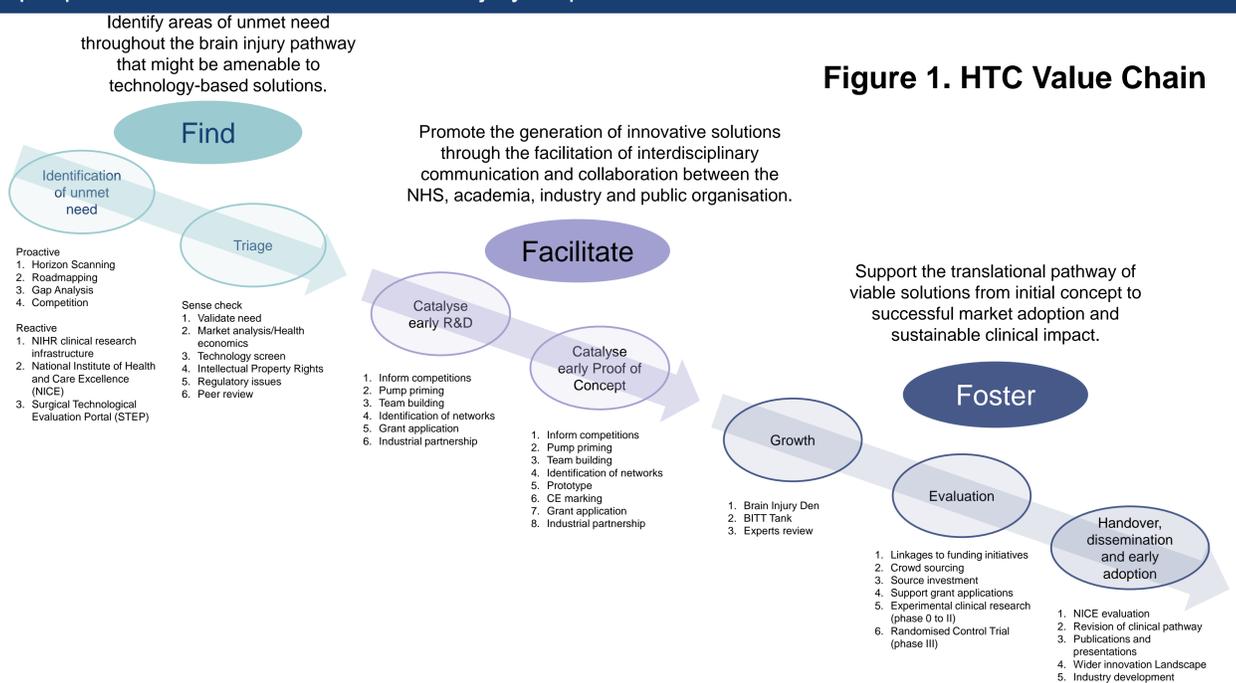
To “Find” unmet needs that people and families have after brain injury as part of the HTC’s value chain.

Methodology:

The development of the Unmet Needs Directory aimed to discover issues faced after brain injury from many different perspectives including; Patient, Carer, Family, Academic, Clinical and Industry.

To achieve this a total of 5 different methods were used. These were; **Horizon Scanning, Roadmapping, Competitions, Reactive Identification and Gap Analysis.**

Horizon Scanning by the project leads provided the areas focused on during the 5 Competitions and 10 Roadmapping events. Different events targeted different stakeholder groups. Reactive Identification was undertaken across the course of the 5 years. The difficulties identified through these methods fed into the Gap analysis that forms The Unmet Needs Directory.



Results:

In total 70 items were identified through the various methods. Of these 12 were removed as duplicates, 2 were no longer valid and 1 was unsuitable as a technological solution. This left a total of 55 items. 22 of these were sent out to patient and public involvement (PPI) sources as they had originated from PPI activities, 9 were accepted as is and 13 were reworked in response to their comments. From these 4 “Common Areas of Need” were found:

Common Areas of Need

Patients and families after brain injury value consistent high quality information⁴. The development and implementation of technologies focused on communication would optimise the experience of patients and their families.

Communication

Through optimising and standardising the access to, and use of existing technologies, patient care can improve⁵. Systems that continually drive quality and technological improvement also need development if progress is to continue⁶.

System Optimisation

The development of specific technologies is needed to solve specific problems in the sphere of brain injury⁷. Many will require development of sophisticated technologies⁸. However, others may be patient specific and may not be financially viable on a large scale.

Technological Developments

Knowledge Building

There continues to be a lack of knowledge around brain injury³. The development of a deeper understanding around all aspects of brain injury is needed⁹.

Conclusions:

Technology shows considerable promise when it comes to improving the lives of people after brain injury. While some needs will be solved by the development of specific technologies, others will require the creation and implementation of systems and best practice guidelines.

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