

NIHR Brain Injury Healthcare Technology Cooperative- Brain Injury Unmet Needs Directory
FINAL DRAFT - MIC MANAGEMENT COMMITTEE (11 OCTOBER 2018)

The Brain Injury Unmet Needs Directory was developed by the NIHR Brain Injury Healthcare Technology Cooperative (HTC). It aims to illustrate some of the possible unmet needs that may exist in the brain injury patient pathway. It is the result of 5 years of unmet need identification activities including workshops, surveys and competitions. Each need and detail is a true representation of the result of the activity. However, each need is the opinion of the person who submitted it and does not reflect the opinion of the NIHR, the Brain Injury HTC or any other body and caution should be used in drawing generalisable conclusion from these. The Methodology by which the need was identified is presented as well as the Brain Injury HTC that covers this need. The directory is also searchable by key word.

Ref	Unmet Need	Detail	Key Words	Method
1	High Quality R+D infrastructure for clinical care to improve understanding of the care of people who have suffered a brain injury and their outcomes	Research and development infrastructure for clinical care remains sub optimal. There are significant gaps especially in areas such as rehabilitation after brain injury. Development of high quality infrastructure would drive improvements in research and therefore public awareness of brain injury and outcomes for patients.	Infrastructure, Research	Roadmapping Brain Injury Patient Pathway, 2014
2	Provision of optimum Neuroprotection to every child who requires it	Neuroprotection is an effective way of reducing secondary brain damage in the neuro neonatal intensive care unit. However access to neuroprotection for neonates after brain injury is not always standardised. Focus should also be on developing further understanding of the mechanisms of neuroprotection, improving current protocols and developing novel adjuncts.	Neonatal, Neuroprotection, Technology	Roadmapping Neonatal Critical Care, 2016
3	While on the Neurological Intensive Care Unit all patients should have consistent access to high quality services which aim to improve their outcomes such as (but not limited to) Physiotherapy, Music therapy and Keyworkers.	Neurocritical care units (NCCUs) improve patients outcomes after brain injury. Services could be improved further through consistent and timely access to high quality therapies such as physiotherapy or music therapy. Communication with family needs to be consistent and this may be improved through the development of key worker roles and a designated point of contact within the patients family. The use of appropriate assessments to reveal the full extent of the injury should become standard practice, as should support for patient and family when the patient is being discharged from the unit since this is a time of considerable strain.	Neurocritical Care, Family, Experience, Therapy	PPI Unmet Needs Initiative Intensive Care Workshop, 2015
4	Patients to have continuing access to high quality care throughout their journey on the Neuro Intensive Care Unit but also after discharge from there to ward, rehabilitation and community based care.	Patients who are discharged from NCCUs often require continued specialist support. The development of staff outside of NCCUs needs to be a priority. Rapid access to high quality rehabilitation services remains sub-optimal, which limits patients' potential. Care after brain injury often includes periods of intense stimulation as well as rest. A fuller understanding of the optimum ratios of stimulation to rest is required to maximise potentials. The development of a patient-owned information platform and consistent communication pathways between NCCU, acute ward, rehabilitation and community services will improve patient outcomes and prevent information loss. Rehabilitation prescriptions may aid in this area however so far their take up has been inconsistent. Patients and families should be central to discussions of expectations and future plans. Practical support should be available to all patients and their families after discharge from inpatient services.	Neurocritical Care, rehabilitation, education, technology	PPI Unmet Needs Initiative Intensive Care Workshop, 2015
5	Patients to experience an optimum journey within the Neuro Intensive Care environment	The experience of the patient should be central to all developments of the NCCU. Measures to impact on patients' mood while on NCCU should be improved. Music and lighting have been hypothesised as possible routes to achieve this however work is required to investigate their use. Patients also often need support in understanding events during their time on intensive care. This is complicated as patients often lack memory of their time on NCCU. <i>Concerns should be ideally dealt with at the time. A culture of collaborative working between family, patient and professionals should be developed in order to deal with issues as they arise to minimise complaints and maximise patient experience.</i>	Experience, Neurocritical Care, Technology	PPI Unmet Needs Initiative Intensive Care Workshop, 2015
6	Consistent and timely high quality communication between all members of the multidisciplinary team, family members and patients within appropriate environments. This should be facilitated through a Lead Point of Contact or Keyworker.	Communication between clinicians and the patient and their family is vital within the NCCU and every effort should be made to improve this. Self management should be promoted by staff where possible and the use of patient diaries may be of benefit in supporting patient understanding. Supporting communication with patient families can be complex but possible solutions could include increased use of information technology in the relatives room, explanation to families of procedures, monitors and supportive equipment, as well as encouragement to talk about their experiences. The charity sector is likely to have a role to play in this arena. Either through currently offered meetings with patients and families or with novel interventions aiming to encourage access to their services. Continuity of care is also vital and should be led through a lead point of contact. Communications methods between staff should be consistent and of high quality to ensure high quality care for the patient and their family.	Neurocritical Care, Communication, Continuity of care, Family	PPI Unmet Needs Initiative Intensive Care Workshop, 2015
7	For clear and concise information on the patient's journey after brain injury to be available to patients and their families when and where they choose to access it.	Providing the correct information to the correct person at the correct time can be challenging on the NCCU. Current information can be "too wordy". Language should be accessible and appropriate to the population targeted. Some items of information identified in particular include what services are available to people after brain injury and how to access them. Possible solutions to this include the increased use of key workers, and the development of information libraries in either paper or digital forms with a variety of fonts and levels of information to enable families and patients to access the information they require as they are able.	Information, Family, Experience, Neurocritical care	PPI Unmet Needs Initiative Intensive Care Workshop, 2015
8	Provision of high quality and fidelity patient monitoring to all who need it.	High quality and fidelity patient monitoring is vital to many patients. This should be further developed and form an active part of clinical decision making. Adequate funding and fostering of collaborations between stakeholders will need to be central to this. Developments should include refining data capture, improving analytical software and specific technological products such as intercranial pressure, non invasive near-infrared spectroscopy, electroencephalogram, sensors and biomarkers.	Monitoring, Technology,	Roadmapping Brain Injury Patient Pathway, 2014
9	Timely access to imaging and monitoring is vital for patient outcomes. This should be routinely available and used to optimise patient care.	Imaging and monitoring is central to modern care of the brain injured patient. This should be made available as close to the point of injury as possible. Differing imaging sources are required and they should be collated to the benefit of the patient. Access especially to blood biomarkers and CT scans should be made available at the earliest opportunities. Further understanding of the impacts of these measures on final outcome or rehabilitation of these patients is still required.	Imaging, Monitoring, Technology, Trauma	Roadmapping Taster, 2014
10	For next generation imaging technologies to be integrated into current clinical patient care in order for clinicians, patients and their families to be able to fully understand a patient's condition and probable outcomes and to plan their future treatments and care.	Many next generation imaging technologies find translation into direct clinical use a difficult barrier to overcome. Costs and accessibility to technologies can both limit their use. The benefits that they can bring however, in terms of a fuller understanding of a person's brain injury and therefore their optimal treatment and likely outcomes cannot be overlooked. Patient's, families and their clinicians are currently often frustrated with the information that the current clinical imaging technologies can provide and the uncertainty this brings. Amongst other technology that could provide clinical benefit but at present has limited real world access are: Software and integration tools for rapid imaging, new ligands for positron emission tomography, single-photon emission computed tomography as well as novel imaging modulation from prone to 2D imaging. An implementation consortium may aid considerably in bridging this gap between new technologies and clinical practice.	Imaging, Technology	Roadmapping Brain Injury Patient Pathway, 2014
11	Technological approaches need to be piloted which aim to prevent avoidable emotional and cognitive problems after acute brain injury.	The development of technological approaches for assessing and addressing cognitive problems is likely to be of benefit to people after brain injury. Funding should be secured to develop pilot programmes to investigate suitable technologies in coordination with patient and carer groups as well as frontline staff and commissioners.	Cognition, Technology	Roadmapping Brain Injury Patient Pathway, 2014
12	To identify public perceptions and modifiable health psycho-social demographics.	The identification of public perceptions of brain injury as well as modifiable health psycho-social elements will better allow allocation of scarce resources to address potentially modifiable aspects that patient will encounter. Identifying these aspects and how to address them may enable patients, rather than disable them further as is often the experience of patients and their families after brain injury. This is likely to improve health outcomes and participation in society.	Attitudes, Environment, Enabling	Roadmapping Community Services, 2015
13	For all patients after brain injury to have a central rehabilitation record which follows them throughout their lifelong journey. This would include validated outcome measures and predictive markers which will enable understanding of response to neurorehabilitation and long term outcomes.	Communication can be difficult across NHS sites. Many trusts have non-compatible systems which limit ability to joint work. This is can be frustrating for patients and introduces the risk of data loss when transfers occur. Technologies should be optimised to encourage joint working in order to improve knowledge transfer and patient outcomes. Useable, open and scalable standardised products and services should be the aim of national procurement and technology innovators. This provides a particular difficulty in lengthy processes such as rehabilitation after brain injury. Currently rehabilitation records are unstandardised and do not provide means for transmission between sectors or services. The development of an integrated patient rehabilitation record is therefore required to prevent duplication and accidental deletion of patient information. This is likely to have impacts on communication between services as well as reducing burden on the patient for constant retelling of their rehabilitation journey. Establishing funding for this is likely to be pivotal.	Rehabilitation, Information, Technology	Roadmapping Brain Injury Patient Pathway, 2014
14	For rehabilitation across the patient's journey to be fully supported by technological solutions. These solutions should be identified in a systematic and transparent way with evaluations of technologies conducted at regular opportunities in order to best inform patients, carers and professionals.	When people have returned home Telerehabilitation may aid in improving outcomes for patients. The best route for doing this however has not been found. Gaining an understanding of the role that telerehabilitation will have on patients outcomes is therefore important. Possible areas include; how to deliver the required level of functional task training to those with significant impairment, designing mobile technologies for self-management of psychological problems and evaluation of telerehabilitation against traditional rehabilitation to ensure quality is not compromised.	Technology, Environment, Community Care	Roadmapping Brain Injury Patient Pathway, 2014 Roadmapping Taster, 2014
15	For people with a brain injury to be able to influence, shape and participate in research at all stages of their journey and for this research to be used to improve their outcomes	Research is a cornerstone of modern clinical practice which drives forwards clinical standards. Currently the focus of this is in the acute hospital environment. After brain injury there are limited opportunities for patients to participate in rehabilitation when they have returned to the community. This holds back clinical practice and patients' experiences of services as well as their final outcomes. Guidelines, clinical attitudes and technologies to facilitate research becoming central to the patient's experience should be fostered.	Research, Community Care	Roadmapping Community Services, 2015
16	Optimising people's self management of their long term chronic condition after brain injury	Brain injury is increasingly becoming a chronic condition. With healthcare services focused on supporting in the short rather than long term, self-management is key to the patient's final outcomes. Technologies and services should be focused on improving peoples' ability to self manage their condition. This could start in the acute hospital and include technology such as health coaching apps. The aim would be to optimise the use of services and resources and improve patient experience.	Technology, Self Management	Roadmapping Community Services, 2015
17	To maximise the physical activity of people post brain injury.	Physical activity is important to all sections of the community and this is particularly true in people after brain injury. The use of commercial off-the-shelf tools and accelerometer-based technologies may help to guide people in progressing against personal goals.	Technology, Self Management, Physical Activity	Roadmapping Brain Injury Patient Pathway, 2014
18	To have a robust process to identify patient unmet needs that can be met with medical devices	Technologies are increasingly moving into the brain injury sphere. A robust method of continually collating patients' unmet needs and presenting these in a format that is accessible to innovators will facilitate development of technologies which will have a real impact on peoples lives after brain injury.	Technology, Research	Roadmapping Taster, 2014
19	To have a robust method of analysing risk with regards to medical technology that would have benefits for people who have suffered a brain injury	Risk analysis provides innovators, clinicians and policy makers with vital information to allow prioritisation of technological developments as well as facilitating their development. A robust method of using this within the brain injury health sphere is therefore required.	Technology Research	Roadmapping Taster, 2014
20	To be able to measure sleep accurately in infants in the neonatal critical care environment	Sleep is vital to all. Infants in the neonatal environment have multiple procedures and cares undertaken which can disrupt their normal rhythms. These may impact on their developing brain. Currently sleep is not measured in the clinical environment. However, a technology which could accurately measure sleep cycles would enable clinicians to minimise disruption to the neonate. This would also allow research to be undertaken in the field and gain a fuller understanding of the importance of sleep in this population.	Neonatal, Monitoring, Technology	Roadmapping Neonatal Critical Care, 2016
21	For all children who have had a brain injury to be able to access medical and therapy expertise as close to their home as possible.	Services for children after brain injury are localised in specialist centres in the UK. This allows expertise to be concentrated with the hope of improving services. However the negative disruption to families and children who have to travel great distances to access care is significant and may mean that they do not access the services they need. Therapy should be able to access medical and therapy expertise as close to their home as possible. This may entail innovative service designs or an increased use of technology to facilitate its development.	Children, Rehabilitation	Roadmapping Paediatric Neurorehabilitation, 2016
22	For all those who come in contact with a child who has had a brain injury to have a shared understanding of that child's journey	Brain injury is poorly understood by the wider community. This places burdens on children and families in repeatedly having to explain symptoms and behaviours. An education platform that provides accessible and context specific brain injury resources, especially (but not limited) to healthcare and education professionals, is needed to fill this space and to enable children to reach their full potentials.	Children, Technology, Education	Roadmapping Paediatric Neurorehabilitation, 2016
23	For family and professionals to have an up to date awareness of resources and support available to help the child and family	Services for children after brain injury are often area specific and everchanging. This provides a difficult situation for clinicians in being aware of and directing families to services which may benefit them. An up-to-date, searchable database which is frequently updated would improve access and reduce duplication of services. The appropriate clinical population, aims of services and effectiveness of these services should be also recorded and form part of the record.	Children, Rehabilitation, Technology	Roadmapping Paediatric Neurorehabilitation, 2016
24	To establish a centre for rehabilitation technology evaluation, advice and coordination of services and research	Technologies for brain injured children are actively developing. Although this brings opportunities for improving outcomes it also provides a dilemma for clinicians in knowing which technologies are beneficial in a limited resource environment. A centre for evaluating rehabilitation technologies and presenting this in a way that is accessible for clinicians will improve families' access to existing and emerging technologies which will improve their lives.	Children, Rehabilitation, Technology	Roadmapping Paediatric Neurorehabilitation, 2016
25	For real time video monitoring to be available to all parents who wish it when their child is in the neuro neonatal critical care environment	Parents with children in the neuro neonatal critical care environment often find themselves having to juggle work and families commitments, limiting the amount of time they can spend with their child. This may impact on bonding and cause considerable distress to parents. Real time video monitoring which is accessible to families who wish to use it may limit this disruption. Considerations to data security will be central to development of this technology, but it may also provide a new path for research to improve children's outcomes.	Neonatal, Technology, Family, Monitoring	Roadmapping Neonatal Critical Care, 2016

26	For real-time multimodal monitoring to influence individual management of preterm infants in the neuro neonatal critical care environment	Real time multimodal monitoring of patients is an emerging health technology. The impacts that this could bring to the care of the pre-term infant is considerable. Technologies should be developed which allow multimodal monitoring to be used in all patients who need it. Development of algorithms which allow clinicians to use this data to individualise patients care may improve the child's care and final outcome.	Neonatal, Technology, Monitoring	Roadmapping Neonatal Critical Care, 2016
27	For all children who may benefit from it to have access to continuous EEG monitoring within the neuro neonatal critical care unit.	Seizures are a common problem in children after brain injury and may cause further damage to the developing brain. The seizures however can be subtle and difficult to diagnose. A consistent use of EEG caps would aid diagnosis of seizures and the development of algorithms which would allow clinicians to better understand the child's seizures and action on this early may improve outcomes. The ability to constantly monitor seizure activity would also be a gateway to research to further improve care.	Neonatal, Technology, Monitoring, Neuroprotection	Roadmapping Neonatal Critical Care, 2016
28	A, complete and easily accessible patient information portal to be available to all people who have had a brain injury. This should signpost them to services and support that are available to them.	People after brain injury often find it difficult to locate appropriate and accessible information on brain injury or services available to them. A central, patient facing portal is required to guide patients to information which could benefit them and their families.	Information, Patient, Family, Technology	Roadmapping Brain Injury Patient Pathway, 2014
29	To maximise the use of mobile tech within the management of the brain injury patient to improve patient outcomes and experience.	Mobile tech shows considerable promise when it comes to improving the lives and outcomes of people post brain injury. A robust method of identifying unmet needs, feeding this forward to technology innovators, overcoming difficulties such as interoperability between service providers and evaluating products is required to foster good practice. A universally agreed standard for data collection and management should be developed for all medical devices and collected information to ensure confidentiality and high quality data.	Technology, Research	Roadmapping Taster, 2014
30	To optimise the data management of patients in order to reduce duplication and fragmentation which may impact on patient care	Data management is key to the introduction of medical technology. While the innovation that is being developed in the field of brain injury promises considerable benefits, there is a risk of duplication and fragmentation which would lead to poor patient care. Integration and interoperability should be a central aspect of medical technology development.	Technology, Data	Roadmapping Community Services, 2015
31	Neuro Neonatal Intensive Care Units to be centres for innovation and development	Research and development is not seen as an essential element of the patient pathway within the Neuro Neonatal Intensive Care Unit (Neuro-NICU). As well as developing a culture of innovation within the Neuro-NICU systems should be in place for repurposing of drugs for rare neurological disorders to improve children's care and outcomes.	Neonatal, Technology, Research	Neonatal neurocritical care – finding and filling the gaps
32	To have a full definition and understanding of paediatric head injury and their long term outcomes	Families and children often find the uncertainty of brain injury difficult. A full definition and understanding of brain injury and its impacts on children is needed. Part of the complexity of this is the role that the hidden injury plays in outcomes and should not be neglected. With the understanding that this would bring, development of the best way to combat problems that children and families find can be developed, and best therapy practice established.	Children, Information, Family, Research	Paediatric neurorehabilitation – finding and filling the gaps
33	For communication to be standardised across the child's journey after rehab and for this to be shared across sectors	There is no standardised way of information to be transferred between services after a child's brain injury. This can mean that handovers are of variable quality and are sometimes missed. A clear defined rehab prescription would minimise burdens on families and enable a shared understanding across family, school and health.	Information, Children, Family, Rehabilitation	Paediatric neurorehabilitation – finding and filling the gaps
34	High quality, consistent and timely information to be available to families at any time following brain injury.	Families require access to the best information possible to ensure the best outcome for their family member. In the hospital setting a single point of information is required to enable family to access consistent and high quality information. This should continue across the care continuum as families' need for high quality information does not change. Times of transition are particularly stressful for patients and support should be particularly focused on these times. This single point of information should also focus on signposting of support, for example local council and financial support.	Family, Information, Communication	Carers workshop Online Survey
35	Families to be central to decision making where they are able to and wish to be involved.	Families should be included in all decision making processes when their loved one has had a brain injury and systems should be in place to allow this to occur when and where patients and families wish for this to happen. This may improve empowerment for those who have had a brain injury and their carers. Identification of who should be involved in this decision making can often be difficult especially in the case of estranged family members. This process should be standardised where able and guidelines agreed.	Family, communication	Carers workshop Online Survey
36	For families to be able to access professionals with appropriate experience when their relative has had a brain injury	After someone suffers a brain injury, support for families should be provided by a team of professionals and carers with experience of working with people who have had a brain injury. The difficulties that families have with services becomes particularly clear when they are dealing with non brain injury specialist services such as social work. Families want confidence that the highest possible quality of care is being provided to the person who has suffered a brain injury. Families often come up against obstacles in accessing these services which means they give up on pursuing something that would benefit their loved one. This should be minimised as much as possible. The development of an education system for non specialist clinicians will aid in building this capacity.	Family, Communication, Experience	Carers workshop Online Survey
37	Consistent staffing around a patient who has suffered a brain injury and their family	Providing consistent staffing around the brain injury patient can prove to be a significant difficulty for many services. The benefits that this can bring however should not be underestimated. Families appreciate the continuity that this brings and builds their confidence in the care that is provided, patients are able to develop relationships with staff which improves their experience and staff are able to provide more informed decisions as well.	Family, Experience	Carers workshop Online Survey
38	Optimising technologies which prevents avoidable brain injury from occurring	Technologies which prevent brain injury from happening should continue to be developed. Two specific examples of preventing falls from heights and protection for cyclists were identified, but there are many more. With regards to protection for cyclists poor helmet design and fit need to be addressed - current technologies are bulky to carry around and there is no built-in indication for when they need to be replaced.	Technology	Mind Your Head Challenge
39	For cognitive aspects of brain injury to have as little impact on patient's functioning and wellbeing as possible	People after brain injury can often find cognitive tasks more difficult. New technologies could have significant impacts on people lives. The following list has been identified but is in no way exhaustive. <ul style="list-style-type: none"> • Performing household tasks (People with BI forget how to perform tasks) • Remembering what has been read (Poor short term memory) • Remembering schedule for day (Poor short term memory) • Dressing in the morning (Can't remember order of clothes) • Watching television (Poor short term memory and attention) • Knitting (Poor memory, hard to follow sequences) • Reading map or understanding directions (Poor planning, memory and easily distracted) • Using public transport (Inability to plan (cognition)) • Shopping (Poor memory) 	Technology, Rehabilitation, Cognition	Mind Your Head Challenge 2015
40	For technologies to be developed which focus on the specific requirements of people living with brain injuries.	Technologies should be actively developed which focus on people who have had a brain injuries specific needs. Needs should be identified by patients and carers in real time and a central record kept. This should be made available to innovators and technological experts who can help develop these products to improve lives. Many people after brain injury in particular value technologies which don't make them stand out. Ideally technologies should be as unobtrusive as possible and other people should not be aware that they are being used.	Technology, Rehabilitation	Mind Your Head Challenge
41	A complete, easily accessible unbiased and understandable resource for people with brain injury and their families to signpost them to support available	Patients and families are often unaware of various services that may help them. A central point of contact to guide them through identifying and accessing this would be of benefit. If this is not possible then a technological solution of a central and updated platform may be able to aid in this need.	Rehabilitation, Family,	Mind Your Head Challenge
42	For administration errors to not impact on the person's journey after brain injury	Administration errors have a frustrating but significant impact on the quality of care that patients receive. All such errors should be minimised or eliminated where possible. Systems and technologies should be in place to focus on this. An identified point of contact for patients and carers to clarify possible errors may be of benefit.	Experience	Acute Care Survey
43	For all patients to have regular outcome measures taken in order to track progression and influence wider understanding of brain injury	Measuring outcomes in people after brain injury is vital across their whole journey. This not only allows progress to be tracked for individual patients but also for a greater understanding of brain injury to be developed. In the UK, this is especially evident in the care of children, while in Brazil, context and language appropriate outcome measures are lacking and must be addressed if care is to be improved.	Outcome Measures, Rehabilitation, Children	UK-Brazil Acquired Brain Injury Researcher Links Workshop
44	For the natural recovery after stroke to be fully understood by clinicians and for this to impact on patient care.	The natural recovery progress after stroke is not understood. Through the consistent and long term functional tracking of patients after stroke a fuller understanding of this would be developed, which would enable care to be improved for these patients. Methods of consistently measuring and recording this throughout the person's after stroke lifetime are therefore required.	Outcome Measures, technology	UK-Brazil Acquired Brain Injury Researcher Links Workshop
45	Service collaboration to be improved through the development of an international map of services.	Research on brain injury occurs in many countries. However these often occur in silos and this limits progress. The development of an international directory of services and research groups would allow greater collaboration internationally and open new avenues for progress.	Research	UK-Brazil Acquired Brain Injury Researcher Links Workshop
46	For children when at home to be supported in participating in wider society.	Children after brain injury often struggle to access the wider world as easily as they would have done pre-injury. This is a particular problem in Brazil but also applies within the UK. The disabling environment that children and their families encounter can make a significant injury even more disabling. Interventions should be focused on encouraging and supporting children and their families in participating in their environment. A systematic way of collating particular elements that inhibit children from participating should be developed as well as a way of addressing them as able.	Children, Rehabilitation, Environment	UK-Brazil Acquired Brain Injury Researcher Links Workshop
47	The impacts of fatigue should be minimised and the management of it should be central to the patients experience at all stages of their journey.	Fatigue is an often overlooked but devastating symptom after brain injury. It has impacts on all parts of the life for people after brain injury. Research into fatigue is of considerable importance as is methods of minimising its impacts. Technology could have a role in both. The development of a central platform to provide information and education to people who have suffered a brain injury, the research community, and clinicians would be one possible avenue. This concentration of information would raise the profile of the issue and may provide new insights which could show the way to improving the lives of people after brain injury.	Technology, Experience	Norway Fatigue Roadmapping Event 2017
48	A consistent method of measuring for possible painful stimuli in the Neonatal Intensive Care Unit	Pain is a complex phenomenon which is especially true in the neonatal population. Many procedures that occur in the Neonatal Intensive Care unit are possibly painful for the child but it is difficult to fully understand this. A consistent method of measuring or assessing pain in neonates is needed in order to improve patient care and to minimise distress to child and parent.	Neonatal, Technology, Experience, Research, Family	Neonatal Parents Roadmapping Event 2017
49	For professionals to be able to access imaging that allows the clinician to provide parents with an understanding of what the impact their child's brain injury is going to have on their child. (reworked)	Imaging in the neonatal population is difficult. Many children are too unwell to be transported to scanning and often images are not able to provide clinicians and families with the information that they need to plan the future. Development of technologies and imaging that provide a complete picture for clinicians and parents for infants after brain injury are required in order to best prepare parents for their child's eventual outcome.	Imaging, Neonatal, Research, Family	Neonatal Parents Roadmapping Event 2017
50	For all parents to be supported in providing Kangaroo Care to all appropriate children within the Neonatal Intensive Care Unit.	Kangaroo care in the Neonatal Intensive Care Unit can provide bonding and developmental benefits to the child and family. However, clinicians skilled in its use are not always available to support this. More staff members with skills in this area are required as are educational resources to parents on its use.	Experience, Rehabilitation, Family	Neonatal Parents Roadmapping Event 2017
51	Communication to be individualised to each family, with information available to them when, how and where they choose to access it, and for clinicians to be available to answer their questions.	Parents whose children are admitted to a Neonatal Intensive Care Unit often require information to best prepare themselves for the future as well as understanding the present. Every parent has different needs and identifying these can be difficult. Provision needs to be made therefore of high quality information through a variety of means, written and spoken when and where the parent is able to access it.	Neonatal, Family, Communication	Neonatal Parents Roadmapping Event 2017
52	For all people after brain injury to have normal sleep patterns	People after brain injury often suffer from disrupted sleep patterns in the long term. This can have significant impact on fatigue and overall health. Understanding of the causes, mechanisms and best treatment/management of this is required. Behavioural interventions have shown some promise however more research and innovation in the area is required.	Research, Community Care, Experience.	Brain Injury Rehabilitation Trust Annual Conference Roadmapping Event 2017
53	Psychosocial support to be available to all after brain injury especially those who lie outside of traditional services.	Many patients after brain injury do not match the criteria for traditional services for psychosocial support. They often however have needs that would benefit from support. Novel methods of providing this support will be required as possible impacts on services which are currently stretched is unlikely to be sustainable, but the benefits that could be found from providing this in terms of early detection of difficulties as well as improved wellbeing and health outcomes are possibly significant.	Experience, Community Care	Brain Injury Rehabilitation Trust Annual Conference Roadmapping Event 2017
54	For nationally agreed gold standard paediatric brain injury outcome measures to be in place and used on all children who require it.	Outcome measures in the paediatric brain injury population are often invalidated in the condition, or sparsely used. This has limited research into childhood brain injury and evaluation and improvement of services. The development of sensitive, valid, reliable and user friendly outcome measures which are appropriate to the child is therefore required. Consistent use by clinicians will also be a barrier to overcome.	Children, Outcome Measures, Research	Brain Injury Rehabilitation Trust Annual Conference Roadmapping Event 2017
55	For all children after brain injury to have access to nationally agreed gold standard care	There is no nationally/internationally agreed gold standard model of care for children in the community after brain injury. Work should be undertaken to develop guidelines for this. Research is likely to be needed as is investment in new and innovative services.	Children, Rehabilitation, Community Care	Brain Injury Rehabilitation Trust Annual Conference Roadmapping Event 2017