Paediatric neurorehabilitation – finding and filling the gaps

Workshop facilitated by the Institute for Manufacturing, Education and Consultancy Services, Cambridge, 9 March 2016

Contents

1. Clinical vision

Acquired brain injury (ABI) in childhood is a leading cause of death and disability nationally and globally. The NHS Service Specification for Paediatric Neuro-rehabilitation estimates that approximately 40,000 children in the UK suffer a brain injury each year.

Audit data from Cambridge University Hospitals (CUH), shows that there are approximately 60 severe, 88 moderate and 886 mild brain injury admissions within the paediatric population across the East of England each year.

The impact of brain injury on a child is complex. As well as physical disability, brain injury will impact upon a child's development, access to education, their family, as well as their social and vocational outcomes, including their employment prospects and risk of offending behaviour.

Children's brains continue to develop throughout childhood and adolescence until their early 20s. The developing brain is particularly vulnerable to injury. The consequences of a brain injury may not become apparent for several years. Developmentally, children 'grow into' difficulties as higher (more complex thinking skills) functions may fail to develop as expected. For children with brain injury, the evidence shows that the earlier the intervention, the better their developmental trajectory and the less the need for long-term interventions in adulthood. Early intervention is therefore cost effective compared with life-course interventions involving multiple agencies (mental health, education, youth justice, employment support, chronic illness).
Access to specialist services (neurosurgery, paediatric intensive care, paediatric neurology) is well organised in the early part of the patient journey. However, as the child moves out of hospital and into the community, equity of access to expertise in paediatric neurorehabilitation becomes more difficult to ensure.

Most of the specialist skills are centralised in Cambridge and geographical barriers are significant. This, combined with the widespread lack of understanding about the nature of brain injury in children, the need for multi-agency collaboration and the delay in manifestation of neurocognitive problems ('sleeper effect'), means that the needs of many children in this group go unrecognised and unmet.

NIHR Brain Injury HTC Paediatric Theme Clinical Leads believe that technological innovation has a large part to play in filling some of the gaps in service provision and improving the outcomes for this vulnerable patient group.

2. Workshop summary

This half-day workshop was designed to explore ways to improve outcomes across the patient journey, create outline ideas for future research and service-development projects, and encourage wider collaboration between brain injury professionals and service providers in these projects. Led by the University of Cambridge Institute for Manufacturing Education and Consultancy Services (IfM ECS), the workshop employed a 'fast-pass' version of the IfM landscaping methodology.

Delegates identified as key challenges:

- The drive for personalised care throughout the NHS
- Lack of co-ordination between agencies in child acquired brain injury (ABI) rehabilitation
- Inconsistent access to specialist and complex care (including for identification of 'hidden' injuries)
- Lack of awareness among families and practitioners of what support may potentially be available.

Delegates' vision for paediatric neurorehabilitation would see care flow seamlessly between agencies in a new neurorehabilitation service (including education and social care), being provided as close to home as is practical, and underpinned through a cloud platform providing effective co-ordination of services and research.

Four potential projects were proposed for further development:

- Access to medical and therapy expertise close(r) to home
- Shared understanding across family, school and health
- Family and professional awareness of resources and support
- Establish a centre for rehabilitation technology evaluation, advice and co-ordination of services and research.

The table on page 5 summarises key details of the selected opportunities.

Delegates found the workshop stimulating and insightful. Next steps are review and development of the four potential project opportunities in order to apply for grant funding.

Title	Opportunity offers…	Benefits	Key actions

Access to medical and therapy expertise close(r) to home	• Improved outcomes and experiences for children and young people (CYP)
	• CYP access to specialist support/advice
	• Third-sector involvement/charity funding
	• Child and family access a prompt and responsive service
		Needed to address the following challenges:
		• Risk of effect on life:
		  ○ youth offending
		  ○ education
		  ○ relationships
		• Lack of experienced therapists
		• ABI hidden injury
		• ABI not a priority
		• Risk of exhausting local services
		• National issue
			• Raise awareness
			• Identify champions
			• Hub/spoke model – key workers
			• Directory of services (dynamic and up to date)
			• Scoping
			• Cloud technology!
			• Linked-up professionals

Shared understanding across family, school and health	• Increased awareness of ABI and how it affects education, learning and behaviour • Informed family, education and health professionals concerning long-term practicalities of living with an ABI	• Improve child educational outcomes and maximise potential • Minimised stress and anxiety in family home • A smooth transition between health/home/education	• Inform school team as part of discharge planning and signposting to existing resources/training • Named lead in healthcare setting to ensure information is passed on to education • Extend information to all 'possible' ABIs – not just those with obvious/ identifiable injuries
Increase family and professional awareness of resources and support	• A searchable and maintained directory of services • A way of determining how different services impact on condition/ well-being	• 'Joining up' of current fragmented knowledge of provision • Increased understanding of what *really* works well	• Identification of working group members • Identification of funding routes • Set up pilot in East of England
Establish a centre for rehabilitation technology evaluation, advice and co-ordination of services and research	• A centre of excellence for rehabilitation technology evaluation and co-ordination of services and research • Provision of a portal to integrate research data with clinical service development and justification	• Support delivery of the right care at the right time for the right cost • Personalisation of care by utilising best technology and understanding of patient needs	• Rolling programme of systematic technology evaluation • Service co-ordination across health economies and providers • Funding – £10m/building/site • Data collection and dissemination tools • Commissioner buy-in

Table 1 Key details of selected opportunities for further development. Paediatric neurorehabilitation workshop, NIHR Brain Injury Healthcare Technology Co-operative, 9 March 2016

3. Aims, objectives and approach

3.1 Aims and objectives

This event was designed to enable the NIHR Brain Injury Healthcare Technology Co-operative (HTC) to explore gaps in the area of paediatric neurorehabilitation, and identify opportunities for enabling projects to address those gaps. Its objectives were to:

- Determine if healthcare technologies can help improve outcomes across the patient journey
- Create outline ideas for future research and service development projects
- Encourage wider collaboration between HTC, brain-injury professionals and service providers in these projects

3.2 Approach

Preparation and participation

The workshop on 9 March 2016 brought together thirteen delegates representing a cross-section of those involved in the patient pathway, for an interactive four-hour programme. A list of delegates is shown in appendix 1 (page 20).

The event builds on a previous session which identified information concerning the issues and opportunities. The resulting information was used to frame this workshop.

A number of those unable to attend on March 9 also provided information and ideas beforehand by email. Their comments are shown in appendix 2 (page 21).

Developing the landscape

In the first part of the workshop, delegates developed a 'paediatric neurorehabilitation landscape', building on individual preparatory work. The landscape development enabled identification of key topics, out of which potential opportunities for research and enabling projects were explored.

The landscaping process was based on the following questions:

- Why do we need to take action (particularly as regards developing needs)?
- How can the patient pathway experience be developed to respond to those needs?
- What enabling projects and resources are required to deliver that pathway experience?

IfM's landscaping process employs individual reflection, group discussion and voting to generate information and ideas, captures and develops these on a large wallchart (the visual format highlighting potential gaps, links, opportunities and challenges), then ranks by voting. The three layers of the landscape are aggregated to identify linkages and clusters (on a 'linkage chart') and hence possible priorities for action. In this 'fast-pass' version of the process delegates, having prepared their individual narratives,

presented their key perspectives directly onto all three layers of the landscape in a series of 2–3 minute 'pitches'.

Prioritising the findings

Delegates collectively reviewed the importance of the items identified then voted on priorities for each layer. The facilitator and client-lead then proposed which themes to investigate.

Having identified a number of priority opportunities by this method, delegates formed syndicate groups, each to develop one outline research or enabling project, using a 'project proposal exploration' template. In the final session, syndicates presented their findings for whole-group review.

Overview of approach

Figure 1 illustrates the workshop approach. Subsequent sections of this report outline the main outputs from the process.

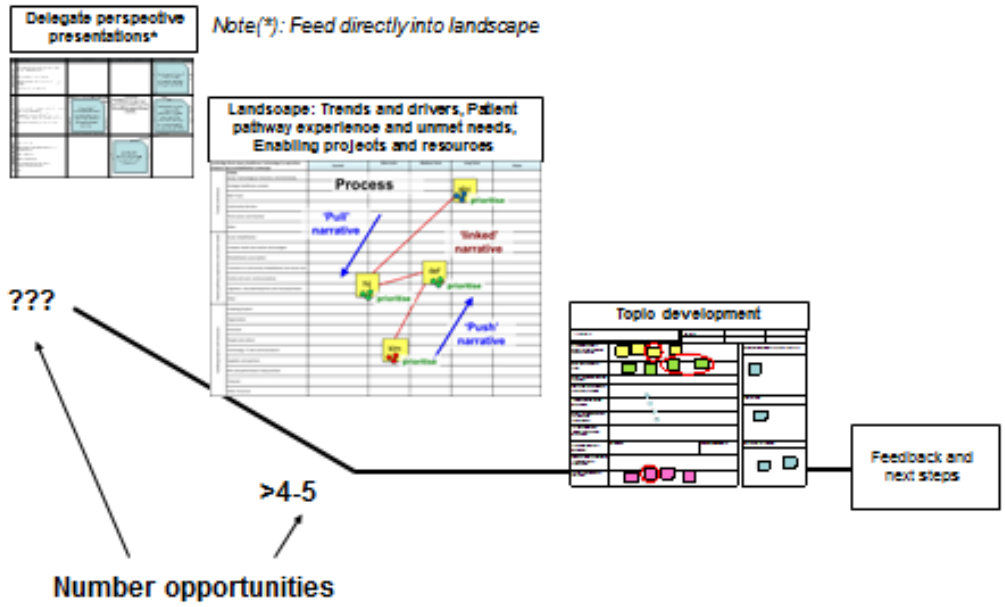


Figure 1 Process employed, Paediatric neurorehabilitation workshop, NIHR Brain Injury Healthcare Technology Co-operative, 9 March 2016, showing templates for individual reflection, whole-group landscape development and syndicate work for topic development.

4. Landscape development

The figures below summarise the key elements of the landscape (figure 2) and associated linkage chart (figure 3).

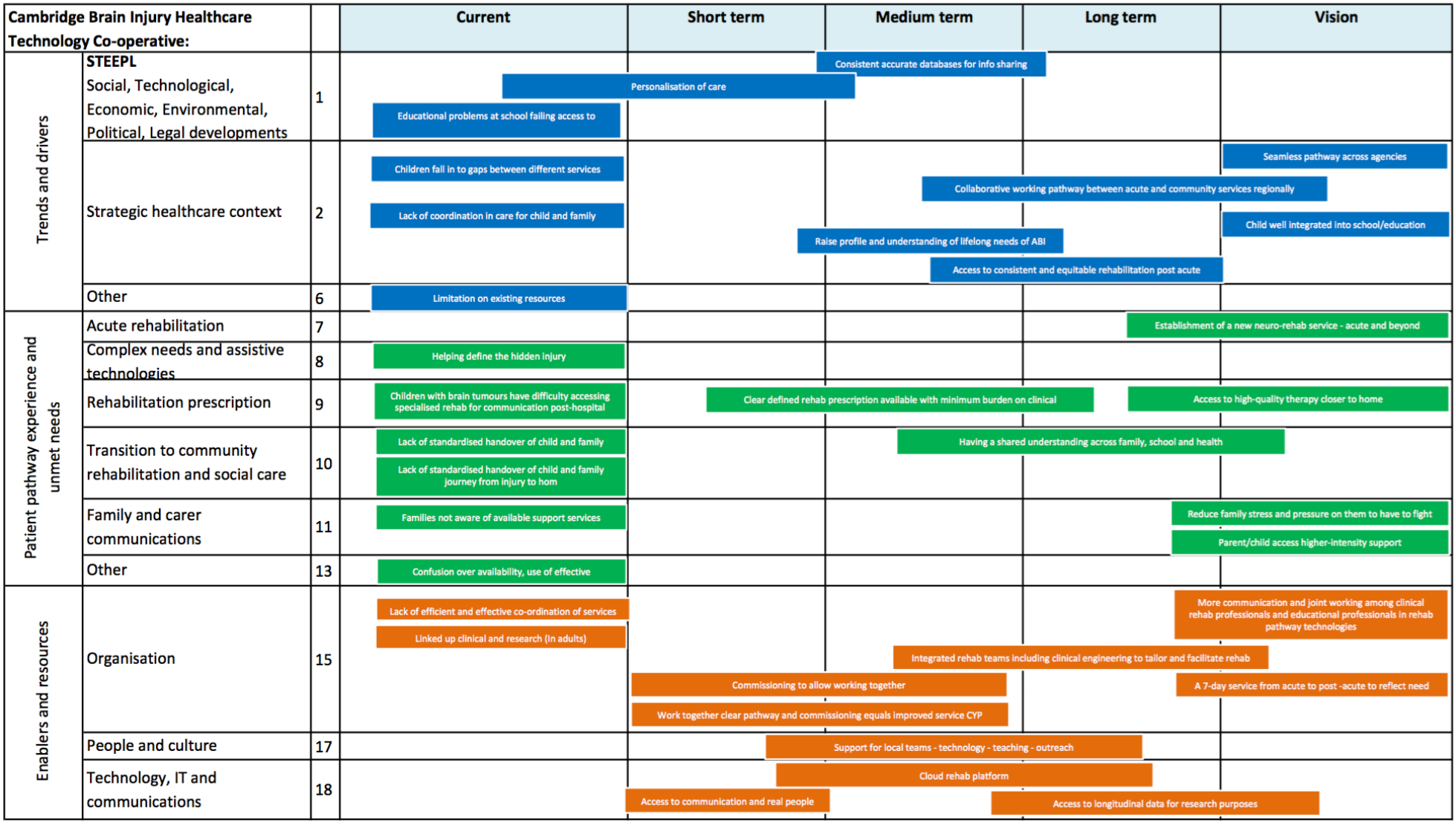


Figure 2 Paediatric neurorehabilitation landscape, NIHR Brain Injury Healthcare Technology Co-Operative Workshop, 9 March 2016

The NIHR Brain Injury Healthcare Co-operative is delivered in partnership between Cambridge University Hospitals NHS Foundation Trust and University of Cambridge

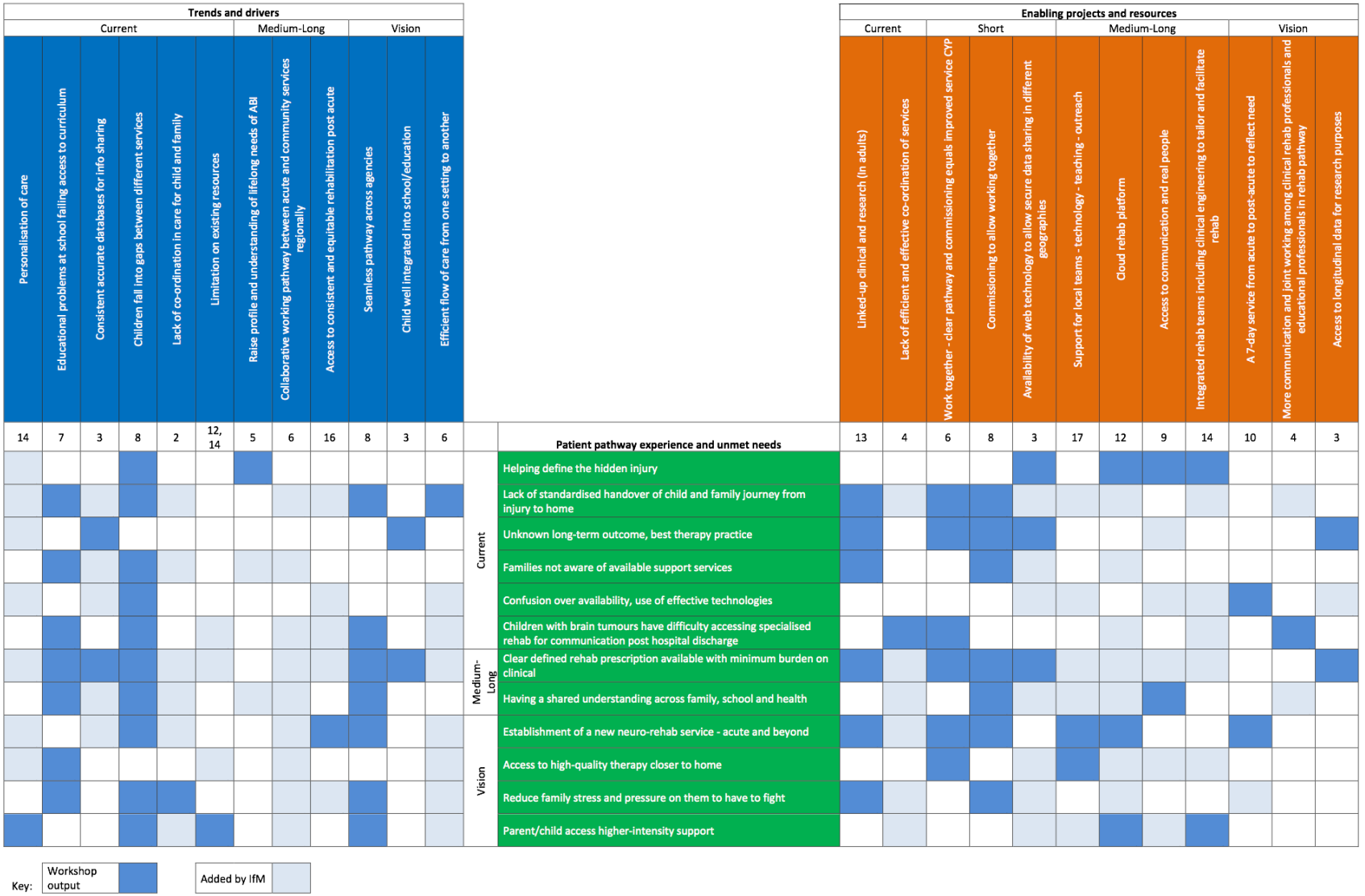


Figure 3 Paediatric neurorehabilitation linkage chart, NIHR Brain Injury Healthcare Technology Co-Operative Workshop, 9 March 2016

The linkage chart visualises relationships between patient pathway experiences/unmet needs and a) trends and drivers and b) enabling projects and resources. It is largely derived from information and ideas contributed by delegates (shown as dark-blue squares), but also includes linkages added retrospectively by IfM (light-blue squares).

The vision implicit in this landscape has the following features:

- Care flows seamlessly between agencies in a new neuro rehabilitation service, including education
- Care provision is as close to home as is practical
- Underpinned through a cloud platform to provide effective co-ordination of services and research

Appendix 3 (page 23) lists the full output relating to 1. Trends and drivers, 2. Patient pathway experience and unmet needs and 3. Enabling projects and resources, showing delegate views of the importance and timeframe attached to each item.

5. Selected topic development

Tables 2–5 below show the topic development outputs as explored by delegates in syndicate groups:

1. Access to medical and therapy expertise close(r) to home
2. Shared understanding across family, school and health
3. Family and professional awareness of resources and support
4. Establish centre for rehabilitation technology evaluation, advice and co-ordination of services and research

5.1 Access to medical and therapy expertise close(r) to home

<table>
<tr><td>Proposed project: What problem are we going to solve?</td><td colspan="2">• Improve outcome and experience for CYP
• Specialist share and support</td><td rowspan="4">Team members: Louise Edwards, Shruti Agrawal, Lucy Andrews</td></tr>
<tr><td>Why should we do this?</td><td colspan="2">• Risk of entering youth justice system – research shows family dynamics/support improves outcome
• Limited and patchy (inequitable) access to community-based sources
• Lack of experienced therapists locally</td></tr>
<tr><td>What is the scale of the problem?</td><td colspan="2">National</td></tr>
<tr><td>Required outcome and timing to complete</td><td colspan="2">• Prompt and responsive service
• Raising awareness
• Outreach</td></tr>
<tr><td>Staged deliverables and dates</td><td>• Bespoke model
• Keyworker
• Therapists
• Hub contact</td><td>• Scoping: June 16
• Engagement: June 16
• Identify key professionals
• Training: December 16</td><td rowspan="3">Because:
• Risk of effect on life:
o Youth offending
o Education
o Relationships
• Lack of experienced therapists
• ABI hidden injury
• ABI not a priority
• Risk of exhausting local services
• National issue</td></tr>
<tr><td>What is missing today, for example information</td><td colspan="2">• Directory of services
• Scope/map local services</td></tr>
<tr><td>Current relevant research and other activities</td><td colspan="2">• Need guidance on paediatric rehab
• Scoping data available (pre-MTC)
• NHS clinical commissioning paediatric neuro rehabilitation</td></tr>
</table>

<table>
<tr><td>Key actions (including proposed team to address)</td><td>Actions:
Determine the scale of the problem:
• Scoping
• Funding
• Time
• Capacity</td><td>Team members:
• Louise Edwards
• Key worker /champion
• Discharge coordinator</td><td rowspan="3">Actions to deliver by 2016:
• Raise awareness
• Identify champions
• Hub/spoke model – key workers
• Directory of services (dynamic and up to date)
• Scoping
• Cloud technology!
• Linked-up professionals
Identify therapists in each area to link into (in-reach) to Addenbrooke’s/acute trust and vice versa (hub/spoke)</td></tr>
<tr><td>Resource requirements (financial and manpower)</td><td colspan="2">• Third-sector involvement/charity funding
• Other resources – brain injury
• Seems ok for financial
• No funded acute neuro rehabilitation therapists
• Potential to exhaust local services</td></tr>
<tr><td>Other enablers and barriers</td><td colspan="2">• ABI and hidden-injury programmes
• ABI not a priority</td></tr>
</table>

Table 2 Topic development *Access to medical and therapy expertiseclose(r) to home*. Paediatric neurorehabilitation workshop, NIHR Brain Injury Healthcare Technology Co-operative, 9 March 2016

5.2 Shared understanding across family, school and health

<table>
<tr><td>Proposed project: What problem are we going to solve?</td><td colspan="2">• Lack of understanding about ABI and support amongst professionals and families
○ How to access services?
○ No identified individual in charge of care
• Handovers make the difference
○ What are school's responsibilities?
○ What are school's resources?
○ What are child's current abilities?
○ What are our duties of care?
○ What can having an ABI mean?</td><td>Team members: Patty Van Rooij, Karen Higgins, Lucie Riches</td></tr>
<tr><td>Why should we do this?</td><td colspan="2">• Increase knowledge of ABI to improve outcomes
• Take pressure off families
• Inform professionals across the pathway
• School is so very important: if school and family feel supported, school is more likely to work with them
• To increase mutual understanding and increase child's prospects</td><td rowspan="3">We have a need/opportunity for:

• Increasing awareness of ABI and how it affects education
• Informing family, education and health professionals about long-term practicalities of living with an ABI</td></tr>
<tr><td>What is the scale of the problem?</td><td colspan="2">• Based on anecdotal evidence of shared knowledge, this is a significant problem. ABI not readily recognised as a problem/issue</td></tr>
<tr><td>Required outcome and timing to complete</td><td colspan="2">• Handover pathway process between healthcare /education/family
• Compulsory training for all education professionals on ABI by 2017</td></tr>
<tr><td>Staged deliverables and dates</td><td>Online/interactive training programme with cross-organisational input (CBIT)</td><td></td><td>Because:
• To improve educational outcomes and maximise</td></tr>
</table>

			potential • To minimise stress and anxiety in family home • To assist a smooth transition between health/home/education
What is missing today, for example information	• Teacher training does not cover ABI sufficiently considering occurrence • School nurse involvement • Include in teacher training • Preparation for school on what to expect		
Current relevant research and other activities	• CBIT training webinars • CBIT well child/nurse • CCPNR • CCPNR recognised research but has stopped?		
Key actions (including proposed team to address)	**Actions:** • Confirm that this is indeed a problem: no education input to this workshop • Involve education in what is needed • Education-to-education/special teachers group/SENCO group	**Team members:** • SENCO lead • Families • CBIT • Discharge planning nurse/team • CCPNR	**Actions to deliver by 2017:** • Inform school team as part of discharge planning and signposting to existing resources/training (e.g. CBIT) • Named lead in healthcare setting to ensure information is passed on to education • Extend information to all 'possible' ABIs – not just those with obvious/ identifiable injuries
Resource requirements (financial and manpower)	• Training portal for schools/families • Questionnaire to families/CBIT/CCPNR to determine what they would like		
Other enablers and barriers	• Information-sharing with school on discharge		

Table 3 Topic development *Shared understanding across family, school and health*. Paediatric neuro rehabilitation workshop, NIHR Brain Injury Healthcare Technology Co-operative, 9 March 2016

5.3 Family and professional awareness of resources and support

<table>
<tr><td>Proposed project: What problem are we going to solve?</td><td>• Lack of a way of identifying gaps in provision
• People missing out on relevant support on their doorstep
• Keeping directory (or equivalent) up to date</td><td>Team members: Anna Maw, Karen DeVilliers and Michael Gifford</td></tr>
<tr><td>Why should we do this?</td><td>• Resource neutral
• Promote participation
• Reduce morbidity
• Empower families
• Resource for clinicians to direct families</td><td rowspan="3">We have a need/opportunity for:
• A searchable and maintained directory of services
• A way of determining how different services impact on condition/well-being</td></tr>
<tr><td>What is the scale of the problem?</td><td>• Not just the numbers involved – there is also a wider societal impact</td></tr>
<tr><td>Required outcome and timing to complete</td><td>• Streamline information; reduce overload, targeted, searchable
• Searchable, current, maintained</td></tr>
<tr><td>Staged deliverables and dates</td><td>• Work out what is available (resources) and develop implementation plan</td><td rowspan="3">Because:
• Currently, knowledge of provision is fragmented
• There is little understanding of what <u>really</u> works well</td></tr>
<tr><td>What is missing today, for example information</td><td>• A data search engine with local information
• A measure of impact of participation in relevant support activities</td></tr>
<tr><td>Current relevant research and other activities</td><td>• Orion
• C.A.L.M. Centre
• Kung Fu</td></tr>
</table>

<table>
<tr><td>Key actions (including proposed team to address)</td><td>Actions:
Identify resources and services
Set up database design/resource
Design and resource the ongoing management products/finance
Address what already exists – EOE directory</td><td>Team members:
Therapist
Technical genius
Project management
Set up and maintenance</td><td rowspan="3">Actions to deliver:
Identification of working group members
Identification of funding routes
Set up pilot in East of England</td></tr>
<tr><td>Resource requirements (financial and manpower)</td><td colspan="2">Research to assess impact</td></tr>
<tr><td>Other enablers and barriers</td><td colspan="2">Local knowledge
Parent and professional involvement
Gets out of date so requires constant update/refresh</td></tr>
</table>

Table 4 Topic development *Family and professional awareness of resources and support*. Paediatric neurorehabilitation workshop, NIHR Brain Injury Healthcare Technology Co-operative, 9 March 2016

5.4 Establish a centre for rehabilitation technology evaluation, advice and co-ordination of services and research

<table>
<tr><td>Proposed project: What problem are we going to solve?</td><td colspan="2">• In solving the patient's questions; 1. Which technology should I access, 2. What would help me?, 3. When: now/later?
• Drawing together evidence of technology
• Limited evidence of tech effectiveness</td><td>Team members: Peter Jarrett, Tamsin Brown, Elizabeth Berry</td></tr>
<tr><td>Why should we do this?</td><td colspan="2">• Huge rehabilitation potential. Patient-recorded self-motivation.
• Would be uniform across areas
• Right care at the right time for maximum effectiveness
• Speed adoption of appropriate medical technologies</td><td rowspan="3">We have a need/opportunity for:
• An East of England centre of excellence for rehabilitation technology evaluation and co-ordination of services and research
• To provide a portal to integrate research data with clinical service development and justification</td></tr>
<tr><td>What is the scale of the problem?</td><td colspan="2">• Almost every patient would benefit – it would make care personalised/tailored to child
• Growing as technology develops</td></tr>
<tr><td>Required outcome and timing to complete</td><td colspan="2">3-year project:
• Quite quickly we would be able to group technologies - working groups to assess technologies
• Regional evaluation and coordination centre for rehab services, advice and evidence within 3 years
• Ongoing timescale outcome desired: access to rehabilitation-technology database</td></tr>
<tr><td>Staged deliverables and dates</td><td>• Short-term review to confirm need
• Agree location
• Agree staffing and</td><td>• Launch 2017/18</td><td>Because:
• We need to deliver the right care at the right time for the right cost</td></tr>
</table>

	operational policy • Launch		• We will be able to personalise care by utilising best technology and understanding of patient needs
What is missing today, for example information	• Evidence-based logical evaluation process • Co-ordinated research and a framework of which technology to use • Extent of clinical scrutiny		
Current relevant research and other activities	• Charity/trust offering funding for health-related technologies for rehabilitation		
Key actions (including proposed team to address)	**Actions:** • Heads of service to agree service needs • Cloud services • Linked-up clinical and research	**Team members:** Co-ordination of services; technology services/ engineers, university, education, health, charities	**Actions to deliver by 2018:** • Rolling programme of systematic technology evaluation • Service co-ordination across health economies and providers • Funding – £10m/building/site • Data collection and dissemination tools • Commissioner buy-in
Resource requirements (financial &manpower)	• £10m new build and service centre		
Other enablers and barriers	• Multiple providers and budgets • Commissioner value proposition • Political will • Multiple health economies		

Table 5 Topic development *Establish a centre for rehabilitation technology evaluation, advice and co-ordination of services and research***.** Paediatric neurorehabilitation workshop, NIHR Brain Injury Healthcare Technology Co-operative, 9 March 2016

6. Feedback and next steps

Delegate feedback as given via the end-of-workshop questionnaire is summarised in appendix 4 (page 27).

All delegates felt they were able to contribute, found the workshop stimulating, enjoyable and worthwhile and thought that it provided useful insights. The workshop process and structure were judged as good. There were some concerns about temperature control in the venue.

This report of the workshop is a draft for circulation, to invite comments from delegates before finalisation.

Following finalisation of the report delegates will be invited to contribute to further development of the identified opportunities in order to support application for grant funding.

Appendices

Appendix 1: Workshop delegates

Name	Role	Organisation
Lucy Andrews	Registered Manager	Sunflowers Care Ltd.
Lucie Riches	Community Support Officer – Central & East England	Meningitis Now
Louise Edwards	Advanced Specialist Speech & Language Therapist – Paediatrics/Neonates	Addenbrookes Hospital
Elizabeth Berry	Advanced Specialist Speech and Language Therapist	Part of the Brainbow Service, Cambridge University Hospitals NHS Foundation Trust
Tamsin Brown	Medical Lead for Community Paediatric Audiology and NHSP across Suffolk	Cambridgeshire Community Services NHS Trust
Shruti Agrawal	Paediatric Intensivist and Paediatric Trauma Lead	Cambridge University Hospitals NHS Trust
Michael Gifford	Director	Mountain Hare Consulting
Karen Higgins	Clinical Director	Sunflowers Care Ltd.
Patty van Rooij	Specialist Children's Occupational Therapist	Cambridge Centre for Paediatric Neuropsychological Rehabilitation and Children and Young People's CFS/ME team
Colin Hamilton	Paediatric Physiotherapist and NIHR Funded MRes Student	Addenbrookes Hospital
Anna Maw	Consultant Paediatric Neurologist	Cambridge University Hospitals NHS Trust
Peter Jarritt	Deputy Director	NIHR Brain Injury HTC
Karen DeVilliers	Children's Occupational Therapist	Child Development Centre, Addenbrookes Hospital

Appendix 2: Input to share knowledge on gaps and ideas

The following suggestions on gaps and potential solutions were made by email by invitees unable to attend the workshop:

1. **'Gap:** Not knowing who needs what and how services or service processes should be optimised/structured to meet efficiently the very wide variety of child and family needs
   - **Tech solution**: Capture and analysis of clinical data from different services/agencies to enable better understanding of stratified needs across the ranges of severity of impairment of functioning and psychosocial complexity

2. **Gap:** Need for parents/child to have a higher intensity of support to enable robust practice of rehab strategies but profound limitations regarding expert availability/time, and family/parent availability to achieve this
   - Tech solution: Use of "cloudrehab" platform (developed by colleagues in Spain but not commercialised and being tested out with some Spanish grant funding they are very interested in collaborating) to support parent and child/young person in day-to-day rehab remotely. See paper with adult case examples - http://ieeexplore.ieee.org/stamp/stamp.jsp?arnumber=6563965 and you tube clip of presentation https://www.youtube.com/watch?v=7yM09pXbnCQ'

3. *'***Gap**: Need for children, families, schools and healthcare professionals to be able to understand injury, work on rehab goals and activities that are helpful for these goals when limited by resources and geography.
   - **Tech solution**: Passport "App" that allows shared formulation, understanding about brain injury, person's strengths and goals that can be monitored for rehabilitation from a distance (i.e. electronic version of passport used by the Sara network in Brazil + cloudrehab?). Would be magical if this could have PCS monitoring (like Gioia's PACE programme: http://childrensnational.org/~/media/cnhs-site/files/healthcare-providers/cnhn/fop-2014/difaziogioiaconcussion_management9b.ashx?la=en) for fatigue management, goal management training etc or at least a facility for uploading resources that are helpful.

4. **Gap:** Need for children with brain injuries to be able to cope with impulsive response to threat.
   - **Tech Solution**?: something that measures biomarkers (like GSR + heart rate?) with in vivo cues for positive coping behaviour (a bit like the Brain In Hand App: http://braininhand.co.uk/what-is-brain-in-hand or the Virtual Hope Box App (https://play.google.com/store/apps/details?id=com.t2.vhb&hl=en_GB). Is there someone from Ireland looking into this?'

Responses to the above suggestions:

- **Solution 3 [passport app solution]** 'really good especially if it means we can also use this is in the brain injury clinic and have something to refer back to in terms of some kind of initial monitoring?'
- 'A very simple version of **3.** might be to take the formulation diagram and develop an interactive / cloud-based version so there is always an updated formulation for a child/family that could potentially be accessed/revised by different professionals maybe including family access? Step 2 of this would be to add some kind of goals so these could be shared/reviewed and updated'

- **Re gap 4 [coping with impulsive response to threat].** 'What you describe is something I tried to get a project running on with a tech group in Belfast (with support from HTC) for adults with ABI. Basic idea is using multiple forms of contextual data (e.g. GSR**,** high frequency HR variability plus GPS) to get a machine to 'learn' situations that are risky for a self-regulation problem and provide tailored, self-regulatory cues. I've done some work with adults looking at randomly occurring text messages to cue 'executive review' for goal management, so the novel bit would be adding tech that can provide 'intelligent' rather than random cues.'

Appendix 3: Workshop outputs showing delegate votes

A3.1 Trends and drivers

Swim lane	Title	Timing	Votes	Linkage number
STEEPL Social, Technological, Economic, Environmental, Political, Legal developments	Consistent accurate databases for information-sharing	Medium	7	3
	Personalisation of care	Current	5	14
	Educational problems at school leading to failure to access the curriculum	Current	3	7
	Many technical solutions available to patients, carers and staff outside NHS	Current	1	10
Strategic healthcare context	Seamless pathway across agencies	Vision	8	8
	Children fall into gaps between different services	Current	5	8
	Collaborative working pathway between acute and community services regionally	Long	4	6
	Lack of coordination in care for child and family	Current	3	2
	Child well integrated into school/education	Vision	3	3
	Raise profile and understanding of lifelong needs of ABI	Medium	2	5
	Access to consistent and equitable rehabilitation post-acute	Long	2	16
	Efficient flow of care from one setting to another	Vision	2	6
	Rehabilitation by distance	Long	1	9
Community services	Long period of time spent in non-local hospital	Current	1	17
Other	Limitation on existing resources	Current	2	12, 14

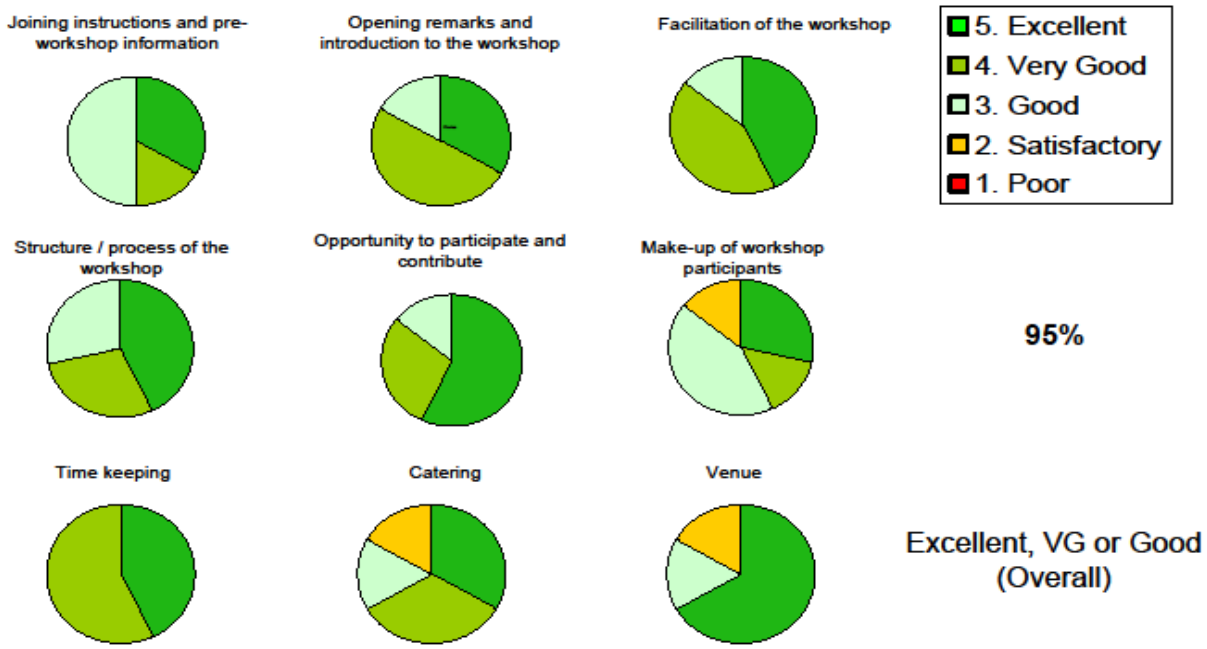
	Better information-sharing amongst ABI professionally along pathway	Current	1	11
	Research in Cambridge is strong, lots of fragmented expertise	Current	1	13

A3.2 Patient pathway experience and unmet needs

Swim lane	Title	Timing	Votes	Linkage number
Acute rehabilitation	Establishment of a new neuro rehabilitation service, acute and beyond	Vision	4	16
	Memory/attention Rx, new visual perception approaches	Medium	1	1, 15
Complex needs and assistive technologies	Helping define the hidden injury	Current	2	5
	Auditory process and memory difficulties	Current	1	7
Rehabilitation prescription	Access to medical and therapy expertise close(r) to home	Vision	8	17
	Children with brain tumours have difficulty accessing specialised rehab for communication post hospital discharge	Current	3	4
	Clear defined rehab prescription available with minimum burden on clinical	Medium	2	3
Transition to community rehabilitation and social care	Having a shared understanding across family, school and health	Long	7	9
	Lack of standardised handover of child and family journey from injury to home	Current	4	6
	Unknown long-term outcome, best therapy practice	Current	4	3
Family and carer communications	Families not aware of available support services	Current	6	11
	Reduce family stress and pressure on them to have to fight	Vision	2	2
	Parent/child access higher-intensity support	Vision	2	12, 14
Other	Confusion over availability, use of effective technologies	Current	2	10

A3.3 Enabling projects and resources

Swim lane	Title	Timing	Votes	Linkage number
Organisation	More communication and joint working among clinical rehab professionals and educational professionals in rehab pathway	Vision	7	4
	Lack of efficient and effective co-ordination of services	Current	6	4
	Linked-up clinical and research (in adults)	Current	5	13
	Integrated rehab teams incl. clinical engineering to tailor & facilitate rehab	Long	3	14
	Commissioning to allow working together	Short	3	8
	A 7-day service from acute to post-acute to reflect need	Vision	3	10
	Work together – clear pathway and commissioning = improved service CYP	Short	2	6
Processes	Improved referral process/patient pathway programme (services to community)	Current	1	11
	Work out how to continue flow of rehab when transition between services	Short	1	6
People and culture	Support for local teams - technology - teaching - outreach	Medium	2	17
Technology, IT and communications	Cloud rehab platform	Medium	7	12
	Access to communication and real people	Medium	3	9
	Availability of web technology to allow secure data-sharing in different geographies	Short	2	3
	Access to longitudinal data for research purposes	Vision	2	3
	Can virtual reality help in improving revision ability (study - memory)?	Current	1	15
	Accurate directory of services and referral criteria for adults (state and charitable)	Current	1	11
	Providing a voice for families to share their journeys	Medium	1	5


Joining instructions and pre-workshop information
Opening remarks and introduction to the workshop
Facilitation of the workshop
5. Excellent
4. Very Good
3. Good
2. Satisfactory
1. Poor
Structure / process of the workshop
Opportunity to participate and contribute
Make-up of workshop participants
95%
Time keeping
Catering
Venue
Excellent, VG or Good (Overall)