

**Brain Injury  
MedTech Co-operative**

  
**National Institute for  
Health Research**

# **Patient & Public Involvement/Engagement Supporting the Next Generation**

**Professor Christi Deaton**

# Key Collaborators



National Institute for  
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The MIC will build on previous HTC commitment for involving and engaging with patients, carers and the public, and ensure PPI/E embedded across research themes and core activities:

- Membership in PPI/E Eastern Collaborative to ensure adoption of best practice and alignment of activities across EoE NIHR landscape
- Representation on NIHR-BRC PPI working group to provide access to broader PPI resources (esp education & training)
- Maintain a brain injury Patient and Carer Register: RHITE
  - Develop the resource to provide a linked unmet needs database



I'm Interested in...

- Influencing what research is funded
- Looking at research protocols
- Reading and assessing patient information sheets
- Giving feedback to researchers about their ideas being on a patient panel
- Driving research from the beginning
- Working with research teams throughout the process
- Promoting research to other patients
- Supporting staff at events like International Clinical Trials Day
- Giving talks and presentations about my experience
- Taking part in research looking into my condition
- I have experience helping with patient and public involvement and would like to do more
- I would like to tell research teams the things that are really important to people who have my condition

- Work closely with patient groups and charity partners (INSPIRE, SHINE, Headway, etc)
- Establish a patient/carer led brain injury **Patient Advisory Group (PAG)** with representation on the Advisory Board
- Enable PPI/E in each technology project
- Facilitate patient and carer engagement in core activities, especially the Brain Injury Think Tank meetings
- Deliver focussed patient and carer workshops

- Looking at research protocols
- Reading and assessing patient information sheets
- Giving feedback to researchers about their ideas
- Being on a patient panel

- [Addenbrooke's Patient & Public Panel](#)  
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# Patient Advisory Group



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- Have a strategic role across MIC and link with other related organisations
- Actively encourage patient, carer, public and staff involvement in all aspects and stages of MIC research
  - From idea/question and design to interpretation and dissemination
  - Inform priorities and research strategies
  - Advise on recruitment and acceptability of procedures
  - Provide input on patient-facing materials



  
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Do you have an acquired brain injury?

How would you rate your NHS treatment?

Would you like to help make services better?

The **Brain Injury Healthcare Technology Co-operative Cambridge** is looking for volunteers with acquired brain injury to form an

## Acquired Brain Injury Advisory Group

**By getting involved you can gain experience in:**

- Inspiring and influencing advances in technologies
- Developing, writing and analysing a national survey about unmet needs
- Marketing, promotion and dissemination of findings
- Planning and managing a national patient-led event



# Patient & Carer Workshops



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## Examples from HTC

Patient Inspired Innovation – Acute Care: BI & Intensive Care  
Family Experience following TBI  
Stakeholder road-mapping (Paediatric neurorehabilitation & Neurocritical Care )

Brain Injury Healthcare Technology Co-operative

Patient Inspired Innovation  
Acute Care: Brain Injury and Intensive Care  
Workshop 1: Tuesday 10<sup>th</sup> November 2015 – Cambridge



In association with:  
**James Lind Alliance**  
Priority Setting Partnerships

“To date the research agenda has largely been developed by medical researchers and scientists, but there is a growing expectation that patients, multidisciplinary clinical staff and research public should be involved in identifying clinical and research priorities for future intensive care research in the UK” results of a James Lind Alliance Priority Setting Partnership. Rapp H et al. JICS 2014, vol.15(4)

**ORIGINAL ARTICLE**  
**Paediatric neurorehabilitation: finding and filling the gaps through the use of the Institute for Manufacturing strategic roadmapping method**  
Colin Hamilton,<sup>1</sup> Anna Maw,<sup>2</sup> Andrew Gill,<sup>3</sup> Mita Brahmhatt,<sup>4</sup> Robert Phaal,<sup>5</sup> John Rickard<sup>6</sup>

**ABSTRACT**  
Innovative Acquired brain injury (ABI) is a major cause of morbidity and mortality in childhood. Specialist rehabilitation services are often situated far from families and local services may be non-standard and fragmented. A strategic level of understanding is needed to improve patient care and outcomes. Roadmapping techniques are commonly used in industry settings to discover and understand a systematic understanding of healthcare settings. With continuing pressures on structures, however, they are rarely used in the strategic roadmapping method used in manufacturing (RM). The Institute for Manufacturing (IfM) identify areas of difficulty and opportunities for professional stakeholders from a wide range of children after ABI.

**Results:** Delphi identified a range of ‘layers’ of needs, from the layers for patients and families, school and health, understanding across awareness of resources and support, and establishing a centre for rehabilitation across evaluation, advice and co-ordination of services and research.

**Conclusion:** The RM strategic roadmapping method identified and developed key areas for development in the field of paediatric neurological rehabilitation. Healthcare professionals looking at strategic level difficulties should strongly consider

**INTRODUCTION AND BACKGROUND**  
Acquired brain injury (ABI) is a major cause of death and disability in the UK and annually in the UK from trauma causes alone. Non-traumatic ABI are less common than traumatic ABI, but these children has improved in recent years. However, the acute assessment that rehabilitation after such an injury, services, and the exact composition and clinical management are understood.

While historically the full extent of the services impacted after initial insult would have been disclosed after an ABI appeared to be a mild brain injury, it is now a growing understanding from specialist input long-term follow-up and risk of injury to childhood are increased of offending behaviours and mental

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# Measures of Success



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- Quantitative indicators
  - Numbers involved & types of activities
  - Training & hours of voluntary activity
  - Demographic information
  - Number and types of issues raised
- Qualitative indicators
  - Observational
  - Case studies to capture meaningfulness

The screenshot shows the registration page for the Register for Healthcare Involvement and Technology Evaluation (RHITE). It features the logos for the University of Cambridge and the NHS National Institute for Health Research. The page title is "Register for Healthcare Involvement and Technology Evaluation". Below the logos, there is a paragraph explaining the purpose of the register: "The NIHR Brain Injury Healthcare Technology Co-operative (HTC) has developed a volunteer register for patients, carers and other interested persons to assist in the development and advance of healthcare technologies. Registering an interest ensures you will receive information about the HTC activities and be notified of opportunities to take part in research. For more information about the Brain Injury HTC, please visit [www.brainhtc.org](http://www.brainhtc.org)". A smaller line of text states: "The patient and carer register is delivered in partnership with the Outcome Registry Intervention and Operation Network (ORION), hosted within the University of Cambridge." The registration form itself is titled "Join the register here" and includes fields for "Title" (a dropdown menu with "please select..." as the current selection), "Forename", "Surname", "Gender" (with radio buttons for "Male", "Female", and "Other"), and "Date of birth" (with a "DDMMYY" format). Below these are "Email" and "Confirm email" fields. At the bottom, there is a question "How else would you prefer us to contact you?" with radio buttons for "by post" and "by telephone".

**Register for Healthcare Innovations  
and Technology Evaluation (RHITE)**

**Standard 1: INCLUSIVE OPPORTUNITIES**

We offer public involvement opportunities that are accessible and that reach people and groups according to research needs.

**Standard 2: WORKING TOGETHER**

We work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.

**Standard 3: SUPPORT & LEARNING**

We offer and promote support and learning that builds confidence and skills for public involvement in research.

**Standard 4: COMMUNICATIONS**

We use plain language for timely, two way and targeted communications, as part of involvement plans and activities.

**Standard 5: IMPACT**

To drive improvement, we capture and share the difference that public involvement makes to research.

**Standard 6: GOVERNANCE**

We involve the public in our governance and leadership so that our decisions promote and protect the public interest.



## Recommendation 10

- *Community: A diverse and inclusive public involvement community is essential if research is relevant to population needs and provides better health outcomes for all. We have been struck by the degree to which researchers and public contributors have encountered barriers when trying to work with different communities and populations.*
- *This suggests a system-wide issue that needs considered and careful attention. We would recommend that a specific NIHR workstream be developed in this area in the same way that it has developed other work programmes such as 'Adding Value' or 'Pushing the Pace.' At a bare minimum, a meeting of NIHR senior leaders and colleagues should be convened in the next 12 months to surface the key issues for wider debate.*

[https://www.rand.org/pubs/research\\_reports/RR2147.html](https://www.rand.org/pubs/research_reports/RR2147.html)



- Establish a framework to support the next generation of nursing, midwife and AHP (NMAHP) clinical academics
- Encourage clinically relevant research in neurosciences
- Address the challenges of developing NMAHP clinical academic careers
  - NMAHP Forum
    - Peer support, links with MIC and research teams
    - Development
  - Initial lunch meeting with members of staff mid-May