Brain Injury MedTech Co-operative



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

## **Professor Christi Deaton**

The NIHR Brain Injury MedTech Co-operative is a partnership between the Cambridge University Hospitals NHS Foundation Trust and the University of Cambridge

## **Key Collaborators**

National Institute for Health Research

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 fullued
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

# Strategy

- 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 Anna Ellis t: 01223 254620 e: ppi@addenbrookes.nhs.uk https:// cambridgebrc.nihr.ac.uk/public
- INsPIRE, Norfolk & Suffolk
   e: inspire@nsft.nhs.uk t: 07468715481
   www.nsft.nhs.uk/research
- Patient & Public Involvement in Research (PPIRes) Norfolk & Sutfolk t: 01603 257009 e: snccg.ppiresoffice@nhs.net www.nspccro.nihr.ac.uk
- Collaboration for Leadership in Applied Health Research & Care (EoE) Lorna Jacobs, PPI Lead t: 01223 746148 e: Lorna.Jacobs@cpft.nhs.uk www.clahrc-eoe.nihr.ac.uk
- NIHR Brain Injury MedTech Co-operative t: 01223 336936 e: involve@brainmic.org www.brainmic.nihr.ac.uk You can register your interest online by visiting: https://orioncloud.org/rhite
- CPFT Service User & Carer Research Group Iliana Rokkou, User & Carer R&D Manager t: 01223 465182 e: Iliana.rokkou@cpft.nhs.uk www.cpft.nhs.uk/research

# **Patient Advisory Group**

## National Institute for Health Research

- 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



NHS National Institute for Health Research

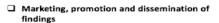
Do you have an acquired brain injury? How would you rate your NHS treatment? Would you like to help make services better?

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



 Planning and managing a national patient-led event

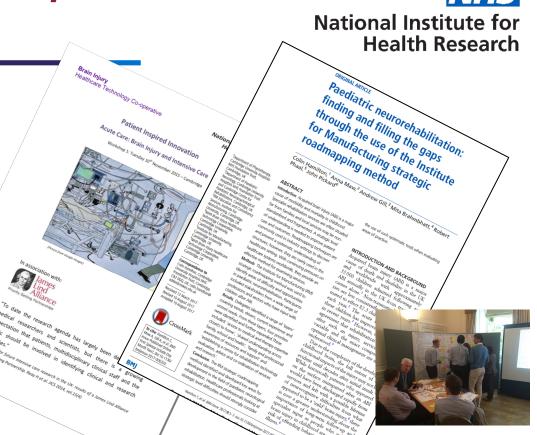
### NIHR Brain-injury HTC Patient Partnership

## **Patient & Carer Workshops**



### Examples from HTC

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



### NIHR Brain Injury Ms. /iech Co-operative

## **Measures of Success**

## National Institute for Health Research

### 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

UNIVERSITY OF CAMBRIDGE	egister for Healthcare Invol	vement and Technol	National Institute Health Resear Iogy Evaluation	for
persons to assist in the developmen HTC activities and be notified of www.brainhtc.org	er register for patients, carers and other interes terest ensures you will receive information about mation about the Brain Injury HTC, please v peration Network (ORION), hosted within the University	the isit		
Title Forename please select \$		ider Male ○ Female ○ Other	Date of birth	
Email	Confirm email			
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# 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.

# **The Future of Health**

## National Institute for Health Research



#### **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

# **Building Capacity**



- 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