Brain Injury
MedTech Co-operative

National Institute for
Health Research

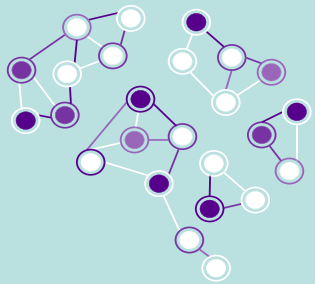
Newsletter, Issue 4, December 2018

Patient Inspired Innovation

Welcome to the issue 4 of the NIHR Brain Injury MedTech Co-operative newsletter. In this edition, find out more about two initiatives you can be involved in, our Neuro-oncology Theme Lead, the publication of the Brain Injury Un-met Needs Directory and many other news.

About us

The MIC is one of eleven national MedTech and In Vitro Diagnostic Co-operatives (MICs) funded by the National Institute for Health Research (NIHR).



The MIC works with patients, carers, academics, clinicians and industry to develop new medical devices, healthcare technologies and technology-dependent interventions to improve treatment and quality of life for patients with brain injuries.

Get Involved!

The MIC has developed a volunteer register for patients, carers and whoever has an interest in the advancement of healthcare technologies. For more information on Register for Healthcare Involvement and Technology Evaluation (RHITE), please visit our website:
http://www.brainmic.nihr.ac.uk/rhite

Important:

To unsubscribe from RHITE and this newsletter please send us an email to:
involve@brainmic.org

What's it like being involved in NIHR research?

A National Feedback Survey for Patients and Carers

The NIHR is running a national survey asking patients, carers, service users and members of the public what's it been like to be involved with them. We want to know if our public contributors think they have made a difference, whether you felt supported and valued, received any feedback on their contribution, and how to improve the way we work with you in the future.

If you are a patient, carer, service user or member of the public who has been involved in our work then the NIHR would like to know.
You may have helped design a research study, review applications, been a member of advisory group or involved in our many other activities. However you have been involved, the NIHR wants to hear from you.

The brief online survey is completely anonymous and hope it will give us some useful information which together with the UK Patient and Public Involvement (PPI) Standards will help us measure progress in future years.
Please click on the following link to take part in the survey:
https://www.surveymonkey.co.uk/r/2KQZCDQ

The survey will run until Monday 7th January 2019 and the results will be made public by the end of March 2019.

If you have other questions or issues raised about the survey then please email: ppisurvey@nihr.ac.uk

Join the Patient Advisory Group in 2019!

Led by Mr Robert Runcie (see photo), the virtual PAG will actively encourage the involvement of patients, carers, and members of the public in all aspects and stages of the research, including:

- Contributing to the design and prioritisation of the MIC work programme
- Planning and development of specific topics
- Reviewing funding applications
- Participating in research activity
- Interpretation of research findings as appropriate

If you are interested in being involved with the group please get in touch with us at: **involve@brainmic.org / tel: 01223 336944**

Series: The Brain Injury MIC presents its Theme Leaders

Neuro-oncology Theme: Mr Stephen Price

As you may be aware, the work of the NIHR Brain Injury MIC is divided into eleven themes led by internationally renowned experts in their respective field and this month we are delighted to introduce to you our Neuro-oncology Theme Lead: Mr Stephen Price, Clinical Consultant in Neurosurgery at Addenbrooke's Hospital (CUH NHS FT).

Mr Stephen Price graduated in medicine from Bart's Medical College in 1994 and he did his basic surgical training in the East Midlands. He trained in neurosurgery in Nottingham and Romford before starting the Cambridge training scheme in 1998. He became Clinical Lecturer in 2005 and was appointed consultant neurosurgeon with a special interest in managing brain tumours in 2008.

He is currently the network lead for brain tumours at the Anglian Cancer Network and clinical lead for surgical neuro-oncology. He is representative to the Central Nervous System (CNS) Oncology Clinical Reference Group. He introduced novel methods using fluorescences to guide surgery and help maximise tumour removal. Working with Colin Watts, he regularly teaches other surgeons how to use these methods. Mr Price's practice is largely based around surgical management of malignant brain tumours (gliomas and metastases).

His research interest involves using advanced imaging methods to understand the difference both between individual patients and within an individual's tumour to better understand the variation in tumour growth, behaviour and response to treatment. He is a member of the National Clinical Research Infrastructure NCRI Brain Tumour Study Group and the Surgical Subcommittee of the British Neuro-oncology Society.

GOOD NEWS **He was awarded a NIHR Career Development Fellowship. This Fellowship will aim to use advanced MR imaging to individualise surgical treatment volumes in patients with glioblastomas and aim to understand what we should be removing and what we can't remove without affecting quality of life.**
It will run for 5 years out of the Cambridge Brain Tumour Imaging Lab, and will help develop academic surgical neuro-oncology in Cambridge.

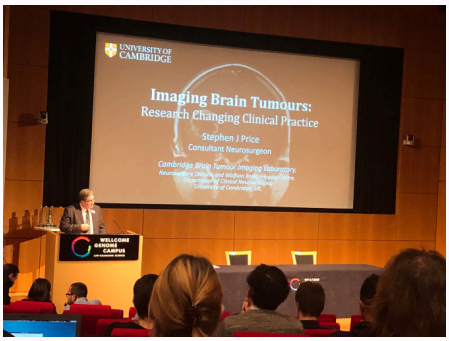
The Brain MIC Neuro-oncology Strategy

1 Year ***Short-Term***	• Develop and validate new technology aproaches to measuring quality fo life and cognition functiont • Determing the true extent of tumours
2 - 3 Years Medium-Term	• Effect of treatment on normal brain functioning and validate methods to assess treatment response • Develop methods that integrate new imaging methods into surgical and radiotherapy treatment planning
4 - 5 Years Long-Term	• Translate these technologies into clinical practise to personalise surgery, radiotherapy and rehabilitation

it continues...at the Clinical Neurosciences Department Away Day

Mr Stephen Price giving a talk on how research on brain tumours imaging can change clinical practice

Wellcome Genome Campus, last 10th December.



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More GOOD NEWS!

MacMillan Service Improvement Excellence Award

The Neuro-oncology Surgery Service of Addenbrooke's Hospital (Cambridge), led by Mr Stephen Price, in collaboration with the Outcome Registry Intervention and Operation Network (ORION) team, have been awarded the MacMillan Service Improvement Excellence Award, last November 2018.

The accolade was awarded for the successful implementation of a multi-component quality improvement programme in their Service involving:

(1) the integration of the routine collection of patient reported quality of life information as part of their service;

(2) the reduction of waiting times through the implementation of electronic referrals of patients with suspected brain tumour;

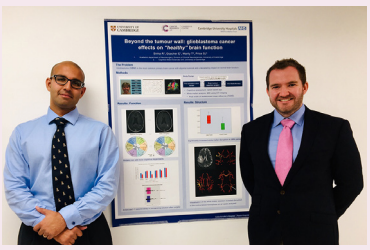
(3) the introduction of a Nurse-led telephone clinic for the follow-up of their patients.

The referral and quality of life transformation was delivered through the Detection and Assessment of Malignancy through Symptom Evaluation (DAMSEL) project led by Dr Alexis Joannides, NIHR Brain Injury MedTech Co-operative Deputy Director, and funded by InnovateUK.

The future plan is to develop a pre-rehabilitation programme using quality of life data and cognitive eval-uation (led by Dr Rohitashwa Sinha) for personalising the rehabilitation care pathway for brain tumour patients.

and other awards... Brain tumour poster voted the public's favourite at Brainworks!

A poster highlighting research into how patients think both before and after surgical treatment for the most common type of brain tumour has won a competition run by NIHR Cambridge BRC. Dr Rohit Sinha and Dr Ed Goacher's poster was one of 17 research posters on display at the popular 'Brainworks' Open Evening, showcasing the latest local research in dementia, mental health and neuroscience, that took place in November.



Dr Sinha, based in the Academic of Neurosurgery at the University of Cambridge, said: "Our research is about understanding how glioblastoma (GBM) and its treatments can affect the way patients think, and we wanted the poster to convey this. "GBM is a rare but eventually fatal cancer that can have a devastating impact on normal brain function. In fact patients often first notice problems with their thinking – including memory, decision-making and language – before they are diagnosed with a brain scan. Surgical treatment and radiotherapy can make these problems worse, and our research explored such effects on patients' brain functions, which are so important to overall quality of life."

For more information about Dr Sinha and Dr Ed Goacher's poster, please click here

to end with...

The Brain Injury Unmet Need Directory is out now!

We are delighted to announce that we have published the Brain Injury Unmet Need Directory.
The "systematic evaluation of the HTC unmet needs directory", a two-year research project, focused on finding unmet needs that people and their families have after brain injury in order to aid development of technological solutions to them.
Please click here to download the **Directory of Unmet Needs**
Here's a sneak peak at the findings from the research project. You can find the complete poster online, **click here to download the poster.**

Results: Needs

70: the number of unmet need identified

15: the number of unmet need removed through validation with patients and carers

55: the total remaining of unmet needs; 22 further reviewed by patients and carers, with 9 accepted and 9 reworked

Results: Themes

Patients and families after brain injury value consistent high quality information(8). The development and implementation of technologies focused on communication would optimise the experience of patients and their families.

Communication

The development of specific technologies is needed to solve specific problems in the sphere of brain injury (9). Many wil require development of sophisticated technologies (10). However, others may be patient specific and may not be financially viable on a large scale.

Technological Development

System Optimisation

Through optimising and standardising access to, and use existing technologies, patient can improve (11). Systems that continually drive quality and technological improvement also need development if progrss is to continue (12).

Knowledge Building

There continues to be a lack of knowledge around brain injury (3). The development of a deeper understanding around all aspects of brain injury is needed (13).

CONCLUSIONS

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

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