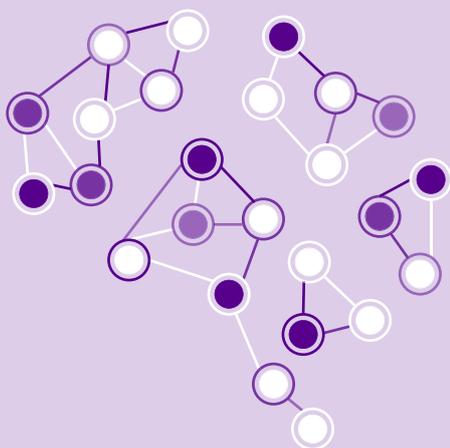


# NIHR Brain Injury HTC Newsletter

**Welcome** to issue 2 of our newsletter, which is aimed at people who have been affected by a brain injury.

## About us

The NIHR Brain Injury HTC is one of eight national Healthcare Technology Co-operatives (HTCs) funded by the National Institute for Health Research (NIHR).



The NIHR Brain Injury HTC 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.

## What's new at the HTC?

### New website launched

The HTC has a new website at [www.brainhtc.org](http://www.brainhtc.org). We have completely revamped our website to make it clearer and easier to find information. There is a new section for patients and carers and we regularly post news and information on the site.

### Register your "unmet needs" online

"Unmet needs" are any of your needs, resulting from your brain injury, which are not met by current technology. These could be physical, psychological, social, or any other need. They could be needs relating to any part of your experience from the initial injury through to rehabilitation.

Our new website now has the facility for patients and carers to tell us about unmet needs.

We shall look at all the information we receive and analyse the themes that emerge and whether there are existing solutions. If there are no solutions to the need then we shall make other organisations aware of the need, and encourage them to address it.

# Finding out what Patients and Carers need

## Brain injury and Intensive Care – Survey and Workshop

*Dr Lara Prisco and Professor David Menon*

To help us develop technology which satisfies the needs of people with brain injuries, we need the views of patients and carers. What do you need? What is most important?

### Unmet needs on intensive care

To answer these questions for intensive care, we ran a survey and workshop, devised by Dr Lara Prisco and Professor David Menon at Cambridge University.

### The survey

The survey asked patients and carers throughout the country who had been affected by brain injury, to tell us about their unmet needs on intensive care.



*Dr Lara Prisco, Clinical Lecturer in Anaesthesia, University of Cambridge*

The survey question was **“What do we need to find out to improve the care of brain injured patients in Intensive Care and to promote survival and improve life?”**

We contacted patient groups and charities that support people affected by brain injury. We visited local groups of patients to discuss the survey and we publicised the survey widely on social media.

**Our survey had over 100 responses, on paper, online by email and by phone**

We had over 100 responses to the survey, on paper, online, by email and by phone.

The people who contacted us had experience of accidental injury, of stroke, of brain tumour and of hydrocephalus. These brain injuries had different causes, but a common patient experience.

A team from the HTC and Cambridge University Hospitals went through every single response and identified the key issues under five themes:

- Service delivery
- Ongoing care
- Experience
- Communication
- Information

All this information was printed on a giant sheet, ready for discussion in the workshop.

## The Workshop

Eight people with experience of brain injury, whether as patient, relative or carer came together in Cambridge to discuss the results of the survey and prioritise the issues.

The workshop members were a diverse group varying in age and experience but the shared experience of intensive care meant that common ground was readily found.

Workshop members added more issues to the list for the survey. Finally after intense discussion, workshop members voted for the issues they felt were the most important.

**“This has been a really good event – given me lots to think about and some excellent contacts to develop services”**

**Workshop participant**



*Workshop participants in deep discussion*

## The final results – the most important issues

Our workshop members identified the following issues as the most important problems. These issues will be taken forward by the HTC in discussion with technology companies.

- Better information for relatives and carers
- Better access to physiotherapy
- Improving the patient experience
- Lost information when patients are transferred
- Non-specialist staff not understanding the problems of people with brain injuries
- Better information for patients

*A full report on the survey and workshop will be published on the NIHR Brain Injury Health-Care website.*

## Tell us your views

What are your unmet needs, whether in acute care or otherwise? Fill in the form on our website at <https://brainhtc.org/surveys/> to tell us. Your views may help shape the technology of the future!

## NIHR Brain Injury HTC at the Cambridge Science Festival 2016

Every year in March the Cambridge Science Festival presents two weeks of lively science talks, demonstrations, exhibitions, theatre, comedy, art and much more.

In 2016, the HTC has been invited to present some of the new ideas in technology for brain injuries. Look out for our showcase on Sunday 20th March at the Cambridge University Hospitals site.

We shall be giving a series of short presentations on “How can technology address the problems of brain injuries, from prevention to rehabilitation?”

Further information including the final program will be posted on the festival website [www.sciencefestival.cam.ac.uk](http://www.sciencefestival.cam.ac.uk)

### PATIENT AND CARER REGISTER

Are you interested in getting involved in the work of the HTC? You can volunteer by joining our register of interested people. You may have experienced a brain injury yourself, or may be a relative or carer of a patient.

By signing up to the register you give us permission to invite you to take part in surveys, focus groups, workshops or other events, but being on the register does not commit you to anything.

For more information and details of how to join please contact us by email, phone or post, or visit: - <https://brainhtc.org/patient-and-carer-register>

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