



ENCEPH UK

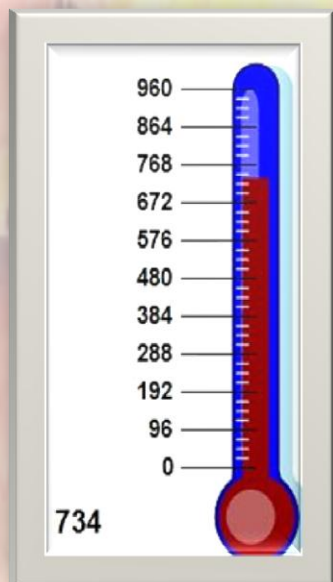
Understanding and Improving the  
Outcome of Encephalitis

## Welcome to the ENCEPH UK Autumn 2014 Newsletter!

Since the last newsletter we have recruited a total of 226 adult patients and 508 paediatric patients with suspected encephalitis into ENCEPH UK study! This brings our grand total of patients to **734**.

### Thermometer Chart

Prospective suspected encephalitis recruitment (adults and pediatrics).



Recruitment for suspected encephalitis is going **really well**. Unfortunately we are lacking certain cases, especially **proven causes of encephalitis** and in particular **HSV**.

See the next page for top tips for patient recruitment.

### Upcoming Events!

We would like to thank everyone who responded to the Research Nurse Update Day survey.

The responses were positive and we will be holding an event in the new year. Details to follow.

If you think of anything that you would like further information on but didn't manage to complete the survey please email: [encephuk@liverpool.ac.uk](mailto:encephuk@liverpool.ac.uk)



## Patient Recruitment – Top Tips



- ❖ Ask microbiology for daily lumbar puncture reports
- ❖ Ask pharmacy for weekly report on who is prescribed aciclovir
- ❖ Attend daily ward rounds
- ❖ Ask Medical Assessment Unit and Infectious Diseases ward to ring researchers if an LP is being performed
- ❖ Screen CT/MRI list and approach anyone ?encephalitis

## Patient enrolment reminder

Please make sure that once you have updated OpenClinica you fax the below completed documents:

- ❖ Enrolment form – 2 pages
- ❖ Consent form – 3 pages
- ❖ Contact details form – 1 page

If you are doing a consultee declaration:

- ❖ Relations to patient – 1 page



## Samples

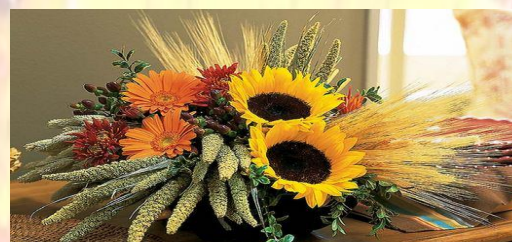
A new system to track samples that have been received from sites has been created so that we can locate patient samples easily.

It is vital for this system to work that the sample logs are completed on OpenClinica.

If you need any samples collected please email [h.e.jelleyman@liverpool.ac.uk](mailto:h.e.jelleyman@liverpool.ac.uk)



# RECRUITMENT LEADERBOARD



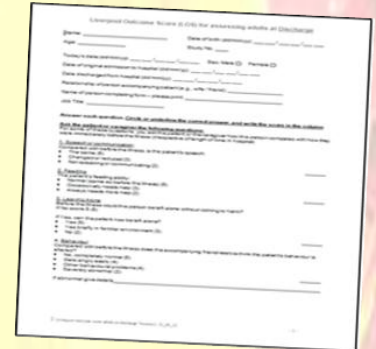
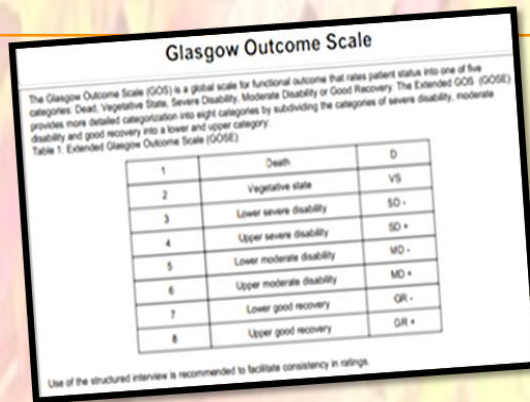
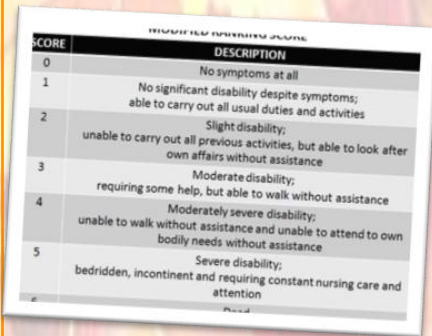
Hospital	Date Opened to recruitment	Number of months opened	Total recruited	Recruit / Month
Royal Liverpool	18/10/2012	23	40 ★	1.74
Royal Berkshire	23/06/2014	4	4	1.00
South Tees	11/07/2013	14	13	0.62
Walton	19/12/2012	21	17	0.85
Bradford Teaching	03/01/2013	20	17	0.85
Aintree	15/11/2012	22	15	0.68
North Manchester General	01/02/2013	19	12	0.63
Manchester Royal	29/07/2013	15	8	0.53
Leeds	19/12/2012	22	11	0.50
Mid Yorkshire	22/03/2013	18	9	0.50
Southampton	28/02/2013	19	9	0.47
Calderdale & Huddersfield	05/06/2013	15	7	0.47
Birmingham Heartlands	10/06/2013	15	6	0.40
Arrowe park	19/02/2013	19	7	0.37
Royal Preston	04/02/2013	19	7	0.37
Morecambe Bay	19/12/2012	22	7	0.32
Guys & St Thomas	15/02/2013	19	6	0.32
Milton Keynes	12/06/2013	15	2	0.13
Salford Royal	30/01/2013	20	5	0.26
North Cumbria	15/02/2013	19	5	0.26
Royal Free	08/02/2013	19	4	0.24
York	24/04/2013	17	3	0.18
St Mary's Charing Cross Hospital	30/10/2013	12	2	0.17
Hull & East Yorkshire	08/01/2013	21	3	0.14
Sheffield Teaching Hospital	13/02/2014	7	1	0.14
St George's Hospital	16/01/2014	8	2	0.11
Chelsea & Westminster	08/03/2013	18	2	0.11
North Bristol	21/10/2013	11	0	0.00
Oxford John Radcliffe	01/07/2014	3	0	0.00
University College London	28/08/2014	1	0	0.00

We would like to say a big

**THANK YOU**

**for your continued support with recruitment into ENCEPH UK.**

For the paediatric recruitment figures please check the UK ChiMES newsletter.



## FEATURE - Outcome Scores

The outcome scores: Glasgow Outcome Score Extended, Modified Rankin and Liverpool Outcome Score are to be completed at:

- ❖ Discharge
- ❖ 3 months after discharge
- ❖ 12 months after discharge

The final score is to be added to the CRF at the relevant time point Open Clinica.

A copy of the scores is to be forwarded via fax **ensuring the subject ID** is on each page of the document.

We appreciate it can be difficult to get a hold of patients at the follow-up points but unfortunately completion of outcome scores is low across the study and it is one of the main outcomes.

When you are speaking to the patient please remind them to complete the questionnaires that have been sent.

Please can you make every effort to contact the patients as we really need this data to be collected. If after 3 attempts you are unsuccessful please email [encephuk@liverpool.ac.uk](mailto:encephuk@liverpool.ac.uk)

**If we can assist in any way for these then please do get in touch.**

## dexENCEPH



dexENCEPH is a prospective randomised controlled trial that will compare the outcomes between patients with herpes simplex virus (HSV) encephalitis that do or do not receive corticosteroids.

Co recruitment with ENCEPH UK will not be a problem. Further information will be coming shortly.

If you are interested in participating in this study or have any questions about it please let us know by emailing [Cristina.fernandez@liverpool.ac.uk](mailto:Cristina.fernandez@liverpool.ac.uk).



## REMEMBER REMEMBER...

### 1. You can recruit patients after discharge

If you have identified a patient but they have been discharged prior to you giving them a patient information sheet up to 12 months post discharge.

We have ethical approval to send the below information sheet out to patients to provide them with the opportunity to participate in the study;

- ❖ ENCEPH UK Prospective Cohort Study Introductory Letter



### 2. Notify of patient deaths

Please make sure you let the team know if a patient dies within 2 - 3 days of becoming aware to prevent questionnaires being sent out causing undue distress to family members.

### 3. Put Subject IDs on ...

- ❖ **Questionnaires** you give to patients at discharge
- ❖ **Outcome scores** that you complete and fax at 3 and 12

### 4. Discharge Letters & Scan Reports

This is important so we can classify the patients into groups to see if we have adequate numbers of patients recruited.

### 5. Screening Logs and Non Enrolled Logs

It is important that you send in your screening logs on a monthly basis so that we can see your site activity and will be able provide targeted support on a site by site basis.



## Last but not least...

I would like to introduce Greg Gibson to the team as the ENCEPH-UK/UK Meningitis Administrative Assistant. Greg will be the main contact for patient enrolment, replenishing study supplies and providing general support.



## Useful Contacts

Brain Infections UK fax number 0151 795 5528

### **Clinical Research Fellow**

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### **Programme Manager**

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### **Data Manager**

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### **Administrator**

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### **Information systems developer**

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ENCEPH-UK cohort studies



UNIVERSITY OF  
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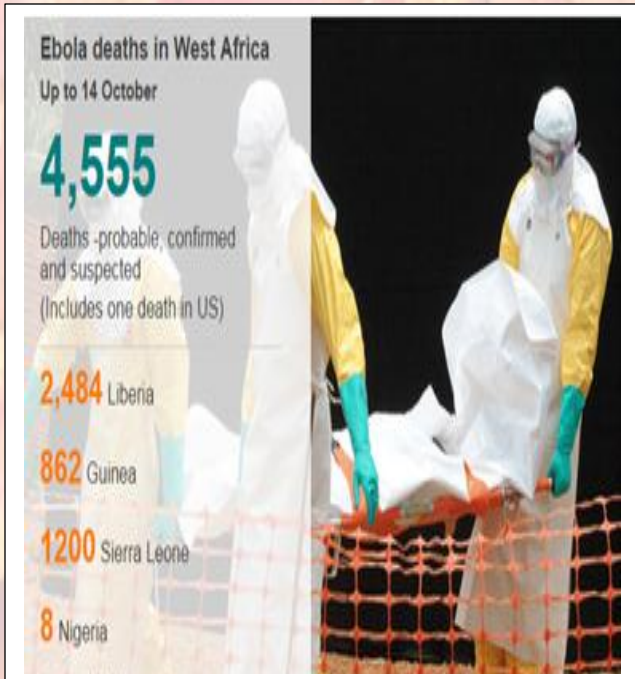


UK-ChiMES  
UK Childhood Meningitis and Encephalitis  
cohort Study

UK  
ChiMES



# EXTRA FEATURE -Ebola



Earlier this year, The University of Liverpool's Institute of Infection and Global Health host of the ENCEPH UK programme was awarded more than £7.5 million from the National Institute for Health Research to establish two Health Protection Research Units (HPRU).

One Liverpool HPRU Emerging and Zoonotic Infections is being led by Professor Tom Solomon (CI of ENCEPH UK).

For more information about the HPRU please visit the website:

[www.liv.ac.uk/HPRUemerginginfections](http://www.liv.ac.uk/HPRUemerginginfections)

## **EBOLA questionnaire**

Researchers at the HPRU are inviting doctors, nurses and other healthcare workers to help us understand their thoughts about helping with the Ebola outbreak in West Africa, by filling in a simple survey.

<https://www.surveymonkey.com/s/HPRUebola>

The results will help to identify and, therefore, potentially address any modifiable barriers there might be to people helping in West Africa.

## **First-hand experience – Andrew Bosworth**

To learn about the first-hand experience of Liverpool HPRU PhD student, Andrew Bosworth, who provided support to healthcare workers trying to contain the virus in West Africa, please visit:

<http://news.liv.ac.uk/2014/08/07/phd-student-works-on-ebola-frontline-2/e>