

EXTRAS News

Issue 4: October 2014

What has been happening since our last newsletter in March 2014....?

1. New study centres

Four new centres have opened to recruitment. These are: York, Sherwood Forest, Somerset and Wigan. A **big thanks** to the staff in these localities who facilitated opening and recruited the first patients. EXTRAS now has a total of 17 study centres (20 NHS Trusts). See page 2 for a list. The final centre will be Cardiff which aims to open in November 2014.

2. Patient recruitment

See pages 3 + 4 for centre recruitment numbers to end of September 2014. The total is **406 patients**, which is excellent news! Of these 406 patients recruited, 305 have been randomised to a study group – this always lags behind because randomisation is at discharge from ESD and recruitment can be any time from just before discharge from hospital to discharge from ESD.

3. Carer recruitment

To end of September 2014, **107 carers** had agreed to take part in EXTRAS. We would really like **more carers** to be involved. When you are performing a patient baseline assessment please try to remember to invite the carer to participate.

3. Data

The co-ordinating team continue to monitor the EXTRAS data which is generally in **very good shape**. Many thanks to those of you at sites who add data to the online database (MACRO) and deal with the monthly data quality reports. As you know, here in the co-ordinating centre we must write several reports every year where the study and the data are reviewed. So, please do keep up the hard work here!

4. Study document changes

Just a reminder that all sites should now have some revised documents for the EXTRAS extended rehabilitation service. These documents were revised based on your feedback.

The following are now in use:

Extended rehabilitation review documentation **v3**.

Goal setting and action planning record **v2**.

EXTRAS service manual **v2**.

5. Important new change to recruitment period

A reminder that recruitment is being extended to 31 March 2015. This may be subject to further change and the co-ordinating centre will keep in touch about this. The increased recruitment period is to ensure that 510 patients are randomised to a study group.

A trial to evaluate an extended rehabilitation service for stroke patients

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Centres opened in EXTRAS project year 1 (Oct 2012 – Sept 2013):

1. Northumbria

Northumbria Healthcare NHS Foundation Trust.

2. Leeds

Leeds Teaching Hospitals NHS Trust.

Leeds Community Healthcare NHS Trust.

3. Newcastle

Newcastle upon Tyne Hospitals NHS Foundation Trust.

4. Pennine

Pennine Acute Hospitals NHS Trust and Pennine Care NHS Foundation Trust

5. South Tyneside

South Tyneside NHS Foundation Trust

6. Cornwall

Royal Cornwall Hospitals NHS Trust

Centres opened in EXTRAS project year 2 (Oct 2013 – Sept 2014):

7. Southampton/Solent

Solent NHS Trust

8. Portsmouth/Solent

Portsmouth Hospitals NHS Trust

9. Plymouth

Plymouth Community Healthcare

10. Norfolk

Norfolk Community Health and Care NHS Trust

11. Stafford

Staffordshire and Stoke on Trent Partnership NHS Trust

12. Bournemouth

Royal Bournemouth and Christchurch NHS Foundation Trust

13. Hull/Humber

Hull and East Yorkshire NHS Trust and Humber NHS Foundation Trust

14. York

York Teaching Hospitals NHS Foundation Trust.

15. Sherwood Forest

Sherwood Forest NHS Foundation Trust

16. Somerset

Somerset Partnership NHS Foundation Trust.

17. Wigan

Wrightington, Wigan and Leigh NHS Foundation

Thanks from the EXTRAS co-ordinating centre to
all study centres

Recruitment data to end of September 2014: centres 1-8

	Northumbria	Newcastle	Leeds	Pennine	S Tyneside	Cornwall	S'ton/ Solent	Portsmouth
Nov-12	2							
Dec-12	3							
Jan-13	1	1	2					
Feb-13	2	0	1	0				
Mar-13	2	2	7	2				
Apr-13	3	2	4	1				
May-13	3	1	5	1				
Jun-13	5	1	3	0				
Jul-13	1	1	5	1				
Aug-13	6	0	5	1	2	1		
Sep-13	1	2	4	3	1	4		
Oct-13	3	0	5	1	0	5	0	
Nov-13	5	0	5	1	3	1	2	0
Dec-13	1	0	7	0	0	3	1	2
Jan-14	1	2	10	1	3	2	1	1
Feb-14	2	0	4	2	1	1	2	1
Mar-14	4	0	9	1	1	2	1	0
Apr-14	2	1	0	0	1	6	2	1
May-14	2	0	4	0	3	4	3	0
Jun-14	2	0	4	0	1	3	1	0
Jul-14	3	2	4	0	0	1	3	1
Aug-14	4	0	4	0	1	6	3	0
Sept-14	3	1	4	2	0	4	1	1
Total	61	16	99	17	17	43	20	7

Recruitment data to end of September 2014: centres 9-17 and total

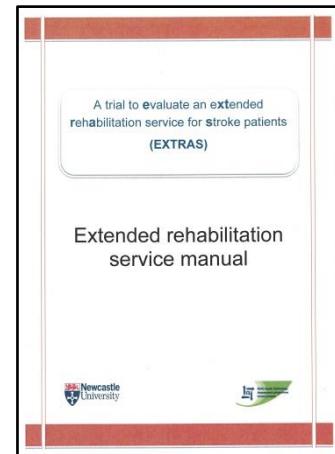
	Plymouth	Norfolk	Staffordshire	Bournemouth	Hull/Humber	York	Sherwood Forest	Somerset	Wigan	Total
Nov-12										2
Dec-12										6
Jan-13										4
Feb-13										3
Mar-13										13
Apr-13										10
May-13										10
Jun-13										9
Jul-13										8
Aug-13										15
Sep-13										15
Oct-13										14
Nov-13	3									20
Dec-13	5	1	2							22
Jan-14	4	1	5							31
Feb-14	4	5	2	0						24
Mar-14	5	1	1	4	0					29
Apr-14	4	1	2	4	2					26
May-14	3	4	2	2	0	0				27
Jun-14	4	2	0	3	2	1				23
Jul-14	3	3	0	1	1	1	2			25
Aug-14	3	3	0	1	0	1	1	2	1	30
Sept-14	4	5	4	3	1	1	2	2	2	40
Total	42	26	18	18	6	4	5	4	3	406

What is EXTRAS?

EXTRAS is a clinical trial to evaluate a new longer term stroke rehabilitation service.

One third of patients have long term disability after stroke but specialist stroke rehabilitation usually last no more than a few months. Patients who have on going rehabilitation needs once specialist stroke rehabilitation finishes may be referred to a range of other health care professionals or services, but most do not offer specialist stroke rehabilitation. One of the reasons why specialist stroke rehabilitation is not provided over a longer period is because it is not yet known if it is beneficial. The EXTRAS clinical trial will determine whether a new extended stroke rehabilitation service is beneficial to patients and carers.

Stroke patients and carers who agree to participate in the trial are randomly allocated to either receive a new extended stroke rehabilitation service or continue with usual NHS care. The new extended rehabilitation service begins when routine Early Supported Discharge (ESD) ends. It involves on going contact, usually by telephone, with a senior ESD stroke therapist or nurse for 18 months after ESD finishes.



A senior stroke therapist or nurse will contact patients and carers at 1, 3, 6, 12 and 18 months after discharge from ESD to review their progress and rehabilitation needs. Rehabilitation goals will be agreed and the therapist or nurse will give advice on how to progress towards these goals. The advice may be verbal advice, for example, exercises to practice at home, or, if required, referral to local rehabilitation services may be arranged.

The effectiveness of the new extended rehabilitation service will be evaluated by comparing the health (e.g. functional abilities and quality of life) of patients and carers who received the new service with those who received usual NHS care.

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