

A trial to evaluate an extended rehabilitation service for stroke patients

EXTRAS News

Issue 3: March 2014

EXTRAS sites open to date:

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

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/Humber NHS Foundation Trust

Another 6 months have flown by since the last EXTRAS newsletter in September 2013!

A lot has been happening....

1. New sites

Congratulations to the new sites that have opened in the last 6 months. These are: Southampton/Solent, Portsmouth/Solent, Plymouth, Norfolk, Stafford, Bournemouth and Hull/Humber.

2. Recruitment

This continues to go very well so as always a **big thanks** from the co-ordinating centre for the dedicated efforts of the site recruiting teams. See page 4 for the site recruitment numbers to 21st March 2014.

Gillian Courtauld in Cornwall won the prize for recruiting the 200th patient recently!

3. Database

The EXTRAS online database was launched in December 2013. Many of you know that this was delayed as Newcastle University needed to update their system. Another **big thanks** from the co-ordinating centre to those of you who painstakingly caught up with data entry just before Christmas.

Having now thanked you, we now need to **make a plea!** We need you to please keep up the good work with the data entry so that we don't fall behind and so that we can review the data for the various reports that trials must routinely write.

Also, we'll take this opportunity to let you know that our data quality reporting system is coming soon.....we'll be showing you missing data and asking you to resolve queries.

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4. Protocol amendment

Just a reminder that we're now working to EXTRAS protocol v3 – the change to protocol v3 was implemented in January 2014. It means you can now recruit aphasic patients using the new 'easy access' EXTRAS documentation. In addition, recruitment of carers is by invitation letter with enclosed information sheet and questionnaire – this should be given out at/near to the time of the patient baseline assessments. In some sites this means the carer invitation is given out by recruiting researchers and in other sites it means it is given out by ESD therapists.

5. Outcome assessments

The EXTRAS outcome assessments are at 12 and 24 months after randomisation. The first patients have just started to reach the 12 month point. In the co-ordinating centre we have recently been joined by Jacky Price who is conducting the 12 and 24 month telephone interviews. Welcome Jacky.

6. EXTRAS co-ordinating centre administration

EXTRAS is now probably at its busiest from a co-ordinating centre administration point of view. Many of you have already been talking and exchanging emails with Anne Harrison who has recently joined the team. Welcome Anne.

7. EXTRAS database

Another person to say welcome to is Richard Francis. Richard has done all the work on the database and continues to beaver away behind the scenes. Welcome Richard.

Thanks again from the EXTRAS co-ordinating centre to all sites



Jacky (outcome assessor)



Richard (database manager)



Anne (project administrator)

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Recruitment data to 21st March 2014

	Northumbria	Newcastle	Leeds	Pennine	S Tyneside	Cornwall	S'ton/Solent	Portsmouth	Plymouth	Norfolk	Staffs	Humber	Bournemouth	Total
Nov-12	2	x	x	x	x	x	x	x	x	x	x	x	x	2
Dec-12	3	0	3	x	x	x	x	x	x	x	x	x	x	6
Jan-13	1	1	2	x	x	x	x	x	x	x	x	x	x	4
Feb-13	2	0	1	0	x	x	x	x	x	x	x	x	x	3
Mar-13	2	2	7	2	x	x	x	x	x	x	x	x	x	13
Apr-13	3	2	4	1	x	x	x	x	x	x	x	x	x	10
May-13	3	1	5	1	x	x	x	x	x	x	x	x	x	10
Jun-13	5	1	3	0	x	x	x	x	x	x	x	x	x	9
Jul-13	1	1	5	1	x	x	x	x	x	x	x	x	x	8
Aug-13	6	0	5	1	2	1	x	x	x	x	x	x	x	15
Sep-13	1	2	4	3	1	4	x	x	x	x	x	x	x	15
Oct-13	3	0	4	1	0	5	x	x	x	x	x	x	x	13
Nov-13	5	0	5	1	3	1	2	0	3	x	x	x	x	20
Dec-13	1	0	7	0	0	3	1	2	5	1	2	x	x	22
Jan-14	1	2	10	1	3	2	1	1	4	1	5	x	x	31
Feb-14	2	0	4	2	1	1	2	1	4	5	2	x	x	24
Mar-14	2	0	8	1	1	2	1	0	4	1	0	0	4	24
Total	43	12	77	15	11	19	7	4	20	8	9	0	4	229

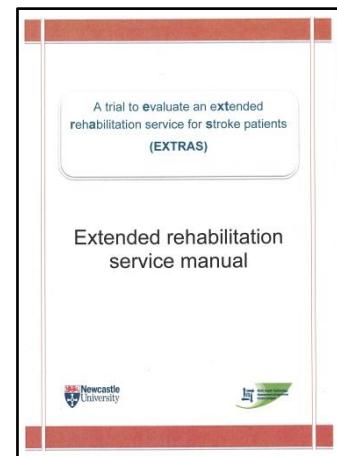
X = site not yet opened

What is EXTRAS?

EXTRAS is a clinical trial to evaluate a 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.



The 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.

EXTRAS is a 5 year project and aims to recruit 510 stroke patients/carers from 12 or more NHS stroke services.

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