A trial to **e**valuate an e**xt**ended reh**a**bilitation service for **s**troke patients

(EXTRAS)

Extended rehabilitation service manual v2

Newcastle University

NIHR Health Technology Assessment programme funded project

Contents

1. Introduction

This manual describes the new service which has been developed to be used in a multicentre randomised controlled trial to evaluate an extended rehabilitation service for stroke patient (the EXTRAS trial). The manual is primarily for members of Early Supported Discharge (ESD) teams who will provide the extended rehabilitation service. The manual also describes the trial procedures to be undertaken by participating ESD team members prior to delivering the extended rehabilitation service.

The EXTRAS trial is funded by the National Institute for Health Research (NIHR), Health Technology Assessment (HTA) Programme. The trial is described in full in the study protocol.

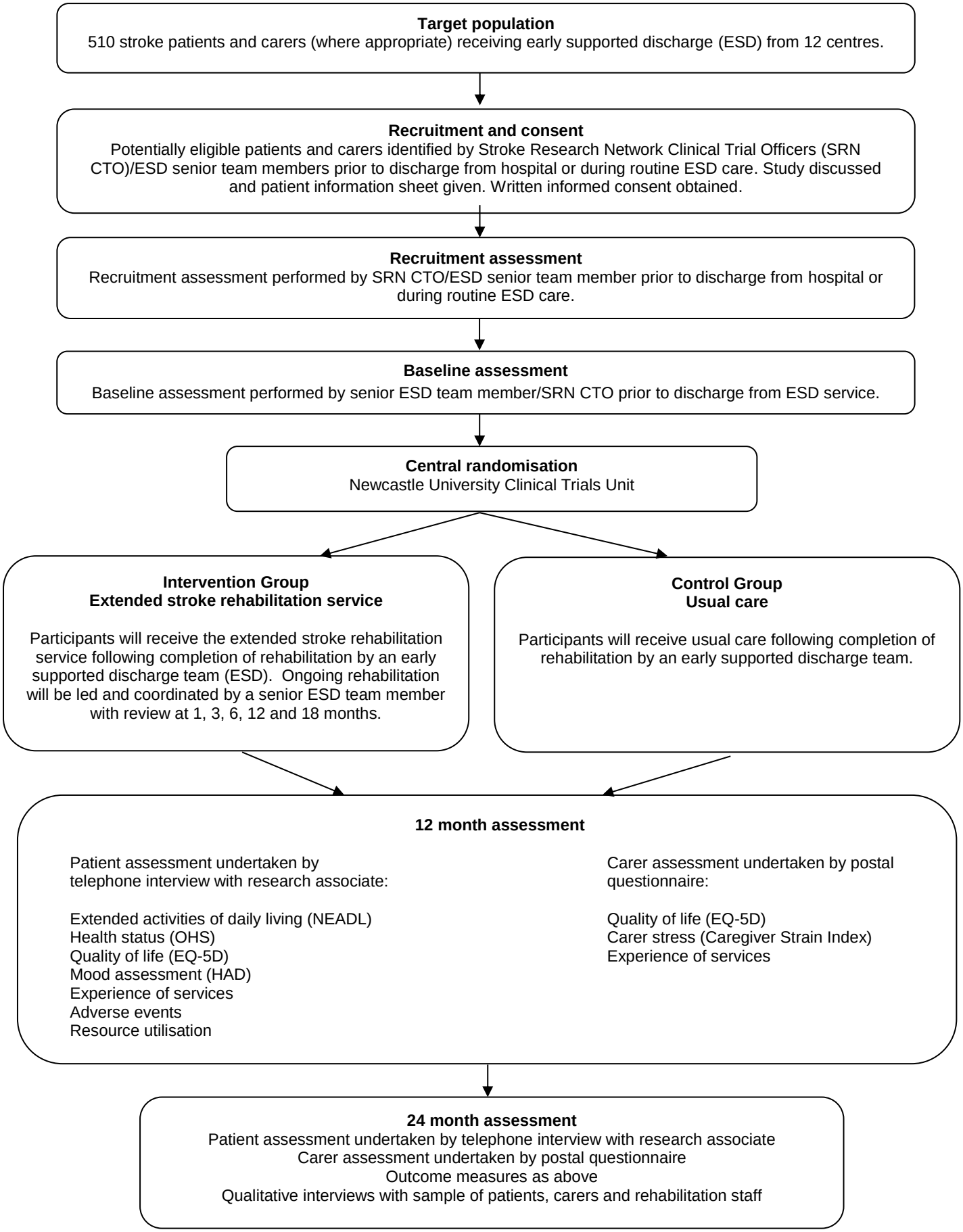
2. Background to the EXTRAS trial

One third of patients remain disabled after acute stroke and there are approximately 300,000 disabled stroke survivors in the UK[1]. Although a recent survey reported that just under half of stroke survivors have unmet rehabilitation needs[2], the longer term provision of stroke rehabilitation is sparse. One of the problems of improving longer term stroke rehabilitation is the limited evidence of clinical and cost effectiveness for specific interventions and service models.

A number of randomised controlled trials, Cochrane reviews and independent patient data meta-analyses have clearly demonstrated that stroke units and ESD services are effective ways to improve patient outcomes and quality of care following stroke[3, 4]. These services are referred to as ‘organised stroke care.’ Their key features consist of multidisciplinary stroke specialist expertise and coordination of care[5, 6]. The duration of ‘organised stroke care’ varies between services but usually it is not longer than a few months.

The EXTRAS trial will evaluate an extended stroke rehabilitation service. The service will extend 'organised stroke care' beyond ESD to include longer term stroke rehabilitation for a further 18 months.

3. EXTRAS trial summary



4. Overview of EXTRAS extended rehabilitation service

The extended stroke rehabilitation service consists of reviews by a senior member of the ESD team at 1, 3, 6, 12, and 18 months post discharge from routine ESD. We have chosen to evaluate a model where care is coordinated rather than delivered by a senior member of the ESD team as this model could potentially be delivered throughout the UK. The role of specialists coordinating rather than delivering rehabilitation has been shown to be effective in other conditions[7].

Each review consists of:

1. A semi-structured interview to identify the patient's progress, current rehabilitation needs and service provision. The interview will address everyday activities (personal care, meal times, domestic activities, indoor mobility, outdoor mobility, shopping, hobbies, driving), social participation and wider rehabilitation issues (mood, memory, pain, communication, medical issues) which may be problematic for stroke survivors. The views of both the patient and carer (where appropriate) will be sought.

2. Joint rehabilitation goal setting. From the identified progress and rehabilitation needs, up to five individual rehabilitation goals will be set by the patient (and carer) in collaboration with the senior ESD team member who conducts the review. The focus of joint goal setting will be increasing participation in everyday activities. The physical, psychological and social factors which may impact on goal attainment will be considered. At each review, progress towards goals from the previous review will be assessed prior to further goal setting. Achievement of goals will be recorded using a Goal Attainment Scale[8].

3. Action planning. The patient (and carer) will agree an action plan for each rehabilitation goal. This may include:

- Verbal advice and encouragement
- Discussion with the stroke team, rehabilitation team, primary care team, or social services involved in care
- Signposting to local activities, community organisations or voluntary services
- Referral to stroke services, rehabilitation services or primary care services for further assessment and treatment if required, according to local guidelines and/or service provision.

The majority of the reviews will be done by telephone. It is intended that the senior ESD team member will know the patient and carer as he/she will have treated the patient as part of the ESD service. However, if the patient and/or carer are unable to participate in a telephone review, a home visit will be undertaken. Patients will be given a study appointment card which will also contain a short checklist of rehabilitation issues to be covered in each review. This is to allow patients (and carers) time to consider the topics to be discussed prior to the interview.

A summary of the review and recommendations for rehabilitation will be sent to the patient, the patient's GP, stroke physician, and therapists who are currently involved in the patient's care (as appropriate).

5. EXTRAS trial procedures to be performed by participating ESD teams

The logistics of delivering the EXTRAS study may vary at different centres. Below is a summary of all the procedures that ESD team members may be involved with. Discussion and agreement of staff roles will take place prior to a centre opening to EXTRAS.

1. **Liaison with the trial co-ordinating centre at Newcastle University.**

   One member of the ESD team should agree to be the study liaison contact. This team member will receive regular updates from the trial co-ordinating centre regarding which patients have agreed to participate in the trial. This liaison contact should ensure that all members of the ESD team who are involved in the EXTRAS trial are kept informed and up to date about trial participants.

2. **Trial patient baseline assessment – *where it has been agreed that ESD team members will do this (in some EXTRAS centres, research staff are doing this assessment).***

   The trial patient baseline assessment is undertaken at discharge from ESD. If this assessment falls some weeks after recruitment to the study (which is possible), prior to conducting the baseline assessment, the senior ESD team member should confirm that the patient is still happy to participate in the EXTRAS trial.

   If the patient no longer wishes to participate, a senior member of the ESD team should complete an 'end of study record' form. This form (and all other study forms) can be found in your EXTRAS study file.

   To conduct patient baseline assessment: use a trial 'patient baseline assessment' form from the EXTRAS study file and conduct an interview with the patient to complete the assessment.

3. **Inviting a carer to take part in EXTRAS – *where it has been agreed that ESD team members will do this (this is done at the patient baseline assessment and is therefore conducted by either research staff or ESD staff as agreed).***

   Carers are invited by letter with enclosed carer information sheet, carer baseline questionnaire and pre-paid envelope.

   The main family member or friend who is providing support after discharge should be given a study invitation letter along with the carer information sheet, carer baseline questionnaire and pre-paid envelope.

   Centres may wish to consider making up several sets of invitation documents to be used as required. The EXTRAS co-ordinating centre will supply the pre-paid envelopes.

4. **Give out booklet 'Care after stroke or transient ischaemic attack. Information for patients and their carers' –** ***where it has been agreed that ESD team members will do this.***

   Once the patient baseline assessment is complete, patients/carers should be given a copy of the booklet 'Care after stroke or transient ischaemic attack. Information for patients and their carers'.

   These booklets are supplied to your ESD team by the study co-ordinating centre.

5. **Trial randomisation –** ***where it has been agreed that ESD team members will do this.***

   Following the patient baseline assessment, trial randomisation should be performed.

   Trial randomisation is done by a website which is accessed at:
   https://apps.ncl.ac.uk/random/

   As this is a website, and most baseline assessments will be conducted in a patient's own home, it is suggested that senior ESD team members telephone a colleague who will be at a computer, to perform randomisation. This colleague will tell the ESD team member which study group the patient has been assigned to.

   Once logged into the site, complete the on screen boxes to randomise. Further guidance on use of the randomisation website can be found in the document entitled 'Guide to randomisation (EXTRAS)'.

   To finish the randomisation process, complete a 'randomisation record' form (found in the EXTRAS study file.

6. **Inform patients about which randomisation group they have been allocated to -** ***where it has been agreed that ESD team members will do this.***

   Following randomisation, a senior member of the ESD team will inform the patient which study group they have been allocated to and remind them of the further trial stages:

   If the patient has been randomised to usual care (control group):

   Inform them that a researcher from Newcastle University will be in touch in 12 months (and again in 24 months) to ask them some questions about their recovery from their stroke and the services they have received.

   If the patient has been randomised to the extended rehabilitation service (intervention group):

   i. Remind them they will receive five stroke review appointments over the next 18 months (at 1, 3, 6, 12, 18 months from randomisation into the trial).

   ii. Make the appointment for their first EXTRAS stroke review. This should be 1 month from now (randomisation).

ii. Give them an EXTRAS appointment card (found in your EXTRAS study file). Note that an ‘easy access’ version of this appointment card exists for patients with communication difficulties.

7. Trial data management – *where it has been agreed that ESD team members will do this.*

Data from the patient baseline assessment form, the randomisation record form, any end of study record forms and the extended service review paperwork (further detail below in section 6) needs to be entered onto the study electronic database. Data entry may be performed by all or selected ESD team members as agreed locally. For guidance on use of the study electronic database please see the document entitled ‘Guide to electronic data entry’.

8. Provision of the EXTRAS extended rehabilitation service.

A senior member(s) of the ESD team will provide the extended rehabilitation service to patients and carers who have been randomised to the intervention group. Full details of this are given in section 6 below.

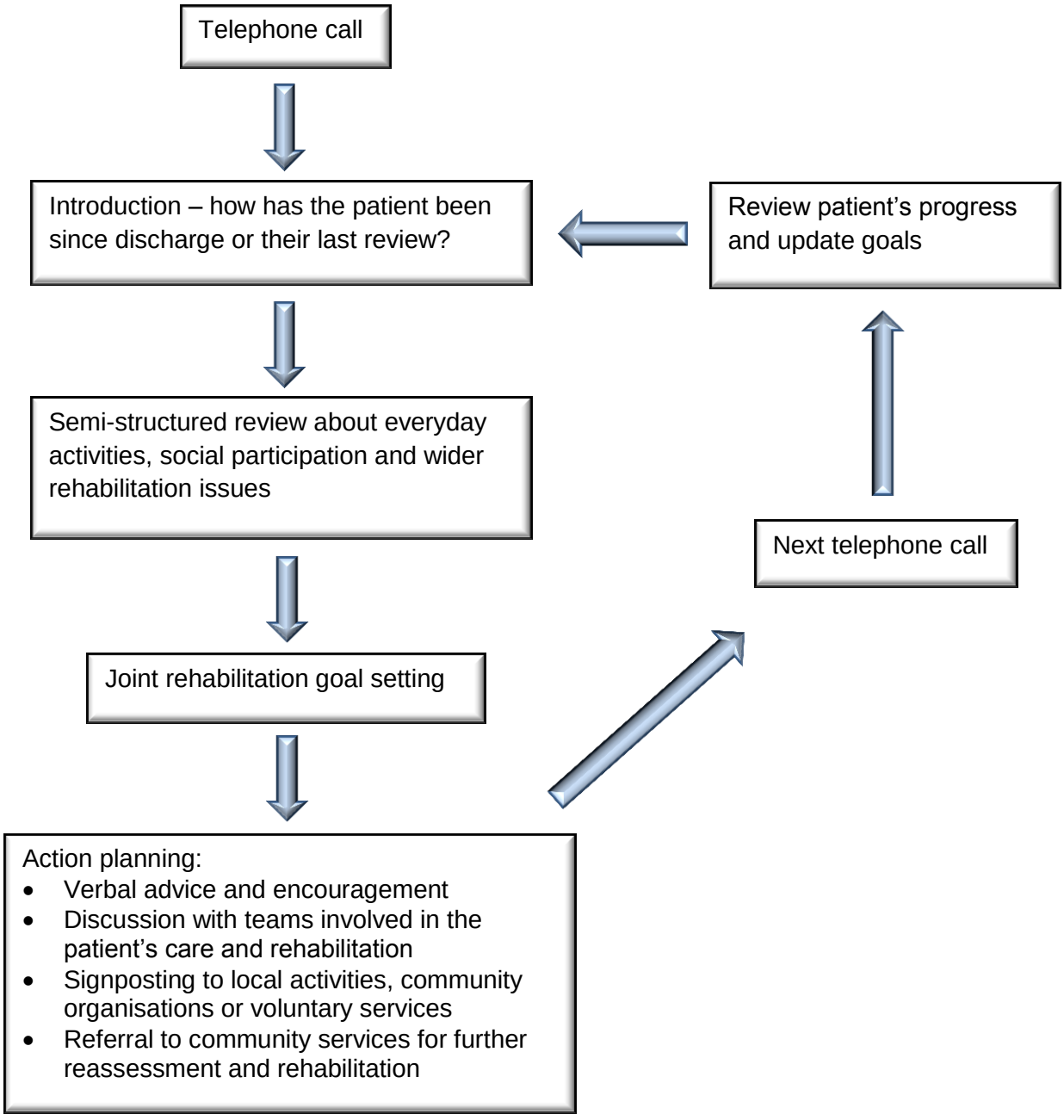
9. Trial safety reporting.

This is detailed in section 7 below.

6. Delivery of the EXTRAS extended rehabilitation service

Each patient randomised to the trial intervention group will receive five stroke rehabilitation reviews over 18 months. Reviews will be completed by a senior member of the ESD team and take place at 1, 3, 6, 12 and 18 months following discharge from ESD and randomisation into the trial. The reviews will be completed using the 'Extended rehabilitation service review documentation', 'Goal setting and action planning record' and the 'Extended rehabilitation service flowcharts'. All documents are supplied by the EXTRAS co-ordinating centre.

A summary of the extended rehabilitation service is shown in the diagram below:



6.1. Performing the semi-structured review to identify rehabilitation needs.

The reviews are performed using the 'Extended rehabilitation service review documentation'. This documentation has been designed to guide the senior ESD team member and patient (and carer) through the review.

The first appointment for the EXTRAS rehabilitation review service (1 month) should be made following randomisation. Subsequent appointments should be made at the end of a review (e.g. make the appointment for the 3 month review, at the end of the 1 month review). To assist with managing appointments, there is an EXTRAS appointment card and a 'letter for EXTRAS stroke review appointments' which can be sent to patients to remind them about the date and time of their appointment.

Each review consists of an initial introductory discussion (section A) which is followed by a series of questions about specific rehabilitation needs (section B). The rehabilitation needs addressed are: everyday activities (mobility, personal care, meal times, domestic activities, work/volunteering, hobbies, driving), social participation and wider rehabilitation issues (communication, memory, mood, medical issues and pain). The next section (section C) is used to summarise (list) the main rehabilitation needs to be prioritised and used for goal setting and action planning.

All sections of the review form should be completed; however, it need not necessarily be completed in the order listed. Issues may be raised at different times by patients (and carers), for example, if a patient raises a prominent issue in the introductory discussion, this may be explored first.

To assist with each review, the 'Extended rehabilitation service flowcharts' have been developed. These contain prompts to assist with exploring the rehabilitation needs to be addressed in the review. The flowcharts may be of particular use if exploring a rehabilitation need outside of a specific professional area. For example, a physiotherapist exploring communication needs. When completing a review, please try to avoid focussing only on the areas that would be relevant to one particular speciality. The flowcharts also contain action planning advice that may be appropriate for the rehabilitation needs highlighted. Examples of how to use the flowcharts are given in section 6.4 below.

Factors to consider whilst completing the review documentation:

Section A: introduction to the review

- At the beginning of each assessment, verbal consent should be obtained from the patient to participate in the review and for a summary of the review to be sent to their GP and other healthcare professionals involved in their rehabilitation at the time (section 6.5 below).
- Section A also contains open ended questions e.g. 'how have you been since your stroke?' and 'have you noticed any improvements in the last month?' to establish general thoughts and feelings about recovery.

Section B: assessment of rehabilitation needs

- Section B contains twelve common rehabilitation issues to be explored.
- For each rehabilitation issue, the lead in question should initially be asked e.g. 'How are you managing with household tasks?'

- Each rehabilitation issue has then been divided into several specific activities which should be explored. The flowcharts contain prompts to assist with questioning.
- For each activity, current status and any rehabilitation issues should be documented. The form should be completed using free text for 'current status',' circling 'yes' or 'no' for 'current rehab issue' and using free text for 'nature of current issue'.

Section C: list of rehabilitation needs

- In the table, the rehabilitation issues that have been identified in section B should be listed. The activity domains highlighted in blue in section B are extended activities of daily living. Rehabilitation issues from any of the extended activities of daily living domains should be listed in the first column of the table. Other issues should be recorded in the second column 'other issues'.
- If a significant number of rehabilitation issues have been identified, these should be prioritised. Discuss and agree with the patient the issues which they would like to prioritise to concentrate on in the months ahead. This may require a frank discussion about rehabilitation potential and realistic expectations.
- Use an asterix (*) in the column provided in the table to highlight the agreed priorities.
- The rehabilitation issues that are highlighted will be used to formulate goals and/or action points on the 'Goal setting and action planning record' (See section 6.2 below for details of goal setting and action planning).

Other factors

- The extended rehabilitation service involves five reviews for each patient. Although the format of each review is essentially the same as that described above, the following minor differences occur at the different time points:
- **Reviews 2-5**: at the start of reviews 2-5 (during section A); the ESD team member is prompted to review the goals and action points which were set at previous reviews. This is explained further in section 6.3.
- **Review 5**: the fifth (final) review will follow the same format as reviews 2-4; however, as this is the last review it is unlikely to be practical to set further goals, as these cannot be assessed at a later date. It will probably be necessary to set action points if unmet needs are highlighted.

6.2. Goal setting and action planning

Once rehabilitation needs have been identified and prioritised, goals and/or action points should be formulated along with a corresponding action plan for each goal/action point. These should be documented on the 'Goal setting and action planning record'. Please note that for patients with communication difficulties, an 'easy access' version of the 'Goal setting and action planning record' exists.

The senior ESD team member, in collaboration with the patient (and carer if applicable) will:

1. Set up to five SMART goals and/or action points.
2. Write an action plan to achieve the goals/action points.
3. As goal attainment will be measured as part of the trial, set a baseline score for goals (action points will not be scored).

Setting SMART goals

Each goal should be described by a single statement which indicates the intended outcome for the goal.

It is believed that goal setting is likely to be more successful when goals are set at the level of 'activity' and 'participation' than when goals are set to address impairments at the level of body structure and body function[9, 10]. For example, a goal to be able to transfer independently from bed to chair (activity level goal) or return to paid employment (participation level goal) is considered more effective for improving patient outcomes than a goal to improve quadriceps muscle strength by 150% (a goal set at the level of body structure or function) [10].

The goals should be Specific, Measurable, Attainable, Realistic and Timely – SMART.

An example of a SMART goal is: 'To get patient's arm through the sleeve of her jacket with only minimal help in 2 months'.

Specific	The goals should be as specific as possible, for example 'walking indoors' rather than 'mobilising'. Also avoid vague phrases such as 'using right hand in functional tasks' instead providing more detail such as 'brushing teeth using right hand'.
Measurable	There are several ways in which a goal can be measurable. Examples include measuring the time taken to achieve an activity (time to walk to the newsagents, time taken to get up and get dressed), describing the amount of a continuous activity performed in a set time (e.g. distance walked in 2 minutes) or the frequency in which an activity occurs.
Attainable and Realistic	It is important to ascertain what the patient's goals and expectations are, and to understand relevant contextual factors (the patient's past medical history, impairments and environment) [9] and previous rehabilitation, to allow attainable and realistic (achievable) goals to be set. The review, along with prior knowledge of the patient during ESD should facilitate this.
Timely	It is important to set a time period in which to achieve a goal. This time will vary depending on the context (post-acute or long-term) and the goal set (short or medium-term goals). As rehabilitation involves changing patient behaviour which can often take time, allowing sufficient time is important. The consecutive reviews provide regular opportunity to review and update goals accordingly.

Action points when SMART goals are not appropriate

In certain instances, it may be more appropriate to set an action point rather than a SMART goal. For example, it may be necessary to make a referral to a community rehabilitation team for an identified need rather than give advice about the issue. In such a case, it would likely be inappropriate to set a rehabilitation goal as specialist review is required. Instead, an action point could be set, for example 'attend community OT assessment for kitchen review'.

Also, on the fifth and final review (at 18 months post discharge from ESD) if unmet needs are identified, it would be inappropriate to set goals as they cannot be evaluated at any further time points. At this review, action points can be set to assist with continued social participation in the community.

Action planning

After the SMART goals and/or action points have been described, an action plan should be formulated for each goal/action point that has been set. The 'Extended rehabilitation service flowcharts' contain suggestions about action plans that may be appropriate for rehabilitation needs highlighted. Further detail about the flowcharts is given in section 6.4.

Action plans may include:

- Verbal advice and encouragement
- Discussion with the stroke team, rehabilitation team, primary care team, or social services involved in care
- Signposting to local activities, community organisations or voluntary services
- Referral to stroke services, rehabilitation services or primary care services for further assessment and treatment if required according to local guidelines and/or service provision

<u>Verbal advice and encouragement</u>

For some goals/action points, it will be possible to provide advice and encouragement over the telephone.

Examples include:

- Educating the patient about how to pace activities to prevent fatigue
- Advising on the correct technique to ascend/descend stairs effectively and efficiently
- Giving nutritional advice

It is important to use encouragement and reassurance throughout the review to remind patients of their on-going achievements. Patients can be vulnerable and isolated in the community; therefore awareness of the psychological and social consequences of stroke is vital.

Encouragement and self-efficacy principles can influence how people feel, think, motivate themselves and behave with regards to their health[11]. Alongside this, principles of self-management including support from self-help groups, family and community support, should be encouraged.

Discussion with teams or individuals involved in the patient's care and rehabilitation

If the patient is currently receiving rehabilitation or care, it may be appropriate to contact the specific team or individual involved. It is vital to have good communication links between the various care and rehabilitation providers in the community for several reasons:

- To avoid conflicting advice
- To gain a specific professional opinion about the patient's progress with rehabilitation
- To ask for a specialist professional opinion regarding the appropriateness of further rehabilitation, to prevent replication or referrals

Signposting to local activities, community organisations or voluntary services

Patients and carers may require information on a range of subjects and/or services. Examples include:

- Return to driving
- Information about holidays and travel insurance
- Availability of and information about local community clubs

The flowcharts provide contact details for a range of national support providers (both stroke specific and general health advice). The trial website (http://research.ncl.ac.uk/extrastrial/) also has a resources page with links to national organisations.

It may be appropriate to provide patients and carers with specific details, for example telephone numbers and/or information leaflets or it may be possible to simply advise the patient where to look for information (signposting). In some cases, it may be appropriate for patients and carers to contact organisations themselves. For others, it may be appropriate for the ESD team member to contact an organisation on behalf of the patient/carer.

The flowcharts cannot contain an exhaustive list of information or services. Local area information, groups and organisations should be accessed as appropriate. It is anticipated that ESD teams will have a good working knowledge of local services.

Referral to community services for further reassessment and rehabilitation

For some rehabilitation needs, it may be necessary to refer for a specialist assessment and further rehabilitation. The flowcharts contain suggestions about services which may be required. However, the provision of community services throughout health and social care organisations in the UK is variable and choice of referral may depend on the structure and availability of local services. In some instances, services may not permit direct referral and discussion and agreement with the patient's GP may be required.

It is important to decide if specialist referral is necessary and we suggest the following should be considered:

- What rehabilitation has the patient had previously?
- What is the further rehabilitation potential?
- Is the patient realistic about their own rehabilitation potential and goals?
- Is the patient already receiving any services?

It is anticipated that ESD teams will have a good working knowledge of local services (both stroke specific and generic) and the referral pathways into them.

Setting a baseline score for goals

Once a goal is set and an action plan has been formulated, a baseline score should be assigned to current function/ability.

The choice of baseline score is either -1 or -2. Select -1 if the patient has some function/ability related to this goal and it is possible for deterioration to occur. If no deterioration is possible, -2 should be selected.

Examples:

Goal: 'To reduce the patient's shoulder pain from 10/10 currently to 7/10 by next review'.

No deterioration in this problem is possible so the baseline score is -2.

Goal: 'To get patient's arm through the sleeve of her jacket with only minimal help (in 2 months)'.

The patient is managing to get their arm through a sleeve with some help currently but this could deteriorate to needing the task to be completed for him/her. The baseline score is -1.

Note: A baseline score only needs to be assigned to a goal, not for an action point.

6.3 Reviewing goal attainment and action points

At reviews 2-5, goals and action points from previous reviews are evaluated. Goals/action points should be evaluated at the review time corresponding with the time that they were set to be achieved in. For example, if you set a goal at 1 month which was to be achieved by 6 months, it should be evaluated at the 6 month review not the 3 month review. However, comments about progress towards longer term goals/action points can be recorded at each review in section A in the 'Extended rehabilitation service documentation'.

To evaluate goal attainment, the senior ESD team member will:

1. Record if a goal/action point has been achieved or not.
2. For goals, assess the level of achievement on the rating scale (this does not need to be done for an action point).
3. For goals and action points, document if the achievement is not what was expected and why.

Firstly, decide if a goal or action point has been achieved or not. In the 'goal setting and action planning record', tick 'Yes' or 'No' in the column titled 'achieved'.

For goals (NOT action points) a verbal rating and numerical score should then be assigned to the level of achievement.

- If the patient has achieved the goal at the **expected** level, tick 'as expected (0)'.

- If the patient achieves a **better** than expected outcome choose and tick either:
    - a little better (+1)
    - much better (+2)

- If the patient has **not** achieved the goal, choose and tick either:
    - partially achieved (-1) - this is ONLY used if baseline score was -2
    - same as baseline (-2/-1)
    - much worse (-2) – this is ONLY used if baseline score was -1

The table below gives an example of how the rating scale may be used:

Baseline status	Goal	Partially achieved (-1)	Same as baseline (-2)	As expected (0)	A little better (+1)	Much better (+2)
Unable to drive, but this may be possible following a full driving assessment at a mobility centre	To be able to drive using an adapted car in 6 months	Had a specialist driving assessment, and waiting for an adapted car	Unable to drive, waiting for a full driving assessment at a mobility centre	Able to drive using an adapted car, but not necessarily using this as her main means of transport yet	Able to drive using an adapted car, but limited distances only	Able to drive unlimited distances

Finally, for goals and action points, document if the achievement is not what was expected and why.

For goals, if the achievement rating is not 'as expected' describe what has been achieved and any reason this differs from 'as expected'. For example, a goal may have been set to 'get the patient's arm through the sleeve of her jacket with only minimal help in 2 months' but this has not been achieved. Reasons for not achieving this include: development of new pain in the arm making the activity more difficult; not yet received assessment/therapy from community occupational therapist due to a long waiting list.

For action points, if the action has not been achieved, document the reason why. For example, an action point may have been to attend a specialist assessment but the appointment date given has not yet been reached.

If a goal has not been achieved in the time set, the goal can remain on-going if it is still relevant and appropriate. The ESD team member should document that it was not achieved and the reason why, then re-write it in the current goal setting section (e.g. if you are performing the 6 month review, re-write in in goals set at 6 months section) and set another action plan to achieve it.

A completed example of the 'Goal setting and action planning record' is below.

The goal attainment scaling guidance and goal setting examples and have been adapted from 'Goal Attainment Scaling (GAS) in Rehabilitation. A practical guide' by Professor Lynne Turner-Stokes[12].

Goal setting and action planning record - goals set at 1 month review (evaluation at later review)

Patient's study number: 5012 Reviewer name: Lisa Shaw (Physiotherapist)

Goal / action point No	Date set	SMART goal or action point	Action plan (advice or information given or referral required)	Baseline score (-1 or -2) *	Date goal / action point evaluated§	Achieved	Verbal rating and numerical score *	Describe achievement if differs from expected and give reasons
1.	25/ 9/ 12	For the patient to be able to walk to the post office daily (in 4 months)	Refer to physiotherapy for outdoor mobility assessment (rang community physio team who agree this is an appropriate referral and the patient is known to the team)	-2	25/02/13	☐ Yes ✓ No	☐ Much better (+2) ☐ A little better (+1) ☐ As expected (0) ✓ Partially achieved (-1) ☐ Same as baseline (-1/-2) ☐ Worse (-2)	Improved outdoor mobility, but unable to get to post office every day due to fatigue
2.	25/ 9/ 12	To reduce the patient's shoulder pain from 7/10 currently to 4/10 (in 2 months)	Advice given regarding positioning for the arm Advised patient to attend GP for analgesia review	-1	25/11/13	✓ Yes ☐ No	☐ Much better (+2) ☐ A little better (+1) ✓ As expected (0) ☐ Partially achieved (-1) ☐ Same as baseline (-1/-2) ☐ Worse (-2)	Shoulder pain is now 4/10
3.	25/ 9/ 12	To attend 2 local stroke group sessions in the next 2 months	Given contact details of local stroke group. Patient will contact them to arrange going.	-1	25/11/13	✓ Yes ☐ No	☐ Much better (+2) ✓ A little better (+1) ☐ As expected (0) ☐ Partially achieved (-1) ☐ Same as baseline (-1/-2) ☐ Worse (-2)	Patient has attended 2 group sessions and also taking on other volunteering opportunities

* indicates these columns only need to be completed when setting goals (NOT when setting action points)

§ Goals/action points do not have to be evaluated at each review – e.g. if you set a goal at 1 month which was to be achieved by 6 months, you should evaluate it at the 6 month review not the 3 month review. You may wish to review progress towards the goal at the 3 month review. If so, comments can be recorded in the 'extended rehabilitation service review documentation'

6.4 Using the extended rehabilitation service flowcharts

The flowcharts have been designed as a guide to explore the patient's rehabilitation needs and to assist goal setting and action planning. There is one flowchart for each of the twelve rehabilitation issues to be explored.

Each flowchart is presented in four steps:

1. A lead in question to identify a potential rehabilitation need
2. Prompts to explore the potential rehabilitation need
3. A reminder to set a goal or action point
4. Suggestions for action planning to achieve the specified goal/action point

The flowcharts are designed to support professional clinical reasoning and to enable delivery of the extended rehabilitation service by a range of health care professionals (e.g. physiotherapists, occupational therapists, speech and language therapist and nurses).

Practical example 1 - identify and explore a need, set a SMART goal, action plan

1. Identify a potential rehabilitation need concerning hobbies and interests:

The lead in question is asked 'What interests and hobbies do you have?'

Mr Smith reports he enjoys reading and watching television but he does not get out of the house as much as he did prior to his stroke.

2. Explore the potential rehabilitation needs concerning hobbies and interests:

Using the prompts in the flowchart, Mr Smith may be asked about what he did prior to his stroke, what constitutes his daily routine, what potential barriers there are to social participation (physical, practical, psychological, cognitive factors).

Further discussion results in Mr Smith reporting that he has lost his confidence when going outdoors.

3. Set a SMART goal:

Following further discussion, the loss of confidence preventing Mr Smith from getting out of the house is agreed as an important rehabilitation issue.

He would like some suggestions on how to find a 'safe' place to visit to build his confidence back up. Using the suggestions for action planning, visiting a local stroke support group is discussed which Mr Smith agrees to.

The following SMART goal is set: 'Mr Smith will attend two stroke group sessions in the next two months.'

4. Set an action plan to achieve the goal:

Contact details for the local stroke group are given to Mr Smith. He is happy to contact the group himself to arrange a visit.

Practical example 2 – identify and explore a need, set an action point, action plan

1. Identify a potential rehabilitation need concerning domestic activities:

The lead in question is asked: ‘How are you managing with household tasks?’

Mrs Jones reports that she can independently do her own housework without problems and her neighbour helps her with gardening on a regular basis. Using the flowchart prompts she is also asked about how she manages her weekly food shopping and reports that this is difficult.

2. Explore the potential rehabilitation need concerning domestic activities:

Using the prompts in the flowchart, Mrs Jones may be asked who normally does the shopping, what kind of shopping is problematic, what is the specific difficulty (e.g. walking outdoors, handling money, carrying bags, fatigue).

Further discussion results in Mrs Jones reporting that she is having difficulty carrying her bags whilst also using her walking stick. She normally uses a walking stick to walk outdoors.

3. Set an action point:

The difficultly carrying shopping bags and using a walking stick is agreed to be an important rehabilitation issue. It is likely that a more appropriate walking aid is available which would assist with this issue.

The following action point is set: ‘to attend a physiotherapy appointment for an outdoor walking aid assessment’.

4. Set an action plan to achieve the action point:

A referral for an outdoor walking aid assessment is made by the ESD team member to an appropriate team, for example, community or domiciliary physiotherapy.

6.5 Tasks to complete following an extended rehabilitation service review

1. Complete the 'EXTRAS summary of stroke review'.

The senior member of the ESD team who performed the extended rehabilitation service review should complete the 'EXTRAS summary of stroke review' letter and arrange for this to be sent to the patient. The letter should be copied to the GP and other healthcare professionals if the patient has agreed to this. The template for the letter can be found in the EXTRAS study file/website and will also be provided electronically. For patients with communuication difficulties, an 'easy access' version of this letter is available.

2. Data management.

Data from the extended rehabilitation service review and the goal setting and action planning record should be entered onto the study database. For guidance on use of the study electronic database please see the document entitled 'Guide to electronic data entry'. Data entry may be performed by all or selected ESD team members as agreed locally.

7. Trial safety reporting

Clinicians and researchers who are involved in a clinical trial have an obligation to report events known as 'Serious Adverse Events'.

A serious adverse event is any untoward medical occurrence that:

1. Results in death *or*
2. Is life-threatening *or*
3. Requires hospitalisation, or prolongation of existing hospitalisation *or*
4. Results in persistent or significant disability or incapacity *or*
5. Consists of a congenital anomaly or birth defect *or*
6. Is otherwise considered medically significant by the investigator

During the course of an extended rehabilitation service review, a senior ESD team member may become aware of an event that fits into the above definition. For example, your patient tells you that they were in hospital last week for a chest infection. Or, you become aware that a patient taking part in the trial has died.

If you become aware of an event which may be a SAE, this should be discussed **IMMEDIATELY (same day)** with the dedicated person(s) at your site who deals with SAEs for the EXTRAS study. Details of this dedicated person(s) can be found in your EXTRAS study file.

The discussed SAE must then be logged on the 'SAE handover log' found in your EXTRAS study file.

The dedicated SAE contact person(s) will complete any reports that need to be made to the EXTRAS co-ordinating centre at Newcastle University.

If there are any queries, or your site SAE contact cannot be accessed, please contact the EXTRAS co-ordinating team directly on 0191 208 6779.

8. EXTRAS co-ordinating centre contact details

For any queries for questions, the EXTRAS study co-ordinating centre can be contacted as below:

Stroke Research Group
Institute for Ageing & Health
Newcastle University
3-4 Claremont Terrace
Newcastle NE2 4AE
Tel: 0191 208 6779

9. References

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