APPENDIX 2

ICGA Interim report and results of scoping exercise

Queen Margaret University
EDINBURGH

Intensive Communication Group for people with aphasia project

Interim report

Introduction

Funding (£35,000) was secured in March 2012 from the Headley Trust towards "the development of intensive speech and language courses for stroke patients".

This report highlights progress to date and outlines plan and timetable for completing the project.

Summary

Phase 1- the scoping exercise - has been completed.

The proposed intensive communication group for people with aphasia has been welcomed by colleagues in the NHS, voluntary organisations and Queen Margaret University.

"School of Health Sciences at Queen Margaret University is delighted to be part of this pilot study. This is an exciting opportunity with potential links and involvement for a variety of Allied Health Professionals and Nurses in this exciting project. To have the opportunity to help people with aphasia manage their speech, language and physical concerns in a learning environment is novel and creative and will enhance the educational experience for many students and staff." Dr Fiona Coutts, Dean School of Health Sciences, Queen Margaret University, Edinburgh.

Together we have identified a range of opportunities and challenges, for the short and longer term. Changes have been made to the proposed pilot model in the light of

feedback. The evaluation process will consider the other identified challenges to see if further amendments may be required in a future model.

The timetable for running the pilot programme has been rescheduled as a result of having to seek ethics approval and the length of time this is taking.

Project team

The project has been developed and is being implemented by:

- Jocelynne Watson (Senior Lecturer and Clinical Director, Speech and Hearing Sciences, Queen Margaret University) – Principal Investigator
- Amanda Bennett – Scoping Exercise Leader and Joint Therapy Leader
- Tricia Mitchell – Joint Therapy Leader

Advisory Group

A small advisory group has been set up involving the key interest groups, and has met twice:

- Queen Margaret University
- NHS speech and language therapy services (Representative: NHS Lothian)
- Voluntary organisations offering service to people with aphasia (Representative: Chest Heart and Stroke Scotland (CHSS)
- People with aphasia (Representative: Co-ordinator of Speakeasy Tayside).

The group will continue until the completion of the project and additional members will be recruited if additional experience/expertise is required.

Promoting inclusion

Clear terms of reference were agreed at the beginning and we aim to follow good practice in order to enable the fullest participation of everyone, including those with communication support needs. For example, papers sent out in advance, agreed groundrules at the beginning of each meeting, clear agenda, regular breaks.

Timetable

The original project timetable was scheduled to run April – August 2012. The aim was to undertake two phases of the project within this period i.e. undertake the scoping exercise and run the pilot programme

This has not been possible. As this project is defined as a research project, ethical approval has to be gained. This process is taking longer than envisaged as it has been difficult for the Principal Investigator to allocate time, given other responsibilities. Until this is granted no direct contact was allowed with potential participants, which made recruitment impossible. Ethical approval has not yet been gained.

Therefore, the timetable has now been extended, with the agreement of all involved including the Headley Trust, to August 2013. See Appendix 2 Timetable July 2012-August 2013.

As the Scoping Exercise has been completed and initial planning for the group undertaken the two Therapy Leaders will step back from September 2012 to March 2013.

Phase 1: Scoping exercise

Aim: To identify potential clients and produce a detailed plan of intervention including design of outcome measures.

The scoping exercise has involved:

- Identifying demand.
- Looking at models of intensive communication therapy groups used elsewhere to learn from others and prevent any unnecessary duplication in services.
- Identifying key drivers influencing policy and strategic development in this area
- Liaising with NHS services and voluntary organisations representing and working with people who have had strokes to discuss their response to the model being proposed.
- Setting up a small advisory group (see above).
- Developing the pilot programme further based on feedback given.

Results

The extent of the scoping is limited due to resources available but the results have given us sufficient information to identify key opportunities and challenges and to amend the proposed pilot where required.

According to the Stroke Association (www.stroke.org.uk) around 13,000 people have a stroke each year in Scotland. Over 3,000 of these people will be under 65. There are over 112,000 stroke survivors in Scotland.

“Aphasia is a condition which affects the speech, language and communication skills of people after they have experienced brain damage. One of the most common sources of such damage in adults is stroke and about a quarter of people who have strokes also have aphasia.

For many of these their aphasia can have a serious, pervasive and long lasting impact on the individual, on their families and on those in their immediate environment.” (Aphasia in Scotland Project, research project, Centre for Integrated Healthcare Research, November 2007)

Intensive communication therapy groups

We found no similar intensive communication therapy groups at present being offered in Scotland.

We looked at the following models of delivery elsewhere:

Dalhousie University, Canada
This is a 4.5 week intensive course 9-5 Monday to Friday costing participants $18,000. Individuals refer themselves and it is available to 6 people 3 times a year and is residential. This allowed for social evening sessions which are seen as key to promoting effectiveness. There are two full time members of staff and speech and language therapy students from the University. Communication partners (for example a spouse/partner/family member) are encouraged to attend.

Newcastle University, England
Intensive therapy is offered in 2 x 10 week blocks linked to each semester (Oct-Dec, Jan-May), and is 50% 1:1 and groupwork. The clinic is not funded by the NHS but all referrals come via the NHS and the clinic is run by in house specialist staff and students.

UCL, London
Clinics are run by 2 members of UCL staff and students. These run twice weekly offering 1:1 and group therapy. It is an open referral system.

Supported self -management groups

In line with the Scottish Government's emphasis on the person centred agenda, the work of their Joint Improvement team (www.jitscotland.org.uk/action-areas/talking-points-user-and-carer-involvement) and the movement towards self-directed payments there is an increasing focus on self-management. We discussed within the Advisory Group as to whether the proposed programme model should focus more on supported self-management than was initially envisaged.

This led to discussion with one of the key suppliers of supported self-management training in the Central Belt of Scotland, the Thistle Foundation. In partnership with the Glasgow Caledonian University and The Stroke Association, the Thistle Foundation are seeking research funding to adapt their existing supported self management training (10 week course with peer support) to be more accessible to those with communication impairments including aphasia.

In order not to duplicate activities, we confirmed the original decision that our pilot should focus primarily on promoting more successful communication though we will touch on aspects of self management in the issues to be discussed.

There may be opportunities of linking with the Thistle Foundation if they attract research funding for their proposal.

Key drivers

In addition to the above some other key drivers impacting on service development for stroke in Scotland are:

- National Advisory Group on Stroke (www.sehd.scot.nhs.uk/stroke/NAC)
- Managed clinical networks for stroke
- Better Heart Disease and Stroke Care Action Plan 2009 (www.scotland.gov.uk/Resource/Doc/277650/0083350.pdf)
- AHP (Allied Health Professionals) Rehabilitation Delivery Plan – in consultation at moment (www.scotland.gov.uk/Publications/2012/02/8445/3)
- Scottish Intercollegiate Guidelines Network (www.sign.ac.uk)
  Sign guideline 118: Management of patients with stroke:
  Rehabilitation, prevention and management of complications, and discharge planning
- **Cross party group on heart and stroke care**
  (www.scottish.parliament.uk/msps/HeartDiseaseAndStroke.aspx**)**

Liaison with NHS and voluntary organisations

Against the backdrop of these key drivers, we liaised with colleagues in:

- NHS boards surrounding Queen Margaret University i.e. NHS Lothian, Borders and Forth Valley. We will be in contact with NHS Fife as well.
- Voluntary organisations – Speakability, CHSS, Different Strokes, the Stroke Association, Talking Mats, Keycom.

See **Appendix 1 Model Draft 1 Details** to see the model we took to them in terms of format, therapy aims and criteria for participation.

Response

NHS services all welcomed the idea of an intensive communication group. None have the capacity to offer such services themselves at present, nor do consistent work with communication partners.

Key issues raised:

- Length of travel time may be an obstacle.

- Level of intensity ie 5 consecutive days may be a challenge.
- Involvement of communication partners may not be possible for everyone who might benefit.
- Should referrals come through NHS or be an open referral system where an individual can self-refer?
- Expectations of what happens post group need to be managed.

Voluntary organisations consulted were generally enthusiastic. Again a key issue was whether there was to be an open referral system or not.

Phase 2: Pilot model

Therapy team structure

One key element of the model being piloted is the involvement of 1 (or 2) interns i.e. newly qualified speech and language therapists requiring further clinical experience to strengthen their CVs, and speech and language therapy students requiring quality clinical placements.

Interns
We have agreed the process of recruitment with QMU HR department and have a recruitment flier and job description ready.

Challenges in involving interns:

- Time needed for recruitment and clinical and management support.
- Implications for therapy programme if the interns recruited drop out.

Students
Clinical placements giving speech and language therapy students the experience of working with people with aphasia are increasingly difficult to secure. This group offers a good opportunity and we will involve 8 students.

We have developed and piloted an induction day for interns and students with the involvement of an individual with aphasia. Feedback from those attending indicated it was extremely useful.

Challenges in involving students:

- Time required for clinical supervision and assessment.
- Tension between offering quality therapy service and clinical education.

Programme

As part of the scoping exercise we explored with Allied Health Professional (AHP) colleagues (music therapy, art therapy, movement therapy, physiotherapy, occupational therapy, dietetics/nutrition, audiology, podiatry) the possibility of involving them in offering sessions in the 5 day programme. This would add depth to the activities offered to participants and promote inter-professional working and practice based learning as part of this model.

There has been general support for the idea but recognition that as this is a pilot we need to limit the number of other AHPs to be involved, and limit the number of students other than speech and language students.

We have agreement from other University facilities e.g. fire officer and events management to support the pilot group and adapt activities to meet the needs of this client group. This will also raise awareness of aphasia amongst University support staff.

Challenges

- Time required from colleagues to develop and supply a session directly relevant to this client group.
- Managing expectations of participants. For example following a positive experience through attending the group they may want and be able to access in the community Exercise after Stroke classes in their local leisure centre but they not so easily be able to access art therapy.
- If other Allied Health Professional students are involved supervisory responsibility needs to be clarified.

Amendments to the Pilot Model Draft 2

We have made some amendments to the model as a result of feedback.

Intensity
We will spread the 5 days therapy over two weeks not one.

Communication partners
We have loosened the criteria that stated that all participants have a communication partners who must attend for some specific sessions. This is not possible for everyone. This may be because there is no regular communication partner, or they are working or feel it is not relevant for them to attend.

Involvement of communication partners is difficult to achieve in the regular clinic session too. However it is generally recognised that this is vital if there is to be carry over from therapy sessions to everyday life.

We believe that this involvement may need to be achieved in other ways e.g. a residential weekend session aimed directly at communication partners.

Therapy aims

The therapy aims remain:

1. To improve the effectiveness of the participants' functional communication by offering a supported and varied environment for people to practise communication strategies.

2. To increase confidence in using computer assisted therapy programmes which meet personal needs.

3. To improve everyday communication with people with aphasia by increasing the knowledge and skills of communication partners.

4. To identify the components that make a successful intensive therapy programme.

The ability to meet aim 3 will be restricted if there is limited involvement of communication partners.

Therapy outcomes

Successful therapy outcomes will be:

- increased confidence to communicate in a variety of situations
- Increased confidence to use on-line therapy computer software programme (react2.com)
- increased knowledge and skill in communicating with people with aphasia
- increased understanding of the components necessary to be included in a successful intensive therapy model

The outcomes will be measured using:

- 1-10 (or 1-5 depending upon comprehension abilities) rating scale on each outcome at the beginning and end of the programme.
- evaluation questionnaire at the end of the programme.

In addition:

- for outcome 2 there will be secure results module contained within the react2.com programme.
- personal goals will be set with each participant at the beginning of the programme using a Solution Focussed BRIEF therapy approach which allows for the identification of small successful steps towards a ‘better’ future. Rating scales will be used to identify whether these have been achieved. If regular small steps are achieved during the programme the goals will also be modified.

Key challenges we face

- Ethics approval process and rescheduled time

- NHS Speech and language services have either had recent restructuring or face this in the near future. This makes planning difficult and can lower morale amongst potential referrers.
- Each area is organised slightly differently.
- All offer different services and have slightly different care pathways.
- Referral system. Should this be an open system available to individuals to refer themselves or should it be restricted to certain avenues e.g. through a local speech and language therapy service.
- Duty of care. The referral system used will impact on who has ultimate duty of care for that individual.
- Potential participants may be involved in other research. For example at the present time Edinburgh University is evaluating the effectiveness of the react2 programme d their results may be influenced by one of those involved attending our intensive group. In the light of this we have included a line in the information sheet to encourage people to discuss the matter with the researcher if they are involved elsewhere.How to best involve communication partners. .
- Keeping momentum going with new timetable and Leader Therapists having to step back for a number of months.

Appendix 1: Model draft 1 details (prior to amendment)

Format

- Intensive communication therapy group (5 days) to be held at Queen Margaret University.
- A ½ day introductory session for all participants to be held in week before.
- For up to 12 people with aphasia (as a result of stroke) and their communication partners.
- To be run by 2 speech and language therapists, 1 intern (newly qualified speech and language therapist), and 8 speech and language therapy students
- Programme to be a mixture of 1:1 and group activities including art, music, movement facilitated by other Allied Health Professionals represented on campus

Therapy aims:

1. To improve the effectiveness of the participants' functional communication by offering a supported and varied environment for people to practise communication strategies.

2. To increase confidence in using computer assisted therapy programmes which meet personal needs. (using react2 software supplied by Propeller for these purposes free – together with free training for interns/students)

3. To improve everyday communication with people with aphasia by increasing the knowledge and skills of communication partners.

4. To identify key components that make a successful intensive programme

Criteria for participation

We welcome adults of all ages who have had a stroke and where their main communication impairment is aphasia.

Individuals must:

- Be willing to attend all 5 days.
- Have a designated communication partner who will attend at specific times in the week (caregiver, partner, family member or friend who are involved in the daily life of the person with aphasia).
- Be cognitively and physically able to endure the intense nature of the programme.

- Be interested in learning about, and practising, computer assisted therapy programs.
- Be able to identify, with the assistance of the therapy team, realistic personal goals for participating in the programme.
- Be medically stable.
- Be able to see the contents of a small television screen (computer screen).

The therapy team can offer help to get to the toilet door and give reminders to take medication. Further assistance on toileting and medication cannot be offered.

Report produced by Amanda Bennett (Joint Therapy Leader) on project team.

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