Dedicated
in memory of
Pauline

Acknowlegements

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Central and North West London NHS
NHS Foundation Trust

Milton Keynes Community Health Services

different Strokes
Support for Younger Stroke Survivors

Introduction

Treatment of Stroke Survivors upon leaving Milton Keynes Foundation Trust Hospital is covered by NHS Early Stroke Rehabilitation Team providing Physiotherapy, Occupational Therapy and Speech and Language Therapy where needed. This intense therapy is provided for a period of 6 weeks. Upon its completion, the patient is assessed to establish if any further therapy is required, and if necessary referred to a NHS Rehabilitation Centre for further treatment. Once NHS treatment has finished many Stroke Survivors feel as though they still need something else to help them progress along their pathway to recovery.

There are Clubs and Charitable Organisations that have been formed over the years to help, one being Different Strokes. Different Strokes of which there are 46 groups throughout the UK provide an exercise class set to music, which together with instruction from a qualified instructor, creates movement and exercise to encourage mobility, confidence, fitness and self-esteem. It also provides a social atmosphere and practical advice and information for all Stroke Survivors and Carers.

Milton Keynes Talkback Club is another group who help Stroke Survivors who have speech and language difficulties.

Another source of exercise is obtained through ARNI, Action for Rehabilitation from Neurological Injury. One or two Different Strokes Groups have instructors who are ARNI trained; Milton Keynes does not, hence the reason for the proposal to hold a six week trial using the ARNI techniques for stroke survivor volunteers from Different Strokes Milton Keynes Group, with a view of looking at the possibility of creating the facility within the area.

For the trial to take place Different Strokes MK Group approached Shenley Leisure Centre Management, to see if they had any suitable Personal Trainers on their staff, who could be trained in the ARNI techniques, and provide the facility at the Leisure Centre. There were none, so Shenley Leisure Centre approached the ARNI charitable trust on Different Strokes behalf, to obtain information on locally trained ARNI instructors. The trust suggested a trained instructor from Aylesbury, Alison Smith, who is party to the trials and contributes to the results.

Shenley Leisure Centre very kindly offered to provide the use of the premises throughout the trial, free of charge. Staff from Milton Keynes Stroke Clinical Specialist Team Ruth Joy and Diane Cooke formed part of the group carrying out the trial and monitored the progress of the people taking part. Different Strokes provided six volunteers from its group, who all

contributed towards the cost of the trial and Different Strokes MK Group sponsored the remainder of the costs.

Throughout the trial period, which ran for six weeks from 16th September 2013 until 21st October 2013 there were visitors from Milton Keynes Early Stroke Rehab Team, the coordinator of AMKERS (Access MK Exercise Referral Scheme), the manager of the Neuro Rehab Unit and the Stroke Strategy Project Manager for Milton Keynes, all to observe first-hand how the volunteers were progressing. Records were kept of people's achievements against their ambitions and form the basis of this report. Video evidence & pictures were taken to record people's progress throughout the trial.

ARNI is a charitable trust which promotes rehabilitation for Stroke Survivors through exercise training sessions and a personalised programme of home training. ARNI supports stroke survivors who have completed their NHS formal rehabilitation programme and want to continue to regain and improve their functional movement.

The ARNI approach was developed by Dr Tom Balchin, himself a stroke survivor and is guided by national leaders in the fields of Neurology, stroke rehabilitation and neurological physiotherapy. The latest clinical evidence is incorporated into ARNI trainings.

Dr Tom Balchin wrote "The Successful Stroke Survivor". This 525 page manual includes detailed advice about exercise for Stroke Survivors and their supporters, as well as a substantial number of suggested training exercises, aimed at different parts of the body, and for various levels of current mobility. The ARNI functional retraining strategies support stroke survivors to take charge of their own recovery. In the ARNI approach, stroke survivors can expect to be training regularly to capitalise on the effects of repetition intensity, and working at the edge of their current ability.

Health Authorities such as Bedford and Luton have already rolled out ARNI training programmes, with the aim of giving stroke survivors in their areas access to ARNI instructed programmes. Evaluations have already indicated substantial savings, for example in paramedic call-outs to falls, as a result of the sessions undertaken. Positive results are emerging from several pilot clinical studies to evaluate techniques which ARNI instructors use with stroke survivors.

Alan Parsons, Different Strokes Milton Keynes Group

ARNI Techniques for Chronic Stage of Stroke in a Group Setting - A Pilot Programme Research Report

Alison Smith, Ruth Joy and Alan Parsons

Contents

1 Summary

Different Strokes Milton Keynes Group, in partnership with Shenley Leisure Centre, Central and North West London NHS Foundation Trust, and Action for Rehabilitation from Neurological Injury (ARNI) set up a series of pilot group sessions for stroke survivors using the ARNI approach. Six participants, volunteers from the Different Strokes Group, took part in the sessions which took place weekly for six weeks. Monthly follow up sessions have also been arranged for November and December 2013 to give participants an opportunity to refresh their programmes, report on progress and boost their motivation.

The main aims for the pilot from the ARNI perspective were that participants would: have information about suitable ARNI techniques for their individual situation; establish, or add to existing independent training outside the sessions using ARNI techniques; and have the tools and motivation to continue with their training after the pilot sessions ceased.

Participants ranged in age from 52 to 72, two are in their 50s, two in their 60s and two in their 70s. Time since stroke was from 2 to 10 years and levels of mobility varied widely from ability to walk independently, to use of wheelchair and hoist. Movement and control in affected arm and hand ranged from gross arm movement with little or no discernible hand movement to virtually full function of arm and hand.

Each week, the participants were given a tailored programme of exercises, designed around their own goals with encouragement to aim for daily practice with one or two rest days per week. All six participants completed the programme and only one missed a session because of a prior commitment.

Blood pressure did not appear to be adversely affected by the exercise class. Some individuals showed a small decrease in blood pressure. Ambulant participants all decreased their time on Timed Up and Go, and one participant who was unable to walk without the stick at all at the beginning of the trial completed the task without a stick at the end of the sessions. Berg Balance Tests for three of the four were improved. The majority noticed small improvements in their upper limb function. 3 of the 4 ambulant participants said their level of mobility had improved in some way. Participants also mentioned being able to return to activities, such as dancing, which they had not done since before their stroke.

Five out of six participants have become more independent or effective in daily activities such as preparing food, eating, getting dressed, or mobility. These participants did home training between sessions, some of them a substantial amount. All of the 4 who are ambulant practiced getting down to the floor and up again from standing in the group sessions, some for the first time. All participants had experimented with attempting new things and tasks they thought they could not do. Five out of six participants said they felt they had made progress towards the goals they set at the beginning of the programme. Confidence increased for the majority of participants both in doing particular tasks, such as walking, and more generally in social situations.

All felt the programme could have been longer than 6 weeks although most said that the time had been effective in getting them started on the ARNI techniques and that they were looking forward to the monthly follow up sessions. All made positive comments about the programme and were keen for ARNI in Milton Keynes to be expanded to provide longer programmes, and that ARNI techniques be made available to a wider audience.

It is recommended that ARNI Instruction be provided in group sessions in Milton Keynes, through the AMKERS referral scheme and that existing AMKERS personal trainers be trained to Qualified Instructor status in the ARNI techniques.

2 Background

> *'Recovery can continue for many years after an individual has had a stroke, so it is important that commissioners consider how to provide access to services over the long-term. ….. The impact of a stroke may continue for as long as the person who has had a stroke lives, which means that services may need to be available for the whole of their life.'*
> *Department of Health (2007) National Stroke Strategy*

A recent review of 339 Randomised Controlled Trials by Teasell et al (2012)[1] found that there is a robust evidence-base for stroke rehabilitation interventions in chronic stroke. Teasell also highlighted the contrast between an 'impressive evidence-base' and the limited optimism and resources available for rehabilitation. The experience of many stroke survivors and their families is that once NHS formal therapy ends they are left to their own devices, sometimes feeling abandoned to cope alone.

> *"There is only so much you can get from the authorities, and then it's up to you."*
> ARNI Pilot Participant, 6 years from stroke

The UK Stroke Strategy highlights the importance of community stroke exercise programmes. The National Institute for Health Research indicates the need for rehabilitation which is one step removed from therapy (cited in Balchin, 2012[2]).

Action for Rehabilitation from Neurological Injury (ARNI) is a UK charitable trust which has refined an approach to stroke recovery utilising intensive task-related practice and resistance training allied to personalising physical coping techniques. ARNI trains and matches specialist exercise instructors with stroke survivors who require further functional training after formal therapy stops. The techniques and background to ARNI are described in The Successful Stroke Survivor (Balchin, 2011)[3].

Evaluations at the ARNI Centre at Chaul End, Luton have already indicated substantial savings in paramedic call-outs to falls and savings on care packages, appliance support and medications, as a result of the sessions undertaken. Luton participants also reported improved mobility, range of movement, energy levels, and confidence (Balchin, 2012). Several clinical studies are under way to evaluate techniques which ARNI instructors use with stroke survivors. Study participants in an early feasibility study[4] have reported improved mobility, range of movement, action control, strength, confidence and reduced fear of the consequences of exercise. Publications are also emerging from the early stages of a randomised control trial on the ARNI approach.[5]

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[1] Teasell R, Mehta S, Pereira S, McIntiyre A, Janzen S, Allen L, Lobo L, Viana R (2012) Time to rethink long-term rehabilitation management of stroke patients. Topics in Stroke Rehabilitiation Nov-Dec;19(6):457-62.
[2] Balchin T and Van As C (2012) 'The Unbroken Care Pathway Ideal: An Innovative Approach to Rehabilitation in the Community using Specialist Exercise Instructors' Poster presentation - World Stroke Conference, Brazil 2012
[3] Balchin T (2011) The Successful Stroke Survivor. Lingfield, Bagwyn.
[4] Kilbride, Norris and Mogaghegi (2012) Brunel University Study at Hillingdon Hospital. (unpublished)
[5] Poltowski, Briggs, Forster, Goodwin, James, Taylor and Dean (2013) *'Informing the design of a randomised controlled trial of an exercise-based programme for long term stroke survivors: lessons from a before-and-after case series study'*. BMC Research Notes 2013, **6**:324 . Accessed on 28/08/13 at http://www.biomedcentral.com/1756-0500/6/324

3 Pilot Evaluation Method

The evaluation of the pilot used a pre-post methodology across a number of measures.

Six stroke survivors took part in the programme. All participants were members of the Milton Keynes Different Strokes Group, and had volunteered to take part. The volunteers were not screened for levels of ability or mobility. Each filled out the ARNI application form (Appendix 1) and obtained sign-off from their GP that they are fit for Exercise After Stroke (Appendix 2). Different Strokes Milton Keynes subsidised the sessions and the individual participants made a small contribution towards the costs.

The participants were interviewed before the programme began about the remaining effects from their stroke, and what they hoped to gain from taking part. A second interview took place after the six week pilot about what, if anything, had changed for them after taking part, their experiences of the ARNI programme and suggestions for improvements. The spouse of one participant was interviewed because the participant was not well enough at the time of the post programme interviews. The interviews were conducted by the ARNI instructor who was able to use the pre-programme interview to get to know the participants, explain that they would be expected to work on the techniques between sessions, and obtain information to prepare initial programmes for the first session. Discussion guides for the interviews are in Appendices 3 and 4.

Blood pressures were taken each week, before and after sessions, for all participants. Because the numbers in the group were small and levels of ability ranged widely other quantitative measurements were tailored for each participant. These included Timed Up and Go, and elements from the Chedoke Hand and Arm Assessment, and Berg Balance Test.

4 The ARNI Programme

The weekly group sessions took place during September and October 2013 at Shenley Leisure Centre in the Dance Studio, a large room which has two fully mirrored walls. Given that an important aim was that participants establish their own independent training regime on the techniques at home, equipment used was kept reasonably simple. Equipment included chairs without arms, small tables suitable for working seated, and crash mats for floor work. Other resources included short wooden sticks, small items for pick-up/let go practice, and gym step boxes. One of the participants made enough wooden sticks from dowel so that all participants could have one to take home. More equipment was available in the Different Strokes store, such as hand weights, indoor games equipment and Pilates resistance bands but not used in the ARNI sessions as the focus in the sessions was setting up programmes that participants could work on independently at home. Participants were encouraged to improvise with ordinary objects found at home.

Apart from the pilot participants, one qualified ARNI instructor and three supporters were present. One participant was also accompanied by their spouse/carer for all the sessions. Two supporters worked with the participants and one recorded the activities in the sessions on video and still photos. All participants gave permission for their pictures to be published.

All six participants completed the programme and only one missed a session because of a prior commitment.

Each week, the participants were given a tailored programme of exercises on a record sheet to take home with encouragement to aim for daily practice of 30 to 45 minutes, and taking one or two rest days each week. Folders for the record sheets were provided and brought to each session. The programmes were added to and refined to add new exercises learned that week and to ensure they were still providing sufficient challenge. Appendix 5 shows a

record sheet for a typical programme. The training programme recording sheet was deliberately simple, designed to fit on one side of A4. Several participants already had an exercise programme of some kind. All were encouraged to integrate the ARNI techniques into their current exercise programme as additions rather than replacements.

In the earlier weeks, some of the exercises (such as wrist stretches, leg stretches and wall press-ups) were introduced to participants as a whole group or in smaller groups. Exercises were also revised and techniques checked. Through the six weeks, participants were gradually encouraged to work more independently on their own programme during the group sessions so that by week 6 they were working independently for most of the session, asking for help when they needed it, under light supervision from the instructor and supporters. From week 3 onwards, the group session ended with some simple Chi Kung exercises.

The main aims for the pilot from the ARNI perspective were that participants would:

1. have information about suitable ARNI techniques for their individual situation
2. establish, or add to existing, independent training routines/programmes outside the sessions using ARNI techniques
3. have the tools and motivation to continue with their training after the pilot sessions ceased.

In a pilot for a larger study of ARNI techniques, Poltowski et al (2013)[6] found that maintaining the motivation to do the exercises after the ARNI sessions had ended was an issue for some participants. Therefore, at the end of the Milton Keynes Pilot, participants received a 'week 6' programme record sheet and further blank sheets for them to create their own programmes. To keep up the momentum, as suggested by Poltowski et al, monthly follow up sessions will take place in November and December 2013 to give participants an opportunity to refresh their programmes and motivation, and report on progress.

Each tailored programme was designed to take account of the participant's own goals, with different emphases on the following general ARNI aims depending on their current levels of ability and mobility. The aims of the ARNI techniques include: improve general fitness; improve flexibility, mobilise affected limbs; initiate and increase voluntary movement in affected extremities; strengthen hand muscles to improve pinch and grip; improve core strength and sitting/standing balance; increase strength in limbs; improve gait.

5 The Participants

Participants ranged in age from 52 to 72, two are in their 50s, two in their 60s and two in their 70s. All participants are at least 2 years on from their stroke. Time since stroke was between 2 and 10 years and the average is 4.5 years. All are affected on the left side of the body.

The participants' mobility at the beginning of the programme varied very widely from ability to walk independently to use of wheelchair and hoist for mobility. Range of movement and control in affected arm and hand ranged from gross arm movement with little or no discernible hand movement to virtually full function of arm and hand.

[6] Poltowski, Briggs, Forster, Goodwin, James, Taylor and Dean (2013) *'Informing the design of a randomised controlled trial of an exercise-based programme for long term stroke survivors: lessons from a before-and-after case series study'*. BMC Research Notes 2013, **6**:324 . Accessed on 28/08/13 at http://www.biomedcentral.com/1756-0500/6/324

Participant Goals

The participants' stated goals at the start of the ARNI programme ranged widely from general to very specific, from long term aspirations to short term targets.

Participant Goals

"To become fitter."

"Inspire me to achieve more. I want to get back to hot rod racing. I'd like to work on my hand, I'm OK with my foot and leg walking with a stick and splint. I would like to get a Saboflex hand to help me with hand movement."

"I would like to be able to walk around as I did before my stroke, use my left hand the same as my right. (*Specific goals for this programme?*) Being more independent in going to the loo and feeding myself."

"I want to be more independent. I would like to build up my core strength to be able to cycle again. I ride a tricycle now. I'd like to improve my left hand to be able to use it in the kitchen - for example for baguette buttering. I have virtually no movement in my left hand, can grip with it but not let go."

"I'd like to get more use of my arm and move towards walking better."

"I would like to get more mobility in my left arm and hand and be able to move on my feet a bit better."

6 Outcomes and Impacts for Participants

Outcomes and impacts were measured with a mix of quantitative and qualitative methods. Because of the individual nature of the levels of ability and mobility of the participants and personal nature of their goals, much of the evidence cited is in the form of personal testimonies from the pre- and post-programme interviews. All participants have given permission for their verbatim quotes to be included in this report.

Blood pressure

Blood pressure was taken at the beginning and end of each session for each person. There was no discernible trend in blood pressure data for the group as a whole. Blood pressure did not appear to be adversely affected by the exercise class. Some individuals showed a small decrease in blood pressure. (see individual graphs – Appendix 6)

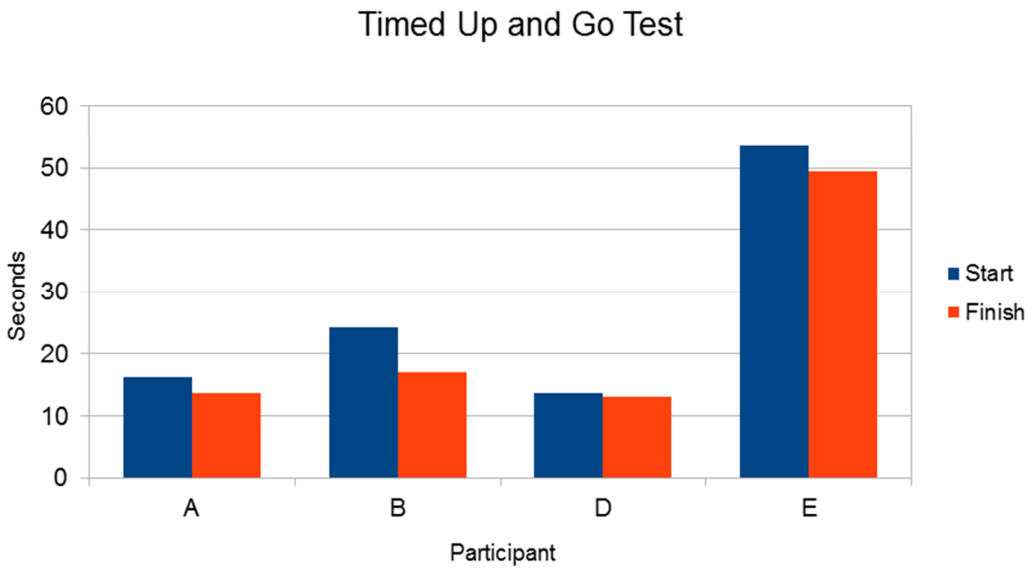
Timed Up and Go Test

This was administered at the beginning and end of the trial. Only 4 of the participants were ambulant and could therefore participate in this test. All participants were able to decrease the time it took them to walk 3 metres turn around and walk back.

Two of the participants said it was not the walking which they found challenging but the turning around at the end point.

One participant who was unable to walk without her stick at all at the beginning of the trial was able to complete the task without use of the stick at the end of the sessions in 55.69 seconds. This was slightly less time than she took for the trial walking with her stick before starting the ARNI programme.

Figure 1



Berg Balance Test

Only certain elements of this test[7] were completed with the participants, on an as-able basis. For one participant, balance and confidence had improved so much all three measures were improved, for example she was able to increase her time standing unsupported with feet together from 15 seconds to over 1 minute.

Table 1 Berg Balance Test Results

Participant	**Test results**
A	Standing unsupported one foot in front of the other – increased from 15 seconds to 60 seconds Standing on one leg – increased from unable to 3 seconds.
B	No changes noted
D	Standing on one leg – increased from 3 seconds to 10 seconds
E	Standing unsupported with feet together – time increased from 15 seconds to over 1 minute. Standing unsupported with one foot in front of the other – changed from unable to 10 seconds. Standing on one leg – changed from unable to 3 seconds. (Important for ability to negotiate steps)

All of the ambulant participants were already able to transfer from sit to stand and back again without the use of their hands prior to the start of the sessions.

[7] Berg K O, Wood-Dauphinee S, Williams J L, & Maki B (1989) Measuring balance in the elderly: preliminary development of an instrument. *Physiotherapy Canada 41,* 304-311

Chedoke Inventory - Upper Limb Movements

Parts of the Chedoke Arm and Hand Inventory[8] were completed with the participants. These are all functional tasks and the participants had adapted the way they carry out the tasks over the years since their strokes, to enable them to complete them one handed. There was no scoreable difference in how well the tasks were completed at the end of the trial.

Regaining lost function in the upper extremities has been found to be more difficult to achieve than in the lower extremities. The majority of participants noticed small improvements in their upper limb function, over the time of the trial. With more time allocated to the trial it is possible that more improvements would take place.

Participant A was able to complete the 3 tasks set without difficulty and using both hands effectively. She did feel she had improved strength in her upper limb by the end of the six week programme.

Participant B had no improvement in the passive or active movement in his affected limb.

Participant C was able to improve his grasp of objects allowing him to hold a bowl still while eating which he was unable to do prior to the sessions. This allows him to participate more actively in family mealtimes and decreases the need for one person to be available to feed him. During the sessions his ability to grasp and release to command improved but his overall weakness means his function is still greatly limited.

Participant D did not see any improvement in active function. He was however able to improve shoulder movements and although there was no increase in fine motor movements there was a difference in how often he used his affected limb as a 'helper' in two handed activities.

Participant E noticed an improvement in the passive movement of her affected arm. She stated that she was better able to extend the fingers for assisted grasp of objects. She did not see an improvement in active movement.

Participant F had a Botox injection in the affected limb towards the beginning of the trial to decrease the tone in his arm. He felt that the continued exercises he was giving to his arm helped to improve the quality of passive movement in his hand and fingers. Again there was no improvement in his active movement.

Daily activities

Participants scored their current level of independence in undertaking a list of daily activities at the start of the programme on a scale of 1 to 6. Their detailed scores are presented in the table at Appendix 7. The scoring exercise was not always simple. More than one said that it depends on the situation and in one case the number of people needed to operate a hoist for transfers differs depending on who is operating it.

> *"If it's me, I do it on my own but if it's the carers, they have to have two of them because of their insurance."*
> Spouse of Milton Keynes Pilot participant, 2 years from stroke

[8] http://www.chedokeassessment.ca/

Table 2 Average Levels of Independence in Daily Activities Before Programme

	Average score
Feeding yourself?	2.5
Brushing your teeth and hair?	1.7
Getting yourself dressed?	3.0
Taking yourself to the toilet?	1.7
Getting yourself out of bed?	2.0
Moving from sitting in a chair to standing up?	2.0
Washing yourself?	2.7
Getting in and out of a car?	2.7
Walking around inside your home?	2.8
Walking around outside eg: enough to cross a road?	3.2
Climbing a flight of stairs?	3.2

Base: All participants

Table 3 Key to Levels of Independence Scores

1	I'm completely independent
2	I do this myself, but need to use equipment, or it takes longer than before my stroke
3	I need to have someone there to feel safe, but not to physically help
4	I need help from 1 person to do this
5	I need help from 2 people
6	I cannot do this at all at present

Daily Activities - changes since ARNI programme

5 out of 6 participants have changed the way they do some elements of their activities of daily living including becoming more independent or effective in eating, preparing food, getting dressed, and mobility.

Eating, food preparation and self-care

"I still use the fork one handed and (spouse) cuts it up for me. I have a plastic toast or bread holder for while I butter it, and once or twice lately that's been in the dishwasher so I've buttered my toast by holding the plate with my left hand which is a real step up, managing to do the job that way. Also I'm holding my yoghurt pot with my left hand which is something I didn't do before. That's a positive."
ARNI Pilot Participant, 6 years from stroke

"One of the things that we said would be nice at the beginning is if he could hold something in his stroke hand, like a bowl, so that he could feed himself with his right hand. Bowls tend to be more difficult than a fork and plate, because you have to steady it. He has worked on that and he's actually had a bowl of soup without me having to feed it to him. And he can hold puddings for himself. I still do it if he gets really tired and when he's been poorly lately I have been helping him."
Spouse of ARNI Pilot Participant, 2 years from stroke

"I do quite a lot more towards getting dressed now. I just don't panic so much, I calm myself down and take longer to do it. I only very occasionally ask for help now I just get on with it. As long as I take my time and don't rush, I can do it."
ARNI Pilot Participant, 2 years from stroke

"In the session, he did put toothpaste on his own toothbrush which he doesn't usually do at home. Now I know that he can if he wants to."
Spouse of ARNI Pilot Participant, 2 years from stroke

"He is a little bit stronger and when I put the sling behind him he can pull himself forward in his wheelchair a bit better, sometimes he gets a really good lean forward which he didn't used to be able to do. I don't feel I'm tugging him so much"
Spouse of ARNI Pilot Participant, 2 years from stroke

"The hand exercises have helped. I can get more movement in my wrist now. I can use my left hand to lift the kettle now with some water in it. At the beginning of the programme I could only do it empty and it would swing to one side. I can do it with about two cups of water in it now."
ARNI Pilot Participant, 4 years from stroke

"I did change the way I wash my hands, to help me do the interlocking fingers exercise. It's easier with a bit of soap on."
ARNI Pilot Participant, 3 years from stroke

Mobility

3 of the 4 ambulant participants say their level of mobility has improved in some way. Participants also mentioned being able to return to activities they had not done since before their stroke. In one case however, ability to walk independently has improved but family are concerned about the participant walking without a stick at home.

"Things have changed a bit since the ARNI programme. I'm finding I can stand up now without having to push myself up on my hands. I'm doing that more often. I've even tried a couple of times from the settee, which is low down, and I've done it."
ARNI Pilot Participant, 4 years from stroke

"I have a 20 minute walk, a circuit around home that I do in the morning and afternoon. I used to use a stick, except the last 100m when I carried it rather than using it. Part way through the pilot, I thought as I was setting off - I wonder how far I can get round my circuit without the stick, and I got all the way round. From that day on I've never used it on my daily walks, I haven't used the stick for weeks now."
ARNI Pilot Participant, 6 years from stroke

"I think walking without my stick in the sessions was the major one."
ARNI Pilot Participant, 2 years from stroke

"Before the ARNI programme, the walking was a bit wobbly, some days I could walk longer than others. I was slow but steady stopping for a brief rest every 2-300 yards. I walked a mile last week in one go, with no rests. I was on a home visit from the church and we walked from the car. The house that we needed was right at the end of the road, a good half a mile down. I didn't realise how far I had walked. Then the people weren't in and we walked back again. And I think I've done exactly the same today, going in and out of shops."
ARNI Pilot Participant, 4 years from stroke

"I can come down the stairs quite easily with one hand now instead of two. I'm far more confident holding on with one hand, sometimes it's my left or my right hand. Going up it depends on how tired I'm feeling whether I have to pull myself up."
ARNI Pilot Participant, 4 years from stroke

Falls, and Getting Down To and Up From the Floor

Baseline

The participants reported very few, or no, falls in recent years. For most, it appeared that risk taking had been reduced and they had settled into their current level of mobility and ability so that falls were very unlikely to occur.

"I haven't fallen over for a long time, only initially when I was too adventurous. I've been more sensible lately."
ARNI Pilot Participant, 6 years from stroke

"I fell in the early stages, not now. Sometimes my left leg drags on the ground. If I do fall I go down into a roll for safety. I've got my own method for getting up from the floor."
ARNI Pilot Participant, 10 years from stroke

"I fell twice early on but not recently."
ARNI Pilot Participant, 2 years from stroke

"Five or six times. I was helped up 3 times because someone was there, especially when I was in rehab. I have usually managed to get up using a chair or the bed."
ARNI Pilot Participant, 3 years from stroke

Post Programme

All of the 4 who are ambulant practiced getting down to the floor and up again from a standing position on the crash mats during the ARNI sessions, using the ARNI techniques. Three gained new ability and increased confidence to come to standing without any assistance. A fifth also tried out getting down to the mat and back up to a wheelchair but was uncertain of the value of practising.

"I didn't have the confidence to try getting down to the floor and up again until you guided me through it. Now I can do it, usually in the morning I'll do five up and downs. I still get a bit out of breath but I've got the confidence to do it now and I don't have any worries about it. I wouldn't call someone to help me get up now. I can do it for myself. It's my latest trick to show off to my daughters and anyone who is prepared to indulge me."
ARNI Pilot Participant, 6 years from stroke

"I have done getting down to the floor and up again from my chair before but I hadn't practiced it. No changes really, I try to concentrate on staying upright. It might have some value to practice it but I don't know what."
ARNI Pilot Participant, 3 years from stroke

"I couldn't do getting down to the floor and up again before the ARNI sessions. It was the first time I'd really attempted it. I got down from standing and up using a chair. "
ARNI Pilot Participant, 2 years from stroke

"Before the programme, I could only get down and up from the floor with great difficulty. Once I wanted to get something from under the bed. I tried it and it took me 10 or 15 minutes to get up, I didn't know how to do it. And now of course I get down

and it's easy. I've practiced doing it at home. I'm getting down to polish the wood on the settee maybe two or three times a week."
ARNI Pilot Participant, 4 years from stroke

Confidence

At the start of the programme, participants scored their general confidence in taking part in daily activities between 1 and 5 where 1 is 'not confident at all' and 5 is 'as confident as before the stroke'. None scored their confidence at 5 or 0, scores averaged at 3 and ranged from 2 to 4 with some participants giving more than one score depending on the activity.

Table 4 General Confidence in Daily Activities

	not at all confident **1**	**2**	**3**	**4**	as confident as before stroke **5**
Number of participants giving score	0	2	4	2	0

Base: All participants
Note: Some participants gave more than one score, depending on the activity

Changes in confidence

5 out of 6 participants said their general confidence in taking part in daily activities has increased. Participants cited specific situations in which they are able to be more independent, and for most there is a general feeling that they can do more now. Some talked about the importance of maintaining a balance between being more confident and being careful to avoid injury.

"My general confidence has definitely increased. I enjoyed it and it gave me more confidence to do lots of things. I'm not reckless but I have more confidence in myself now. I swim twice a week and my left hand is now operating a bit more effectively when I'm swimming. I'm tending to have a go more."
ARNI Pilot Participant, 6 years from stroke

"My confidence has increased a little bit. I feel a bit more confident doing the various exercises than I would be otherwise and feel a bit more confident in the gym."
ARNI Pilot Participant, 3 years from stroke

"My confidence as increased, definitely. I don't feel so embarrassed now about going out and trying to do things like going out for a meal and that."
ARNI Pilot Participant, 2 years from stroke

"His confidence has slightly increased. When he comes along to the sessions he's much more upbeat with the other people around. At the sessions he puts more into it, you get more out of him than when I'm at home trying to motivate him. He appreciates the company around him, and seeing what other people are doing. He gets distracted I know but he gets more from being there than at home. He joins in more with other people there and other people's ways of approaching things."
Spouse of ARNI Pilot Participant, 2 years from stroke

"I'm on my way back to getting stronger and a lot more confident. I wouldn't have dared do that long walk before. I can kneel down now and get back up again in church. It used to be too much bother to get back up. There are a lot of little changes

going on. Things I've not been able to do and they are changing now. I've got the confidence to do them without worrying about it. I know I'll be back to nearly normal."
ARNI Pilot Participant, 4 years from stroke

"I try to push myself to do what I can. I wouldn't say that my confidence has changed much at all. I was pretty confident in what I was doing myself. That's why I was keen to demonstrate to the others and encourage them."
ARNI Pilot Participant, 10 years from stroke

"I'm very conscious of not damaging the parts that are good on my body, my good arm and good leg. Everything I do, I have to think twice beforehand so I don't do stupid things to injure the good parts. It's important because if you damage the good parts, you've really had it."
ARNI Pilot Participant, 10 years from stroke

"I tell him how good it is that he can now feed himself and it makes him feel a lot better about himself. Sometimes he doesn't realise how well he has done since the early days when they didn't think he would survive. I think he appreciates it now."
Spouse of ARNI Pilot Participant, 2 years from stroke

Training at home

Participants were asked about the training they did at home between sessions. 5 participants reported doing at least some ARNI practice at home between sessions, some of them a substantial amount. Those with an existing exercise programme have integrated the ARNI techniques into it. Some have gone back to the physiotherapy exercises they were given in the early days such as core strength and sitting balance. There was some concern that they could not remember the full techniques of some of the exercises but they were able to check at the next session when there was revision of basic exercises.

"He came back to doing the sit-ups and his other physio exercises because of the ARNI programme."
Spouse of ARNI Pilot Participant, 2 years from stroke

"I did do training every day. One of the things that half worried me was you put in the programme to do the ARNI exercises every day on top of my other exercise, but to have a rest day once or twice a week, and I didn't always have a rest day. That was possibly not wise, but I just couldn't make up my mind which day to rest. I probably had a rest from my walk, but not from my ARNI."
ARNI Pilot Participant, 6 years from stroke

"I haven't done that much practice in between the sessions. Things I'm doing anyway I carried on with. I'd say I do five days a week on exercises, doing the wrist and hand exercises, face exercises, standing exercises, and some back and shoulder exercises. I go to the gym twice a week and do the standing exercises there and at home as well. At the gym I take a few steps along the rail and use an exercise cycle and a cable machine for pulling weights. I've added into my programme at the gym the push-ups away from the rail sitting down. From the ARNI programme, I have also added leg stretches, changing weight when standing, things like that."
ARNI Pilot Participant, 3 years from stroke

"I did quite a bit actually. Every other day I should think. I did a bit of the list every day until I'd done the whole list. About half an hour or so each time, but I didn't really time it."
ARNI Pilot Participant, 2 years from stroke

"I've done all of it. Some I had forgotten how to do them but I've done my own exercises too. When I started I was only doing 10 and 12 repetitions and now I'm up to 26, twice a day. And the wrist stretches I'm doing 20 of those once in the morning and once in the afternoon. "
ARNI Pilot Participant, 4 years from stroke

One participant stated that increased tone (clenching/tightening of muscles) when attempting to use affected limbs was a barrier to doing more with the ARNI techniques. He reported that the most effective time for stretches and mobilising of his paretic hand is in the morning. However, during one session he was able to fold his hands, interlinking the fingers, which he thought he would not be able to do.

"I can't really do much with my left side at all. That doesn't stop me from trying. But the harder I try the tighter everything gets. It tones everything up. Once my hand screws up it's so hard to get it to open again. It's a lot easier in the mornings, I'm working a lot on that now, especially when I'm beginning to come round from sleep I try to relax and open the hand up and do stretches in bed. That's working pretty well at the moment. In fact I felt quite pleased the other day how well things were going. I felt I was getting on top of things because I've been working a lot with stretches, trying to open my fingers naturally as much as I can. This is a continuation of what I was doing before. To be honest I haven't really done anything really different in my exercises since beginning the ARNI programme."
ARNI Pilot Participant, 10 years from stroke

Progress towards goals

5 out of 6 participants said they have made progress towards the goals they set at the beginning of the programme.

"I do more, yes. I tell myself I can do it. It may not work first time but I have a go at things I wouldn't have before. I remember you saying to use my left hand in as many opportunities as possible. For example when going into a room I went through a phase of trying to turn on the light with my left hand. That meant using my shoulder, getting the hand up to the light switch and pressing it. Sometimes it went off then on and I had to try again. I do use my left hand now when I might not have done before. I'll tend to walk out of the room and on purpose I'll turn the light off with my left hand. OK most of the effort is coming from my shoulder I know but I'm making the effort to move my left hand. OK I can't use my fingers yet to operate the switch but I'm using the hand."
ARNI Pilot Participant, 6 years from stroke

"I have a little more mobility in my left arm and I've been trying to look after my right arm."
ARNI Pilot Participant, 3 years from stroke

"There is an increase in the arm movement. I can do the prayer bends now in the morning. My walking is stronger and I'm still doing the squats down to sitting."
ARNI Pilot Participant, 2 years from stroke

"I would say he's pleased with how he has progressed. And just to get praise from someone else for picking up the dinosaurs! The look on his face when he is doing it is 'I can do this'. It was quite a boost for him. He did really enjoy it although you can't really compare with what other people did because some of the others were doing more, but then they could walk and stand anyway. … Once he gets over these latest problems hopefully he can get stronger and stronger."
Spouse of ARNI Pilot Participant, 2 years from stroke

"I would say the biggest thing is holding a bowl, because if he can do that with a bowl, there are all other things he can do. That is a big one. If we're out with family or out on our own for a meal, I haven't got to sit there and feed him. If we're out, he can sit normally and hold a bowl and feed himself."
Spouse of ARNI Pilot Participant, 2 years from stroke

"I've definitely made progress towards my goal of becoming fitter. I'm able now to walk a mile or so without rests. That alone has helped me to get my confidence back. A few times I've actually begun to try and run. It's only been two or three steps but it's a start. I've been dancing too with my husband. Only slow dancing, a waltz, but that's the first time I've done it since my stroke. We've been to many dances since my stroke but last Thursday was the first time we really did dance."
ARNI Pilot Participant, 4 years from stroke

Next goals and the future

Participants spoke about what is next for them and their future goals, including returning to activities enjoyed before stroke and specific mobility targets. One participant has been re-referred back into health services, and another is hoping for referral to an exercise scheme.

"One of my next goals is to use both hands on the handrail of the steps when I get in and out the swimming pool. At the moment I just use the right hand and my balance and I want to be able to use the left hand to guide me and help with balance."
ARNI Pilot Participant, 6 years from stroke

"The physios have called me back in and there is a new physio there who was the physio at the initial rehab unit I went to. She says she can see I've made some progress since she last saw me. I'll be going for various assessments about strengthening and they are going to give me a healthcare assistant to help with exercises. I think the ARNI helped with that. The ARNI gave me a plan I can respond to. I think it's helped."
ARNI Pilot Participant, 3 years from stroke

"I've set myself certain goals, all of them are an extension of what I'm doing now. I want to walk to the local shops that are in the next grid square, usually I go there by tricycle. I know I'm going to have to walk with my stick to start with but ultimately I'm going to do it without, there and back. And I'm going to be jogging within a year. When I read Tom's book, which I've got on Kindle, I like his attitude. Nothing is impossible. I just feel I can jolly well do this. I can do it."
ARNI Pilot Participant, 6 years from stroke

"I'm considering all sorts of strange things, including acupuncture, acupressure, ultra-sound therapy. They wanted me to have a go with the ultra-sound but the doctor said no as it's too far gone. Tai Chi ideas might help. The chi kung we did at the end of the sessions was OK, it's a way to warm down."
ARNI Pilot Participant, 3 years from stroke

"I want to get him helping more in the garden. He did do a little bit, trying to pot stuff up when he was at Oxford, but now he can hold something there is nothing to stop him filling up a pot with soil and perhaps doing things like that. He's got such knowledge there, he was always the gardener. I'm learning."
Spouse of ARNI Pilot Participant, 2 years from stroke

"I'm hoping to go on the AMKERS courses that are held at the college in the New Year. That's a government thing to help people get on the move. They send you for

10 lessons, at the gym that you use. They tell you what you can do in the gym and get you to build up slowly. They keep a record of it. My doctor sent me back for a second session so I had 20 sessions 2 ½ years ago. I'm hoping to get back on that."
ARNI Pilot Participant, 4 years from stroke

"I want to do my ARDS (Association of Racing Drivers Schools) test next spring. I had my other card for sprint and hill climb but I got bored with that because you are only racing against the clock. It's quite a challenge but I prefer racing to challenge myself more. I did a driving experience with a driving instructor at Brands Hatch in a top of the range BMW, I really enjoy speed, I enjoy the adrenalin and the challenge of competition. At the end I braked very hard because I can't change down the gears. I tend to frighten the instructors!"
ARNI Pilot Participant, 10 years from stroke

Participant views on the programme

Recording sheet

All those who were using ARNI techniques at home found the record sheet helpful in reminding them of the exercises and providing a way to record what they have done each day. Some made suggestions about improving the design.

"It worked for me, firstly having it there as a record, knowing which exercises I had to do. And then there was the opportunity, for example when I did my walk without my stick I could record that and any other things that happened. I made some additions, exercises of my own such as an arm windmill. And I've picked out more exercises from Tom's book, like the side step and swinging leg out to right and left, and balancing."
ARNI Pilot Participant, 6 years from stroke

"The recording sheet was very useful. It focusses you. What have I done, what should I be doing. I don't think it needs any changes, it's a bit basic and that's a good thing."
ARNI Pilot Participant, 3 years from stroke

"I thought it was good. It reminds you of what you needed to do and what you had done."
ARNI Pilot Participant, 2 years from stroke

"The recording sheet was very helpful. You can see what needs to be done. In his case, some can be done in bed, some when he's up. Breaking it down into those blocks, not doing too much at a time so that he gets fatigued by it. He will do a couple of things then have a break but by picking up the sheet, he can see which ones he's done. If there was one thing perhaps we could have more notes to remind what the exercise is. Some are quite self-explanatory but some, I got a bit confused and had to go over them with you."
Spouse of ARNI Pilot Participant, 2 years from stroke

"The record sheet worked for me. I've been using the blank sheets and my husband is going to run me off some more copies. But on the weekly sheet, if you made the boxes double the size we could write things in as well as tick. And as the course grows, you may need two sheets. And having your contact information on the sheet too in case people have questions."
ARNI Pilot Participant, 4 years from stroke

Length of programme

All felt the programme could have been longer than 6 weeks although most said that the 6 weeks had been effective in getting them started on the ARNI techniques.

> *"I would have been happy for it to go on for few more weeks to be pushed. I'm looking forward to the two follow up sessions. It will be good to come back and share progress and for you to see what's developed. But I'm happy that I've got the literature and I sit here ploughing through it again and again and then I make notes, and then I try and do the exercises."*
> ARNI Pilot Participant, 6 years from stroke

> *"Longer would have been better but it was adequate for what we were trying to do."*
> ARNI Pilot Participant, 3 years from stroke

> *"I think it could be a bit longer. But to get you into it, it was fine."*
> ARNI Pilot Participant, 2 years from stroke

> *"For an initial, six weeks was probably about right, it got everybody into the rhythm of it. Probably there would be benefit from it being a bit longer. Or do these follow ups but maybe once a fortnight rather than once a month. From [stroke survivor]'s point of view it was the motivation of being at the sessions."*
> Spouse of ARNI Pilot Participant, 2 years from stroke

> *"On my side of things I would say it was too short but for those who were more disabled than me it may have been too long. It could have gone on for maybe 10 weeks. And afterwards an opportunity to meet up and get together with an instructor too. Maybe have someone who could check blood pressures like we did, to set people's minds at rest that things are normal."*
> ARNI Pilot Participant, 4 years from stroke

Venue and equipment

All participants are very familiar with the room and venue as the weekly Different Strokes meetings take place there. Most were happy with the equipment available although solid parallel bars would have been helpful for standing work. One participant mentioned a wide range of additional simple equipment that could be used, some of which is available from the Different Strokes equipment stored at the venue. Another participant was disappointed that more sophisticated equipment such as Saeboflex was not available.

> *"We use the venue every week, we're used to it, we know the building and the room well. The equipment was fine. We had the mats and that was safe for us to go down and up again. The rest of the equipment was fine. The one thing that we missed that we have at the gym was parallel bars. This would be very useful but they are not cheap."*
> ARNI Pilot Participant, 6 years from stroke

> *"I thought the sticks were a good idea. Trying to get the other hand to follow. The only thing that I've seen him use before that we didn't have were those stretchy bands."*
> Spouse of ARNI Pilot Participant, 2 years from stroke

> *"The equipment was fine. But there are different types of gadgets people can use for their hands. For example I've got these Chinese balls, I've used them a lot and now I'm finding I can move them around in my left hand which feels an achievement. The ARNI course started me off wanting to improve. I have them next to me and most*

nights I use them. And then there are the tennis sponge balls they are very good to squeeze. I used them when I first had my stroke and now I feel I need stronger ones, stress balls. The Pilates stretchy bands are good too."
ARNI Pilot Participant, 4 years from stroke

"I think that ARNI needs to have more equipment, such as the Saeboflex hand, to try and bring them on a bit, give them a bit more encouragement. It would enable people to move parts of the body they can't move now, it's got the springs that open up the fingers."
ARNI Pilot Participant, 10 years from stroke

Group or one to one

Participants appreciated the benefits of being in a group, particularly with people who know them well. Individual attention during the sessions made up for any disadvantages of working in a group and it was recognised that group sessions could be more cost effective than working one to one. Although one participant was often distracted by watching the others, he enjoyed being with other people and was more upbeat in the group. One participant suggested having more ARNI instructors in the session.

"Being in a group worked. It was almost one to one in that we knew you three were always circulating, moving between us and keeping an eye on each of us. We all knew we had sufficient activities which we could get on with if we were on our own. Nobody had any reason to be sitting there idle. It wasn't obvious that we weren't one to one. I don't think we were disadvantaged by not being pure one to one, because we weren't far off it."
ARNI Pilot Participant, 6 years from stroke

"I could drop into management speak and use words like synergy. I think you get more of that if you do something in a group, and on another occasion if you can do something one on one. Doing ARNI one to one would be a big ask in terms of resources, but it would be good if it could be done."
ARNI Pilot Participant, 3 years from stroke

"From his point of view the distraction wouldn't be there if it was one to one. But then because of the range of the stroke and the brain injury I don't think any of them could have worked for an hour and a half, and concentrated continually. Being in the group there was a bit of diversion. He did some on his own and some with the group."
Spouse of ARNI Pilot Participant, 2 years from stroke

"With a group, you may have people who are there, but don't want to be there, who don't even try. Because the group eggs you on, it pushes you into wanting to do more. I think that's the beauty of a group. When you've got others saying – you can do it, go on – it pushes you, encourages you to do more than you are even trying to do."
ARNI Pilot Participant, 4 years from stroke

"With more instructors so it was one to one, or one to two you could maybe have a shorter session and still be spending more time with each person."
Spouse of ARNI Pilot Participant, 2 years from stroke

Most participants mentioned the strength of the Different Strokes group, the sense of camaraderie between the members, and how this provided extra encouragement.

"There is a rapport between us, we meet every week. We have an identity, a relationship, all of us. We are a fine group, we knew when people were achieving

something. We are good friends and although we joke and mess around, we are a team and care about each other. I think that's a great advantage in a group."
ARNI Pilot Participant, 6 years from stroke

"I know he enjoyed being in the group. There was a lot of support, which is why I think we got more out of him because there is that camaraderie. It was a good atmosphere but I don't know how it would be in a group where you didn't know everybody. In this group they already know each other. Whether people would be a bit more reserved. Maybe a group for some of it then some one to one time too that would be a bit more intense concentration."
Spouse of ARNI Pilot Participant, 2 years from stroke

Family and carers

Family and carers of the participants often support them by undertaking tasks the stroke survivor finds difficult, and are concerned that they may over-reach their capacity and come to harm. The ARNI approach promotes self-reliance which meant a change for family and carers, having to stand back and watch the participant struggle with practical tasks.

"I think it gave me a boost and a bit of a push because I think I'm a bit over protective and I do things for him rather than trying to make him do it for himself. This made me sit back and think we could aim to do more. It made me stop doing as much, and realise that I'm trying to mother him a bit too much."
Spouse of ARNI Pilot Participant, 2 years from stroke

"My husband used to say don't do anything difficult while I'm out because I can do it for you."
ARNI Pilot Participant, 4 years from stroke

"He and [Session supporter] had quite a system going, she got a rhythm going for the repetitions and sometimes I walked away and let her do it her way, she's got a different approach and I think he benefitted from that greatly. I think sometimes somebody in my position you tend to get overprotective and try and do too much, interfere too much instead of standing back a little bit. It is hard."
Spouse of ARNI Pilot Participant, 2 years from stroke

Positive attitude and being active

Participants talked about the importance of a positive attitude, not giving up, and some mentioned being very physically active before their stroke. One feels that her fitness before stroke was very important in her recovery.

"Just because we've had a rough deal and dealt a bad hand, it doesn't mean you should chuck it all in and sit in a corner and curl up. It's another challenge."
ARNI Pilot Participant, 6 years from stroke

"I've always been working on trying to keep myself motivated since my stroke. If I've got nothing to inspire myself and get myself going I can get quite depressed. Not being able to achieve what you want to without pushing yourself to the point of not being able to achieve it, then you become depressed. I've pushed myself so hard, in my motor sport I'm pushing myself hard, even now, trying to get myself ready for next year. I put myself under a lot of pressure. People say why – to keep myself going. Even though I'm knocking on a bit, I want to get back to it and I hope that I can inspire others."
ARNI Pilot Participant, 10 years from stroke

"Because he's had so many problems before the stroke with his surgery and the problems he's having now, I think - it would be nice if you could do these things but if you can't, enjoy what you've got. Part of me feels like that, why keep on nag, nag, nag if he doesn't feel very well or doesn't want to do it. What have we got to gain. I think now that's really negative, taking part in the ARNI programme has made me a bit more positive, thinking, yes, make him do it, it won't hurt."
Spouse of ARNI Pilot Participant, 2 years from stroke

"Before my stroke I could do anything. I was very competitive and exercised regularly."
ARNI Pilot Participant, 6 years from stroke

"Before my stroke I was at the gym 4 times a week. I'm sure that helped my recovery, you've got a lot of strength behind you."
ARNI Pilot Participant, 4 years from stroke

"I'm not one to relax much. It tones my body but I'm always on the go."
ARNI Pilot Participant, 10 years from stroke

Overall views of ARNI

All made positive comments about the programme, including those who feel they personally had got the least out of taking part. All participants were keen for ARNI techniques be made available to a wider audience in Milton Keynes, and that programmes be expanded to be longer than 6 weeks.

"I've got nothing but good to say about it. I had a wonderful time and it's done me a power of good. I've been wanting for a long time somebody or something to extend me and develop. I just needed a bible or some guidance. I have only positive things to say. I really did enjoy it and got a lot out of it."
ARNI Pilot Participant, 6 years from stroke

"On the ARNI, I'd say it would be good to organise something permanent for people to get access to it more regularly. That would be a great help for some people, including me."
ARNI Pilot Participant, 3 years from stroke

"I think they ought to advertise it more so more people can do it. I'm one of these who will do anything, anything that might help me. If you don't try you don't know do you."
ARNI Pilot Participant, 2 years from stroke

"It's a different approach, it's not just physical physio. You say, 'I want you to pick that up and put it into the pot, and even if your hand doesn't move, you tell it to be moving.' You don't necessarily get that on the physio side. And the marching on the spot, even if your leg doesn't move, tell it it's moving. It's like brain training rather than just physical physiotherapy."
Spouse of ARNI Pilot Participant, 2 years from stroke

"I want to work with you guys to make ARNI more available to more people. If I can help ARNI in any way. To encourage others, not to give up, keep trying even if you are getting a bit older."
ARNI Pilot Participant, 10 years from stroke

7 Discussion and ARNI Recommendations

The ARNI approach was designed initially for one to one provision but is also delivered in group settings, often to provide a more cost effective option. Participants in the Milton Keynes pilot felt the group setting was also valuable in providing and receiving extra encouragement and support from each other. It is likely that, as well as the benefits of receiving support, providing peer support also enhanced self-esteem.

In this case, the group members knew each other well. For group settings where members do not know each other, it is recommended that group leaders make efforts to build group cohesion by encouraging participants get to know each other and their goals.

All participants completed the course, and the majority did home training between sessions, some of them a substantial amount. Poltowski et at (2013) suggested that a greater emphasis on goal setting and review skills would support higher activity rates and continuation after the programme. It may be that motivation in the Milton Keynes programme was helped by the extra efforts made by the instructor to strengthen the relationship and trust between instructor and participant. This was done in part by recognising participants' goals, particular interests and special situations faced. Participants will be asked again at the follow up sessions about their home training and follow up interviews are planned for 2014.

It is recommended that a simple interview format such as that at Appendix 3 be adopted by ARNI instructors to gather and record information at the start of ARNI training. This conversation would be in addition to the ARNI Application Form (Appendix 1) and cover the stroke survivor's long and short term goals, in their own words, as well as brief information about current abilities and mobility. In this way the ARNI trainees can connect strongly with their own goals right at the start and the notes would provide a source for instructors during training to remind the trainees of their goals, and how far they have come. To add to the evidence base for ARNI training, instructors may also find it helpful to use a simple post-programme interview guide such as that at Appendix 4.

Long term stroke survivors, their families and carers may face challenges from change. Even a positive change may be difficult to adjust to as it may have an impact on well established routines of support and care requirements. Changes in ability may even introduce worries about a potential impact on benefits. Some stroke survivors may feel reluctant to participate fully in a programme that requires substantial effort on their part without being sure that there will be positive results. Investing a great deal into a programme risks an equivalently large disappointment if they do not get the desired results. Whilst ARNI instructors cannot directly influence these challenges, simply acknowledging them if they arise may make participants feel understood and supported, thereby stronger to face them.

In addition to the nature of the ARNI approach, the non-medical setting in a leisure centre where people go for active exercise and fun rather than medical treatment may have contributed to participants feeling that their own efforts were important. Poltowski et al (2013) noted that being treated as a client to be coached and trained rather than a patient to be 'made well' helped create sense of normalisation contributing to self-confidence and self-image.

Confidence was increased for the majority of participants both in doing particular tasks, such as walking, and there was a general increase in confidence in going out, being in social situations, and feeling less embarrassed. All participants had experimented with attempting new things, and tasks they thought they could not do. Participation in the ARNI programme had re-introduced experimentation which is likely to have increased confidence.

This study has confirmed the conclusions of Poltowski et al (2013) that positive outcomes can result from providing training in ARNI techniques to stroke survivors in chronic stage, who have widely ranging levels of ability and mobility. In this study, it was also demonstrated that positive results from training in ARNI techniques can be achieved within a group setting. All participants wanted to see ARNI techniques be made more widely available with longer programmes.

8 Recommendations for Milton Keynes

Based on the outcomes of this pilot study and other evidence about the effectiveness of ARNI Instructed programmes, it is recommended that consideration be given to widening the availability of ARNI Instructed programmes for stroke survivors in Milton Keynes.

The target audience would be those who have completed their formal rehabilitation programme with the NHS. Since studies have shown that improvements in movement can still be achieved many years after stroke, potential participants need not be limited to those newly emerging from their NHS treatment.

ARNI programmes can be provided in a wide range of settings, such as leisure centres, community halls, gyms, or in the participant's own home. Formats can be one to one or in a group.

One to one training has the advantage of personal focus and working more intensely without distractions. However, one to one training involves less efficient use of the trainer's time, and the Milton Keynes Group Pilot found distinct advantages from working in a group. The group setting allowed for peer support, with potentially increased likelihood of regular attendance and motivation. In the longer term, it may be effective to provide ARNI instruction in Milton Keynes in more than one type of setting, and/or in more than one format. At present, the recommended scenario for Milton Keynes is to offer the scheme as a group in 12 weekly sessions with follow-up group sessions every 4 weeks to maintain progress and motivation. It is recommended that groups of approximately 6 participants are run by 2 instructors and one supporter.

It is further recommended that ARNI be delivered through the AMKERS referral scheme since it is already well established and administration is already in place. Existing AMKERS personal trainers would be trained to deliver the ARNI techniques. Providing ARNI instructor training would take around 6-9 months depending on when the next ARNI instructor training cohort begins. If required, ARNI is usually able to provide tailored training on site for some elements if there are sufficient numbers of people to be trained. In the shorter term, until AMKERS trainers are qualified, existing independent ARNI trainers are likely to be available to run groups and these might provide good opportunities for AMKERS personal trainers to shadow ARNI instruction locally.

Resources and Costs

Ideal resources for delivering ARNI include a venue with:

- Accessible parking and safe access
- Suitable indoor space, preferably with full length mirrors
- Floor mats
- Chairs without arms
- Small tables
- Gym Steps
- Parallel Bars
- Other gym equipment

Table 5 Estimated Costs

Venue and Equipment Costs				
	number		**£**	**Total**
Venue hire per hour	2	@	27	54
Floor mats 1m by 1m	6	@	30	180
Gym Steps	2	@	8	16
Parallel Bars	1	@	600	600
Training Costs				
	number		**£**	**Total**
ARNI Instructor Training	2	@	800	1600
ARNI Delivered One to One through AMKERS				
ONE hour sessions	**number**		**£**	**Total £**
AMKERS per hour	12	@	40	480
per participant excl. training costs				*480*
ARNI Delivered in a Group using ARNI Trained AMKERS Instructors				
Group of 6 participants - TWO Hour Sessions	**number**		**£**	**Total £**
Two AMKERS ARNI Instructors at £40ph	12	@	160	1920
One Supporter	12	@	15	180
per participant excl. training costs				*350*
Follow-up Group ARNI Sessions				
Group of 6 participants - TWO Hour Sessions	**number**		**£**	**Total £**
Two ARNI Instructors at £40ph	2	@	80	160
One Supporter	2	@	15	30
per session				*190*
per session per participant if 6 participants				*32*

Note: All costs are estimated and approximate.

1 Measuring timed up and go Week 6

2 Wall press-ups

3 to 6 Get up off the floor Week 5

Picture 1

Picture 2

Picture 3

Picture 4

Picture 5

Picture 6

Picture 7

Picture 8

Picture 9

Picture 10

Picture 11

Picture 12

Picture 13

7 to 10 Pick up and release

11 Working to open hand

12 Working with sticks

13 In the group

9 Appendices

1 ARNI Application Form
2 GP sign-off form and Information Note for GPs
3 Pre Pilot Interview Guide
4 Post Pilot Interview Guide
5 Typical Programme Record Sheet
6 Blood Pressure Charts
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Appendix 1

Appendix 2

GP Sign-off Form & Information Note

MILTON KEYNES PILOT
EXERCISE AFTER STROKE PROGRAMME
ARNI TRUST

DOCTOR'S APPROVAL FOR PARTICIPATION

TO WHOM IT MAY CONCERN

patient name……date of birth……..

address…….
.

I confirm that the above patient is fit to attend the ARNI Exercise After Stroke Programme.

Doctor's signature……..

Doctor's name…….

Date……

GP Practice address or GP Practice Stamp

……..

……..

……..

INFORMATION NOTE FOR DOCTORS
ARNI Stroke Survivor Exercise Training Sessions – Milton Keynes Pilot

- **Action for Rehabilitation from Neurological Injury** (ARNI) is a charitable trust which promotes rehabilitation for stroke survivors through exercise training sessions and a personalised programme of home training. ARNI supports stroke survivors who have completed their NHS formal rehabilitation programme and want to continue to regain and improve their functional movement.
- The ARNI approach was developed and is **led by Dr Tom Balchin**, himself a stroke survivor, and is guided by national leaders in the fields of neurology, stroke rehabilitation and neuro-physiotherapy. The latest clinical evidence[9] is incorporated into ARNI trainings. ARNI Trustees include Professor Alan Roberts (former Vice-President, RSM), and Lord Lingfield.
- Dr Tom Balchin wrote **'The Successful Stroke Survivor'**. This 525 page manual includes detailed advice about exercise for stroke survivors and their supporters as well as a substantial number of suggested training exercises aimed at different parts of the body, and for various levels of current mobility. The ARNI functional 'retraining' strategies support stroke survivors to take charge of their own recovery. In the ARNI approach, stroke survivors can expect to be training regularly to capitalise on the effects on rehabilitation of repetition, intensity, and working at the edge of current ability.
- The **Milton Keynes Pilot sessions** will be led by ARNI Instructor Alison Smith. The local Different Strokes Group is generously funding the Milton Keynes pilot which is supported by Milton Keynes Community Health Service and hosted by Shenley Leisure Centre.
- The **GP's approval** is required that a stroke survivor is fit for exercise before they start their ARNI programme. A form is attached for your signature. If you have any concerns or questions please do contact Alison on 07790 894493.
- **You may be interested to know** that Health Authorities such as Luton and Bedford have rolled out ARNI training programmes with the aim of giving all stroke survivors in their area access to ARNI Instructed programmes. Evaluations have already indicated substantial savings, for example in paramedic call-outs to falls, as a result of the sessions undertaken. Several clinical studies are under way to evaluate techniques which ARNI Instructors use with stroke survivors. Study participants in an early feasibility study[10] have reported improved mobility, range of movement, action control, strength, confidence and reduced fear of the consequences of exercise. Publications from the early stages of a randomised control trial on the ARNI approach are emerging.[11]
- **Further information** about ARNI is available at www.arni.uk.com. Alison is also very happy to talk with stroke survivors and health professionals who would like to know more.

Alison Smith
07790 894493

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[9] For example from the annual reviews of evidence by Teasell et al: Teasell, R, Foley, N, Salter, K, Bhogal, S, Jutai, J and Speechley, M (2012) Evidence-Based Review of Stroke Rehabilitation 15th edition. Executive Summary. Accessed on 30/11/12 at http://www.ebrsr.com/uploads/Executive-summary-SREBR-15.pdf

[10] Kilbride, Norris and Mogaghegi (2012) Brunel University Study at Hillingdon Hospital

[11] Poltowski, Briggs, Forster, Goodwin, James, Taylor and Dean (2013) *'Informing the design of a randomised controlled trial of an exercise-based programme for long term stroke survivors: lessons from a before-and-after case series study'*. BMC Research Notes 2013, **6**:324 . Accessed on 28/08/13 at http://www.biomedcentral.com/1756-0500/6/324

Appendix 3

Pre-Pilot Interview Guide for ARNI Participants

1 <u>Independence in Daily Life</u>

How independent are you in doing these activities of daily life?
(Circle a number using the key below)

Feeding yourself?	1	2	3	4	5	6
Brushing your teeth and hair?	1	2	3	4	5	6
Getting yourself dressed?	1	2	3	4	5	6
Taking yourself to the toilet?	1	2	3	4	5	6
Getting yourself out of bed?	1	2	3	4	5	6
Moving from sitting in a chair to standing up?	1	2	3	4	5	6
Washing yourself?	1	2	3	4	5	6
Getting in and out of a car?	1	2	3	4	5	6
Walking around inside your home?	1	2	3	4	5	6
Walking around outside eg: enough to cross a road?	1	2	3	4	5	6
Climbing a flight of stairs?	1	2	3	4	5	6

KEY

- **1** I'm completely independent
- **2** I do this myself, but need to use equipment, or it takes longer than before my stroke
- **3** I need to have someone there to feel safe, but not to physically help
- **4** I need help from 1 person to do this
- **5** I need help from 2 people
- **6** I cannot do this at all at present

2 <u>Falls</u>

How many times have you fallen and not been able to get up without help since your stroke?

3 <u>Confidence</u>

In general, how confident do you feel about taking part in activities of daily life, compared with before your stroke?
(Circle a number from 1 to 5 where 1 is 'not confident at all' and 5 is 'as confident as before my stroke')

(Not at all confident) 1 2 3 4 5 *(As confident as before stroke)*

4 Is there anything in particular you hope to gain from attending the ARNI sessions? *(please continue on the back if you need more space)*

Appendix 4

Post Pilot Interview Guide for Participants

1. **Independence in Daily Life**
Before you started the ARNI programme, I asked how independent you are in doing some activities of daily life. Has there been any change in any of these since you began the ARNI programme? *(have pre-questionnaire answers handy and write comments)*

Feeding yourself?	
Brushing your teeth and hair?	
Getting yourself dressed?	
Taking yourself to the toilet?	
Getting yourself out of bed?	
Moving from sitting in a chair to standing up?	
Washing yourself?	
Getting in and out of a car?	
Walking around inside your home?	
Walking around outside eg: enough to cross a road?	
Climbing a flight of stairs?	

2. **Getting down to and up from the floor**

   Were you able to do this before the programme?

   And how about now? Any change in technique or confidence?

3. **Training between sessions – How much, how often**

4. **Confidence - Since you began the ARNI programme do you feel your general confidence about taking part in activities of daily life has increased, decreased or not changed at all?** *(record comments)*

   Confidence decreased / No Change / Confidence increased

5. **Looking back at what you hoped to gain from attending the ARNI sessions before you started – how do you feel about that now? Have you seen any progress towards your goals?** *(have pre-questionnaire answers handy)*

6. **Any other comments about taking part in the ARNI programme?**
   (ask about recording sheet, length of programme, venue, group vs one to one, any other comments)

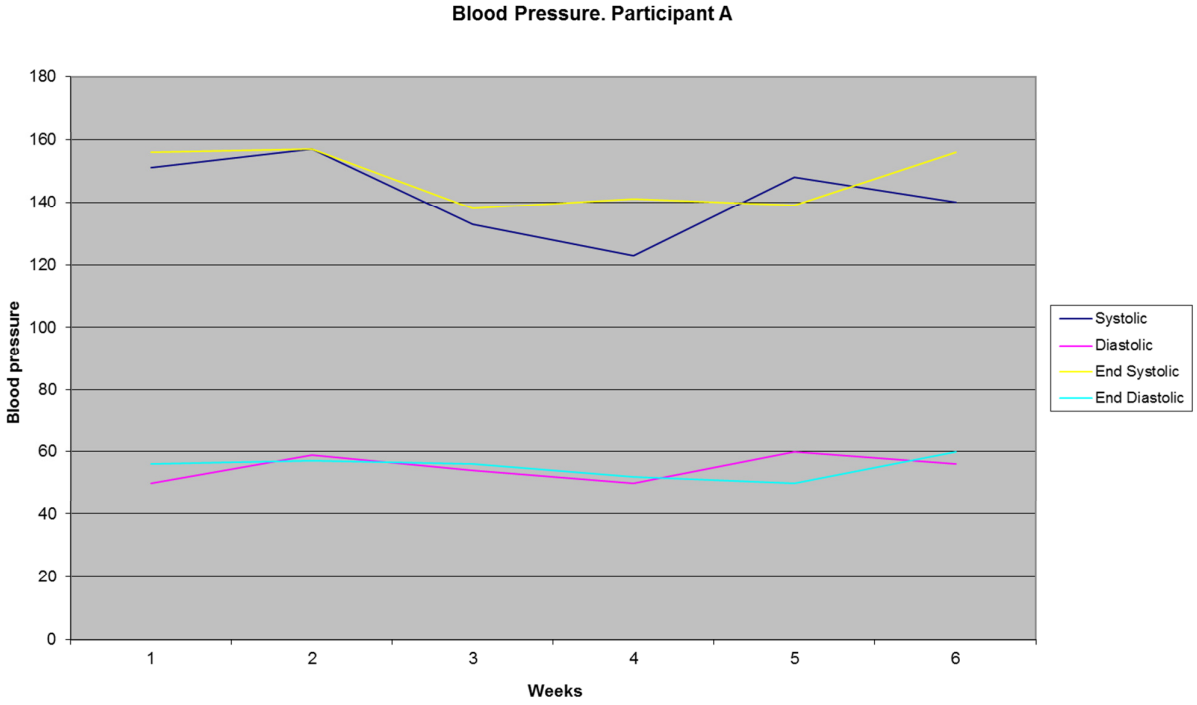
Appendix 5

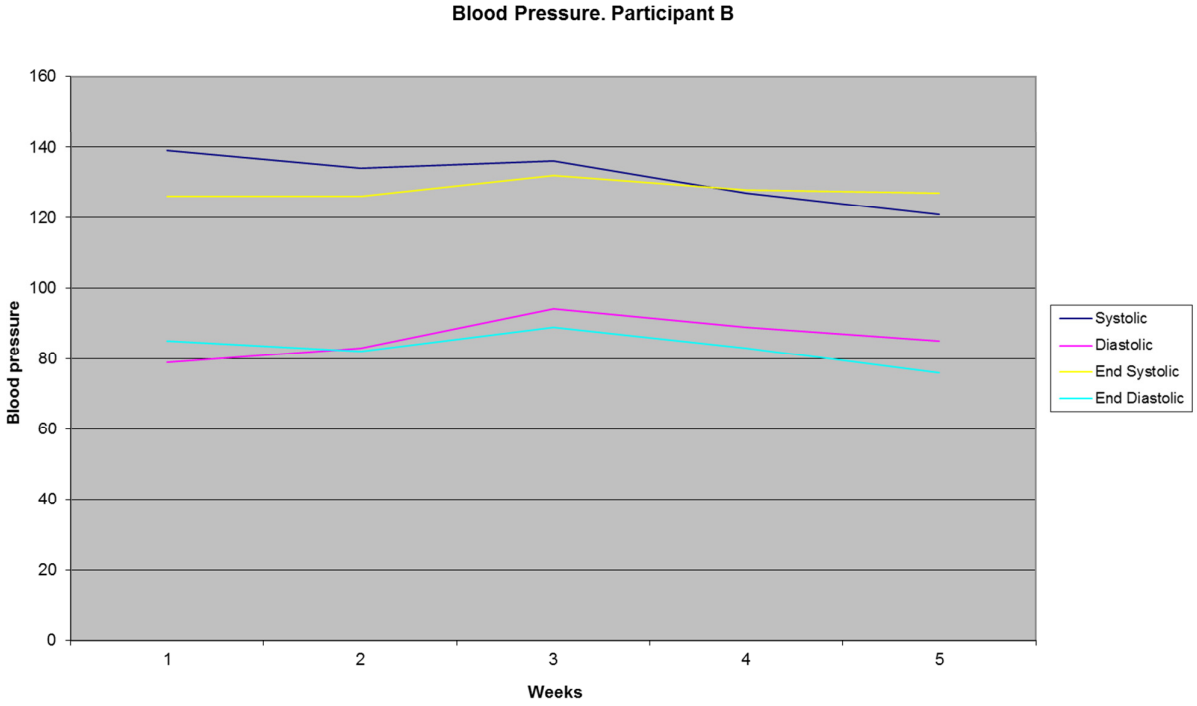
Typical ARNI Programme Record Sheet

	07-Oct	08-Oct	09-Oct	10-Oct	11-Oct	12-Oct	13-Oct	14-Oct	15-Oct	16-Oct	17-Oct	18-Oct	
Week 4	M	T	W	Th	F	Sa	Su	M	T	W	Th	F	
calf and hamstring stretches													
sitting calf stretches													
sitting balance													
squats													
standing balance													
walking no supports +distance													
wall pressups													
WRIST up & downs, handovers,													
curls, extensions, hammer, prayer bends													
hand on table, finger raises													
folds and rotates													
stick play													
ANYTIME - use left hand - standing with knees unlocked - spend time at home without splint incl. some walking													
aim for 30 mins per day ARNI with one or two rest days per week, combine with existing exercise programme													

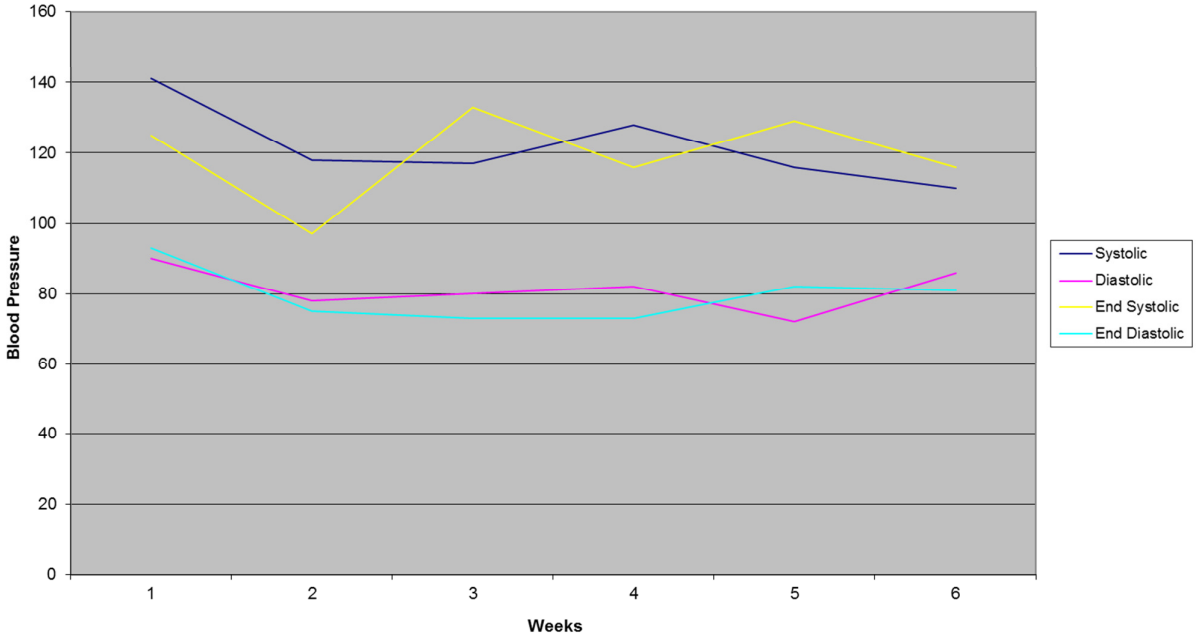
Appendix 6

Blood Pressure Charts

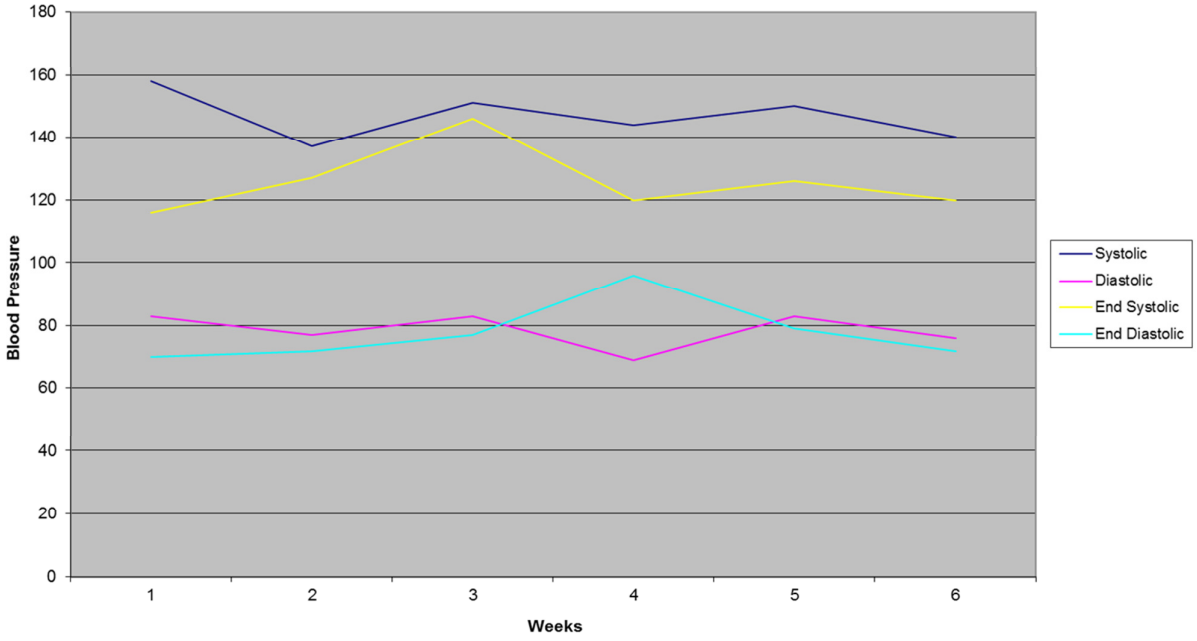


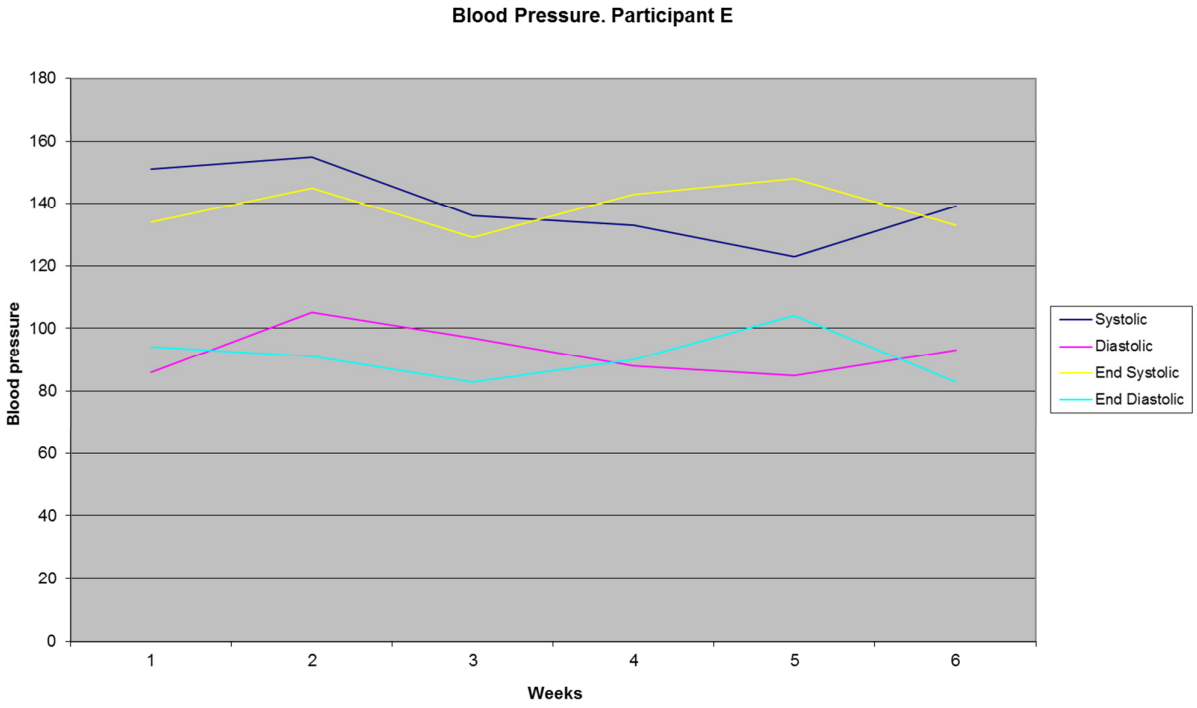


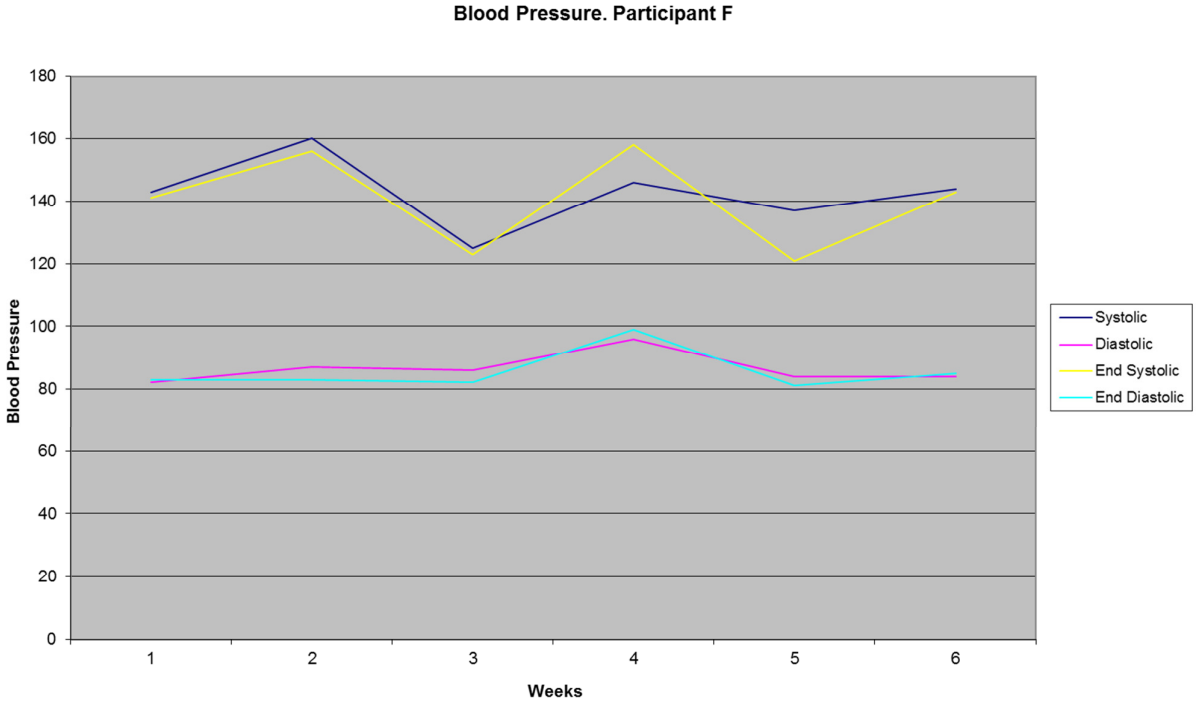
Blood Pressure. Participant C



Blood Pressure. Participant D




Blood Pressure. Participant E
Blood prassure
180
160
140
120
100
80
60
40
20
0
1
2
3
4
5
6
Weeks
Systolic
Diastolic
End Systolic
End Diastolic


Blood Pressure. Participant F
Blood Pressure
180
160
140
120
100
80
60
40
20
0
1
2
3
4
5
6
Weeks
Systolic
Diastolic
End Systolic
End Diastolic

Appendix 7

Levels of Independence in Daily Activities – Number of Participants Giving Each Score

	I'm completely independent	I do this myself, but need to use equipment, or it takes longer than before my stroke	I need to have someone there to feel safe, but not to physically help	I need help from 1 person to do this	I need help from 2 people	I cannot do this at all at present	Total	Average score
	1	**2**	**3**	**4**	**5**	**6**		Average score
Feeding yourself?	1	3		2			6	2.5
Brushing your teeth and hair?	4	1		1			6	1.7
Getting yourself dressed?	1	2		2	1		6	3.0
Taking yourself to the toilet?	4	1		1			6	1.7
Getting yourself out of bed?	3	2			1		6	2.0
Moving from sitting in a chair to standing up?	4	1				1	6	1.2
Washing yourself?	3			2	1		6	2.7
Getting in and out of a car?	4					2	6	1.0
Walking around inside your home?	3	1				2	6	1.2
Walking around outside eg: enough to cross a road?	2	1	1			2	6	1.5
Climbing a flight of stairs?	1	3				2	6	1.5
Base: All participants								