

Developing stroke care for adults in the community: Rehabilitation through Conductive Education

RESEARCH STUDY FINDINGS 2009-2012

The Foundation for Conductive Education in partnership with Birmingham City University



Funded by Birmingham City Council – Adults and Communities



Objectives set by Birmingham City Council Adults and Communities on allocation of the grant:

- 1. To provide evidence on the extent to which the use of conductive education has made a distinct improvement on quality of life.
- 2. To provide evidence on the extent to which conductive education users feel that their quality of life has improved and whether it has played a significant role in supporting them to achieve their desired outcomes
- 3. To determine whether there is evidence that the use of conductive education can make a financial saving on the future costs of care, a guide to the value and type of these savings.
- 4. An overall cost/benefit approach that would guide further decision making at the end of the grant regime
- 5. Conclusions on the future role of a conductive education approach to stroke and where in the care pathway it could be successfully located.

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Conductive Education for adults has been delivered within the City of Birmingham since 1990. Since this time no formal evaluation of the potential benefit and impact of this system on stroke survivors has been carried out.

Our thanks go to Birmingham City Council – Adults and Communities who have enabled this study to be carried out.

Executive Summary:

Introduction

"Stroke is a global health-care problem that is common, serious and disabling. Because most patients with stroke survive the initial illness, the greatest health effect is usually caused by the long-term consequences for the patients and their families. The prevalence of stroke-related burden is expected to increase over the next two decades" (Langhorne et al (2011) The Lancet Vol 377).

This statement shows that there will be an increasing need and future demand for rehabilitation services for stroke survivors. The National Stroke Strategy and Stroke Care Pathway recognise the need for longer term rehabilitation for people who are able to make functional gains and this research shows that Conductive Education could play a crucial, cost effective role in the delivery of such rehabilitation.

Background

Conductive Education (CE) is an approach to reablement and rehabilitation which focuses on teaching and learning strategies. The programmes are specifically designed according to diagnosis and structured to work at improving quality of life of both the person and the carer. CE has been available in Birmingham since 1990 however to date only anecdotal evidence of benefit has been available. This current study provides the first formal evaluation of CE as a potential option for stroke survivors and their families to improve their quality of life.

Research findings

The main focus of the research project is a randomised waiting list control trial. The methodology includes a range of quantitative measures to evaluate the impact of Conductive Education for stroke survivors. This report is based on the collated results of 87 people.

There are strong indicators of areas where Conductive Education has had a significant impact on the quality of life for people who have survived a stroke. This report demonstrates positive statistically significant changes from the Stroke Impact Scale in the areas of strength, hand function, activities of daily living, mobility, memory and thinking and stroke recovery. Statistical significance was also found in the reduction of depression through HADS and a positive trend towards reduction in anxiety. These results show the significance of providing a holistic rehabilitation system, one which simultaneously spans the physical and psychological changes which occur as a result of a stroke.

The vast majority of participants are classed as having long term chronic conditions (mean 40.14 months post stroke). This is a significant factor in the role of Conductive Education in the stroke care pathway as stroke survivors have engaged in a rehabilitation programme much longer post stroke than traditionally provided (Forster & Young, 2002). The results of this study indicate that following only 15 hours of intervention people with long term

strokes are able to make quantifiable changes in their quality of life and sustain these over a three month post intervention period.

Within the research framework we are looking for changes which may help to improve the lives of people who have suffered a stroke and their families. These must then of course be balanced against the cost of providing such a service. The cost analysis completed shows that CE can be considered cost-effective in relation to potential benefit and considerably lower (£15,849 per QALY) than the currently accepted NICE threshold of £20,000 per QALY. The NICE Stroke Strategy (2012) suggests that an intervention which costs less than £20,000 per QALY offers good value for money.

The cost of providing CE should be considered against the cost of long term care for stroke survivors. Many of the results also show how those in the control group worsened over the same period of time. Whilst stroke can be considered a stable medical condition our results show that there is a consistent reduction in quality of life where no intervention is given. The overall cost analysis does not take this reduction into account; it assumes a static situation therefore the impact of CE is greater than that indicated below.

The positive response to the service provision and, more importantly, achievement of personal aims are significant factors in any form of rehabilitation. CE, as a philosophy, works on creating a positive, motivating environment; one which enables individuals to feel safe, secure and significant; one that encourages and instils a sense of purpose and desire to achieve potential. These factors are crucial if we are to support people with long term conditions to play an active role in their daily lives.

Importantly, after three months of CE sessions the positive changes reported post CE have remained for most participants based on the stroke impact scale, and the HADS, a measure of anxiety and depression.

In conclusion the results are showing many positive results and trends. CE is a cost effective service in supporting and teaching people to continue to develop new skills, it offers a sense of hope, aspiration to achieve and is able to deliver this in a number of critical areas of daily life.

The role of CE in the Stroke Care Pathway

Current recommendations for rehabilitation for long term management are based around 45 minutes per day for 5 days a week (National Clinical Guideline Centre). This study shows that for as little as 90 minutes per week long term stroke survivors are able to make significant progress within a cost effective service provision. This is extremely important if we are to consider that many stroke survivors will continue to make progress for a number of years post stroke. The potential cost of CE in comparison to that recommended makes CE a high quality, cost effective service.

The National Stroke Strategy sets a number of quality markers. CE has the potential to support the achievement of a number of these:

QM3 – CE provides an opportunity for local authorities and health services to work directly with the voluntary sector to support stroke survivors and their carers.

QM4 – CE offers the opportunity for stroke survivors and their carers to be meaningfully involved in the service provision. By setting individual goals, monitoring progress and reporting directly on the service provision all aim to improve the effectiveness and relevance of the service.

QM10 – CE is able to provide a highly specialised service which simultaneously covers many of the facets of a multi-disciplinary team e.g. mobility, communication, everyday care activities, cognitive difficulties, visual perceptual difficulties as well as emotional well-being for both the stroke survivor and the carer.

QM13 – CE works directly in supporting people to live independently and not only identifies psychological and emotional challenges but actively supports and reduces these. The positive response from participant satisfaction surveys indicates the breadth and strength of this approach.

QM14 – CE has the potential to offer a regular review of progress and assessment of need for long term stroke survivors.

QM15 – CE services not only include direct access to rehabilitation but also offer carers support sessions; Wii-habilitation and conversational speech sessions. The National Institute has developed this 'menu' of services in response to local need and can therefore enhance community provision available for residents of the City of Birmingham.

QM18/19 – all staff at the National Institute have completed a minimum 3 year degree training in the field of CE and have all specialised in the area of stroke, Parkinson's, MS, cerebral palsy and head injury. This ensures that participants will only have services delivered by experts in the field of stroke. QM20 – the National Institute has a high commitment to research, evaluation and staff development.

From the National Stroke Strategy this research project provides evidence of Conductive Education as an effective rehabilitation intervention after the acute stage of stroke and into the longer term.

The results show that CE could have a significant role in reducing the overall cost of caring for and supporting stroke survivors who are living within their own homes. CE can enhance current health provision and offer a programme of reablement at any stage post stroke. The results show that this form of provision needs to be considered more widely as one way of improving quality of life, reducing the cost of care, preventing deterioration long term and enabling people to remain within their own home environment. To build upon these findings, the next stage for CE will be to identify predictors for optimal length of attendance of CE sessions. This will enable participants to make the step towards intuitively fostering the learning philosophy of CE into their daily lives.



DETAILED FINDINGS

Methodology:

Measures were chosen through analysis of Conductive Education philosophy, methodology and anecdotal evidence of benefit available to date. There is very little literature specific to CE and stroke and even less in relation to research methodology. A randomised cross-over trial using waiting list control groups was designed. In addition to this an interview study provided qualitative data on participants' experiences of CE.

Validated measures used:

- Barthel Index
- Stroke Impact Scale (SIS)
- ♣ Hospital Anxiety and Depression Scale (HADS)
- ♣ 10m walk test
- Timed Up and Go (TUG)
- ♣ ED-5D

Additional measures:

- qualitative interview study of participants' and carers' experiences of CE/NHS, in collaboration with the University of Birmingham
- participants' evaluation of progress towards rehabilitative aims on completion of CE course
- Service evaluation form completed by participants
- cost-effectiveness evaluation based on quality-adjusted life years (QALYs), clinically-relevant outcomes, health and social care resource use and intervention costs

Procedure:

Baseline assessments were completed for all participants who had given consent after an initial consultation. At this stage participants were randomised into immediate intervention or waiting list control group. Intervention group participants then commenced a 10 week programme of CE (15 hours of intervention), while control participants commenced a waiting period of equal duration, during which they attend two introductory sessions (with no intervention). Reassessments of all participants were completed after this period.

Following reassessment control (waiting list) participants were offered a place on the CE programme and were again reassessed on completion of the course. After completing the CE programme, all participants were invited to attend two follow up meetings (no intervention) and a final assessment was completed after 3 months. At each time point motor, cognitive and questionnaire measures were completed in a fixed order by all participants.

Recruitment and participants:

The target sample size was 100 participants. We recruited a sample of 108 and fully assessed a sample size of 87.

21 participants in total dropped out due to ill health, death or problems with commitment to programme, and only one participant did not want to continue with the sessions.

Pre-post data have been collected from 87 participants; 50 completing a CE programme and 37 completing an equivalent waiting period.

To date, this is the largest sample size to be recruited to assess stroke rehabilitation in the history of CE. The advantage of a larger sample size is that is provides greater "power size" for statistical analysis. The overall size of sample was hindered by the availability of services and the need for consistent recruitment.

Demographics and baseline measures:

The immediate intervention group consisted of 50 participants (33 male, 17 female) aged between 34 and 88 years (mean = 61.23), who were between 3 and 336 months post stroke (mean = 40.14) at baseline. The waiting list (control) group consists of 37 participants (21 male, 15 female) aged between 42 and 88 years (mean = 64.05) who were between 3 and 132 months post stroke (mean = 38.6) at baseline.

No significant differences were found between immediate and waiting list groups on age, mean time post stroke, gender or type of stroke. The two groups did not differ significantly on any of the outcome measures at baseline.

It is, however, important to note that the length of time post stroke is considerably higher than that usually expected for those accepted into rehabilitation programmes. This indicates not only the long term need for rehabilitation, but the potential of CE to address these needs irrespective of length of time post stroke.

Analyses and results

Initial data screening was undertaken to check for differences at baseline in demographic variables. The main analysis concerned changes from baseline to post-intervention/post waiting period, comparing these between the two groups (intervention/control). Non-parametric tests were used due to the unequal size of the groups.

Within-group changes were also analysed. For intervention participants changes from baseline to post-intervention were examined; as well as post-intervention to 3-month follow up. Changes in control participants were examined from baseline to post-waiting period and from post-wait to post-intervention. These changes were also analysed using non-parametric tests.

From the data collected so far we have looked at both statistical significance and positive trends. We present the areas in which these were identified below.

Quality of life

We have taken a range of aspects of quality of life and the following data includes:

- Stroke Impact Scale
- Barthel
- HADS

In relation to the 10m walk test and the Timed Up and Go we have found no significant results in relation to timing however there is a distinct change in gait pattern noticeable on the video material collected. We now plan to carry out a further single blind study to analyse the quality of gait.

The Stroke Impact Scale (SIS)

The SIS assesses 8 domains: strength, hand function, ADL, mobility, communication, emotion, memory and thinking, participation/role. It also has a stroke recovery scale. Significance was set in line with accepted levels in rehabilitation of p=0.05.

Within-groups analyses showed statistically significant improvements in the intervention group for 4 of the 8 domains on the Stroke Impact Scale:

Activities of daily living (p = 0.01) Hand function (p=0.001) Strength (p=0.01) Mobility (p=0.004)

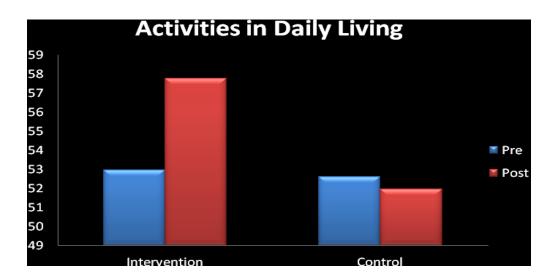
For the remaining domains of communication (p=0.906), emotion (p=0.216), memory and thinking (p=0.085) and participation (p=0.172) positive trends towards improvement were also reported.

The Stroke Recovery scale showed statistical significance (p=0.006) for the intervention group. The stroke recovery scale asks participants to rate on a scale of 0 to 100 "how much do they think they have recovered from their stroke?" No statistically significant differences towards improvement were shown in the control group during this period of time.

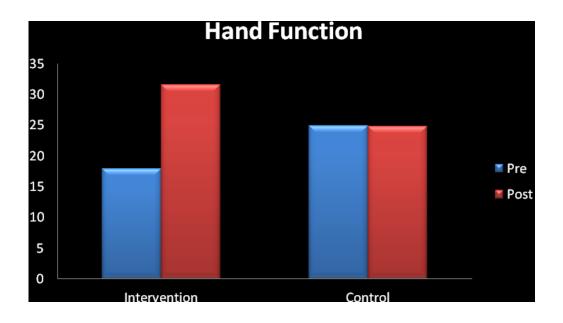
The reported overall percentage of recovery has also shown an increase in the intervention group while decreasing in the control group during the same period of time (see graphs below). Taking into consideration length of time post-stroke and that each person only received 15 hours of intervention, these results show that not only can improvement be made, but without intervention a decline may be seen in spite of the underlying condition being medically stable.

These overall results clearly indicate the holistic nature of the CE programme where a diverse range of areas are considered simultaneously. For a stroke survivor to have a meaningful quality of life they require not only mobility but also hand function and an ability to play an active role in daily life activities. The added dimension of memory and thinking will have a profound impact on the quality of life and level of activity of the person. The CE programme enables these areas to develop simultaneously, with one transdisciplinary professional.

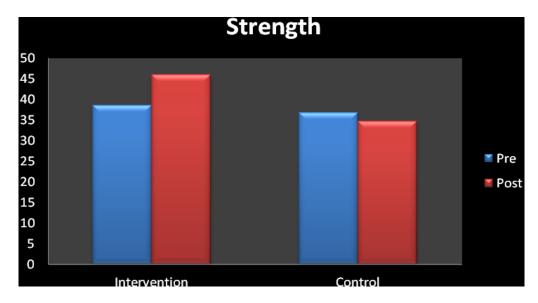
Stroke Impact Scale – summary of results



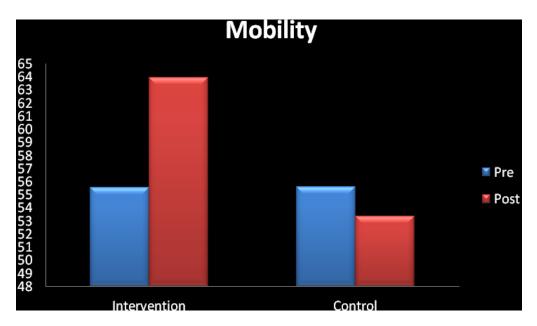
It is significant to note that the control group showed some deterioration which may not be anticipated with a non-progressive condition. This suggests that with no input individuals may show negative changes in their condition potentially requiring additional care support in the future.



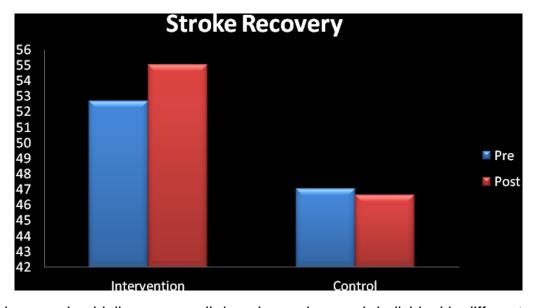
Many stroke survivors place an initial focus on standing and walking rather than on their hand and arm movements. As the conductive education programme explores potential and covers all domains of everyday movement the change in hand function is very positive. This not only enables the person to increase their level of activity but also provides a concrete reason for increasing general mobility. E.g. a person will only walk somewhere if they can do something when they get there!



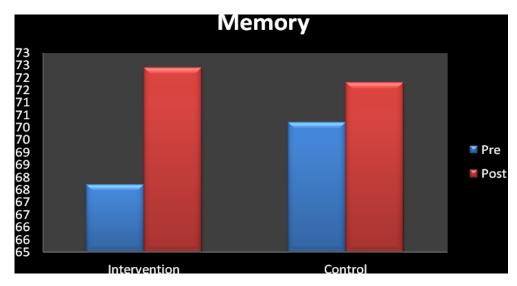
Increased strength is likely to occur from general increased use during daily activities. Throughout the programme participants were not asked to carry out exercises at home but to use the techniques taught. Any increase in strength will therefore derive from either the rehabilitation sessions and/or the increased use within daily activities. Note the small reduction in the control group.



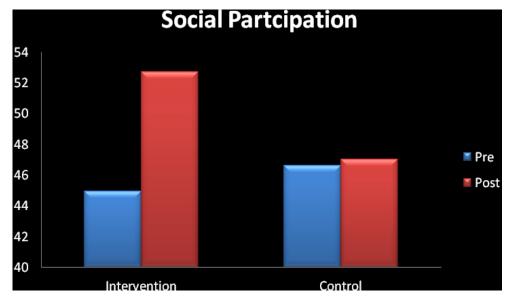
Here there is a marked improvement in the intervention group but a recurring pattern of a slight deterioration in the control group. The significance here is the variation between the two groups and indicates that stroke survivors will not maintain their current level of ability longer term.



This is a good guideline across all domains and as each individual is different and has different needs this graph shows the varied impact of Conductive Education. The impact of the stroke could be wide ranging and include any domain impacting on quality of life. CE has the potential to simultaneously address a wide range of aspects of QOL within one programme of intervention.



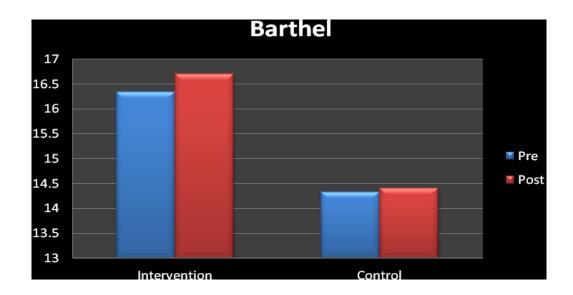
This is an esssential pre-requisite for learning and problem solving. The positive changes in memory will have an equivalent impact on all other aspects of daily life and support people in self care programmes and longer term management.



We would naturally expect an increase in social participation as CE works in groups (although the questions relate more directly to community activities rather than formal rehabilitation/hospital type visits). In order to ascertain whether this is due to increased mobility and/or confidence we need to look at the three month follow up data.

Barthel Index:

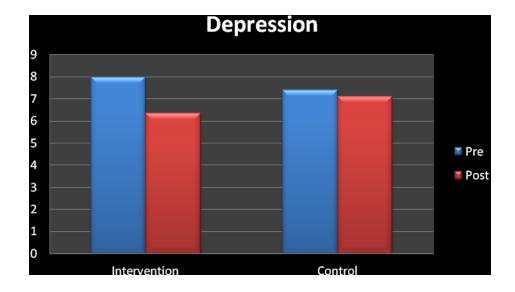
The results did not show statistical significance (p=0.758) however did show a trend towards improvement on the Barthel Index of everyday activities in the intervention group.

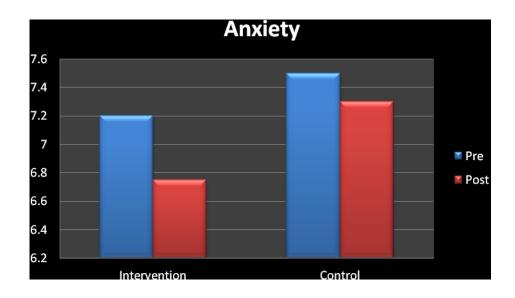


Depression and anxiety - Summary of HADS scores

Within group analysis showed a significant reduction in depression for the intervention group (p = 0.012). There was also a trend towards a reduction in anxiety for the intervention group (p=0.266).

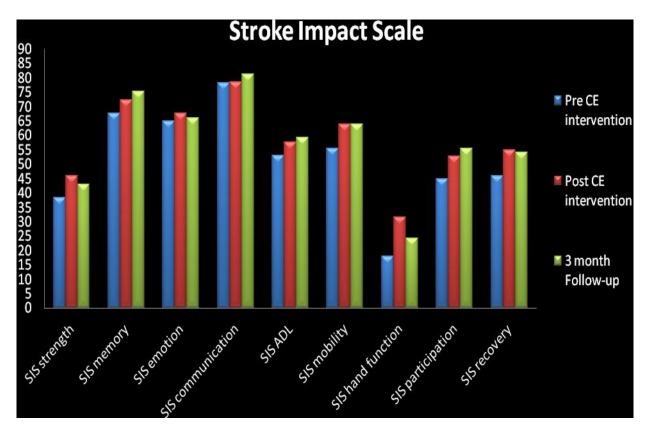
The impact of anxiety and depression on generic quality of life is well reported. This result demonstrates that CE can work, not only at a physical level but also an emotional level of impact. Reduced anxiety and depression can result in a more active lifestyle and hence reduce future medical and social needs.





Stroke Impact Scale – summary of results for 3 month follow up

The results below show the impact of CE three months post intervention. CE is a system based on teaching and learning and therefore some more permanent changes would be anticiapted following intervention.



These results suggest that continued improvement post intervention is possible. Domains including memory, communication, ADL and social participation have all continued to improve with no further intervention. The benefits on mobility have been sustained however there has been a reduction in hand function, strength and emotion.

Whilst the extent of the positive benefit may not have been maintained in all areas we can see that there has been a positive change from baseline in every domain.

We can infer that the participants have continued to develop an active lifestyle and thus CE has acted as a catalyst in the longer term rehabilitation process. As many of the participants were long term stroke survivors we can anticipate that their habits of movements and lifestyle would be well embedded, as would their belief that further change is not possible. These results however show that change can be sustained with 15 hours of intervention and raise the question of an optimal level of input to ensure learning and changes in lifestyle. The stroke care pathway (National Clinical Guideline Centre) suggests that long-term management should consist of 45 minutes rehabilitation for 5 days of the week; assuming that the person has the capacity to participate and continue to make functional gains. The results indicated above are based on a small fraction of the recommended input and yet show the potential longer term benefits from Conductive Education as a transdisciplinary rehabilitation system.

ACHIEVEMENT OF REHABILITATION GOALS

Prior to commencing the CE programme, participants are asked to identify their aims for rehabilitation. On completion of the intervention, participants complete a form rating their progress towards each of their specific rehabilitation aims, as well as rating their overall progress. Progress is rated on a scale of 1-5, from 'no' progress (1) to 'achieved aim' (5). Based on data from 87 participants:

Appraisal of rehabilitation aims:

- average overall progress rating = 4.2/5
- average progress towards specific aims set by participants = 4.0/5
- ➤ 69% of participants reported making 'a good deal of progress' (4/5) towards one or more of their aims
- > 32.4% of participants reported having achieved one or more of their aims.

Service evaluation:

Following completion of the CE programme participants complete an anonymous evaluation form, in which they are asked to rate various aspects of the CE service under the headings: Service, Support, Communication and Environment. Each element is rated on a scale of 1 to 5, from "very poor" (1) to "very good" (5). Ratings are shown in the table below:

Aspect of Conductive Education	Average rating (1-5)
Service	4.6
Support	4.6
Communication	4.6
Environment	4.2

Service provision costs:

The cost of providing one 1.5 hour CE session is £67.60 (including staffing and overheads). The cost of an initial consultation is £101.40. A 10 week course of CE, including consultation, therefore costs £777.40

Costs to participants:

Based on self-reported data from 87 participants:

- Average transport cost incurred by participants to attend 10 sessions = £84.51
- 62% of participants are accompanied to sessions by a carer or relative;
 - 13% are accompanied by carers who take time off work
 - 10% are accompanied by carers who incur a loss of earnings/holiday as a result

Loss of earnings incurred by carers attending sessions was estimated based on half a day's earnings (including travel time) at the national average wage for 2010^1 (£499 per week). At £49.90 per half day, the total gross loss of earnings for 10 sessions would be £499. Average cost per participant = £57.35

The total average cost to participants in attending a 10 week course of CE was estimated at £141.86.

Resource use and falls:

At each reassessment (post-intervention/post-wait/3 month follow-up) participants are asked to provide information on their use of health and social care resources during that time period. This includes frequency of any other therapies received (physiotherapy, occupational therapy, speech and language therapy etc.) and any changes to formal care provision. Participants are also asked to report any falls they may have had during that period, and

¹ Data obtained from the 2010 Annual Survey of Hours and Earnings, <u>www.statistics.gov.uk</u>.

whether these resulted in medical treatment. The data collected so far are summarised in Table 1.

<u>Table 1.</u> Numbers of participants reporting events during intervention/wait periods

	Intervention period (N = 50)	Waiting period (N = 37)
Resource accessed		
Physiotherapy	9	10
Speech & language therapy	2	3
Occupational therapy	2	2
Other (e.g. exercise class)	13	10
Change in frequency of care visits	1	2
Falls (one or more)	8	7
Requiring medical treatment	0	0

Total costs:

The use of health and social care resources did not differ between intervention and control groups and so the costs for these were assumed to be equal. Medical costs incurred by falls did not apply in either the intervention or control group and were not included in the total cost. The total average cost of the 10 week intervention was therefore estimated at £919.26 (service cost of £777.40 + participant cost of £141.86).

Cost-utility analysis Quality-adjusted life years (QALYS):

The main outcome measure for the economic analysis was the increase in quality-adjusted life years (QALYS) associated with Conductive Education. Data were collected using the EQ-5D questionnaire at baseline and reassessment.

QALYS gained were calculated using the difference between intervention and control participants' average health state values over the study period, multiplied by the proportion of one year over which they were measured (approximately 12 weeks = 0.213). The total cost associated with the intervention was then divided by the QALY difference to obtain a cost per QALY gained.

Based on data from 87 participants:

- QALY gained by intervention group relative to control group = average quality of life difference (0.25) x time period (0.231) = 0.058
- Cost per QALY gained = intervention cost (£919.26)/QALY gained (0.058) = £15,849

The calculated cost per quality-adjusted life year gained falls well within the range generally considered to be cost-effective. The NICE Stroke Strategy (2012) suggests that the principles to be considered whether an intervention offers good for value for money are:

- a. Intervention dominates other relevant strategies
- b. Intervention costs less than £20,000 per QALY.

Based on the cost effectiveness alone this demonstrates that CE should be recognised as an appropriate intervention for long term management of stroke survivors.

Interview study

A qualitative study was undertaken by researchers from the University of Birmingham in which 11 participants and 8 carers were interviewed about their experiences of both conductive education and the NHS. The study is now complete and the results have been submitted for publication.

The following extract is taken from the conclusion of the study report (Soundy, Flatters, Bek & Brown, submitted):

"Participants gained hope from personal improvement, from observing others and through taking action and having the possibility of achieving their potential. Experiences of the NHS indicated how the system could demoralise a participant. CE provides a very good setting for personalised care and was able to re-moralise participants."

The final words go to the people who have taken part in this project

These comments have been taken from the service questionnaire completed by each participant at the end of their sessions.

"Helpful and thoughtful to helpers and patients"

"All conductors and staff have always been accommodating to questions being asked, if any concerns have been identified"

"Conductors have always encouraged new ideas for the patient. Carers have always been welcomed to join in group work"

"I would like to do more sessions...I cannot afford it"

"Excellent support provided during the groups sessions by the conductors"

"Very good but I would need a lot longer to be really objective about its benefit, say 12 months"

"It's been good meeting other people"

All the staff at The National Institute of Conductive Education would like to thank the participants for their involvement in this important project.