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Social support after a stroke

Appendices

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Volume Two

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**THE FOLLOWING PARTS OF THIS THESIS HAVE BEEN REDACTED
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Appendix 1

Critical appraisal tools

Critical appraisal skills programme (CASP): Qualitative research

CRITICAL APPRAISAL SKILLS PROGRAMME Making sense of evidence about clinical effectiveness



10 questions to help you make sense of qualitative research

These questions consider the following:

Are the results of the review valid?

What are the results?

Will the results help locally?

A number of italicised prompts are given after each question. These are designed to remind you why the question is important. There will not be time in the small groups to answer them all in detail!

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Screening Questions

1. Was there a clear statement of the aims of the research?

Consider:

- *What the goal of the research was*
- *Why is it important*
- *Its relevance*

2. Is a qualitative methodology appropriate?

Consider:

- *If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants*

Detailed questions

3. Was the research design appropriate to address the aims of the research?

Consider:

- *If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)?*

4. Was the recruitment strategy appropriate to the aims of the research?

Consider:

- *If the researcher has explained how the participants were selected*
- *If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study*
- *If there are any discussions around recruitment (e.g. why some people chose not to take part)*

5. Were the data collected in a way that addressed the research issue?

Consider:

- *If the setting for data collection was justified*
- *If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)*
- *If the researcher has justified the methods chosen*
- *If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)?*
- *If methods were modified during the study. If so, has the researcher explained how and why?*
- *If the form of data is clear (e.g. tape recordings, video material, notes etc.)*
- *If the researcher has discussed saturation of data*

6. Has the relationship between researcher and participants been adequately considered?

Consider:

- *If the researcher critically examined their own role, potential bias and influence during:*
 - *Formulation of the research questions*
 - *Data collection, including sample recruitment and choice of location*
- *How the researcher responded to events during the study and whether they considered the implications of any changes in the research design*

7. Have ethical issues been taken into consideration?

Consider:

- *If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained*
- *If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)*
- *If approval has been sought from the ethics committee*

8. Was the data analysis sufficiently rigorous?

Consider:

- *If there is an in-depth description of the analysis process*
- *If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?*
- *Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process*
- *If sufficient data are presented to support the findings*
- *To what extent contradictory data are taken into account*
- *Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation*

9. Is there a clear statement of findings?

Consider:

- *If the findings are explicit*
- *If there is adequate discussion of the evidence both for and against the researcher's arguments*
- *If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)*
- *If the findings are discussed in relation to the original research question*

10. How valuable is the research?

Consider:

- *If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature?*
- *If they identify new areas where research is necessary*
- *If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used*

Critical appraisal skills programme (CASP): Cohort studies

CRITICAL APPRAISAL SKILLS PROGRAMME Making sense of evidence about clinical effectiveness



12 questions to help you make sense of cohort study

General comments

- Three broad issues need to be considered when appraising a cohort study.

Are the results of the study valid?

What are the results?

Will the results help locally?

The 12 questions on the following pages are designed to help you think about these issues systematically.

- The first two questions are screening questions and can be answered quickly. If the answer to those two is "yes", it is worth proceeding with the remaining questions.
- There is a fair degree of overlap between several of the questions.
- You are asked to record a "yes", "no" or "can't tell" to most of the questions.
- A number of italicised hints are given after each question. These are designed to remind you why the question is important. There will not be time in the small groups to answer them all in detail!

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A/ Are the results of the study valid?

Screening Questions

1 Did the study address a clearly focused issue? <i>HINT: A question can be focused in terms of?</i> <ul style="list-style-type: none">• the population studied• the risk factors studied• the outcomes considered• is it clear whether the study tried to detect a beneficial or harmful effect?	Yes <input type="checkbox"/>	Can't tell <input type="checkbox"/>	No <input type="checkbox"/>
2 Did the authors use an appropriate method to answer their question? <i>HINT: Consider</i> <ul style="list-style-type: none">• is a cohort study a good way of answering the question under the circumstances?• did it address the study question?	Yes <input type="checkbox"/>	Can't tell <input type="checkbox"/>	No <input type="checkbox"/>

Is it worth continuing?

Detailed Questions

3 Was the cohort recruited in an acceptable way? <i>HINT: We are looking for selection bias which might compromise the generalisability of the findings:</i> <ul style="list-style-type: none">• Was the cohort representative of a defined population?• Was there something special about the cohort?• Was everybody included who should have been included?	Yes <input type="checkbox"/>	Can't tell <input type="checkbox"/>	No <input type="checkbox"/>
---	--	---	---------------------------------------

<p>4 Was the exposure accurately measured to minimize bias?</p> <p><i>HINT: We are looking for measurement or classification bias:</i></p> <ul style="list-style-type: none"> • <i>Did they use subjective or objective measurements?</i> • <i>Do the measures truly reflect what you want them to (have they been validated)?</i> • <i>Were all the subjects classified into exposure groups using the same procedure?</i> 	<p>Yes</p> <input type="checkbox"/>	<p>Can't tell</p> <input type="checkbox"/>	<p>No</p> <input type="checkbox"/>
<p>5. Was the outcome accurately measured to minimize bias?</p> <p><i>HINT: We are looking for measurement or classification bias:</i></p> <ul style="list-style-type: none"> • <i>Did they use subjective or objective measurements?</i> • <i>Do the measures truly reflect what you want them to (have they been validated)?</i> • <i>Has a reliable <u>system</u> been established for detecting all the cases (for measuring disease occurrence)?</i> • <i>Were the measurement methods similar in the different groups?</i> • <i>Were the subjects and/or the outcome assessor blinded to exposure (does this matter)?</i> 	<p>Yes</p> <input type="checkbox"/>	<p>Can't tell</p> <input type="checkbox"/>	<p>No</p> <input type="checkbox"/>
<p>6 A. Have the authors identified all important confounding factors?</p> <p>List the ones you think might be important, that the author missed.</p> <p>B. Have they taken account of the confounding factors in the design and/or analysis?</p> <p>HINT:</p> <ul style="list-style-type: none"> • <i>Look for restriction in design, and techniques eg modelling, stratified-, regression-, or sensitivity analysis to correct, control or adjust for confounding factors</i> 	<p>Yes</p> <input type="checkbox"/>	<p>Can't tell</p> <input type="checkbox"/>	<p>No</p> <input type="checkbox"/>
	<p>Yes</p> <input type="checkbox"/>	<p>Can't tell</p> <input type="checkbox"/>	<p>No</p> <input type="checkbox"/>
	<p>List:</p>		

<p>7. A. Was the follow up of subjects complete enough?</p> <p>B. Was the follow up of subjects long enough?</p> <p>HINT:</p> <ul style="list-style-type: none"> • <i>The good or bad effects should have had long enough to reveal themselves</i> • <i>The persons that are lost to follow-up may have different outcomes than those available for assessment</i> • <i>In an open or dynamic cohort, was there anything special about the outcome of the people leaving, or the exposure of the people entering the cohort?</i> 	<p>Yes</p> <input type="checkbox"/>	<p>Can't tell</p> <input type="checkbox"/>	<p>No</p> <input type="checkbox"/>
	<p>Yes</p> <input type="checkbox"/>	<p>Can't tell</p> <input type="checkbox"/>	<p>No</p> <input type="checkbox"/>

B/ What are the results?

<p>8 What are the results of this study?</p> <p>HINT:</p> <ul style="list-style-type: none"> • <i>What are the bottom line results?</i> • <i>Have they reported the rate or the proportion between the exposed/unexposed, the ratio/the rate difference?</i> • <i>How strong is the association between exposure and outcome (RR,)?</i> • <i>What is the absolute risk reduction (ARR)?</i> 			
<p>9. How precise are the results?</p> <p>HINT:</p> <ul style="list-style-type: none"> • <i>Size of the confidence intervals</i> 			
<p>10. Do you believe the results?</p> <p>HINT:</p> <ul style="list-style-type: none"> • <i>Big effect is hard to ignore!</i> • <i>Can it be due to bias, chance or confounding?</i> • <i>Are the design and methods of this study sufficiently flawed to make the results unreliable?</i> • <i>Consider Bradford Hills criteria (eg time sequence, dose-response gradient, biological plausibility, consistency).</i> 	<p>Yes</p> <input type="checkbox"/>	<p>Can't tell</p> <input type="checkbox"/>	<p>No</p> <input type="checkbox"/>

C/ Will the results help me locally?

<p>11. Can the results be applied to the local population?</p> <p><i>HINT: Consider whether</i></p> <ul style="list-style-type: none"><i>The subjects covered in the study could be sufficiently different from your population to cause concern</i><i>Your local setting is likely to differ much from that of the study</i><i>Can you quantify the local benefits and harms?</i>	Yes <input type="checkbox"/>	Can't tell <input type="checkbox"/>	No <input type="checkbox"/>
12. Do the results of this study fit with other available evidence?	Yes <input type="checkbox"/>	Can't tell <input type="checkbox"/>	No <input type="checkbox"/>

One observational study rarely provides sufficiently robust evidence to recommend changes to clinical practice or within health policy decision making.

However, for certain questions observational studies provide the only evidence.

Recommendations from observational studies are always stronger when supported by other evidence.

Quality assessment of predictive models

Taken from: Counsell C and Dennis M. Systematic review of prognostic models in patients with acute stroke. *Cerebrovasc Dis.* 2001; 12: 159-70.

Table 1. Quality assessment of predictive models

A. External validity

- (i) Was the model generated on a community- or hospital-based population? Patients admitted to hospitals are not representative of all patients with stroke in the community, and different hospitals admit different types of stroke patient [20]. Models generated on hospital-based patients may therefore not be applicable to other stroke patients.
- (ii) Were patients with transient ischaemic attacks and subarachnoid haemorrhages included (prognostic factors for these may be different from those for stroke)?
- (iii) Were there major exclusion criteria (such as age, sex, or type of stroke) that may limit generalisability?
- (iv) Was there a description of the cohort of patients (e.g. age, sex, treatment) on which the models were developed so that clinicians could assess how similar it was to their own patients?

B. Internal validity

- (i) Was an inception cohort established? Prognosis should be studied in patients who are at a similar stage in the disease process (an 'inception cohort') since factors that affect prognosis may vary with the time since stroke. Studies in which patients were seen within one week of onset were defined as having the most adequate inception cohort.
- (ii) Were an adequate number of patients in the inception cohort followed up to minimise bias? We arbitrarily defined losses of less than 10% of the original cohort as adequate.
- (iii) Were baseline data collected prospectively? Data collected retrospectively e.g. from case notes may be less accurate than prospectively collected data.
- (iv) Were references made to the outcomes' validity and reliability?
- (v) Were outcomes assessed at appropriate times? Outcomes should be assessed at a fixed time after stroke onset so that all patients are at a similar stage in the disease process, and long-term outcomes (130 days) are more meaningful.
- (vi) Were some potentially important predictors not entered into the models? Models that do not include variables known to be important independent predictors are probably less reliable than those that do. It was difficult to define which factors were important in prognosis before completing this systematic review. However, age and stroke severity were likely to be important in prognosis and so we documented whether these variables were entered into the analysis.
- (vii) Were the predictive variables clearly defined, clinically valid, and was reference made to their reliability?

C. Statistical validity

- (i) Was the sample size adequate as defined by an EPV of 10 or more. The number of variables included any interaction terms.
- (ii) Was some form of stepwise analysis used and if not was collinearity between the variables assessed? Multiple regression can produce spurious results if all the variables are simply entered into a model and certain highly predictive variables are strongly correlated with each other (collinearity) [23]. This is less problematic in stepwise regression.

D. Evaluation of the model

- (i) Was the final model validated on the data that were used to generate the model (internal validation)? Models that do not produce accurate predictions on the patients who were used to generate it are clearly unreliable.
- (ii) Was the final model validated on patients who were not used to generate the model (external validation)? Models that predict well on the patients who were used to produce the model may still not provide accurate predictions on other patients. The accuracy must also be tested in an independent cohort of patients, ideally, on several independent cohorts to assess its generalisability.
- (iii) Are the model's predictions better than predictions based on clinical judgement? If prognostic models are to be used in clinical practice, they should be at least as good as clinical judgement.
- (iv) Was the effect of using the model in clinical practice established? If the model's predictions are to be used in clinical practice, their effect on patient outcome should be evaluated. This is best done in randomised trials [19]. The use of a model may harm patients if, for example, patients who are falsely predicted to have a poor outcome are given hazardous treatments or alternatively are left untreated because treatment is judged to be futile

E. The ease of use (practicality) of the model

- (i) Were the data required to make predictions easily available? Models that include complex variables or those that are not available when the clinician needs to make a prediction are unhelpful. Variables were defined as complex after discussion between the two authors.
 - (ii) Was the actual model and the coding of variables described so it could be used?
 - (iii) Were confidence intervals given for the predictions? Models that only give point estimates for the probability of an outcome can give a false impression of accuracy. Clinicians need to know whether the confidence interval for a prediction is sufficiently narrow to allow a specific prognosis to be given
-

Appendix 2

Ethics approval

Quality of life after stroke

Research Project

Research proposal with amendments

Sections 2 and 4 contain changes related to the proposed amendments. Changes are in small capitals and in bold.

Number in parenthesis refers to number of proposed amendment/addition

1. Full title: **Assessing health related quality of life after stroke**

2. Aims

Stroke rehabilitation programmes aim to produce changes in clients' quality of life¹. Yet, there are hardly any outcome measures that can capture meaningful changes for the clients in this area. The purpose of the proposed study is to evaluate the Stroke and aphasia quality of life scale (SAQOL-39) as an outcome measure for stroke interventions. The project will evaluate:

1. the reliability (internal consistency and test-retest reliability)
2. the construct validity (known groups, convergent and discriminant)
3. and the responsiveness to change of the SAQOL-39, in a cohort of people admitted to hospital with stroke.

SECONDARY AIMS OF THIS PROJECT ARE:

- **(2) TO EVALUATE THE IMPACT OF STROKE ON SOCIAL SUPPORT AND SOCIAL NETWORKS**
- **(3) TO EXPLORE THE WELL-BEING OF INFORMAL CARERS OF STROKE PEOPLE**

3. Background information

Stroke is the most common cause of long-term disability in the western world. In the Health Survey for England, 2.3% of men and 2.1% of women reported having had a stroke². More than 50% of people who survive a stroke are left with physical disabilities³ and 15% with marked communication problems (aphasia)⁴. The cost of stroke care exceeds 4% of the NHS expenditure¹. All this suggests that stroke and its resulting disability have a considerable impact in modern society and in health service provision.

The National Clinical Guidelines for Stroke¹ identify as key aims of stroke rehabilitation: to maximise the clients' sense of well-being/quality of life and their social position/roles. However, few stroke outcome measures tap into these domains. The ones that do, commonly, are not useable with the sub-group of stroke survivors that is most prone to social isolation and exclusion: people with aphasia. This is because aphasia affects people's ability to understand and use language. There are currently three stroke-related quality of life scales: the SS-QOL (Stroke specific quality of life scale⁵), the SIS (Stroke impact scale⁶) and the SA-SIP (Stroke adapted sickness

impact profile⁷). None of these measures have been tested with people with aphasia.

We have adapted the SS-QOL for use with people with aphasia⁸. This resulted in the Stroke and aphasia quality of life scale – 39 item version (SAQOL-39). This instrument has been evaluated for acceptability, reliability and validity with people with chronic aphasia with very good results⁹.

The SAQOL-39 is the first rigorously tested disease-specific measure of health-related quality of life (HRQL) that can be used with the majority of stroke survivors, i.e., including people with aphasia. The proposed study will evaluate the psychometric properties of this adapted measure with the stroke population as a whole (i.e., not just people with aphasia). It will also test its suitability as an outcome measure that can capture changes in clients' quality of life, which is the main focus of stroke rehabilitation. Such a measure would be useful not just to one group of professionals but to the whole multidisciplinary stroke team.

4. Methodology

4.1. Design

The study will be a repeated-measures cohort study of people admitted to one NHS hospital with stroke, within a 12-month period. The primary investigator will give information about the project to eligible participants, will obtain written consent and will assess participants at 2 weeks (baseline), 3 months and 6 months post stroke (± 1 week). **(2) FOR THE SOCIAL SUPPORT EVALUATION, A SUBGROUP OF STROKE PARTICIPANTS (25) WILL BE FOLLOWED UP TO ONE YEAR. (3) PARTICIPANTS' INFORMAL CARERS WILL COMPLETE DATA AT THE 3 MONTHS AND 6 MONTHS DATA COLLECTION POINTS.**

4.2. Participants

Stroke participants must meet the following eligibility criteria: are admitted to hospital with a first ever stroke; stay in hospital for at least 3 days because of the stroke; lived at home prior to the stroke; have no known history of mental health problems or cognitive decline prior to the stroke; and have no other severe or potentially terminal comorbidity. Due to the high case fatality of stroke (about 30%³) the aim will be to recruit at least 150 participants at baseline. In the participating site, review of medical records will identify eligible participants. **(3) INFORMAL CARERS WILL BE FAMILY MEMBERS OF CLOSE FRIENDS OF THE STROKE PARTICIPANTS WHO LIVE TOGETHER WITH THE STROKE PARTICIPANTS AND ARE ABLE TO SELF REPORT ON THE ASSESSMENTS USED.**

4.3. Procedure

Ethical approval will be obtained from the participating NHS Trust and City University. The recruitment and data collection period will be 18 months. Eligible participants will be invited to take part in the study and written consent will be obtained from those willing to take part. All **STROKE** respondents will be interviewed face-to-face. **(3) INFORMAL CARERS WILL SELF-COMplete THE QUESTIONNAIRES USED, WHILE STROKE RESPONDENTS ARE INTERVIEWED AT THE 3 MONTH AND 6 MONTH DATA COLLECTION POINTS.** Test-retest reliability data will be collected at the 3-month data collection point, from the first 30 participants of a randomly selected sample who agree to have the SAQOL-39 administered twice.

The test-retest period will be 7(\pm 4) days. **(1) DIFFERENT MODES OF ADMINISTRATION OF THE SAQOL-39 WILL BE TESTED WITH ALL PARTICIPANTS WHO AT A SET TIME PERIOD (E.G., SEPTEMBER 2005 TO FEBRUARY 2006) ARE 3 MONTHS POST ONSET (TELEPHONE ADMINISTRATION) OR 6 MONTHS POST ONSET (POSTAL ADMINISTRATION). (2) STROKE PARTICIPANTS FOLLOWED UP TO THE ONE YEAR POST STROKE WILL COMPLETE A QUALITATIVE INTERVIEW, WHICH WILL BE TAPE-RECORDED WITH THE PARTICIPANTS' CONSENT.**

TO MINIMISE STROKE PARTICIPANTS' RESPONDENT BURDEN, TEST-RETEST RELIABILITY, DIFFERENT MODES OF ADMINISTRATION OF THE SAQOL-39 (1) AND THE LONG-TERM SOCIAL SUPPORT EXPLORATION (2) WILL BE TESTED IN DIFFERENT SUBGROUPS OF THE PARTICIPANTS.

4.4. Measures

The SAQOL-39 and a number of other measures will be used at each data collection point **WITH STROKE RESPONDENTS**. The SAQOL-39 consists of 39 questions that cover four domains: physical, psychosocial, communication and energy. To test the validity of the scale and its sub-domains, measures that capture each of these areas are needed. Proposed measures are: for the physical and energy domains, the Barthel Index¹⁰; for communication, the Frenchay Aphasia Screening Test (FAST)¹¹; and for the psychosocial and energy domains, the General Health Questionnaire – 12 item version (GHQ-12)¹². These measures have good psychometric properties, have been widely used with stroke survivors (including people with aphasia) and are quick and easy to administer. Participants will also be asked to rate their overall quality of life compared with before the stroke on a 5-point scale. **(3) INFORMAL CARERS WILL COMPLETE THE SHORT-FORM 36 (SF-36)^A, THE GHQ-12, THE CAREGIVER STRAIN INDEX (CSI)^B AND THE GENERAL SELF-EFFICACY SCALE (GSE)^C, THE MOS SOCIAL SUPPORT SURVEY^D AND A QUESTIONNAIRE ON SOCIAL NETWORK.**

4.5. Data analysis

Reliability: the internal consistency of the scale will be assessed by Cronbach's alpha ($>.70$)¹³ and item-total correlations ($\geq.30$)¹³; and its test-retest reliability by intraclass correlation coefficients ($ICC >.75$)¹⁴.

Validity: within scale analyses will be performed to evaluate the construct validity of the scale and its domains. These will include Cronbach's alpha ($>.70$), intercorrelations between subdomains, and correlations of subdomains and corrected total score (.30-.80). Analyses against external criteria will include known group differences and evidence of convergent and discriminant validity. Analysis of variance (ANOVA) will be used to see whether there are significant differences in the mean SAQOL-39 scores of 3 groups: respondents who rate their HRQL as the same or better (group 1), a little worse (group 2) or a lot worse (group 3) than before the stroke. To evaluate convergent and discriminant validity, clear hypotheses will be set a priori about the expected correlations of the SAQOL-39 scores and other measures. For example, the physical domain of the SAQOL-39 should have a moderate/high correlation ($>.30$) with the Barthel Index (convergent validity) and a low correlation ($<.30$) with the FAST (discriminant validity).

Responsiveness to change: effect sizes (ES)¹⁵, standardised response means¹⁶ and *t*-statistics¹⁷ will be used to evaluate the responsiveness of the SAQOL-39. It is anticipated that: a) The SAQOL-39 scores of people with mild initial stroke severity will improve significantly more compared to those of people with severe initial strokes; b) The SAQOL-39 scores of people who do not suffer a further stroke or other medical

complication during the data collection period will improve as opposed to those of people who do; c) the SAQOL-39 domain scores (e.g., communication) will show similar patterns of change as the related measures (e.g., the FAST), across time.

(1) DIFFERENT MODES OF ADMINISTRATION: THE RELIABILITY OF THE TELEPHONE AND POSTAL SAQOL-39 WILL BE TESTED AS INDICATED ABOVE. RESPONSE RATES AND MISSING DATA WILL ALSO BE COMPARED BETWEEN DIFFERENT VERSIONS.

(2) QUALITATIVE INTERVIEW DATA ON SOCIAL SUPPORT AND NETWORK: INTERVIEW DATA WILL BE TRANSCRIBED VERBATIM AND ISSUES ARISING FROM THE INTERVIEWS WILL BE CLASSIFIED, INDEXED AND ANALYSED USING THE 'FRAMEWORK' METHOD^E

(3) INFORMAL CARERS' WELL BEING: DESCRIPTIVE STATISTICS WILL BE USED TO EXPLORE HOW CARERS PERFORM IN THE DIFFERENT QUESTIONNAIRES USED. MULTIPLE REGRESSION WILL BE USED TO SEE WHICH FACTORS (STROKE PARTICIPANTS' RELATED AND CARERS' RELATED) PREDICT QUALITY OF LIFE IN THE CARERS.

5. Ethical issues

Well-being of the participants: This research does not pose any risk to the physical health of the participants and it will not interfere with routine care. To minimise potential psychological distress and undue intrusion, clear information on the project will be given to potential participants. Appropriate times for data collection will be agreed with participants. To minimise respondent burden, quick to administer measures have been selected. If the recruitment site routinely uses similar measures to the measures proposed for the project (e.g., rather than the FAST, they use the Aphasia Screening Test¹⁸), their measures will be used instead, to avoid duplication of information and to minimize respondent burden.

Informed consent: All eligible participants will be given information on the project face to face and in writing. In accordance with the Department of Health guidelines*, consent will be obtained in writing at least 2 days after information giving, in order to give time to the participants to absorb the information and make their decision¹⁹.

Data protection: Electronic records will be kept in a computer at City University, requiring a password to access. Hard copy data will be kept in a locked filing cabinet at City University. Identifying information will be stored separately from data, which will be filed by I.D. number only. Identifying information will be shredded following completion of the project.

6. Intended analysis

Gold standard methods^{13;14} will be used to evaluate the psychometric properties of the SAQOL-39. For further details, refer to section 4.5. on data analysis above.

* The Department of Health guidelines for good practice in consent primarily refer to consent to examination and treatment. Still, the authors indicate that "the same principles apply to consent in research as in clinical practice" .

7. Contribution to the development of health care practice/policy in the UK

In a recent report from the Health Foundation and the Nuffield Trust, ways of enhancing the contribution of health services research to improving services and policy making in the UK were explored²⁰. Three pertinent questions were raised: is research pursuing the right agenda? Is it examining the right questions in the right way? And are the results being communicated to and applied by the people who need them?

Pursuing the right agenda: this project directly relates to NHS directives on user involvement²¹ and evidence-based practice²². There is general consensus in the NHS that patients and carers are experts in their own conditions and they are becoming increasingly involved in treatment decisions²¹. Patients are the best informants about the ways in which illness affects what is important to them²³. The SAQOL-39 is both patient-based, i.e., the items of the questionnaire were generated through interviews with stroke survivors⁵, and patient-reported, i.e., the clients self-report on the measure. The SAQOL-39 is therefore a potentially important outcome measure for the evaluation of health related quality of life in stroke. It is well recognised that the effectiveness of interventions should be based on critical, objective and rigorous scientific evidence using a wide range of outcome measures²². This project will extend the existing evidence base for the SAQOL-39 and also provide new evidence on its responsiveness.

Addressing the question in the right way: section 4 on methodology and section 6 on intended analysis have demonstrated that the suggested project directly answers the research questions set, using appropriate methods.

Communicating the findings: we have adopted a dissemination strategy that puts emphasis on both rigorous scientific evidence and user-friendly presentation of findings (see section 8 on dissemination, below).

8. Dissemination strategy

The main findings of this work will be disseminated in a variety of outputs targeting different audiences:

- a. Findings will be published in high impact peer-reviewed journals with a multidisciplinary audience, e.g., *Stroke*
- b. Findings will be presented in a variety of professional conferences, e.g., the Patient Involvement, Empowerment and Information conference, the International Society for Quality of Life research conference and the National Service Delivery and Organisation conference
- c. Findings will also be published in journals read by stroke survivors and their carers/families, e.g., 'Stroke News' by the Stroke Association and 'Speaking Up' by Speakability
- d. Findings will be publicised through the C.H.A.I.N network, which specifically aims to break down barriers between research, clinical practice, education and the management of services.
- e. A study day will be organised to disseminate the findings to NHS service providers; stroke charitable organisations and patient groups. These groups will

also be involved in discussion on the further dissemination and use of the findings.

- f. A leaflet will be produced with the main findings for the participants of the study and the participating recruitment sites

By targeting a timely question, which puts emphasis on stroke patients' perspective and quality of life, in an appropriate way and by communicating the findings in effective ways, this project has the potential to contribute to the development of health care practice and policy in the UK.

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Central Office for Research Ethics Committees (COREC)

NOTICE OF SUBSTANTIAL AMENDMENT

For use in the case of all research other than clinical trials of investigational medicinal products (CTIMPs). For substantial amendments to CTIMPs, please use the EU-approved notice of amendment form (Annex 2 to ENTR/CT1) at <http://eudract.emea.eu.int/document.html#guidance>.

To be completed in typescript by the Chief Investigator and submitted to the Research Ethics Committee that gave a favourable opinion of the research ("the main REC"). In the case of multi-site studies, there is no need to send copies to other RECs unless specifically required by the main REC.

Further guidance is available in section 5 of our Standard Operating Procedures available at www.corec.org.uk/applicants/help/docs/SOPs.doc.

Details of Chief Investigator:	
<i>Name:</i>	Dr Katerina Hilari
<i>Address:</i>	Department of Language and Communication Science, City University, Northampton Square, London EC1V 0HB
<i>Telephone:</i>	██████████
<i>E-mail:</i>	████████████████████
<i>Fax:</i>	██████████

Full title of study:	Assessing health related quality of life after stroke
Name of main REC:	St Mary's NHS Trust LREC
REC reference number:	04/Q0403/109
Date study commenced:	Data collection at St Mary's commenced 10 January 2005
Protocol reference (if applicable), current version and date:	V2, May 13 th 2005
Amendment number and date:	Additions 1,2,3 (described in this form).

Type of amendment (indicate all that apply in bold)

(a) *Amendment to information previously given on the REC application form*

Yes No

If yes, please refer to relevant sections of the REC application in the “summary of changes” below.

(b) Amendment to the protocol

Yes **No**

If yes, please **submit either the revised protocol with a new version number and date, highlighting changes in bold, or** a document listing the changes and giving both the previous and revised text

(c) *Amendment to the information sheet(s) and consent form(s) for participants, or to any other supporting documentation for the study*

Yes **No: For the proposed amendments we will be targeting either subgroups of the original participants’ cohort or their carers. For this reason, we have not changed the original sheets, as the changes do not apply to all participants. We have created addendums to the information sheets and consent forms. These are being submitted. The original information sheet and consent form is also submitted for reference.**

If yes, please submit all revised documents with new version numbers and dates, highlighting new text in bold

Summary of changes

Briefly summarise the main changes proposed in this amendment. Explain the purpose of the changes and their significance for the study.

Supporting scientific information should be given (or enclosed separately) where the amendment significantly alters the research design or methodology, or could otherwise affect the scientific value of the study.

We are proposing 3 amendments, which are all *additions* rather than *changes* to the study protocol that has been already approved.

Addition 1: Comparison of interview administration of SAQOL-39 with postal and telephone administration

In the existing study the questionnaire Stroke and Aphasia Quality of Life scale (SAQOL-39) is administered to all participants in an interview format and its test-retest reliability is tested on a subgroup of 30 people. We are planning to ask two further subgroups of about 30 participants to have the SAQOL-39 administered twice, but this time the second time it will be a phone interview or a postal version.

Purpose and significance of addition: Information on the performance of the SAQOL-39 under different modes of administration can inform clinicians and researchers on the best mode to use in different circumstances. It also informs the interpretation of results of studies using different modes of administration of the SAQOL-39.

Supporting scientific information: Different modes of administration have different advantages and disadvantages. Postal questionnaires are cheaper, large numbers can be completed more quickly and interviewers do not have to be recruited and trained (Smeeth et al., 2001). Live interviews have higher response rates and less missing data (Bowling, 1997) and also allow for facilitation of people with language problems (e.g., aphasia following stroke, as in the current study). Telephone interviews are somewhere in the middle, with higher response rates than postal questionnaires in stroke participants (Duncan et al., 2005) and being cheaper than live interviews.

We wanted to draw these comparisons from the beginning of this study. However, we did not know whether we would have the resources and time to carry out the extra interviews and therefore we did not include it in the original proposal. Having completed 4 months of data collection on the project, we now know that a) it is feasible for us to undertake this extra work and b) as a preliminary exploration we have asked some participants whether they would be willing to have the SAQOL-39 administered twice in a different mode at a later stage, and they all said yes.

Addition 2: exploration of social support using qualitative techniques in the chronic stage post stroke

In the existing study stroke participants are asked at baseline (about 2 weeks after their stroke) about their pre-morbid social support and social networks, and then interviewed again to monitor changes at 3 and 6 months post stroke. We are planning to follow up a selected subset of this population in the chronic stage (around 9-12 months post stroke) and re-administer the social support questionnaires as well as carry out an in-depth qualitative interview.

Purpose and significance of addition:

Following people up in the chronic stage will allow us to understand better the long-term social impact of stroke. Using qualitative techniques will help us to interpret the quantitative data collected and provide insight into social support needs and the processes involved in changing patterns of support.

Supporting scientific information:

Researching social support after stroke in more depth is a topical area. Evidence suggests that the social consequences of having a stroke can

be severe: there is often a significant reduction in social activities, and contact with the wider social network is vulnerable (Astrom et al., 1992; Greveson and James, 1991). Reduced social support following stroke is associated with poor life satisfaction and worse functional outcomes (Glass and Maddox, 1992; Wyller et al., 1998). Indeed, supporting people with the long-term social consequences of stroke has been identified as a key element in implementing the National Service Framework for Older People (Department of Health, 2004).

Our proposed addition to our study will add the following in this area of literature: a) a qualitative perspective to complement the quantitative data; and b) a longer-term (1 year post stroke) perspective.

Carrying out in-depth qualitative interviews in this population is a methodology shown to be useful for exploring participants' experiences and perspectives (Parr et al., 1997). We will be able to compare detailed qualitative information with longitudinal quantitative information, which may provide new insights in this area.

Adding a longer term data collection point (beyond 6 months) will also provide further useful information. Firstly, research has suggested that during the first year post-stroke, many people are still hoping to make a full recovery. It seems that it is often only in this chronic stage that they begin to realise the long-term consequences of their disability (Dowswell et al., 2000). There is also suggestion in the literature that support needs change with time over this first year (Glass and Maddox, 1992; Robinson et al., 1999). Extending the timeframe of the project would allow us to unpick the changing needs of people and the evolving roles of different types of support.

Lastly, this extension to the study will allow us to compare in detail the social support experiences and needs of people with aphasia, who have been neglected in previous research, to those of the general stroke population.

Addition 3: exploration of the well-being of partners/carers of people with stroke

Purpose and significance of addition: The current study looks at the impact of stroke on the stroke survivors. There is strong evidence in the literature that stroke also has a considerable impact on the informal carers of stroke survivors. Initially we considered this beyond the scope of the current study. We now think it would be useful to collect information on the health and well-being of the carers and the factors affecting it across time, not only because of its scientific merit (see below) but also because of practical considerations.

With regard to the latter, during our data collection, we have found that carers of our participants are particularly keen to be involved in our research and share with us their feelings and views. It seems a missed opportunity not to

systematically collect information that is willingly available. Moreover, another consideration is the following. While the stroke participants are in hospital we carry out our interviews with them on a one-to-one basis. However, we have noticed that in the 3-month data collection point, when most participants are at home, their carers want to sit in during the interviews. This can influence the stroke participants' responses on the questionnaires we are using in the current study (particularly on emotional well-being, availability of social support and satisfaction with social network). Asking their carers during these interviews to fill-in questionnaires on their own well-being would not only increase the scientific value of the current study, but also address this issue.

Supporting scientific information: Two systematic reviews on the impact of stroke on informal carers have demonstrated that they show elevated levels of depression (Han et al., 1999; Low et al., 1999). Both reviews have identified significant gaps in the literature, with few studies evaluating the effectiveness of service provision or caregiver interventions; addressing caregivers overall health –rather than just psychological health- and quality of life; and employing a longitudinal/ repeated measures design rather than a cross-sectional design. With the proposed addition to our study, we will be addressing these issues (see research proposal), except for evaluating service provision, which has received attention in recent literature (e.g., Mant et al., 2000; Foster et al., 2001; Karla et al., 2004; Patel et al., 2004).

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Any other relevant information

Applicants may indicate any specific ethical issues relating to the amendment, on which the opinion of the REC is sought.

The proposed amendments do not add any ethical issues to this project. Ethical issues have been considered in the original REC form and the original research proposal (seen also in the version with amendments which is now submitted with this application form).

List of enclosed documents

- Research proposal for 04/Q0403/109 with AMENDMENTS
- Addendum 1 info and consent form for 04Q0403109
- Addendum 2 info and consent form for 04Q0403109
- Addendum 3 info and consent form for 04Q0403109
- And also, for reference, the original information and consent form:
Pt info sheet and consent for 04Q0403109

Declaration

- I confirm that the information in this form is accurate to the best of my knowledge and I take full responsibility for it.
- I consider that it would be reasonable for the proposed amendment to be implemented.

Signature of Chief Investigator:

Print name: KATERINA HILARI

Date of submission: 17 May 2005

Appendix 3

Patient information sheet and consent form Stage One (repeated measures cohort study)

Quality of life after stroke

Research Project

Information sheet

You are being invited to take part in a research study. Before you decide, it is important to understand why we are doing this research and what it involves.

- Please read this information carefully and discuss it with others if you wish.
- Ask us if there is anything that is not clear.
- Take time to decide whether you wish to take part.

Thank you for considering this.

If you want to talk to somebody about this project, please contact:

Dr Katerina Hilari

Chief Investigator

Tel: [REDACTED]

Or

Ms Sarah Northcott

Research Assistant

Tel: [REDACTED]

What is the purpose of the study?

This is a 3-year study that will look at how people are affected by stroke. Most stroke studies have concentrated on how stroke affects people's physical abilities.

This study focuses on the **impact of stroke on people's lives**. It looks at:

- Your **physical health**
- **Activities** that you do
- **Emotions** and **feelings**
- **Family** and **social life**.

We will also look at **how these change** with time and rehabilitation after stroke.

We have developed a **new questionnaire** that looks at all these. It is called **SAQOL-39** (Stroke and Aphasia Quality of Life scale).

We want to see how good this measure is in capturing the important **effects of stroke on your life**.

Why you?

We are looking for people who had a **first ever stroke**. We aim to see about 150-200 people for this study.

Taking part

Taking part in this study **is entirely voluntary**. It is up to you to decide if you want to take part or not.

If you take part, you have the **right to withdraw** at any time.

Withdrawing or not taking part **will NOT affect your normal care**.

Benefits

Taking part in this study will have no direct benefits to you.

Your taking part, will help us **understand better how to assess the broader impact of stroke** on people's lives.

The information we get **may help us treat future stroke patients better**.

What the project involves

If you decide to take part, you will be asked to **sign a consent form**.

If you consent to take part the researcher will look at your **medical notes**.

Then the researcher will **interview** you **3 times**:

- About **2 weeks** after your stroke
- **3 months** after your stroke
- **6 months** after your stroke.

The interview

In each interview you will be asked to complete some **questionnaires** and **tests** on **areas that may be affected by stroke**:

- Physical abilities
- Communication
- Activities
- Emotions and feelings
- Social life
- Social support

Each interview will take about **45 minutes**.

If you get **tired**, we will **stop** and start again **later** or on **another day**.

When and where

The researcher will arrange a **convenient time** with you.

The researcher will come and see you where you are:

- In hospital
- At an outpatient appointment
- At home

Potential risks of taking part

Taking part poses **NO risks** to your health and well-being.

Who else will be involved?

The researcher will **inform your clinical team** in hospital and, with your permission, **your GP** that you are **taking part** in the study.

If you **find it hard to talk** or **to remember things**:

- ⇒ the researcher may get **information about you** from a **person who knows you well** e.g., your spouse/partner, one of your children, a close friend.

If you are happy with this, please name a person: _____

Confidentiality

All information which is collected about you during this research will be kept **strictly confidential**.

When we take your data out of the hospital, your **name and address** will be **removed** from it.

NB: During this research, we may find that you have **difficulties** that you and/or your clinical team and/or GP were **unaware of**. For example, we may find that some people may suffer from depression after their stroke.

The researcher will only **reveal this information** to others **with your consent**.

What will happen to the results

The results will be available in 2007. **You will be sent a report** of our main findings.

We will **publish** our findings in journals and **present** them in **conferences**.

Your name will not be used at any time.

Other information

This study has received ethical approval from St Mary's NHS Research Ethics Committee.

This study is funded by the Consortium for Healthcare Research of the Health Foundation.

You will be given a copy of the information sheet and your consent form.

Quality of life after stroke

Research Project

Consent form

Study number: 04/Q0403/109
Name of researcher:

Participant ID number:

Please initial box

1. I confirm that I **understand** the information sheet dated October 2004 (v3) for the above study and have had the opportunity to ask questions

2. I understand that my participation is **voluntary** and I can **withdraw** at any time, without my medical care or legal rights being affected

3. I understand that sections of my **medical notes** may be looked at by the researchers named at the front of the information sheet. I give permission for them to have access to my records.

4. I agree to take part in the above study

Name of participant

Date

Signature

Name of researcher

Date

Signature

Thank you for agreeing to take part

1 for participant; 1 for researcher; 1 for hospital notes

Appendix 4

Patient information and consent form Stage Two (qualitative interviews)

**Quality of life after stroke
Research Project**

**Addendum 2 (Social Support) to
Information sheet and Consent form: V3 October 2004
Study number: 04/Q0403/109**

Information for stroke participant

An extra aim of this project is to find out more about how you are in the **long term after the stroke** (9-12 months). In particular, we want to find out about your **social support** (friends, family, social activities) and how this is affected by having a stroke. The information we get may help us to **support future stroke patients better**.

If you decide to take part, we will visit you **about a year** after you had the stroke. We will organise a **convenient time and place** with you (for example, your own home). The interview will take about **one hour**. If you get **tired**, we can **stop** and start again later or on another day.

We will ask you to complete again the questionnaires on social support, social networks, and how you are feeling generally, that you have already completed for this study. We will also talk to you **more informally** about your friends, family and social activities. We want to get **your perspective** on how life has changed after the stroke, and what kind of social support is important to you.

In you want further information on this project, you can contact Sarah Northcott on 020 7040 3206.

Consent

Please tick box

- | | |
|---|--------------------------|
| 1. I confirm that I understand the above information and have had the opportunity to ask questions | <input type="checkbox"/> |
| 2. I agree to take part in the above study | <input type="checkbox"/> |
| 3. All other conditions of my original consent apply (e.g., confidentiality, right to withdraw) | <input type="checkbox"/> |

Name of participant

Date

Signature

Name of researcher

Date

Signature

Thank you for agreeing to take part

Appendix 5

Scoring forms for measures used in repeated measures cohort study

Medical Outcomes Study Social Support Survey (SSS)

Stroke Social Network Scale (SSNS)

General Health Questionnaire-12 (GHQ)

Barthel Index (BI)

Frenchay Activities Index (FAI)

Frenchay Aphasia Screening Test (FAST)

National Institute of Health Stroke Scale (NIHSS)

The full text of this article has been removed for copyright reasons

Appendix 6

Stroke Social Network Scale: development and psychometric evaluation of a new patient-reported measure

Northcott S and Hilari K. Stroke Social Network Scale: development and psychometric evaluation of a new patient-reported measure. *Clinical rehabilitation*.

Date of Electronic Publication: April 2013

**The full text of this article has been
removed for copyright reasons**

Appendix 7

Topic guide used in qualitative interviews

The role of social support after a stroke

Objectives:

- To explore different types of social support and their role in adjusting to life after a stroke
- To explore beliefs and expectations surrounding friendships, family and the wider social network, noting changes that have arisen following the stroke
- To understand which types of social support and relationships may be vulnerable following a stroke, and gain insight into possible protective factors
- To understand how different factors influence patterns of social support and also support needs (factors include: aphasia; age; gender; severity of stroke; pre-morbid social networks; ethnicity)
- To explore whether support needs vary with time following a stroke (ie comparing support needs in the acute, sub acute and chronic stages post stroke)

Pre-interview

- Consent form; Tape recording

Introduction

Thank you – appreciate time etc

Reassurances – confidential; if feel uncomfortable at any stage

Time – 1 to 1½hours

No right or wrong answers. I'm just interested in hearing their perspective.

Background to project: Joint between City University and St Mary's hospital. Hope it will help us to improve stroke services in the future.

Aims of project: to find out about the role of social support after a stroke; will ask questions about friends, family and others in their social network

1. Present Circumstances

'Helpful to just start with some background information.'

- When had the stroke
- Length of stay in hospital (incl if they went to rehabilitation wards, when came home etc)
- Living situation
 - who with
 - length of time lived there
- Work
 - before and after stroke
- Group memberships
- Family structure
 - Children
 - ages
 - marital status
 - if have children
 - proximity
 - Relatives
 - Partner
 - confirm details are correct

2. Current social contacts

I'd like now to get a picture of your life, and find out who you see and what you do with them in a typical week.

2.1. Over last week

So over this last week, can you remember

- Who seen
- Telephone, email, letter contact (what about people you spoke to over the telephone...)

Researcher to map out social contacts mentioned

2.2 Discussion about each social contact

[‘So you said you saw X, can you tell me a little bit more about what you did together?’]

- What they did together/ where
- What talked about
- How arranged (prearranged, who initiated contact)
- Regularity/ frequency of contact

2.3 Checks

- How typical - check week described was typical. In what way was it not typical? What would be more typical? Anybody you normally see that you haven’t seen?
- Important relationships not mentioned

Checklist of contacts:

- | | | |
|--------------------|---------------|--|
| 1) Partner | 4) Friends | 7) Acquaintances |
| 2) Children | 5) Groups | 8) Other (eg professionals, shopkeepers, volunteers) |
| 3) Other relatives | 6) Neighbours | |

3. Changes since stroke

‘I’d like to think now a little about your life before the stroke.’

3.1 Changes to typical week

- In terms of week just described – the same as before the stroke? Ways in which different?

- Missing people: Who seen – any people now missing? ‘Are there people you used to see, but don’t see any longer?’
- People still seen: any changes?
 - Frequency
 - Where seen
 - How arranged/initiated
 - What they do/activities
 - What talked about

(Reflections on change incl. causes for change)

Prompts: ‘other people have mentioned various things which they feel have changed how much they want to see others’:

- Energy levels
- Mobility
- Feeling ‘down’

Possible issues:

- | | | |
|--------------------------------------|--|---------------|
| 1) Reciprocity | 4) Ability to share activities/experiences | 7) Depression |
| 2) Expectations (extent met) | 5) Ability to travel after the stroke | 8) Disability |
| 3) Points of anxiety/conflict | 6) Increased support needs | 9) Pain |

4. Importance of members in network

4.1 Friends - General

'I'd like now to talk more about friendships'

What has happened to your friendships since the stroke?

4.1.2 The 'good' friend

- **Name** (eg 'Think of a really good friend' Someone you feel is particularly important to you/you feel particularly close to)
- **Description** of a 'friendly' act (eg 'Tell me about a particular time or occasion or conversation, that illustrates why they are a good friend')
- **Attributes** of a good friend (eg 'What makes them a good friend?' 'What's important in a friendship?')
- **Changes** since the stroke (and reasons for changes)

4.1.3 The 'lost' friend

- **Name** (eg 'Now think of a friend that you feel less close to after the stroke')
- **Reasons** for estrangement (eg 'Why do you think you have become less close?')
- **Meaning** attached to this (eg 'How do you feel about this?')

Anyone they still see, but now different?

[nb: if they have maintained all their friendships, discuss why this is the case, protective factors etc]

4.1.4. What do their friends give them?

4.2. Family

4.2.1. General:

What has happened to your relationships with your family since stroke?

- **Close family member:** Family member they feel close to. What makes them feel close?
- **Family member less close to since the stroke.**

4.3 Friends versus family

- What friends versus family 'give' them
- **Role** of friends versus family in adjusting to life after a stroke
- **Expectations** of friends versus family (what friends provide that family don't and vice versa)

4.4. Wider social network

Talked about friends and family. What about the wider social network, acquaintances etc. What does that give you?

5. Types of support

Now various people have written about social support. Various types. Run them past you to get your thoughts on them.

- **Source** (eg Who gives them this type of support; Who do they get X support from?)
- **Role in adjusting to stroke** (eg has this kind of support been helpful since the stroke? what role do they feel this kind of support has had since their stroke)
- **Meaning** (eg What does this kind of support mean to them?)
- **Sufficiency** (eg do they feel they have amount of support they need? Do they get enough of it?)
- **Temporal** – was there a particular time since the stroke when this type of support was particularly important to you?

Definitions of different types of support

1. Emotional support

(feeling there is someone you can confide in and talk to about what's worrying you, feeling that there is someone who will understand and will listen sympathetically)

2. Practical support

(feeling that there is someone who can help with practical things, for example, if you were feeling unwell, they could help with daily chores, or get your shopping)

3. Social companionship

(feeling that there is someone you can relax with, that seeing them will take your mind off things, that you can have a good time together)

4. Informational support

(feeling there is someone who will give you advice or useful information)

5. Any other types?

(eg. 'Are there any other types of support that I haven't mentioned, but that you feel are important?')

Additional areas to explore:

- **Role of friends and family in recovering from a stroke?** Adjusting to life after a stroke?
- **Support not received.** (Any sort of support that you **didn't** receive that would have been helpful?)
- **Unhelpful support.** (Any kind of support that you found **unhelpful**? Eg unwanted advice, unwanted practical support)

Support from **professionals, charities** and other organizations

7. Suggestions/learning from their experience

Sign post coming to end of interview

7.1 Advice

- To someone who's just had a stroke (in terms of social support)
- To the friends and relatives of someone who's just had a stroke

7.2 Further comments

- Eg Anything else about friends, family, your social network, that we haven't mentioned today, but which they feel is important?
- What would you say really helped in terms of support from family and friends after the stroke?

Provision of any relevant information (eg local or national services)
Reassurances about confidentiality, what will happen next
Thank yous!

Appendix 8

Thematic index used for indexing data

Index

‘The role of social support after a stroke’; Sarah Northcott (17.10.07)

1. Background Details

- 1.1 When had stroke(s); nature of stroke/ complications
- 1.2 How long in hospital/rehab, other investigations while in hospital
- 1.3 About where they live now
- 1.4 About where they have lived; about home and place
- 1.5 Ethnicity/Religion
- 1.6 Health of significant others
- 1.7 Other

2. Family

- 2.1 Description of family relationships: family structure; meaning; logistics (contact during past/typical week, where seen, how arranged, what do together)
- 2.2 Changes (or not) since the stroke (and how feel about changes, reasons for changes)
- 2.3 Non stroke reasons for change
- 2.4 Support received; what was helpful/unhelpful; how help initiated/negotiated; limiting/facilitative factors
- 2.5 How family different from ‘outsiders’; expectations of family
- 2.6 Other

3. Friends and other social contacts

- 3.1 Description of friendships and other social contacts (incl. logistics)
- 3.2 Changes (or not) since the stroke (feelings, reasons)
- 3.3 Non-stroke reasons for not seeing a friend/ changes to social contacts
- 3.4 Support received; what was helpful/unhelpful; how help initiated/negotiated; limiting/facilitative factors
- 3.5 Thoughts on what makes a good friendship, what keeps a friendship going (and why less close to some)
- 3.6 Expectations of friends and others
- 3.7 Other

4. Professional involvement

- 4.1 Paid carer
- 4.2 Medical (Drs, AHP, OP appts, NHS in general)
- 4.3 Social services
- 4.4 Religious person (eg priest)
- 4.5 Day Hospital, Day Centres, Stroke Groups etc
- 4.6 Other

5. General views and attitudes towards support (about contact with other people, but not person specific)

- 5.1 What helps; how help initiated/negotiated
- 5.2 What doesn't help
- 5.3 About support, social contact and social network (incl. change)
- 5.4 Different modes of social contact (telephone, letter, email etc)
- 5.5 Role of others in getting better (or not) after stroke
- 5.6 Lack of support/feeling alone
- 5.7 Satisfaction with support; how feel about help received, or not received
- 5.8 Other

6. Being Ill

- 6.1 What a stroke is; suspected causes
- 6.2 Symptoms of the stroke incl. aphasia, fatigue, cognitive change (consequences, feelings, compensation strategies)
- 6.3 Experience of hospital (in patient) and leaving hospital; early days post stroke
- 6.4 Progress /thoughts and hopes about future progress; thoughts about rehab process
- 6.5 Other physical problems (and interplay with stroke)
- 6.6 Thoughts on future illness and possible future support needs
- 6.7 Other

7. Identity

- 7.1 How I feel about the stroke; the 'story' of the stroke
- 7.2 What I think about myself, and how I am (pre and post stroke); reflections on life, death and meaning; depression, increased emotion and other feelings caused by stroke
- 7.3 On 'being normal'
- 7.4 What I think about others who are sick and/or old (and how they compare to me)
- 7.5 Other people's attitude to stroke, illness and aphasia (general)
- 7.6 Other people's attitude to *my* illness; telling them I am sick (or choosing not to)
- 7.7 Independence and wanting to do things on own; privacy; how it feels to receive/ give help; feeling obliged, a burden etc.
- 7.8 My role in my own recovery; what I do that helps (when not related to other people)
- 7.9 Other

8. Life before and after the stroke

- 8.1 Work (before and after the stroke)
- 8.2. Changes to lifestyle/activities
- 8.3 Description of life now
- 8.4 Description of life before the stroke
- 8.5 Other

9. Other

- 9.1 Mop up (possibly significant)
- 9.2 Not relevant
- 9.3 Incomprehensible
- 9.4 Mop up of spouse comments
- 9.5 Other

Appendix 9

Example Chart

Chart 2: Family

**This content has been removed for data
protection reasons**

Appendix 10

Example presenter's forms

Social Support Survey Presenter's form

Stroke Social Network Scale Presenter's form

MOS Social Support Survey

Sherbourne & Stewart (1991)

Sometimes we look to others for companionship, assistance or other kinds of support.

We would like to know:

- **If you need** companionship or assistance...
- **How often** is it available to you?

For example:

Someone to cook for you if you were sick ?
--

None of the time	A little of the time	Some of the time	Most of the time	All of the time
-------------------------	-----------------------------	-------------------------	-------------------------	------------------------

Point to the box that applies to you.

How often is this support available to you if you need it?

1	Someone to help you if you were confined to bed?
2	Someone you can count on to listen to you when you need to talk?
3	Someone to give you good advice about a crisis?
4	Someone to take you to the doctor if you needed it?

None of the time	A little of the time	Some of the time	Most of the time	All of the time
-------------------------	-----------------------------	-------------------------	-------------------------	------------------------

How often is this **support** available to you **if you need it**?

5	Someone who shows you love and affection ?
6	Someone to have a good time with?
7	Someone to give you information to help you understand a situation ?
8	Someone to confide in or talk to about yourself or your problems ?
9	Someone who hugs you ?

None of the time	A little of the time	Some of the time	Most of the time	All of the time
-----------------------------	---------------------------------	-----------------------------	-----------------------------	----------------------------

How often is this **support** available to you **if you need it?**

10	Someone to get together with for relaxation?
11	Someone to prepare your meals if you were unable to do it yourself?
12	Someone whose advice you really want?
13	Someone to do things with to help you get your mind off things?
14	Someone to help you with daily chores if you were sick?

None of the time	A little of the time	Some of the time	Most of the time	All of the time
-----------------------------	---------------------------------	-----------------------------	-----------------------------	----------------------------

How often is this support available to you if you need it?

15	Someone to share your most private worries and fears with?
16	Someone to turn to for suggestions about how to deal with a personal problem ?
17	Someone to do something enjoyable with?
18	Someone who understands your problems ?
19	Someone to love and make you feel wanted ?

None of the time	A little of the time	Some of the time	Most of the time	All of the time
-------------------------	-----------------------------	-------------------------	-------------------------	------------------------

Stroke Social Network Scale

Northcott and Hilari (2013)

Friends and Family

In the **past month ...**

1. Are you

Single	Married	Have partner	Widowed	Divorced

2. Who are you living with?

Children

How many?

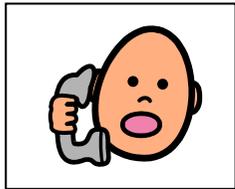


In the **past month**, how often did you **see** your children?

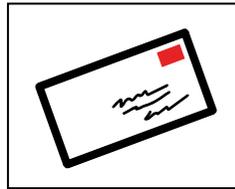
Every day	2 or 3 times a week	At least once a week	2 or 3 times in the month	About once in the month	Not at all

Children

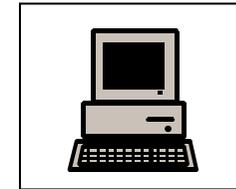
In the **past month**, how often were you **in contact** by



Telephone



Letter



Email?

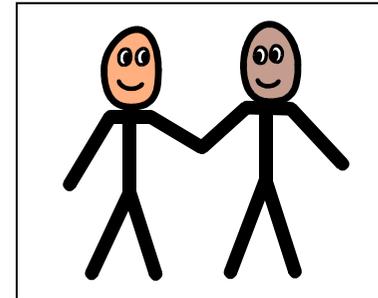
Every day	2 or 3 times a week	At least once a week	2 or 3 times in the month	About once in the month	Not at all

Children

How **satisfied** were you?

						
6 – very satisfied √√√	5 – fairly satisfied √√	4 – a little satisfied √	3 – a little dissatisfied X	2 – fairly dissatisfied XX	1 – very dissatisfied XXX	

Friends



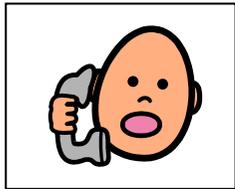
How many?

In the past month, how often did you see your friends?

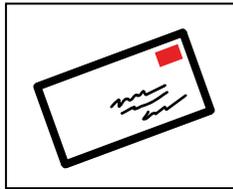
Every day	2 or 3 times a week	At least once a week	2 or 3 times in the month	About once in the month	Not at all

Friends

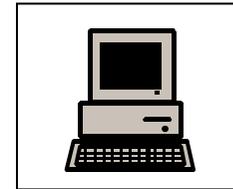
In the **past month**, how often were you in contact by



Telephone



Letter



Email?

Every day	2 or 3 times a week	At least once a week	2 or 3 times in the month	About once in the month	Not at all

Friends

How **satisfied** were you?

	6 -	5 - fairly satisfied	4 - a little satisfied	3 - a little dissatisfied	2 - fairly dissatisfied	1 -	
very satisfied √√√	very satisfied √√√	5 - fairly satisfied √√	4 - a little satisfied √	3 - a little dissatisfied X	2 - fairly dissatisfied XX	1 - very dissatisfied XXX	

Relatives

How many?

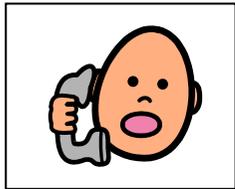


In the **past month**, how often did you **see** your relatives?

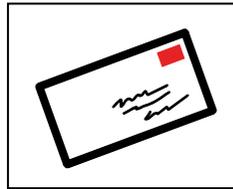
Every day	2 or 3 times a week	At least once a week	2 or 3 times in the month	About once in the month	Not at all

Relatives

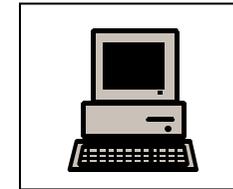
In the **past month**, how often were you in contact by



Telephone



Letter



Email?

Every day	2 or 3 times a week	At least once a week	2 or 3 times in the month	About once in the month	Not at all

Relatives

How **satisfied** were you?

					
6 – very satisfied √√√	5 – fairly satisfied √√	4 – a little satisfied √	3 – a little dissatisfied X	2 – fairly dissatisfied XX	1 – very dissatisfied XXX

Neighbours

In the **past month**, how often did you **have a chat** with a neighbour?

Every day	2 or 3 times a week	At least once a week	2 or 3 times in the month	About once in the month	Not at all

Neighbours

How **satisfied** were you?

						
6 – very satisfied √√√	5 – fairly satisfied √√	4 – a little satisfied √	3 – a little dissatisfied X	2 – fairly dissatisfied XX	1 – very dissatisfied XXX	

Groups

Do you **belong to any groups?**

How active are you?

Very active	Fairly active	Not active (belong but hardly ever go)	Do not belong to any groups

Examples of groups:

Political parties, trade unions, environmental groups

Neighbourhood: Tenants groups, residents' groups, Neighbourhood Watch

Religious: Church or other religious groups, charitable groups

Education, arts, or music groups, evening classes

Social clubs (eg Rotary club, Women's Institute)

Sports clubs, gyms, exercise classes

Other groups or organisations

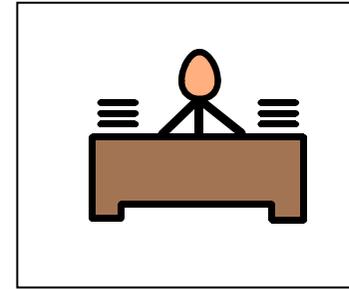
Work

Paid work:
(Full time/part-time)

Voluntary work:

Retired:

No work: (housewife, other)



Proximity (how near is...)

How far away does your nearest child or close relative live?

No relatives	Same house/ within 1 mile	1-5 miles	6-15 miles	16-50 miles	50+ miles

How many of your close friends live nearby (within 5 miles)

None of them	Some of them	Most of them	All of them

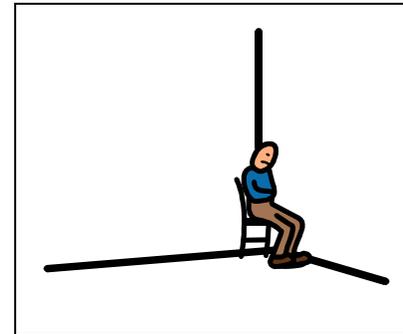
Satisfaction

How satisfied are you **overall** with your social network?

	<p>6 – very satisfied √√√</p>	<p>5 – fairly satisfied √√</p>	<p>4 – a little satisfied √</p>	<p>3 – a little dissatisfied X</p>	<p>2 – fairly dissatisfied XX</p>	<td data-bbox="1854 576 2051 730">  </td> <p>1 – very dissatisfied XXX</p>	

Loneliness

How often do you feel lonely?



5 – never lonely	4- lonely a little of the time	3 – lonely some of the time	2 – lonely most of the time	1 – lonely all of the time

Appendix 11

**Patient information sheet, adapted for people
with aphasia**



School of Allied Health Sciences

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Head of Department

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www.city.ac.uk

Quality of life after stroke
Research Project

Information sheet

You are being invited to take part in a **research study**.

Before you decide, it is important to **understand why** we are doing this research and **what it involves**.

- Please read this information carefully and **discuss it** with others if you wish.
- **Ask us** if there is anything that is not clear.
- **Take time** to decide whether you wish to take part.

Thank you for considering this.

If you want to talk to somebody about this project, please contact:

Dr Katerina Hilari

Chief Investigator

Tel: [REDACTED]

Or

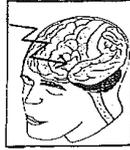
Ms Sarah Northcott

Research Assistant

Tel: [REDACTED]

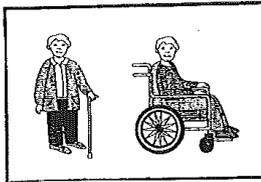
What is the purpose of the study?

This is a 3-year study that will look at how people are affected by **stroke**.



This study focuses on the **impact of stroke on people's lives**. It looks at:

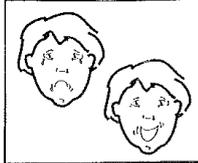
- Your **physical health**



- **Activities** that you do



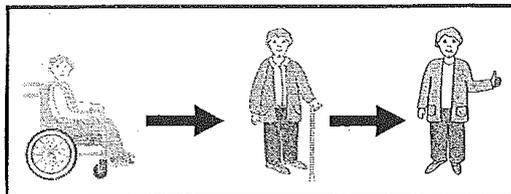
- **Emotions and feelings**



- **Family and social life.**

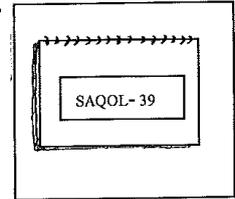


We will also look at **how these change** with time and rehabilitation after stroke.



We have developed a **new questionnaire** that looks at all these. It is called **SAQOL-39** (Stroke and Aphasia Quality of Life scale).

We want to see **how good this measure is** in capturing the important **effects of stroke on your life**.



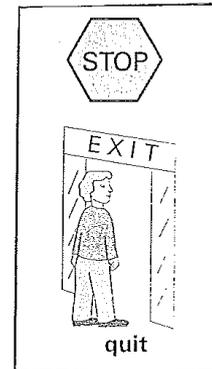
Why you?

We are looking for people who had a **first ever stroke**. We aim to see about 150-200 people for this study.

Taking part

Taking part in this study is **entirely voluntary**. It is **up to you** to decide if you want to take part or not.

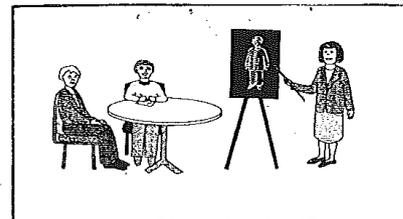
- If you take part, you have the **right to withdraw** at any time.
- It is **OK to stop**
- Stopping will **NOT affect your normal care**.



Benefits

If you decide to take part in this project, you will:

- help us **understand better** how to assess the broader **impact of stroke** on people's lives.
- help us **treat future stroke patients better**.

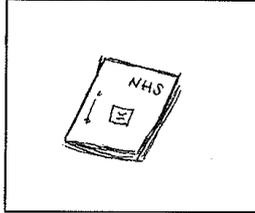


This is **NOT therapy**. Taking part in this study will have no direct benefits to you.

What the project involves

If you decide to take part, you will be asked to **sign a consent form**.

If you consent to take part the researcher will look at your **medical notes**.



Then the researcher will **interview** you **3 times**:

- About **2 weeks** after your stroke
- **3 months** after your stroke
- **6 months** after your stroke.



January



July



February



August



March



September



April



October



May



November



June



December

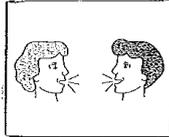
The interview

In each interview you will be asked to complete some **questionnaires** and **tests** on **areas that may be affected by stroke:**

- **Physical** abilities



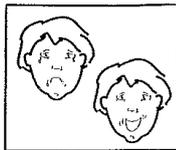
- **Communication**



- **Activities**



- **Emotions** and feelings

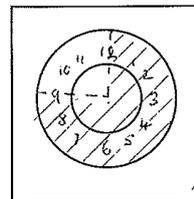


- **Social life** and social support

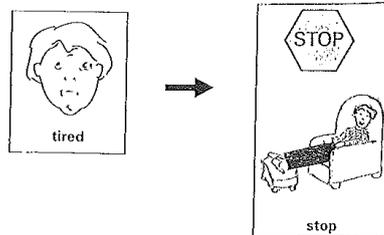


How long?

Each interview will take about **45 minutes**.



If you get **tired**, we will **stop** and start again **later** or on **another day**.

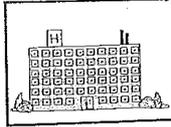


When and where

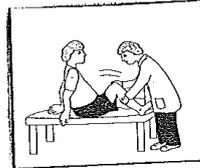
The researcher will arrange a **convenient time** with you.

The researcher will come and see you where you are:

- In **hospital**



- At an **outpatient appointment**



- At **home**

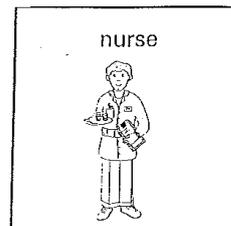
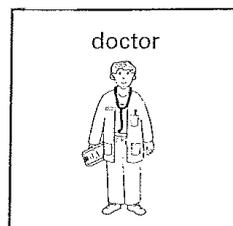


Potential risks of taking part

Taking part poses **NO risks** to your health and well-being.

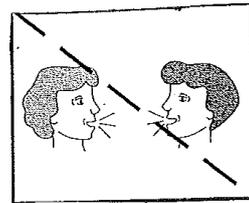
Who else will be involved?

The researcher will **inform your clinical team** in hospital

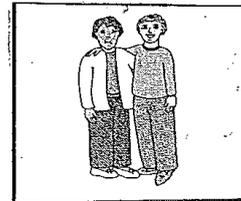


and, with your permission, **your GP** that you are **taking part** in the study.

If you **find it hard to talk** or **to remember things**:



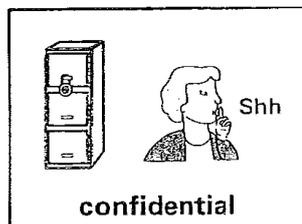
the researcher may get **information about you** from a **person who knows you well**
(e.g., your partner, one of your children, a friend).



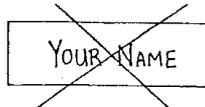
If you are happy with this, please name a person: _____

Confidentiality

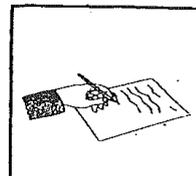
All information which is collected about you during this research will be kept strictly **confidential**.



When we take your data out of the hospital, your **name and address** will be **removed** from it.



NB: With **your permission**, we can tell your **GP** or medical team **how you did**.
The researcher will only **reveal this information** to others **with your consent**.



What will happen to the results

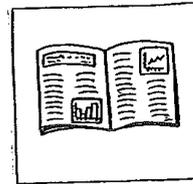
The results will be available in 2007.

- We will **send you a report** of our main findings.

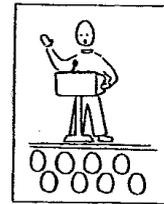


We will also:

- **Publish** our findings in **journals**



- **Present** them in **conferences**.



Your name will **not be used** at any time.



Other information

This study has received **ethical approval** from St Mary's NHS Research Ethics Committee.

This study is funded by the Consortium for Healthcare Research of the Health Foundation.

You will be **given a copy** of the information sheet and your consent form.



Appendix 12

**Topic book used with people with aphasia
during qualitative interviews**

Social support after a stroke

What to expect today:

- Informal
- Your story
- Confidential
- Tape recording

Background details

The stroke

- 🌐 **When** did you have your stroke?
- 🌐 **How long** were you **in hospital**?

Your home

- 🌐 **Where** do you live?
- 🌐 **How long** have you lived here?
- 🌐 **Who** do you live with?

Work

- 🌐 **Before** the stroke
- 🌐 **After** the stroke

Last week

1. **Who** did you see?

Where did you see them?

What did you do?

Do you see them **regularly**?

2. What about

Telephone?

Letter?

Email?

3. Was this a **typical** week?

Who else do you see normally?

Checklist – people

- Family
 - partner
 - children
 - brothers & sisters
 - parents
 - relatives (eg nephews, cousins)

- Friends

- Groups (eg Stroke Group)

- Neighbours

- Professionals
 - Doctors & Nurses
 - Social workers
 - Speech therapists
 - Physiotherapists
 - Occupational therapists

- Other
 - eg shopkeepers, café owners

Checklist - Places

- 🌐 Home
- 🌐 Other people's homes
- 🌐 Work
- 🌐 Going out
 - pubs
 - café or restaurant
 - theatre or cinema
 - clubs
- 🌐 Religion
 - church
 - mosque, synagogue, other
- 🌐 Groups
 - eg Stroke Group, Women's Institute
- 🌐 Hobbies
 - eg sports, evening classes, shopping
 - arts and music groups

Checklist – what you do

- 🌐 Talk
- 🌐 Have a coffee
- 🌐 Have something to eat
- 🌐 Go out
- 🌐 Do an activity together

How regular?

- 🌐 Regular
- 🌐 Not regular

How often?

- 🌐 **More** than once a week
- 🌐 About **once a week**
- 🌐 About **2 or 3 times a month**
- 🌐 About **once a month**
- 🌐 **Less** than once a month

Changes since the stroke

🌐 Who you see:

People you **don't see** now

People you see **less** now

People you see **more** now

What is
different?

🌐 Other differences:

Where you see people

What you do

What you **talk about**

Causes – why are things different?

Checklist:

- 🌐 Difficulty **talking**
- 🌐 Less **energy**
- 🌐 Difficulty **walking**
- 🌐 Feeling **depressed** or sad

Friends

What has happened to your friends (since your stroke)?

🌐 A 'good' friend

What makes them a good friend?

A 'good' friend

- 🌐 **Kind**
- 🌐 Understand me
- 🌐 Thoughtful
- 🌐 Give **practical** help – eg buy me a newspaper
- 🌐 **Fun** – we can joke
- 🌐 **Share things** – eg activities, interests, joint friends
- 🌐 Gossip!

Friends

● Any **changes** since the stroke?

Changes to friendships:

- They come here now
- **Less spontaneous**
- They do more things for me
- I see them **less**
- I'm **more passive** now
- It's **harder to join in** conversations
- I **can't joke**
- Harder for them to **understand**
- Less in common

A 'lost' friend

Someone you feel **less close** to

Why?

Reasons for 'losing' a friend

-  I **can't go out**
-  I feel **embarrassed**/ They feel embarrassed
-  I **can't drive** any more
-  Live **too far** away
-  **No energy**
-  They're not well
-  No longer share same **interests**
-  **Less money** now

 What do friends give you?

Are friends **important** to you?

Why?

Family

- Any **changes** since stroke?
- Family members **less close** to?
- Family members **more close** to?

Negatives

- Harder to share worries
- It's more strained
- They take control
- I feel guilty

Positives

- They are very supportive
- We are closer now

What do family give you?

Are family important to you?

Why?

Friends versus family

- 🌐 **Role** of friends vs. family
- 🌐 **Expectations** (friends vs. family)

Types of support

Emotional support

"someone to talk to"

"someone who understands"

🌐 **Who** gives you emotional support?

🌐 **Helpful** after a stroke?

🌐 Do you get **enough**?

🌐 What does it **mean** to you?

Practical support

"someone to do my shopping"

"someone to sort out bills"

🌐 **Who** gives you practical support?

🌐 **Helpful** after a stroke?

🌐 Do you get **enough**?

🌐 What does it **mean** to you?

Companionship

"someone to **relax** with"

"someone to **have fun** with"

🌐 **Who** gives you this support?

🌐 **Helpful** after a stroke?

🌐 Do you get **enough**?

🌐 What does it **mean** to you?

Summary

🌐 **Role** of friends and family after a stroke

were they **helpful** in your new life?

🌐 Support you **didn't receive**

🌐 **Unhelpful** support - eg unwanted advice

- eg unwanted practical support

Advice

Your advice!

🌐 To person **after a stroke**

- 🌐 Don't be afraid to **ask for help**
- 🌐 **Keep talking**
- 🌐 Don't shut yourself away
- 🌐 Don't complain too much
- 🌐 **It takes time**
- 🌐 Try to get dressed every day!

🌐 **Advice to friends and family**

- 🌐 **Be patient**
- 🌐 Offer help, but don't insist
- 🌐 **Don't fuss** too much
- 🌐 **Show that you care**

Final questions!

🌐 Anything else? (about social support)

🌐 What has **really helped?** (in terms of **support** from friends and family)

🌐 Knowing someone is there

🌐 Sharing a **joke**

🌐 Cheering me up

🌐 **Encouraging me**

🌐 Little **practical** things

🌐 Making time

🌐 **Someone cares**

Thank you!!

Appendix 13

Distributions of independent variables

National Institute of Health Stroke Scale (NIHSS)

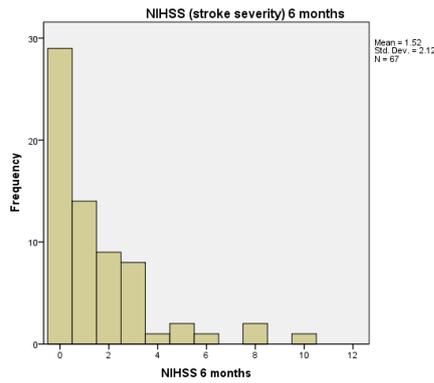
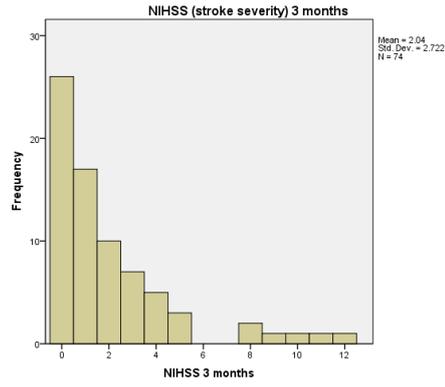
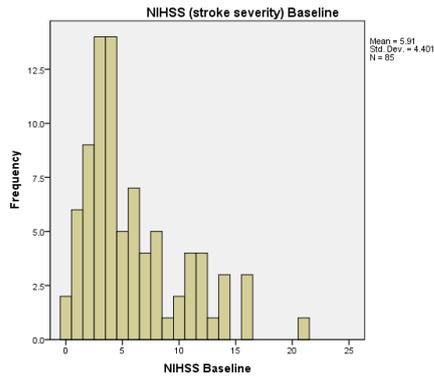
Barthel Index (BI)

Frenchay Activities Index (FAI)

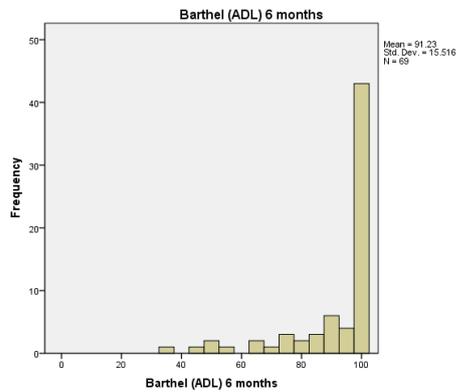
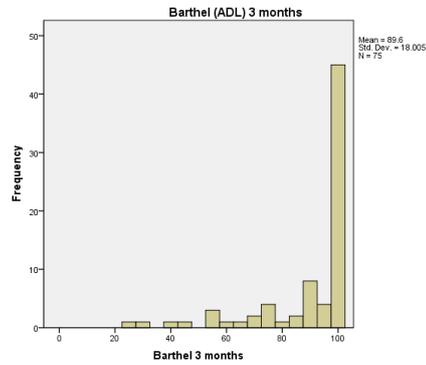
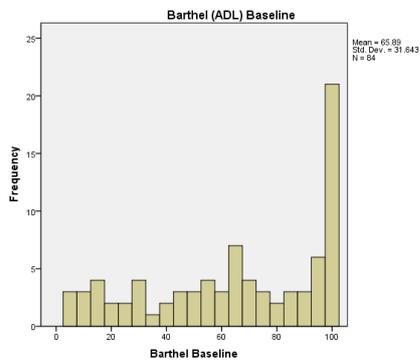
General Health Questionnaire (GHQ-12)

Frenchay Aphasia Screening Test (FAST)

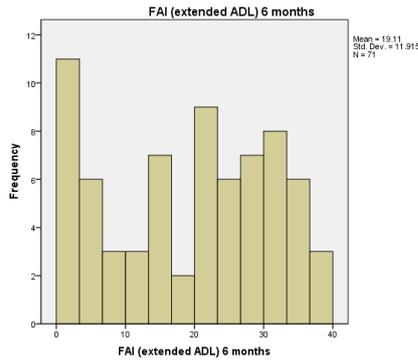
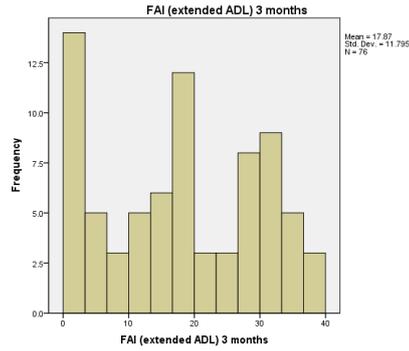
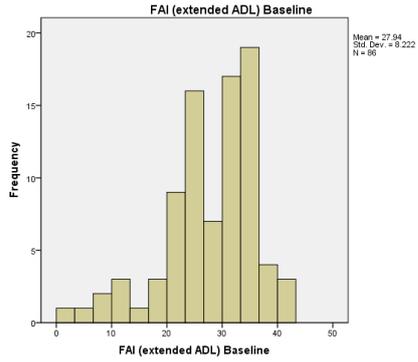
Distribution of National Institute of Health Stroke Scale (NIHSS)



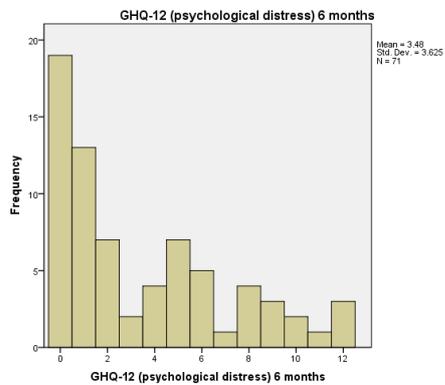
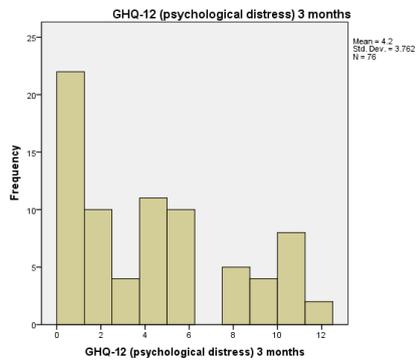
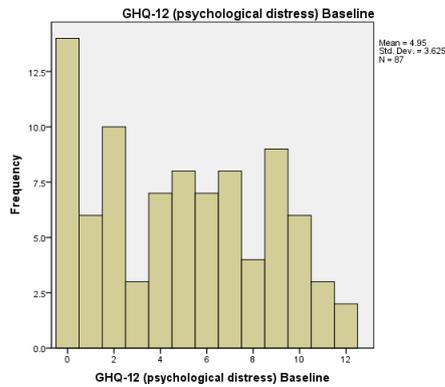
Distribution of Barthel Index (BI)



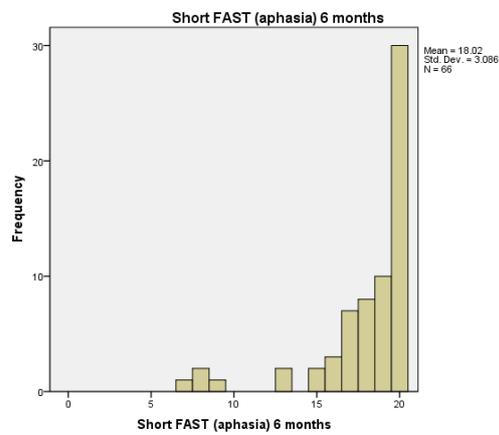
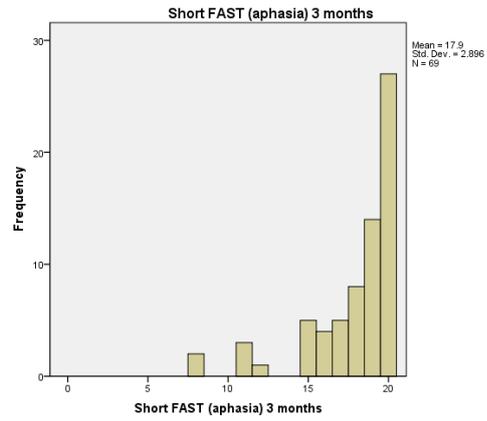
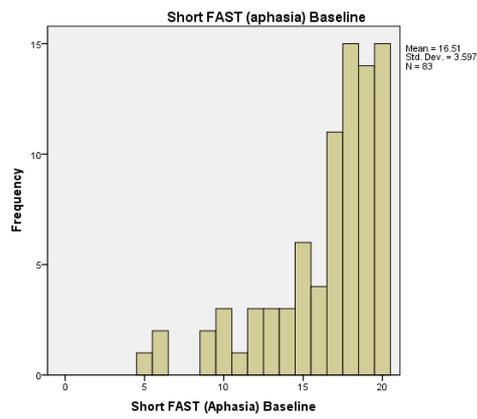
Distribution of Frenchay Activities Index (FAI)



Distribution of General Health Questionnaire (GHQ-12)



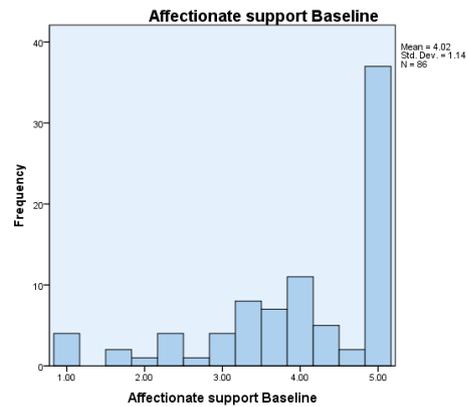
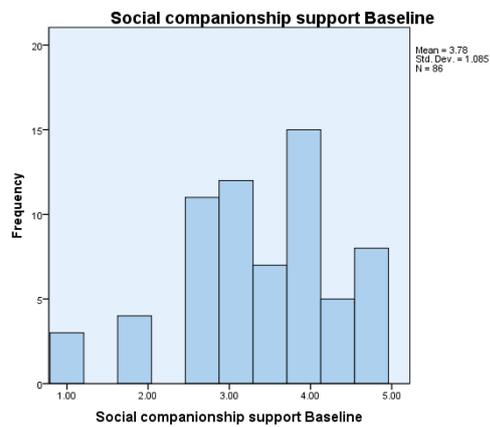
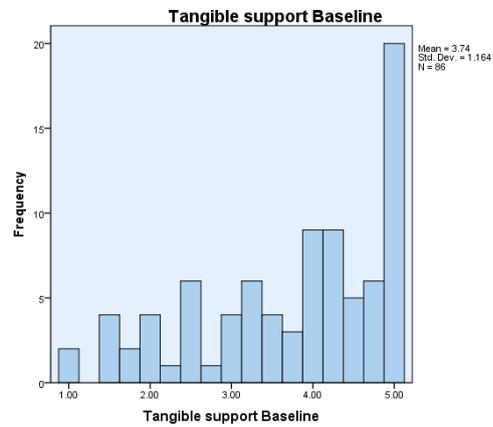
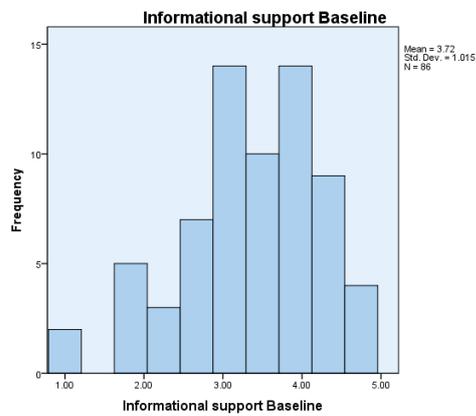
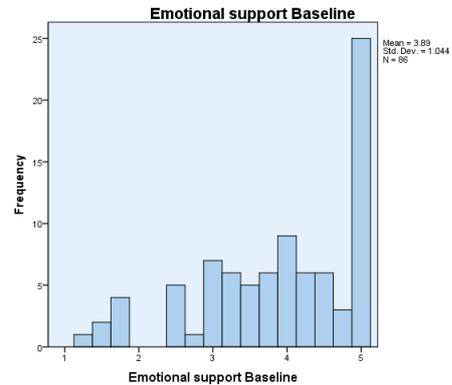
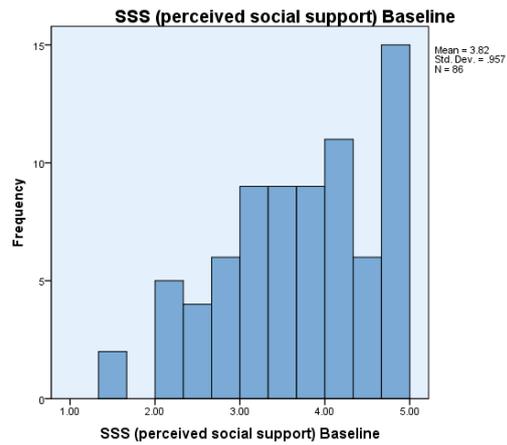
Distribution of short Frenchay Aphasia Screening Test (FAST): aphasia



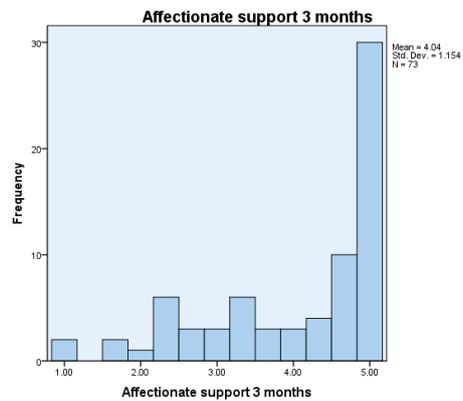
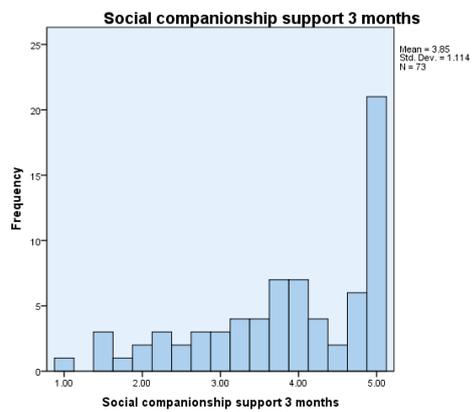
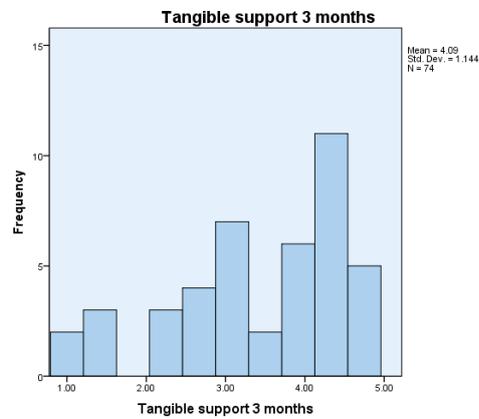
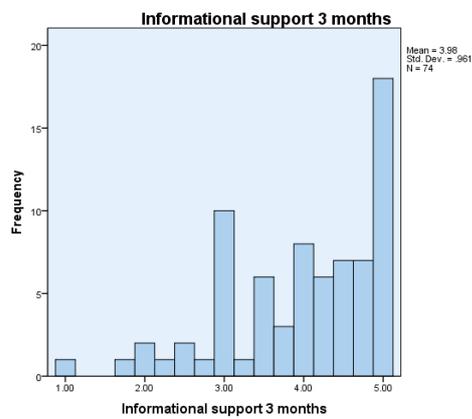
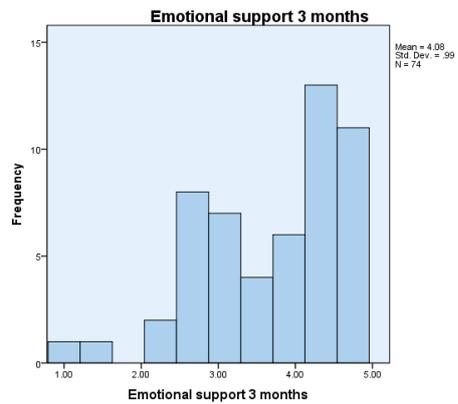
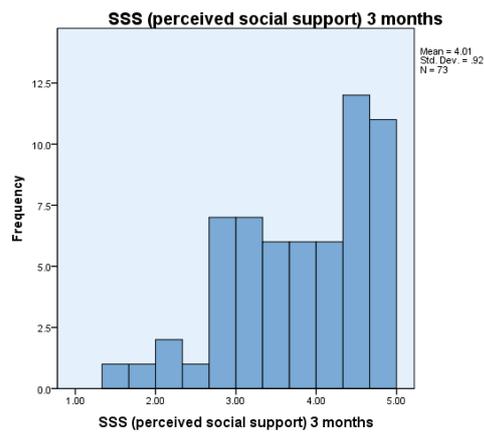
Appendix 14

Distribution of overall MOS Social Support Survey (SSS) and subdomains

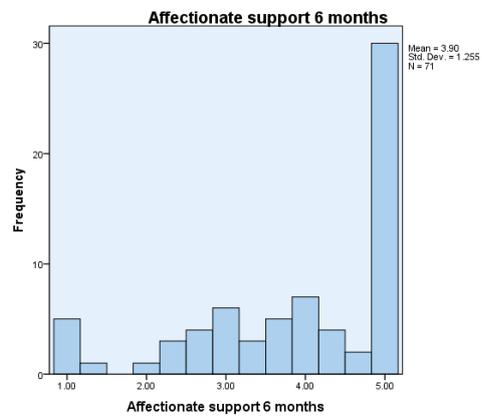
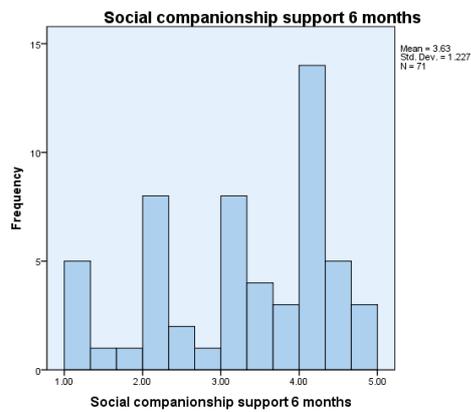
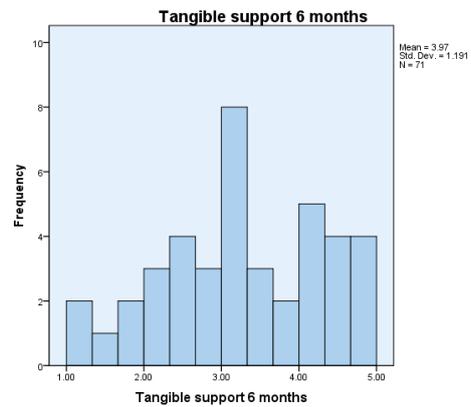
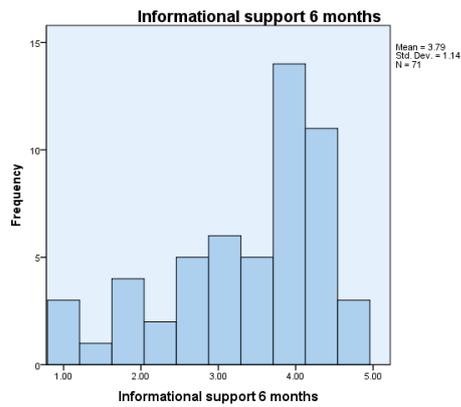
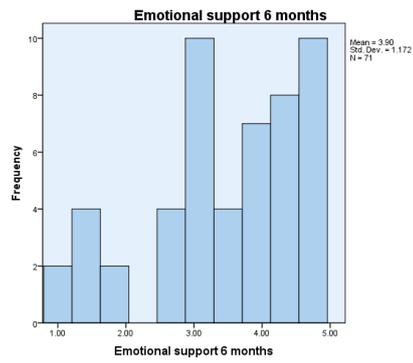
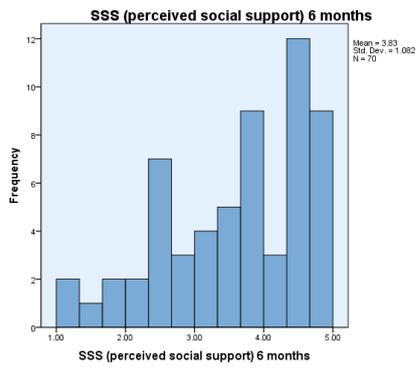
Distributions for overall scale (SSS) and subdomains at baseline



Distributions of overall scale (SSS) and subdomains at three months



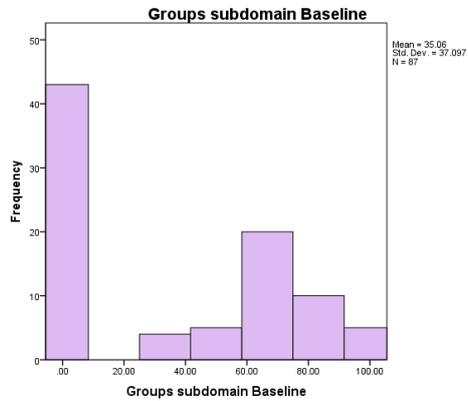
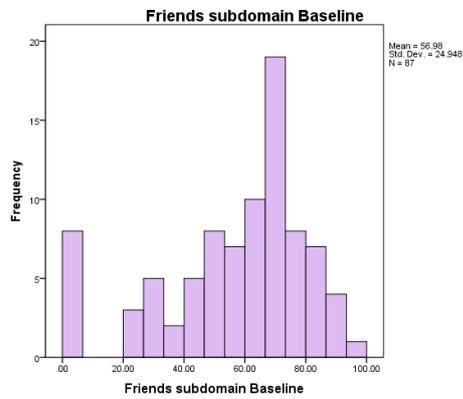
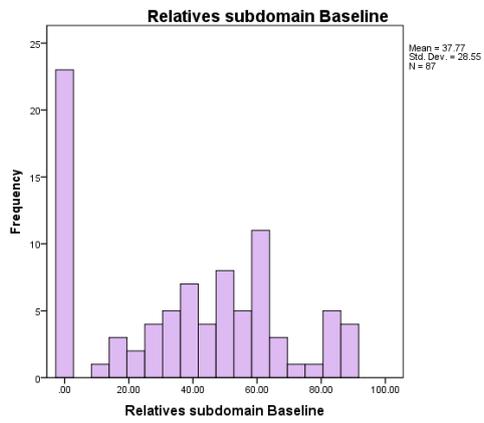
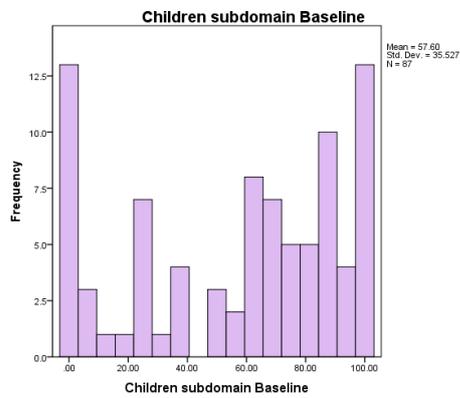
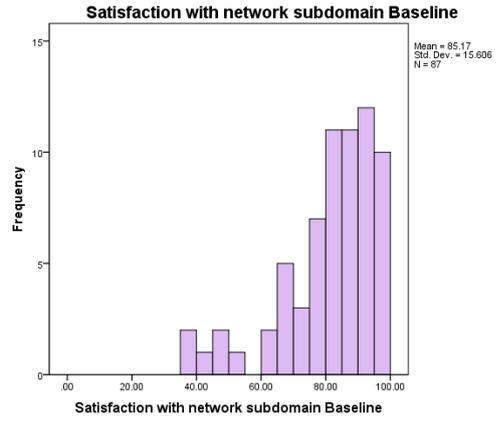
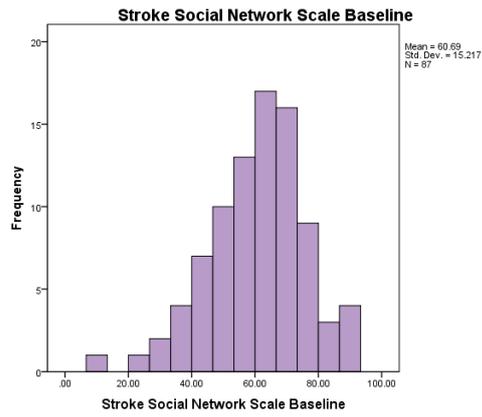
Distributions of overall scale (SSS) and subdomains at six months



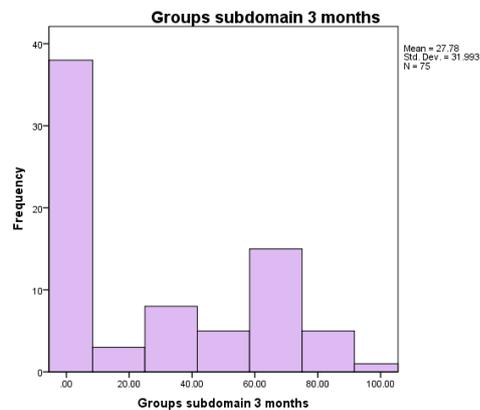
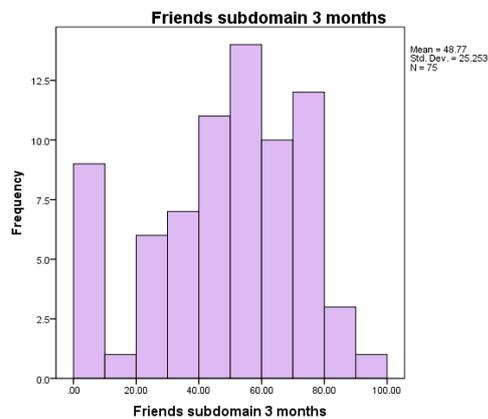
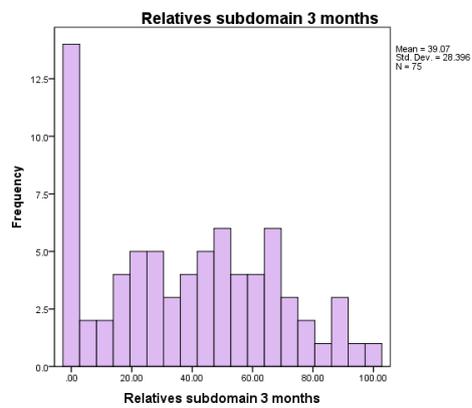
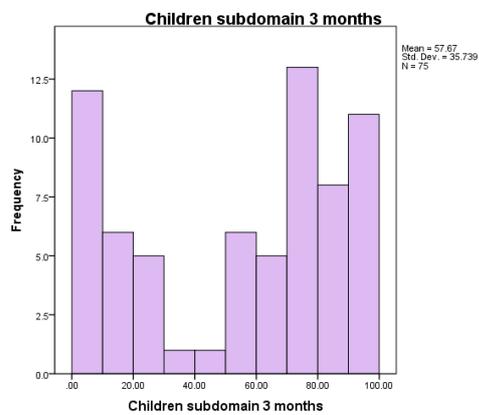
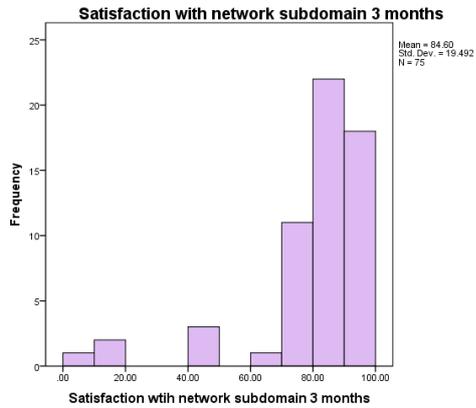
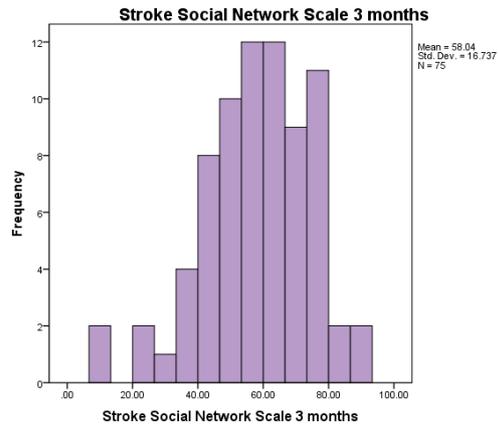
Appendix 15

Distribution of Stroke Social Network Scale and subdomains

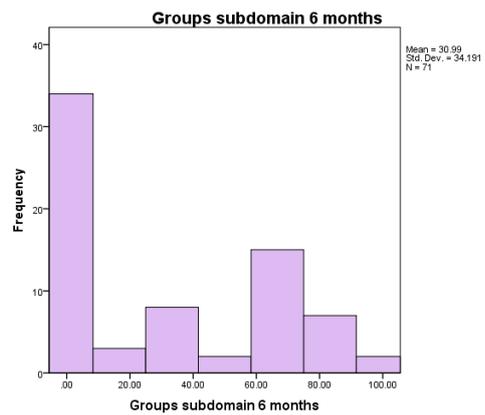
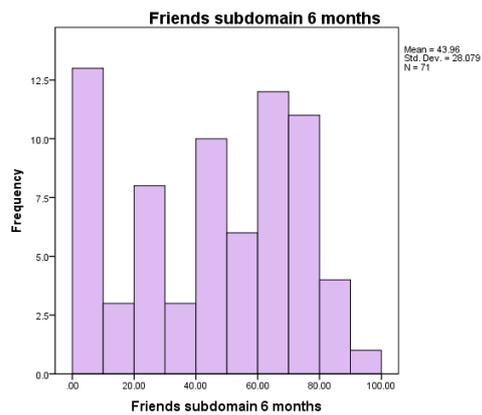
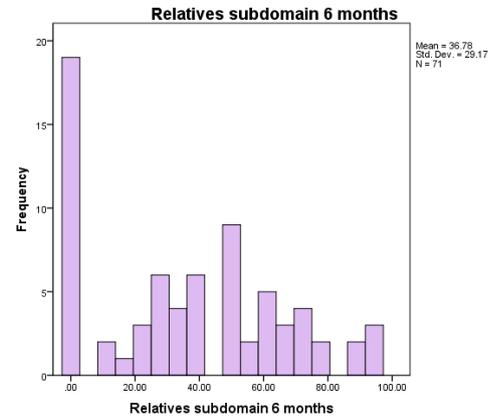
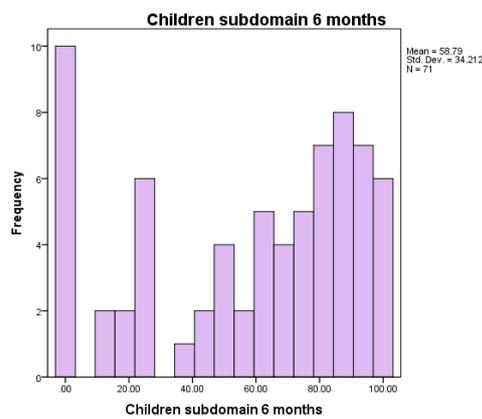
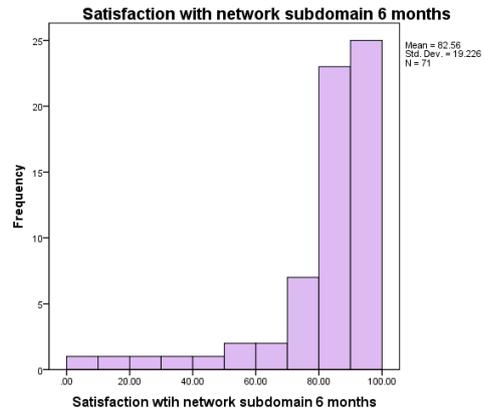
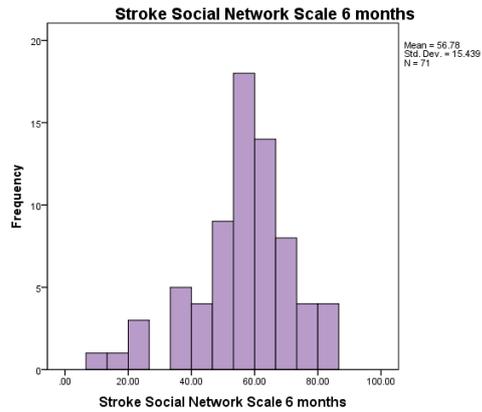
Distribution of overall scale (SSNS) and subdomains at baseline



Distribution of overall scale (SSNS) and subdomains at three months



Distribution of overall scale (SSNS) and subdomains at six months



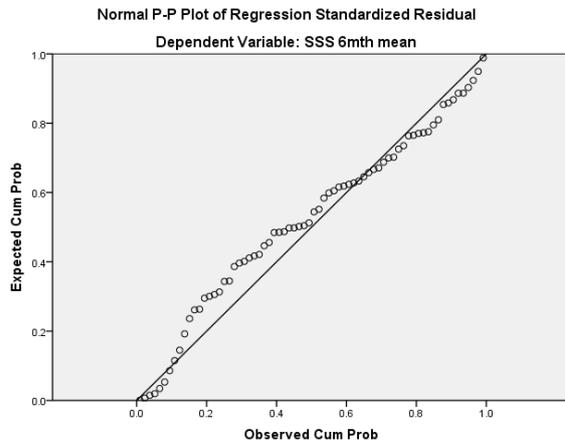
Appendix 16

Multiple regression assumptions for RQs4-7

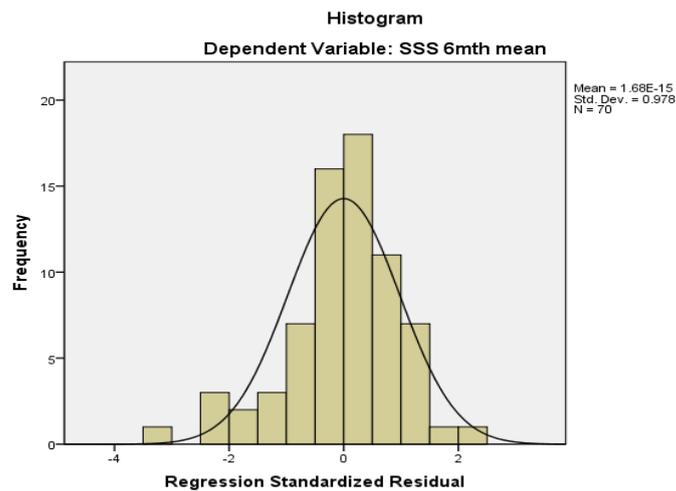
RQ4 Normal probability plot, histogram and scatterplot of the standardised residuals

(What concurrent factors predict perceived social support six months post stroke?)

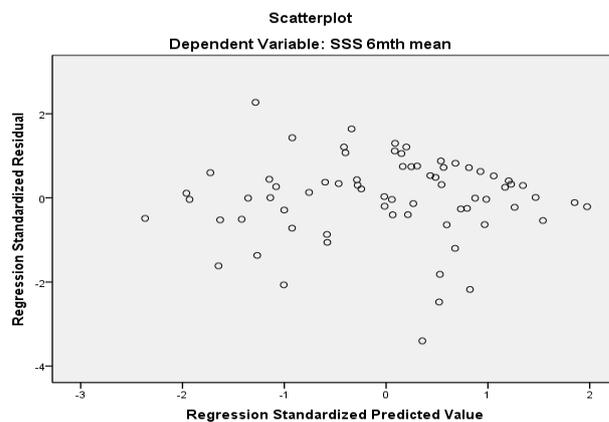
Normal probability plot of the standardised residuals



Histogram of the standardised residuals



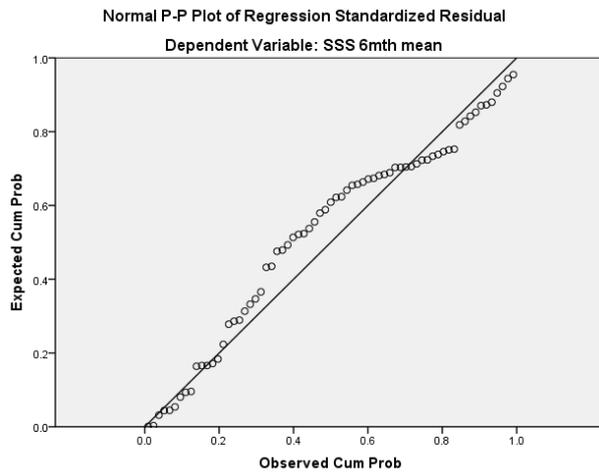
Scatterplot of the standardised residuals



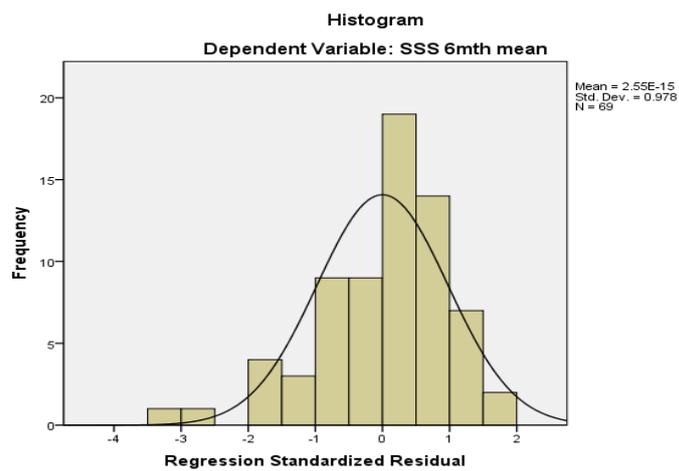
RQ5 Normal probability plot, histogram and scatterplot of the standardised residuals

(What baseline factors predict perceived social support six months post stroke?)

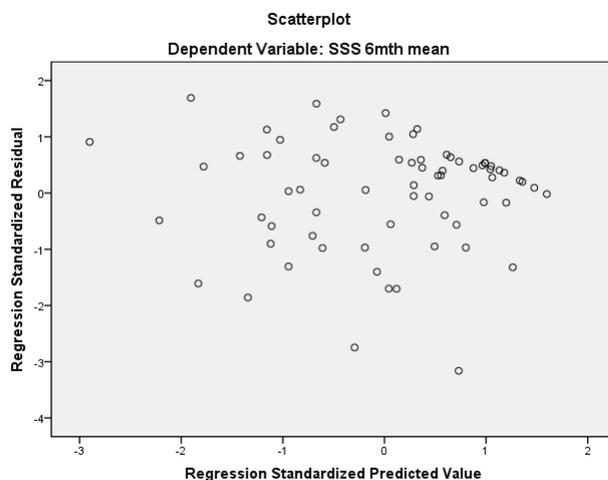
Normal probability plot of the standardised residuals (RQ5)



Histogram of the standardised residuals (RQ5)



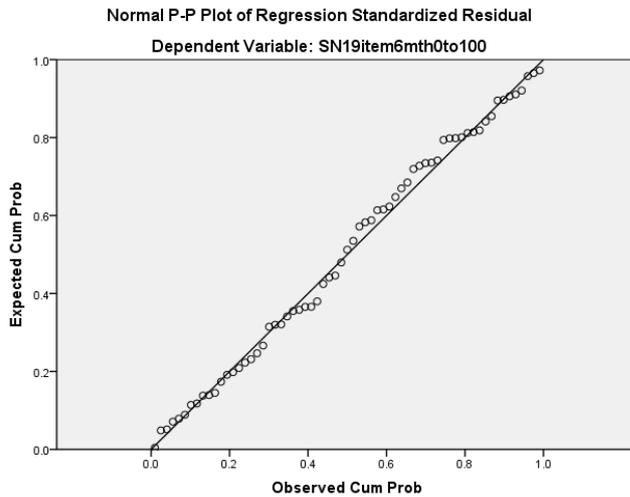
Scatterplot of the standardised residuals (RQ5)



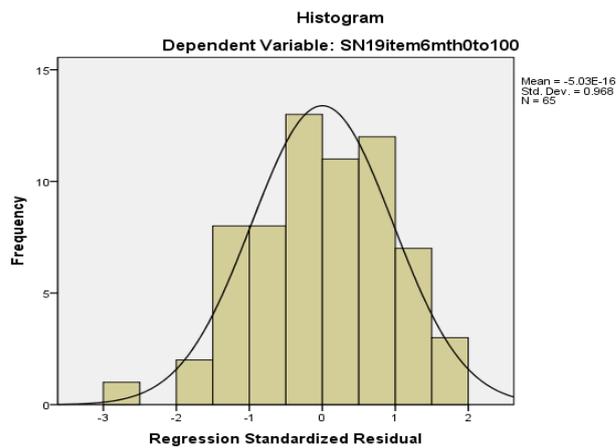
RQ6 Normal probability plot, histogram and scatterplot of the standardised residuals

(What concurrent factors predict social network six months post stroke?)

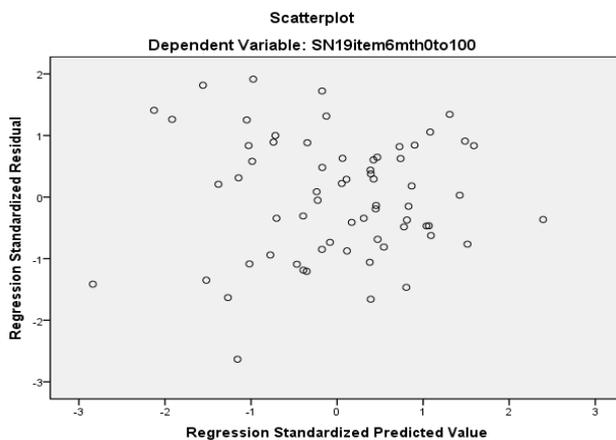
Normal probability plot of the standardised residuals (RQ6)



Histogram of the standardised residuals (RQ6)



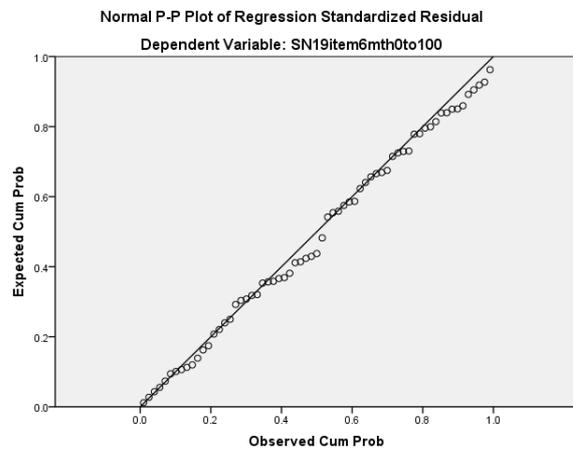
Scatterplot of the standardised residuals (RQ6)



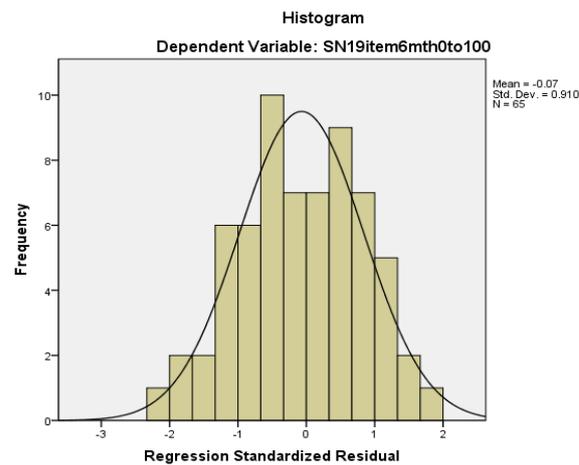
RQ7 Normal probability plot, histogram and scatterplot of the standardised residuals

(What baseline factors predict social network six months post stroke?)

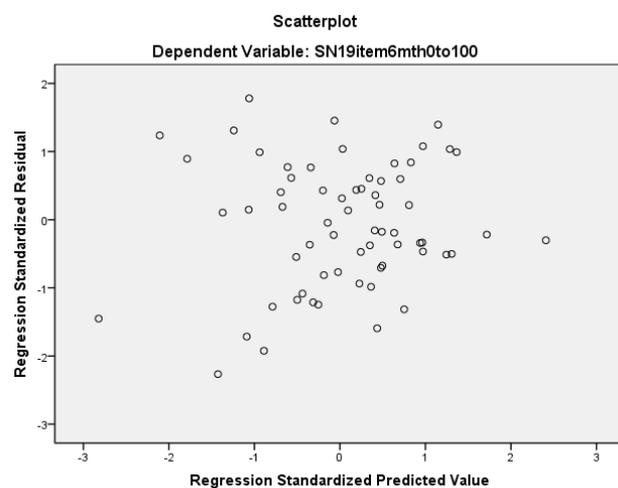
Normal probability plot of the standardised residuals (RQ7)



Histogram of the standardised residuals (RQ7)



Scatterplot of the standardised residuals (RQ7)



Appendix 17

Why do people lose their friends after a stroke?

Northcott S and Hilari K. Why do people lose their friends after a stroke? *International journal of language & communication disorders* 2011; 46: 524-34.

The full text of this article has been removed for copyright reasons

Appendix 18

Cluster Analysis

Between groups hierarchical cluster analysis: full agglomeration schedule

Agglomeration Schedule

Stage	Cluster Combined		Coefficients	Stage Cluster First Appears		Next Stage
	Cluster 1	Cluster 2		Cluster 1	Cluster 2	
1	54	87	.001	0	0	12
2	44	79	.045	0	0	38
3	37	39	.090	0	0	26
4	38	46	.097	0	0	20
5	5	55	.102	0	0	13
6	19	66	.118	0	0	36
7	7	16	.162	0	0	34
8	25	77	.175	0	0	31
9	20	82	.178	0	0	19
10	4	33	.186	0	0	42
11	36	59	.218	0	0	49
12	54	61	.250	1	0	42
13	5	27	.263	5	0	35
14	21	84	.264	0	0	43
15	8	41	.273	0	0	45
16	15	70	.293	0	0	50
17	56	69	.298	0	0	61
18	35	78	.314	0	0	39
19	20	85	.337	9	0	44
20	18	38	.382	0	4	31
21	13	17	.383	0	0	37
22	40	75	.400	0	0	32
23	26	67	.409	0	0	48
24	29	52	.443	0	0	26
25	1	28	.507	0	0	33
26	29	37	.559	24	3	57
27	10	80	.565	0	0	39
28	3	53	.569	0	0	30
29	51	74	.622	0	0	35
30	3	65	.732	28	0	54
31	18	25	.754	20	8	47
32	40	73	.805	22	0	55
33	1	60	.809	25	0	45
34	7	14	.842	7	0	53
35	5	51	.848	13	29	52
36	19	83	.929	6	0	44
37	13	72	.931	21	0	54
38	12	44	1.102	0	2	46

39	10	35	1.204	27	18	58
40	49	62	1.224	0	0	50
41	2	30	1.356	0	0	52
42	4	54	1.463	10	12	53
43	21	43	1.469	14	0	56
44	19	20	1.469	36	19	62
45	1	8	1.602	33	15	60
46	12	23	1.635	38	0	56
47	6	18	1.860	0	31	59
48	9	26	1.876	0	23	55
49	22	36	1.923	0	11	51
50	15	49	2.051	16	40	58
51	22	42	2.101	49	0	65
52	2	5	2.169	41	35	59
53	4	7	2.174	42	34	65
54	3	13	2.226	30	37	69
55	9	40	2.590	48	32	63
56	12	21	2.923	46	43	63
57	29	86	2.975	26	0	60
58	10	15	3.002	39	50	64
59	2	6	3.104	52	47	64
60	1	29	3.597	45	57	61
61	1	56	3.925	60	17	66
62	19	71	4.268	44	0	68
63	9	12	4.639	55	56	66
64	2	10	5.446	59	58	67
65	4	22	5.793	53	51	67
66	1	9	6.197	61	63	69
67	2	4	7.531	64	65	68
68	2	19	8.447	67	62	70
69	1	3	9.026	66	54	70
70	1	2	9.786	69	68	0

Furthest neighbour hierarchical cluster analysis: full agglomeration schedule

Agglomeration Schedule

Stage	Cluster Combined		Coefficients	Stage Cluster First Appears		Next Stage
	Cluster 1	Cluster 2		Cluster 1	Cluster 2	
1	54	87	.001	0	0	12
2	44	79	.045	0	0	37
3	37	39	.090	0	0	29
4	38	46	.097	0	0	23
5	5	55	.102	0	0	19
6	19	66	.118	0	0	33
7	7	16	.162	0	0	40
8	25	77	.175	0	0	35
9	20	82	.178	0	0	22
10	4	33	.186	0	0	43
11	36	59	.218	0	0	45
12	54	61	.255	1	0	31
13	21	84	.264	0	0	42
14	8	41	.273	0	0	48
15	15	70	.293	0	0	50
16	56	69	.298	0	0	58
17	35	78	.314	0	0	46
18	13	17	.383	0	0	41
19	5	27	.388	5	0	38
20	40	75	.400	0	0	52
21	26	67	.409	0	0	44
22	20	85	.412	9	0	51
23	18	38	.437	0	4	35
24	29	52	.443	0	0	29
25	1	28	.507	0	0	34
26	10	80	.565	0	0	46
27	3	53	.569	0	0	30
28	51	74	.622	0	0	38
29	29	37	.717	24	3	54
30	3	65	.738	27	0	56
31	14	54	.902	0	12	43
32	2	73	.996	0	0	39
33	19	83	1.007	6	0	51
34	1	60	1.023	25	0	53
35	18	25	1.094	23	8	49
36	49	62	1.224	0	0	50
37	12	44	1.279	0	2	44
38	5	51	1.295	19	28	55

39	2	30	1.356	32	0	55
40	7	23	1.421	7	0	61
41	13	72	1.447	18	0	52
42	21	43	1.676	13	0	57
43	4	14	1.960	10	31	61
44	12	26	2.174	37	21	57
45	36	42	2.231	11	0	47
46	10	35	2.254	26	17	60
47	22	36	2.440	0	45	63
48	8	86	2.611	14	0	54
49	6	18	2.639	0	35	62
50	15	49	2.667	15	36	60
51	19	20	2.832	33	22	59
52	13	40	3.309	41	20	56
53	1	9	3.655	34	0	64
54	8	29	3.850	48	29	58
55	2	5	4.079	39	38	62
56	3	13	4.726	30	52	64
57	12	21	4.801	44	42	65
58	8	56	4.913	54	16	67
59	19	71	4.993	51	0	69
60	10	15	5.943	46	50	66
61	4	7	6.167	43	40	63
62	2	6	8.350	55	49	65
63	4	22	9.629	61	47	66
64	1	3	9.789	53	56	67
65	2	12	11.263	62	57	68
66	4	10	12.227	63	60	68
67	1	8	16.563	64	58	70
68	2	4	18.336	65	66	69
69	2	19	19.914	68	59	70
70	1	2	28.562	67	69	0

Ward's method hierarchical cluster analysis: full agglomeration schedule

Agglomeration Schedule

Stage	Cluster Combined		Coefficients	Stage Cluster First Appears		Next Stage
	Cluster 1	Cluster 2		Cluster 1	Cluster 2	
1	54	87	.001	0	0	18
2	44	79	.023	0	0	37
3	37	39	.068	0	0	30
4	38	46	.117	0	0	24
5	5	55	.168	0	0	17
6	19	66	.226	0	0	44
7	7	16	.307	0	0	33
8	25	77	.394	0	0	38
9	20	82	.484	0	0	20
10	4	33	.577	0	0	50
11	36	59	.685	0	0	43
12	21	84	.818	0	0	40
13	8	41	.954	0	0	48
14	15	70	1.101	0	0	52
15	56	69	1.250	0	0	58
16	35	78	1.407	0	0	41
17	5	27	1.565	5	0	39
18	54	61	1.732	1	0	50
19	13	17	1.923	0	0	34
20	20	85	2.118	9	0	49
21	40	75	2.318	0	0	32
22	26	67	2.523	0	0	45
23	29	52	2.744	0	0	30
24	18	38	2.982	0	4	38
25	1	28	3.236	0	0	31
26	10	80	3.518	0	0	41
27	3	53	3.803	0	0	29
28	51	74	4.114	0	0	39
29	3	65	4.507	27	0	53
30	29	37	4.933	23	3	59
31	1	60	5.388	25	0	62
32	40	73	5.858	21	0	56
33	7	14	6.392	7	0	57
34	13	72	6.949	19	0	53
35	2	83	7.544	0	0	44
36	49	62	8.156	0	0	42
37	12	44	8.884	0	2	54
38	18	25	9.622	24	8	47

39	5	51	10.369	17	28	61
40	21	43	11.304	12	0	54
41	10	35	12.289	26	16	52
42	23	49	13.304	0	36	60
43	30	36	14.325	0	11	51
44	2	19	15.427	35	6	49
45	9	26	16.610	0	22	56
46	22	42	17.830	0	0	55
47	6	18	19.194	0	38	64
48	8	86	20.689	13	0	58
49	2	20	22.266	44	20	67
50	4	54	23.898	10	18	57
51	30	71	25.758	43	0	55
52	10	15	28.375	41	14	61
53	3	13	31.001	29	34	66
54	12	21	33.694	37	40	60
55	22	30	36.529	46	51	65
56	9	40	39.385	45	32	62
57	4	7	42.368	50	33	65
58	8	56	45.434	48	15	59
59	8	29	49.956	58	30	63
60	12	23	54.716	54	42	68
61	5	10	59.998	39	52	64
62	1	9	65.498	31	56	63
63	1	8	75.441	62	59	66
64	5	6	89.190	61	47	68
65	4	22	103.789	57	55	67
66	1	3	123.884	63	53	70
67	2	4	145.547	49	65	69
68	5	12	173.378	64	60	69
69	2	5	213.796	67	68	70
70	1	2	280.000	66	69	0

K-means cluster analysis: ANOVA

ANOVA						
	Cluster		Error		F	Sig.
	Mean Square	df	Mean Square	df		
Zscore: ChildF6mth0to100	6.902	3	.736	67	9.380	.000
Zscore: FriendF6mth0to100	14.323	3	.403	67	35.503	.000
Zscore: RelsF6mth0to100	10.812	3	.561	67	19.283	.000
Zscore: GroupsF6mth0to100	13.410	3	.444	67	30.180	.000

The F tests should be used only for descriptive purposes because the clusters have been chosen to maximize the differences among cases in different clusters. The observed significance levels are not corrected for this and thus cannot be interpreted as tests of the hypothesis that the cluster means are equal.