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Running Title: Evaluating the Stroke IPQ-R

Title: Evaluating a Stroke-Specific Version of the Illness Perception Questionnaire-Revised, using the Think-Aloud method

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Abstract

The main purpose was to evaluate, using the Think-Aloud method, a version of the Illness Perception Questionnaire-Revised (IPQ-R) for stroke survivors (the Stroke IPQ-R). Six stroke survivors (mean age=58.8 years, range=31 to 78 years, SD=18.9 years) took part in Think-Aloud interviews, analysed according to established guidelines. Overall, 179 problems emerged. The most noteworthy was missing or insufficient Think-Aloud data generated, where participants did not think out loud. Others included complex and negative item wording, and items on the treatment control sub-scale. Questionnaire length, simpler wording and verbal probing are important considerations in further development of an IPQ-R for stroke.

<u>Introduction</u>

Illness beliefs are an important component of the Common Sense Model (CSM) (Leventhal et al., 1980). The CSM posits that when confronted with a threat to their health, individuals form beliefs about their illness and treatment that guide what they do to cope and feel better, and in doing so, help them to maintain their health status quo (Leventhal et al., 1998, Leventhal et al., 1980). Illness beliefs incorporate several domains (Leventhal et al., 1997, Leventhal et al., 2003, Leventhal et al., 1980) that can be measured using various questionnaires. For example: the Illness Perception Questionnaire (IPQ) (Weinman et al., 1996); Illness Perception Questionnaire-Revised (IPQ-R) (referred to hereafter as the original IPQ-R) (Moss-Morris et al., 2002); and Brief IPQ (Broadbent et al., 2006).

The IPQ-R was borne out of concerns about the psychometric properties of the first iteration of this questionnaire, the IPQ. It measures nine domains of illness beliefs. Identity' describes individuals' beliefs about the label of the illness and associated symptoms. 'Timeline' refers to beliefs about the duration of the illness, which may be short-term (acute), or long-term (chronic). 'Timeline-cyclical' refers to beliefs about a fluctuating or episodic nature of the illness. 'Consequences' refer to perceptions about the seriousness of the illness and impact on peoples' lives. 'Personal control' covers peoples' beliefs around their ability to manage their illness themselves. 'Treatment control' focuses on peoples' perceptions of the effectiveness of their treatment. 'Illness coherence' beliefs describe peoples' understanding of their illness. 'Emotional representations' refer to peoples' emotional response to the illness. 'Causes' describes peoples' personal views about the causes of their condition, and may be internal (e.g., genes) or external (e.g., a germ or virus; stress or overwork; or pollution). The Brief IPQ comprises nine-items, with a single summary question to assess each illness belief domain (Broadbent et al., 2006). It was developed to enable a quick assessment of illness beliefs when time is limited, or for specific patients (e.g., people who are very ill, or the elderly) (Broadbent

et al., 2006). The authors of these questionnaires have recommended that questions are adapted to suit specific illnesses.

We chose to adapt the IPQ-R to stroke survivors for two reasons. First, the reliability and validity of the IPQ-R is well-established for several patient groups, including those with neurological conditions (e.g., multiple sclerosis) (Moss-Morris et al., 2002). Second, it has been argued that while the Brief IPQ may have the advantage of brevity, it might lack content validity (van Oort et al., 2011). van Oort et al. (2011) emphasised that items on the Brief IPQ were developed by "forming one question that best summarised the items contained in each sub-scale of the IPQ-R" (Broadbent, Petrie et al. 2006, p632). However, they suggested that in order to fully assess content validity, all aspects of a construct should be examined, which may not be possible to do using a single summary measure (van Oort et al., 2011).

Illness belief questionnaires (most commonly, the IPQ/IPQ-R) are increasingly being used to assess survivors' beliefs about their stroke (Ford, 2007, Johnston et al., 2007, Johnston et al., 1999, Joice et al., 2003, Joice et al., 2002, Klinedinst et al., 2012, O'Carroll et al., 2013, O'Carroll et al., 2011, Phillips et al., 2015, Sjölander et al., 2013, Twiddy et al., 2012). However, it is unclear how suitable the IPQ-R is for assessing illness beliefs in this population.

A version of the IPQ-R has previously been developed for stroke survivors (referred to hereafter as the Twiddy-scale) (Twiddy, 2008). Several sub-scales of the Twiddy-scale have shown reliability for survivors in the acute (Cronbach's alpha (α) =0.59-0.82) and chronic phase of stroke (α=0.68-0.91). However, some psychometric properties of the Twiddy-scale (e.g., criterion and construct validity) were not sufficiently tested, and the questionnaire excluded most of the items on the treatment control sub-scale. These issues raised concerns about the generalisability of the questionnaire. Furthermore, the Twiddy-scale did not make use of the Think-Aloud method, which has increasingly been shown to have great utility in developing optimal survey questions (Willis, 2005), and examining face and content validity

of questionnaires (van Oort et al., 2011). Therefore, we sought to undertake a further iteration of the IPQ-R for stroke, which we evaluate in this study using the Think-Aloud method.

The Think-Aloud method is a cognitive interviewing paradigm that involves encouraging respondents to verbalise their thoughts, without probing or additional explanations while, for example, answering questions in a questionnaire (Willis, 2005, van Someren et al., 1994). As a result, individuals express thoughts that would have otherwise remained silent (Ericsson and Simon, 1993). Unlike other approaches (e.g., surveys, qualitative interviews etc.), the Think-Aloud method offers an opportunity to understand in detail respondents' thought processes when solving a problem (i.e., what they are really thinking), without being too directive so as to introduce bias (Charters, 2003, Willis and Artino, 2013). Several studies have employed a Think-Aloud approach to examine what people think about when responding to items on various questionnaires (Boeije and Janssens, 2004, Darker and French, 2009, French et al., 2007, Murtagh et al., 2007, Westerman et al., 2008, French and Hevey, 2008). Two of which have focused on illness belief questionnaires (McCorry et al., 2013, van Oort et al., 2011).

McCorry et al. (2013) used a version of the IPQ-R adapted for people with type 2 diabetes mellitus. The authors identified several problems with completion of this questionnaire. These included written responses that were incongruous to participants' verbalisations and beliefs about their condition; confusion over negatively worded items; and incomprehension of items perceived to be non-personally relevant, such as those referring to the concept of 'cure' and 'symptoms.' The findings from this study are important for three reasons. First, they highlight that individuals do encounter problems when completing the IPQ-R, despite attempts to adapt items to suit specific illnesses. Second, they demonstrate that there are discrepancies between what people think or believe, and how they respond to items on the IPQ-R, which can influence the interpretation of peoples' scores on the questionnaire. Third, the findings illustrate the utility of the Think-Aloud approach in uncovering these specific issues with the IPQ-R.

Therefore, the main purpose of our study was to evaluate a version of the IPQ-R modified to stroke (referred to hereafter as the Stroke IPQ-R), using the Think-Aloud method. Two further aims were to first, examine the internal consistency of sub-scales of the Stroke IPQ-R for survivors within the acute phase of stroke (≤three-months post-stroke); and second, to comment on the utility of the Think-Aloud method for developing questionnaires for stroke survivors.

Methods

Initial Development of the Stroke IPQ-R

Prior to undertaking our Think-Aloud study, we reviewed the literature, which resulted in the identification of the Twiddy-scale (Twiddy, 2008). Given the problems that we previously cited in relation to the Twiddy-scale, we opted to use the original version of the IPQ-R as the starting point for our adaptation to stroke. Our only change to the IPQ-R at this early stage was to replace the word 'illness' with 'stroke,' as per the suggestions by the authors of the IPQ-R (Moss-Morris et al., 2002). We then consulted with an expert stroke panel for feedback on this version of the questionnaire. The panel included clinicians, academics, and a patient advocate group, which comprised stroke survivors with different types and severity of stroke and at varying stages of recovery.

We met with the patient advocate group on two occasions. The first meeting involved four members of the group and comprised a presentation of the research, and an in-depth discussion of the original version of the IPQ-R, including: relevance to stroke; stroke survivors' needs; and initial recommendations for stroke-specific adaptation. The feedback was discussed with our clinical and academic experts, and a revised version of the questionnaire was taken to a second meeting with the patient advocate group for further discussion. This meeting involved

five members, and the agenda was specifically focused on three general issues relating to the questionnaire. First, the ordering of the items and in particular whether the questions should be presented in a mixed order or in groups pertaining to each illness belief domain. Second, the response format for the main part of the questionnaire (i.e., all sub-scales except for the identity domain). Third, the general appearance of the questionnaire and optimal formatting. Feedback from the patient advocate group was again discussed after the meeting with our clinical and academic experts.

A summary of all of the modifications made to the Stroke IPQ-R during this initial phase of consultation is shown in the Appendix (Tables A, B and C). Two significant modifications are noteworthy. First, questions were presented in groups pertaining to each illness belief domain rather than in random order (as in the original IPQ-R), and each group included a preamble with examples to describe the illness belief domain being assessed and minimise the repetitious nature of the questions. Second, the treatment control sub-scale was separated according to peoples' medical treatment and rehabilitation to reflect the distinct packages of care that patients receive after stroke. Other minor modifications made at this stage included: addition/removal of items relevant/non-relevant to stroke; addition of 'I believe' as a prefix to personalise each question; removal of abstract items; and re-wording of the neutral response category from 'Neither agree nor disagree' to 'I don't know.' Further, the questionnaire was re-formatted according to the Twiddy-scale to ensure ease of responding for stroke survivors (e.g., large font). This version of the Stroke IPQ-R was then evaluated in the Think-Aloud study; the details of which are provided below.

Think-Aloud Study

<u>Design and Setting</u>

Qualitative (audio-recorded) interviews were carried out adopting a Think-Aloud approach, by an experienced researcher in participants' homes or at a research clinic. The

Think-Aloud interviews were conducted and reported in accordance with the recommended guidelines (van Someren et al., 1994).

Participants and Recruitment

Participants were recruited from acute stroke and rehabilitation wards and outpatient clinics in one hospital, and from a patient advocate group in Nottingham, United Kingdom (UK) between December 2013 to January 2014. Audio-recorded interviews lasted between 30- and 60-minutes, and were transcribed verbatim using standard transcription conventions (Bailey, 2008) as soon as possible after each interview ended. The transcripts were examined after each interview, and interviews were stopped when in our opinion, it became clear that no further problems with the questionnaire were being picked up that had not already been identified and included within our existing coding framework. We reached this point after our sixth interview. The National Research Ethics Service (NRES) Committee East Midlands (UK) – Leicester (13/EM/0392), granted ethical approval.

We attempted to recruit a purposive sample of six stroke survivors (two male, and four female). Participants aged 18 years or over with a history of acute stroke were eligible to take part, though individuals with severe cognitive/communication problems (assessed through liaison with the clinical care team and review of medical notes), and/or English language skills insufficient to participate in the research were excluded.

The characteristics of our sample are summarised in Table 1. The mean age was 58.8 years (standard deviation (SD) =18.9 years; range=31 to 78 years). Over 80% of the sample was white-British, and three out of six participants were University educated. The time since acute stroke ranged from one-month to 14-years. The majority of participants (five out of six) were hospitalised for an ischaemic stroke, though the sub-type varied. One participant was excluded from the analysis based on a diagnosis of subarachnoid haemorrhage, which differs in clinical presentation to ischaemic stroke or intracerebral haemorrhage. The Think-Aloud

interviews highlighted that many of the items on the Stroke IPQ-R were not relevant to subarachnoid haemorrhage, and were therefore, unanswerable by this participant. Further participants with subarachnoid haemorrhage were excluded following this interview.

Materials

Participants completed the version of the Stroke IPQ-R described above, and shown in Tables A, B and C in the Appendix.

Procedure

Participants initially received verbal instructions (see Box 1), adapted from Green and Gilhooly (1996), Ericsson and Simon (1993) and French et al. (2007). Respondents were informed that the interviewer could provide them with practical support in relation to completing the questionnaire (for example, reading the questions, or circling answers/ticking boxes), but was not able to elaborate on any of the questions. Prior to proceeding with the Think-Aloud task, participants completed a proforma that recorded demographic information, including age, sex, ethnicity, type of stroke, and year of diagnosis.

The Think-Aloud interview involved a practise phase comprised of the initial 10 questions of the identity sub-scale, which appeared first in the questionnaire. The purpose of the warm-up task was to allow participants to familiarise themselves with the Think-Aloud method; check that they were able to think aloud; and clarify any misunderstandings individuals had about the requirements of the task. Any questions or uncertainties were resolved at this stage. We opted to assign a warm-up task associated with the questionnaire to minimise confusion amongst stroke survivors with impaired cognition by engaging participants in one task instead of splitting their focus on two distinct tasks, as in other studies (Darker & French, 2009; French et al., 2007; van Oort et al., 2011).

Consistent with prior Think-Aloud studies, participants were not interrupted once they began completing the questionnaire, unless they were silent for around 10-seconds (Darker & French, 2009; French et al., 2007; van Oort et al., 2011).

<u>Analysis</u>

The Think-Aloud interviews were analysed according to established guidelines (van Someren et al., 1994). The first step involved sectioning each transcript to obtain episodes of text referring to each illness belief domain (e.g., identity, consequences, personal control etc.) This was followed by segmenting of the text (coding), where relevant sections of participants' responses to particular items within each episode were assigned to specific categories (codes). The coding framework was developed iteratively following each interview, as described above. Many of our categories reflected the coding frameworks that have been employed by previous Think-Aloud studies (e.g., Tourangeau, Rips, and Rasinski (2000), French et al. (2007), van Oort et al. (2011), and McCorry et al. (2013)). The coding framework used in the present analysis was as follows:

1. No problems, indicating that participants demonstrated no problems with the item (i.e., thought out loud while responding to the question);

2. Missing or insufficient thinking aloud, where a response for a particular item was missing, because of inadequate thinking out loud (i.e., participant was silent while responding to the question);

3. Re-read or stumbled in reading (e.g., stammered, stuttered, or repeated the question several times), indicating problems with peoples' understanding of the question;

4. Difficulty generating an answer, where participants expressed that they were not sure of the response that they would provide, which was either because of problems with how well people understood the question, or an item that was not applicable to their current circumstances;

5. Difficulty with the response format, where respondents expressed problems with indicating their answer;

6. Questioned content, suggesting problems with how the question was worded;

7. Confusion or misinterpreted, where participants expressed that they did not fully understand the question, or answered a different question to that being asked;

8. Incongruent response, where respondents' written and verbal responses did not match.

Problems relating to the above-mentioned categories were then thematically organised. The resultant themes covered sub-scale specific issues with the Stroke IPQ-R, and issues also pertinent to use of the Think-Aloud method in our sample.

Final Version and Testing of the Stroke IPQ-R

Following the Think-Aloud interviews, we conducted a further phase of consultation with our expert stroke panel of clinicians, academics, and a representative from our patient advocate group, in order to finalise the questionnaire. The internal consistency of this version was then evaluated in a group of 50 stroke survivors (mean age=66.9 years (SD=14.5 years); 68% male gender; 98% white-British ethnicity) within the acute phase of stroke (≤three-months post-stroke), recruited based on consecutive admissions to acute stroke and rehabilitation wards and outpatient clinics in one hospital in Nottingham (UK). Participants completed the Stroke IPQ-R at baseline (after study enrolment) and at three-months post-stroke.

STATA 13 (StataCorp LP, College Station, TX, USA) was used to examine internal consistency. Scores were generated for each Stroke IPQ-R sub-scale by summating individual item-scores (where strongly disagree =1; disagree =2; I don't know = 3; agree = 4; and strongly agree = 5) (Moss-Morris et al., 2002). The coding for negatively worded items was reversed as appropriate. Mean scores and standard deviations (or where data were non-normal, the median and interquartile range) were subsequently computed. The internal consistency of the sub-

scales was then assessed using the Cronbach's alpha statistic; the accepted range for which is between 0.7 and 0.8 (Field, 2013).

Results

Our analysis identified two groups of problems: 1) with completion of the Stroke IPQ-R; and 2) with using the Think-Aloud method with our participants. In this section, we have presented our summary of these findings according to these groups of problems.

Summary of Problems with Completing the Stroke IPQ-R

Overall, participants experienced few problems with sub-scales of the Stroke IPQ-R. The total number of problems encountered was 179 out of a possible 658 (27.2%). The problems per sub-scale are summarised in Table 2. Items relating to causes (18%); identity (17%); treatment control – rehabilitation (12%); and treatment control – medical treatment (10%) yielded the greatest percentage of problems. Conversely, the categories that encapsulated most of the problems were: missing or insufficient Think-Aloud data generated (37.4%); confusion or misinterpreted the question (18.4%); re-read or stumbled while reading the question (14.5%); difficulty generating an answer (14%); and questioning the content (11.7%).

INSERT TABLE 2 HERE

Problems with the Wording of Items

Complexity of Wording

Problems with the complexity of wording emerged for several items across the sub-scales, and prompted respondents to seek elaboration or reassurance of their understanding from the interviewer. For example, the wording of specific symptoms on the identity sub-scale caused problems (6 out of 30 problems), and these affected two out of six of the respondents (e.g., "What's fatigue?" [Participant 5])

Similar was the case for the 'hereditary' causal attribution, which was queried by Participant 6: "What's that word mean?" In addition, the wording of the 'high cholesterol' item created difficulties for two out of six participants, and for one of these participants, it affected their ability to generate a confident answer:

"High cholesterol…I did have high cholesterol I think, so I'll put that. I don't know cos I never had it checked. I'll just leave that one shall I?...I'm not sure so shall I just put disagree?" [Participant 4]

Further, two out of six participants experienced problems with the word 'consequences' from an item on the consequences sub-scale: "My stroke has major consequences on my life…What do you mean consequences?" [Participant 5]. Participant 5 also struggled with the word 'anxious' from an item on the emotional representations sub-scale: "Ah, explain a little bit how you mean anxious?"

Negative Wording

Negatively worded items also caused problems. This mostly affected the personal control and illness coherence sub-scales. For example, four out of six participants had problems with a particular item from the personal control sub-scale, and this tended to be demonstrated by people re-reading or stumbling in reading the question:

"I believe that nothing I do will affect my recovery from stroke. (Silence) I believe that nothing I do will affect my recovery from stroke." [Participant 1]

Similarly, two out of six participants had problems with a further item from this sub-scale:

"I believe that my actions will have no effect on the outcome of my recovery. I believe that my actions will have NO effect on the outcome of my recovery…" [Participant 3]

This was also found for two items from the illness coherence sub-scale for two out of six participants, and again resulted in people re-reading or stumbling in reading the questions. For these items, it led to an inability to formulate a response. For example:

"I don't understand my recovery from stroke. (Silence) I don't really understand that one. I don't understand my recovery from stroke…Hmm…(Silence) Not sure what to put for that one." [Participant 4]

"My condition doesn't make any sense to me. (Silence) My condition doesn't make any sense. Any sense to me. What?" [Participant 6]

Problems with negative wording did not generally emerge for the remainder of items on the questionnaire despite the similar way in which they were worded (e.g., 'My stroke does not have much effect on my life' from the consequences sub-scale). This may perhaps have been because participants became accustomed to this style of wording by the time they needed to respond to these items that appeared later in the questionnaire.

Problems with Answering Items on the Treatment Control Sub-Scale

The treatment control sub-scales were generally problematic (40 out of 179 problems overall). These sub-scales had been separated for medical treatment and rehabilitation, and appeared with a short preamble (including examples). However, participants in this study tended to blur the questions on these two separate sub-scales, becoming confused as to whether they were responding for their medical treatment or rehabilitation. For example, Participant 4 responded to an item from the treatment control – medical treatment sub-scale as though it was asking about rehabilitation:

"I believe there is nothing which…can help my recovery from stroke. Disagree because there's people (silence) people have been really good actually you know, and there's been (silence)…Physiotherapists were good. Getting me out the house, a bit up the road you know. Erm (silence) erm the doctor. I think everybody really you know." [Participant 4]

Conversely, Participant 2 answered the same item for the treatment control – rehabilitation sub-scale but as though they were answering for their medical treatment:

"I believe there is nothing which can help my recovery from stroke. No. I disagree. Like erm the medication I take is Warfarin, and there are already drug trials being done for an alternative so again you've got to put your faith in research." [Participant 2]

Comprehension problems also emerged on this sub-scale, which were demonstrated in various ways, including re-reading or stumbling while reading and being unable to generate an answer. For example:

"I believe that my rehabilitation can control the symptoms of my stroke (Silence) I don't know, I don't understand that one either. I believe that my rehabilitation can control the symptoms of my stroke." [Participant 4]

Challenges in Using the Think-Aloud Method

We also observed that our respondents struggled with the Think-Aloud method in two ways. First, missing or insufficient Think-Aloud data (i.e., participant was silent while responding to the question), which as mentioned previously, generated most problems (67 of 179 problems) in this study. This affected most of the sub-scales of the Stroke IPQ-R (Table 2). For example, missing Think-Aloud data contributed to 10 out of 30 problems on the identity sub-scale; 23 out of 33 problems on the causal sub-scale; and 34 out of 116 problems on the sub-scales for the remainder of illness belief domains. For the identity sub-scale, this was evident for three out of six respondents, and the most noteworthy example occurred for Participant 4, who did not have Think-Aloud data for various concurrent symptoms: 'bladder problems' and 'bowel problems,' and then again for 'dizziness' and 'poor balance.' However, there were Think-Aloud data for the symptom, 'sleep difficulties,' which appeared intermediate in the list comprising the abovementioned symptoms. This could have been because the participant was responding to the items without any problems, and/or they forgot to think aloud.

Indeed, this participant was prompted by the interviewer to 'keep talking' at this point in their interview. The remainder of problems with missing or insufficient Think-Aloud data occurred towards the end of the questionnaire. For instance, four out of six respondents had missing or insufficient Think-Aloud data for the causal sub-scale, and this was evident for several of the causal attributions. The causal sub-scale appeared last in a lengthy questionnaire. Participant 1 commented at the end of the interview: *"The length is…long…a disadvantage…Quite a few questions."*

Second, participants expressed a desire to elaborate on their responses to questions on the Stroke IPQ-R, and share their views and experiences of their post-stroke journey. However, this is beyond the scope of the Think-Aloud method where the interviewer's role is to remain passive in the interaction, except for providing instructions to participants to 'think aloud' (Willis, 2005, Beatty and Willis, 2007). An example from Participant 2 is: "I believe that what I do will determine whether my stroke gets better or worse…at this stage in my career…I think I've adapted really well, and I know what I have to do now. And for me it's not about getting better or worse, it's about maintaining what I have…and making sure it doesn't deteriorate and I know things might not, some things won't get better and I know they won't get better. Some things MIGHT get better (silence) so yeah, agree."

Final Version of the Stroke IPQ-R

A summary of the amendments/final version of the Stroke IPQ-R is shown in Tables D, E, and F in the Appendix. After the Think-Aloud interviews, we consulted again with our expert stroke panel. Discussions led to three further modifications to the questionnaire. First, the 'I believe' prefix was re-considered, and deemed too abstract and likely to cause difficulties in comprehension in stroke survivor respondents. Therefore, we removed the prefix from the beginning of each question. Second, questions on treatment control sub-scales that were previously separated for medical treatment and rehabilitation were re-combined in accordance

with the original IPQ-R. Third, a longer preamble was added to the treatment control sub-scale to provide a more thorough description (with examples) of what was to be understood by 'treatment' and 'rehabilitation' (termed 'therapy' in this final version).

We also decided to make other minor modifications to the questionnaire prior to testing, based on the problems encountered by respondents in our Think-Aloud interviews. These changes included: removal of several repetitious causal attributions from the causal subscale; simplification of the wording of items; and removal of surplus negatively worded items that were not included in the original/validated version of the IPQ-R.

Internal Consistency of Stroke IPQ-R Sub-Scales

The mean/median scores for each Stroke IPQ-R sub-scale and findings for internal consistency are summarised in Table 3. Cronbach's alphas indicated that all sub-scales, except for the treatment control sub-scale, were internally consistent. Cronbach's alpha was lower than desired for this sub-scale (α=0.42).

INSERT TABLE 3 HERE

Discussion

The main purpose of this study was to evaluate a version of the Illness Perception Questionnaire-Revised (IPQ-R) for stroke survivors, using the Think-Aloud method. We also had two further aims. First, to examine the internal consistency of Stroke IPQ-R sub-scales for survivors within the acute phase of stroke ($\leq$three-months post-stroke). Second, to comment on the utility of the Think-Aloud method for developing questionnaires for stroke survivors.

The Think-Aloud interviews identified several problems with completion of the Stroke IPQ-R. First, participants struggled to comprehend items on the Stroke IPQ-R that had complex wording or were negatively worded. Complex wording is a common issue in health questionnaires (D'Alonzo, 2011, Mathers et al., 2007). It has been argued that measurement

instruments should generally be worded for age 12 reading skills (Streiner and Norman, 2003). Therefore, future researchers are reminded to ensure that the wording of questionnaires (including the IPQ-R) is kept as simple as possible. Problems with negatively worded items is consistent with the study by McCorry et al. (2013), and is particularly relevant to the IPQ-R, which includes many negatively worded items. It is generally considered beneficial to include negatively worded items in order to address problems with biased responding in questionnaires (Streiner and Norman, 2003). However, McCorry et al. (2013) suggested that the process of agreeing or disagreeing with a negatively worded item increases the cognitive complexity of the task of responding to a questionnaire. This is likely to have added an additional layer of complexity for stroke survivors in responding to items on the Stroke IPQ-R. These were designed to elicit individuals' beliefs about their stroke, which some may argue is an already cognitively demanding task. While it has been suggested that negatively worded items should be avoided in the construction of questionnaires (Roszkowski and Soven, 2010), it is yet to be decided whether the benefits of reducing response bias outweigh the added complexities in responding. Given the large number of negatively worded items on the IPQ-R, this is an important question that would be helpful to consider in future research.

Despite these problems with the wording of the Stroke IPQ-R, we found that all sub-scales, except for the treatment control sub-scale, were internally consistent for patients within the acute phase of stroke. This finding seems to reinforce the problems that arose in our study relating to questions on the treatment control sub-scale. We elaborate on this issue below as we now move into discussing the challenges that we faced in using the Think-Aloud method with our participants.

The first challenge related to respondents demonstrating a desire to elaborate on their responses to questionnaire items. However, as mentioned earlier, the Think-Aloud method is not conducive to any kind of elaboration (Willis, 2005, Beatty and Willis, 2007). The role of

the interviewer is to remain passive in the interaction, and simply provide prompts to the participant to 'keep talking.' We instructed participants to "tell me everything that you are thinking as you read each question" but to "not try to explain to me what you are saying." However, from an ethical point of view, this is a challenge. Essentially, we are preventing our interview volunteers from talking about an important and life-changing experience that they have had. An issue that is likely to also be applicable to other illness groups. It is also important from a methodological perspective. For example, by allowing our participants to elaborate on their post-stroke journey of recovery (as they had desired to), we may have been able to uncover exactly why respondents had struggled so much in answering questions on the treatment control sub-scale. Important information that is missing from our analyses. Prior research by Twiddy (2008) indicated that participants did not consider themselves to have received any treatment, but we can only speculate as to the relevance of this explanation to our respondents.

Therefore, it may be that future researchers consider elaboration in Think-Aloud interviews as an opportunity (for gaining insight, high quality and valid data etc.) rather than a problem per se. For example, by modifying the Think-Aloud using elements of the alternative 'verbal probing' cognitive interviewing paradigm (Willis, 2005, Beatty and Willis, 2007). This involves the interviewer guiding the interview by asking specific, direct questions about how respondents have formed their responses (Willis, 2005, Beatty and Willis, 2007). This approach would allow a conversation to happen between the interviewer and respondent (as and when appropriate during the course of the interview), to determine what respondents felt were the issues that needed to be addressed with problematic questions. It could also leave respondents feeling more satisfied that their voice had been heard, and experiences shared.

In addition, a more general theoretical point based on our experience and also that of Twiddy (2008) is that a re-examination of the way in which beliefs about treatment effectiveness are conceptualised in the CSM may be worthy of further consideration. While the

CSM assesses a dimension of peoples' treatment beliefs within the treatment control domain, there is a considerable body of literature that has extended the CSM to specifically consider patients' views about their medication: the 'Necessity and Concerns Framework' (Horne and Weinman, 1999, Horne et al., 1999). The 'Necessity-Concerns Framework' suggests that people undertake a cost-benefit analysis of their medication, where their own beliefs about the necessity of their medication for improving or maintaining their health are weighed up against their concerns about possible adverse effects (Horne and Weinman, 1999). These medication beliefs can be measured using a validated questionnaire, such as the Beliefs about Medicines Questionnaire (Horne et al., 1999).

However, treatment can be much more complex than simply medication-taking, especially in conditions such as stroke that often require an integrated package of care, such as rehabilitation, lifestyle changes, surgery etc. (Intercollegiate Stroke Working Party, 2016). But these other aspects of treatment have not yet been fully considered in the CSM, and may explain why stroke survivors in our study seemed to struggle most with the treatment control sub-scale. These struggles persisted despite our attempts to elaborate these questions to cover the most common aspects of post-stroke treatment (i.e., medical treatment and rehabilitation).

To our knowledge, only one CSM study thus far has examined peoples' beliefs about receiving diverse treatments (medication or revascularisation surgery e.g., angioplasty or bypass procedures), and was carried out in a group with coronary artery disease (Hirani and Newman, 2005). The findings from this study demonstrated that individuals evaluate their treatment based not only on beliefs about the ability of the treatment to cure their condition (as per Leventhal's treatment control domain from the CSM), but also on their concerns and risks of undergoing the treatment (consistent with the 'Necessity-Concerns Framework'); the value that they ascribe to their treatment; and their satisfaction with the choice of treatment that they have been offered. The authors subsequently developed a study-specific instrument to measure

these diverse treatment beliefs, named the 'Treatments Representations Inventory' (Hirani et al., 2008). Therefore, the findings by Hirani and Newman (2005) importantly show that there is scope to further elaborate the CSM treatment control domain, above and beyond what has already been undertaken in the 'Necessity and Concerns Framework,' and to develop suitable instruments to accurately measure these newly elaborated treatment beliefs. We strongly advise future researchers to consider this as a fruitful avenue for further research on the CSM in relation to stroke, and other conditions with treatment packages that are similarly complex.

Our second challenge in using the Think-Aloud method with stroke survivors was missing or insufficient Think-Aloud data generated, where participants were not consistently verbalising their thoughts during the Think-Aloud task. This was a considerable problem in our study, and was also observed by McCorry et al. (2013). McCorry et al. (2013) argued that this can be a problem for studies using the Think-Aloud approach, though missing or insufficient Think-Aloud generated did not emerge for other studies to have used this method that did not examine the IPQ-R (e.g., Darker and French (2009); French et al. (2007); French and Hevey (2008); and van Oort et al. (2011)). Therefore, this may be an issue specifically for Think-Aloud analyses of the IPQ-R.

It is important to note that while missing or insufficient Think-Aloud data generated may not indicate a problem at all (i.e., participants could be responding to the item without any problems), the Think-Aloud method is highly dependent upon thinking aloud (van Someren et al., 1994). Therefore, peoples' silence limits the validity and potential usefulness of the approach. One explanation from the present study is the length of the IPQ-R (comprised of > 50 items), which was likely to increase the burden of completion on participants. This can lead to fatigue, inadequate completion and poor quality data (Rolstad et al., 2011), and is particularly problematic for stroke survivors, who are already commonly affected by issues such as fatigue and forgetfulness after stroke (Glader et al., 2002, Maud, 2006). Indeed, absent

responses in the present study tended to happen more frequently towards the end of the Stroke IPQ-R. For example, these contributed to 23 out of 33 problems on the causal sub-scale, which appears last in the questionnaire. Therefore, respondents may have become fatigued and forgot to 'keep talking.' By contrast, the study by van Oort et al. (2011) examined peoples' responses to the Brief IPQ, which is a shorter, nine-item version of the IPQ-R (Broadbent et al., 2006). van Oort et al. (2011) found that the Think-Aloud analysis of the Brief IPQ was less affected by absent responses.

This may indicate a more general challenge in using the Think-Aloud method with stroke survivors, and other patient groups with similar difficulties (e.g., cognitive/communication impairments, fatigue etc.). The implications of this for future use of the Think-Aloud approach are two-fold. First, more frequent prompts to 'keep talking' might be necessary to enhance the validity of the method for stroke survivors. Second, consideration should be given to questionnaire length. For instance, it may be that the Think-Aloud method performs well with stroke survivors, but that the quality of the data obtained is compromised in longer scales. This seems particularly relevant to illness belief questionnaires. For example, Rolstad et al. (2011) argued that in addition to length, a cognitively demanding questionnaire (which the IPQ-R is likely to be) can also affect the quality of responses. This means that we are presenting respondents with an even more difficult challenge that originally anticipated. We are asking them to think aloud whilst completing a long questionnaire requiring them to consider what they believe about their condition. Therefore, it may be helpful for future researchers to examine ways in which the IPQ-R could be shortened, for example using Rasch techniques (Rasch, 1960). Studies have shown that Rasch analysis is able to determine which are the best performing items on a questionnaire for a specific illness group (e.g., Lerdal et al. (2014)). Or alternatively, researchers could consider using the Brief IPQ, which has recently been advocated as a promising questionnaire with good psychometric properties to use for

measuring illness beliefs in a range of patients (Broadbent et al., 2015). But, it is important to bear in mind that the Brief IPQ is a generic questionnaire that will also require adaptation to a specific illness group (Broadbent et al., 2006).

Strengths and Limitations

A strength of the present study was that it was the first to use the Think-Aloud method with stroke survivors. Furthermore, it is one of only two studies that have used the Think-Aloud approach to uncover what people think when completing the IPQ-R; the preeminent scale for measuring illness beliefs.

The present study was limited in two ways. First, our sample size was small in comparison to some of the studies utilising this approach that involved between 23 and 85 participants (average of around 40) (Boeije and Janssens, 2004, Darker and French, 2009, French and Hevey, 2008, McCorry et al., 2013, Westerman et al., 2008). However, there are currently no guidelines for the number of participants to be included in a Think-Aloud study. In addition, it has been argued that even in larger samples, themes can be formed as early as six interviews (as was the case in our study) (Guest et al., 2006), rendering the collection of further data unnecessary (Mason, 2010).

Second, while we recruited purposively in terms of age, gender, education, type of stroke, stroke severity, and time since stroke, our sample was not ethnically diverse. Given the disparities that can occur between ethnic groups with regard to questionnaire responses (Wang et al., 2013), it may have been helpful to consider the perspectives of people from other ethnicities in the present research.

Conclusions and Implications

In conclusion, through Think-Aloud interviews, the present study identified several problems with completion of the Stroke IPQ-R, including missing or insufficient Think-Aloud data generated (i.e., participants did not think out loud); problems with complex and negative

item wording; and questions on the treatment control sub-scale. Nevertheless, we modified the Stroke IPQ-R on the basis of our Think-Aloud findings and expert feedback, and found that all sub-scales, except for the treatment control sub-scale, were internally consistent for patients within the acute phase of stroke (≤three-months post-stroke).

However, in order to reduce the impact of missing or insufficient Think-Aloud generated, we recommended that future researchers consider the length of questionnaires evaluated with this method, particularly in a group (such as stroke survivors) where burden, fatigue, and forgetfulness are likely. In addition, we highlighted that it may be beneficial to probe respondents to encourage elaboration of their answers. Not only would this satisfy participants' desire to share their story, such as of their post-stroke journey of recovery, but it would also allow for an in-depth exploration of specific areas in which difficulties with items occurred. For example, the treatment control sub-scale of the Stroke IPQ-R. It is clear from our findings that this sub-scale needs a further elaboration, but what is less clear is the best way in which this should be done. We suggest that developing a better understanding of individuals' beliefs about their post-stroke treatment, such as through semi-structured qualitative interviews, would be a good point at which to start. This could then facilitate an elaboration of the CSM treatment control domain initially for stroke, with possibilities for eventual extension to other conditions.

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References

BEATTY, P. C. & WILLIS, G. B. 2007. Research synthesis: the practice of cognitive interviewing. Public Opinion Quarterly, 71**,** 287-311.

BOEIJE, H. R. & JANSSENS, A. C. J. W. 2004. 'It might happen or it might not': how patients with multiple sclerosis explain their perception of prognostic risk. Social Science & Medicine, 59**,** 861-868.

BROADBENT, E., PETRIE, K. J., MAIN, J. & WEINMAN, J. 2006. The Brief Illness Perception Questionnaire. Journal of Psychosomatic Research, 60**,** 631-637.

BROADBENT, E., WILKES, C., KOSCHWANEZ, H., WEINMAN, J., NORTON, S. & PETRIE, K. J. 2015. A systematic review and meta-analysis of the Brief Illness Perception Questionnaire. Psychology & Health, 30**,** 1361-1385.

CHARTERS, E. 2003. The Use of Think-Aloud Methods in Qualitative Research. An Introduction to Think-Aloud methods. Brock Education 12**,** 68-82.

D'ALONZO, K. T. 2011. Evaluation and revision of questionnaires for use among low-literacy immigrant Latinos. Revista Latino-Americana De Enfermagem, 19**,** 1255-1264.

DARKER, C. D. & FRENCH, D. P. 2009. What sense do people make of a theory of planned behaviour questionnaire? A think-aloud study. Journal of Health Psychology, 14**,** 861-871.

ERICSSON, K. A. & SIMON, H. A. 1993. Protocol analysis: verbal reports as data (rev. ed.), Cambridge, Massachusetts, The MIT Press.

FIELD, A. P. 2013. Discovering statistics using IBM SPSS Statistics: and sex and drugs and rock 'n' roll, London, Sage Publications Ltd.

FORD, C. 2007. The relationship between beliefs about stoke and post-stroke depression Doctor of Clinical Psychology, University of East Anglia.

FRENCH, D. P., COOKE, R., MCLEAN, N., WILLIAMS, M. & SUTTON, S. 2007. What do people think about when they answer theory of planned behaviour questionnaires? A 'think aloud' study. Journal of Health Psychology, 12**,** 672-87.

FRENCH, D. P. & HEVEY, D. 2008. What do people think about when answering questionnaires to assess unrealistic optimism about skin cancer? A think aloud study. Psychology, Health & Medicine, 13**,** 63-74.

GLADER, E.-L., STEGMAYR, B. & ASPLUND, K. 2002. Post-stroke fatigue: a 2-year follow-up study of stroke patients in Sweden. Stroke, 33**,** 1327-1333.

GUEST, G., BUNCE, A. & JOHNSON, L. 2006. How many interviews are enough? Field Methods, 18**,** 59-82.

HIRANI, S. P. & NEWMAN, S. P. 2005. Patients' beliefs about their cardiovascular disease. Heart, 91**,** 1235-1239.

HIRANI, S. P., PATTERSON, D. L. H. & NEWMAN, S. P. 2008. What do coronary artery disease patients think about their treatments? An assessment of patients' treatment representations. Journal of Health Psychology, 13**,** 311-322.

HORNE, R. & WEINMAN, J. 1999. Patients' beliefs about prescribed medicines and their role in adherence to treatment in chronic physical illness. Journal of Psychosomatic Research, 47**,** 555-567.

HORNE, R., WEINMAN, J. & HANKINS, M. 1999. The beliefs about medicines questionnaire: the development and evaluation of a new method for assessing the cognitive representation of medication. Psychology and Health, 14**,** 1-24.

INTERCOLLEGIATE STROKE WORKING PARTY 2016. National clinical guideline for stroke. Fifth edition. London, United Kingdom: Royal College of Physicians.

JOHNSTON, M., BONETTI, D., JOICE, S., POLLARD, B., MORRISON, V., FRANCIS, J. J. & MACWALTER, R. 2007. Recovery from disability after stroke as a target for a behavioural intervention: results of a randomized controlled trial. Disability & Rehabilitation, 29**,** 1117-1127.

JOHNSTON, M., MORRISON, V., MACWALTER, R. & PARTRIDGE, C. 1999. Perceived control, coping and recovery from disability following stroke. Psychology & Health, 14**,** 181-192.

JOICE, S., BONETTI, D., MACWALTER, R. & MORRISON, V. 2004. Illness representations and distress in stroke patients: an analysis using the SRM. British Psychological Society, Division of Health Psychology Conference., 2003.

JOICE, S., JOHNSTON, M. & BONETTI, D. 2003. Using Leventhal's self-regulation model to explore non-adherence to a workbook intervention for stroke patients. British Psychological Society, Division of Health Psychology Conference., 2002.

KLINEDINST, N. J., DUNBAR, S. B. & CLARK, P. C. 2012. Stroke survivor and informal caregiver perceptions of post-stroke depressive symptoms. The Journal of Neuroscience Nursing, 44**,** 72-81.

LERDAL, A., KOTTORP, A., GAY, C. L., GROV, E. K. & LEE, K. A. 2014. Rasch analysis of the Beck Depression Inventory-II in stroke survivors: A cross-sectional study. Journal of Affective Disorders, 158**,** 48-52.

LEVENTHAL, H., BENYAMINI, Y., BROWNLEE, S., DIEFENBACH, M., LEVENTHAL, E., PATRICK-MILLER, L. & ROBITAILLE, C. 1997. Illness representations: theoretical foundations. In: PETRIE, K. J. & WEINMAN, J. (eds.) Perceptions of health and illness. Amsterdam: Harwood Academic.

LEVENTHAL, H., BRISSETTE, I. & LEVENTHAL, E. A. 2003. The common-sense model of self-regulation of health and illness. In: CAMERON, L. D. & LEVENTHAL, H. (eds.) The self-regulation of health and illness behaviour. Oxon, United Kingdom: Routledge.

LEVENTHAL, H., LEVENTHAL, E. A. & CONTRADA, R. J. 1998. Self-regulation, health and behavior: a perceptual-cognitive approach. Psychology & Health, 13**,** 717 - 733.

LEVENTHAL, H., MEYER, D. & NERENZ, D. R. 1980. The common sense representation of illness danger. In: RACHMAN, S. (ed.) Contributions to medical psychology. New York, United States of America: Pergamon.

MASON, M. 2010. Sample size and saturation in PhD studies using qualitative interviews. 2010, 11.

MATHERS, N., FOX, N. & HUNN, A. 2007. Surveys and questionnaires. The NIHR RDS for the East Midlands/Yorkshire & the Humber.

MAUD, A. 2006. Memory loss after stroke. Neurology, 67**,** E14-E15.

MCCORRY, N. K., SCULLION, L., MCMURRAY, C. M., HOUGHTON, R. & DEMPSTER, M. 2013. Content validity of the illness perceptions questionnaire – revised among people with type 2 diabetes: A think-aloud study. Psychology & Health, 28**,** 675-685 11p.

MOSS-MORRIS, R., WEINMAN, J., PETRIE, K. J., HORNE, R., CAMERON, L. D. & BUICK, D. 2002. The revised illness perception questionnaire (IPQ-R). Psychology & Health, 17**,** 1-16.

MURTAGH, F. E. M., ADDINGTON-HALL, J. M. & HIGGINSON, I. J. 2007. The value of cognitive interviewing techniques in palliative care research. Palliative Medicine, 21**,** 87-93.

O'CARROLL, R. E., CHAMBERS, J. A., DENNIS, M., SUDLOW, C. & JOHNSTON, M. 2013. Improving adherence to medication in stroke survivors: a pilot randomised controlled trial. Annals of Behavioural Medicine, 46**,** 358-68.

O'CARROLL, R. E., WHITTAKER, J., B, H., JOHNSTON, M., SUDLOW, C. & DENNIS, M. 2011. Predictors of adherence to secondary preventive medication in stroke patients. Annals of Behavioral Medicine, 41**,** 383-390.

PHILLIPS, L. A., DIEFENBACH, M. A., ABRAMS, J. & HOROWITZ, C. R. 2015. Stroke and TIA survivors' cognitive beliefs and affective responses regarding treatment and future stroke risk differentially predict medication adherence and categorised stroke risk. Psychology & Health, 30**,** 218-232.

RASCH, G. 1960. Probabilistic models for some intelligence and attainment tests., Chicago, The University of Chicago Press.

ROLSTAD, S., ADLER, J. & RYDÉN, A. 2011. Response burden and questionnaire length: is shorter better? A review and meta-analysis. Value in Health, 14**,** 1101-1108.

ROSZKOWSKI, M. J. & SOVEN, M. 2010. Shifting gears: consequences of including two negatively worded items in the middle of a positively worded questionnaire. Assessment & Evaluation in Higher Education, 35**,** 113-130.

SJÖLANDER, M., ERIKSSON, M. & GLADER, E.-L. 2013. The association between patients' beliefs about medicines and adherence to drug treatment after stroke: a cross-sectional questionnaire survey. BMJ Open, 3.

STREINER, D. L. & NORMAN, G. R. 2003. Health measurement scales, United States, Oxford University Press.

TWIDDY, M. 2008. Beliefs about stroke: negotiating shared understandings. Doctor of Philosophy, University of Leeds.

TWIDDY, M., HOUSE, A. & JONES, F. 2012. The association between discrepancy in illness representations on distress in stroke patients and carers. Journal of Psychosomatic Research, 72**,** 220-225.

VAN OORT, L., SCHRODER, C. & FRENCH, D. P. 2011. What do people think about when they answer the Brief Illness Perception Questionnaire? A 'think-aloud' study. British Journal of Health Psychology, 16**,** 231-45.

VAN SOMEREN, M. W., BARNARD, Y. F. & SANDBERG, J. A. C. 1994. The Think Aloud method: a practical guide to modelling cognitive processes. London, UK: Academic Press.

WANG, R., HEMPTON, B., DUGAN, J. P. & KOMIVES, S. R. 2013. Cultural differences: why do Asians avoid extreme responses? Survey Practice, 1.

WEINMAN, J., PETRIE, K. J., MOSS-MORRIS, R. & HORNE, R. 1996. The illness perception questionnaire: a new method for assessing the cognitive representation of illness. Psychology & Health, 11**,** 431-445.

WESTERMAN, M. J., HAK, T., SPRANGERS, M. A. G., GROEN, H. J. M., WAL, G. & THE, A.-M. 2008. Listen to their answers! Response behaviour in the measurement of physical and role functioning. Quality of Life Research, 17**,** 549-558.

WILLIS, G. B. 2005. Cognitive interviewing: a tool for improving questionnaire design, Thousand Oaks, CA, Sage Publications.

WILLIS, G. B. & ARTINO, A. R. 2013. What do our respondents think we're asking? Using cognitive interviewing to improve medical education surveys. Journal of Graduate Medical Education, 5**,** 353-356.

Table 1. Characteristics of the Think-Aloud sample

Participant	Age	Gender	Ethnicity	Type of stroke	Year of diagnosis	University education?
1	78	Male	White-British	Ischaemic	1999	✔
2	31	Female	White-British	Ischaemic	1999	✔
3	40	Female	African-British	SAH	2012	✔
4	64	Female	White-British	Ischaemic	2013	✘
5	72	Female	White-British	Ischaemic	2013	✘
6	68	Male	White-British	Ischaemic	2013	✘

Symbols and abbreviations: SAH; Subarachnoid Haemorrhage

Table 2. Total problems across sub-scales of the Stroke IPQ-R

	Labels								
	No problems	Missing, or no sufficient thinking aloud	Re-read or stumbled in reading	Difficulty generating an answer	Difficulty with response format	Questioned content	Confusion or misinterpreted	Incongruent response	TOTAL PROBLEMS N (%)
Identity	130	10	2	7	4	2	4	1	30 (16.8%)
Timeline (acute/chronic)	31	1	2	1	2	3	1	0	10 (5.6%)
Timeline-cyclical	16	2	2	0	0	3	5	0	12 (6.7%)
Consequences	60	1	1	3	0	5	3	0	13 (7.3%)
Personal control	39	1	8	3	0	1	3	0	16 (8.9%)
Treatment control (medical treatment)	21	12	3	1	0	1	1	0	18 (10.1%)
Treatment control (rehabilitation)	12	11	3	2	0	2	4	0	22 (12.3%)
Illness coherence	13	0	4	0	0	0	5	0	9 (5.0%)
Emotional representations	61	6	1	4	0	3	2	0	16 (8.9%)
Causes	96	23	0	4	0	1	5	0	33 (18.4%)
TOTAL PROBLEMS N (%)	479	67 (37%)	26 (14.5%)	25 (14.0%)	6 (3.4%)	21 (11.7%)	33 (18.4%)	1 (0.6%)	179

Symbols and abbreviations: IPQ-R; Illness Perception Questionnaire-Revised

Table 3. Mean/median scores for the Stroke IPQ-R sub-scales, and internal consistency of the sub-scales

Stroke IPQ-R sub-scale	N Median (IQR), unless otherwise stated	Cronbach's alpha
Timeline (acute/chronic)	N=46 Mean=15.4 (SD=4.2)	0.83
Consequences	N=46 Mean=30.8 (SD=6.5)	0.82
Personal control	N=45 Mean=32.7 (SD=4.4)	0.77
Illness coherence	N=45 19 (4)	0.89
Timeline-cyclical	N=45 10 (6)	0.88
Treatment control	N=45 20 (2)	0.42
Emotional response	N=45 24 (7)	0.77
Causes	-	0.72
Identity	N=45 9 (7)	0.83

Symbols and abbreviations: IPQ-R: Illness Perception Questionnaire-Revised; IQR: Interquartile Range; SD: Standard Deviation.

"I have developed a questionnaire to learn more about peoples' beliefs about their stroke, such as what it is, what might have caused it, and how it affects their lives. I have tried to tailor this questionnaire to stroke survivors, and now want to find out whether what I have developed is okay for people, or whether there are ways that I can make it even better. I also want to check that people understand the questions in the way that I had meant them. To do this, I would like you to complete this questionnaire while thinking out loud. So I want you to tell me everything that you are thinking as you read each question and decide how to answer it. There is no right or wrong answer. It is okay if you find some of the questions easy or difficult to answer. I would like you to talk constantly. Please do not plan what you are going to say, just say whatever comes into your head. Do not try to explain to me what you are saying either. Just act as if you are alone in the room. If you remain silent for any long period of time, I will ask you to 'keep talking.' Please try to speak as clearly as possible, as I shall be recording you as you speak. Do you understand what I want you to do?

If you need any help with reading the questions, or indicating your responses (for example, by circling answers or ticking boxes), then I can help you with this. However, I will not be able to explain any of the questions to you. This is because part of the research is around making sure that the questionnaire is really clear for people who have had a stroke to answer.

I would like to first ask you for some information about you. This is so that when I report what I have found from the interviews, I can describe the kind of people that I had spoken to about my questionnaire."

Box 1. Verbal instructions provided to participants

APPENDIX

Table A. Summary of the initial modifications to the identity sub-scale of the Stroke IPQ-R

Item	Change(s)	Rationale
Pain	-	-
Difficulty swallowing	Added	Included in Twiddy-version
Sore throat	Removed	Not considered relevant to stroke by Stroke Research Partnership Group
Nausea	Removed	Not considered relevant to stroke by Stroke Research Partnership Group
Breathlessness	Removed	Not considered relevant to stroke by Stroke Research Partnership Group
Weight loss	-	-
Fatigue	-	-
Tight muscles	Added	Considered relevant to stroke by expert panel
Headaches	-	-
Bladder problems	Added	Considered relevant to stroke by expert panel
Bowel problems	Added	Considered relevant to stroke by expert panel
Sore eyes	Removed	Not considered relevant to stroke by Stroke Research Partnership Group
Wheeziness	Removed	Not considered relevant to stroke by Stroke Research Partnership Group
Upset stomach	Removed	Not considered relevant to stroke by Stroke Research Partnership Group
Sleep difficulties	-	-
Dizziness	-	-
Loss of strength	Removed	Incorporated in 'Paralysis' item
Poor balance	Added	Considered relevant to stroke by expert panel
Paralysis	Added; wording changed to 'Weakness or paralysis in arm or leg'	Considered relevant to stroke by expert panel; wording subsequently changed to be consistent with Twiddy-version
Poor vision	Added	Considered relevant to stroke by expert panel
Difficulty speaking	Added	Included in Twiddy-version
Forgetfulness	Added	Considered relevant to stroke by expert panel
Difficulty writing	Added	Included in Twiddy-version
Emotionality	Added; wording changed to 'Crying or laughing inappropriately'	Considered relevant to stroke by expert panel; wording subsequently changed following feedback from Stroke Research Partnership Group to improve comprehension by stroke survivors.
Poor concentration	Added	Considered relevant to stroke by expert panel
Difficulty reading	Added	Included in Twiddy-version
What I'm like as a person has changed	Added	Included in Twiddy-version
Getting upset or weepy	Added	Included in Twiddy-version
Clumsiness	Added	Included in Twiddy-version
Hearing difficulties	Added	Considered relevant to stroke by expert panel
Difficulty walking or getting around	Added	Considered relevant to stroke by expert panel
Reduced sensation	Added; wording changed to 'Tingling or numbness'	Considered relevant to stroke by expert panel; wording subsequently changed to be consistent with Twiddy-version
Stiff joints	-	-

Symbols and abbreviations: Twiddy-version; Stroke-specific version of the IPQ-R developed by (Twiddy 2008)

Table B. Summary of the initial modifications to the main sub-scales of the Stroke IPQ-R

Item	Change(s)	Rationale
Timeline Acute/Chronic		
My stroke will last a short time	Wording changed to 'I believe that the effects of my stroke will last for a short time'	Retained from original IPQ-R with wording initially amended from 'my illness' to 'my stroke' following recommendations by IPQ-R authors; wording subsequently changed to 'the effects of my stroke' and 'my condition' for greater relevance to stroke following feedback from Stroke Research Partnership Group; 'I believe' phrasing added to each statement following discussion with an expert panel who considered that making each question more personally relevant would improve comprehension by stroke survivors
My stroke is likely to be permanent than temporary	Wording changed to 'I believe that my condition is likely to be permanent than temporary'	
My stroke will last for a long time	Wording changed to 'I believe that the effects of my stroke will last for a long time'	
This stroke will pass quickly	Wording changed to 'I believe that the effects of my stroke will pass quickly'	
I expect to have this stroke for the rest of my life	Wording changed to 'I expect to have these symptoms of my stroke for the rest of my life'	
My stroke will improve in time	Wording changed to 'I believe that the symptoms of my stroke will improve in time'	
Consequences		
My stroke does not have much effect on my life	-	-
My stroke is a serious condition.	Wording changed to 'I believe that my stroke is a serious condition'	Retained from original IPQ-R with wording initially amended from 'my illness' to 'my stroke' following recommendations by IPQ-R authors; 'I believe' phrasing added to each statement following discussion with an expert panel who considered that making each question more personally relevant would improve comprehension by stroke survivors
My stroke has major consequences on my life	Wording changed to 'I believe that my stroke has major consequences on my life'	
My stroke strongly affects the way others see me	Wording changed to 'I believe that my stroke strongly affects the way others see me'	
My stroke causes difficulties for those who are close to me	Wording changed to 'I believe that my stroke causes difficulties for those who are close to me'	
My stroke has serious financial consequences	Wording changed to 'I believe that my stroke has had serious financial consequences'	
Since my stroke I fear becoming a burden on others	Added	Included in Twiddy-version
Item	**Change(s)**	*Rationale*
Consequences		
Memory problems since my stroke are affecting my life	Added; wording changed to 'I believe that memory problems since my stroke are affecting my life'	Included in Twiddy-version; 'I believe' phrasing added to each statement following discussion with an expert panel who
My stroke has strongly affected how I see myself	Added; wording changed to 'I believe that my stroke has strongly affected how I see myself'	
My stroke has badly affected my relationship with my family	Added; wording changed to 'I believe that my stroke has badly affected my relationship with my family'	

Item	Change(s)	Rationale
Emotional problems since my stroke are affecting my life	Added; wording changed to 'I believe that emotional problems since my stroke are affecting my life'	considered that making each question more personally relevant would improve comprehension by stroke survivors
Personal Control		
I need to avoid doing too much as this may cause another stroke	Added	Included in Twiddy-version
There is nothing I can do to prevent another stroke occurring	Added; wording changed to 'I believe that there is nothing I can do to prevent another stroke occurring'	Included in Twiddy-version; 'I believe' phrasing added to each statement following discussion with an expert panel who considered that making each question more personally relevant would improve comprehension by stroke survivors
What I do can determine whether my stroke gets better or worse	Wording changed to 'I believe that what I do will determine whether my stroke gets better or worse'	Retained from original IPQ-R with wording initially amended from 'my illness' to 'my stroke' following recommendations by IPQ-R authors; 'I believe' phrasing added to each statement following discussion with an expert panel who considered that making each question more personally relevant would improve comprehension by stroke survivors
The course of my stroke depends on me	Wording changed to 'I believe that the course of my recovery from stroke depends on me'	Retained from original IPQ-R with wording initially amended from 'my illness' to 'my stroke' following recommendations by IPQ-R authors; wording subsequently changed to 'my recovery' for greater relevance to stroke following feedback from Stroke Research Partnership; 'I believe' phrasing added to each statement following discussion with an expert panel who considered that making each question more personally relevant would improve comprehension by stroke survivors
Nothing I do will affect my stroke	Wording changed to 'I believe that nothing I do will affect my recovery from stroke'	
I have the power to influence my stroke	Wording changed to 'I believe that I have the power to influence my recovery from stroke'	
My actions will have no effect on the outcome of my stroke	Wording changed to 'I believe that my actions will have no effect on the outcome of my recovery from stroke'	
There is a lot which I can do to control my symptoms	Wording changed to 'I believe that there is a lot which I can do to control my symptoms'	Retained from original IPQ-R; 'I believe' phrasing added to each statement following discussion with an expert panel who considered that making each question more personally relevant would improve comprehension by stroke survivors
I am confident that I can manage my recovery well	Added	Considered relevant to stroke by expert panel and stroke literature
Item	**Change(s)**	*Rationale*
Treatment Control		
There is very little that can be done to improve my stroke	Wording changed to 'I believe that there is very little that can be done to improve my condition'	Retained from original IPQ-R with wording initially amended from 'my illness' to 'my stroke' following recommendations by IPQ-R authors; wording subsequently changed to 'my condition for greater relevance to stroke following feedback from Stroke Research Partnership Group

Item	Change(s)	Rationale
My treatment will be effective in curing my stroke	Wording changed to 'I believe that my medical treatment/rehabilitation will be effective in preventing another stroke from happening'	Retained from original IPQ-R with wording initially amended from 'my illness' to 'my stroke' following recommendations by IPQ-R authors; did not make sense to survivors from the Stroke Research Partnership Group, so item duplicated and separated according to medical treatment e.g., tablets to lower blood pressure and rehabilitation (therapy) e.g., physiotherapy for greater relevance to stroke; wording changed to emphasise stroke prevention to be consistent with Twiddy-version
The negative effects of my stroke can be prevented (avoided) by my treatment	Wording changed to 'I believe that the negative effects of my stroke can be prevented (avoided) by my medical treatment/rehabilitation'	Retained from original IPQ-R with wording initially amended from 'my illness' to 'my stroke' following recommendations by IPQ-R authors; did not make sense to survivors from the Stroke Research Partnership Group, so items duplicated and separated according to medical treatment e.g., tablets to lower blood pressure and rehabilitation e.g., physiotherapy for greater relevance to stroke; wording changed to 'symptoms of my stroke' to improve understanding of items by stroke survivors; 'I believe' phrasing added to each statement following discussion with an expert panel who considered that making each question more personally relevant would improve comprehension by stroke survivors
My treatment can control my stroke	Wording changed to 'I believe that my medical treatment/rehabilitation can control the symptoms of my stroke'	
Item	**Change(s)**	*Rationale*
Treatment Control		
My treatment will help me to recover	Added; wording changed to 'I believe that my medical treatment/rehabilitation will help me to recover'	Included in Twiddy-version; items duplicated and separated according to medical treatment e.g., tablets to lower blood pressure and rehabilitation e.g., physiotherapy for greater relevance to stroke; 'I believe' phrasing added to each statement following discussion with an expert panel who considered that making each question more personally relevant would improve comprehension by stroke survivors
There is nothing which can help my stroke	Wording changed to 'I believe that there is nothing which can help my recovery from stroke'	Retained from original IPQ-R with wording initially amended from 'my illness' to 'my stroke' following recommendations by IPQ-R authors; did not make sense to survivors from the Stroke Research Partnership Group, so wording was subsequently changed to 'my recovery' for greater relevance to stroke following discussion with an expert panel; 'I believe' phrasing added to each statement following discussion with an expert panel who considered that making each question more

Item	Change(s)	Rationale
		personally relevant would improve comprehension by stroke survivors
Illness Coherence		
The symptoms of my stroke are puzzling to me	Removed	Feedback from Stroke Research Partnership Group indicated difficulties with comprehension by stroke survivors
My stroke is a mystery to me	Removed	
I have a clear picture or understanding of my stroke	-	-
I don't understand my stroke	Wording changed to 'I don't understand my recovery from stroke'	Retained from original IPQ-R with wording initially amended from 'my illness' to 'my stroke' following recommendations by IPQ-R authors; wording subsequently changed to 'my recovery' for greater relevance to stroke following feedback from Stroke Research Partnership Group
My stroke doesn't make any sense to me	-	-
Item	**Change(s)**	*Rationale*
Timeline-Cyclical		
My stroke is very unpredictable	Wording changed to 'I believe that the effects of my stroke are very unpredictable'	Retained from original IPQ-R with wording initially amended from 'my illness' to 'my stroke' following recommendations by IPQ-R authors; wording subsequently changed to 'the effects of my stroke,' 'symptoms of my stroke' and 'my condition' for greater relevance to stroke following feedback from Stroke Research Partnership Group; 'I believe' phrasing added to each statement following discussion with an expert panel who considered that making each question more personally relevant would improve comprehension by stroke survivors
The symptoms of my stroke change a great deal from day to day	Wording changed to 'I believe that the symptoms of my stroke change a great deal from day to day'	
I go through cycles in which my stroke gets better or worse	Wording changed to 'I believe that I go through cycles in which my condition gets better or worse'	
My symptoms come and go in cycles	Wording changed to 'I have good days with few or no symptoms and bad days, when I have a lot of symptoms'	Original IPQ-R wording did not make sense to stroke survivors from Stroke Research Partnership Group, so item was subsequently changed for improved comprehension following discussion with an expert panel
Emotional Representations		
I feel embarrassed	Added; wording changed to 'I get embarrassed by the way I am since my stroke'	Considered relevant to stroke by expert panel and stroke literature; wording subsequently changed to be consistent with Twiddy-version
My stroke does not worry me	-	Retained from original IPQ-R with wording amended from 'my illness' to 'my stroke' following recommendations by IPQ-R authors

When I think about my stroke I get upset	-	Retained from original IPQ-R with wording amended from 'my illness' to 'my stroke' following recommendations by IPQ-R authors
I get depressed when I think about my stroke	Wording changed to 'Since my stroke I get depressed'	Retained from original IPQ-R with wording initially amended from 'my illness' to 'my stroke' following recommendations by IPQ-R authors; wording subsequently simplified following feedback from an expert panel to improve comprehension by stroke survivors
Having this stroke makes me feel anxious	Wording changed to 'The symptoms of my stroke make me feel anxious'	Retained from original IPQ-R with wording initially amended from 'my illness' to 'this stroke' following recommendations by IPQ-R authors; wording subsequently changed to be consistent with Twiddy-version
My stroke makes me afraid	-	-
My stroke makes me feel angry	-	-
I feel lost since my stroke	Added	Considered relevant to stroke by expert panel
I have lost confidence in myself since my stroke		
I do not feel in control of my emotions	Added	Included in Twiddy-version
My stroke is very worrying to those closest to me		
Those closest to me get very distressed about my stroke		

Symbols and abbreviations: IPQ-R: Illness Perception Questionnaire-Revised; Twiddy-version; Stroke-specific version of the IPQ-R developed by (Twiddy 2008)

Table C. Summary of the initial modifications to the causal sub-scale of the Stroke IPQ-R

Item	Change(s) made	Rationale
Stress or worry	-	-
Hereditary – it runs in my family	-	-
Diet or eating habits	-	-
Poor medical care in my past	-	-
My own behaviour	-	-
My mental attitude e.g., thinking about life negatively	-	-
Family problems or worries caused my stroke	-	-
Overwork	-	-
My emotional state e.g., feeling down, lonely, anxious, empty	-	-
Ageing	-	-
Alcohol	-	-
Smoking	-	-
My personality	-	-
High cholesterol	Added	Considered relevant to stroke by expert panel
High blood pressure	Added	
Diabetes	Added	
Irregular heartbeat	Added; wording changed to 'Problems with my heart'	Considered relevant to stroke by expert panel; wording subsequently changed in order to improve comprehension by stroke survivors
A germ or virus	-	-
Chance or bad luck	-	-
Inactive lifestyle	Added; wording changed to 'Not taking enough exercise'	Considered relevant to stroke by expert panel; wording subsequently changed to be consistent with Twiddy-version
Accident or injury	-	-
Pollution in the environment	Removed	Not considered relevant to stroke by expert panel
Altered immunity	Removed	

Table D. Summary of final changes to the identity sub-scale of the Stroke IPQ-R

Item	Change(s)	Rationale
Pain	Wording changed to 'Pain (not headaches)	Feedback from one participant in the Think-Aloud interviews suggested that the original wording overlapped too much with the 'Headaches' item
Difficulty swallowing	-	-
Weight loss	-	-
Fatigue	Wording changed to 'Extreme tiredness'	Original wording emerged from Think-Aloud interviews to be too complex
Tight muscles	Wording changed to 'Stiffness in muscles'	Expert feedback suggested that the revised wording would improve comprehension by stroke survivors
Headaches	-	-
Bladder problems	-	-
Bowel problems	-	-
Sleep difficulties	-	-
Dizziness	-	-
Poor balance	-	-
Weakness or paralysis in arm or leg	-	-
Poor vision	Wording changed to 'Difficulty seeing things'	Wording revised to be consistent with other related symptoms (e.g., reading, writing, and hearing)
Difficulty speaking	-	-
Forgetfulness	Wording changed to 'Feeling forgetful'	Expert feedback suggested that the revised wording would improve comprehension by stroke survivors
Difficulty writing	Wording changed to 'Difficulty writing things down'	Wording revised to improve comprehension by stroke survivors
Crying or laughing inappropriately	-	-
Poor concentration	-	-
Difficulty reading	Wording changed to 'Difficulty reading what things say'	Wording revised to improve comprehension by stroke survivors
What I'm like as a person has changed	-	-
Getting upset or weepy	Wording changed to 'Feeling low'	Expert feedback suggested that the original wording overlapped too much with the emotionality symptom ('Crying or laughing inappropriately')
Clumsiness	-	-
Hearing difficulties	-	-
Difficulty walking or getting around	-	-
Confusion	Added	Feedback from one participant in the Think-Aloud interviews suggested that the 'Headaches' item did not adequately capture their post-stroke symptom of fuzzy head/confusion
Tingling or numbness	-	-
Falling over	Added	Expert feedback suggested that falls are particularly common after stroke because of limb weakness/paralysis
Stiff joints	-	-

Table E. Summary of final changes made to the main sub-scales of the Stroke IPQ-R

Item	Change(s)	Rationale
Timeline Acute/Chronic		
I believe that the effects of my stroke will last for a short time	'I believe' prefix removed	Expert feedback suggested that this wording was too abstract for stroke survivors (particularly with cognitive difficulties) to understand
I believe that my condition is likely to be permanent than temporary		
I believe that the effects of my stroke will last for a long time		
I believe that the effects of my stroke will pass quickly		
I believe that the symptoms of my stroke will improve in time		
I expect to have these symptoms of my stroke for the rest of my life	Wording changed to 'I will have the difficulties from my stroke for the rest of my life'	Wording changed to enhance relevance to stroke survivors
Consequences		
My stroke is a serious condition.	-	-
I believe that my stroke has major consequences on my life	'I believe' prefix removed; wording changed to 'My stroke has a major impact on my life'	Expert feedback suggested that this wording was too abstract for stroke survivors (particularly with cognitive difficulties) to understand; original wording emerged from Think-Aloud interviews to be too complex
I believe that my stroke has had serious financial consequences	'I believe' prefix removed; wording changed to 'My stroke has seriously affected how much money I have'	
I believe that memory problems since my stroke are affecting my life	'I believe' prefix removed	Expert feedback suggested that this wording was too abstract for stroke survivors (particularly with cognitive difficulties) to understand
I believe that my stroke strongly affects the way others see me		
I believe that my stroke causes difficulties for those who are close to me		
I believe that my stroke has strongly affected how I see myself		
I believe that my stroke has badly affected my relationship with my family		
I believe that emotional problems since my stroke are affecting my life		
My stroke does not have much effect on my life	-	-
Since my stroke I fear becoming a burden on others	-	-
Item	**Change(s)**	*Rationale*
Personal Control		
I believe that there is a lot which I can do to control my symptoms	'I believe' prefix removed; wording changed to 'There is a lot which I can do to manage the effects of my stroke'	Expert feedback suggested that this wording was too abstract for stroke survivors (particularly with cognitive difficulties) to understand; wording changed to enhance relevance to stroke survivors
I believe that there is nothing I can do to prevent another stroke occurring	'I believe' prefix removed; wording changed to 'I cannot prevent another stroke from occurring'	Expert feedback suggested that this wording was too abstract for stroke survivors (particularly with cognitive difficulties) to understand; negative wording emerged from Think-Aloud interviews to be too complex

Item	Change(s)	Rationale
I believe that what I do will determine whether my stroke gets better or worse	'I believe' prefix removed	Expert feedback suggested that this wording was too abstract for stroke survivors (particularly with cognitive difficulties) to understand
I believe that nothing I do will affect my recovery from stroke		
I believe that the course of my recovery from stroke depends on me		
I believe that I have the power to influence my recovery from stroke		
I believe that my actions will have no effect on the outcome of my recovery from stroke		
I need to avoid doing too much as this may cause another stroke	-	-
I am confident that I can manage my recovery well	-	-
Item	**Change(s)**	***Rationale***
Treatment Control		
I believe that there is very little that can be done to improve my condition	'I believe' prefix removed	Expert feedback suggested that this wording was too abstract for stroke survivors (particularly with cognitive difficulties) to understand
I believe that my medical treatment/rehabilitation will be effective in preventing another stroke from happening I believe that the negative effects of my stroke can be prevented (avoided) by my medical treatment/rehabilitation	'I believe' prefix removed; medical treatment/rehabilitation items combined, so wording changed to 'treatment'	Expert feedback suggested that this wording was too abstract for stroke survivors (particularly with cognitive difficulties) to understand; expert feedback suggested to revert sub-scale back to the original version of the IPQ-R, meaning that items appeared only once and referred generically to 'treatment'
I believe that my medical treatment/rehabilitation can control the symptoms of my stroke	'I believe' prefix removed; wording changed to 'My treatment can control the difficulties from my stroke'; medical treatment/rehabilitation items combined, so wording changed to 'treatment'	Expert feedback suggested that this wording was too abstract for stroke survivors (particularly with cognitive difficulties) to understand; expert feedback suggested to revert sub-scale back to the original version of the IPQ-R, meaning that items appeared only once and referred generically to 'treatment'; wording changed to enhance relevance to stroke survivors
I believe that there is nothing which can help my recovery from stroke	-	-
I believe that my medical treatment/rehabilitation will help me to recover	Removed	Expert feedback suggested to revert sub-scale back to the original version of the IPQ-R
Illness Coherence		
The symptoms of my stroke are puzzling to me	Re-added; wording changed to 'The effects of my stroke are confusing to me'	Expert feedback suggested to revert sub-scale back to the original version of the IPQ-R; wording changed to enhance relevance to stroke survivors and reduce complexity

Item	Change(s)	Rationale
My stroke is a mystery to me	Re-added	Expert feedback suggested to revert sub-scale back to the original version of the IPQ-R
I don't understand my recovery from stroke	-	-
My stroke doesn't make any sense to me	Wording changed to 'The effects of my stroke don't make any sense to me'	Wording changed to enhance relevance to stroke survivors
I have a clear picture or understanding of my stroke	-	-
Item	**Change(s)**	*Rationale*
Timeline-Cyclical		
I believe that the symptoms of my stroke change a great deal from day to day	'I believe' prefix removed; wording changed to 'The difficulties from my stroke change a great deal from day to day'	Expert feedback suggested that this wording was too abstract for stroke survivors (particularly with cognitive difficulties) to understand; wording changed to enhance relevance to stroke survivors
I have good days with few or no symptoms and bad days, when I have a lot of symptoms	-	-
I believe that the effects of my stroke are very unpredictable	'I believe' prefix removed	Expert feedback suggested that this wording was too abstract for stroke survivors (particularly with cognitive difficulties) to understand
I believe that I go through cycles in which my condition gets better or worse		
Emotional Representations		
I do not feel in control of my emotions	-	-
I get embarrassed by the way I am since my stroke	-	-
My stroke does not worry me	-	-
Since my stroke I get depressed	-	-
When I think about my stroke I get upset		
The symptoms of my stroke make me feel anxious	Wording changed to 'The effects of my stroke make me feel anxious'	Wording changed to enhance relevance to stroke survivors
My stroke makes me afraid	-	-
My stroke makes me feel angry	-	-
I feel lost since my stroke	-	-
I have lost confidence in myself since my stroke	-	-
My stroke is very worrying to those closest to me	Removed	Feedback from Think-Aloud interviews suggested that participants did not know how to answer these questions without asking a carer/loved one
Those closest to me get very distressed about my stroke		

Symbols and abbreviations: IPQ-R: Illness Perception Questionnaire-Revised

Table F. Summary of final changes made to the causal sub-scale of the Stroke IPQ-R

Item	Change(s) made	Rationale
Stress or worry	Wording changed to 'Stress or worry, including family problems'	Item combined with 'Family problems or worries caused my stroke' attribution to avoid repetition
Hereditary – it runs in my family	-	-
Diet or eating habits	-	-
Poor medical care in my past	-	-
My own behaviour	Removed	To avoid repetition
My mental attitude e.g., thinking about life negatively	-	-
Family problems or worries caused my stroke	Removed	To avoid repetition
Overwork	-	-
My emotional state e.g., feeling down, lonely, anxious, empty	-	-
Ageing	-	-
Alcohol	-	-
Smoking	-	-
High cholesterol	-	-
High blood pressure	-	-
Diabetes	-	-
Problems with my heart	Wording changed to 'Problems with my heart, such as an irregular heartbeat'	Considered relevant to stroke by expert panel; wording subsequently changed in order to improve comprehension by stroke survivors
My personality	Removed	To avoid repetition
A germ or virus	Removed	Not considered relevant to stroke following Think-Aloud interviews
Accident or injury		
Chance or bad luck	-	-
Not taking enough exercise	-	-