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Facilitating the participation of people with aphasia in research: a description of strategies

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Background: People with aphasia are often excluded from research because of their communication impairments, especially when an investigation into the communication impairment is not the primary goal. In our research concerning social participation of people with aphasia, we wanted to include people with mild, moderate as well as severe aphasia.

Aim: To suggest strategies and techniques for research in people with aphasia based upon experiences in conducting research in this group of people.

Methods: We conducted a qualitative study and a quantitative study in people with aphasia concerning their social participation. In these studies different strategies were developed based upon the literature, conversations with people with aphasia and speech and language therapists, to facilitate the inclusion of people with aphasia, even those with severe communication problems. Several strategies were evaluated. The strategies used and our experiences are outlined in this report.

Main contribution: It is possible to conduct research in this group. Several strategies were helpful to make this mission possible: the use of pre-structured diaries, the use of in-depth interviews with attention to non-verbal communication, the use of existing measurements, adjusted for people with aphasia by: using pictograms, placing one question per page, bolding the key concepts in the question, using large font, visualizing the answering possibilities in words and in pictures, reducing the question length, and excluding negatives in the question.

Conclusion: Research in people with aphasia is possible when using strategies adjusted to the communicative impairment.

Introduction

People with aphasia are often excluded from research.¹ One important reason for this is the difficulty of measuring anything when the question is based upon language.² There is a pattern of recruiting only those individuals who have the competence to express their perspective, or to express verbally with a reflective and clear style.³ Other people with cognitive impairments who

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have problems in expressing themselves verbally, such as those with traumatic brain injuries, dementia⁴ and learning disabilities⁵ are also often excluded in research.

People with severe aphasia in particular are excluded from research because of their difficulties in understanding verbal instruction. They are confronted with their language problems in everyday life, making access to public services very difficult.⁶ People with aphasia are often not included or not described as a separate group in stroke studies concerning participation.⁷ Consequently, people with aphasia experience many problems that remain unknown. Further, the aphasic stroke population reports that quality of life and psychosocial issues related to their language loss are typically not adequately addressed within the therapeutic process.⁸ Individuals become marginalized and made invisible by the labels of their conditions or situations when an individual's personal response and perspective are overlooked on the basis of an assumed inability to communicate.

However, some researchers have conducted studies in people with aphasia. Luck and Rose⁹ studied the issue of which method adjustments needed to be made in using qualitative research in people with aphasia, and reported that it is necessary to step out of the traditional role of the qualitative interviewer by altering questioning style, offering ideas to participants, and using supportive conversation techniques. Howe *et al.*¹⁰ audio-taped the interviews in their qualitative study and made field notes, used strategies to facilitate the communication of people with aphasia during the interviews such as encouraging participants to draw, write or gesture if they had difficulties in talking. Furthermore, they organized meetings with the participants in which the results of the study were discussed (member check meetings) to check the analysis, supported with a verbal and written summary using pictures of the key emerging study results. According to Beukelman,¹¹ people with aphasia prefer personally relevant photographs over non-personal photographs and iconic symbols in message representation. The accuracy for message presentation is higher for personally relevant pictures in the use of alternative and augmentative communication. In contrast, Fujimori *et al.*¹² found no significant

difference between the comprehension of written text, photographs and illustrations compared with the comprehension of pictograms. Brennan *et al.*¹³ reported that aphasia-friendly formats (simplified vocabulary and syntax, large print, increased white space, and pictures) increase the reading comprehension of people with aphasia. Aleligay *et al.*¹⁴ found that written health materials obtained from people with aphasia were written at an average grade nine readability level (Flesch Kincaid Readability Index^{15,16}) and contained low-frequency words, low-imageability words and complex sentences. Written health materials are not sufficiently modified to suit the reading ability of people with aphasia.

Although there is some information available for doing research in people with aphasia, those people are mostly still excluded from research. We wanted to perform a study into participation of people with mild, moderate as well as severe aphasia. In this article we describe the strategies (including some strategies based upon the information from the studies that are described above) used in two studies; and we discuss our experiences with these strategies.

Method

We conducted two studies in people with aphasia: a qualitative study as well as a quantitative study. The strategies used in both studies will be described here.

Qualitative study

In the qualitative study¹⁷ the aim was to explore how people with aphasia and their central caregivers perceive their social participation and the factors influencing it.

The only way to capture the perspective of individuals with aphasia is to ask them to express themselves. However, in severe aphasia it is not obvious that the person can express him or herself, and there are certainly difficulties. In the qualitative study 13 people with aphasia and 12 central caregivers were included. Three different methods were used to collect data: using a pre-structured diary for two weeks, followed by a semi-structured in-depth interview, and a focus-group interview

(after analysing the data gathered through the diaries and the in-depth interviews).

We involved the central caregiver as an assistant as well as an informant in filling in the pre-structured diary, and as a translator and informant during the interviews.

Before explaining the use of the pre-structured diary to the participant in the study, the Frenchay Aphasia Screening Test (FAST)¹⁸ was used to measure the communicative abilities of the person with aphasia. The total FAST score (maximum 30) determines overall aphasia severity (1–10: severe, 11–20: moderate, 21–26: mild, 27–30: no aphasia). Based upon the FAST score the interview was adjusted to the communicative capabilities of the participant. For example: if the person with aphasia was not able to read, the interviewer pointed at the pictogram while reading the questions aloud. If the participant was able to read, the interviewer pointed at the written question.

Pre-structured diaries

The strategies used were:

- Reducing time pressure
- Using a structured outlined layout
- Augmentative communication by using pictograms to be placed in the diaries
- Separate space in the diary for the caregiver to express his or her perspective
- Including the caregiver as an assistant for the person with aphasia
- Giving oral and written information concerning the use of the pre-structured diary.

People with aphasia often cannot express themselves because of the stress caused by time pressure.^{19–21} An important advantage of writing a diary was the absence of time pressure. Yet another important obstacle needed to be tackled: people with aphasia often have problems expressing themselves in writing as well as orally. Therefore we used a structured outlined layout in the diary that would help the person with aphasia to express him or herself (Figure 1). Since, in some cases, the person was not able to write down his or her thoughts at all, we developed pictograms of important activities of daily living to be put into the diary, as well as pictograms


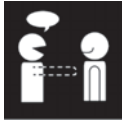
Monday	Activity	Performance
	Domestic life 	
	Interpersonal relationships 	

Figure 1 Prestructured diary.

of emotions, health condition, etc. We used a standard pictographic system ('Sclera's Pictograms'²²) which uses white silhouettes with little details against a black background.

A separate space was created at the end of each page for the central caregiver. In this space the central caregiver could express his or her perspective on the social participation of the person with aphasia. Further, the central caregiver could assist the person with aphasia in expressing him or herself by writing down what the person with aphasia said, or by applying the sticker that the person with aphasia pointed out. The central caregiver and the person with aphasia received oral and written instructions regarding the diary (see Appendix 1). They could ask questions to the researcher at any time, when something was not clear.

The researcher returned after two weeks to collect the diary and to make an appointment for the interview. The researcher encouraged the participants to describe their experiences with regard to writing the diary.

In-depth interviews

The data collected in the diary formed the basis for the in-depth interview to elicit new experiences and perceptions from the point of view of the person with aphasia.

Several people participated in the in-depth interview: the person with aphasia, a central

caregiver, the interviewer and the interview-assistant. Before the interview started, the interviewer explained the role of the interviewer (asking the interview questions), the interview-assistant (monitoring the non-verbal behaviour and audio-taping the interview), the person with aphasia (expressing his perception of social participation and the involved influencing factors) and the central caregiver (functioning as a translator in the first place and being an informant in the second place).

The interview took place in a quiet environment in the home of the subjects. We used several strategies to promote the involvement of the person with aphasia:

- 1) The interviewer checked the communicative abilities of the interviewee based upon the FAST, and reduced the cognitive load of the questions (e.g. ensuring rich environmental context with regard to setting, people, objects, phrasing the question in simple terms, asking one question at a time, reducing the question length) based upon this ability.
- 2) The interview was audio-taped. This was important in case the person with aphasia was not able to express him or herself verbally. Further, the interview-assistant monitored the audio-tape recording and made records of non-verbal communication and the conversational context, so that the non-verbal communication could also be included in the analysis. We decided not to use a video tape to include non-verbal communication, because it could intimidate the person with aphasia and because an interview-assistant can observe situations that might occur beyond the eye of the video recording. Further the interview-assistant checked the trustworthiness by overviewing the interview, by listening very carefully. The interview-assistant asked questions if there seemed to be discrepancies in non-verbal and verbal behaviour, as well as between the utterances of the person with aphasia and their central caregiver.
- 3) For each question, the interviewer always addressed the person with aphasia first, ensuring time and space to express him or herself, before asking the perception of the central caregiver.
- 4) Questions were made short and simple, and were supported by the use of pictures or photographs which could be used as a prompt and aid to comprehension.
- 5) High frequency words were used.
- 6) Other forms of communication were encouraged when oral communication was not possible for the interviewee, for example the use of pencil and paper and the use of non-verbal communication.
- 7) The interviewer tried to convey and receive ideas in different ways, and checked whether she had understood the person correctly, and checked the understanding of the person with aphasia by looking at non-verbal behaviour as well as by asking, using straightforward language.
- 8) When the person with aphasia was losing attention or was showing other signs of fatigue, a short time break was included.
- 9) The central caregiver was invited to be present during the interview. The central caregiver had a double role: in the first place he or she was invited to be a 'translator' for the person with aphasia when the interviewer could not understand the person with aphasia fully. After each 'translation', the interviewer addressed the person with aphasia again to check if that was indeed what he or she was trying to say. Furthermore, the central caregiver could express his or her own perception of the social participation of the person with aphasia.

Focus group interview

After analysing the data from the diaries and the in-depth interviews, we wanted to check whether the analysis of the collected data really captured what the participants wanted to express. For that purpose, ten of the interviewed people with aphasia and nine central caregivers participated in a focus group interview. To ensure the involvement of the people with aphasia, the following actions were taken:

- 1) The participants received a short report of the data analysis to prepare themselves for the

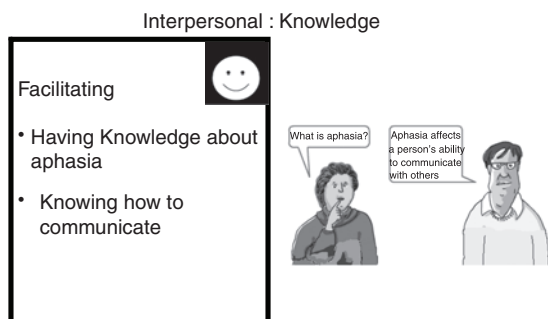


Figure 2 Example of a sheet supporting the focus interview. Reproduced with kind permission by Connect – the communication disability network (<http://www.ukconnect.org/index>).

focus group interview. The report was aphasia friendly¹³: written in simple language, using an outlined layout, using font Verdana, using large font (size 16), a lot of white space between each key point, and using support by pictures and pictograms.

- 2) The interviewer first presented the main outcomes using a Power Point presentation (Figure 2). Then, after a short break, the participants were invited to express their point of view.
- 3) During the discussion, central key concepts of the interview were visualized (by means of a Power Point sheet with the key concepts in writing, as well as expressed with a pictogram).
- 4) Some conversation rules were pointed out before and during the discussion, such as: listen to each other; check whether you understand what the other person is saying before you react; do not interrupt when another person is speaking; talk slowly.

The interviewer tried to encourage each person with aphasia to express themselves, by addressing them personally.

Quantitative research in people with aphasia

Before conducting the quantitative study in people with aphasia, a systematic review² was conducted to investigate which participation measurements are suitable for use in people with aphasia. Measurement instruments were

confirmed as possibly suitable for use in this group when the following strategies are used: simplified language, multimodal presentation of the questions (support by pictograms, drawings, etc.), a small set of response choices, a careful ordering of the items, and a short length. The review suggested that questions including a negative or denial, and/or using complex sentences, and/or imposing a large demand upon memory should be avoided.

For the quantitative study, a set of instruments was selected based upon the criteria of the systematic review. The selected measurement instruments needed adjustments before we could use them in people with aphasia. Six speech and language therapists working with people with aphasia as well as researchers in populations with cognitive impairments were consulted in individual conversations.

Further, data from the literature were used to adapt the instruments.^{23,24} Several studies have found discrepancies between the readability levels compared to the reading skills of the patients who read them.²⁵ The literature generally recommends that a reading grade of 5–6 (Flesch Kincaid Readability Index) should be used when developing written language for patients whose reading abilities are unknown.^{6,26}

Based upon these considerations, adjustments were made to existing instruments:

- using large font (size 16),
- using font style Verdana,
- bolding key concepts,
- reducing each question to the essence (mean question length ranged from 4.6 to 11.5 words for the measurement instruments used, after simplification of the questionnaires),
- supporting questions with a specifically designed pictogram,
- using an increased amount of white space between the question and the response set,
- supporting each response set with pictograms,
- using a separate page for each question, so that people were not distracted by other questions.

After these adjustments were made, the instruments were tried out in four people with aphasia. Further adjustments (for example a pictogram

of a number was supported with dots equal to the number) were made during the interviews. The objective was to make a question as comprehensible as possible for people with aphasia. People with mild, moderate as well as severe aphasia were included in this stage.

Then, based upon this first experience, the instruments were fine-tuned and tested in 10 new people with aphasia with different degrees of expressive and comprehension problems. They all stated that the instruments were clear.

In the next stage, the adapted instruments were sent to five other speech and language therapists working daily with people with aphasia, and to one researcher in people with cognitive impairments, for feedback, using a structured questionnaire (see Appendix 2). The instruments were further adapted following their comments and some pictograms were further adjusted, leading to the final version of the instruments. Figure 3 shows an example of an adjusted question.

Questions were administered during an interview. The following strategies were used:

- Good preparation: the FAST was assessed to gain an impression of the communicative abilities of the person with aphasia.
- Based upon the data from the FAST, strategies adjusted to the communicative abilities of the person with aphasia were used.



Who usually plans social arrangements?



Figure 3 Example of an adjusted item.

- The interviewer always tried to be aware of non-verbal behaviour.
- The interviewer gave plenty of time to answer each question.
- After each questionnaire, people with aphasia were asked which strategies were helpful for them to understand the questions.
- The interviewer took impairments such as neglect or hearing impairment into account (e.g. by sitting at the right side, asking the person if he or she fully heard the question).

Results

The strategies used in the qualitative as well as in the quantitative study facilitated people with aphasia to participate in the studies.

Qualitative study

Using the techniques and strategies described, we found that all the participants, even those with quite severe aphasia, could communicate their ideas and concerns. The characteristics of people successfully included are shown in Table 1.

Pre-structured diaries

People with aphasia focused on the performed activity, and barely described feelings that accompanied a certain activity. Also, the experience of success in performing an activity was described only minimally or not at all.

People expressed themselves using two- to three-word sentences, or made simple drawings to support their written information. Five people with aphasia did not use the stickers. People with severe writing problems used stickers to express themselves. Some people used stickers to express the activity as well as the accompanying feeling and the experienced success or failure. The use of stickers made it possible to give some information about a day in the life of a person with a severe communication problem, expressed by the person him or herself.

Whereas the person with aphasia focused on the performed activity, the central caregiver also described the well-being of the person with aphasia during that particular day.

Table 1 Information about the people with aphasia

	Male/ female	Age	Time post stroke (years)	r_s FAST	z-score	Comprehensive	Expression	Reading	Writing	Marital status	Children	Employment pre-stroke ^a
1)	Liv ^b F		48	2.1	12	-0.9	3	4	3	2	Married	Son
2)	Rita F		56	7.7	27	1.43	8	10	5	4	Married	Son, daughter
3)	Bert M		49	3.6	19	0.19	7	7	3	2	Married	Son, daughter
4)	Mia F		55	5	22	0.65	6	9	5	2	Married	4 sons
5)	Jos M		57	1.4	26	1.27	10	8	5	2	Married	Daughter, son
6)	Roos F		45	3	29	1.74	10	10	5	4	Married	Daughter
7)	Hans M		58	9	24	0.96	9	7	5	3	Married	None
8)	Stan M		71	11	12	-0.9	6	3	3	0	Married	3 daughters
9)	Roel M		65	3.9	22	0.65	7	6	5	4	Married	2 sons
10)	Tom M		55	3	10	-1.21	5	2	3	0	Married	2 sons
11)	Sally F		69	5	19	0.19	4	8	5	2	Married	Housewife
12)	Jef M		66	4	24	0.96	7	8	5	4	Married	Transportation and material moving occupation G.814
13)	Sara F		52	8	26	1.27	10	8	5	3	Divorced	2 sons

^aOccupation as classified using the US Standard Occupational Classification System: Major Occupational Groups (MOG).
^bThe names of the people with aphasia are changed to ensure anonymity.
 FAST, Frenchay Aphasia Screening Test.

One central caregiver wrote a separate diary because he thought his wife would be displeased with his perception.

In-depth interview

The subjects in this study were very willing to express their experiences, their perceptions and emotions concerning their social participation in life.

Although three people with aphasia (2 with FAST score = 12, 1 with FAST score = 10) experienced many problems in expressing themselves verbally, they succeeded in expressing their perception in different ways, such as by prosody, by gestures or through mimicking. The interviewer sometimes used closed questions when people had very severe expression problems, so as to elicit perceptions. When the interviewer misunderstood the person with aphasia, the search for understanding was continued for about 5 minutes, asking closed questions. In some occasions it was not possible to discover what the person with aphasia was trying to say, not for the interviewer, nor for the interview-assistant or the central caregiver. On these occasions, there was a time-out for this topic: the topic was picked up again at a later time during the interview, to check if it was possible to find out what the person with aphasia was trying to say earlier. When the tension provoked by the miscommunication was taken away and the person with aphasia was able to be more relaxed, this increased the chance of exposing the word, description, gesture or drawing to make clear what he or she was trying to say. In all the interviews, the people with aphasia expressed that they were happy to get the chance to express their experiences. People with mild aphasia could express themselves very well orally; people with moderate aphasia could bring out their voice with or without the support of paper and pencil or gestures. Deep interviews could be performed, and a large body of data could be collected.

For all the participants, there needed to be space for breaks during the interviews, because fatigue was an important barrier. It was important that the interviewer was particularly vigilant to non-verbal signals that indicated discomfort. After a short break (between 15 and 25 minutes), the

person with aphasia was fit again to participate in the interview.

The interviewer needed to be very aware of the different roles of the caregiver at certain times, because the boundaries between those roles were sometimes very narrow. For example, when the central caregiver was translating the expression of the person with aphasia, he or she could add his or her own point of view without specifying this.

Sometimes the interviewer needed to control the central caregiver to ensure that he or she did not overrule the person with aphasia and impede their ability for expression. In some cases, the person with aphasia or the central caregiver expressed themselves in another way when the other person was out of the room. Although the interviewer always tried to use the different expressions to fully understand the situation, it sometimes remained unclear if one person did fully express him or herself in the presence of the other.

The interview-assistant sometimes intervened when there appeared to be a discrepancy between the verbal expression and the non-verbal behaviour of the person with aphasia, however this happened rather rarely. Sometimes the interview-assistant asked the question differently when the question seemed not to be answered completely.

Focus interviews

Although people with aphasia often found it very difficult to participate in conversations with more than one person, it appeared to be possible to conduct a focus interview with people with aphasia and their central caregivers. Participants encouraged each other to express their experience and point of view. They shared experiences, they gave comments about the collected data, they expressed an interpretation descriptive of their situation, and they gave examples. They really listened to each other, and they gave each other time to express themselves.

Quantitative study

The main purpose was to gather relevant information from stroke survivors, even those with severe aphasia. In total 128 people with aphasia (FAST score <27) were interviewed. The different

strategies used to support people with aphasia seemed to be very helpful. Different strategies were used for different people: sometimes the bolded key concept in the question was most helpful, while in other situations (e.g. when the person was not able to read) the pictogram was the most important support. All the participants stated that the pictograms as well as the bolded key concepts were supportive for comprehension of the questions. The person with aphasia never expressed verbally that he or she could not comprehend the question, however sometimes the facial expression indicated that the question was not understood completely. If this was the case, the interviewer paraphrased the question (e.g. by giving an example of an activity) without changing the content.

One questionnaire used a six-point scale, and it was found to be too difficult for people with very severe aphasia to handle so much information at the same time. The following adjustment was made to make it possible to assess this questionnaire: The questions needed to be answered in two phases. First a two-point answering set was used: (satisfying versus unsatisfying), then a three-point scale was used. For example, if the person found that specific situation satisfying in the two-point scale, the three-point scale: almost satisfying, satisfying and very satisfying was used.

All the adjusted questionnaires seemed to be feasible for use in people with aphasia, even in people with very severe expression problems.

Discussion

People with aphasia, even severe aphasia, were successfully included in both qualitative and quantitative research studies using adjusted techniques and strategies. These revolved around reducing the cognitive load as far as possible by means of such techniques as simplifying communication, reducing the content of communication to simple clear concepts, using bold type and clear font in the layout of the question, using a clear visual structure, and allowing as much time as needed. Further, it seemed to be important to provide alternative forms of communication, such as pictograms, pictures, writing, gesture, mime, etc.

Also the use of data triangulation in the qualitative study (diary, in-depth interview, focus group interview) was helpful when people had difficulties in understanding or expressing themselves.

Although a structured outlined layout was helpful, an important disadvantage of using a pre-structured diary was the possibility of influencing the thoughts of people who already had difficulties in expressing themselves. Another important issue is the involvement of the central caregiver as a translator and informant during the study: it might be that the thoughts and expressions of the people with aphasia could be influenced by the presence of the central caregiver. Otherwise, the presence of the central caregiver could give the person with aphasia a feeling of safety, making it easier to express them. The caregiver sometimes had the role of an informant. In the literature²⁷ proxy respondents demonstrated a significant systematic negative bias in rating their aphasic partners' global quality of life, physical functioning, general or overall health, pain, and vitality. Conversely, proxy respondents rated statistically the same as their aphasic partners on physical fitness, feelings, daily activities, quality of life, total well-being, autonomy, environmental mastery, and purpose in life, with at least moderate agreement. During the interview the person with aphasia and his or her central caregiver seemed to agree most of the time. In order to elicit thoughts of people who had problems in expressing their perspective and feelings, it was important to communicate at the level of the communicative abilities of the person with aphasia. Sometimes, we needed to deviate from the usual interview style in qualitative research, occasionally using closed questions, supporting most questions with pictures, photographs or pictograms. By asking closed questions, the perspective of the person with aphasia could be compromised. However, the interviewer always checked whether the answer was influenced by the closed question of the interviewer. Therefore the interview-assistant had an important role as well.

The focus group interview was an important part of the triangulation process and made sure that the voice of the people with aphasia was disclosed. By discussing the data analysis with the participants, it was confirmed that the researchers did understand the participants correctly and that

the outcome represents the authentic perception of the people with aphasia.

In the aphasia literature some information could be found regarding strategies used in qualitative studies, but none could be found with regard to strategies used to adjust questionnaires for people with aphasia in quantitative studies. There are very few instruments that are especially developed for people with aphasia and there seems to be no consensus in these instruments concerning the use of visual support: some use pictures to support the question,^{28,29} others use no visual support³⁰ except written information.

In our quantitative study the questionnaires were adjusted based upon (1) conversations with speech and language therapists working with people with aphasia, (2) the literature concerning aphasia-friendly information and most importantly the adjustments that were made based upon the experiences in using the questionnaires in people with aphasia, asking them what is really helpful in making the questionnaires comprehensible and accessible. People with severe aphasia often find it easier to understand when the message is given in two input modalities in parallel (e.g. orally and visually).³¹

We are happy to say that in our quantitative study the mission to include people with aphasia successfully in research seemed to be accomplished. The participants in our study, even people with severe aphasia, were able to express their perception using support from pictograms in combination with oral and written information. Therefore we hope that, based upon perceptions of their language problems, people with aphasia will not be excluded from future research studies.

Clinical messages

- Including people with aphasia in stroke studies is possible by using several communication strategies.
- Measurements can be adjusted by reducing the cognitive load and providing alternative forms of communication.
- The challenge to include people with aphasia in research should be taken up in order to promote accessibility.

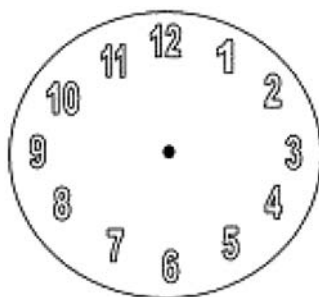
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Appendix 1 – Instructions diary

- You and your partner (or relative or close friend) could best plan a **fixed moment** in the evening to keep up the diary.



- The diary is **divided** in different life domains.
- The aim is to report **performed activities** per life domain.
- If you did not perform activities in a certain life domain, you can report that as well.
- Please, report the **things that facilitated** you in performing an activity.
- Please, report the **barriers** in performing an activity.
- You can use **stickers** if writing is difficult.
- The stickers are attached at the **end** of the diary.
- If you cannot find a sticker that represents your thoughts, please try to **express your thoughts otherwise** (e.g. make a drawing)
- You may **ask assistance** from your partner (close relative or friend) if it is difficult to fill in the diary yourself.
- For you, as a partner (close relative or friend) there is **space/day** to write down **your remarks** concerning the experiences of the partner's day.
- It will take about **20 minutes per day** to keep up the diary.

Appendix 2 – Structured questionnaire: adjustments to the instrument for use in people with aphasia

Measurement instrument:

Participant:

Date:

Duration of assessment?

Yes

No

Number of items suitable?

Use of bolded key concepts helpful?

Use of pictograms:

Are they supportive?

Are they clear?

Is the formulation of the items clear?

The answering set:

Are the answering possibilities clear?

Are the answering possibilities suitable?

Total