

## Appendix 1: Description of the qualitative instruments

### *Am I Satisfied?*

The "Am I Satisfied?" instrument concerned two ways of collecting data: 1) interviews and 2) impressions. In the original version of the instrument, a familiar professional from the client conducts the interview. For this research, we evaluated whether interviewing together with a co-researcher added any value. The interviews were conducted by both a co-researcher and a professional who was familiar to the client, and the topic of the interview was preferably the relationship with that professional. For clients who could not express themselves, the second manner applies: discuss the client's impressions made by a care professional and client representative. The impressions were discussed by a client representative (proxy) and a professional known to the client. Co-researchers and professionals followed a training session provided by two trainers of Praktikon (an independent organisation for research and development and one of the owners of the instrument). Professionals reflected after the data collection on cases from client experiences in a team reflection meeting. The first reflection meeting was supervised by Praktikon.

Main adjustments of the original instrument:

- The original interview was performed by one care professional, for this study the interviews were carried out by pairs of one co-researcher and one care professional.
- The instrument content was narrowed down from broad questions on the quality of life towards questions focusing on care relationships.

### *Clients about Quality*

This instrument consisted of four steps: 1) interviews, 2) a mirror group conversation, 3) writing a report and 4) drawing up an improvement plan based on the report. The instrument has been developed by LSR, a Dutch client council organisation with a nationwide scope. Clients were interviewed by one co-researcher and an LSR quality employee on the basis of a structured questionnaire with space/room for open answers. Important outcomes from the interviews were then discussed with a group of clients and their professionals in a mirror conversation. Then a report was written by the LSR, which was used by the care organisation for drawing up an improvement plan. The client council, the research team (client researchers and a researcher), a few employees, the location manager and executive officer made the plan together in a meeting, resulting in a shortlist of SMART formulated goals for improvement for the organisation and locations.

Main adjustments of the original instrument:

- The original interview is often completed digital and independently within care organisations, and the mirroring meetings are then facilitated by an employee of the developer LSR. For this study the interviews and mirroring meetings were performed by pairs of one co-researcher and one LSR employee and filled in on paper.
- The instrument content was narrowed down from questions on the quality of life towards questions focused on care relationships.

### *WIEK*

Co-researchers interviewed clients about the quality of a care relationship with their health care professional. Ten cards are the core of this instrument, each describing one care relationship theme on the one side and open questions on the other side. The client chose 2 theme cards they are willing to talk about and the co-researcher asked questions about these chosen themes. Notes were made during the interview to make an *individual traceable client* report afterwards to send to the professional. The professional read and reflected on the improvement suggestions, and discussed the results with the client when needed. The WIEK cards were formulated by the research team.

Main adjustment of the original instrument:

The WIEK theme cards were specified to questions focusing on care relationships. The original WIEK instrument included broader themes focusing on quality of life.

### *Feedback consultation*

This instrument focused on clients and professionals of a single ward and the experiences and improvement areas as mentioned by clients. The instrument consisted of two meetings:

**1. Group discussion:** Under the guidance of one or two co-researchers, clients exchanged experiences about their care relationships with professionals. Clients first jointly chose 2 themes to discuss. The discussion focused on positive experiences, negative experiences and areas for improvement. Four

basic rules were followed and monitored by the co-researchers: speak from your own experiences, let each other talk freely, respect each other, and give everyone a chance to provide input. Everyone was allowed to respond to each other's input. The feedback could address both the client's own role and the roles of care professionals. The feedback consultation results in 2 action points for the ward, placed visibly on a large sheet of paper in the ward.

*2. Follow-up meeting:* After one month, the progress of the issues was discussed with a delegation of the attendees at a group discussion: 1 client, 1 professional, the manager and the co-researcher.

Main adjustment of the original instrument:

- For the current study, the feedback consultations were primarily focused on experiences on the quality of care relationships and related interactions.

#### *Participatory narrative inquiry*

This instrument included three aspects: a workshop, data collection with interviews and storytelling, and a reflective meeting. First a workshop was organised in which clients, family and care professionals determine the content of the questions and answer categories. Data collection consisted of individual interviews and a group meeting. Clients were interviewed by co-researchers. An interview consisted of an open narrative and some additional questions by which the client interprets their own story. Co-researchers were given the option to make an audio recording so that the results can subsequently be transcribed and they did not have to do this themselves. In the group meeting of about 90 minutes, 6-15 clients shared their stories with each other and interpreted these stories. After the data collection, a meeting was held with professionals, the manager, the research team (co-researchers), and possibly a representative of the client council. Central themes were discussed and areas for improvement determined based on anonymous stories from the interviews and stories meeting.

Main adjustments of the original instrument:

- The original interview is often completed digitally by people independently. For this study the interviews were performed by pairs of one co-researcher and one supporting interviewer and filled in on paper.
- The central questions were focused on the experiences related to the quality of care relationships.

**Appendix 2: list of inventoried qualitative instruments**

<b>Name instrument</b>	<b>Method description</b>	<b>Developed for client group</b>	<b>Website</b>
Am I satisfied (Ben ik tevreden)	Open interview and dialogue between client and professional combined with general ratings (Likert scores)	ID	<a href="https://www.beniktevreden.nl/">https://www.beniktevreden.nl/</a>
This is my opinion! (Dit vind ik ervan!)	Open interview and dialogue between client and professional	ID	<a href="http://www.platformditvindikervan.nl/">http://www.platformditvindikervan.nl/</a>
Narrative approach	Open interview & dialogue	Not specified	
Participatory Narrative Inquiry	Collecting narratives by: a) Narrative interviews b) Storytelling meeting	General instrument, in NL applied to OA	<a href="https://www.workingwithstories.org/aboutpni.html">https://www.workingwithstories.org/aboutpni.html</a>
Quality Cube	Questionnaire of 12-30 closed survey questions and 2 open questions.	ID	<a href="http://www.buntinx.org/quality_cube">http://www.buntinx.org/quality_cube</a>
WIEK interview	Semi-structured interview by using theme cards	MH	<a href="http://www.arkinmagazines.nl/jaarverslag#1/betere-kwaliteit-van-leven-in-gedwongen-setting">http://www.arkinmagazines.nl/jaarverslag#1/betere-kwaliteit-van-leven-in-gedwongen-setting</a>
Say it yourself! (Zeg het zelf!)	Participatory research using structured questionnaires including closed questions and (some) open questions.	ID	<a href="https://hetlsr.nl/kwaliteitstoetsing/diensten/methode-zeg-het-zelf/">https://hetlsr.nl/kwaliteitstoetsing/diensten/methode-zeg-het-zelf/</a>
Quality assessment from a patient perspective with experts of experience.	Participatory research using a structured questionnaire.	MH	<a href="https://hetlsr.nl/kwaliteitstoetsing/diensten/verdiepend-kwaliteitsonderzoek-ggz/">https://hetlsr.nl/kwaliteitstoetsing/diensten/verdiepend-kwaliteitsonderzoek-ggz/</a>
Peer consultation	Peer to peer interview, not yet specified.	General	<a href="https://www.zorgbelanginclusief.nl/participatie-in-de-langdurige-zorg/participatiemethodieken/peer-consultatie/">https://www.zorgbelanginclusief.nl/participatie-in-de-langdurige-zorg/participatiemethodieken/peer-consultatie/</a>
Feedback consultation with experts of experience	Instrument is performed by experts by experience and consists of: a) Focus group b) Follow up meeting (one month later)	MH	
World café method	Group consultations in different groups around different tables	General	<a href="http://www.theworldcafe.com/key-concepts-resources/world-cafe-method/">http://www.theworldcafe.com/key-concepts-resources/world-cafe-method/</a>
Appreciative inquiry	Group consultations with clients, family members, volunteers, care professionals and members of the client council.	OA	<a href="https://docplayer.nl/13523157-Coloriet-samen-kleur-geven-aan-waardevol-leven-plan-van-aanpak-door-co-creatie-duurzame-liefdevolle-zorg-">https://docplayer.nl/13523157-Coloriet-samen-kleur-geven-aan-waardevol-leven-plan-van-aanpak-door-co-creatie-duurzame-liefdevolle-zorg-</a>

			<a href="https://www.met-de-mensen-en-middelen-die-er-zijn.html">met-de-mensen-en-middelen-die-er-zijn.html</a>
Mirror conversations	Group conversation of a group of clients in the inner circle. Care professionals are sitting in the outer circle to listen.	General	<a href="https://participatiekompas.nl/spiegelgesprekken-patienten-houden-zorgverleners-een-spiegel-voor">https://participatiekompas.nl/spiegelgesprekken-patienten-houden-zorgverleners-een-spiegel-voor</a>
Dementia Care Mapping	Participant observation by an independent observer.	OA & ID	<a href="https://www.dcmnederland.nl/">https://www.dcmnederland.nl/</a>
Shadowing	A person follows a client closely to see how the process works from a patient perspective.	General	
Visualizations of quality (Beelden van kwaliteit)	Participant observations by an independent observer.	ID & OA	<a href="http://www.beeldenvankwaliteit.nl/">http://www.beeldenvankwaliteit.nl/</a>
Look at wat we say (Kijken naar wat we zeggen)	Video observations	ID	<a href="http://www.kijknaarwatwezeggen.nl/">http://www.kijknaarwatwezeggen.nl/</a>
Care professionals in the picture (Begeleiders in beeld)	Video feedback in training for care professionals	ID	<a href="http://www.begeleidersinbeeld.nl/">http://www.begeleidersinbeeld.nl/</a>
Video stimulated recall	Feedback method for specific cases based on video recordings or audio recordings.	OA	<a href="https://journals.sagepub.com/doi/full/10.1177/1609406917719623">https://journals.sagepub.com/doi/full/10.1177/1609406917719623</a>
The human measure (De Menselijke maat)	General mixed method tool for client councils	OA	<a href="http://api.ning.com/files/4bIsJDjFjL4NJb9N4V9oatW6ZG58pz4nZtGpl0QpVXpMRQMG5wXf3oTdhTBYTQwcXh9aa0xi2He914mw3r19kkSQR9*uvkEX/de_menselijkemaatpon2007.pdf">http://api.ning.com/files/4bIsJDjFjL4NJb9N4V9oatW6ZG58pz4nZtGpl0QpVXpMRQMG5wXf3oTdhTBYTQwcXh9aa0xi2He914mw3r19kkSQR9*uvkEX/de_menselijkemaatpon2007.pdf</a>
Experience based co design	Mixed method English approach to organise quality improvement with all stakeholders included.	General	<a href="http://www.kingsfund.org.uk/projects/ebcd">http://www.kingsfund.org.uk/projects/ebcd</a>
Client about quality (Cliënt over kwaliteit)	a) Semi-structured interviews b) Mirroring focus group	ID	<a href="https://hetlsr.nl/kwaliteitstoetsing/diensten/clienten-over-kwaliteit/">https://hetlsr.nl/kwaliteitstoetsing/diensten/clienten-over-kwaliteit/</a>
Walking interview	General method from anthropology in which the researcher walks along with a person. Combination of participant observation and open or semi-structured interviewing.	General	

**Abbreviations used:**

ID = people with intellectual disabilities

OA = older adults with a physical or mental frailty

MH = people with mental health problems

Note: for most instruments there are no academic studies available yet, as the instruments were developed in practice and used for practical aims primarily.

## Appendix 3: Evaluation materials

### A. Observation list – for interview

Date and time

Method:

Interview number:

Co-researcher:

Family/relative:

Support role:

Researcher:

#### Content of the conversation (in keywords) and/or notes in a text field

##### Role of the interviewer: co-researcher and (where applicable) the support role

1. Does the interviewer put the client at ease?
2. Does the interviewer ask the questions clearly and in the agreed way?
3. Does the interviewer listen to the client's answers and do they drill down from there?
4. Does the client (helped by the person in the supporting role) come up with points for improvement for the staff?  
See also question 22.
5. Does the interviewer stick to the process as described in the method? See also question 19.
6. Extent to which the interviewer steers the conversation
7. Does the interviewer summarise the answers clearly?
8. What does the interviewer find difficult (researcher's interpretation)? See also question 21.

##### Cooperation between the co-researcher and the support role (if applicable)

9. Attitude, interaction and any agreement between the co-researcher and supporting researcher takes place between equals and in a natural way, before the test activity
10. Co-operation, attitude, interaction and any agreement between the co-researcher and supporting researcher takes place between equals and in a natural way, during the test activity
11. Ratio between the times the co-researcher and supporting researcher are speaking
12. Co-operation, attitude, interaction and any agreement between the co-researcher and supporting researcher takes place between equals and in a natural way, after the test activity

##### Client /respondent

13. Does the client understand the questions?
14. Which questions does the client answer easily? Which questions does the client find difficult?
15. Does the client feel at ease? Or does the client seem tense?
16. Does the client appeared to be tired; does the test activity require a lot of concentration?
17. Extent to which the client understands the subject matter and purpose of the investigation
18. Is there anything worth noting about how the client responds to the co-researcher and support research?

##### General

19. Were all parts of the method conducted? Which parts of the method went as intended and which did not?
20. What is typical for this interview?
21. Was the co-researcher able to carry out their role?

**Researcher**

22. Reflection on the role of the researcher presents during the test activity: Did you remain neutral during the test activity, only observing and not interviewing?

**Answers to the assessment questions that the researcher asked the client at the end of the test activity**

In the presence of the co-researcher and any support interviewer

- How did you think this conversation went?
- What did you think of the fact that (a) another client, (b) a familiar professional, (c) a researcher was present during the interview?
- Do you have any tips you would like to give us?
- Would you be ready to take part in another interview?
- Have all the points for improvement in the relationship been discussed?
- Is it clear to you what we will be doing with the results? What do you think of that?
- Do you think that the point is that improvement will actually be implemented? Why (or why not)?
- What did you think of the duration/length of the interview?

**Notes on the conversation afterwards with the co-researcher and any support interviewer**

- How did you think this conversation went?
- How do you think your role went?
- What did you think of the client's answers? Do you now know what they think of their relationship?
- What did you think of the cooperation/division of tasks with the other person (care professional/co-interviewer)?
- What would you do differently next time?
- Did the amount of time you spent match what you expected beforehand?

**After conducting the method**

- Length of interview
- Number of questions asked
- Elements conducted as planned
- Were the results and points for improvement written down clearly?
- Can differences be seen between the interviewers?
- Can a learning effect be seen in the kind researcher or support interviewer? (Does it get easier, within single interviews as well?)
- Do you think that the co-researcher could perform their role outside the research setting?

**B. Evaluation with care professionals (e.g. by phone)**

- What do you think of the results of the method? Are they recognisable? Did the method yield new insights?
- Have you discussed the results with the client?
- Has the method yielded specific points for improvement? Based on the results, do you know what you can do to improve the care relationship with the clients who took part in the study?
- Can you identify moments or processes in the approach and during its implementation (planning, conditions, etc.) that played a role in the success or failure of the method?
- What do you think of the co-researcher role?
- What have you noticed about the implementation of the method?
- What did you think of your role in the method?
- Was it clear to you what was expected of you?
- Did the amount of time you spent match what you expected beforehand?
- What do you think of the length of time it takes?
- Did implementing the method affect your other work activities? If so, what effect did it have?
- Did carrying out the method set undesirable or indeed desirable unforeseen processes in motion?
- Did it reach the intended target group of clients?
- What groups of clients were missing and what were the consequences?
- What has to be arranged within the organisation if the implementation is to be successful? What are the key preconditions?
- Would you want to be involved in implementing the method in the future as well? Why (or why not)?

## Appendix 4 Findings regarding the two instruments that did not pass the first phase

### *Am I satisfied? – Elderly care*

**Table 3. Descriptive data for the “Am I satisfied?” instrument**

Client group	No. co-researchers and professionals involved	Total number of respondents (n)			Duration (mean, min.)	
		Interviews	Impression	Team reflection meeting	Interviews	Team reflection meeting
Elderly care	2 co-researchers 4 professionals	9 clients	1 client *	4 professionals	56	120

\* At the impression, no co-researcher was involved

#### *Feasibility*

Researchers and professionals found that the feasibility of the “Am I Satisfied?” interviews was low. The collaboration between professionals and co-researchers generally did not work out well. Professionals gave little support to the co-researchers and they reported confusion about the roles that made it hard for them to intervene when a co-researcher forgot something or asked a leading question. Professionals were generally not critical and very directive, for example in asking questions that prompted for positive answers and by filling in answers based on their own interpretations instead of the actual answers of the client. Co-researchers also found it difficult to perform their role, specifically in asking neutral open questions or probing questions to clarify the answer of a client. The impression was with one client insufficiently tested. In the care environment, almost all clients were able to discuss the care relationship themselves. General descriptive statistics are shown in Table 6.

#### *Usability*

The instrument yielded few areas for improvement for professionals. In two interviews, areas for improvement came to the fore that were useful for improving the contact with the professional present. The clients who were interviewed often gave socially desirable answers, which was explained by co-researchers by the presence of the professional involved. According to professionals, the setting was too formal and unnatural.

### *Clients about Quality – Intellectual disability care*

**Table 7. Descriptive data for the “Clients about Quality” instrument**

Client group	No. co-researchers and supporting interviewers involved	Total number of respondents (n)			Duration (mean, min.)		
		Interviews	Mirror meeting	Meeting formulating goals	Interviews	Mirror meeting	Meeting formulating goals
Intellectual disability care	3 co-researchers + 2 professional interviewers	10 clients	6 clients*	2 co-researchers 1 quality employee 1 professional	57	75	105

\* The clients taking part in the mirror meeting were also interviewed.

#### *Feasibility*

Interviews and mirror conversations were applicable according to co-researchers, but the feasibility was low with respect to the amount of time the instrument takes for the clients who participate and the content of the instrument. Co-researchers were able to ask the questions with the support provided and satisfied with the collaboration. Concerning the questionnaire, some clients found certain questions difficult, for example those including broad or vague terms like 'respect' or 'match'. The smileys were useful for some clients in helping them answer the closed questions of the questionnaire. The interviewers reported overlap between various questions and felt that the ordered questionnaire

was too long for clients. Specifically, the manner of interviewing was very open, whereas the questionnaire consisted of multiple choice questions, which resulted in time-consuming interviews and overlapping topics. Two hours were scheduled for the mirror conversations, but this was too long for the concentration spans and energy levels of clients and difficult to fit in the work schedules of the professionals. Furthermore, some professionals reported that the questions in the mirror conversations were too difficult. General descriptive statistics are shown in Table 7.

#### *Usability*

The observations showed that an improvement area for the professional was mentioned by a client in half the interviews. The mirror conversations did not yield any additional points for improvement. The presence of the professionals may possibly have inhibited clients from sharing areas for improvement in the mirror conversation. According to the professional interviewers of LSR, the co-researchers and the observations, a more open approach in the interviews (without closed questions) would have matched the clients' wishes and the purpose of the interview better.

## Appendix 5: Examples of the results of the instruments that were tested in phase 2

### Participatory Narrative Inquiry

Two narratives of older adults with an physical or mental frailty

#### Hygiene

"I had lived here for a while and I noticed several times that the shower chair had not been cleaned after it was used. Once there was even bath foam on it! The chair was not really cleaned or disinfected. I complained about this to the manager. The care professional did not apologise and insisted it wasn't true. Then I said that I no longer wanted to be helped by this care professional, because he simply wasn't honest. In general, hands are also washed far too infrequently, whereas the protocol is that the care professionals must disinfect after every client before they take care of me. It really doesn't happen enough."

#### Sympathy

"If I feel bad when I have flu, I occasionally need a helping hand from someone. Then it's very nice if a nurse wants to talk to me. And asks if she can do anything for me. I'm not here for fun: it's my body forcing me into it. Some care professionals don't even greet me and they remember for a long time if I give negative feedback even once. They don't always have attention and time for me. Don't ask simple questions to show interest. Then I feel so unnecessary."

### Feedback consultation

Goals formulated for professionals of a mental health ward.

Goal 1: The professionals are aware of the following points regarding respecting each other:

- ☐ Don't touch other people's property
- ☐ When entering an apartment, first ring or knock and wait for a response.
- ☐ Actively listening to the client

Goal 2: The professionals make more time to get in touch with clients (both on request and spontaneously). In particular also approaching clients who never ask for help:

- ☐ Doing things together is progress!
- ☐ Tip: give each other compliments and feedback
- ☐ Also mention what has gone well

### WIEK

The report on two WIEK theme cards discussed in an interview with a person with an intellectual disability.

#### Building a relationship

[Name of client] clicks well with [name of professional]. [Name of professional] is now one of the supervisors of [name of client] for one year. They are building a better relationship together. [Name of client] is gradually able to tell him more and more. This is because [name of client] is getting to know [name of professional] better and better.

*What are points for improvement for the topic:* Continue to supervise this client for a longer time.

#### Trust

[Name of client] trusts that [name of professional] will not tell anything to others. The professional could sometimes be a little more on time, but this is actually true for all professionals. The client would also appreciate it if the professional were to send a message when he's running late to say how much later he will be coming. If an appointment has been made, [name of client] will stay at home for it and he is therefore reliable for the professionals. The longer [name of client] knows [name of professional], the more he feels at ease with him.

*What are points for improvement for the topic:* That the professional arrives on time and sends a message if he will be arriving late.