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# BMJ Open

## Protocol for a participatory study for developing qualitative instruments measuring the quality of long-term care relationships

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Manuscripts

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4 of long-term care relationships  
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## 5 **Abstract**

6 **Introduction** In long-term care (LTC), it is unclear which qualitative instrument or instruments are  
7 most effective and useful for monitoring the quality of the care relationship from the client's  
8 perspective. In this paper we describe the research design for a study aimed at finding and optimising  
9 the most suitable and useful qualitative instruments for monitoring the care relationship in long-term  
10 care.

11 **Methods and analysis** The study will be performed in three organizations providing care to the  
12 following client groups: physically or mentally frail elderly, people with mental health problems and  
13 people with intellectual disabilities. Using a participatory research method, we will determine which  
14 determinants influence the quality of a care relationship and evaluate up to six instruments in  
15 cooperation with client-researchers. We will also determine whether the instruments (or parts thereof)  
16 can be applied across different LTC settings.

17 **Ethics and dissemination** This study protocol describes a participatory research design for  
18 evaluating the quality of the care relationship in long-term care. The Medical Ethics Committee of the  
19 Radboud University Nijmegen Medical Centre decided that formal approval was not needed under the  
20 Dutch Medical Research Involving Human Subjects Act. This research project will result in a toolbox  
21 and implementation plan, which can be used by clients and care professionals to measure and  
22 improve the care relationship from a client's perspective. Results will also be published via  
23 international peer-reviewed journals.

## 25 **Strengths and limitations of this study**

- 26 ➤ The study will result in useful optimised instruments for care organisations and client councils  
27 to collect information and feedback of clients on care relationships in long-term care.
- 28 ➤ The participation of client-researchers in the research teams will improve the validity,  
29 relevance and support of the research project.
- 30 ➤ The success of the study will depend on the willingness of client-researchers and care  
31 organisations to be involved and contribute to the study.
- 32 ➤ The success of the implementation will depend on the willingness of care organisations to use  
33 the optimised qualitative instruments, and the degree of support from national stakeholders.

## 1. Introduction

In long-term care, the relationship between clients and care professionals is seen as fundamental for the delivery of high-quality care. This importance is related to the longer period of care provision and the chronic health conditions of clients [1]. Long-term care consists of 'a range of services and assistance for people who, as a result of mental and/or physical frailty and/or disability over an extended period of time, depend on help with their daily living activities and/or need permanent nursing care.' [2]. A good care relationship between a client and professional requires an equal relationship in which professionals provide care with dignity and sensitivity to the clients' wishes [3]. It allows clients to express any questions or complaints they may have about the care given. This open environment has not yet been achieved in all organisations, according to a recent Dutch study [3]. Another study shows that care professionals believe they listen to the needs of clients and offer care in a person-centred manner, but entrenched habits and time pressure mean that opportunities for person-centred communication are often missed [4]. Worldwide, there is a drive to redress the imbalance in care from an ethos that is medically dominated, disease orientated and often fragmented, to one that is relationship focused [5].

Monitoring the quality of the care relationship should be set up from a client's perspective. Clients have unique experiential knowledge providing valuable insights into the quality of everyday care and care relationships that are missed otherwise. Care providers, clients and family perceive different determinants as influencing the closeness of the care relationship between client and care professional. McGilton and Boscart (2006) showed that care professionals in elderly care felt that close relationships were primarily about feeling connected with the resident. Family members focused primarily on the actions staff took to present a caring attitude. Residents on the other hand felt that close relationships included staff acting as their confidants [6]. By focusing on client experiences, a more comprehensive evaluation of clients' experiences of the care provided and areas for improvement is generated [7]. However, little research in long-term care has focused on the client's perspective on these relationships [6].

An excellent way to include the clients' perspective is by carrying out participatory research. In participatory research, clients are invited to become part of a research team [8-11]. This empowers the clients and improves the validity and relevance of the research project [12]. Clients' involvement can also lead to broader support for the outcomes of the research project and related quality improvement

1  
2  
3 65 initiatives among clients and care professionals [13]. Clients can be involved in several stages of a  
4 66 research project. In data collection, by actively helping conduct interviews or focus groups [14, 15].  
5  
6 67 Client-researchers can also be involved in the data analysis [15] or have an advisory role, for example  
7  
8 68 from the design phase onwards, by constructing the research design, a topic list or by attending  
9  
10 69 steering group meetings [11, 14].

11 70 Clients' experiences with the care relationship can be explored using qualitative instruments [16]. One  
12  
13 71 advantage of qualitative research is that it aims to understand social phenomena in natural settings,  
14  
15 72 giving due emphasis to the meanings, experiences and wishes of people [17]. Qualitative procedures  
16  
17 73 give clients freedom to respond, allowing direct expression of their own concerns rather than those of  
18  
19 74 the researchers [18]. As a result, qualitative research can tackle aspects of complex behaviours,  
20  
21 75 attitudes and interactions that are not amenable to quantitative research [17]. It has also been shown  
22  
23 76 that care organisations can translate qualitative results more easily into improvement actions, as such  
24  
25 77 results are capable of including the nuances and complexity of care practices [19, 20].

26 78 In Western countries, a shift can be seen in long-term care practice from focusing on solely  
27  
28 79 quantitative instruments to using qualitative instruments for measuring quality [18]. For example,  
29  
30 80 interview instruments such as narrative sensibility and storytelling [21, 22], focus groups [23-25],[26]  
31  
32 81 and observational instruments [27-30] are used to improve the relationship between client and care  
33  
34 82 professional and to encourage clients or their relatives to provide feedback. Corresponding to this  
35  
36 83 trend, there is a call for qualitative instruments in the Netherlands that can be used in daily practice to  
37  
38 84 hear client experiences of their care relationship. However, it is not clear whether existing qualitative  
39  
40 85 instruments are useful and effective for monitoring and improving the care relationship from a client's  
41  
42 86 perspective in long-term care and whether they focus on the important determinants of a good care  
43  
44 87 relationship. Some determinants of a good care relationship might differ between client groups, as  
45  
46 88 may the preferred instrument of evaluating the relationship. At the same time, we expect that there are  
47  
48 89 also general determinants that influence the quality of a care relationship in all LTC settings, such as  
49  
50 90 trust or communications skills. In this study, we have attempted to find both specific and more generic  
51  
52 91 determinants of care relationship.

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### 93 **Aim**

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3 94 The aim of the present paper is to describe the research design of the study. It is a participatory study  
4 95 to find and optimise qualitative instruments for evaluating care relationships in long-term care from the  
5  
6 96 client's perspective. This project seeks to answer the following research questions:

7  
8 97 A. What determinants influence the quality of the care relationship in long-term care for the  
9  
10 98 various client groups, according to both clients and care professionals?

11 99 B. What qualitative instruments can be used for monitoring and improving the relationship  
12  
13 100 between clients and care professionals from a client's perspective?

14  
15 101 C. Which qualitative instruments or parts thereof can be used across client groups and how?

16  
17 102 D. How can the most suitable qualitative instruments be used by the various user groups (such  
18  
19 103 as care professionals, care organisations, client councils and health insurance companies) to  
20  
21 104 improve the quality of the care relationship?

22 105 This research project will result in a toolbox that can be used by professionals and clients to measure  
23  
24 106 and improve the quality of the care relationships in long-term care. The results of this study will be  
25  
26 107 published in peer-reviewed international journals and presented at several congresses, preferably at  
27  
28 108 the annual conference of the international Collaboration for Participatory Health Research and the  
29  
30 109 International Conference on Communication in Healthcare.

31 110

## 32 33 111 **2. Methods and analysis**

### 34 35 112 **Setting**

36  
37 113 The study will take place in the Netherlands. In the Netherlands, long-term care consists of three client  
38  
39 114 groups: physically or mentally frail older adults, people with mental health problems and people with  
40  
41 115 an intellectual, physical or audio-visual disability. For this research, we focus within the client group of  
42  
43 116 people with a disability solely on clients with intellectual disabilities. Three Dutch care organisations  
44  
45 117 will be involved in this multicentre study, one delivering care to one client group. To make sure that we  
46  
47 118 can reach a diverse group of clients, we will select care organisations that provide care to a large  
48  
49 119 client population with a diversity of recurring care needs and receiving both intramural and extramural  
50  
51 120 care and that comprise multiple locations.

52 121

### 53 122 *Respondents*

1  
2  
3 123 Clients who have at least weekly recurring contact with a care professional and receive care for at  
4  
5 124 least three months in/from long-term care organisations are included. Physically or mentally frail older  
6  
7 125 adults may need assistance due to somatic complaints or suffer from mental decline because of  
8  
9 126 dementia. Persons with mental health problems may suffer from a personality disorder, schizophrenia,  
10  
11 127 or an anxiety disorder. An intellectual disability may be caused by chromosome abnormalities or by a  
12  
13 128 brain injury. Clients receiving acute health care are outside the scope of this study. We will focus on  
14  
15 129 care relationships between clients and care professionals who take care of clients directly, those who  
16  
17 130 see clients most often to provide assistance, supporting care and physical care. The focus is not on  
18  
19 131 professionals who are further removed from providing recurrent physical and supporting care, such as  
20  
21 132 clinicians, psychiatrists and general practitioners. Moreover, caregivers who provide informal care are  
22  
23 133 not included. Clients will be involved as client-researchers and respondents in the different phases.  
24  
25 134 Inclusion criteria for both groups are described in Table 1.

26 136 *Table 1 Inclusion criteria for clients as respondents and client-researchers*

	Respondents	Client-researchers
18 or older (no upper limit)	X	X
Currently a client of residential elderly care and home care, mental healthcare or disabled care	X	X
Receiving care for at least three months	X	X
Receiving care at least once every week	X	
Able to communicate verbally in Dutch	X	X
Able to generalise from their own experiences		X
Able to hold a conversation without assistance of a close relative or friend		X
Able to read and write at a basic level		X
Has a fairly stable health situation		X
Able to travel short distances		X

51  
52 137

53  
54 138 *Figure 1 Ladder of Participation, Arnstein (2015) [31]*

55  
56 139



## 140 **Patient and public involvement**

141 This study is participatory research: having clients participate in this study as client-researchers will  
142 help us counteract the social distance between clients and researchers. Gradations of client  
143 participation are often described using a participation ladder (see Figure 1). The participation levels in  
144 Arnstein's frequently used Participation Ladder are manipulation, therapy, informing, consultation,  
145 placation, partnership, delegated power and client control [32]. In this study, we are aiming for the  
146 'partnership' participation level. Client-researchers will be asked to be involved in preparation activities  
147 such as developing the design of the study and drafting the topic list for interviews and focus groups  
148 and selection of the qualitative instruments that will be tested. Moreover, client-researchers will help in  
149 the interviews, focus groups and instrument testing. Some of the client-researchers will also be  
150 involved in the selection and invitation of respondents. As members of the research team, client-  
151 researchers will be involved in the analysis stage as well: in work meetings, the results of interviews,  
152 focus groups and instrument evaluation will be summarised and discussed. At the end of the research,  
153 client-researchers can optionally help in the dissemination phase of the research. Earlier studies show  
154 there are several barriers for participatory research [11] and sharing responsibilities is not always easy  
155 for researchers [33]. Studies underline the importance to start the research process really open and  
156 flexible to make true client participation, empowerment and a valuable collaboration process possible  
157 [11, 34]. The intensity and manner of participation will be agreed in a group meeting with the client-  
158 researchers of each client group. To ensure meaningful cooperation between client-researchers and  
159 researchers, we will provide a training and introduction at the start of the research, create an safe  
160 working environment, and make basic agreements for our cooperation with the client-researchers at  
161 the start. During the research phases, we will discuss the conditions for cooperation of the research  
162 team regularly. Furthermore, we will communicate on a clear manner, tailored to the literacy and  
163 coping level of the client-researchers. Moreover, we will have a researcher available for questions  
164 continuously, and take availability of client-researchers into account when meetings will be planned.

165

## 166 **Five phases of selection and development of a qualitative instrument**

167 This research contains five different phases that will take place during the timespan 2016-2019 (see  
168 Figure 2): 1) Preparation: recruitment of care organisations & client-researchers and a literature study;  
169 2) Consultation: individual interviews and focus groups on the determinants of the quality of the care

1  
2  
3 170 relationship according to clients and care professionals; 3) Selection of the most promising qualitative  
4 171 instruments; 4) Evaluation: selected qualitative instruments will be tested and evaluated within one  
5  
6 172 client group, with the best qualitative instruments then being tested and evaluated in the other two  
7  
8 173 groups; 5) Dissemination: formulating an implementation plan for the most suitable qualitative  
9  
10 174 instruments.

11  
12 175

13 176 *Figure 2 Phases of the study*

14  
15 177

### 16 17 178 **Supervisory committee**

18  
19 179 A supervisory committee will supervise the research project from start to finish. A delegation  
20  
21 180 consisting of several stakeholders in long-term care will be invited to be on the supervisory committee.  
22  
23 181 The stakeholders involved are representatives of care providers, client organisations and health  
24  
25 182 insurers. The committee will monitor the research process according to the project plan and give  
26  
27 183 advice on the content of the study. Eight meetings are planned and members of the supervisory  
28  
29 184 committee can be asked for further input by e-mail if needed.

30 185

### 31 186 **2.1 Preparation**

32  
33 187 The first phase of this study is the three-part preparation of the research.

#### 34 35 188 **a. Inviting three care organisations**

36  
37 189 Three care organisations and their client councils are invited to participate in the consultation and  
38  
39 190 instrument selection phase. The care organisations invited provide care to one of the three different  
40  
41 191 client groups.

#### 42 192 **b. Inviting and selecting client-researchers**

43  
44 193 The invitation of client-researchers starts on a small scale from a personal approach, in cooperation  
45  
46 194 with members of client councils and care professionals. We aim to have three or four client-  
47  
48 195 researchers from each client group. Because the participating clients need to have sufficient skills for  
49  
50 196 participating so actively in the study, it is important to realise that the client-researchers may not be  
51  
52 197 fully representative of the target group. See Table 1 for the inclusion criteria. The selected client-  
53  
54 198 researchers will be offered a training to prepare and practice the qualitative interview technique. The  
55  
56 199 training will be provided by the NIVEL researchers in two interactive workshops. The topics covered by

1  
2  
3 200 the training are tuned to the needs of client-researchers. In the training, the distribution of tasks and  
4  
5 201 responsibilities will be discussed and established. Tasks and responsibilities can depend on  
6  
7 202 someone's capacities and wishes.

8 203 **c. Literature study**

9  
10 204 Three literature studies will be conducted:

11 205 A. A systematic review to gain an understanding of determinants influencing the quality of the care  
12  
13 206 relationship

14  
15 207 B. A scoping review to identify existing qualitative instruments that measure the quality of the  
16  
17 208 relationship between clients and care professionals in the Netherlands

18  
19 209 C. A scoping review to collect best practices of client participation in long-term care research to  
20  
21 210 determine a participation strategy for client-researchers

22 211 The literature studies will include scientific databases such as Medline, Embase, Cinahl and  
23  
24 212 PsycINFO, and grey literature. For the first study (A), a systematic search strategy will be drawn up.

25  
26 213 Eligible articles need to be written in English and published in the last ten years (between 2006 and

27  
28 214 2016) due to time constraints. A preselection will be made by one researcher who will screen the titles

29  
30 215 of all articles. All abstracts then will be screened and assessed by two researchers. If they rate an

31  
32 216 abstract differently, consensus will be reached in a discussion between the two researchers. If

33  
34 217 necessary, a third researcher will be involved. Subsequently, two researchers will assess the included

35  
36 218 articles by reading the full texts. Again, consensus will be reached in a discussion between them if

37  
38 219 they rate papers differently. If necessary, a third researcher will be involved. The quality of the paper

39  
40 220 will be rated for all articles included using the criteria of the Mixed Methods Appraisal Tool (MMAT)

41  
42 221 [35, 36].

43  
44 222 For the second and third studies (B and C), we will also carry out a grey literature search in addition to

45  
46 223 the scientific literature search. Articles eligible for selection need to be written in English or Dutch and

47  
48 224 published between 2006 and 2016.

49  
50 225

51 226 Products of the preparation phase:

52 227 

- established cooperation with 3 care organisations and cooperation with 3 to 4 client-researchers in

53  
54 228 each organisation

55  
56 229 

- a systematic review article on determinants influencing the quality of the care relationship

- 1  
2  
3 230   ▪ an overview of existing qualitative instruments in long-term care in the Netherlands  
4  
5 231

## 6 232       **2.2 Consultation**

7  
8 233 In the consultation phase, the results from the first (systematic) literature search into determinants of  
9  
10 234 the quality of the care relationship will be verified amongst clients and care professionals. In every  
11  
12 235 care organisation, clients will be interviewed individually face-to-face until saturation occurs. It is  
13  
14 236 expected that saturation will occur when we have interviewed 8-10 clients, but it is difficult to  
15  
16 237 determine the saturation point in advance as one size does not fit all in qualitative research [37].  
17  
18 238 Additionally, 4-6 care professionals from each organisation will be invited for a focus group meeting.  
19  
20 239 Clients who meet the inclusion criteria (see Table 1) will be approached by the client-researchers. We  
21  
22 240 will work with a convenience sample to include clients who are willing and available to participate.  
23  
24 241 Even so, we will aim for as much variation as possible in terms of relevant client characteristics such  
25  
26 242 as gender, age, ethnicity and whether the care is intramural or extramural. The care professionals will  
27  
28 243 be selected and invited in close cooperation with the care organisation.  
29  
30 244 The data collection and analysis will be conducted by the research team, consisting of 1 researcher  
31  
32 245 and 3 to 4 client-researchers from each care organisation. The focus groups will take about 2 hours  
33  
34 246 and will take place in a meeting room of the care organisation. Interviews will take place in the  
35  
36 247 residency of a client or in a meeting room of the care organisation. Depending on the concentration  
37  
38 248 span of each client, interviews will take approximately 30 minutes. Clients will be asked to give  
39  
40 249 informed consent prior to the start of the interview. In interviews we will adopt a 'process consent'  
41  
42 250 approach, meaning that we constantly observe during the interview whether consent is still present by  
43  
44 251 paying attention to verbal and nonverbal indications of reluctance or hesitation to participate [38]. The  
45  
46 252 focus groups and interviews will be audio-recorded, transcribed verbatim and analysed in three  
47  
48 253 phases: open coding, axial coding and selective coding [16]. The data analysis method is inspired by  
49  
50 254 the Interpretative Phenomenological Analysis, which places the clients' experiences and the meaning  
51  
52 255 they assign to those experiences at the core [39]. 25% of the interviews will be analysed by two  
53  
54 256 researchers. If these researchers disagree on the interpretation of a fragment, they will try to reach  
55  
56 257 consensus by discussion. If they do not reach consensus, a third researcher will be consulted. The  
57  
58 258 main findings will be discussed by the entire research team in work meetings. The transcripts will be  
59  
60 259 analysed using the qualitative software programme MAXQDA.

260

261 Product of consultation:

- 262     ▪ Overview of determinants influencing the quality of the care relationship in the three client
- 263         groups

264

### 265           **2.3 Selection of up to six instruments**

266 Based on the overview of existing qualitative instruments in the Netherlands, the research teams and  
267 supervisory committee will select the two most promising qualitative instruments for each client group.

268 The selection will be based on the available information about issues such as corroboration, the fit of  
269 the purposes for which the information provided can be used, clear structure, usability of instruments  
270 in various client groups, validity and reliability, implementation information and the extent to which  
271 clients are involved in applying instruments. The instruments may include (a combination of) individual  
272 interviews, observations, and/or focus groups. This information will be presented to the supervisory  
273 committee using the Delphi method [40]. For the selection of instruments, the supervisory committee  
274 may be supplemented with other stakeholders.

275

276 Products of the selection:

- 277     ▪ Overview of assessed qualitative instruments for evaluating the care relationship
- 278     ▪ Two instruments per client group that will be evaluated

279

### 280           **2.4 Evaluation of qualitative instruments**

281 During the fourth phase of this study, each instrument will be tested with at least ten clients and an  
282 expected maximum of thirteen clients from one of the client groups (see Figure 3). It is expected that  
283 saturation will occur in between this quantity. The respondents of the evaluation phase are not  
284 necessarily the same as respondents of the consultation phase and it is likely that most respondents  
285 will only participate in one phase of this study. If necessary we will adjust the selected qualitative  
286 instruments to the specific client group. We use the same evaluation criteria as used in the selection  
287 phase, supplemented by criteria such as generalisability to other client groups, and information  
288 needed for applying the instrument as a client and care professional. Next, the most promising  
289 instrument from each client group will be cross-tested in the other two client groups with six to eight

1  
2  
3 290 clients. If no instrument appears to be suitable for all three client groups, we will investigate whether  
4 291 there are common elements in the qualitative instruments that can be used in more than one client  
5 292 group. In the case of equal suitability, instruments with generic elements are preferred over  
6 293 instruments that are solely applicable to one specific client group. This evaluation leads to a new  
7  
8 294 ranking based on a summary judgement of each qualitative instrument in which the advantages and  
9 295 disadvantages are listed as well as the conditions necessary for successful implementation. These  
10 296 results will be presented to the supervisory committee.

11 297

12 298 The qualitative instruments will be applied and evaluated with the help of six client-researchers from  
13 299 each client group. In addition, we will include at least 32 clients from each care organisation as  
14 300 respondents in this phase. They will be approached by their daily care professionals, client-researcher  
15 301 or the client council to ask them to take part in the study. A convenience sample technique will be  
16 302 used to include clients who meet the inclusion criteria and are willing and available to participate.  
17 303 Nevertheless, we will aim for as much variation as possible with regard to relevant client  
18 304 characteristics such as gender, age, ethnicity, and intramural or extramural care.

19 305

20 306 Products of the evaluation:

- 21 307
  - 22 308     ▪ Selection of the qualitative instruments that were evaluated as best

23 309

24 310 *Figure 3 Research respondents*

25 311

## 26 312 **2.5 Dissemination**

27 313 In close cooperation with the client-researchers and participating care organisations, we will develop a  
28 314 toolbox including an implementation plan and the (adjusted) qualitative instruments for measuring and  
29 315 improving the quality of the care relationship for each client group in long-term care. The  
30 316 implementation plan focuses on implementing the qualitative instruments that were selected at the end  
31 317 of the evaluation phase. The toolbox will include a training module to let clients and healthcare  
32 318 providers apply the instrument, plus guidance for the analysis and use of results for improving the care  
33 319 relationship.

1  
2  
3 319 We will also examine whether the results of the qualitative instruments can be used for other  
4 320 purposes, such as healthcare procurement and monitoring for external accountability. Several  
5  
6 321 meetings will be held with stakeholders, the research team and care organisations in order to  
7  
8 322 disseminate and discuss the results of the project and the implementation plan.  
9

10 323

11 324 Product of the dissemination phase:

- 12  
13 325
  - Toolbox including the qualitative instruments (adjusted if necessary) to measure and improve
- 14  
15 326 the quality of the care relationship for each client group in long-term care. The implementation
- 16  
17 327 plan is part of the toolbox.
- 18  
19 328
  - Recommendations based on external verification of the toolbox.

20 329

### 21 330 **Ethics**

22  
23  
24 331 Participants will receive verbal and written information about the research. Participants will provide  
25  
26 332 written informed consent and process consent will also be used in the interviews with clients [38]. The  
27  
28 333 Medical Ethics Committee of the Radboud University Nijmegen Medical Centre was asked whether  
29  
30 334 their approval of the study was required under the Dutch Medical Research Involving Human Subjects  
31  
32 335 Act. The Committee decided that formal approval was not needed.

33 336

## 34 337 **3. Discussion and conclusion**

### 35 338 **3.1. Discussion**

36  
37  
38 339 Prior work has documented the importance of the care relationship for clients in long-term care [1, 4,  
39  
40 340 41]. In practice, there is a lack of qualitative instruments for evaluating or monitoring the care  
41  
42 341 relationship. We will carry out a study to find and optimise the most suitable qualitative instruments for  
43  
44 342 monitoring the quality of care relationships in long-term care from a client's perspective. The aim of the  
45  
46 343 present paper is to describe the research design of this study. Due to the differences between client  
47  
48 344 groups in long-term care, it is likely that different instruments will fit each group best. This study will  
49  
50 345 therefore result in a toolbox containing an implementation plan and the optimised qualitative  
51  
52 346 instruments.

53 347 Clients will participate in this participatory study as client-researchers. We are therefore working  
54  
55 348 closely with client-researchers in activities such as conducting interviews, preparation activities and

1  
2  
3 349 analysis. According to Roberts (2012), participatory research is more time-consuming than  
4 350 conventional research methods. It takes time to achieve the desired level of trust in a community, and  
5  
6 351 extra time is also needed for the joint process for thinking about the research results. This extra time  
7  
8 352 will be taken into account in the time schedule of this study. In order to create backing in the  
9  
10 353 environment and thereby increase the probability of participation of clients, client-researchers, care  
11  
12 354 organisations, client councils and client organisations are cooperating in this study [42]. Their  
13  
14 355 willingness to join is an important prerequisite to perform this research. The study depends on the  
15  
16 356 close cooperation of client-researchers, and it is therefore important to work together in an equal,  
17  
18 357 respectful, attentive and open way [42, 43]. Lessons learned in previous participatory research will be  
19  
20 358 used to prevent repetition of avoidable errors, such as tokenism, client-researchers facing difficult  
21  
22 359 situations, experienced workload, and proto-professionalisation [44] [45]. A scoping review will be  
23  
24 360 conducted for this purpose. In order to make the project practically feasible, we will exclude some  
25  
26 361 specific groups in long-term care, such as people with physical or sensory disabilities or people  
27  
28 362 receiving palliative care.

29  
30 363 When organisations use one of the optimised instruments from the toolbox, it will provide useful  
31  
32 364 information and feedback for clients and care professionals on the care relationship in long-term care.  
33  
34 365 This makes the research project practically relevant. Nevertheless, this study risks being  
35  
36 366 overshadowed by everyday demands that care organisations face, which precludes implementation of  
37  
38 367 the selected instrument on large scale. The likelihood of successful implementation depends on the  
39  
40 368 willingness of organisations to change their instruments for measuring the quality of the care  
41  
42 369 relationship, and the degree of support from national stakeholders. The participatory research design  
43  
44 370 and involvement of the supervisory committee will increase the probability that the most preferred  
45  
46 371 instruments will be implemented and disseminated in the field.

47 372

### 48 373 **3.2. Conclusion**

49 374 In long-term care, care relationships are seen as a fundamental element in the delivery of high quality  
50  
51 375 care [4, 46-48]. But good care relationships have not been set up everywhere yet. It is therefore  
52  
53 376 important that care professionals, client councils and care organisations determine areas in which  
54  
55 377 improvement of the care relationship is possible. As far as we are aware, this will be the first study to  
56  
57 378 use a participatory research design to represent the client perspective in the selection and



1  
2  
3 379 optimisation of qualitative instruments for monitoring care relationships. Scientific articles will be  
4 380 published to expand scientific knowledge on care relationships in long-term care. This approach  
5  
6 381 allows participatory research to link the practical and scientific purposes. Backing will be generated for  
7  
8 382 the set of qualitative instruments developed through the meetings of the supervisory committee, the  
9  
10 383 involvement of client-researchers and the creation of a LinkedIn group to share the findings and  
11  
12 384 issues.

13 385

### 15 386 **3.3 Practice Implications**

16  
17 387 The study will result in a toolbox with qualitative instruments that can be used for effective monitoring  
18  
19 388 of the quality of a care relationship. Clients, client councils and care organisations can use the toolbox  
20  
21 389 to monitor the care relationship in a structured way from a client perspective. More generally, the  
22  
23 390 content of this paper could serve as guideline for developing other studies with the combined purpose  
24  
25 391 of practical outcomes and sharing empirical evidence.

26 392

## 28 393 **4. Declarations**

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32  
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34  
35 397 collection, analysis, and interpretation of data, and in writing the manuscript.

### 37 398 **Author's contributions**

38  
39 399 All authors contributed to, reviewed and approved the article drafts and final manuscript. AS was  
40  
41 400 responsible for writing the manuscript. MH, NB, KL and SvD read several versions of the manuscript  
42  
43 401 and provided their feedback and suggestions regularly.

### 44 402 **Competing interests**

45  
46 403 The authors declare that they have no competing interests.

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48 404

405 **References**

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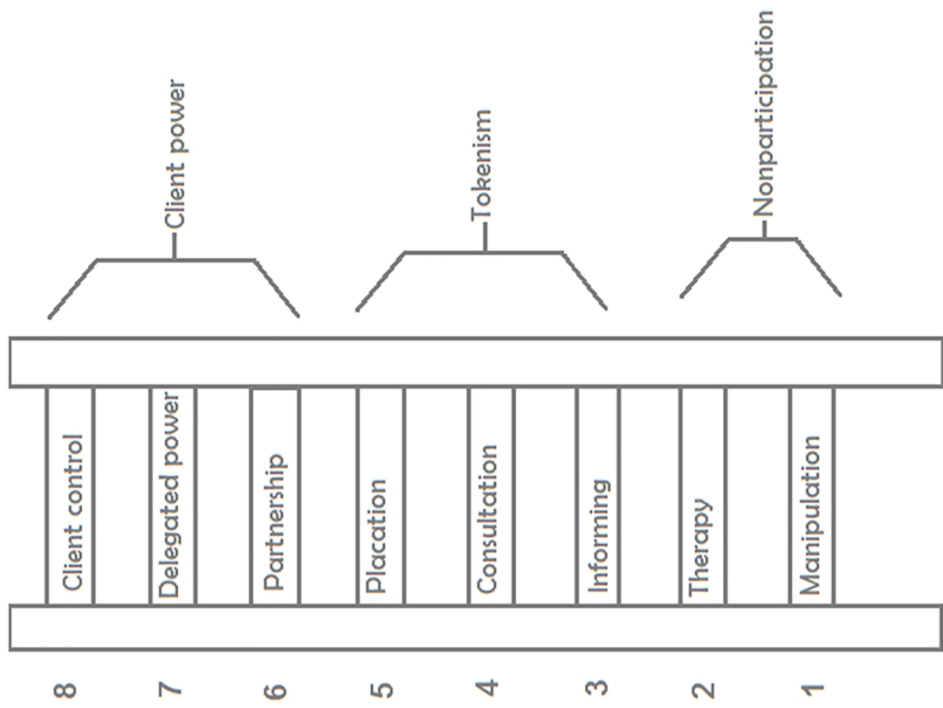


Figure 1 Ladder of Participation, inspired on Arnstein (2015)  
254x190mm (300 x 300 DPI)



Figure 2 Phases of the study

253x20mm (300 x 300 DPI)

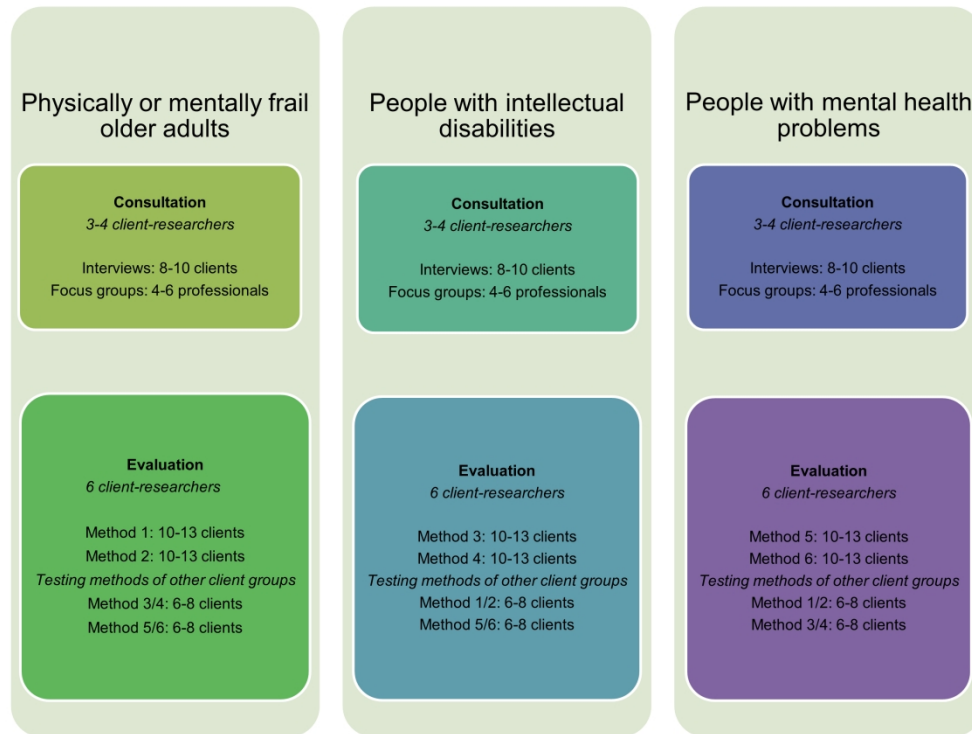


Figure 3 Research respondents

254x190mm (300 x 300 DPI)

# BMJ Open

## Protocol for a participatory study for developing qualitative instruments measuring the quality of long-term care relationships

Journal:	<i>BMJ Open</i>
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<b>Primary Subject Heading</b>:	Health services research
Secondary Subject Heading:	Qualitative research
Keywords:	Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, QUALITATIVE RESEARCH, Care relationship, Participatory research, Client perspective, Long-term care

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4 of long-term care relationships  
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## 5 Abstract

6 **Introduction** In long-term care (LTC), it is unclear which qualitative instrument or instruments are  
7 most effective and useful for monitoring the quality of the care relationship from the client's  
8 perspective. In this paper we describe the research design for a study aimed at finding and optimising  
9 the most suitable and useful qualitative instruments for monitoring the care relationship in long-term  
10 care.

11 **Methods and analysis** The study will be performed in three organizations providing care to the  
12 following client groups: physically or mentally frail elderly, people with mental health problems and  
13 people with intellectual disabilities. Using a participatory research method, we will determine which  
14 determinants influence the quality of a care relationship and evaluate up to six instruments in  
15 cooperation with client-researchers. We will also determine whether the instruments (or parts thereof)  
16 can be applied across different LTC settings.

17 **Ethics and dissemination** This study protocol describes a participatory research design for  
18 evaluating the quality of the care relationship in long-term care. The Medical Ethics Committee of the  
19 Radboud University Nijmegen Medical Centre decided that formal approval was not needed under the  
20 Dutch Medical Research Involving Human Subjects Act. This research project will result in a toolbox  
21 and implementation plan, which can be used by clients and care professionals to measure and  
22 improve the care relationship from a client's perspective. Results will also be published via  
23 international peer-reviewed journals.

## 25 Strengths and limitations of this study

- 26 ➤ The study will result in useful optimised instruments for care organisations and client councils  
27 to collect information and feedback of clients on care relationships in long-term care.
- 28 ➤ The participation of client-researchers in the research teams will improve the validity,  
29 relevance and support of the research project.
- 30 ➤ The success of the study will depend on the willingness of client-researchers and care  
31 organisations to be involved and contribute to the study.
- 32 ➤ The success of the implementation will depend on the willingness of care organisations to use  
33 the optimised qualitative instruments, and the degree of support from national stakeholders.

## 1. Introduction

In long-term care, the relationship between clients and care professionals is seen as fundamental for the delivery of high-quality care. This importance is related to the longer period of care provision and the chronic health conditions of clients [1]. Long-term care consists of 'a range of services and assistance for people who, as a result of mental and/or physical frailty and/or disability over an extended period of time, depend on help with their daily living activities and/or need permanent nursing care.' [2]. A good care relationship between a client and professional requires an equal relationship in which professionals provide care with dignity and sensitivity to the clients' wishes [3]. It allows clients to express any questions or complaints they may have about the care given. This open environment has not yet been achieved in all organisations, according to a recent Dutch study [3]. Another study shows that care professionals believe they listen to the needs of clients and offer care in a person-centred manner, but entrenched habits and time pressure mean that opportunities for person-centred communication are often missed [4]. Worldwide, there is a drive to redress the imbalance in care from an ethos that is medically dominated, disease orientated and often fragmented, to one that is relationship focused [5].

Monitoring the quality of the care relationship should be set up from a client's perspective. Clients have unique experiential knowledge providing valuable insights into the quality of everyday care and care relationships that are missed otherwise. Care providers, clients and family perceive different determinants as influencing the closeness of the care relationship between client and care professional. McGilton and Boscart (2006) showed that care professionals in elderly care felt that close relationships were primarily about feeling connected with the resident. Family members focused primarily on the actions staff took to present a caring attitude. Residents on the other hand felt that close relationships included staff acting as their confidants [6]. By focusing on client experiences, a more comprehensive evaluation of clients' experiences of the care provided and areas for improvement is generated [7]. However, little research in long-term care has focused on the client's perspective on these relationships [6].

An excellent way to include the clients' perspective is by carrying out participatory research. In participatory research, clients are invited to become part of a research team [8-11]. This empowers the clients and improves the validity and relevance of the research project [12]. Clients' involvement can also lead to broader support for the outcomes of the research project and related quality improvement

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3 65 initiatives among clients and care professionals [13]. Clients can be involved in several stages of a  
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5 66 research project. In preparation activities, or in data collection by actively helping conduct interviews or  
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7 67 focus groups [14, 15]. Client-researchers can also be involved in the data analysis [15] or have an  
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9 68 advisory role, for example from the design phase onwards, by constructing the research design, a  
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11 69 topic list or by attending steering group meetings [11, 14].

12  
13 70 Clients' experiences with the quality of a care relationship can be explored using qualitative  
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15 71 instruments [16]. One advantage of qualitative research is that it aims to understand social  
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17 72 phenomena in natural settings, giving due emphasis to the meanings, experiences and wishes of  
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19 73 people [17]. Qualitative procedures give clients freedom to respond, allowing direct expression of their  
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21 74 own concerns rather than those of the researchers [18]. As a result, qualitative research can tackle  
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23 75 aspects of complex behaviours, attitudes and interactions that are not amenable to quantitative  
24  
25 76 research [17]. It has also been shown that care organisations can translate qualitative results more  
26  
27 77 easily into improvement actions, as such results are capable of including the nuances and complexity  
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29 78 of care practices [19, 20].

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31 79 In Western countries, a shift can be seen in long-term care practice from focusing on solely  
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33 80 quantitative instruments to using qualitative instruments for measuring quality [18]. For example,  
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35 81 interview instruments such as narrative sensibility and storytelling [21, 22], focus groups [23-25],[26]  
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37 82 and observational instruments [27-30] are used to improve the relationship between client and care  
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39 83 professional and to encourage clients or their relatives to provide feedback. Corresponding to this  
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41 84 trend, there is a call for qualitative instruments in the Netherlands that can be used in daily practice to  
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43 85 hear client experiences of their care relationship. However, it is not clear whether existing qualitative  
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45 86 instruments are useful and effective for monitoring and improving the care relationship from a client's  
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47 87 perspective in long-term care and whether they focus on the important determinants of a good care  
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49 88 relationship. Some determinants of a good care relationship might differ between client groups, as  
50  
51 89 may the preferred instrument of evaluating the relationship. At the same time, we expect that there are  
52  
53 90 also general determinants that influence the quality of a care relationship in all LTC settings, such as  
54  
55 91 trust or communications skills. In this study, we have attempted to find both specific and more generic  
56  
57 92 determinants of care relationship.

58  
59  
60 93  
94

**Aim**

The aim of the present paper is to describe the research design of the study. It is a participatory study to find and optimise qualitative instruments for evaluating care relationships in long-term care from the client's perspective. This project seeks to answer the following research questions:

- A. What determinants influence the quality of the care relationship in long-term care for the various client groups, according to both clients and care professionals?
- B. What qualitative instruments can be used for monitoring and improving the relationship between clients and care professionals from a client's perspective?
- C. Which qualitative instruments or parts thereof can be used across client groups and how?
- D. How can the most suitable qualitative instruments be used by the various user groups (such as care professionals, care organisations, client councils and health insurance companies) to improve the quality of the care relationship?

The purpose of the first research question is to understand the determinants that influence the quality of the care relationship in long-term care. The second and third research question are aimed to evaluate qualitative instruments to know whether they are useful for evaluating the quality of individual care relationships in long-term care across client groups. This research project will result in a toolbox that can be used by professionals and clients to measure and improve the quality of the care relationships in long-term care. The results of this study will be published in peer-reviewed international journals and presented at several congresses, preferably at the annual conference of the international Collaboration for Participatory Health Research and the International Conference on Communication in Healthcare.

**2. Methods and analysis****Setting and participants**

The study will take place in the Netherlands. In the Netherlands, long-term care consists of three client groups: physically or mentally frail older adults, people with mental health problems and people with an intellectual, physical or audio-visual disability. For this research, we focus within the last client group of people with a disability solely on clients with intellectual disabilities. Three Dutch care organisations are willing to be involved in this multicentre study, each of the three care organisations serves care to one client group. A convenience sample technique was used. To make sure that we

1  
2  
3 125 can reach a diverse group of clients, we selected care organisations that provide care to a large client  
4 126 population with a diversity of recurring care needs and receiving both inpatient and outpatient care and  
5  
6 127 that comprise multiple locations. The three care organisations provide care to more than 2000 clients,  
7  
8 128 and have more than 2000 care employees. If a care organisation will withdraw later on, we will invite  
9  
10 129 another care organisation to become part of the research project .  
11  
12 130

### 13 131 *Respondents and client-researchers*

14  
15 132 Clients will be involved as client-researchers and respondents in the different phases. Inclusion criteria  
16  
17 133 for both groups are described in Table 1. Clients who have at least weekly recurring contact with a  
18  
19 134 care professional and receive care for at least three months in/from long-term care organisations are  
20  
21 135 included. Physically or mentally frail older adults may need assistance due to somatic complaints or  
22  
23 136 suffer from mental decline because of dementia. Persons with mental health problems may suffer from  
24  
25 137 a personality disorder, schizophrenia, or an anxiety disorder. An intellectual disability may be caused  
26  
27 138 by chromosome abnormalities or by a brain injury. We will focus on care relationships between clients  
28  
29 139 and care professionals who take care of clients directly, those who see clients most often to provide  
30  
31 140 assistance, supporting care and physical care. For instance, care aids, personal carers, and different  
32  
33 141 types of nurses. Clients receive care for at least once a week. The focus is not on professionals who  
34  
35 142 are further removed from providing recurrent physical and supporting care, such as clinicians,  
36  
37 143 psychiatrists and general practitioners. Also, clients receiving acute health care are outside the scope  
38  
39 144 of this study. Moreover, caregivers who provide informal care are not included.  
40  
41 145

42 146 *Table 1 Inclusion criteria for clients as respondents and client-researchers*

	Respondents	Client-researchers
18 or older (no upper limit)	X	X
Currently a client of residential elderly care and home care, mental healthcare or disabled care	X	X
Receiving care for at least three months	X	X
Receiving care at least once every week	X	
Able to communicate verbally in Dutch	X	X
Able to generalise from their own experiences		X

Able to hold a conversation without assistance of a close relative or friend		X
Able to read and write at a basic level		X
Has a fairly stable health situation		X
Able to travel short distances		X

147

148 Different inclusion criteria apply for clients as respondents and client-researchers, for the reason that  
 149 participating client-researchers need to have more skills for participating actively. It is important to  
 150 realise that the client-researchers may not be fully representative of the target group of respondents.

151 *Figure 1 Ladder of Participation, Arnstein (2015) [31]*

152

### 153 **Patient and public involvement**

154 This study is participatory research: having clients participate in this study as client-researchers will  
 155 help us counteract the social distance between clients and researchers. Gradations of client  
 156 participation are often described using a participation ladder (see Figure 1). The participation levels in  
 157 Arnstein's frequently used Participation Ladder are manipulation, therapy, informing, consultation,  
 158 placation, partnership, delegated power and client control [32]. In this study, we are aiming for the  
 159 'partnership' participation level. Client-researchers will be asked to be involved in preparation activities  
 160 such as developing the design of the study, compose a definition of a high quality care relationship,  
 161 and drafting the topic list for interviews and focus groups and selection of the qualitative instruments  
 162 that will be tested. Moreover, client-researchers will help in the interviews, focus groups and  
 163 instrument testing. Some of the client-researchers will also be involved in the selection and invitation  
 164 of respondents. As members of the research team, client-researchers will be involved in the analysis  
 165 stage as well: in work meetings, the results of interviews, focus groups and instrument evaluation will  
 166 be summarised and discussed. At the end of the research, client-researchers can optionally help in  
 167 the dissemination phase of the research. Earlier studies show there are several barriers for  
 168 participatory research [11] and sharing responsibilities is not always easy for researchers [33]. Studies  
 169 underline the importance to start the research process really open and flexible to make true client  
 170 participation, empowerment and a valuable collaboration process possible [11, 34]. The intensity and

1  
2  
3 171 manner of participation will be agreed in a group meeting with the client-researchers of each client  
4 172 group. To ensure meaningful cooperation between client-researchers and researchers, we will provide  
5  
6 173 a training and introduction at the start of the research, create an safe working environment, and make  
7  
8 174 basic agreements for our cooperation with the client-researchers at the start. During the research  
9  
10 175 phases, we will discuss the conditions for cooperation of the research team regularly. Furthermore,  
11  
12 176 we will communicate on a clear manner, tailored to the literacy and coping level of the client-  
13  
14 177 researchers. Moreover, we will have a researcher available for questions continuously, and take  
15  
16 178 availability of client-researchers into account when meetings will be planned. Client-researchers  
17  
18 179 receive a small allowance for their contribution, depending on the invested amount of time. Client-  
19  
20 180 researchers can always quit or call off participation during the research process. Halfway, we added a  
21  
22 181 moment to evaluate the process so far with client-researchers and to ask them whether they want to  
23  
24 182 continue.  
25

183

#### 184 **Five phases of selection and development of a qualitative instrument**

185 This research contains five different phases that will take place during the timespan 2016-2019 (see  
186 Figure 2): 1) Preparation: inviting and selecting client-researchers and a literature study;  
187 2) Consultation: individual interviews and focus groups on the determinants of the quality of the care  
188 relationship according to clients and care professionals; 3) Selection of the most promising qualitative  
189 instruments; 4) Evaluation: selected qualitative instruments will be tested and evaluated within one  
190 client group, with the best qualitative instruments then being tested and evaluated in the other two  
191 groups; 5) Dissemination: formulating an implementation plan for the most suitable qualitative  
192 instruments.

193

194 *Figure 2 Phases of the study*

195

#### 196 **Supervisory committee**

197 A supervisory committee will supervise the research project from start to finish. A delegation  
198 consisting of several stakeholders in long-term care will be invited to be on the supervisory committee.  
199 The stakeholders involved are representatives of care providers and branch organisations, client  
200 (council) organisations with a nationwide scope, contact persons of the involved care organisations,



1  
2  
3 201 and health insurers. The committee will monitor the research process according to the project plan  
4 202 and give advice on the content of the study. Eight meetings are planned and members of the  
5  
6 203 supervisory committee can be asked for further input by e-mail if needed. The whole research team  
7  
8 204 will be present at the meetings, including two professors.  
9  
10 205

## 11 206 **2.1 Preparation**

12  
13 207 The first phase of this study is the two-part preparation of the research.

### 14 208 **a. Inviting and selecting client-researchers**

15  
16  
17 209 The invitation of client-researchers starts on a small scale from a personal approach, in cooperation  
18  
19 210 with members of client councils and care professionals. An individual acquaintance meeting is held  
20  
21 211 with every client who shows interest to participate. We aim to have three or four client-researchers  
22  
23 212 from each client group. Because the participating clients need to have sufficient skills for participating  
24  
25 213 so actively in the study, it is important to realise that the client-researchers may not be fully  
26  
27 214 representative of the target group. See Table 1 for the inclusion criteria. The selected client-  
28  
29 215 researchers will be offered a training to prepare and practice the qualitative interview technique. The  
30  
31 216 training will be provided by the NIVEL researchers in two interactive workshops. The topics covered by  
32  
33 217 the training are tuned to the needs and literacy of client-researchers. In the training, the distribution of  
34  
35 218 tasks and responsibilities will be discussed and established. Tasks and responsibilities can depend on  
36  
37 219 someone's capacities, capabilities and wishes.

### 38 220 **b. Literature review**

39 221 Three literature studies will be conducted:

- 40 222 A. A systematic review to gain an understanding of determinants influencing the quality of the care  
41  
42 223 relationship  
43  
44 224 B. A scoping review to identify existing qualitative instruments that measure the quality of the  
45  
46 225 relationship between clients and care professionals in the Netherlands  
47  
48 226 C. A scoping review to collect best practices of client participation in long-term care research to  
49  
50 227 determine a participation strategy for client-researchers

51 228 The literature review will include scientific databases such as Medline, Embase, Cinahl and  
52  
53 229 PsycINFO, and grey literature. For the first study (A), a systematic search strategy will be drawn up.  
54  
55 230 When necessary, a librarian will be consulted during this process. Eligible articles need to be written in

1  
2  
3 231 English and published in the last ten years (between 2006 and 2016) due to time constraints. A  
4  
5 232 preselection will be made by one researcher who will screen the titles of all articles. All abstracts then  
6  
7 233 will be screened and assessed by two researchers. If they rate an abstract differently, consensus will  
8  
9 234 be reached in a discussion between the two researchers. If necessary, a third researcher will be  
10  
11 235 involved. Subsequently, two researchers will assess the included articles by reading the full texts.  
12  
13 236 Again, consensus will be reached in a discussion between them if they rate papers differently. If  
14  
15 237 necessary, a third researcher will be involved. The quality of the paper will be rated for all articles  
16  
17 238 included using the criteria of the Mixed Methods Appraisal Tool (MMAT) [35, 36].

18  
19 239 For the second and third studies (B and C), we will also carry out a grey literature search in addition to  
20  
21 240 the scientific literature search. Articles eligible for selection need to be written in English or Dutch and  
22  
23 241 published between 2006 and 2016.

24  
25 242

26  
27 243 Products of the preparation phase:

- 28  
29 244
- 245     ▪ established cooperation with 3 care organisations and cooperation with 3 to 4 client-researchers in
  - 246     each organisation
  - 247     ▪ a systematic review article of the literature regarding determinants influencing the quality of the
  - 248     care relationship
  - 249     ▪ an overview of existing qualitative instruments in long-term care in the Netherlands

30  
31  
32  
33  
34  
35  
36  
37 249

## 38 250 **2.2 Consultation**

39  
40 251 In the consultation phase, the results from the first (systematic) literature search into determinants of  
41  
42 252 the quality of the care relationship will be complemented amongst clients involved as respondents and  
43  
44 253 care professionals. In every care organisation, clients will be interviewed individually in semi-  
45  
46 254 structured, face-to-face interviews until saturation occurs. It is expected that saturation will occur when  
47  
48 255 we have interviewed 8-10 clients of each care organisation, but it is difficult to determine the saturation  
49  
50 256 point in advance as one size does not fit all in qualitative research [37]. Clients who meet the inclusion  
51  
52 257 criteria (see Table 1) will be approached by the client-researchers together with the researcher. We  
53  
54 258 will work with a convenience sample to include clients who are willing and available to participate.  
55  
56 259 Even so, we will aim for as much variation as possible in terms of relevant client characteristics such  
57  
58 260 as gender, age, ethnicity and whether the care is inpatient or outpatient.

1  
2  
3 261 Interviews will take place in the residency of a client or in a meeting room of the care organisation.  
4  
5 262 Depending on the concentration span of each client, interviews will take approximately 30 minutes.  
6  
7 263 Clients will be asked to give informed consent prior to the start of the interview. In some instances the  
8  
9 264 legal representatives of persons with intellectual disabilities will be asked for permission first. It is the  
10  
11 265 responsibility of the researcher that the inform consent form is signed. In interviews we will adopt a  
12  
13 266 'process consent' approach, meaning that we constantly observe during the interview whether consent  
14  
15 267 is still present by paying attention to verbal and nonverbal indications of reluctance or hesitation to  
16  
17 268 participate [38].

18  
19 269 Additionally, 4-6 care professionals from each organisation will be invited for a focus group meeting.  
20  
21 270 As with client respondents, we will work with a convenience sample to include professionals who are  
22  
23 271 willing and available to participate. The care professionals will be selected and invited in close  
24  
25 272 cooperation with the care organisation. The focus groups will take about 2 hours and will take place in  
26  
27 273 a meeting room of the care organisation. A topic list will be made in advance to lead the group  
28  
29 274 conversations on a semi-structured manner.

30  
31 275 The data collection and analysis will be conducted by the research team, consisting of 1 researcher  
32  
33 276 and 3 to 4 client-researchers from each care organisation. The focus groups and interviews will be  
34  
35 277 audio-recorded, transcribed verbatim by an independent transcription agency and analysed in three  
36  
37 278 phases: open coding, axial coding and selective coding [16]. The data analysis method is inspired by  
38  
39 279 the Interpretative Phenomenological Analysis, which places the clients' experiences and the meaning  
40  
41 280 they assign to those experiences at the core [39]. A portion of the interviews will be analysed by two  
42  
43 281 researchers. If these researchers disagree on the interpretation of a fragment, they will try to reach  
44  
45 282 consensus by discussion. If they do not reach consensus, a third researcher will be consulted. The  
46  
47 283 remaining interviews will be observed by one of the researchers. The main findings will be discussed  
48  
49 284 by the entire research team in work meetings. The transcripts will be analysed using the qualitative  
50  
51 285 software programme MAXQDA.

52 286

53 287 Product of consultation:

- 54 288     ▪ Overview of determinants influencing the quality of the care relationship in the three client  
55 289 groups

56 290

### 2.3 Selection of up to six instruments

Based on the overview of existing qualitative instruments in the Netherlands, the research teams and supervisory committee will select the two most promising qualitative instruments for each client group. The selection will be based on the available information about issues such as corroboration, the fit of the purposes for which the information provided can be used, clear structure, usability of instruments in various client groups, validity and reliability, implementation information and the extent to which clients are involved in applying instruments. The supervisory committee will have input in the formulation of criteria on which the qualitative instruments will be assessed and selected. The instruments may include (a combination of) individual interviews, observations, and/or focus groups. This information will be presented to the supervisory committee using the Delphi method [40]. For the selection of instruments, the supervisory committee may be supplemented with other stakeholders, such as representatives of cooperating care organisations.

Products of the selection:

- Overview of assessed qualitative instruments for evaluating the care relationship
- Two instruments per client group that will be evaluated

### 2.4 Evaluation of qualitative instruments

The purpose of the systematic review and consultation phase is to understand the determinants that influence the quality of the care relationship in long-term care. In the evaluation phase, the selected instruments will be reviewed to know whether they are useful for evaluating the quality of individual care relationships in long-term care. This evaluation phase consist of three parts.

#### A. (If necessary) supplementing questions of selected instruments

The selected qualitative instruments might need some adaptations in order to be useful for the purpose of this study: to create insight in the experienced quality of the care relationship from a client perspective. Some instruments cover a broader focus on quality of life and quality of care. Therefore, the determinants of the care relationship quality coming forward in the consultation of clients and professionals and the systematic review, will be used to supplement the questions whenever the instrument does not cover all relevant determinants of the quality of care relationships yet. The instrument might also be adjusted to be suitable for client participation of client-researchers. For

1  
2  
3 321 example, the instructions may be rewritten in easier words, and the training might be adapted to their  
4 322 literacy. Furthermore, the selected instruments will be adjusted to the specific client group if the  
5  
6 323 instrument is normally used for another client-group.  
7

#### 8 324 **B. Evaluation of the instruments in one client group**

9  
10 325 Each instrument will be tested with at least ten clients and an expected maximum of thirteen clients  
11 326 from one of the client groups (see Figure 3). It is expected that saturation will occur in between this  
12  
13 327 quantity. The respondents of the evaluation phase are not necessarily the same as respondents of the  
14  
15 328 consultation phase and it is likely that most respondents will only participate in one phase of this study.  
16  
17 329 We use the same evaluation criteria as used in the selection phase, supplemented by criteria such as  
18  
19 330 generalisability to other client groups, and information needed for applying the instrument as a client  
20  
21 331 and care professional.

#### 22 332 **C. Evaluation of the instruments in other client groups**

23  
24 333 Next, the most promising instrument from each client group will be cross-tested in the other two client  
25  
26 334 groups with six to eight clients. If no instrument appears to be suitable for all three client groups, we  
27  
28 335 will investigate whether there are common elements in the qualitative instruments that can be used in  
29  
30 336 more than one client group. In the case of equal suitability, instruments with generic elements are  
31  
32 337 preferred over instruments that are solely applicable to one specific client group. This evaluation leads  
33  
34 338 to a new ranking based on a summary judgement of each qualitative instrument in which the  
35  
36 339 advantages and disadvantages are listed as well as the conditions necessary for successful  
37  
38 340 implementation. These results will be presented to the supervisory committee.  
39

40  
41 342 The qualitative instruments will be applied and evaluated with the help of six client-researchers from  
42  
43 343 each client group. In addition, we will include at least 32 clients from each care organisation as  
44  
45 344 respondents in the whole evaluation. They will be approached by their daily care professionals, client-  
46  
47 345 researcher or the client council to ask them to take part in the study. A convenience sample technique  
48  
49 346 will be used to include clients who meet the inclusion criteria and are willing and available to  
50  
51 347 participate. Nevertheless, we will aim for as much variation as possible with regard to relevant client  
52  
53 348 characteristics such as gender, age, ethnicity, and inpatient or outpatient care.

54 349

55 350 Products of the evaluation:

- 1  
2  
3 351     ▪ Selection of the qualitative instruments that were evaluated as best  
4  
5 352

6 353 *Figure 3 Research respondents*  
7  
8 354

## 9 355           **2.5 Dissemination**

10 356 In close cooperation with the client-researchers and participating care organisations, we will develop a  
11  
12 357 toolbox including an implementation plan and the (adjusted) qualitative instruments for measuring and  
13  
14 358 improving the quality of the care relationship for each client group in long-term care. The  
15  
16 359 implementation plan focuses on implementing the qualitative instruments that were selected at the end  
17  
18 360 of the evaluation phase. The toolbox will include a training module to let clients and healthcare  
19  
20 361 providers apply the instrument, plus guidance for the analysis and use of results for improving the care  
21  
22 362 relationship.

23  
24 363 We will also examine whether the results of the qualitative instruments can be used for other  
25  
26 364 purposes, such as healthcare procurement of health insurances and monitoring for external  
27  
28 365 accountability on quality measurement and improvement, primarily to the National Health Care  
29  
30 366 Institute (In Dutch: Het Zorginstituut). Several meetings will be held with stakeholders, the research  
31  
32 367 team and care organisations in order to disseminate and discuss the results of the project and the  
33  
34 368 implementation plan. Moreover, we will look for opportunities to present the research findings and  
35  
36 369 research products such as the toolbox to interested care organisations and client councils. The owner  
37  
38 370 of the qualitative instrument will stay responsible for further implementation and dissemination. The  
39  
40 371 National Health Care Institute might also play a role in the dissemination of the instrument.

41 372

42 373 Product of the dissemination phase:

- 43  
44 374     ▪ Toolbox including the qualitative instruments (adjusted if necessary) to measure and improve  
45  
46 375 the quality of the care relationship for each client group in long-term care. The implementation  
47  
48 376 plan is part of the toolbox.
- 49 377     ▪ Recommendations based on external verification of the toolbox.  
50  
51 378

52  
53 379 **Ethics**  
54  
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56  
57  
58  
59  
60

1  
2  
3 380 Participants will receive verbal and written information about the research. Participants will provide  
4 381 written informed consent and process consent will also be used in the interviews with clients [38]. The  
5  
6 382 Medical Ethics Committee of the Radboud University Nijmegen Medical Centre was asked whether  
7  
8 383 their approval of the study was required under the Dutch Medical Research Involving Human Subjects  
9  
10 384 Act. The Committee decided that formal approval was not needed.

11  
12 385

### 13 386 **3. Discussion and conclusion**

#### 14 15 387 **3.1. Discussion**

16  
17 388 Prior work has documented the importance of the care relationship for clients in long-term care [1, 4,  
18  
19 389 41]. In practice, there is a lack of qualitative instruments for evaluating or monitoring the care  
20  
21 390 relationship. We will carry out a study to find and optimise the most suitable qualitative instruments for  
22  
23 391 monitoring the quality of care relationships in long-term care from a client's perspective. The aim of the  
24  
25 392 present paper is to describe the research design of this study. Due to the differences between client  
26  
27 393 groups in long-term care, it is likely that different instruments will fit each group best. This study will  
28  
29 394 therefore result in a toolbox containing an implementation plan and the optimised qualitative  
30  
31 395 instruments.

32  
33 396 Clients will participate in this participatory study as client-researchers. We are therefore working  
34  
35 397 closely with client-researchers in activities such as conducting interviews, preparation activities and  
36  
37 398 analysis. According to Roberts (2012), participatory research is more time-consuming than  
38  
39 399 conventional research methods. It takes time to achieve the desired level of trust in a community, and  
40  
41 400 extra time is also needed for the joint process for thinking about the research results. This extra time  
42  
43 401 will be taken into account in the time schedule of this study. In order to create backing in the  
44  
45 402 environment and thereby increase the probability of participation of clients, client-researchers, care  
46  
47 403 organisations, client councils and client organisations are cooperating in this study [42]. Their  
48  
49 404 willingness to join is an important prerequisite to perform this research. The study depends on the  
50  
51 405 close cooperation of client-researchers, and it is therefore important to work together in an equal,  
52  
53 406 respectful, attentive and open way [42, 43]. Lessons learned in previous participatory research will be  
54  
55 407 used to prevent repetition of avoidable errors, such as tokenism, client-researchers facing difficult  
56  
57 408 situations, experienced workload, and proto-professionalisation [44] [45]. A scoping review will be  
58  
59 409 conducted for this purpose. In order to make the project practically feasible, we will exclude some



1  
2  
3 410 specific groups in long-term care, such as people with physical or sensory disabilities or people  
4 411 receiving palliative care.

5  
6 412 When organisations use one of the optimised instruments from the toolbox, it will provide useful  
7  
8 413 information and feedback for clients and care professionals on the care relationship in long-term care.

9  
10 414 This makes the research project practically relevant. Nevertheless, this study risks being  
11  
12 415 overshadowed by everyday demands that care organisations face, which precludes implementation of  
13  
14 416 the selected instrument on large scale. The likelihood of successful implementation depends on the  
15  
16 417 willingness of organisations to change their instruments for measuring the quality of the care  
17  
18 418 relationship, and the degree of support from national stakeholders. The participatory research design  
19  
20 419 and involvement of the supervisory committee will increase the probability that the most preferred  
21  
22 420 instruments will be implemented and disseminated in the field.

23 421 From a quantitative point of view, this study protocol might be interpreted as limited as some details  
24  
25 422 are still left open. To make client participation meaningful, we feel it is not good to define every detail  
26  
27 423 on beforehand and make decisions during the process as well. Therefore, the global structure and  
28  
29 424 decision moments of the research process are described while there is still space left open to fill in  
30  
31 425 aspects later on. This is not unusual in qualitative research.

32 426

### 33 427 **3.2. Conclusion**

34  
35 428 In long-term care, care relationships are seen as a fundamental element in the delivery of high quality  
36  
37 429 care [4, 46-48]. But good care relationships have not been set up everywhere yet. It is therefore  
38  
39 430 important that care professionals, client councils and care organisations determine areas in which  
40  
41 431 improvement of the care relationship is possible. As far as we are aware, this will be the first study to  
42  
43 432 use a participatory research design to represent the client perspective in the selection and  
44  
45 433 optimisation of qualitative instruments for monitoring care relationships. Scientific articles will be  
46  
47 434 published to expand scientific knowledge on care relationships in long-term care. This approach  
48  
49 435 allows participatory research to link the practical and scientific purposes. Backing will be generated for  
50  
51 436 the set of qualitative instruments developed through the meetings of the supervisory committee, and  
52  
53 437 the involvement of client-researchers and care organisations.

54 438

### 55 439 **3.3 Practice Implications**



1  
2  
3 440 The study will result in a toolbox with qualitative instruments that can be used for effective monitoring  
4 441 of the quality of a care relationship. Clients, client councils and care organisations can use the toolbox  
5  
6 442 to monitor the care relationship in a structured way from a client perspective. More generally, the  
7  
8 443 content of this paper could serve as guideline for developing other studies with the combined purpose  
9  
10 444 of practical outcomes and sharing empirical evidence.

11 445

#### 12 13 446 **Strengths and limitations of this study**

- 14  
15 447 ➤ The study will result in useful optimised instruments for care organisations and client councils  
16  
17 448 to collect information and feedback of clients on care relationships in long-term care.  
18  
19 449 ➤ The participation of client-researchers in the research teams will improve the validity,  
20  
21 450 relevance and support of the research project.  
22  
23 451 ➤ The success of the study will depend on the willingness of client-researchers and care  
24  
25 452 organisations to be involved and contribute to the study.  
26  
27 453 ➤ The success of the implementation will depend on the willingness of care organisations to use  
28  
29 454 the optimised qualitative instruments, and the degree of support from national stakeholders.

30 455

#### 31 456 **4. Declarations**

##### 32 33 457 **Funding**

34  
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36  
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38  
39 460 collection, analysis, and interpretation of data, and in writing the manuscript.

##### 40 41 461 **Author's contributions**

42  
43 462 All authors contributed to, reviewed and approved the article drafts and final manuscript. AS was  
44  
45 463 responsible for writing the manuscript. MH, NB, KL and SvD read several versions of the manuscript  
46  
47 464 and provided their feedback and suggestions regularly.

##### 48 49 465 **Competing interests**

50 466 The authors declare that they have no competing interests.

51 467

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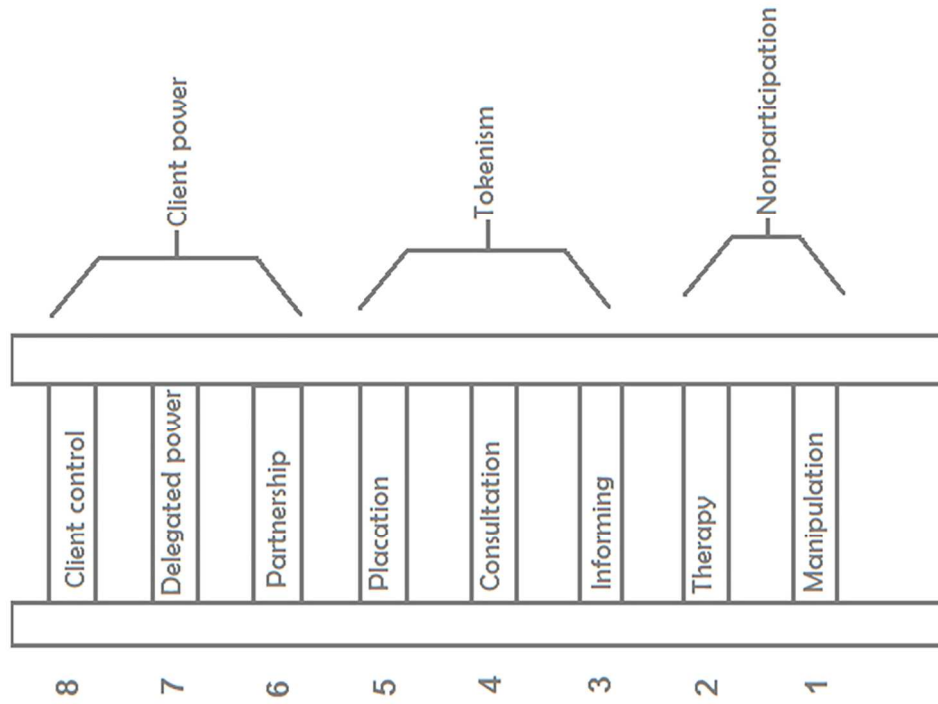


Figure 1 Ladder of Participation, inspired on Arnstein (2015)

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Figure 2 Phases of the study

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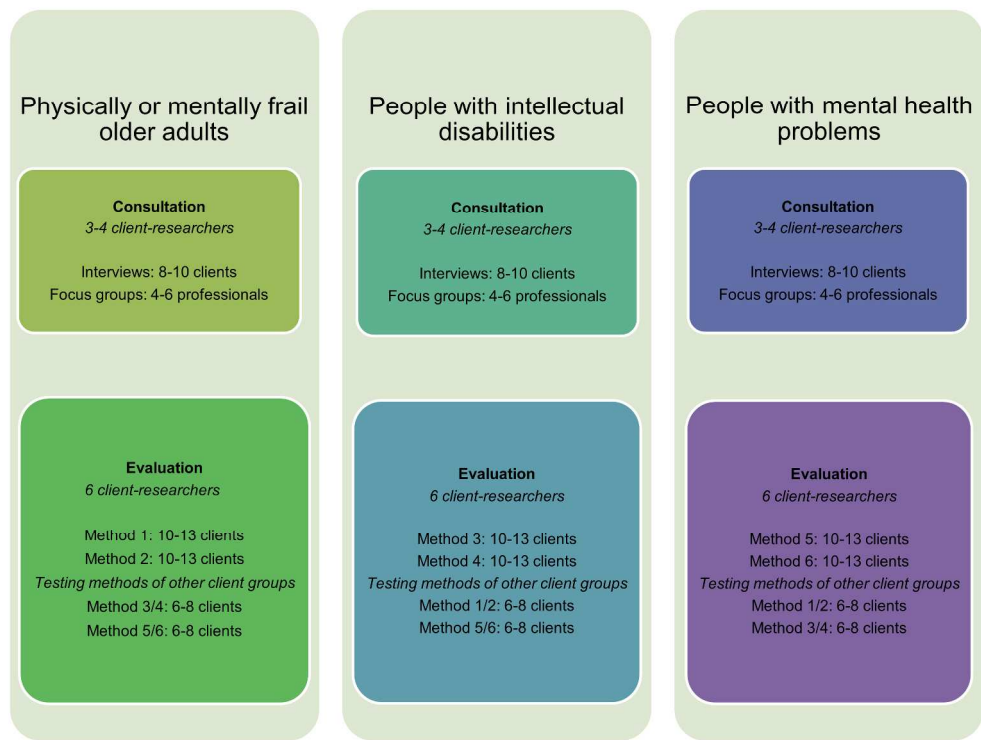


Figure 3 Research respondents

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# BMJ Open

## Protocol for a participatory study for developing qualitative instruments measuring the quality of long-term care relationships

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## 5 **Abstract**

6 **Introduction:** In long-term care (LTC), it is unclear which qualitative instruments are most effective  
7 and useful for monitoring the quality of the care relationship from the client's perspective. In this paper  
8 we describe the research design for a study aimed at finding and optimising the most suitable and  
9 useful qualitative instruments for monitoring the care relationship in long-term care.

10 **Methods and analysis:** The study will be performed in three organisations providing care to the  
11 following client groups: physically or mentally frail elderly, people with mental health problems and  
12 people with intellectual disabilities. Using a participatory research method, we will determine which  
13 determinants influence the quality of a care relationship and we will evaluate up to six instruments in  
14 cooperation with client-researchers. We will also determine whether the instruments (or parts thereof)  
15 can be applied across different LTC settings.

16 **Ethics and dissemination:** This study protocol describes a participatory research design for  
17 evaluating the quality of the care relationship in long-term care. The Medical Ethics Committee of the  
18 Radboud University Nijmegen Medical Centre decided that formal approval was not needed under the  
19 Dutch Medical Research Involving Human Subjects Act. This research project will result in a toolbox  
20 and implementation plan, which can be used by clients and care professionals to measure and  
21 improve the care relationship from the client's perspective. The results will also be published in  
22 international peer-reviewed journals.

## 24 **Strengths and limitations of this study**

- 25 ➤ The study will result in useful optimised instruments for care organisations and client councils  
26 to collect information and feedback from clients on care relationships in long-term care.
- 27 ➤ The participation of client-researchers in the research teams will improve the validity and  
28 relevance of the research project and support for it.
- 29 ➤ The success of the study will depend on the willingness of client-researchers and care  
30 organisations to be involved in and contribute to the study.
- 31 ➤ The success of the implementation will depend on the willingness of care organisations to use  
32 the optimised qualitative instruments, and the degree of support from national stakeholders.

## 1. Introduction

In long-term care, the relationship between clients and care professionals is seen as fundamental for the delivery of high-quality care. This importance is related to the longer period of care provision and the chronic health conditions of clients [1]. Long-term care consists of 'a range of services and assistance for people who, as a result of mental and/or physical frailty and/or disability over an extended period of time, depend on help with their daily living activities and/or need permanent nursing care' [2]. A good care relationship between a client and a professional requires an equal relationship in which the professional provides care with dignity and sensitivity to the client's wishes [3]. It allows clients to express any questions or complaints they may have about the care given. This open environment has not yet been achieved in all organisations, according to a recent Dutch study [3]. Another study shows that care professionals believe they listen to the needs of clients and offer care in a person-centred manner, but entrenched habits and time pressure mean that opportunities for person-centred communication are often missed [4]. Worldwide, there is a drive to redress the imbalance in care from an ethos that is medically dominated, disease orientated and often fragmented, to one that is relationship focused [5].

Monitoring the quality of the care relationship between a client and a professional should be set up from the client's perspective. Clients have unique experiential knowledge providing valuable insights into the quality of everyday care and care relationships that are missed otherwise. Care providers, clients and family perceive different determinants as influencing the closeness of the care relationship between the client and care professional. McGilton and Boscart (2006) showed that care professionals in elderly care felt that close relationships were primarily about feeling connected with the resident. Family members focused primarily on the actions staff took to present a caring attitude. Residents on the other hand felt that close relationships included staff acting as their confidants [1]. By focusing on client experiences, a more comprehensive evaluation of clients' experiences of the care provided and areas for improvement is generated [6]. However, little research in long-term care has focused on the client's perspective on these relationships [1].

An excellent way to include the clients' perspective is by carrying out participatory research. In participatory research, clients are invited to become part of a research team [7-10]. This empowers the clients and improves the validity and relevance of the research project [11]. Clients' involvement can also lead to broader support for the outcomes of the research project and related quality improvement

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3 64 initiatives among clients and care professionals [12]. Clients can be involved in several stages of a  
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5 65 research project: in preparatory activities, or in data collection by actively helping conduct interviews or  
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7 66 focus groups [13, 14]. Client-researchers can also be involved in the data analysis [14] or have an  
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9 67 advisory role, for example from the design phase onwards, by constructing the research design, a  
10  
11 68 topic list or by attending steering group meetings [10, 13].

12 69 Clients' experiences with the quality of a care relationship can be explored using qualitative  
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14 70 instruments [15]. One advantage of qualitative research is that it aims to understand social  
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16 71 phenomena in natural settings, giving due emphasis to the meanings, experiences and wishes of  
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18 72 people [16]. Qualitative procedures give clients freedom to respond, allowing direct expression of their  
19  
20 73 own concerns rather than those of the researchers [17]. As a result, qualitative research can tackle  
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22 74 aspects of complex behaviours, attitudes and interactions that are not amenable to quantitative  
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24 75 research [16]. It has also been shown that care organisations can translate qualitative results more  
25  
26 76 easily into improvement actions, as such results are capable of including the nuances and complexity  
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28 77 of care practices [18, 19].

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30 78 In Western countries, a shift can be seen in long-term care practice from focusing on solely  
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32 79 quantitative instruments to using qualitative instruments for measuring quality [17]. For example,  
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34 80 interview instruments such as narrative sensibility and storytelling [20, 21], focus groups [22-24],[25]  
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36 81 and observational instruments [26-29] are used to improve the relationship between client and care  
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38 82 professional and to encourage clients or their relatives to provide feedback. Corresponding to this  
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40 83 trend, there is a call for qualitative instruments in the Netherlands that can be used in daily practice to  
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42 84 hear clients' experiences of their care relationship. However, it is not clear whether existing qualitative  
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44 85 instruments are useful and effective for monitoring and improving the care relationship from a client's  
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46 86 perspective in long-term care and whether they focus on the important determinants of a good care  
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48 87 relationship. Some determinants of a good care relationship might differ between client groups, as  
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50 88 may the preferred instrument for evaluating the relationship. At the same time, we expect that there  
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52 89 will also be general determinants that influence the quality of a care relationship in all LTC settings,  
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54 90 such as trust or communications skills.

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92 **Aim**

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3 93 The aim of the present paper is to describe the research design of the study. It is a participatory study  
4 94 aimed at finding and optimising qualitative instruments for evaluating care relationships in long-term  
5 95 care from the client's perspective. This project seeks to answer the following research questions:

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8 96 A. What determinants influence the quality of the care relationship in long-term care for the  
9 97 various client groups, according to both clients and care professionals?  
10 98 B. What qualitative instruments can be used for monitoring and improving the relationship  
11 99 between clients and care professionals from a client's perspective?  
12  
13 100 C. Which qualitative instruments or parts thereof can be used across client groups and how?  
14  
15 101 D. How can the most suitable qualitative instruments be used by the various user groups (such  
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17 102 as care professionals, care organisations, client councils and health insurance companies) to  
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19 103 improve the quality of the care relationship?  
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22 104 The purpose of the first research question is to understand the determinants that influence the quality  
23 105 of the care relationship in long-term care. The second and third research questions are aimed at  
24 106 evaluating qualitative instruments to ascertain whether they are useful for evaluating the quality of  
25 107 individual care relationships in long-term care across client groups. This research project will result in  
26 108 a toolbox that can be used by professionals and clients to measure and improve the quality of the care  
27 109 relationships in long-term care. The results of this study will be published in peer-reviewed  
28 110 international journals and presented at several congresses, preferably at the annual conference of the  
29 111 international Collaboration for Participatory Health Research and the International Conference on  
30 112 Communication in Healthcare.  
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## 41 114 **2. Methods and analysis**

### 42 115 **Setting and participants**

43  
44 116 The study will take place in the Netherlands. In the Netherlands, long-term care is provided primarily to  
45 117 three client groups: 1) physically or mentally frail older adults, 2) people with mental health problems  
46 118 and 3) people with an intellectual, physical or sensory disability. Our study focuses on these three  
47 119 client groups. However, as regards the third group (people with a disability), we only aim to include  
48 120 clients with intellectual disabilities, as this is by far the largest group of clients with a disability receiving  
49 121 long-term care in the Netherlands. Three Dutch care organisations are willing to be involved in this  
50 122 multicentre study. Each of the three care organisations delivers care to one of the three client groups:  
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3 123 one care organisation provides care to physically or mentally frail older adults, another care  
4 124 organisation provides mental health care, and the third organisation focuses on people with an  
5  
6 125 intellectual disability. A convenience sampling technique was used. To make sure that we can reach a  
7  
8 126 diverse group of clients, we have selected care organisations that provide care to a large client  
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10 127 population with a diversity of recurring care needs, that deliver both inpatient and outpatient care and  
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12 128 that comprise multiple locations. The three care organisations provide care to more than 2000 clients,  
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14 129 and have more than 2000 care employees. If one of the care organisations withdraws later on, we will  
15  
16 130 invite another care organisation to become part of the research project.

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18  
19 132 *Respondents and client-researchers*

20 133 Clients will be involved as client-researchers and respondents in the different phases. Inclusion criteria  
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22 134 for both groups are described in Table 1. Clients who have at least weekly recurring contact with a  
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24 135 care professional and receive care for at least three months in/from long-term care organisations will  
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26 136 be included. Physically or mentally frail older adults are clients who may need assistance due to  
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28 137 somatic complaints or may suffer from mental decline because of dementia. Persons with mental  
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30 138 health problems are clients who may suffer from a personality disorder, schizophrenia or an anxiety  
31  
32 139 disorder. An intellectual disability may be caused by chromosome abnormalities or by a brain injury.  
33  
34 140 We will focus on care relationships between clients and care professionals who take care of clients  
35  
36 141 directly, those who see clients most often to provide assistance, supporting care and physical care, for  
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38 142 instance, care aides, personal carers and different categories of nurses. Clients will be included if they  
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40 143 receive care at least once a week. We will not focus on professionals who are further removed from  
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42 144 providing recurrent physical and supporting care, such as clinicians, psychiatrists and general  
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44 145 practitioners. Also, clients receiving acute health care are outside the scope of this study. Moreover,  
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46 146 caregivers who provide informal care will not be included.

47 147

48 148 *Table 1 Inclusion criteria for clients as respondents and client-researchers*

	Respondents	Client-researchers
18 or older (no upper limit)	X	X
Currently a client of residential elderly care and home care, mental healthcare or disabled care	X	X

Receiving care for at least three months	X	X
Receiving care at least once a week	X	
Able to communicate verbally in Dutch	X	X
Able to generalise from their own experiences		X
Able to hold a conversation without the assistance of a close relative or friend		X
Able to read and write at a basic level		X
Has a fairly stable health situation		X
Able to travel short distances		X

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150 Different inclusion criteria will apply for clients as respondents and client-researchers, as participating  
 151 client-researchers need to have more skills for active participation. It is important to realise that the  
 152 client-researchers may not be fully representative of the target group of respondents.

153 *Figure 1 Ladder of Participation, Arnstein (2015) [30]*

154

### 155 **Patient and public involvement**

156 This study is participatory research: having clients participate in this study as client-researchers will  
 157 help us counteract the social distance between clients and researchers. Gradations of client  
 158 participation are often described using a participation ladder (see Figure 1). The participation levels in  
 159 Arnstein's frequently used Participation Ladder are manipulation, therapy, informing, consultation,  
 160 placation, partnership, delegated power and client control [30]. In this study, we are aiming for the  
 161 'partnership' participation level. Client-researchers will be asked to be involved in preparation activities  
 162 such as developing the design of the study, formulating a definition of a high-quality care relationship,  
 163 and drafting the topic list for interviews and focus groups and selection of the qualitative instruments  
 164 that will be tested. Moreover, client-researchers will help in the interviews, focus groups and  
 165 instrument testing. Some of the client-researchers will also be involved in the selection and invitation  
 166 of respondents. As members of the research team, client-researchers will be involved in the analysis  
 167 stage as well: in work meetings, the results of interviews, focus groups and instrument evaluation will  
 168 be summarised and discussed. At the end of the research, client-researchers can help in the

1  
2  
3 169 dissemination phase of the research. Earlier studies show there are several barriers for participatory  
4 170 research [10], and sharing responsibilities is not always easy for researchers [31]. Studies underline  
5  
6 171 the importance of starting the research process in a really open and flexible way to enable true client  
7  
8 172 participation, empowerment and a valuable collaboration process [10, 32]. The intensity and manner  
9  
10 173 of participation will be agreed in a group meeting with the client-researchers of each client group. To  
11  
12 174 ensure meaningful cooperation between client-researchers and researchers, we will provide training  
13  
14 175 and an introduction at the start of the research, create a safe working environment, and make basic  
15  
16 176 agreements for our cooperation with the client-researchers at the start. During the research phases,  
17  
18 177 we will regularly discuss the conditions for cooperation within the research team. Furthermore, we will  
19  
20 178 communicate in a clear manner, tailored to the literacy and coping level of the client-researchers.  
21  
22 179 Moreover, we will have a researcher available for questions continuously, and we will take the  
23  
24 180 availability of client-researchers into account when planning meetings. Client-researchers will receive  
25  
26 181 an allowance for their contribution, depending on the amount of time invested, not exceeding the  
27  
28 182 maximum payment allowed for those receiving long-term care benefit. Client-researchers will always  
29  
30 183 be able to quit or call off participation during the research process. We added a step halfway through  
31  
32 184 the study in which we will evaluate the process so far with client-researchers and ask them whether  
33  
34 185 they want to continue.

35 186

### 36 187 **Five phases of selection and development of a qualitative instrument**

37 188 This research consists of five different phases that will take place during the period 2016-2019 (see  
38  
39 189 Figure 2): 1) Preparation: inviting and selecting client-researchers and a literature study;  
40  
41 190 2) Consultation: individual interviews and focus groups on the determinants of the quality of the care  
42  
43 191 relationship according to clients and care professionals; 3) Selection of the most promising qualitative  
44  
45 192 instruments; 4) Evaluation: selected qualitative instruments will be tested and evaluated within one  
46  
47 193 client group, with the best qualitative instruments then being tested and evaluated in the other two  
48  
49 194 groups; 5) Dissemination: formulating an implementation plan for the most suitable qualitative  
50  
51 195 instruments.

52 196

53 197 *Figure 2 Phases of the study*

54  
55 198



1  
2  
3 199 **Supervisory committee**

4 200 A supervisory committee will supervise the research project from start to finish. A delegation  
5  
6 201 consisting of several stakeholders in long-term care will be invited to be on the supervisory committee.  
7  
8 202 The stakeholders involved are representatives of care providers and branch organisations, client  
9  
10 203 (council) organisations with a nationwide scope, contact persons at the care organisations in the  
11  
12 204 study, and health insurers. The committee will monitor the research process according to the project  
13  
14 205 plan and give advice on the content of the study related to national developments. Eight meetings are  
15  
16 206 planned and members of the supervisory committee can be asked for further input by e-mail if needed.  
17  
18 207 The researchers, including two professors, will attend the meetings.  
19

20  
21 208

22 209 **2.1 Preparation**

23 210 The first phase of this study is the two-part preparation of the research.

24 211 **a. Inviting and selecting client-researchers**

25  
26 212 The invitation of client-researchers will start on a small scale from a personal approach, in cooperation  
27  
28 213 with client councilmembers and care professionals. An individual acquaintance meeting will be held  
29  
30 214 with every client who shows interest in participating. We aim to have three or four client-researchers  
31  
32 215 from each client group. See Table 1 for the inclusion criteria. The selected client-researchers will be  
33  
34 216 offered training to prepare for and practice the qualitative interview technique. The training will be  
35  
36 217 provided by the NIVEL researchers in two interactive workshops. The topics covered by the training  
37  
38 218 will be tuned to the needs and literacy of client-researchers. In the training, the distribution of tasks  
39  
40 219 and responsibilities will be discussed and established. Tasks and responsibilities will depend on  
41  
42 220 someone's capacities, capabilities and wishes.

43 221 **b. Literature review**

44 222 Three literature studies will be conducted:

- 45  
46 223 A. A systematic review to gain an understanding of determinants influencing the quality of the care  
47  
48 224 relationship  
49  
50 225 B. A scoping review to identify existing qualitative instruments that measure the quality of the  
51  
52 226 relationship between clients and care professionals in the Netherlands  
53  
54 227 C. A scoping review to collect best practices of client participation in long-term care research to  
55  
56 228 determine a participation strategy for client-researchers  
57  
58  
59  
60

1  
2  
3 229 The literature review will include scientific databases such as Medline, Embase, Cinahl and  
4  
5 230 PsycINFO, and grey literature. For the first study (A), a systematic search strategy will be drawn up. If  
6  
7 231 necessary, a librarian will be consulted during this process. Eligible articles need to be written in  
8  
9 232 English and published in the last twelve years (between 2006 and 2018) due to time constraints. A  
10  
11 233 preselection will be made by one researcher who will screen the titles of all articles. All abstracts then  
12  
13 234 will be screened and assessed by two researchers. If they rate an abstract differently, consensus will  
14  
15 235 be reached in a discussion between the two researchers. If necessary, a third researcher will be  
16  
17 236 involved. Subsequently, two researchers will assess the included articles by reading the full texts.  
18  
19 237 Again, consensus will be reached in a discussion between them if they rate papers differently. If  
20  
21 238 necessary, a third researcher will be involved. The quality of the paper will be rated for all articles  
22  
23 239 included using the criteria of the Mixed Methods Appraisal Tool (MMAT) [33, 34].  
24  
25 240 For the second and third studies (B and C), we will also carry out a grey literature search in addition to  
26  
27 241 the scientific literature search. Articles eligible for selection need to be written in English or Dutch and  
28  
29 242 published between 2006 and 2016.

243

244 Products of the preparation phase:

- 245 ▪ established cooperation with three care organisations and cooperation with three or four client-  
246 researchers in each organisation
- 247 ▪ a systematic review article of the literature regarding determinants influencing the quality of the  
248 care relationship
- 249 ▪ an overview of existing qualitative instruments in long-term care in the Netherlands

250

## 251 **2.2 Consultation**

252 In the consultation phase, the results from the first (systematic) literature search into determinants of  
253 the quality of the care relationship will be supplemented with information from clients involved as  
254 respondents and care professionals. In each care organisation, clients will be interviewed individually  
255 in semi-structured, face-to-face interviews until saturation occurs. It is expected that saturation will  
256 occur when we have interviewed eight to ten clients in each care organisation, but it is difficult to  
257 determine the saturation point in advance as one size does not fit all in qualitative research [35].  
258 Clients who meet the inclusion criteria (see Table 1) will be approached by the client-researchers

1  
2  
3 259 together with the researcher. We will work with a convenience sample to include clients who are  
4 260 willing and able to participate. Even so, we will aim for as much variation as possible in terms of  
5  
6 261 relevant client characteristics such as gender, age, ethnicity and whether they receive care as an  
7  
8 262 inpatient or outpatient.

9  
10 263 Interviews will take place in the client's home or in a meeting room at the care organisation.

11  
12 264 Depending on the concentration span of each client, interviews will take approximately 30 minutes.

13  
14 265 Clients will be asked to give informed consent prior to the start of the interview. In some instances the  
15  
16 266 legal representatives of persons with intellectual disabilities will be asked for permission first. It will be  
17  
18 267 the responsibility of the researcher to make sure the informed consent form is signed. In interviews we  
19  
20 268 will adopt a 'process consent' approach, meaning that we constantly observe during the interview  
21  
22 269 whether consent is still present by paying attention to verbal and nonverbal indications of reluctance or  
23  
24 270 hesitation to participate [36].

25  
26 271 Additionally, four to six care professionals from each organisation will be invited for a focus group  
27  
28 272 meeting. As with client respondents, we will work with a convenience sample to include professionals  
29  
30 273 who are willing and able to participate. The care professionals will be selected and invited in close  
31  
32 274 cooperation with the care organisation. The focus groups will take about two hours and will take place  
33  
34 275 in a meeting room at the care organisation. A topic list will be drawn up in advance to guide the group  
35  
36 276 discussions in a semi-structured manner.

37  
38 277 The data collection and analysis will be conducted by the research team, consisting of one researcher  
39  
40 278 and three or four client-researchers from each care organisation. The focus groups and interviews will  
41  
42 279 be audio-recorded, transcribed verbatim by an independent transcription agency and analysed in three  
43  
44 280 phases: open coding, axial coding and selective coding [15]. The data analysis method is inspired by  
45  
46 281 Interpretative Phenomenological Analysis, which places the clients' experiences and the meaning they  
47  
48 282 assign to those experiences at the core [37]. A portion of the interviews will be analysed by two  
49  
50 283 researchers. If these researchers disagree on the interpretation of a fragment, they will try to reach  
51  
52 284 consensus by discussion. If they do not reach consensus, a third researcher will be consulted. After  
53  
54 285 the construction of the final coding tree, the remaining interviews will be analysed by the first author.  
55  
56 286 The main findings will be discussed by the entire research team in work meetings. The transcripts will  
57  
58 287 be analysed using the qualitative software programme MAXQDA.  
59  
60 288

1  
2  
3 289 Product of consultation:

- 4 290     ▪ Overview of determinants influencing the quality of the care relationship in the three client  
5  
6 291         groups

7  
8 292

9  
10 293         **2.3 Selection of up to six instruments**

11 294 Based on the overview of existing qualitative instruments in the Netherlands, the research teams and  
12  
13 295 supervisory committee will select the two most promising qualitative instruments for each client group.

14  
15 296 The selection will be based on the available information about issues such as corroboration, the fit of  
16  
17 297 the purposes for which the information provided can be used, clear structure, usability of instruments  
18  
19 298 in various client groups, validity and reliability, implementation information and the extent to which  
20  
21 299 clients are involved in applying instruments. The supervisory committee will have input in the  
22  
23 300 formulation of criteria for the assessment and selection of the qualitative instruments. The instruments  
24  
25 301 may include individual interviews, observations, focus groups, or combinations thereof. This  
26  
27 302 information will be presented to the supervisory committee using the Delphi method [38]. For the  
28  
29 303 selection of instruments, the supervisory committee may be supplemented with other stakeholders,  
30  
31 304 such as representatives of the cooperating care organisations.

32 305

33 306 Products of the selection:

- 34  
35 307     ▪ Overview of assessed qualitative instruments for evaluating the care relationship  
36  
37 308     ▪ Two instruments per client group that will be evaluated

38  
39 309

40  
41 310         **2.4 Evaluation of qualitative instruments**

42 311 The purpose of the systematic review and consultation phase is to understand the determinants that  
43  
44 312 influence the quality of the care relationship in long-term care. In the evaluation phase, the selected  
45  
46 313 instruments will be reviewed to ascertain whether they are useful for evaluating the quality of individual  
47  
48 314 care relationships in long-term care. This evaluation phase consist of three parts.

49 315         **A. (If necessary) adapting the questions in the selected instruments**

50  
51 316 The selected qualitative instruments might need some adaptations in order to be useful for the purpose  
52  
53 317 of this study: to create insight into the experienced quality of the care relationship from a client  
54  
55 318 perspective. Some instruments have a broader focus on quality of life and quality of care. Therefore,

1  
2  
3 319 the determinants of the care relationship quality that emerge in the consultation of clients and  
4 320 professionals and the systematic review will be incorporated in additional questions if the instrument  
5 321 does not yet cover all relevant determinants of the quality of care relationships. The instrument might  
6 322 also need to be adjusted to be suitable for the participation of client-researchers. For example, the  
7  
8 323 instructions may need to be rewritten using easier words, and the training might have to be adapted to  
9  
10 324 their level of literacy. Furthermore, the selected instruments will be adjusted to suit the specific client  
11  
12 325 group if the instrument is normally used for another client group.

### 13 326 **B. Evaluation of the instruments in one client group**

14  
15 327 Each instrument will be tested with at least ten clients and an expected maximum of thirteen clients  
16  
17 328 from one of the client groups (see Figure 3). It is expected that saturation will occur after this number  
18  
19 329 of clients. The respondents in the evaluation phase will not necessarily be the same respondents as in  
20  
21 330 the consultation phase; it is likely that most respondents will only participate in one phase of this study.  
22  
23 331 We use the same evaluation criteria as used in the selection phase, supplemented by criteria such as  
24  
25 332 generalisability to other client groups, and information needed for applying the instrument as a client  
26  
27 333 and care professional.

### 28 334 **C. Evaluation of the instruments in other client groups**

29  
30 335 Next, the most promising instrument from each client group will be cross-tested in the other two client  
31  
32 336 groups with six to eight clients. If no instrument appears to be suitable for all three client groups, we  
33  
34 337 will investigate whether there are common elements in the qualitative instruments that can be used in  
35  
36 338 more than one client group. In the case of equal suitability, instruments with generic elements are  
37  
38 339 preferred over instruments that are solely applicable to one specific client group. This evaluation will  
39  
40 340 lead to a new ranking based on a summary judgement of each qualitative instrument in which the  
41  
42 341 advantages and disadvantages are listed as well as the conditions necessary for successful  
43  
44 342 implementation. These results will be presented to the supervisory committee.

45  
46 343 The qualitative instruments will be applied and evaluated with the help of six client-researchers from  
47  
48 344 each client group. In addition, we will include at least 32 clients from each care organisation as  
49  
50 345 respondents in the whole evaluation. They will be approached by their daily care professionals, client-  
51  
52 346 researcher or the client council, who will ask them to take part in the study. A convenience sample  
53  
54 347 technique will be used to include clients who meet the inclusion criteria and are willing and able to

1  
2  
3 348 participate. Nevertheless, we will aim for as much variation as possible with regard to relevant client  
4 349 characteristics such as gender, age, ethnicity, and inpatient or outpatient care.

5  
6 350

7  
8 351 Products of the evaluation:

- 9  
10 352
  - Selection of the qualitative instruments that were evaluated as best

11 353

12  
13 354 *Figure 3 Research respondents*

14  
15 355

## 16 356 **2.5 Dissemination**

17  
18 357 In close cooperation with the client-researchers and participating care organisations, we will develop a  
19 358 toolbox including an implementation plan and the (adjusted) qualitative instruments for measuring and  
20 359 improving the quality of the care relationship for each client group in long-term care. The  
21 360 implementation plan will focus on implementing the qualitative instruments that were selected at the  
22 361 end of the evaluation phase. The toolbox will include a training module to let clients and healthcare  
23 362 providers apply the instrument, plus guidance for the analysis and use of results for improving the care  
24 363 relationship. The toolbox will also describe the levels at which the results of the instrument are  
25 364 expected to be useful, such as the individual care relationship, reflection at the team level, or at the  
26 365 organisational level of a care organisation.

27  
28 366 We will also examine whether the results of the qualitative instruments can be used for other  
29 367 purposes, such as healthcare procurement by health insurers and monitoring for external  
30 368 accountability on quality measurement and improvement, primarily by the National Health Care  
31 369 Institute. Several meetings will be held with stakeholders, the research team and care organisations in  
32 370 order to disseminate and discuss the results of the project and the implementation plan. Moreover, we  
33 371 will look for opportunities to present the research findings and research products such as the toolbox  
34 372 to interested care organisations and client councils. Client-researchers will be asked to share their  
35 373 experiences by co-presenting at various platforms. In this way they will have an essential role in the  
36 374 implementation and application of the qualitative instruments. The owner of the qualitative instrument  
37 375 will stay responsible for further implementation and dissemination. The National Health Care Institute  
38 376 might also play a role in the dissemination of the instrument.

39  
40 377 Product of the dissemination phase:

1  
2  
3 378     ▪   Toolbox including the qualitative instruments (adjusted if necessary) to measure and improve  
4 379           the quality of the care relationship for each client group in long-term care. The implementation  
5 380           plan is part of the toolbox.

6  
7  
8 381     ▪   Recommendations based on external verification of the toolbox.  
9

10 382

## 11 383 **Ethics**

12  
13 384 Participants will receive verbal and written information about the research. Participants will provide  
14  
15 385 written informed consent and process consent will also be used in the interviews with clients [36]. The  
16  
17 386 Medical Ethics Committee of the Radboud University Nijmegen Medical Centre was asked whether  
18  
19 387 their approval of the study was required under the Dutch Medical Research Involving Human Subjects  
20  
21 388 Act. The Committee decided that formal approval was not needed.  
22

23 389

## 24 390 **3. Discussion and conclusion**

### 25 391 **3.1. Discussion**

26  
27  
28 392 Prior work has documented the importance of the care relationship for clients in long-term care [1, 4,  
29  
30 393 39]. In practice, there is a lack of qualitative instruments for evaluating or monitoring the care  
31  
32 394 relationship. We will carry out a study to find and optimise the most suitable qualitative instruments for  
33  
34 395 monitoring the quality of care relationships in long-term care from a client's perspective. The aim of the  
35  
36 396 present paper is to describe the research design of this study. Due to the differences between client  
37  
38 397 groups in long-term care, it is possible that different instruments will fit each group best. This study will  
39  
40 398 result in a toolbox containing an implementation plan and the optimised qualitative instruments.

41  
42 399 Clients will participate in this participatory study as client-researchers. We are therefore working  
43  
44 400 closely with client-researchers in activities such as conducting interviews, preparation activities and  
45  
46 401 analysis. According to Roberts (2012), participatory research is more time-consuming than  
47  
48 402 conventional research methods. It takes time to achieve the desired level of trust in a community, and  
49  
50 403 extra time is also needed for the joint process for thinking about the research results. This extra time  
51  
52 404 will be taken into account in the time schedule of this study. In order to create backing in the  
53  
54 405 environment and thereby increase the probability of participation by clients, client-researchers, care  
55  
56 406 organisations, client councils and client organisations will cooperate in this study [40]. Their  
57  
58 407 willingness to join is an important prerequisite for the performance of this research. The study depends



1  
2  
3 408 on the close cooperation of client-researchers, and it is therefore important to work together in an  
4 409 equal, respectful, attentive and open way [40, 41]. Lessons learned in previous participatory research  
5  
6 410 will be used to prevent repetition of avoidable errors, such as tokenism, client-researchers facing  
7  
8 411 difficult situations, experienced workload, and proto-professionalisation [32, 42]. A scoping review will  
9  
10 412 be conducted for this purpose. In order to make the project practically feasible, we will exclude some  
11  
12 413 specific groups in long-term care, such as people with physical or sensory disabilities or people  
13  
14 414 receiving palliative care.

15 415 If client-researchers in care organisations use one of the optimised instruments from the toolbox, it will  
16  
17 416 provide useful information and feedback for clients and care professionals on the care relationship in  
18  
19 417 long-term care. This makes the research project practically relevant. Nevertheless, this study risks  
20  
21 418 being overshadowed by the everyday demands that care organisations face, which precludes  
22  
23 419 implementation of the selected instrument on a large scale. The likelihood of successful  
24  
25 420 implementation depends on the willingness of organisations to change their instruments for measuring  
26  
27 421 the quality of the care relationship, and the degree of support from national stakeholders. Moreover,  
28  
29 422 the willingness and enthusiasm of client-researchers to be involved in the performance of the  
30  
31 423 instruments will be essential for the implementation and application of the qualitative instruments. The  
32  
33 424 participatory research design and involvement of the supervisory committee will increase the  
34  
35 425 probability that the most preferred instruments will be implemented and disseminated in the field.

36 426 The qualitative and participatory research method was chosen to study the experiences of participants  
37  
38 427 and interactions between respondents and client-researchers in natural settings. The research relies  
39  
40 428 heavily on the observational and interviewing skills of researchers and client-researchers and  
41  
42 429 reflectivity on 'our' perspectives on the findings. In qualitative research, studying the perspectives of  
43  
44 430 multiple stakeholders and interpreting the results with different client-researchers and researchers is  
45  
46 431 likely to result in an increased understanding of complex phenomena such as care relationships  
47  
48 432 between clients and professionals. This will diminish possible limitations inherently attached to the  
49  
50 433 qualitative research method [16] [43]. Also, this research takes place on a small scale in three care  
51  
52 434 organisations focused on three client groups within their own contexts. The generalisability to other  
53  
54 435 client groups in other care settings, such as clients with a severe intellectual disability or dementia,  
55  
56 436 might be limited.



1  
2  
3 437 From a quantitative point of view, this study protocol might be interpreted as limited because some  
4 438 details are still left open. To make client participation meaningful, we feel it is not good to define every  
5 439 detail beforehand to be able to make decisions during the process as well. Therefore, the global  
6 440 structure and decision moments of the research process are described, but at the same time space is  
7  
8 441 left open so that some aspects can be filled in later on. This is not unusual in qualitative research.  
9  
10  
11

12 442

13 443 **3.2. Conclusion**

14  
15 444 In long-term care, care relationships are seen as a fundamental element in the delivery of high quality  
16 445 care [4, 44-46]. But good care relationships have not yet been set up everywhere. It is therefore  
17 446 important that care professionals, client councils and care organisations determine areas in which  
18 447 improvement of the care relationship is possible. As far as we are aware, this will be the first study to  
19 448 use a participatory research design to represent the client perspective in the selection and  
20 449 optimisation of qualitative instruments for monitoring care relationships. Scientific articles will be  
21 450 published to expand scientific knowledge on care relationships in long-term care. This approach  
22 451 allows participatory research to link the practical and scientific purposes. Backing will be generated for  
23 452 the set of qualitative instruments developed through the meetings of the supervisory committee, and  
24 453 the involvement of client-researchers and care organisations.  
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33 454

34 455 **3.3 Practice Implications**

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36 456 The study will result in a toolbox with qualitative instruments that can be used for effective monitoring  
37 457 of the quality of a care relationship. Clients, client councils and care organisations can use the toolbox  
38 458 to monitor the care relationship in a structured way from a client perspective. More generally, the  
39 459 content of this paper could serve as a guideline for developing other studies with the combined  
40 460 purpose of practical outcomes and sharing empirical evidence.  
41  
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45

46 461

47 462 **4. Declarations**48 463 **Funding**

49  
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52 466 the study, collection, analysis and interpretation of data, nor in writing the manuscript.  
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3 467 **Author's contributions**

4 468 All authors contributed to, reviewed and approved the article drafts and final manuscript. AS was  
5  
6 469 responsible for writing the manuscript and MH, NB, KL and SvD read several versions of the  
7  
8 470 manuscript and provided their feedback and suggestions regularly.

9  
10 471 **Competing interests**

11 472 The authors declare that they have no competing interests.

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For peer review only

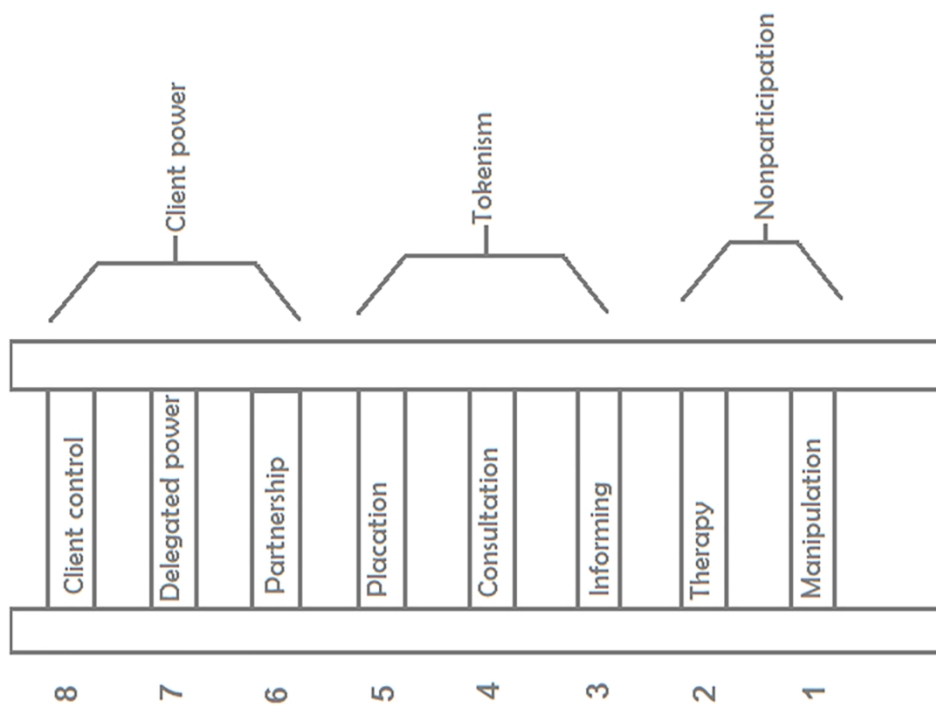


Figure 1 Ladder of Participation, inspired on Arnstein (2015)

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Figure 2 Phases of the study  
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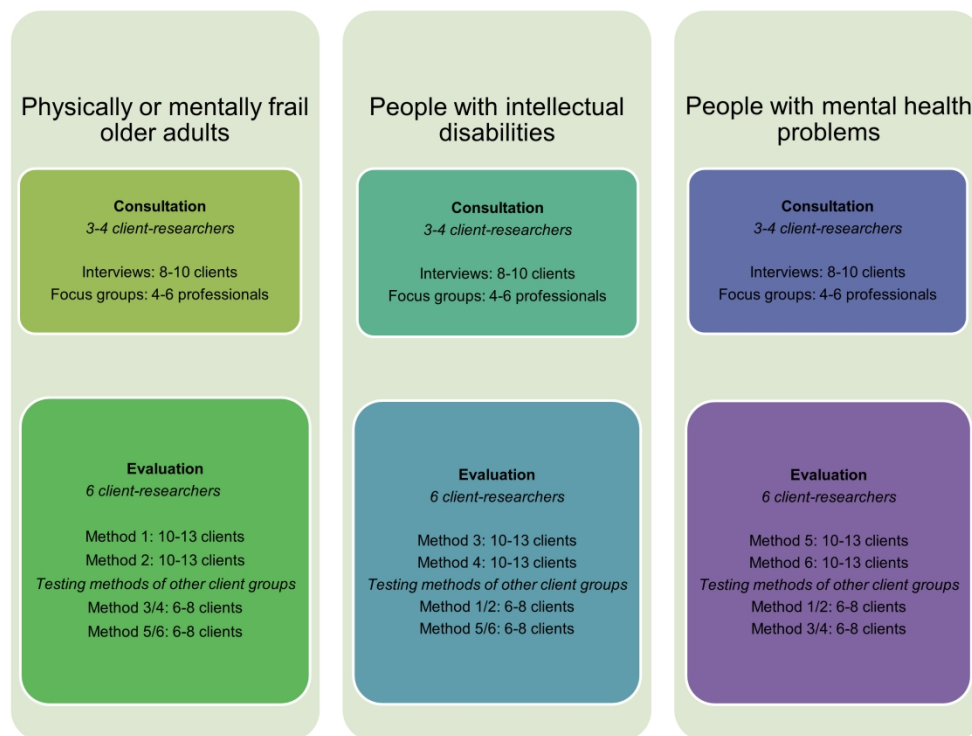


Figure 3 Research respondents

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# BMJ Open

## Protocol for a participatory study for developing qualitative instruments measuring the quality of long-term care relationships

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Keywords:	Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, QUALITATIVE RESEARCH, Care relationship, Participatory research, Client perspective, Long-term care

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## 5 **Abstract**

6 **Introduction:** In long-term care (LTC), it is unclear which qualitative instruments are most effective  
7 and useful for monitoring the quality of the care relationship from the client's perspective. In this paper  
8 we describe the research design for a study aimed at finding and optimising the most suitable and  
9 useful qualitative instruments for monitoring the care relationship in long-term care.

10 **Methods and analysis:** The study will be performed in three organisations providing care to the  
11 following client groups: physically or mentally frail elderly, people with mental health problems and  
12 people with intellectual disabilities. Using a participatory research method, we will determine which  
13 determinants influence the quality of a care relationship and we will evaluate up to six instruments in  
14 cooperation with client-researchers. We will also determine whether the instruments (or parts thereof)  
15 can be applied across different LTC settings.

16 **Ethics and dissemination:** This study protocol describes a participatory research design for  
17 evaluating the quality of the care relationship in long-term care. The Medical Ethics Committee of the  
18 Radboud University Nijmegen Medical Centre decided that formal approval was not needed under the  
19 Dutch Medical Research Involving Human Subjects Act. This research project will result in a toolbox  
20 and implementation plan, which can be used by clients and care professionals to measure and  
21 improve the care relationship from the client's perspective. The results will also be published in  
22 international peer-reviewed journals.

## 24 **Strengths and limitations of this study**

- 25 ➤ The study will result in useful optimised instruments for care organisations and client councils  
26 to collect information and feedback from clients on care relationships in long-term care.
- 27 ➤ The participation of client-researchers in the research teams will improve the validity and  
28 relevance of the research project and support for it.
- 29 ➤ The success of the study will depend on the willingness of client-researchers and care  
30 organisations to be involved in and contribute to the study.
- 31 ➤ The success of the implementation will depend on the willingness of care organisations to use  
32 the optimised qualitative instruments, and the degree of support from national stakeholders.

## 1. Introduction

In long-term care, the relationship between clients and care professionals is seen as fundamental for the delivery of high-quality care. This importance is related to the longer period of care provision and the chronic health conditions of clients [1]. Long-term care consists of 'a range of services and assistance for people who, as a result of mental and/or physical frailty and/or disability over an extended period of time, depend on help with their daily living activities and/or need permanent nursing care' [2]. A good care relationship between a client and a professional requires an equal relationship in which the professional provides care with dignity and sensitivity to the client's wishes [3]. It allows clients to express any questions or complaints they may have about the care given. This open environment has not yet been achieved in all organisations, according to a recent Dutch study [3]. Another study shows that care professionals believe they listen to the needs of clients and offer care in a person-centred manner, but entrenched habits and time pressure mean that opportunities for person-centred communication are often missed [4]. Worldwide, there is a drive to redress the imbalance in care from an ethos that is medically dominated, disease orientated and often fragmented, to one that is relationship focused [5].

Monitoring the quality of the care relationship between a client and a professional should be set up from the client's perspective. Clients have unique experiential knowledge providing valuable insights into the quality of everyday care and care relationships that are missed otherwise. Care providers, clients and family perceive different determinants as influencing the closeness of the care relationship between the client and care professional. McGilton and Boscart (2006) showed that care professionals in elderly care felt that close relationships were primarily about feeling connected with the resident. Family members focused primarily on the actions staff took to present a caring attitude. Residents on the other hand felt that close relationships included staff acting as their confidants [1]. By focusing on client experiences, a more comprehensive evaluation of clients' experiences of the care provided and areas for improvement is generated [6]. However, little research in long-term care has focused on the client's perspective on these relationships [1].

An excellent way to include the clients' perspective is by carrying out participatory research. In participatory research, clients are invited to become part of a research team [7-10]. This empowers the clients and improves the validity and relevance of the research project [11]. Clients' involvement can also lead to broader support for the outcomes of the research project and related quality improvement

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3 64 initiatives among clients and care professionals [12]. Clients can be involved in several stages of a  
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5 65 research project: in preparatory activities, or in data collection by actively helping conduct interviews or  
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7 66 focus groups [13, 14]. Client-researchers can also be involved in the data analysis [14] or have an  
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9 67 advisory role, for example from the design phase onwards, by constructing the research design, a  
10  
11 68 topic list or by attending steering group meetings [10, 13].

12 69 Clients' experiences with the quality of a care relationship can be explored using qualitative  
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14 70 instruments [15]. One advantage of qualitative research is that it aims to understand social  
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16 71 phenomena in natural settings, giving due emphasis to the meanings, experiences and wishes of  
17  
18 72 people [16]. Qualitative procedures give clients freedom to respond, allowing direct expression of their  
19  
20 73 own concerns rather than those of the researchers [17]. As a result, qualitative research can tackle  
21  
22 74 aspects of complex behaviours, attitudes and interactions that are not amenable to quantitative  
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24 75 research [16]. It has also been shown that care organisations can translate qualitative results more  
25  
26 76 easily into improvement actions, as such results are capable of including the nuances and complexity  
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28 77 of care practices [18, 19].

29  
30 78 In Western countries, a shift can be seen in long-term care practice from focusing on solely  
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32 79 quantitative instruments to using qualitative instruments for measuring quality [17]. For example,  
33  
34 80 interview instruments such as narrative sensibility and storytelling [20, 21], focus groups [22-24],[25]  
35  
36 81 and observational instruments [26-29] are used to improve the relationship between client and care  
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38 82 professional and to encourage clients or their relatives to provide feedback. Corresponding to this  
39  
40 83 trend, there is a call for qualitative instruments in the Netherlands that can be used in daily practice to  
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42 84 hear clients' experiences of their care relationship. However, it is not clear whether existing qualitative  
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44 85 instruments are useful and effective for monitoring and improving the care relationship from a client's  
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46 86 perspective in long-term care and whether they focus on the important determinants of a good care  
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48 87 relationship. Some determinants of a good care relationship might differ between client groups, as  
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50 88 may the preferred instrument for evaluating the relationship. At the same time, we expect that there  
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52 89 will also be general determinants that influence the quality of a care relationship in all LTC settings,  
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54 90 such as trust or communications skills.

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92 **Aim**

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3 93 The aim of the present paper is to describe the research design of the study. It is a participatory study  
4 94 aimed at finding and optimising qualitative instruments for evaluating care relationships in long-term  
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6 95 care from the client's perspective. This project seeks to answer the following research questions:

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8 96 A. What determinants influence the quality of the care relationship in long-term care for the  
9  
10 97 various client groups, according to both clients and care professionals?

11 98 B. What qualitative instruments can be used for monitoring and improving the relationship  
12  
13 99 between clients and care professionals from a client's perspective?

14  
15 100 C. Which qualitative instruments or parts thereof can be used across client groups and how?

16  
17 101 D. How can the most suitable qualitative instruments be used by the various user groups (such  
18  
19 102 as care professionals, care organisations, client councils and health insurance companies) to  
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21 103 improve the quality of the care relationship?

22 104 The purpose of the first research question is to understand the determinants that influence the quality  
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24 105 of the care relationship in long-term care. The second and third research questions are aimed at  
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26 106 evaluating qualitative instruments to ascertain whether they are useful for evaluating the quality of  
27  
28 107 individual care relationships in long-term care across client groups. This research project will result in  
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30 108 a toolbox that can be used by professionals and clients to measure and improve the quality of the care  
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32 109 relationships in long-term care. The results of this study will be published in peer-reviewed  
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34 110 international journals and presented at several congresses, preferably at the annual conference of the  
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36 111 international Collaboration for Participatory Health Research and the International Conference on  
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38 112 Communication in Healthcare.

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## 40 114 **2. Methods and analysis**

### 41 115 **Setting and participants**

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44 116 The study will take place in the Netherlands. In the Netherlands, long-term care is provided primarily to  
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46 117 three client groups: 1) physically or mentally frail older adults, 2) people with mental health problems  
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48 118 and 3) people with an intellectual, physical or sensory disability. Our study focuses on these three  
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50 119 client groups. However, as regards the third group (people with a disability), we only aim to include  
51  
52 120 clients with intellectual disabilities, as this is by far the largest group of clients with a disability receiving  
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54 121 long-term care in the Netherlands. Three Dutch care organisations are willing to be involved in this  
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56 122 multicentre study. Each of the three care organisations delivers care to one of the three client groups:

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3 123 one care organisation provides care to physically or mentally frail older adults, another care  
4 124 organisation provides mental health care, and the third organisation focuses on people with an  
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6 125 intellectual disability. A convenience sampling technique was used. To make sure that we can reach a  
7  
8 126 diverse group of clients, we have selected care organisations that provide care to a large client  
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10 127 population with a diversity of recurring care needs, that deliver both inpatient and outpatient care and  
11  
12 128 that comprise multiple locations. The three care organisations provide care to more than 2000 clients,  
13  
14 129 and have more than 2000 care employees. If one of the care organisations withdraws later on, we will  
15  
16 130 invite another care organisation to become part of the research project.

17 131

18  
19 132 *Respondents and client-researchers*

20 133 Clients will be involved as client-researchers and respondents in the different phases. Inclusion criteria  
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22 134 for both groups are described in Table 1. Clients who have at least weekly recurring contact with a  
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24 135 care professional and receive care for at least three months in/from long-term care organisations will  
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26 136 be included. Physically or mentally frail older adults are clients who may need assistance due to  
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28 137 somatic complaints or may suffer from mental decline because of dementia. Persons with mental  
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30 138 health problems are clients who may suffer from a personality disorder, schizophrenia or an anxiety  
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32 139 disorder. An intellectual disability may be caused by chromosome abnormalities or by a brain injury.  
33  
34 140 We will focus on care relationships between clients and care professionals who take care of clients  
35  
36 141 directly, those who see clients most often to provide assistance, supporting care and physical care, for  
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38 142 instance, care aides, personal carers and different categories of nurses. Clients will be included if they  
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40 143 receive care at least once a week. We will not focus on professionals who are further removed from  
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42 144 providing recurrent physical and supporting care, such as clinicians, psychiatrists and general  
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44 145 practitioners. Also, clients receiving acute health care are outside the scope of this study. Moreover,  
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46 146 caregivers who provide informal care will not be included.

47 147

48 148 *Table 1 Inclusion criteria for clients as respondents and client-researchers*

	Respondents	Client-researchers
18 or older (no upper limit)	X	X
Currently a client of residential elderly care and home care, mental healthcare or disabled care	X	X

Receiving care for at least three months	X	X
Receiving care at least once a week	X	
Able to communicate verbally in Dutch	X	X
Able to generalise from their own experiences		X
Able to hold a conversation without the assistance of a close relative or friend		X
Able to read and write at a basic level		X
Has a fairly stable health situation		X
Able to travel short distances		X

149

150 Different inclusion criteria will apply for clients as respondents and client-researchers, as participating  
 151 client-researchers need to have more skills for active participation. It is important to realise that the  
 152 client-researchers may not be fully representative of the target group of respondents.

153 *Figure 1 Ladder of Participation, Arnstein (2015) [30]*

154

### 155 **Patient and public involvement**

156 This study is participatory research: having clients participate in this study as client-researchers will  
 157 help us counteract the social distance between clients and researchers. Gradations of client  
 158 participation are often described using a participation ladder (see Figure 1). The participation levels in  
 159 Arnstein's frequently used Participation Ladder are manipulation, therapy, informing, consultation,  
 160 placation, partnership, delegated power and client control [30]. In this study, we are aiming for the  
 161 'partnership' participation level. Client-researchers will be asked to be involved in preparation activities  
 162 such as developing the design of the study, formulating a definition of a high-quality care relationship,  
 163 and drafting the topic list for interviews and focus groups and selection of the qualitative instruments  
 164 that will be tested. Moreover, client-researchers will help in the interviews, focus groups and  
 165 instrument testing. Some of the client-researchers will also be involved in the selection and invitation  
 166 of respondents. As members of the research team, client-researchers will be involved in the analysis  
 167 stage as well: in work meetings, the results of interviews, focus groups and instrument evaluation will  
 168 be summarised and discussed. At the end of the research, client-researchers can help in the



1  
2  
3 169 dissemination phase of the research. Earlier studies show there are several barriers for participatory  
4 170 research [10], and sharing responsibilities is not always easy for researchers [31]. Studies underline  
5  
6 171 the importance of starting the research process in a really open and flexible way to enable true client  
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8 172 participation, empowerment and a valuable collaboration process [10, 32]. The intensity and manner  
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10 173 of participation will be agreed in a group meeting with the client-researchers of each client group. To  
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12 174 ensure meaningful cooperation between client-researchers and researchers, we will provide training  
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14 175 and an introduction at the start of the research, create a safe working environment, and make basic  
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16 176 agreements for our cooperation with the client-researchers at the start. During the research phases,  
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18 177 we will regularly discuss the conditions for cooperation within the research team. Furthermore, we will  
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20 178 communicate in a clear manner, tailored to the literacy and coping level of the client-researchers.  
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22 179 Moreover, we will have a researcher available for questions continuously, and we will take the  
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24 180 availability of client-researchers into account when planning meetings. Client-researchers will receive  
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26 181 an allowance for their contribution, depending on the amount of time invested, not exceeding the  
27  
28 182 maximum payment allowed for those receiving long-term care benefit. Client-researchers will always  
29  
30 183 be able to quit or call off participation during the research process. We added a step halfway through  
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32 184 the study in which we will evaluate the process so far with client-researchers and ask them whether  
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34 185 they want to continue.

186

### 187 **Five phases of selection and development of a qualitative instrument**

188 This research consists of five different phases that will take place during the period 2016-2019 (see  
189 Figure 2): 1) Preparation: inviting and selecting client-researchers and a literature study;  
190 2) Consultation: individual interviews and focus groups on the determinants of the quality of the care  
191 relationship according to clients and care professionals; 3) Selection of the most promising qualitative  
192 instruments; 4) Evaluation: selected qualitative instruments will be tested and evaluated within one  
193 client group, with the best qualitative instruments then being tested and evaluated in the other two  
194 groups; 5) Dissemination: formulating an implementation plan for the most suitable qualitative  
195 instruments.

196

197 *Figure 2 Phases of the study*

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3 199 **Supervisory committee**

4 200 A supervisory committee will supervise the research project from start to finish. A delegation  
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6 201 consisting of several stakeholders in long-term care will be invited to be on the supervisory committee.  
7  
8 202 The stakeholders involved are representatives of care providers and branch organisations, client  
9  
10 203 (council) organisations with a nationwide scope, contact persons at the care organisations in the  
11  
12 204 study, and health insurers. The committee will monitor the research process according to the project  
13  
14 205 plan and give advice on the content of the study related to national developments. Eight meetings are  
15  
16 206 planned and members of the supervisory committee can be asked for further input by e-mail if needed.  
17  
18 207 The researchers, including two professors, will attend the meetings.  
19

20  
21 208

22 209 **2.1 Preparation**

23 210 The first phase of this study is the two-part preparation of the research.

24 211 **a. Inviting and selecting client-researchers**

25  
26 212 The invitation of client-researchers will start on a small scale from a personal approach, in cooperation  
27  
28 213 with client councilmembers and care professionals. An individual acquaintance meeting will be held  
29  
30 214 with every client who shows interest in participating. We aim to have three or four client-researchers  
31  
32 215 from each client group. See Table 1 for the inclusion criteria. The selected client-researchers will be  
33  
34 216 offered training to prepare for and practice the qualitative interview technique. The training will be  
35  
36 217 provided by the NIVEL researchers in two interactive workshops. The topics covered by the training  
37  
38 218 will be tuned to the needs and literacy of client-researchers. In the training, the distribution of tasks  
39  
40 219 and responsibilities will be discussed and established. Tasks and responsibilities will depend on  
41  
42 220 someone's capacities, capabilities and wishes.

43 221 **b. Literature review**

44 222 Three literature reviews will be conducted:

- 45  
46 223 A. A systematic review to gain an understanding of determinants influencing the quality of the care  
47  
48 224 relationship  
49  
50 225 B. A scoping review to identify existing qualitative instruments that measure the quality of the  
51  
52 226 relationship between clients and care professionals in the Netherlands  
53  
54 227 C. A scoping review to collect best practices of client participation in long-term care research to  
55  
56 228 determine a participation strategy for client-researchers  
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3 229 The literature review will include scientific databases such as Medline, Embase, CINAHL and  
4  
5 230 PsycINFO, and grey literature. For the first review (A), a systematic search strategy will be drawn up. If  
6  
7 231 necessary, a librarian will be consulted during this process. Eligible articles need to be written in  
8  
9 232 English and published in the last twelve years (between 2006 and 2018) due to time constraints. A  
10  
11 233 preselection will be made by one researcher who will screen the titles of all articles. All abstracts then  
12  
13 234 will be screened and assessed by two researchers. If they rate an abstract differently, consensus will  
14  
15 235 be reached in a discussion between the two researchers. If necessary, a third researcher will be  
16  
17 236 involved. Subsequently, two researchers will assess the included articles by reading the full texts.  
18  
19 237 Again, consensus will be reached in a discussion between them if they rate papers differently. If  
20  
21 238 necessary, a third researcher will be involved. The quality of the paper will be rated for all articles  
22  
23 239 included using the criteria of the Mixed Methods Appraisal Tool (MMAT) [33, 34].  
24  
25 240 For the second and third review (B and C), we will also carry out a grey literature search in addition to  
26  
27 241 the scientific literature search. Articles eligible for selection need to be written in English or Dutch and  
28  
29 242 published between 2006 and 2018.

30 243

31 244 Products of the preparation phase:

- 32 245 ▪ established cooperation with three care organisations and cooperation with three or four client-  
33 246 researchers in each organisation
- 34 247 ▪ a systematic review article of the literature regarding determinants influencing the quality of the  
35 248 care relationship
- 36 249 ▪ an overview of existing qualitative instruments in long-term care in the Netherlands

37 250

## 38 251 **2.2 Consultation**

39 252 In the consultation phase, the results from the first (systematic) literature search into determinants of  
40 253 the quality of the care relationship will be supplemented with information from clients involved as  
41 254 respondents and care professionals. In each care organisation, clients will be interviewed individually  
42 255 in semi-structured, face-to-face interviews until saturation occurs. It is expected that saturation will  
43 256 occur when we have interviewed eight to ten clients in each care organisation, but it is difficult to  
44 257 determine the saturation point in advance as one size does not fit all in qualitative research [35].  
45 258 Clients who meet the inclusion criteria (see Table 1) will be approached by the client-researchers

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2  
3 259 together with the researcher. We will work with a convenience sample to include clients who are  
4 260 willing and able to participate. Even so, we will aim for as much variation as possible in terms of  
5  
6 261 relevant client characteristics such as gender, age, ethnicity and whether they receive care as an  
7  
8 262 inpatient or outpatient.

9  
10 263 Interviews will take place in the client's home or in a meeting room at the care organisation.  
11 264 Depending on the concentration span of each client, interviews will take approximately 30 minutes.

12  
13 265 Clients will be asked to give informed consent prior to the start of the interview. In some instances the  
14  
15 266 legal representatives of persons with intellectual disabilities will be asked for permission first. It will be  
16  
17 267 the responsibility of the researcher to make sure the informed consent form is signed. In interviews we  
18  
19 268 will adopt a 'process consent' approach, meaning that we constantly observe during the interview  
20  
21 269 whether consent is still present by paying attention to verbal and nonverbal indications of reluctance or  
22  
23 270 hesitation to participate [36].

24 271 Additionally, four to six care professionals from each organisation will be invited for a focus group  
25  
26 272 meeting. As with client respondents, we will work with a convenience sample to include professionals  
27  
28 273 who are willing and able to participate. The care professionals will be selected and invited in close  
29  
30 274 cooperation with the care organisation. The focus groups will take about two hours and will take place  
31  
32 275 in a meeting room at the care organisation. A topic list will be drawn up in advance to guide the group  
33  
34 276 discussions in a semi-structured manner.

35 277 The data collection and analysis will be conducted by the research team, consisting of one researcher  
36  
37 278 and three or four client-researchers from each care organisation. The focus groups and interviews will  
38  
39 279 be audio-recorded, transcribed verbatim by an independent transcription agency and analysed in three  
40  
41 280 phases: open coding, axial coding and selective coding [15]. The data analysis method is inspired by  
42  
43 281 Interpretative Phenomenological Analysis, which places the clients' experiences and the meaning they  
44  
45 282 assign to those experiences at the core [37]. A portion of the interviews will be analysed by two  
46  
47 283 researchers. If these researchers disagree on the interpretation of a fragment, they will try to reach  
48  
49 284 consensus by discussion. If they do not reach consensus, a third researcher will be consulted. After  
50  
51 285 the construction of the final coding tree, the remaining interviews will be analysed by the first author.  
52  
53 286 The main findings will be discussed by the entire research team in work meetings. The transcripts will  
54  
55 287 be analysed using the qualitative software programme MAXQDA.  
56  
57 288

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3 289 Product of consultation:

- 4 290     ▪ Overview of determinants influencing the quality of the care relationship in the three client  
5  
6 291         groups

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9  
10 293         **2.3 Selection of up to six instruments**

11 294 Based on the overview of existing qualitative instruments in the Netherlands, the research teams and  
12  
13 295 supervisory committee will select the two most promising qualitative instruments for each client group.

14  
15 296 The selection will be based on the available information about issues such as corroboration, the fit of  
16  
17 297 the purposes for which the information provided can be used, clear structure, usability of instruments  
18  
19 298 in various client groups, validity and reliability, implementation information and the extent to which  
20  
21 299 clients are involved in applying instruments. The supervisory committee will have input in the  
22  
23 300 formulation of criteria for the assessment and selection of the qualitative instruments. The instruments  
24  
25 301 may include individual interviews, observations, focus groups, or combinations thereof. This  
26  
27 302 information will be presented to the supervisory committee using the Delphi method [38]. For the  
28  
29 303 selection of instruments, the supervisory committee may be supplemented with other stakeholders,  
30  
31 304 such as representatives of the cooperating care organisations.

32 305

33 306 Products of the selection:

- 34  
35 307     ▪ Overview of assessed qualitative instruments for evaluating the care relationship  
36  
37 308     ▪ Two instruments per client group that will be evaluated

38  
39 309

40  
41 310         **2.4 Evaluation of qualitative instruments**

42 311 The purpose of the systematic review and consultation phase is to understand the determinants that  
43  
44 312 influence the quality of the care relationship in long-term care. In the evaluation phase, the selected  
45  
46 313 instruments will be reviewed to ascertain whether they are useful for evaluating the quality of individual  
47  
48 314 care relationships in long-term care. This evaluation phase will consist of three parts.

49 315         **A. Adapting the items in the selected instruments**

50 316 The selected qualitative instruments might need some adaptations in order to be useful for the purpose  
51  
52 317 of this study: to create insight into the experienced quality of the care relationship from a client  
53  
54 318 perspective. Some instruments may have a broader focus on quality of life and quality of care.

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2  
3 319 Therefore, the determinants of the care relationship quality that emerge from the consultation of clients  
4 320 and professionals and the systematic review will be incorporated in additional items if the instrument  
5  
6 321 does not yet cover all relevant determinants of the quality of care relationships. The instrument might  
7  
8 322 also need to be adjusted to be suitable for the participation of client-researchers. For example, the  
9  
10 323 instructions may need to be rewritten using easier words, and the training might have to be adapted to  
11  
12 324 their level of literacy. Furthermore, the selected instruments will be adjusted to suit the specific client  
13  
14 325 group if the instrument is normally used for another client group.

#### 15 326 **B. Evaluation of the instruments in one client group**

16  
17 327 Each instrument will be tested with at least ten clients and an expected maximum of thirteen clients  
18  
19 328 from one of the client groups (see Figure 3). It is expected that saturation will occur after this number  
20  
21 329 of clients. The respondents in the evaluation phase will not necessarily be the same respondents as in  
22  
23 330 the consultation phase; it is likely that most respondents will only participate in one phase of this study.  
24  
25 331 We will use the same evaluation criteria as used in the selection phase, supplemented by criteria such  
26  
27 332 as generalisability to other client groups, and information needed for applying the instrument as a  
28  
29 333 client and care professional.

#### 30 334 **C. Evaluation of the instruments in other client groups**

31  
32 335 Next, the most promising instrument for each client group will be cross-tested in the other two client  
33  
34 336 groups with six to eight clients. If no instrument appears to be suitable for all three client groups, we  
35  
36 337 will investigate whether there are common elements in the qualitative instruments that can be used in  
37  
38 338 more than one client group. In the case of equal suitability, instruments with generic elements will be  
39  
40 339 preferred over instruments that are solely applicable to one specific client group. This evaluation will  
41  
42 340 lead to a new ranking based on a summary judgement of each qualitative instrument in which the  
43  
44 341 advantages and disadvantages are listed as well as the conditions necessary for successful  
45  
46 342 implementation. These results will be presented to the supervisory committee.

47  
48 343 The qualitative instruments will be applied and evaluated with the help of six client-researchers from  
49  
50 344 each client group. In addition, we will include at least 32 clients from each care organisation as  
51  
52 345 respondents in the whole evaluation. They will be approached by their daily care professionals, client-  
53  
54 346 researcher or the client council, who will ask them to take part in the study. A convenience sample  
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56 347 technique will be used to include clients who meet the inclusion criteria and are willing and able to  
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3 348 participate. Nevertheless, we will aim for as much variation as possible with regard to relevant client  
4 349 characteristics such as gender, age, ethnicity, and inpatient or outpatient care.

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7  
8 351 Products of the evaluation:

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10 352
  - Selection of the qualitative instruments that were evaluated as best

11 353

12  
13 354 *Figure 3 Research respondents*

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15 355

## 16 356 **2.5 Dissemination**

17  
18 357 In close cooperation with the client-researchers and participating care organisations, we will develop a  
19 358 toolbox including an implementation plan and the (adjusted) qualitative instruments for measuring and  
20 359 improving the quality of the care relationship for each client group in long-term care. The  
21 360 implementation plan will focus on implementing the qualitative instruments that were selected at the  
22 361 end of the evaluation phase. The toolbox will include a training module to let clients and healthcare  
23 362 providers apply the instrument, plus guidance for the analysis and use of results for improving the care  
24 363 relationship. The toolbox will also describe the levels at which the results of the instrument are  
25 364 expected to be useful, such as the individual care relationship, reflection at the team level, or at the  
26 365 organisational level of a care organisation.

27  
28 366 We will also examine whether the results of the qualitative instruments can be used for other  
29 367 purposes, such as healthcare procurement by health insurers and monitoring for external  
30 368 accountability on quality measurement and improvement, primarily by the National Health Care  
31 369 Institute. Several meetings will be held with stakeholders, the research team and care organisations in  
32 370 order to disseminate and discuss the results of the project and the implementation plan. Moreover, we  
33 371 will look for opportunities to present the research findings and research products such as the toolbox  
34 372 to interested care organisations and client councils. Client-researchers will be asked to share their  
35 373 experiences by co-presenting at various platforms. In this way they will have an essential role in the  
36 374 implementation and application of the qualitative instruments. The owner of the qualitative instrument  
37 375 will remain responsible for further implementation and dissemination. The National Health Care  
38 376 Institute may also play a role in the dissemination of the instrument.

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3 378 Product of the dissemination phase:

4 379     ▪ Toolbox including the optimised qualitative instruments to measure and improve the quality of  
5  
6 380 the care relationship for each client group in long-term care, and the implementation plan.

7  
8 381     ▪ Recommendations based on external verification of the toolbox.  
9

10 382

### 11 383 **Ethics**

12  
13 384 Participants will receive verbal and written information about the research. Participants will provide  
14  
15 385 written informed consent and process consent will also be used in the interviews with clients [36]. The  
16  
17 386 Medical Ethics Committee of the Radboud University Nijmegen Medical Centre was asked whether  
18  
19 387 their approval of the study was required under the Dutch Medical Research Involving Human Subjects  
20  
21 388 Act. The Committee decided that formal approval was not needed.  
22

23 389

## 24 390 **3. Discussion and conclusion**

### 25 26 391 **3.1. Discussion**

27  
28 392 Prior work has documented the importance of the care relationship for clients in long-term care [1, 4,  
29  
30 393 39]. In practice, there is a lack of qualitative instruments for evaluating or monitoring the care  
31  
32 394 relationship. We will carry out a study to find and optimise the most suitable qualitative instruments for  
33  
34 395 monitoring the quality of care relationships in long-term care from a client's perspective. The aim of the  
35  
36 396 present paper is to describe the research design of this study. Due to the differences between client  
37  
38 397 groups in long-term care, it is possible that different instruments will fit each group best. This study will  
39  
40 398 result in a toolbox containing an implementation plan and the optimised qualitative instruments.

41  
42 399 Clients will participate in this participatory study as client-researchers. We are therefore working  
43  
44 400 closely with client-researchers in activities such as conducting interviews, preparation activities and  
45  
46 401 analysis. According to Roberts (2012), participatory research is more time-consuming than  
47  
48 402 conventional research methods. It takes time to achieve the desired level of trust in a community, and  
49  
50 403 extra time is also needed for the joint process for thinking about the research results. This extra time  
51  
52 404 will be taken into account in the time schedule of this study. In order to create support in the  
53  
54 405 environment and thereby increase the probability of participation by clients, client-researchers, care  
55  
56 406 organisations, client councils and client organisations will cooperate in this study [40]. Their  
57  
58 407 willingness to join is an important prerequisite for the performance of this research. The study depends  
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3 408 on the close cooperation of client-researchers, and it is therefore important to work together in an  
4 409 equal, respectful, attentive and open way [40, 41]. Lessons learned in previous participatory research  
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6 410 will be used to prevent repetition of avoidable errors, such as tokenism, client-researchers facing  
7  
8 411 difficult situations, experienced workload, and proto-professionalisation [32, 42]. A scoping review will  
9  
10 412 be conducted for this purpose. In order to make the project practically feasible, we will exclude some  
11  
12 413 specific groups in long-term care, such as people with physical or sensory disabilities or people  
13  
14 414 receiving palliative care.

15 415 If client-researchers in care organisations carry out one of the optimised instruments from the toolbox,  
16  
17 416 it will provide useful information and feedback for clients and care professionals on the care  
18  
19 417 relationship in long-term care. This makes the research project practically relevant. Nevertheless, this  
20  
21 418 study risks being overshadowed by the everyday demands that care organisations face, which  
22  
23 419 precludes implementation of the selected instrument on a large scale. The likelihood of successful  
24  
25 420 implementation will depend on the willingness of organisations to change their instruments for  
26  
27 421 measuring the quality of the care relationship, and the degree of support from national stakeholders.  
28  
29 422 Moreover, the willingness and enthusiasm of client-researchers to be involved in the performance of  
30  
31 423 the instruments will be essential for the implementation and application of the qualitative instruments.  
32  
33 424 The participatory research design and involvement of the supervisory committee will increase the  
34  
35 425 probability that the most preferred instruments will be implemented and disseminated in the field.

36 426 The qualitative and participatory research method was chosen to study the experiences of participants  
37  
38 427 and interactions between respondents and client-researchers in natural settings. The research relies  
39  
40 428 heavily on the observational and interviewing skills of researchers and client-researchers and  
41  
42 429 reflectivity on 'our' perspectives on the findings. In qualitative research, studying the perspectives of  
43  
44 430 multiple stakeholders and interpreting the results with different client-researchers and researchers is  
45  
46 431 likely to result in an increased understanding of complex phenomena such as care relationships  
47  
48 432 between clients and professionals. This will diminish possible limitations inherently attached to the  
49  
50 433 qualitative research method [16] [43]. Also, this research takes place on a small scale in three care  
51  
52 434 organisations focused on three client groups within their own contexts. The generalisability to other  
53  
54 435 client groups in other care settings, such as clients with a severe intellectual disability or dementia,  
55  
56 436 may be limited.

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3 437 From a quantitative design point of view, this study protocol may be interpreted as limited because  
4 438 some details are still left open. To make client participation meaningful, we feel it is not good to define  
5 439 every detail beforehand to be able to make decisions during the process as well. Therefore, the global  
6 440 structure and decision moments of the research process are described, but at the same time space is  
7  
8 441 left open so that some aspects can be filled in later on. This is not unusual in qualitative research.  
9

10 442

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13 443 **3.2. Conclusion**

14  
15 444 In long-term care, care relationships are seen as a fundamental element in the delivery of high quality  
16 445 care [4, 44-46]. But good care relationships have not yet been set up everywhere. It is therefore  
17 446 important that clients, client-researchers, care professionals, client councils and care organisations  
18 447 determine areas in which improvement of the care relationship is possible. As far as we are aware,  
19 448 this will be the first study to use a participatory research design to represent the client perspective in  
20 449 the selection and optimisation of qualitative instruments for monitoring care relationships. Scientific  
21 450 articles will be published to expand scientific knowledge on care relationships in long-term care. This  
22 451 approach allows participatory research to link the practical and scientific purposes. Support for the set  
23 452 of qualitative instruments developed will be generated through the meetings of the supervisory  
24 453 committee, and the involvement of client-researchers and care organisations.  
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35 455 **3.3 Practice Implications**

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37 456 The study will result in a toolbox with qualitative instruments that can be used for effective evaluation  
38 457 of the quality of a care relationship. Clients, client councils and care organisations can use the toolbox  
39 458 to monitor the care relationship in a structured way from a client perspective. More generally, the  
40 459 content of this paper may serve as a guideline for developing other studies with the combined purpose  
41 460 of practical outcomes and sharing empirical evidence.  
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47  
48 462 **4. Declarations**49 463 **Funding**

50  
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53 466 the study, collection, analysis and interpretation of data, nor in writing the manuscript.  
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3 467 **Author's contributions**

4 468 All authors contributed to, reviewed and approved the article drafts and final manuscript. AS was  
5  
6 469 responsible for writing the manuscript and MH, NB, KL and SvD read several versions of the  
7  
8 470 manuscript and provided their feedback and suggestions regularly.

9  
10 471 **Competing interests**

11 472 The authors declare that they have no competing interests.

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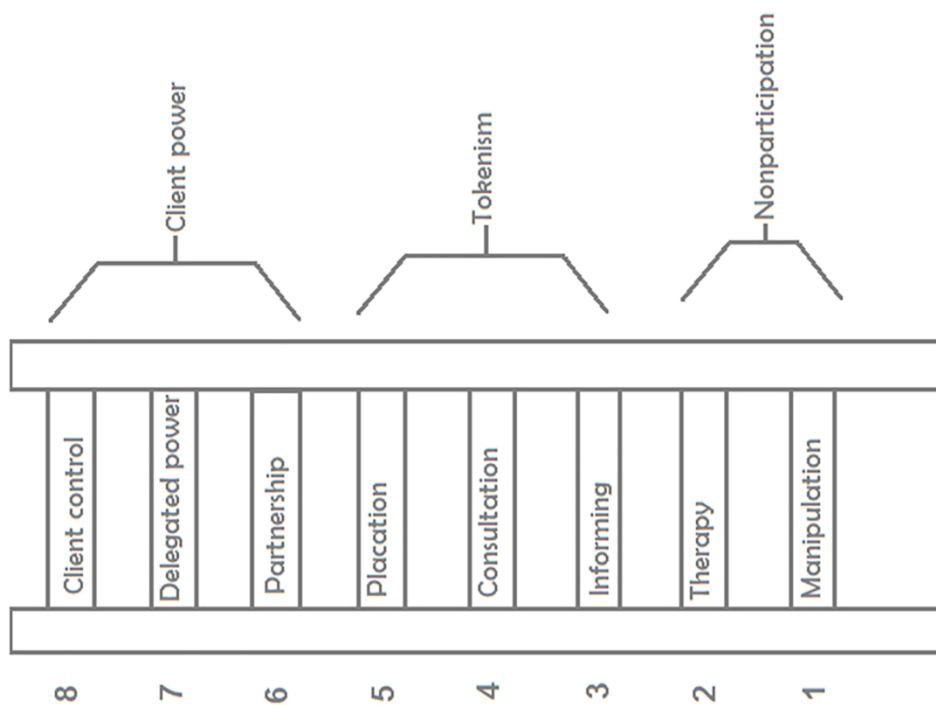


Figure 1 Ladder of Participation, inspired on Arnstein (2015)

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Figure 2 Phases of the study  
253x20mm (300 x 300 DPI)





Figure 3 Research respondents

254x190mm (300 x 300 DPI)