



Assessing the experience of person-centred coordinated care of people with chronic conditions in the Netherlands: validation of the Dutch P3CEQ

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3 **Assessing the experience of person-centred coordinated care of people with chronic conditions in**
4 **the Netherlands: validation of the Dutch P3CEQ**
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10 **ABSTRACT**
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13 Background

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15 Countries are adapting their health and social care systems to better meet the needs of growing
16 populations with (multiple) chronic conditions. To guide this process, assessing the “patient
17 experience” is becoming increasingly important. For this purpose, the Person-Centred Coordinated
18 Care Experience Questionnaire (P3CEQ) was developed in the United Kingdom, and translated in
19 several languages.
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28 Aim

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30 To assess the internal and construct validity of the Dutch P3CEQ to capture the experience of person-
31 centred coordinated care of people with chronic conditions in the Netherlands.
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37 Participants and methods

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39 Adults with chronic conditions (N=1,098) completed the Dutch P3CEQ, measures of health literacy
40 and patient activation, and reported the use and perceived quality of care services. Data analysis
41 included Principal Component and reliability analysis (internal validity), analysis of variance and
42 Student’s T-tests (construct validity).
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51 Results

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53 The two-component structure found was pretty much the same as in the UK validation study. Socio-
54 demographic correlates also resembled those found in the UK. Women, persons who were lower
55 educated, less health literate or less activated experienced less person-centred coordinated care.
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3 P3CEQ scores correlated positively with GP performance scores and quality ratings of the total care
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5 received.
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10 Conclusion

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12 The Dutch P3CEQ is a valid instrument to assess the experience of person-centred coordinated care
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14 among people with chronic conditions in the Netherlands. Awareness of inequity and more attention
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16 to communication skills in professional training is needed to ensure that care professionals better
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18 recognise the needs of women, lower educated or less health literate persons, and improve their
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20 experiences of care.
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26 Patient contribution

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28 The P3CEQ has been developed in collaboration with a range of stakeholders. Eighteen persons with
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30 (multiple) chronic conditions participated as patient representatives and codesign experts in (four)
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32 codesign workshops. Other patient representatives participated in cognitive testing of the English-
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34 language instrument. The usability of the P3CEQ to capture the experience of person-centred
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36 coordinated care of older persons has been examined by interviewing 228 older European service
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38 users, including 13 living in the Netherlands, as part of the SUSTAIN project. More than thousand
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40 persons with chronic conditions participated in the validation study of the Dutch P3CEQ.
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45 **KEY WORDS**

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48 patient experience; person-centred care; care coordination; patient-reported experience measure;
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50 validation study; chronic conditions
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INTRODUCTION

In many countries, a growing number of people are living longer with (multiple) chronic conditions[1,2]. To maintain quality of life and better meet the needs of these people, countries are adapting their health and social care systems. Improving care continuity, coordination and integration, and prioritising a person-centred relational approach, are core tenants of system redesign across the European Union and the United States[3,4]. To guide the transformation towards more person-centred and integrated care, assessing the “patient experience” - which is conceptually akin to person-centred care[5] - is becoming increasingly important.[6]

To assess the care experiences of service users, many so called ‘patient reported experience measures’ (PREMs) are available[7], and their application in quality improvement initiatives and health system performance assessment is growing[8]. However, many of these PREMs fail to capture key elements of quality of care from the perspective of people with multimorbidity - who make up an increasing proportion of the population with chronic conditions in countries -, such as care coordination and multidisciplinary collaboration.[6-7,9,10] Moreover, PREMs to assess high-quality chronic care should cover key elements of person-centredness: a comprehensive approach to a person’s needs and working in partnership with the patient and, if applicable, family/carers.[3,11,12]

The Person-centred Coordinated Care Experience Questionnaire (P3CEQ)[5] is a brief questionnaire that meets the requirements for a PREM that could assess the quality of care and guide quality improvement for people with (multiple) chronic conditions. It has been specifically designed to assess the experience of person-centred coordinated care, informed by a theoretical model which was developed to consider the relationship between care coordination, continuity and person-centred care[5,9]. Person-centred coordinated care has been defined as ‘care and support that is guided by and organised effectively around the needs and preferences of individuals’, and is a comprehensive approach to care incorporating changes to organisational structures and behaviours of care professionals and service users[5].

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3 The P3CEQ was originally developed in the United Kingdom (UK) for persons with chronic conditions
4 using primary care services. It has been shown a reliable and valid instrument, with strong face,
5 construct and ecological validity, and sensitivity to change[13]. To expand its usability for quality
6 assessment of innovative models of integrated care across Europe, the questionnaire was translated
7 into several languages, including Dutch, as part of the EU funded SUSTAIN project[14]. In this paper
8 we report on the internal validity and construct validity of the Dutch P3CEQ to capture the
9 experience of person-centred coordinated care of people with chronic conditions registered in
10 general practices in the Netherlands.
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20 21 22 23 **Research questions**

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- 1) Internal validity: Does the Dutch P3CEQ administered among people with chronic conditions registered in general practices in the Netherlands reflect the dimensionality and internal consistency of the English P3CEQ as confirmed in the UK validation study?
 - 2) Construct validity: To what extent do the care experiences as assessed with the Dutch P3CEQ of persons with chronic conditions relate to their:
 - a) socio-demographic characteristics;
 - b) illness characteristics;
 - c) health literacy and patient activation level;
 - d) health service use in the previous twelve months; and
 - e) ratings of the quality of their general practitioner (GP) and of the total care they received over the previous twelve months?

52 In answering our research questions 1 and 2a, we repeated the analyses of the UK validation study.
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54 As for research questions 2b to 2e, we formulated a number of hypotheses based on the theoretical
55 construct of person-centred coordinated care to determine the construct validity of the Dutch
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60 P3CEQ.

Hypotheses

1. Persons with more chronic conditions experience less care coordination, as these people are likely to receive care from more care disciplines and sectors. Although GPs and district nurses in the Netherlands are tasked with care coordination, coordinating care across disciplines and sectors is complicated as the Dutch health and social care systems are not integrated.[15] This may also impede person-centredness.
2. Persons with lower levels of health literacy or patient activation experience less person-centred care. This hypothesis arises from the concept of health candidacy [16], which suggests that people with low perceived candidacy for certain care interventions are offered less opportunities to engage in active person-centred care. These people may also lack the confidence and awareness of what this requires, for instance articulation of what matters to them in the form of a narrative[17], which is key routine for person-centred care.
3. Persons who had been in contact with a GP over the last twelve months experience more person-centred coordinated care than persons who did not have contact with their GP, because a 'whole person' approach, continuity and coordination of care are considered key features of general practice and family medicine [18].
4. Persons who had been in contact with more care disciplines experience less person-centred coordinated care, because of a higher risk of care fragmentation for reasons already mentioned.
5. Persons who experience more person-centred coordinated care give higher rates for the performance of their GP and the overall quality of the care they receive, because person-centredness and care coordination are core elements of high-quality primary care and high-quality chronic care from the perspective of people with (multiple) chronic conditions [19-22].

METHOD

Study sample

The study sample was selected from the National Panel of people with Chronic illness or Disability (NPCD), a nationwide panel-study in the Netherlands [23-24]. People with chronic conditions are recruited each year from (random samples of) general practices in the Netherlands according to the following criteria: diagnosis of at least one somatic chronic disease, aged ≥ 15 years, not being permanently institutionalised, life expectancy > 6 months (according to the GP), being mentally capable to participate, and having an adequate command of the Dutch language. Panel members participate in surveys twice a year, for a maximum of four years. They can choose to complete online or paper-and-pencil questionnaires. GPs provide data about their chronic disease(s) with permission of the panel members. NPCD is registered with the Dutch Data Protection Authority (registration no. 1283171); all data are collected and handled in accordance with the privacy protection guidelines of the Authority. According to Dutch legislation, approval by a medical ethics committee is not mandatory for this study.

The Dutch P3CEQ was included in the NPCD survey of October 2017. A total of 1452 persons (≥ 18 years) with chronic conditions were invited to complete the questionnaire; 1160 (80%) did. We excluded the data of 17 respondents who appeared not to have a diagnosed somatic chronic disease according to their GP. Furthermore, we excluded the data of 45 persons who reported not to have been in contact with a care provider during the previous twelve months, resulting in a final sample of 1098 individuals.

Measures

Dutch P3CEQ

The included Dutch P3CEQ was developed as part of the EU funded SUSTAIN project[14]. The translation process was guided by principles of good practice for translation and cultural adaptation of patient reported outcomes measures developed by ISPOR[25] (see Box 1).

Box 1. Translation process followed for the Dutch P3CEQ

The translation process followed a stepwise approach:

1. Preparation: Dutch SUSTAIN researchers (ML, AS, NZ, SB) reviewed the English P3CEQ instrument in order to ensure their understanding of the instrument's goal. They clarified any questions with the developers of the instrument (JC, HL).
2. Forward translation: The instrument was independently translated into Dutch by three Dutch researchers (ML, AS, NZ).
3. Reconciliation: The three translations were discussed by ML, AS, NZ and merged into a single translation. This forward translation was then reviewed for language use (SB) and relevance to practice (by an elderly care specialist).
4. Backward translation: the final forward translation was translated back into English by an independent translator who had not been involved in the forward translation.
5. Backward translation review: The developers of the English P3CEQ collected the backward translation results and compared these with the original. Any discrepancies were discussed with the Dutch researchers in order to resolve issues and revise the translation accordingly.
6. Harmonisation: As the P3CEQ was translated into other languages parallel to the Dutch translation (as part of the SUSTAIN project), the developers of the English P3CEQ compared the backward translations from the multiple language translations to identify any discrepancies and achieve consistency across the translations.
7. Cognitive debriefing: The Dutch P3CEQ was then tested with five patient-experts in order to check for comprehensibility and interpretation, to try out translation alternatives and highlight any items that may have performed insufficiently at a conceptual level.

8. Review of cognitive debriefing results and finalisation: the Dutch researchers compared the patient-experts' interpretations with the English P3CEQ to highlight and amend discrepancies.
9. Proofreading: A final review for typographic and grammatical errors was carried out by the Dutch researchers.

The English P3CEQ originally contained 11 items, but Q4 was excluded from the final version because of too many missing responses in the UK validation study. The last item (Q11a, b) is optional, but was included in the Dutch P3CEQ. In the UK validation study, Principle Component Analysis supported the two-component structure (Person-centredness, Care coordination), with scalability demonstrated by a Partial Credit Rasch Analysis indicating good fit for both components. Person-centredness is assessed by eight items (Q1, Q2, Q3, Q5, Q6, Q9, Q10, Q11); care coordination by five (Q6, Q7, Q8, Q9, Q10).

The Dutch P3CEQ included in the NPCD survey had slightly different response options compared to the original. The response codes of most items in the English P3CEQ were 'not at all' (0), 'to some extent' (1), 'more often than not' (2) and 'always' (3), whereas the options of these items in the NPCD survey were 'never' (0), 'sometimes' (1), 'often' (2) and 'always' (3). Furthermore, we did not offer the 'not applicable' option, whereas this option is offered in the English version, but is then treated as a missing value in constructing the scale scores.

Other measures

Sociodemographic characteristics included participants' self-reported gender, age, migration background, education and living situation. Migration background was based on the country of birth of participants' parents and of the participant, in accordance with Statistics Netherlands [26], resulting in three categories: Dutch, western (not Dutch) and non-western. Level of education was determined by the highest level of completed education.

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3 *Illness characteristics* included were participants' registered chronic diseases and illness duration
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5 (since diagnosis of first chronic disease), which were derived from their general practice health
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7 records. Participants themselves reported on motor, visual and hearing impairments by completing a
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9 Dutch validated questionnaire [27]. For each type of impairment, scores could range from 0 (no
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11 impairment) to 3 (severely impaired).

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14 *Health literacy* was assessed with the 16-item Health Literacy Survey-Europe (HLS-EU-16)[28]. Items
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16 are formulated as questions ("How easy would you say it is to ..., e.g., find information on treatments
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18 of illnesses" or [...] "understand your doctor's or pharmacist's instructions on how to take a
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20 medicine") and rated on a four-point scale, from 'very easy' to 'very difficult'. In this study, we used a
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22 slightly modified version with a fifth answering option 'not applicable', treated as a missing value.
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24 Health literacy scores were calculated by coding a response of 'very easy' or 'easy' as 1 and of
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26 'difficult' or 'very difficult' as 0, and summing the answers. Participants had to provide a valid answer
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28 on at least 13 questions to get a total score. Total scores were subsequently categorised: a score of 0
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30 to 8 indicating insufficient health literacy, a score between 9 and 12 as limited health literacy and a
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32 score of 13 or higher indicating sufficient health literacy[28].

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36 *Participants' activation level* was assessed with the short Patient Activation Measure (PAM-13)[29-
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38 30]. Having checked the internal consistency of the scale (Cronbach's alpha .87), we calculated
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40 participants' scale scores following the guidelines of Insignia Health[31]. Based on these scores,
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42 participants were assigned to one of four activation stages: 1) overwhelmed and does not consider
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44 an active role in managing his/her own health, 2) an active role in managing his/her health but lacks
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46 knowledge and confidence for self-management, 3) beginning to take action but may lack
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48 confidence and skills to adopt new behaviours, and 4) confident and active but may have difficulty
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50 maintaining adequate behaviour under stressful circumstances.

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54 *Health service use* was assessed by participants reporting their contacts with a number of care
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56 providers over the previous twelve months: GP, practice nurse, medical specialist(s), occupational
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58 physician, specialised nurse working in a hospital, community nurse, home care, physiotherapist,
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3 pharmacist and other care provider(s). We calculated the number of different care disciplines the
4 participant had been in contact with during the twelve months prior to completion of the P3CEQ.
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7 *Quality of care* as perceived by the participants was assessed by a performance score for the GP they
8 had been in contact with over the last twelve months (ratings from 0 to 10) and a similar rating of the
9 quality of the total care they had received over the last twelve months, from 0 (very poor) to 10
10 (excellent).
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19 **Statistical analysis**

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21 Statistical analysis was performed using PASW Statistics 18[32]. Univariate analyses were applied to
22 describe the sample. To answer our first research question, we analysed the distribution of the
23 P3CEQ item scores. For Q8 (Care planning), an overall score was calculated by averaging the scores
24 from questions 8a, 8b, 8c and 8d, as per the UK validation study. Next, we explored the
25 dimensionality of the Dutch P3CEQ by means of Principal Component Analysis determining principal
26 components based on an Eigenvalue of >1, Varimax rotation and min imputation (missing values set
27 at 0), as was done in the validation study of the English P3CEQ. Also similar to the UK validation
28 study, we calculated Cronbach's alpha as a measure of internal consistency and constructed scale
29 scores. To answer our second research question, we calculated the mean scale scores and standard
30 deviations for various subgroups of participants and conducted T-tests and analysis of variance
31 (ANOVA) to test for differences across subgroups.
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48 **RESULTS**

49 **Sample characteristics**

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51 The sample of 1,098 persons consisted of slightly more women (54%) than men (46%). The mean age
52 was 67.9 years, with 73 persons younger than 50 and 163 aged 80 or older. Only ten participants
53 were of non-western origin. A quarter (24%) lived alone and almost three quarters (73%) lived with a
54 spouse or partner. About a third (34%) had been diagnosed with one chronic disease, another third
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3 with two chronic diseases, 17% with three and 15% with four or more chronic diseases. The average
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5 illness duration was 14.2 years. Motor impairments were present in the majority of the participants,
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7 with 28% experiencing mild and 30% severe impairments. Fourteen percent experienced visual
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9 impairments and 31% reported hearing problems. Almost 90% had been in contact with their GP
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11 over the last twelve months. On average, participants had been in contact with four different care
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13 disciplines over the same period (range: 1-10).
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19 **Internal validity**

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21 Table 1 provides a summary of the P3CEQ item scores. The proportion of missing values per question
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23 ranged from 3.9% (Q11: Confidence to self-manage) to 11.7% (Q7: Single named contact). Scores
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25 provided for all items ranged between 0 and 3 (not in table). Mean scores ranged between 0.09 (Q8),
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27 indicating that most participants did not experience that their care was guided by an individual care
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29 plan, and 2.31 (Q5), indicating that most participants did not need to repeat information that should
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31 have been in their medical records. Considering values for skewness and kurtosis between -2 and 2
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33 as acceptable [25], all questions were sufficiently normally distributed, except Q8 (Care planning
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35 overall). The non-normal distribution of the scores of this question can be explained by a large
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37 majority of participants reporting not to have an individual care plan.
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48 [insert Table 1]

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50 The Principal Component Analysis resulted in a two-component solution (Table 2). The first
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52 component explained 38% of the variance of the item scores; the second an additional 13%. Based
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54 on these results, we followed the UK validation study and constructed two scales by calculating the
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56 sum of the scores of the questions assigned to these scales (marked in bold in Table 2): Person-
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58 centredness and Care coordination. Cronbach's alpha was .82 for the Person-centredness scale (eight
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60 items) and .68 for the Care coordination scale (five items).

[insert Table 2]

Correlates with socio-demographic characteristics

Men experienced higher levels of person-centred coordinated care than women (Table 3). Age groups differed in their reporting of person-centredness, with people aged 70 to 79 experiencing lower levels of person-centred care than people aged 50 to 69. There were no significant differences between age groups in experienced care coordination. Education related significantly to experienced person-centredness, with people who had no formal education, who attended primary school only or with low or preparatory vocational training only reporting less person-centred care than those with completed high vocational education. No effect of education was found on experienced care coordination. Living situation was not related to the experience of person-centred coordinated care.

Correlates with illness characteristics

The number of chronic diseases did not relate to the experience of person-centred coordinated care (Table 3). However, people with mild motor impairments, e.g. those who experience difficulties walking outdoors or climbing stairs, reported lower levels of experienced person-centred coordinated care than people without such impairments. Visual and hearing impairments did not have an effect on experienced person-centredness or care coordination.

[insert Table 3]

Correlates with health literacy, patient activation and health service use

Table 4 shows that higher levels of health literacy and patient activation were associated with experiencing more person-centred coordinated care. Regarding health service use, we found no difference in the experienced person-centred coordinated care between persons who had been in contact with their GP over the last twelve months and those who had not (Table 4). However, the

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3 number of different care disciplines one had been in contact with was related to the experience of
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5 both person-centredness and care coordination. Persons who had been in contact with seven or
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7 more disciplines reported the highest levels of person-centredness and differed in that respect from
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9 people who had had contact with one or two disciplines. Those who had been in contact with only
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11 one discipline also reported lower levels of experienced person-centredness than people who had
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13 been in contact with four or five disciplines. Regarding care coordination, the pattern was rather
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15 similar. This means that those who had been in contact with seven or more disciplines experienced a
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17 higher level of care coordination than people who had had contact with maximally four disciplines.
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19 Persons who had been in contact with only one discipline reported the lowest level of coordinated
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21 care and differed in that respect from persons who had had contact with four or more disciplines.
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23 People who had been in contact with two disciplines also experienced a low level of care
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25 coordination and differed from persons who had been in contact with five or seven disciplines.
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32 [insert Table 4]
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36 **Correlates with quality of care ratings**

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38 Table 5 shows a rather linear association between participants' person-centredness scores and their
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40 GP performance scores, although the small group of persons rating the performance of their GP
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42 lower than 6 (N=42) did not have the lowest mean score for person-centredness. The association of
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44 experienced person-centredness with the ratings for the overall quality of care is stronger. The
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46 associations for care coordination show a similar pattern.
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DISCUSSION

Our results support the internal validity of the Dutch P3CEQ to assess the experience of person-centred coordinated care among people with chronic conditions registered with general practices in the Netherlands. The two-component structure of the Dutch P3CEQ resembled the structure found in the UK validation study, though some differences emerged. The only difference is that Q6 ('Care joined up') loaded on both components in our study, whereas in the UK validation study this question strongly related to the Person-centredness component (0.7051) and less to the Care coordination component (0.243)[13]. In contrast, Q10 ('Information to self-manage') did not load sufficiently on the Care coordination component in our study, whereas it loaded on both components in the UK validation study. The low factor loading of Q10 on this component in our study also explains the relatively low Cronbach's alpha of the Care coordination scale (.68), though this may still be considered acceptable[33] given that the scale consists of only five items. It is important to understand that person-centredness and care coordination are related concepts, with coordination of care being a key element of person-centred care.[34-35] This is reflected in the P3C (Person-Centred Coordinated Care) construct[5,9] underlying the P3CEQ, which is the main reason for allowing questions to load on both components.

The scale scores of both scales of the Dutch P3CEQ were substantially lower than in the UK validation study. This might be explained by the use of slightly different response options in the two studies. In addition, differences in response style between Dutch and English respondents may be considered. Differences in acquiescence and extreme responding have been found across European countries[36], though such differences seem less likely between western European countries, as the previously mentioned study did not find differences between French, German and UK respondents (Dutch citizens were not involved). A third and perhaps more plausible explanation is that primary care users with chronic conditions in the Netherlands genuinely experience less person-centred coordinated care compared to their counterparts in the UK validation study. For instance, developing an individualised care plan is not common practice for all chronic patients within primary care in the

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3 Netherlands [37]. This is also illustrated by our results regarding Q8 (Care planning overall): a large
4 majority of participants reported not to have an individual care plan. In contrast, the participants in
5 the UK validation study were recruited from a primary care system (Somerset) where substantial and
6 ongoing initiatives are in operation to develop countywide person-centred coordinated care[38-39].
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14 Similar to the UK validation study, men scored higher than women on both scales, which is in line
15 with other studies reporting women to be less positive about the care they receive [e.g. 40-41]. It has
16 been argued that current health services are predominantly built on a 'male model', with women
17 being less involved in their design and, consequently, less attention being paid to women's needs
18 and a gender-sensitive management of health conditions[42]. Differences between women and men
19 in communication styles may also play a role[43-44].
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28 In contrast to the results found in the UK, participants' age appeared to be associated with the level
29 of experienced person-centredness. However, a closer look at the distributions across age categories
30 shows that in both studies persons aged 60 to 69 had slightly higher person-centredness scores than
31 persons aged 50 to 59 and persons aged 70 and over. [This contrasts with the frequent observation of
32 older people reporting more positive care experiences \[e.g. 45\]. A detailed analysis across age groups
33 including more than 145,000 patients from various studies showed however that a general tendency
34 of older people responding more positively about their care may not exist.\[46\]](#) In the UK validation
35 study mean scores were also calculated for four age groups younger than 50, although some of these
36 groups were very small. This may have caused a less stable pattern across age categories younger
37 than 50, resulting in a non-significant age effect in that study.
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51 Importantly, our study shows that lower educated persons experience less person-centred care,
52 which was also found in the UK validation study. This may relate to their lower socioeconomic status
53 (SES), as other studies have shown that people of low SES receive less guidance, less collaborative
54 care, less positive feedback and receive more clinically directed care than people with higher
55 SES[16,47]. This may be explained by the concept of health candidacy[16], already mentioned in the
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3 introduction. People with low perceived candidacy for certain care interventions may be offered less
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5 opportunities to engage in active person-centred care or find it more difficult to engage. People of
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7 low SES or less educated people are also at risk of epistemic injustice[48], both due to a lack of
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9 understanding about their health and how to improve it, and by not being taken seriously and 'heard'
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11 in clinical encounters. People who lack health knowledge may find self-representation and
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13 communication with care professionals less effective. Since person-centred care builds on a person's
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15 narrative and the pursuit of a partnership between patient and care professional, notions of
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17 epistemic injustice and candidacy may therefore explain why less educated people report poorer
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19 experiences of person-centred care. A previous study provided some evidence that implementing
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21 person-centred care benefits less educated persons in terms of increased self-efficacy[49].
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28 We found partial support for our hypotheses specifying the relationships of participants' P3CEQ
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30 scores with their illness characteristics, levels of health literacy and patient activation, health service
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32 use and ratings of the quality of care they received. Participants with more chronic conditions did not
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34 experience less person-centred coordinated care than participants with less chronic conditions
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36 (hypothesis 1 rejected). We had expected people with more chronic conditions to experience a lack
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38 of care coordination more often, [as in general less positive care experiences have been found among](#)
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40 [people with more chronic conditions\[e.g. 45\], and because](#) these people will usually be in contact
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42 with more care disciplines, ~~[which and primary care providers and hospitals \(and social care providers\)](#)~~
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44 ~~[in the Netherlands](#)~~ do not use shared records [in the Netherlands](#). However, this lack of care
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46 coordination may be less felt by people with chronic conditions that are managed by chronic disease
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48 management programmes (DMPs) within primary care. People included in these programmes may
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50 experience more care coordination, as far as it concerns care covered by the DMP, though not
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52 necessarily more person-centredness, as the single-disease focus of these programmes might even
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54 blur a view on the 'whole person'[50-51].
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3 Our findings confirm our second hypothesis that persons with lower levels of health literacy and/or
4 patient activation experience less person-centred care. Participants with limited health literacy or
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6 less activated participants also appeared to experience less care coordination. We already pointed to
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8 the concepts of health candidacy and epistemic injustice as possible explanatory phenomena. Given
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10 that inequitable treatment of people within healthcare is unacceptable, care providers and policy-
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12 makers should give the highest priority to improving care for disadvantaged people who are precisely
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14 the ones who may need more and possibly also other types of support from care professionals to
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16 manage their health and care.
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21 Our third hypothesis, that contact with the GP would increase the experience of person-centred
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23 coordinated care, was not confirmed. This may be because of the specific nature of our sample: all
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25 participants had one or more chronic conditions known by their GP and almost 90%
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27 reported to have been in contact with the GP over the last year. Although the persons who reported
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29 contact with the GP had slightly higher mean scores on both P3CEQ scales, the T-test may have
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31 lacked power because of the small number of participants not having seen their GP.
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35 Surprisingly and in contrast with our fourth hypothesis, persons who had been in contact with more
36
37 different care disciplines did not experience less person-centred coordinated care. People who had
38
39 been in contact with only one care discipline experienced the lowest levels of person-centred
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41 coordinated care. This may be explained by these people experiencing or expressing less need for
42
43 person-centred coordinated care. However, care professionals should be aware that person-centred
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45 care is equally important for people with less complex care needs, to support their self-management
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47 and prevent deterioration of their health problems as much as possible and to signal any new health
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49 problems or related problems in other domains of life at an early stage. For people who receive care
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51 from many disciplines, the necessity for person-centred coordinated care may be more visible and
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53 recognised by care professionals, eliciting more care coordination and possibly also more attention
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55 to quality of life and wellbeing from a broader perspective. We do not know whether our participants
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57 with a more complex care need were receiving care from an integrated care programme. Integrated
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3 care programmes for frail older people are increasingly being implemented in Dutch primary
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5 healthcare[52].

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7 Finally, our fifth hypothesis about the correlates of the P3CEQ scale scores with other patient-
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9 reported experience measures was confirmed. People experiencing more person-centred
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11 coordinated care were also more positive about their GP's performance and the quality of the total
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13 care they received, which can be considered support for the convergent validity of the Dutch P3CEQ.
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18 **Methodological considerations**

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20 A strength of our study is the large sample of people with chronic conditions randomly selected in
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22 general practices throughout the Netherlands. The NPCD panel has shown to be representative for
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24 the Dutch population of people with chronic conditions registered with general practices regarding
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26 age and gender distribution, but people with limited health literacy and people from non-Western
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28 origin are underrepresented[53]. The translation process that resulted in the Dutch P3CEQ followed
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30 the principles of good practice for translation and cultural adaptation of patient reported outcomes
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32 measures as developed by ISPOR in great detail. Nevertheless, further testing of the Dutch P3CEQ on
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34 the comprehensibility of the items by means of cognitive interviews, in particular among the oldest
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36 age group, is recommended based on what we have learned from applying the P3CEQ in the SUSTAIN
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38 project[54]. This cognitive testing will be done this year (2021), as part of the development of the
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40 [International Survey of People Living with Chronic Conditions \(PaRIS\) survey](#)[55] initiated by the
41
42 Organization for Economic Cooperation and Development (OECD). The PaRIS survey aims to support
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44 countries in making their health systems more people-centred by collecting patient-reported data, in
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46 particular from primary care service users aged 45 years and older who are likely to have – or
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48 develop – chronic conditions. The PaRIS survey questionnaires, including the P3CEQ, have recently
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50 been adopted by all participating countries, including the Netherlands.
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59 **Implications for policy and practice**

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3 [The results of our study provide guidance for training of care professionals and quality improvement](#)
4 [initiatives within primary care. In particular, a targeted focus on improving candidacy, health literacy,](#)
5 [and on person-centred care for women and people with lower educational attainment may enhance](#)
6 [the care experiences of many people with chronic conditions as well as their health and wellbeing.](#)
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8 [Furthermore, given the persisting and even growing inequalities in health and access to health](#)
9 [services within and across countries, person-centred coordinated care should be prioritised for all](#)
10 [marginalised groups.](#)
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20 21 **Conclusion**

22
23 The Dutch P3CEQ has proven to be a valid instrument to assess the experience of person-centred
24 coordinated care among people with chronic conditions registered with general practices in the
25 Netherlands. Its internal validity was confirmed by the high resemblance in dimensionality with the
26 English P3CEQ validated in the UK. Correlates with other patient-reported experience measures
27 support its convergent validity. Findings of the Dutch P3CEQ point to the experience of less person-
28 centred coordinated care by women and/or lower educated, less health literate or less activated
29 persons. This calls for increased [awareness of attention to inequity in developing primary care and](#)
30 [health services in general,](#) and ~~more attention~~ to the attitude and communication skills of care
31 professionals in professional training to ensure that care professionals are able to recognise and
32 discuss the needs for care and support of [patients and clients from marginalised groups](#)~~these people~~
33 [at an early stage in a way that suits their communication preferences and skills.](#)
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Table 1. P3CEQ-Dutch item scores of primary care patients with chronic conditions

		Missing %	Mean	SD	Skewness	SE	Kurtosis	SE
Q1	Discuss what's important	5.2	1.26	0.96	0.39	0.08	-0.76	0.15
Q2	Involved in decisions	7.0	2.05	0.95	-0.74	0.08	-0.40	0.15
Q3	Considered 'whole person'	6.1	1.69	0.98	-0.17	0.08	-0.99	0.15
Q5	Repeating information	7.7	2.31	0.70	-0.71	0.08	-0.02	0.15
Q6	Care joined up	10.7	1.15	0.94	0.54	0.08	-0.52	0.16
Q7	Single named contact	11.7	0.59	1.19	1.53	0.08	0.33	0.16
Q8	Care planning (overall)	6.3	0.09	0.43	4.87	0.08	23.52	0.15
Q9	Support to self-manage	8.7	1.40	0.97	-0.54	0.08	-1.21	0.15
Q10	Information to self-manage	7.7	1.87	1.29	-0.40	0.08	-1.63	0.15
Q11	Confidence to self-manage	3.9	2.11	0.69	-0.59	0.08	0.71	0.15

For Peer Review

Table 2. Principle component analysis with Varimax rotation of Dutch P3CEQ items

		Component 1 Person-centredness	Component 2 Care coordination
Q1	Discuss what's important	0.618	0.283
Q2	Involved in decisions	0.814	0.117
Q3	Considered 'whole person'	0.805	0.150
Q5	Repeating information	0.495	-0.202
Q6	Care joined up	0.530	0.465
Q7	Single named contact	0.231	0.688
Q8	Care planning (overall)	-0.112	0.692
Q9	Support to self-manage	0.594	0.415
Q10	Information to self-manage	0.725	0.200
Q11	Confidence to self-manage	0.524	-0.295

For Peer Review

Table 3. Mean and standard deviation of P3CEQ scales for subgroups with different sociodemographic and illness characteristics

	N	Person-centredness		Care coordination	
		M	SD	M	SD
Total sample	1098	12.88	5.40	4.64	3.36
Gender					
Male	510	13.41	5.26	5.06	3.48
Female	588	12.41	5.47	4.27	3.21
T-test		T(1096)=3,098, P=.002		T(1096)=3.905, P<.001	
Age (in years)					
18 to 49	73	13.47	4.45	4.64	2.95
50 to 59	167	13.50	5.24	4.98	3.20
60 to 69	312	13.67	5.13	4.63	3.14
70 to 79	383	12.05	5.52	4.32	3.45
80 and older	163	12.39	5.85	5.05	3.86
ANOVA		F(4, 1093)=5.116, P<.001		F(4, 1093)=1.891, P=.110	
Education					
None / primary school	77	11.57	5.95	4.19	3.71
Low / preparatory vocational education	252	12.19	5.89	4.59	3.67
Intermediate general education	231	12.63	5.66	4.45	3.43
Intermediate vocational education	158	13.17	5.18	4.78	3.50
Advanced general education	84	13.31	4.65	4.57	3.11
High vocational education	208	13.88	4.56	4.94	2.93
University	58	13.95	4.52	5.07	2.74
ANOVA		F(6, 1061)=3.329, P=.003		F(6, 1061)=0.844, P=.536	
Living situation					
Alone	256	12.33	5.07	4.47	3.42
With spouse / partner	785	13.06	5.44	4.70	3.35
With family (not spouse)	37	13.84	5.29	5.04	3.22
With roommates*	3	-	-	-	-
ANOVA		F(2, 1075)=2,378, P=.093		F(2, 1075)=0,692, P=.501	
Number of diagnosed somatic chronic diseases					
One	376	12.83	5.37	4.64	3.35
Two	368	12.89	5.51	4.46	3.38
Three	195	13.04	5.36	4.80	3.29
Four or more	159	12.77	5.31	4.86	3.46
ANOVA		F(3, 1094)=0.092, P=.965		F(3, 1094)=0.710, P=.546	
Motor impairment(s)					
None	447	13.27	5.67	4.64	3.43
Mild	291	12.21	5.14	4.30	3.24
Moderate / severe	313	13.09	5.00	5.06	3.41
ANOVA		F(2, 1048)=3.655, P=.026		F(2, 1048)=3.826, P=.022	

Visual impairment(s)						
None	924	13.02	5.33		4.63	3.33
Mild	74	12.53	5.07		4.92	3.39
Moderate / severe	79	11.66	6.08		4.50	3.73
ANOVA		F(2, 1074)=2.493, P=.083			F(2, 1074)=0.330, P=.719	
Hearing impairment(s)						
None	733	13.16	5.46		4.68	3.30
Mild	218	12.51	4.90		4.44	3.32
Moderate / severe	112	12.66	5.47		5.04	3.77
ANOVA		F(2, 1060)=1.446, P=.236			F(2, 1060)=1.179, P=.308	

* As this category contained only three persons, it was not included in the analysis.

For Peer Review

Table 4. Mean scores and standard deviation of P3CEQ scales for subgroups with different levels of health literacy and patient activation and different health service use

		Person-centredness			Care coordination	
	N	M	SD		M	SD
Health literacy						
Inadequate	76	10.88	4.63		3.93	2.99
Limited	179	13.30	4.55		5.07	3.19
Sufficient	551	14.22	5.02		5.09	3.27
ANOVA		F(2, 803)=16.343, P<.001			F(2, 803)=4.398, P=.013	
Patient activation						
Stage 1	156	11.44	4.54		4.09	3.06
Stage 2	235	12.18	4.91		4.34	3.06
Stage 3	336	13.14	5.05		5.03	3.44
Stage 4	296	14.51	5.44		5.03	3.41
ANOVA		F(3,1019)=15.782, P<.001			F(3, 1019)=4.764, P=.003	
Contact with GP in previous year						
No	124	12.77	6.03		4.33	3.39
Yes	956	12.94	5.29		4.69	3.35
T-test		T(148.618)=-0.303, P=.762			T(1078)=-1.140, P=.254	
Number of different care disciplines contacted in previous year						
1	51	9.86	6.77		2.92	3.22
2	138	11.80	6.23		3.90	3.48
3	249	12.53	5.68		4.21	3.42
4	283	13.49	4.80		4.83	3.08
5	201	13.50	4.85		5.08	3.18
6	102	12.82	5.11		4.92	3.24
7 or more	74	14.16	4.59		6.37	3.75
ANOVA		F(6, 1091)=5.644, P<.001			F(6, 1091)=8.468, P<.001	

Table 5. Mean scores and standard deviation of P3CEQ scales for subgroups with different ratings of the quality of care

	N	Person-centredness		Care coordination		
		M	SD	M	SD	
GP Performance score over the last 12 months						
5 or lower	42	11.55	6.49	4.02	3.58	
6	50	10.90	4.57	3.61	3.18	
7	152	10.93	4.48	3.51	2.84	
8	414	13.12	4.87	4.84	3.19	
9	203	14.04	5.20	5.13	3.38	
10	81	15.62	5.92	6.28	3.68	
ANOVA		F(5, 936)=13.682, P<.001		F(5, 936)=10.311, P<.001		
Rating of quality of the total care received over the last 12 months						
5 or lower	13	6.85	3.29	2.00	2.55	
6	58	9.53	3.66	3.12	3.29	
7	223	11.60	4.30	4.03	3.00	
8	498	13.86	4.44	5.01	3.02	
9	160	15.77	4.63	5.87	3.46	
10	54	17.48	5.50	7.38	3.55	
		F(5, 1000)=40.839, P<.001		F(5, 1000)=19.430, P<.001		

Table with responses to reviewers' comments

<p>Reviewer 1: <i>Adaptation/validation study of the P3CEQ in the Netherlands. It is well laid out, the methodology is appropriate and clearly described. The steps taken seem to me to be correct. The study is relevant and useful for those who speak Dutch. The study presents comparative data with the English original.</i></p>	
<p>Comments reviewer 1:</p>	
<p><i>The second factor has a low internal consistency. This aspect could be given more attention by the authors. I do not know if they have thought of any measures to correct this aspect which affects the measure using the instrument.</i></p>	<p>We thank the reviewer for this comment. Internal consistency of the Care coordination scale was indeed relatively low, indicated by a Cronbach's alpha of .68. Given that this scale consists of only five items and knowing that the number of items affects Cronbach's alpha, we believe this is still acceptable, as it is just below the boundary that George and Mallory (2003) provide as a rule of thumb for an acceptable alpha (.70). Nevertheless, we agree with the reviewer that this issue needs to get more attention in the paper. The rather low alpha of this scale is caused by the item Q10 (Information to self-manage), which has a factor loading of only 0.20 on the Care coordination dimension (and 0.73 on the Person-centredness scale). In the original validation study, this question loaded on both factors (0.63 on the Person-centredness dimension and 0.32 on the care coordination dimension). Though also in that study the question seemed to be more related to other questions capturing the person-centredness dimension, it was decided to keep all (three) questions that loaded on both factors in both scales. The rationale for keeping Q10 in both scales is that person-centredness and care coordination are considered overlapping constructs, as care coordination is a key feature of person-centred care. This is why the concept of P3C (Person-Centred Coordinated Care) includes both dimensions. We now discuss this in the Discussion section (page 14, lines 19-37).</p>
<p><i>Presenting 3 decimals in the text (twice) I think it could be left at 2.</i></p>	<p>We have rounded the two 3-decimal factor loadings mentioned in the text (Discussion section, page 14, lines 17 and 19).</p>
<p><i>I think the discussion could include comparisons of these results with studies both within and outside Europe.</i></p>	<p>We added two studies to compare our results with, one from Australia (reference 45) and another from the Netherlands using a dataset from a large number of studies (reference 46). As we had already included several studies in the previous draft to compare our findings regarding gender and SES with, the newly added studies focus on whether care experiences of people differ according to their age (page 15, lines 34-41) and health (number of chronic condition, self-reported health) (page 16, lines 39-41). Given that the Discussion</p>

	section was already lengthy and that we had already 50 references in the previous draft manuscript (now 55), we believe it is better not to add any more.
<i>Although implications for practice are cited in the conclusions, these could be developed in the discussion section.</i>	We have added a short paragraph ‘Implications for policy and practice’ in the Discussion section (page 18 line 59 to page 19 line 17). Furthermore, we revised some sentences of the conclusion, to better align with this new paragraph (page 19, lines 37-46).
<p>Reviewer 2: <i>This paper provides a well-presented and interesting account of the validation of the Dutch version of the P3CEQ measure and the assessment of person-centred care and coordinated care of people with chronic conditions and is written to a high standard.</i> <i>This was an enjoyable paper to read and review and it appears to be very relevant to the journal aims. I found only one comment to make about the paper overall.</i> <i>The Introduction is well explained with a helpful and relevant description of the background to the subject matter and contains very clear Research questions and hypotheses. The method section also provides a clear description of how the study was undertaken and analysed. The Results describe the outcomes in a clear manner, consistent with the Research questions and hypotheses and the accompanying tables are well presented. The Discussion gives a useful summary of the findings and its relevance to other research and the Conclusion section provides implications for health care professionals.</i></p>	
<p>Comments reviewer 2: <i>I have no further comment to improve the paper save one suggestion, that on page 19 line 410 the authors add what PaRIS stands for in full to aid the reader with this acronym.</i></p>	<p>We thank the reviewer for her/his positive evaluation of our paper. In the revised manuscript we now provide the official name of the PaRIS survey in full (page 18, line 43/44). For your information: Some years ago, the OECD used the name ‘Patient Reported Indicators Survey’, which explains the abbreviation ‘PaRIS’, but later the OECD felt it better not to use the word ‘patient’ anymore. This is why the official name is now ‘International Survey of People living with Chronic Conditions’, whereas the abbreviation PaRIS is still used.</p>