Questionnaire

‘Perceived control in health care’
**Explanation**

This questionnaire is about the extent to which you feel that you are in control, while using health care.

**Health care:**

‘Using health care’ means that you have received care from one or more of the following health caregivers, during the past year:

- General Practitioner
- medical specialist
- homecare (domestic help, personal care, nursing care)
- other caregivers (such as physiotherapist, nurse, physician assistant / assistant practitioner, dietitian, dentist etc.)
- informal caregiver (meaning that you receive regular help or care from people close to you)

**Control:**

With control we refer to ‘the feeling that you are in control of different situations that are related to the care that you receive’.

For example, that you can arrange the care that you need (with or without help from others), that you can deal with the medication that your healthcare professional(s) prescribed to you, or that you can indicate any wishes you have to your caregivers.
Part A – General questions

Instruction:

Included below are a number of statements. Please indicate for each statement to what degree you feel that is applicable to you, by rating it from 0 (not at all) to 10 (completely). You can do so by putting a cross in the box that best describes your situation.

1. In general I am able to keep control of my health care

☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

(not at all) 0 1 2 3 4 5 6 7 8 9 10 (completely)

2. In general I feel I can get enough support from people close to me (for example from my partner, family, relatives, neighbours or friends) for my health or care situation, should it be necessary

☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

(not at all) 0 1 2 3 4 5 6 7 8 9 10 (completely)

3. At the moment, control of my care falls largely on:

Please note: only one answer allowed!

Myself ☐
My family/relatives/ friends/neighbours ☐
Myself and family/relatives/friends/neighbours, both in equal measure ☐
Someone else, i.e. ........................................................................................................

4. I feel it is important to stay in control of my care as much as possible

☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

(not at all) 0 1 2 3 4 5 6 7 8 9 10 (completely)
Part B – Specific questions

Instruction 1

In this part we provide a number of statements again. Please indicate for each of them to what degree you feel that is difficult / easy for you, regardless of whether or not you receive help from the people close to you!

1. = not, or with great difficulty
2. = with difficulty
3. = not difficult, not easy
4. = with ease
5. = with great ease

Please encircle the answer that comes closest to your situation.

Instruction 2

Please think back over the past year when answering the questions about your experiences with health care.

When you think back on diverse or contradicting situations for a particular statement, please follow your general (average) impression.
Part b (1) – Organising professional health care

Please note!: With professional care we refer to care from the General Practitioner, medical specialist, formal homecare professionals (domestic help, personal or nursing care), or from other professionals such as physiotherapist, physician assistant, dietitian etc.

1. = not, or with great difficulty
2. = with difficulty
3. = not difficult, not easy
4. = with ease
5. = with great ease

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<tr>
<td>5.</td>
<td>I know when it is time to call in care…………………………………</td>
<td>1</td>
<td>2</td>
<td>3</td>
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(for example decide when to visit the GP/family doctor, or return to therapist, specialist)

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<tr>
<td>6.</td>
<td>I can find information about health or care when I need it…………</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>7.</td>
<td>I will find out if there are any aids or services I could really use …</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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(examples of aids and services are: rollator, scooter, meal services, taxi services, but also home care services)

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<tr>
<td>8.</td>
<td>I know where to apply for care, aids or services ................</td>
<td>1</td>
<td>2</td>
<td>3</td>
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(such as home care, rollator, scooter, meal services, taxi services)

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<tr>
<td>9.</td>
<td>I am able to arrange any care, aids or services I need…………</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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(for example make phone calls, submit applications)

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<tr>
<td>10.</td>
<td>I understand the regulations of care organisations that are relevant for me……………………</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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(such as the regulations of home care services, hospital, health insurance company)

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<tbody>
<tr>
<td>11.</td>
<td>I can manage to get to my healthcare professional(s) when I need to……………………</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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(for example use own transportation, use public transportation, walk, other people take you there or collect you, or the care professional visits you)

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<tr>
<td>12.</td>
<td>I can keep track of all appointments with my healthcare professional(s)……………………</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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(for example the date of follow-up appointment or other appointments)
### Part b (2) – In contacts with your healthcare professional(s)

**Please note:** With professional care we refer to care from the General Practitioner, medical specialist, formal homecare professionals, or from other professionals such as physiotherapist, nurse, dietitian etc.

When receiving care from more than just one healthcare professional, please give your overall impression. It is important that you rate your own abilities in general.

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<tbody>
<tr>
<td>1.</td>
<td>= not, or with great difficulty</td>
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<tr>
<td>2.</td>
<td>= with difficulty</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>= not difficult, not easy</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>4.</td>
<td>= with ease</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td>= with great ease</td>
<td></td>
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</table>

13. I explain what is going on to my healthcare professional(s) …
   1. 2. 3. 4. 5

14. I ask any questions I have about my health or treatment …
   1. 2. 3. 4. 5

15. I indicate any wishes I have *(for example regarding the treatment, care or help I am receiving).* …
   1. 2. 3. 4. 5

16. If I feel the care situation is not satisfactory, I will stand up for myself …
   *(for example confront your care professional or the organisation when you feel they have made a mistake or they have treated you unfairly)*
   1. 2. 3. 4. 5

### Part b (3) – Taking care of yourself in your home situation

17. I can deal with the medication I am prescribed by my healthcare professional(s) *(pills, ointments, injections etc.)* …
   1. 2. 3. 4. 5
   *not applicable, I do not use medication* …
   na

18. I am able to carry out the recommendations I am prescribed by my healthcare professional(s) *(such as diet, movement, exercises)* …
   1. 2. 3. 4. 5
   *not applicable, I do not receive recommendations* …
   na

19. I do what is necessary to maintain my health as much as possible …
   1. 2. 3. 4. 5

20. I generally adapt to setbacks in my health or my care situation …
   *(for example accept situations that cannot be changed, demand a little less of yourself, or rest more etc.)*
   1. 2. 3. 4. 5
Part b (4) – If you need (more) complex care in the future

Please note!
With (more) complex care we refer to a combination of personal and/or nursing care at home with additional domestic or practical help. Also you can think of the transition from living independently to living in a care/nursing home.

1. = not, or with great difficulty
2. = with difficulty
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4. = with ease
5. = with great ease

21. I expect to be able to determine the right moment that I will need (more) complex care ................................................................. 1 2 3 4 5

22. When I need (more) complex care, I expect to participate in the decision which care this should be ........................................ 1 2 3 4 5

23. When I need (more) complex care, I expect to have a financial solution..................................................................................... 1 2 3 4 5
(apart from sufficient income, a supplementary reimbursement of healthcare costs or a Personal Health Budget also count as solutions; the point is that you experience a solution is available)

24. In order to retain control in the event that my mind deteriorates, I can make the appropriate preparations before this happens ...... 1 2 3 4 5
(for example record your wishes in writing or inform the people close to you of your wishes, for example regarding home help, care/nursing home, end-of-life wishes)
Part b (5) – Help from your family/friends/neighbours

Please note!
The questions you answered so far were about the control that you experienced over your care, with or without help from others.

Now we wish to focus, in particular, on the help from others, such as help from people close to you. For example: to what degree do you feel you can fall back on them, and do you accept their help?

With people close to you we refer to: your partner, family, relatives, neighbours, friends, etc.

1. = not, or with great difficulty
2. = with difficulty
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25. If I need help in and around the house, I can fall back on people close to me………………………………………………………………………………………………………………. (for example assistance with paperwork, household, transportation, but also personal care)

26. If I need help to get professional care (for example help arranging care, visiting a doctor together) I can fall back on people close to me……………………………………………………………………………………………………………….

27. When I am alone and I find myself in an emergency situation (for example suddenly becoming unwell or falling) I can fall back on an emergency plan……………………………………………………………………………………………………………….

28. I ask people close to me for help when I need it………………. 1 2 3 4 5

not applicable, I have no family or other people close to me……….. na

29. I participate in the decision what happens when I get help from people close to me……………………………………………………………………………………………………………….

not applicable, I don’t receive help from family/people close to me… na

THANK YOU VERY MUCH FOR YOUR COOPERATION!