

Appendix A

Questionnaire

You can fill in the questionnaire, if you:

- Have one or more chronic diseases and
- Take medications for chronic diseases, prescribed by a general practitioner, medical specialist, or a nurse prescribed longer than 3 months ago or
- Are an informal caregiver of a person who meets the above mentioned criteria.

If you are an informal caregiver, please fill in the questions from the perspective of the persons for which you give support in the medication.

Thank you for your interest.

Questions

Part one. Current medication use

Hereafter you find two questions concerning your current medications prescribed by a general practitioner, medical specialist, or a nurse.

1 How often do you take medication?

- Every day
- Once per week or more often
- Less than once per week

2 How many different prescription medications do you use?

- One
- Two-three

- Four-five
- Six-ten
- Eleven or more

Part two. Support for medication adherence management

3 Do you get support in medication use by (one of your) loved ones (for example your partner or child[ren])?

- Yes, always
- Yes, often
- Yes, some-times
- No

4 Do you get support by a home care nurse?

- Yes
- No

5 Do you get support in medication use (for example preparing, or ordering medication) by a home care nurse?

- Yes
- No

6 Which positive experiences do you have concerning home care nurses' support in medication use?

7 Which negative experiences do you have concerning home care nurses' support in medication use?

8 What need to be changed in home care nurses' support for medication use?

9 Please indicate for each of the following types of support if you receive the support. If you don't receive the support, you can indicate whether you desire the support.

	Yes, I receive this support by a home care nurse	No, I don't receive this support by a home care nurse and I don't need it	No, I don't receive this support by a home care nurse but I need it
Regularly asking questions about problems with medication use	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Regularly asking if I am concerned about my medications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Regularly asking whether I have taken my medication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Noticing when I don't take medication as prescribed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Helping me to remember when I should use my medication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Helping me to find solutions to overcome problems with using medications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Helping me with medication taking (e.g. opening packages)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Clearly explaining how and when I should use my medicines	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Explaining the importance of taking medication at the right moment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Regularly discussing how I feel about managing medication use	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Regularly making agreements about managing medication use	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Asking questions to check if I correctly understood nurses' information about proper medication usage	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Arranging extra support for correct medication usage (if I want to)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Engaging a relative/informal caregiver for discussing medication usage and determining agreements about medication usage	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10 On a scale from 0 (very dissatisfied) to 10 (very satisfied), how satisfied are you with home care nurses' support in medication use?

1	2	3	4	5	6	7	8	9	10
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Part three. Socio- and demographic questions

11 What is your gender?

- Female
- Male

12 What is your country of birth?

<input type="checkbox"/> Nederland	<input type="checkbox"/> Duitsland
<input type="checkbox"/> Suriname	<input type="checkbox"/> Groot-Brittannië
<input type="checkbox"/> Nederlandse Antillen	<input type="checkbox"/> België
<input type="checkbox"/> Indonesië	<input type="checkbox"/> Polen
<input type="checkbox"/> Turkije	<input type="checkbox"/> Overig, namelijk...

<input type="checkbox"/> Marokko	
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13 What is your mother's' country of birth?

<input type="checkbox"/> Nederland	<input type="checkbox"/> Duitsland
<input type="checkbox"/> Suriname	<input type="checkbox"/> Groot-Brittannië
<input type="checkbox"/> Nederlandse Antillen	<input type="checkbox"/> België
<input type="checkbox"/> Indonesië	<input type="checkbox"/> Polen
<input type="checkbox"/> Turkije	<input type="checkbox"/> Overig, namelijk...
<input type="checkbox"/> Marokko	

14 What is your father's' country of birth?

<input type="checkbox"/> Nederland	<input type="checkbox"/> Duitsland
<input type="checkbox"/> Suriname	<input type="checkbox"/> Groot-Brittannië
<input type="checkbox"/> Nederlandse Antillen	<input type="checkbox"/> België
<input type="checkbox"/> Indonesië	<input type="checkbox"/> Polen
<input type="checkbox"/> Turkije	<input type="checkbox"/> Overig, namelijk...
<input type="checkbox"/> Marokko	

15 What is your date of birth?

_____ [Day-month-year]

16 Which chronic diseases do you have?

- Asthma/COPD
- Rheumatic disease

- Lower gastrointestinal disorder
- Diabetes mellitus
- Cardiovascular disease
- Cancer
- Physical limitation
- Upper gastrointestinal disorder
- Psychological disorder
- Mental disorder
- Other, namely

17 What is your living situation?

- Living with a partner or other family member
- Living with roommates
- Living alone
- Other, namely

18 Do you have children?

- Yes, they live at my home
- Yes, they live not at my home
- Yes, some live at my home and some not
- No

18 Please indicate your health insurance company.

<input type="checkbox"/> Aevitae	<input type="checkbox"/> HollandZorg	<input type="checkbox"/> Promovendum
<input type="checkbox"/> Anderzorg	<input type="checkbox"/> Interpolis	<input type="checkbox"/> Salland Zorgverzekeringen

<input type="checkbox"/> Aon	<input type="checkbox"/> InTwente	<input type="checkbox"/> StadHolland
<input type="checkbox"/> Averro Achmea	<input type="checkbox"/> IZA	<input type="checkbox"/> UMC
<input type="checkbox"/> AZVZ	<input type="checkbox"/> IZZ zorgverzekering (VGZ voor de zorg)	<input type="checkbox"/> UnitedConsumers
<input type="checkbox"/> Besured	<input type="checkbox"/> Menzis	<input type="checkbox"/> Univé Verzekeringen
<input type="checkbox"/> Bewuzt	<input type="checkbox"/> National Academic	<input type="checkbox"/> Vanbreda Risk & Benefits
<input type="checkbox"/> CZ	<input type="checkbox"/> Nationale-Nederlanden	<input type="checkbox"/> VGZ
<input type="checkbox"/> CZdirect	<input type="checkbox"/> OHRA	<input type="checkbox"/> VvAA
<input type="checkbox"/> De Amersfoortse	<input type="checkbox"/> ONVZ	<input type="checkbox"/> ZEKUR
<input type="checkbox"/> De Friesland	<input type="checkbox"/> OZF	<input type="checkbox"/> Ziezo
<input type="checkbox"/> Ditzo	<input type="checkbox"/> PlusGezond	<input type="checkbox"/> Zilveren Kruis
<input type="checkbox"/> DSW	<input type="checkbox"/> PMA Zorgverzekering	<input type="checkbox"/> Zorg en Zekerheid
<input type="checkbox"/> FBTO	<input type="checkbox"/> PNOzorg	<input type="checkbox"/> ZorgDirect
<input type="checkbox"/> FLKS	<input type="checkbox"/> PolitieZorgpolis	<input type="checkbox"/> Don't have an insurance
<input type="checkbox"/> Hema	<input type="checkbox"/> Pro Life	<input type="checkbox"/> Other, namely

19 In which province do you live?

- Drenthe
- Flevoland
- Friesland
- Gelderland
- Groningen
- Limburg
- North Brabant
- North Holland

- Overijssel
- Utrecht
- Zeeland
- South Holland

20 What is the highest degree or level of school you have completed?

- Primary education
- Lower and upper secondary education and vocational education
- Bachelor's degree or higher

21 Do you want to participate in an interview study?

- Yes
- No

The end of the questionnaire

Appendix B

Interview guide

The start of the interview

Explain the purpose of the interview to the participant.

Explanation: I'm going to ask you ask you questions concerning home care nurses' support for medication adherence. Questions are for example about your experiences with the support of the nurses in ordering medications or reminding you to take medications.

One year ago, you have completed an online questionnaire of the Netherlands Patients Federation. You have indicated that you get support of a home care nurse. This interview is about the support of the nurse.

The interview takes about 30 minutes and if you consent, I record the interview. I will treat your information as confidential shall. The information can't be traced to you as a person. I will remove the audio record as soon as the interview has been transcribed. If any questions are not clear or if you don't want to answer a questions, don't hesitate to indicate this.

Do you have any questions?

Interview questions

Part one. Questions concerning experiences support by home care nurses

1 Introduction question:

Do you still have support in the medication therapy by a home care nurse?

Further questions for participants who indicates that they receive support by a home care nurse:

- a. Which support do you get and how many times per week?
- b. Did you get any extra support in the last one and a half year?
If yes, which extra support do you receive, when and by whom?
- c. What are your experience about the support?

If any positive experiences:

- Can you explain why this is a positive experience?
- Can you indicate more positive experiences?

If any negative experiences:

- Can you explain why this is a negative experience?
- Do you have an idea how this can be improved?

Further questions for participants who indicates that they do not receive support any more by a home care nurse:

Can you explain more:

- a. Which support did you received and till when?
- b. How many times per week did you receive support?
- c. What is the reason you don't get support anymore?

(Explore whether the support is not needed anymore, or has been taken over by another person [e.g. family member] or support has been stopped but is still needed).

d. What was your experience about the support?

If any positive experiences:

- Can you explain why this is a positive experience?
- Can you indicate more positive experiences?

If any negative experiences:

- Can you explain why this is a negative experience?
- Do you have an idea how this can be improved?

If yes, can you give an example?

2 Introduction question:

Do you need (extra or again) support with the use of your medications?

Further questions:

- a. Can you indicate which extra support by a home care nurse you desire?
- b. How many times per week or month do you want to receive this support?
- c. Can you indicate why you don't have this extra support yet?

Part two. Questions concerning improvements in support by home care nurses

3. Introduction: We have read in the questionnaire data of last year that a couple of patients desire improvements in medication support by home care nurses.

I will read the improvement and ask afterwards if you have also these experiences.

The improvements are: more frequent discussion with a home care nurse about the medication, more time during home visits for medication support, providing more information/knowledge of medication (e.g. what side effects can be expected), cleaning skin plaster residue, perform the nursing care (e.g. cleaning nebulizing equipment in the same way) in the same way, and involve an informal caregiver when medication tasks has to be performed.

Introduction question:

Does some of these experience sounds familiar to you?

If yes, further questions:

a. Can you explain more about it, do you have an example?

b. What does that mean to you?

c. Do you have an idea how this can be improved?

If yes, can you give an example?

d. Summarize all information, ask the participant if he want to add information, and indicate that there are a few questions left.

If not, summarize all information, ask the participant if he want to add information, and indicate that there are a few questions left.

Part three. Socio- and demographic questions

4 What is your gender?

Male

Female

5 What is your age?

----- years.

6 What is the highest degree or level of school you have completed?

Primary education

Lower and upper secondary education and vocational education

Bachelor's degree or higher

7 What is your living situation?

- Living alone
- Living with a partner or other family member

8 How many prescription medications do you use?

..... prescription medications.

The end of the interview

Thank the participant for participation and information.