

## Your use of information and communication technologies

This section explores how you use information and communication technologies (ICT) in your daily and professional life. There are a total of 5 questions in this section.

The following definitions are being used in this survey:

**ICTs:** A product intended to fulfill or enable the function of information processing and communication by electronic means including transmission and display

**PC/laptop:** can be a desktop computer, laptop, netbook or a tablet PC

**Handheld devices:** mobile phone, smart phone (e.g. iPhone, BlackBerry), tablet/slate device (e.g. iPad).

**Collaboration:** working or learning with other individuals to achieve a task. Includes activities like organizing meetings and building relationships.

1. In your **personal life** indicate which of the following technologies you have used in the last 6 months and where applicable which device you used them on. *Select all that apply.*

	Used	Not Used	
Messaging (SMS or text messaging, Blackberry Messaging)	<input type="checkbox"/>	<input type="checkbox"/>	
<b>For the following tools also indicate which device was used</b>	Used on Desktop/laptop computer	Used on handheld device	Not Used
Email/email lists (email mailing lists)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Secure internet messaging	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Message boards (web pages to list questions and view answers)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Chat services (e.g. MSN messenger, Google Talk)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social Networking sites (e.g. Facebook)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Blogs and microblogs (e.g. twitter)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Internet based voice calls (e.g. Skype, Google Talk)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Video sharing (e.g. YouTube)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Web or video conferencing (e.g. Skype)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Wikis (e.g. Wikipedia)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. In the last 2 months have you used Telephone calls (e.g. calls on a landline, cell phone) to **collaborate (includes learning) or interact with health care staff (mentors and mentees included)?**

Yes

No

If you answered No go to question 3 otherwise complete 2 a, b and c.

a. In the last 2 months how do you make telephone calls to any members of health care staff (select all that apply)

- Fixed line conventional phone
- Cellular/mobile phone service

b. In the last 2 months how often have you used telephone calls to collaborate and interact with the members of health care staff?

- Several times a day       About once a day       3-5 days/week
- 1-2 days/week       Every few weeks

c. For which of the following purposes do you use telephone calls when collaborating and interacting with the members of health care staff (select all that apply)

- Communicate to set up face to face meetings
- To discuss health care related issues
- Communicate with health care staff administration (e.g. about meetings)
- To build relationships with health care staff members
- Other uses

**3. In the last 2 months how often have you interacted with health care staff? Select one.**

Once a day or more often	Once a week up to once a day	1-3 times/month	Less often	None
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**4. Indicate which of the following technologies that *you are not already using* which might be interesting to you to communicate with health care staff. Select all that apply**

	Already using		Not using	
		Interested	Not Interested	Do not know enough about this tool
Messaging (e.g. SMS)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Email/ email lists (e.g. LISTSERV)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Secure internet messaging	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Message boards	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Chat services (e.g. MSN messenger)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social Networking sites (e.g. Facebook)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Blogs and microblogs (e.g. Twitter)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Voice calls (e.g. Skype)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Video sharing (e.g. YouTube)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Web/video conferencing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Wikis (e.g. Wikipedia)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**5. What things do you think influence you the most to use technologies with health care staff?**

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**End of the survey  
Thank you!**

## **Experiences with dialysis**

**Questionnaire for peritoneal dialysis and  
haemodialysis patients who are dialysed at home**

1. **How are you dialysed?**  
 Home hemodialysis  
 Peritoneal dialysis
2. **How long have you been on dialysis?**  
please indicate below:

\_\_\_\_\_

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### **Nephrologist**

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The questions below are about your experiences with your nephrologist from the dialysis centre over the past year.

3. **How often does your nephrologist explain things to you in an understandable way?**  
 never  
 sometimes  
 usually  
 always
4. **Does your nephrologist give you information so you can take part in decisions on your treatment?**  
 never  
 sometimes  
 usually  
 always
5. **How often does your nephrologist give you information that conflicts with information from other healthcare providers\*?**  
 never  
 sometimes  
 usually  
 always
6. **How often does your nephrologist listen attentively to you?**  
 never  
 sometimes  
 usually  
 always
7. **How often does your nephrologist take you seriously?**  
 never  
 sometimes  
 usually  
 always
8. **How often does your nephrologist treat you with courtesy?**  
 never  
 sometimes  
 usually  
 always
9. **How often does your nephrologist spend enough time on you?**  
 never  
 sometimes  
 usually  
 always
10. **Does your nephrologist give you the chance to take part in decisions about your treatment?**  
 never  
 sometimes  
 usually  
 always
11. **Does your nephrologist ask about your medication use?**  
 never  
 sometimes  
 usually  
 always
12. **Does your nephrologist spend time and attention on physical complaints?**  
 never  
 sometimes  
 usually  
 always  
 n/a
13. **Is it possible to make an additional appointment with your nephrologist?**  
 never  
 sometimes  
 usually  
 always  
 I don't know/no experience
14. **Does your nephrologist refer you to other specialists in a timely manner?**  
 never  
 sometimes  
 usually  
 always  
 I don't know/no experience

**15. Give your overall assessment of your nephrologist below?**

- 0 *worst possible nephrologist*
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10 *best possible nephrologist*

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**Nurses**

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The questions below are about your experiences with your nurses from the dialysis centre over the past year.

**16. Do your nurses explain things to you in an understandable way?**

- never
- sometimes
- usually
- always

**17. Do your nurses give you conflicting information?**

- never
- sometimes
- usually
- always

**18. Do the nurses take you seriously?**

- never
- sometimes
- usually
- always

**19. Do the nurses encourage you to do things yourself?**

- never
- sometimes
- usually
- always

**20. Do you know who your lead nurse\* is?**

- yes
- no, *proceed to question 22*

**21. Do you have contact with your lead nurse during every outpatient clinic visit?**

- never
- sometimes
- usually
- always

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**Social worker**

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The questions below are about your experiences with the social worker from the dialysis centre over the past year.

**22. Does your social worker explain things to you in an understandable way?**

- never
- sometimes
- usually
- always
- n/a, no social worker

**23. Does the social worker take you seriously?**

- never
- sometimes
- usually
- always
- n/a

**24. Do you feel that the social worker helps you?**

- never
- sometimes
- usually
- always
- I don't know/no experience

**25. Can you make an appointment with the social worker on short notice if you want to speak with him/her?**

- never
- sometimes
- usually
- always
- I don't know/no experience

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## Dietician

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The questions below are about your experiences with the dietician from the dialysis centre over the past year.

**26. Does your dietician explain things to you in an understandable way?**

- never
- sometimes
- usually
- always
- n/a, no dietician

**27. Does your dietician give you information on your diet that you must follow?**

- never
- sometimes
- usually
- always
- n/a, no dietician

**28. Does the dietician take you seriously?**

- never
- sometimes
- usually
- always
- n/a

**29. Can you make an appointment with the dietician on short notice if you want to speak with him/her?**

- never
- sometimes
- usually
- always
- n/a, no dietician

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## Cooperation

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The questions below are about the cooperation between different healthcare providers from the dialysis centre over the past year.

**30. Have you been affected by insufficient cooperation between healthcare providers at the dialysis centre?**

- never
- sometimes
- usually
- always

**31. Have you been affected by insufficient cooperation between your medical specialists (nephrologist and other specialists)?**

- never
- sometimes
- usually
- always
- n/a

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## Dialysis centre

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The questions below are about the dialysis centre and your experiences with it over the past year.

**32. Do you receive information on the examinations you must undergo?**

- never
- sometimes
- usually
- always

**33. Do you receive the results of the examinations you have undergone within the agreed time period?**

- never
- sometimes
- usually
- always
- n/a, no time agreed

**34. Do you receive information from the dialysis centre on the options for a kidney transplant?**

- yes
- no
- n/a

**35. Have you been informed that, because of your physical condition, you may be (temporarily) taken off the transplant waiting list?**

- yes
- no
- n/a

**36. Do you receive information so can tell your employer/educational institution about your dialysis?**

- yes
- no
- n/a

37. Do you receive information if there is a change in the organisation of the dialysis centre?

- yes
- no
- n/a

38. Do you receive information on options for dialysis during holidays?

- yes
- no
- n/a

39. Do you receive information on the activities of the local patients' association\*?

- never
- sometimes
- usually
- always
- n/a, no local patients' association

40. Do you receive information on the activities of the national patients' association\*?

- never
- sometimes
- usually
- always

41. In your experience, do the employees of the dialysis centre treat your patient data as confidential?

- never
- sometimes
- usually
- always
- I don't know/no experience

42. If you had peritonitis, were you helped quickly at that time?

- yes
- no
- n/a

43. Did the dialysis centre inform you about the complaint procedure?

- yes
- no

44. If you submitted a complaint, was it dealt with within 3 months?

- yes
- no
- n/a, no complaint submitted

45. Are appointments times for examinations scheduled in consultation with you?

- never
- sometimes
- usually
- always

46. Did you receive any accessory equipment at the start of your home dialysis (stand, thermal case, etc.)?

- yes
- no

47. Can the dialysis centre be reached by phone during business hours?

- never
- sometimes
- usually
- always
- I don't know/no experience

48. Can the dialysis centre be reached by phone outside of office hours for urgent matters?

- never
- sometimes
- usually
- always
- I don't know/no experience

49. Can you park your car near the dialysis centre?

- never
- sometimes
- usually
- always
- n/a

50. Below, give your overall assessment of your dialysis centre, 0 being the worst possible dialysis centre and 10 the best possible dialysis centre.

- 0 *worst possible dialysis centre*
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10 *best possible dialysis centre*



51. **Would you recommend this dialysis centre to other dialysis patients?**

- definitely not
- probably not
- probably
- definitely

**What would you like to change about the dialysis centre where you are dialysed or that supervises your home dialysis?**

(What could be better? Are there things that you need? What could change, or should work differently?)

52. **Can you reach the dialysis centre within half an hour by public transport?**

- yes
- no
- I don't know/no experience

### **Additional questions on Predialysis**

**Predialysis** is the period that precedes the dialysis, in which the patient is prepared for the dialysis. The questions below are about the predialysis phase.

53. **Over the past year, have you gone through the predialysis phase in The Capital District Renal Clinic at the QEII site?**

- yes
- no

54. **Did you receive information for choosing between the different forms of dialysis?**

- yes
- no

55. **Did you receive information on the different forms of kidney transplants?**

- yes
- no

56. **Were you given time to process all of the information?**

- yes
- no

57. **Medical problems related to the dialysis may arise. Did you receive information about this?**

- yes
- no

58. **Did you receive information on the equipment that is used in the dialysis?**

- yes
- no

59. **Did you receive information on the impact of dialysis on your day-to-day life?**

- yes
- no

60. **Were you informed about hygiene for dialysis?**

- yes
- no

61. **Did you receive information on the supply of dialysis fluid and the quantity of waste materials?**

- yes
- no
- n/a

62. **Were employees of the dialysis centre attentive to you during the predialysis phase?**

- never
- sometimes
- usually
- always

63. **Were employees of the dialysis centre attentive to your partner (or relative) during the predialysis phase?**

- never

- sometimes
- usually
- always
- n/a

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**About you**

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The questions below are **about you**. This information will be used to gain insight into the experiences of different groups of people (such as men and women).

**64. What is your highest level of education completed? (completed with a diploma or adequate certificate)**

- no education (no primary education, or primary education not completed)
- Primary education (primary school, or special primary education or secondary education not completed)
- Secondary education (high school education or post secondary education not completed)
- Post secondary education (college or university education)
- Post graduate education
- other, please indicate below:


**65. In general, how would you describe your health?**

- excellent
- very good
- good
- moderate
- poor

**66. What language do you speak the most at home?**

- English
- French
- Other, please indicate below:

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

**67. Did anyone help you complete this questionnaire?**

- yes → *If so: go to question 69*

- no

**68. Who helped you complete the questionnaire?**

- (more than one answer possible)*
- my partner/family member/housemate
  - a relative
  - my helper
  - another social/relief worker
  - someone else .....

**69. How did this person help you?**

- (more than one answer possible)*
- Read the questions out to me
  - Crossed my responses
  - Answered the questions for me
  - Translated the questions into my language
  - Helped in another way, please indicate below:

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**70. How do you travel to the QEII renal clinic/dialysis unit?**

- (more than one answer possible)*
- Public Transit System
  - Access-A-Bus services
  - Drive
  - Pick up and drop off by Capital health employ
  - Pick up and drop off by friend or family
  - Walk
  - Other, please indicate below:

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

**71. On average per day, how much time do you spend travelling to and from the QEII renal clinic/dialysis unit?**

- Less than 30 mins
- 30 mins to 1hr
- 1 hr or more
- 2 hrs or more
- 3 hrs or more
- 4 hours or more

**72. What city do you live in currently?**

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**Many thanks for completing the questionnaire!**

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## **Explanatory glossary**

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### **Anonymously**

You do not need to give your name. Your responses will not be associated with you personally. Therefore, neither the employees in the dialysis centre nor anyone else will know what responses you gave.

### **APD (Automatic Peritoneal Dialysis)**

In automatic peritoneal dialysis (APD), the dialysis fluid is refreshed using a device (cycler). This is usually done at night. If the patient keeps fluid in the abdomen during the day, this is called continuous cycling peritoneal dialysis (CCPD). If the abdomen remains empty during the day, this is called nocturnal peritoneal dialysis (NPD).

### **CAPD (Continuous Ambulatory Peritoneal Dialysis)**

With Continuous Ambulatory Peritoneal Dialysis (CAPD) the dialysis fluid is refreshed manually. This is usually done four or five times a day.

### **Hemodialysis (HD)**

Dialysis method that uses an artificial kidney. This is usually done in a dialysis centre, but this treatment can also be performed at home.

### **Healthcare providers**

Persons that you receive care from. This includes, for instance, nurses, nephrologists, other specialists, the social worker and the dietician.

### **Lead nurse**

The lead nurse is also known as an 'EVV'er in the Netherlands. The lead nurse is the patient's personal supervisor and the primary point of contact.

### **Local patients association**

An association for persons suffering from the same condition and who are treated in a particular centre or region.

### **National patients association**

A national association for persons suffering from the same illness. For kidney patients in the Netherlands, this is the Nierpatiënten Vereniging Nederland (NVN).

### **Peritoneal Dialysis (PD)**

In this dialysis treatment, the abdominal lining (peritoneum) is used as an 'artificial kidney'. For this, the patient lets dialysis fluid flow into the abdominal cavity through a small tube placed in the abdomen. This fluid is refreshed regularly.

### **Predialysis phase**

This is the period preceding the kidney replacement therapy. During this period, the patient is prepared for dialysis or kidney transplant.

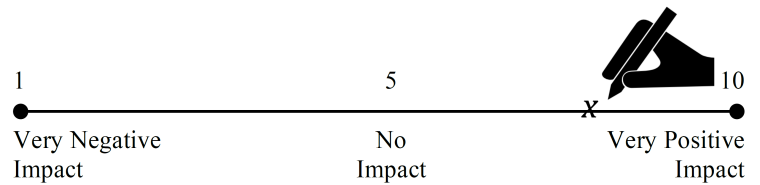
### **Quality aspects**

Matters related to the quality of care that you receive in the dialysis centre.

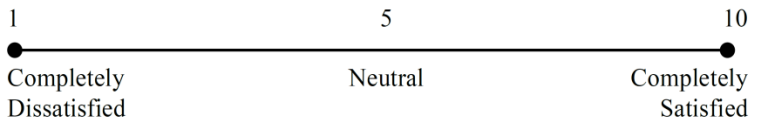
## Self-Efficacy Questionnaire

Please mark an 'x' on the line connecting 1 to 10 to show your responses.

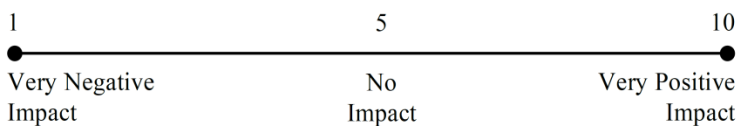
**Example:**



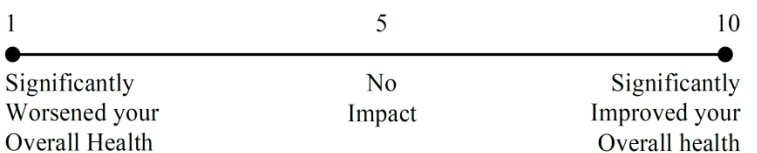
10. Please rate your **Overall Satisfaction** with the communication portal (CP):



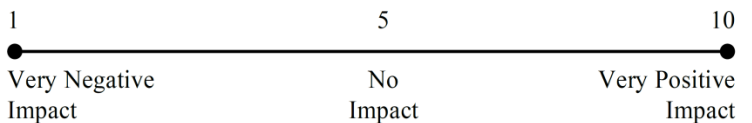
11. The impact the communication portal had on your **chances of needing (re)admission to the hospital** was:



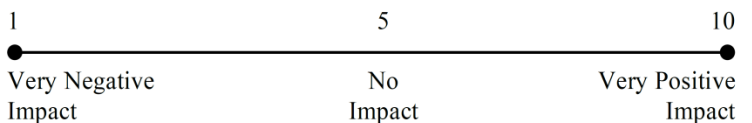
12. The impact of the CP had on your **overall health** was:



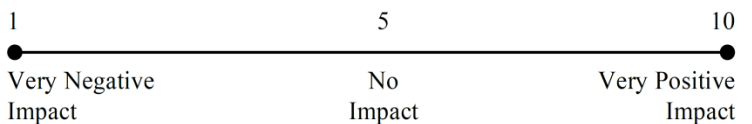
13. The impact of the CP on **helping you understand which medications to take, correct doses, and when to take them** was:



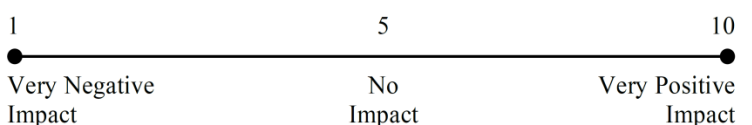
14. The impact of the CP on **helping you with technical aspects of dialysis** (dialysis machine, alarms, water system) was:



15. The impact of the CP on **helping you get appointments with specialist doctors** was:

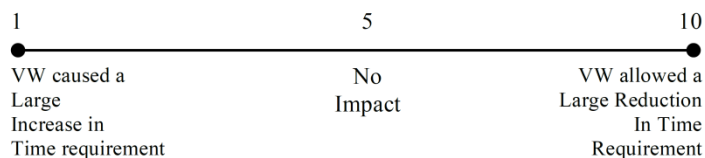


16. The impact of the CP on **helping you access or get to speak to your kidney specialist** was:

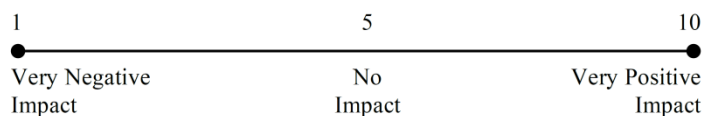


## Self-Efficacy Questionnaire

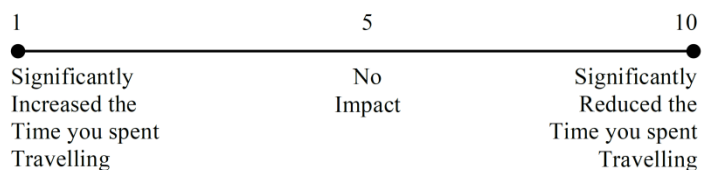
17. The impact of the CP on **helping to minimizing the overall time spent managing your medical conditions** was:



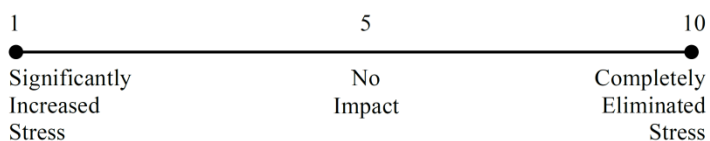
18. The impact of the CP had on **your personal privacy** was:



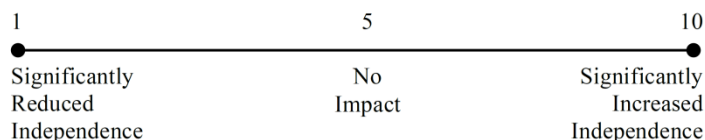
19. The impact of the CP on **time spent travelling to get dialysis-related care** was:



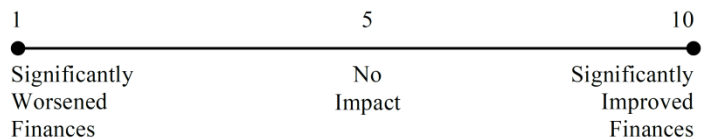
20. The impact the CP had on the **stress related to performing home dialysis**:



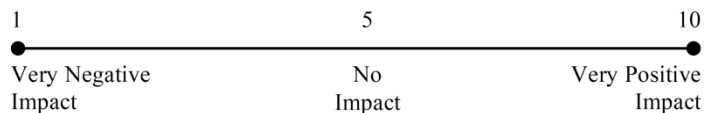
21. The impact the CP had on **your personal Independence** was:



22. The impact the CP had on **your personal finances** was:



23. The impact the CP had on **your mood** was:



## Self-Efficacy Questionnaire

24. Please rate how well you agree or disagree with the following statement:

**If you are currently on home dialysis**

(peritoneal dialysis or home hemodialysis)

“Given the opportunity, I will continue to use the communication portal for my home dialysis care”

(Circle the best option)

- Strongly Disagree
- Disagree
- Neither Agree or Disagree
- Agree
- Strongly Agree

**If you are not receiving home dialysis** (peritoneal dialysis or home hemodialysis)

“Given the opportunity, if I return to home dialysis I will continue to use the communication portal for my home dialysis care” (Circle the best option)

- Strongly Disagree
- Disagree
- Neither Agree or Disagree
- Agree
- Strongly Agree

25. New approaches to patient care may have unintended benefits and/or drawbacks. Please describe any benefits and drawbacks you experienced from using the portal:

A. BENEFITS:

B. DRAWBACKS:

**Acceptability Scale:** We would like to ask you about your thoughts on using this communication portal.

1. How easy was this communication portal for you to use?
  - a. 1—very difficult
  - b. 2
  - c. 3
  - d. 4
  - e. 5—very easy
  
2. How understandable were the responses you received to your portal messages?
  - a. 1—difficult to understand
  - b. 2
  - c. 3
  - d. 4
  - e. 5—easy to understand
  
3. How much did you enjoy using this communication portal?
  - a. 1—not at all
  - b. 2
  - c. 3
  - d. 4
  - e. 5—very much
  
4. How helpful was this communication portal in describing your symptoms and quality of life?
  - a. 1—very unhelpful
  - b. 2
  - c. 3
  - d. 4
  - e. 5—very helpful
  
5. Was the amount of time it took to complete messages using this communication portal acceptable?
  - a. 1—very unacceptable
  - b. 2
  - c. 3
  - d. 4
  - e. 5—very acceptable
  
6. How would you rate your overall satisfaction with this communication portal?
  - a. 1—very dissatisfied
  - b. 2
  - c. 3
  - d. 4
  - e. 5—very satisfied
  
7. On average, how many minutes/day did you spend **sending** messages on the portal? \_\_\_\_\_
  
8. On average, how many minutes/day did you spend **checking** messages on the portal? \_\_\_\_\_



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  - d. 4
  - e. 5—very satisfied
  
7. On average, how many minutes/day did you spend **sending** messages on the portal? \_\_\_\_\_
  
8. On average, how many minutes/day did you spend **checking** messages on the portal? \_\_\_\_\_

## **Experiences with dialysis**

**Questionnaire for peritoneal dialysis and  
haemodialysis patients who are dialysed at home**

1. **How are you dialysed?**  
 Home hemodialysis  
 Peritoneal dialysis
2. **How long have you been on dialysis?**  
please indicate below:

\_\_\_\_\_

---

### **Nephrologist**

---

The questions below are about your experiences with your nephrologist from the dialysis centre over the past year.

3. **How often does your nephrologist explain things to you in an understandable way?**  
 never  
 sometimes  
 usually  
 always
4. **Does your nephrologist give you information so you can take part in decisions on your treatment?**  
 never  
 sometimes  
 usually  
 always
5. **How often does your nephrologist give you information that conflicts with information from other healthcare providers\*?**  
 never  
 sometimes  
 usually  
 always
6. **How often does your nephrologist listen attentively to you?**  
 never  
 sometimes  
 usually  
 always
7. **How often does your nephrologist take you seriously?**  
 never  
 sometimes  
 usually  
 always
8. **How often does your nephrologist treat you with courtesy?**  
 never  
 sometimes  
 usually  
 always
9. **How often does your nephrologist spend enough time on you?**  
 never  
 sometimes  
 usually  
 always
10. **Does your nephrologist give you the chance to take part in decisions about your treatment?**  
 never  
 sometimes  
 usually  
 always
11. **Does your nephrologist ask about your medication use?**  
 never  
 sometimes  
 usually  
 always
12. **Does your nephrologist spend time and attention on physical complaints?**  
 never  
 sometimes  
 usually  
 always  
 n/a
13. **Is it possible to make an additional appointment with your nephrologist?**  
 never  
 sometimes  
 usually  
 always  
 I don't know/no experience
14. **Does your nephrologist refer you to other specialists in a timely manner?**  
 never  
 sometimes  
 usually  
 always  
 I don't know/no experience

**15. Give your overall assessment of your nephrologist below?**

- 0 *worst possible nephrologist*
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10 *best possible nephrologist*

---

**Nurses**

---

The questions below are about your experiences with your nurses from the dialysis centre over the past year.

**16. Do your nurses explain things to you in an understandable way?**

- never
- sometimes
- usually
- always

**17. Do your nurses give you conflicting information?**

- never
- sometimes
- usually
- always

**18. Do the nurses take you seriously?**

- never
- sometimes
- usually
- always

**19. Do the nurses encourage you to do things yourself?**

- never
- sometimes
- usually
- always

**20. Do you know who your lead nurse\* is?**

- yes
- no, *proceed to question 22*

**21. Do you have contact with your lead nurse during every outpatient clinic visit?**

- never
- sometimes
- usually
- always

---

**Social worker**

---

The questions below are about your experiences with the social worker from the dialysis centre over the past year.

**22. Does your social worker explain things to you in an understandable way?**

- never
- sometimes
- usually
- always
- n/a, no social worker

**23. Does the social worker take you seriously?**

- never
- sometimes
- usually
- always
- n/a

**24. Do you feel that the social worker helps you?**

- never
- sometimes
- usually
- always
- I don't know/no experience

**25. Can you make an appointment with the social worker on short notice if you want to speak with him/her?**

- never
- sometimes
- usually
- always
- I don't know/no experience

---

## Dietician

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The questions below are about your experiences with the dietician from the dialysis centre over the past year.

**26. Does your dietician explain things to you in an understandable way?**

- never
- sometimes
- usually
- always
- n/a, no dietician

**27. Does your dietician give you information on your diet that you must follow?**

- never
- sometimes
- usually
- always
- n/a, no dietician

**28. Does the dietician take you seriously?**

- never
- sometimes
- usually
- always
- n/a

**29. Can you make an appointment with the dietician on short notice if you want to speak with him/her?**

- never
- sometimes
- usually
- always
- n/a, no dietician

---

## Cooperation

---

The questions below are about the cooperation between different healthcare providers from the dialysis centre over the past year.

**30. Have you been affected by insufficient cooperation between healthcare providers at the dialysis centre?**

- never
- sometimes
- usually
- always

**31. Have you been affected by insufficient cooperation between your medical specialists (nephrologist and other specialists)?**

- never
- sometimes
- usually
- always
- n/a

---

## Dialysis centre

---

The questions below are about the dialysis centre and your experiences with it over the past year.

**32. Do you receive information on the examinations you must undergo?**

- never
- sometimes
- usually
- always

**33. Do you receive the results of the examinations you have undergone within the agreed time period?**

- never
- sometimes
- usually
- always
- n/a, no time agreed

**34. Do you receive information from the dialysis centre on the options for a kidney transplant?**

- yes
- no
- n/a

**35. Have you been informed that, because of your physical condition, you may be (temporarily) taken off the transplant waiting list?**

- yes
- no
- n/a

**36. Do you receive information so can tell your employer/educational institution about your dialysis?**

- yes
- no
- n/a

37. Do you receive information if there is a change in the organisation of the dialysis centre?

- yes
- no
- n/a

38. Do you receive information on options for dialysis during holidays?

- yes
- no
- n/a

39. Do you receive information on the activities of the local patients' association\*?

- never
- sometimes
- usually
- always
- n/a, no local patients' association

40. Do you receive information on the activities of the national patients' association\*?

- never
- sometimes
- usually
- always

41. In your experience, do the employees of the dialysis centre treat your patient data as confidential?

- never
- sometimes
- usually
- always
- I don't know/no experience

42. If you had peritonitis, were you helped quickly at that time?

- yes
- no
- n/a

43. Did the dialysis centre inform you about the complaint procedure?

- yes
- no

44. If you submitted a complaint, was it dealt with within 3 months?

- yes
- no
- n/a, no complaint submitted

45. Are appointments times for examinations scheduled in consultation with you?

- never
- sometimes
- usually
- always

46. Did you receive any accessory equipment at the start of your home dialysis (stand, thermal case, etc.)?

- yes
- no

47. Can the dialysis centre be reached by phone during business hours?

- never
- sometimes
- usually
- always
- I don't know/no experience

48. Can the dialysis centre be reached by phone outside of office hours for urgent matters?

- never
- sometimes
- usually
- always
- I don't know/no experience

49. Can you park your car near the dialysis centre?

- never
- sometimes
- usually
- always
- n/a

50. Below, give your overall assessment of your dialysis centre, 0 being the worst possible dialysis centre and 10 the best possible dialysis centre.

- 0 *worst possible dialysis centre*
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10 *best possible dialysis centre*

51. **Would you recommend this dialysis centre to other dialysis patients?**

- definitely not
- probably not
- probably
- definitely

**What would you like to change about the dialysis centre where you are dialysed or that supervises your home dialysis?**

(What could be better? Are there things that you need? What could change, or should work differently?)

52. **Can you reach the dialysis centre within half an hour by public transport?**

- yes
- no
- I don't know/no experience

### **Additional questions on Predialysis**

**Predialysis** is the period that precedes the dialysis, in which the patient is prepared for the dialysis. The questions below are about the predialysis phase.

53. **Over the past year, have you gone through the predialysis phase in The Capital District Renal Clinic at the QEII site?**

- yes
- no

54. **Did you receive information for choosing between the different forms of dialysis?**

- yes
- no

55. **Did you receive information on the different forms of kidney transplants?**

- yes
- no

56. **Were you given time to process all of the information?**

- yes
- no

57. **Medical problems related to the dialysis may arise. Did you receive information about this?**

- yes
- no

58. **Did you receive information on the equipment that is used in the dialysis?**

- yes
- no

59. **Did you receive information on the impact of dialysis on your day-to-day life?**

- yes
- no

60. **Were you informed about hygiene for dialysis?**

- yes
- no

61. **Did you receive information on the supply of dialysis fluid and the quantity of waste materials?**

- yes
- no
- n/a

62. **Were employees of the dialysis centre attentive to you during the predialysis phase?**

- never
- sometimes
- usually
- always

63. **Were employees of the dialysis centre attentive to your partner (or relative) during the predialysis phase?**

- never

- sometimes
- usually
- always
- n/a

---

**About you**

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The questions below are **about you**. This information will be used to gain insight into the experiences of different groups of people (such as men and women).

**64. What is your highest level of education completed? (completed with a diploma or adequate certificate)**

- no education (no primary education, or primary education not completed)
- Primary education (primary school, or special primary education or secondary education not completed)
- Secondary education (high school education or post secondary education not completed)
- Post secondary education (college or university education)
- Post graduate education
- other, please indicate below:


**65. In general, how would you describe your health?**

- excellent
- very good
- good
- moderate
- poor

**66. What language do you speak the most at home?**

- English
- French
- Other, please indicate below:

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

**67. Did anyone help you complete this questionnaire?**

- yes → *If so: go to question 69*

- no

**68. Who helped you complete the questionnaire?**

- (more than one answer possible)*
- my partner/family member/housemate
  - a relative
  - my helper
  - another social/relief worker
  - someone else .....

**69. How did this person help you?**

- (more than one answer possible)*
- Read the questions out to me
  - Crossed my responses
  - Answered the questions for me
  - Translated the questions into my language
  - Helped in another way, please indicate below:

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

**70. How do you travel to the QEII renal clinic/dialysis unit?**

- (more than one answer possible)*
- Public Transit System
  - Access-A-Bus services
  - Drive
  - Pick up and drop off by Capital health employ
  - Pick up and drop off by friend or family
  - Walk
  - Other, please indicate below:

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

**71. On average per day, how much time do you spend travelling to and from the QEII renal clinic/dialysis unit?**

- Less than 30 mins
- 30 mins to 1hr
- 1 hr or more
- 2 hrs or more
- 3 hrs or more
- 4 hours or more

**72. What city do you live in currently?**

---



**Many thanks for completing the questionnaire!**

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## **Explanatory glossary**

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### **Anonymously**

You do not need to give your name. Your responses will not be associated with you personally. Therefore, neither the employees in the dialysis centre nor anyone else will know what responses you gave.

### **APD (Automatic Peritoneal Dialysis)**

In automatic peritoneal dialysis (APD), the dialysis fluid is refreshed using a device (cycler). This is usually done at night. If the patient keeps fluid in the abdomen during the day, this is called continuous cycling peritoneal dialysis (CCPD). If the abdomen remains empty during the day, this is called nocturnal peritoneal dialysis (NPD).

### **CAPD (Continuous Ambulatory Peritoneal Dialysis)**

With Continuous Ambulatory Peritoneal Dialysis (CAPD) the dialysis fluid is refreshed manually. This is usually done four or five times a day.

### **Hemodialysis (HD)**

Dialysis method that uses an artificial kidney. This is usually done in a dialysis centre, but this treatment can also be performed at home.

### **Healthcare providers**

Persons that you receive care from. This includes, for instance, nurses, nephrologists, other specialists, the social worker and the dietician.

### **Lead nurse**

The lead nurse is also known as an 'EVV'er in the Netherlands. The lead nurse is the patient's personal supervisor and the primary point of contact.

### **Local patients association**

An association for persons suffering from the same condition and who are treated in a particular centre or region.

### **National patients association**

A national association for persons suffering from the same illness. For kidney patients in the Netherlands, this is the Nierpatiënten Vereniging Nederland (NVN).

### **Peritoneal Dialysis (PD)**

In this dialysis treatment, the abdominal lining (peritoneum) is used as an 'artificial kidney'. For this, the patient lets dialysis fluid flow into the abdominal cavity through a small tube placed in the abdomen. This fluid is refreshed regularly.

### **Predialysis phase**

This is the period preceding the kidney replacement therapy. During this period, the patient is prepared for dialysis or kidney transplant.

### **Quality aspects**

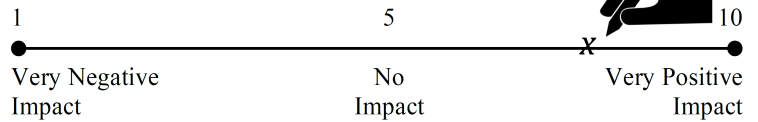
Matters related to the quality of care that you receive in the dialysis centre.

# Satisfaction Questionnaire

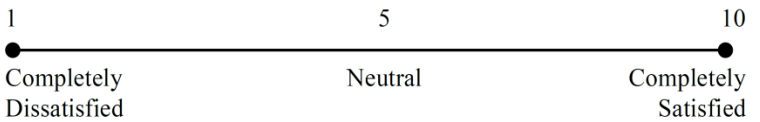
Please mark an 'x' on the line connecting 1 to 10 to show your responses.



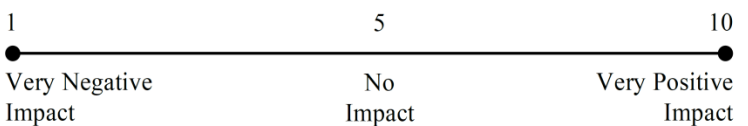
**Example:**



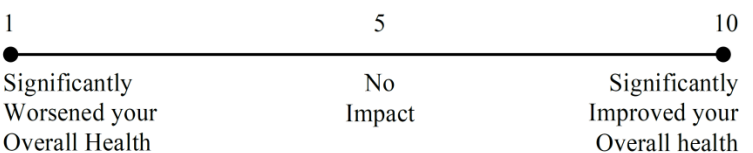
10. Please rate your **Overall Satisfaction** with the communication portal (CP):



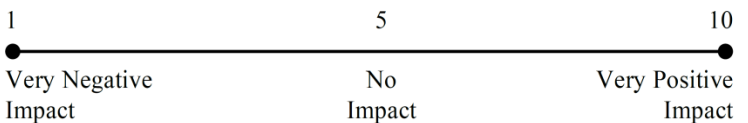
11. The impact the communication portal had on your **chances of needing (re)admission to the hospital** was:



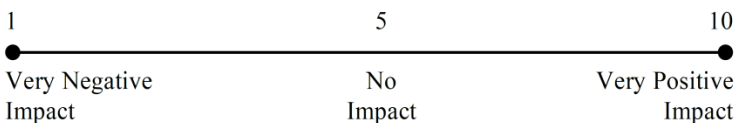
12. The impact of the CP had on your **overall health** was:



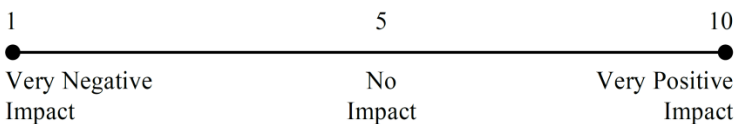
13. The impact of the CP on **helping you understand which medications to take, correct doses, and when to take them** was:



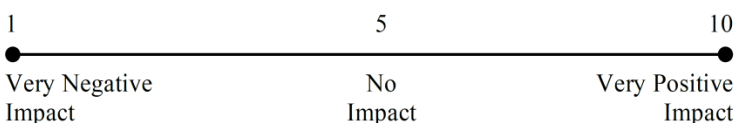
14. The impact of the CP on **helping you with technical aspects of dialysis** (dialysis machine, alarms, water system) was:



15. The impact of the CP on **helping you get appointments with specialist doctors** was:

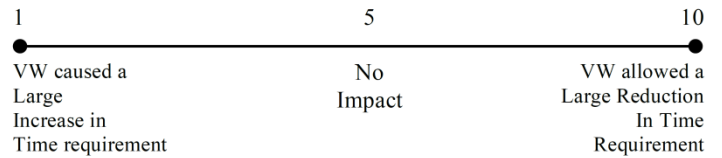


16. The impact of the CP on **helping you access or get to speak to your kidney specialist** was:

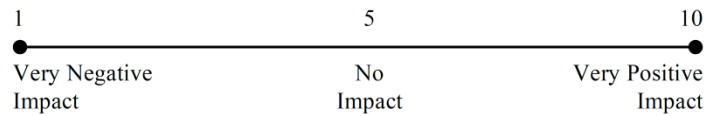


Satisfaction Questionnaire

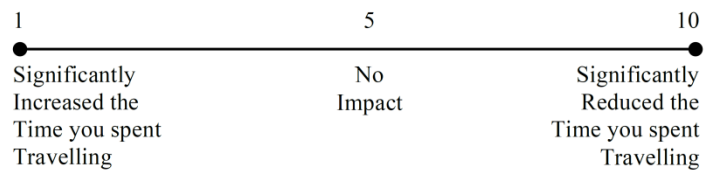
17. The impact of the CP on **helping to minimizing the overall time spent managing your medical conditions** was:



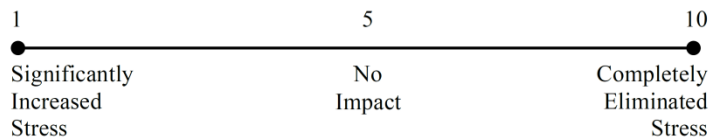
18. The impact of the CP had on **your personal privacy** was:



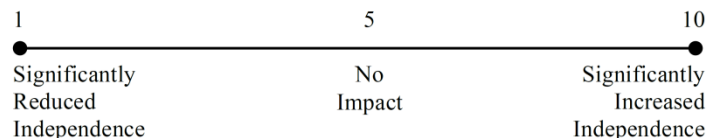
19. The impact of the CP on **time spent travelling to get dialysis-related care** was:



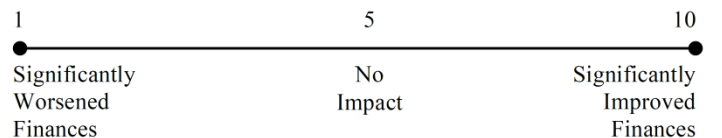
20. The impact the CP had on the **stress related to performing home dialysis**:



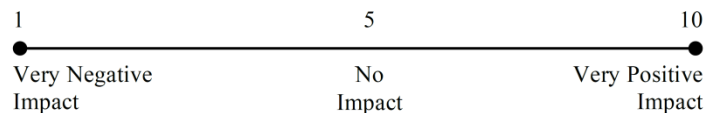
21. The impact the CP had on **your personal Independence** was:



22. The impact the CP had on **your personal finances** was:



23. The impact the CP had on **your mood** was:



## Satisfaction Questionnaire

24. Please rate how well you agree or disagree with the following statement:

**If you are currently on home dialysis**

(peritoneal dialysis or home hemodialysis)

“Given the opportunity, I will continue to use the communication portal for my home dialysis care”

(Circle the best option)

- Strongly Disagree
- Disagree
- Neither Agree or Disagree
- Agree
- Strongly Agree

**If you are not receiving home dialysis** (peritoneal dialysis or home hemodialysis)

“Given the opportunity, if I return to home dialysis I will continue to use the communication portal for my home dialysis care” (Circle the best option)

- Strongly Disagree
- Disagree
- Neither Agree or Disagree
- Agree
- Strongly Agree

25. New approaches to patient care may have unintended benefits and/or drawbacks. Please describe any benefits and drawbacks you experienced from using the portal:

A. BENEFITS:

B. DRAWBACKS: