

Costs of ADPKD patients at different stages of disease
in the Nordic countries

Site ID

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Subject
Number

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Questionnaire

Instructions and clarifications appear throughout this form in italic

Introduction

In this questionnaire, we ask you to provide information related to your cystic kidney disease. This information is crucial to the understanding of the disease. Primarily we are interested in complementing the data from your specialist clinic with information on other cystic kidney disease-related care and also with information on travel costs and help you may receive around your home.

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Questionnaire

1. What type of residence do you live in?

- House/apartment
- Nursing home
- Other, please specify: _____

2. Help around the home from family and friends

a. During the past four weeks, have you due to your cystic kidney disease received help around the home from family and/or friends?

- Yes
- No

b. If yes, on average during the past four weeks, how many hours per week did you get help?

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 hours per week

3. Home care service

a. During the past four weeks, have you due to your cystic kidney disease received home care service?

- Yes
- No

b. If yes, on average during the past four weeks, how many hours per week did you get help?

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 hours per week

4. Doctor/nurse home visit

a. During the past four weeks have you, due to your cystic kidney disease, received help in your home from a doctor, nurse or other health care professional?

- Yes
- No

b. If yes, how many times during the past four weeks did you receive a home visit?

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 times

5. During the past four weeks, due to your cystic kidney disease, how many visits have you made to the following...

For each question below, please write "0" if you have not had the visit.

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- a. ... nephrology clinic other than your kidney specialist clinic from which you received this questionnaire?

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 visits

- b. ... physician/nurse office (primary care) outside of your nephrology clinic (kidney specialist)?

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 visits

- c. ... physiotherapist?

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 visits

- d. ... psychologist/psychiatrist?

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 visits

- e. ...alternative medicine clinic (for example, massage, acupuncture, chiropractic therapy, osteopathy, etc.)?

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 visits

- f. ...other specialist care (not listed above)?

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 visits

6. During the past four weeks, due to cystic kidney disease, to what amount have you bought over-the-counter drugs (i.e. drugs not requiring a prescription)?

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 DKK/EURO/NOK/SEK

7. Dialysis

- a. Do you regularly travel to a dialysis unit for dialysis?

- Yes
 No

- b. If yes, what type of transport do you usually use to travel to your dialysis unit?

- Public transportation
 Car
 Taxi/Community transport
 Walking
 Other, please specify: _____

- c. If yes, how long does it take for you to travel to the dialysis unit?

- less than 30 min
 30 min to 1 hour
 1 to 2 hours
 longer than 2 hours