

APPENDIX B

Breast cancer patient decision aid

Component 1: consultation sheet

The consultation sheet (printed or digital) contains a visualisation of a risk estimation of the personalised risk for breast cancer recurrence (local regional recurrences and secondary primary breast tumours), combined with a display of available options for post-treatment surveillance (e.g. frequency, imaging and duration). The personalised risk is estimated based on individual patient, tumour, and treatment characteristics, using the web-based INFLUENCE-nomogram. The nomogram was validated based on a large set of outcome data from the Netherlands Cancer Registry and shows a good predictive ability in the Dutch population.[12]

Breast Cancer Surveillance Decision Aid pat12345 ▾

1. Your situation 2. Surveillance 3. Quiz 4. Considerations 5. Preferences 6. Questionnaire 7. Summary

2. Surveillance

What is post-treatment surveillance?	✓
What is the risk for recurrence of breast cancer?	✓
Which choices do I have about surveillance?	✓
Annual surveillance or less?	✓
Which diagnostic tests for surveillance?	✓
Do I want the results at the hospital or by telephone?	✓
What is cancer survivorship care?	✓
What do I need to pay attention to?	✓
What if I don't have surveillance?	✓

What is the risk for recurrence of breast cancer?

You and your healthcare professional have discussed your personal risk for recurrence of breast cancer. This risk is different for every patient.

The risk for a new breast tumor or recurrence depends on the following characteristics:

- Your age
- The size of the primary breast tumor when it was discovered
- If lymph nodes in the armpit were affected
- The characteristics of the primary breast cancer:
 - if there was one or more tumors in the breast
 - how different the breast cancer cells look from normal breast cells (grade)
 - if the tumor cells were sensitive to hormones (estrogen and/or progesterone)
 - if the tumor cells were sensitive to certain proteins (HER2)
- The treatment you have received for breast cancer

Your personal risk

Your healthcare professional has calculated your personal risk for recurrence of breast cancer. In 2 to 3 out of 100 women with the same characteristics as you, the breast cancer recurs in the breast area within 5 years after treatment.

For the calculation a prediction model was used. The characteristics above are incorporated into this model.

[> Read more about the prediction model](#)

Component 2: online interactive PtDA

The online interactive PtDA contains information about SDM, post-treatment surveillance, available options and a clarification of the risk estimation. Interactive elements include a knowledge quiz, and value-clarification exercises. As part of using the PtDA, patients are asked to complete a patient-reported

outcome on fear of recurrence.[46] Data is processed in real-time and linked to tailored feedback on individual outcomes including comprehensive self-care advice (tips and tools).

Breast Cancer Surveillance Decision Aid pat12345 ▾

1. Your situation 2. Surveillance 3. Quiz 4. Considerations 5. Preferences 6. Questionnaire 7. Summary

6. Questionnaire

You may feel anxious and insecure after breast cancer. This questionnaire will give you an indication how you currently feel.

	Never	Hardly ever	Sometimes	Almost always
How often have you thought about your chances of getting breast cancer again?	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have these thoughts affected your mood?	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Have these thoughts interfered with your abilities to do daily activities?	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
How concerned are you about the possibility of getting breast cancer again one day?	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often do you worry about developing breast cancer again?	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
How much of a problem is this worry?	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your score				12

What does your score mean?

A completed questionnaire gives a score between 6 and 24.

A score of 11 or lower indicates that you are *rarely concerned* about recurrence of breast cancer

A score of 12 or higher indicates that you are *regularly concerned* about recurrence of breast cancer

Tip Discuss this with you healthcare professional if you feel limited by fear of recurrence in your daily life. Together you will decide if additional support may be useful. You can also read more about how to deal with fear or recurrence on the website of the [Breast Cancer Association](#).

Component 3: summary sheet

A summary sheet (printed or digital), to be used in the clinical consultation, containing women's preferences, personal considerations, and the individual outcomes on fear of recurrence.

 Breast Cancer Surveillance Decision Aid

pat12345

Your summary

This is the summary of your situation and preferences. Bring summary to your next consultation with your healthcare professional. Together you decide what surveillance options suit you best.


My situation

My personal risk	2.3 %
Surveillance for a maximum duration of	5 years
Options for diagnostic tests	Mammography, physical examination

My preferences about surveillance

How often?	Every year
How many years?	5 years
Which diagnostic tests?	Mammography, physical examination
Results at the hospital or by phone?	Consultation at the hospital
My remarks	- Argument
My role in decision making	I prefer that my healthcare professional and I make the decision together
My questions	- Question

My considerations

I don't mind going to the hospital for surveillance		I don't want to go to the hospital for surveillance
I want to go for surveillance, even though it makes me restless		I want as little surveillance as possible to avoid stress and unrest
Periodical surveillance makes me feel safe and reassured		I only want surveillance when I feel it is necessary
I want to have periodical surveillance, even if it takes time and effort		I prefer to spend as little time and effort as possible on surveillance
I want surveillance in the hospital, regardless of the costs		I don't want surveillance in the hospital, because of the costs
My loved ones think it is important that I have periodical surveillance		My loved ones understand if I don't have periodical surveillance
My score on the fear of recurrence questionnaire	12	

Stroke patient decision aid

Component 1: consultation sheet

The consultation sheet contains basic information about the diagnosis (i.e. a visual representation of the brain to use as a topic starter on stroke and associated consequences), the type of stroke (i.e. ischemic or haemorrhagic), the individual stroke severity score as measured by the National Institutes of Health Stroke Scale (NIHSS), and options eligible for discharge locations.

Stroke decision aid

Your diagnosis
Your healthcare professional marks your diagnosis

Your diagnosis Ischaemic stroke Haemorrhagic stroke

Your NIHSS 0-4 5-15 16-42

This score quantifies stroke severity. A higher score indicates higher stroke severity.

Observations of your healthcare professionals

Your vascular neurologist
 name
 name

Your nurse practitioner
 name

Your physician assistant
 name
 name

You received this consultation sheet from:
.....

Use the decision aid and share the summary with your healthcare professional before:
date.....time.....

Use the decision aid

In the online decision aid, you can read information about stroke and your hospital admission. Also, you can clarify your values and preferences concerning discharge planning.

After being discharged from the hospital, you can still consult the decision aid for information about the effects of stroke.

Go to:
<https://cva.keuzehulp.nl>

Username Password
<<naam>> <<ww>>

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Component 2: online interactive PtDA

The online interactive PtDA contains information about the aetiology and impact of stroke, prognosis and discharge planning. As part of the PtDA, patients are asked to complete PROM questionnaires on their physical and mental condition and to elaborate on their situation prior to admission to the hospital, as well as to indicate personal treatment goals. Also, the process of SDM is explained and value clarification exercises are included. The PtDA contains an interactive “patients-like-me” model: patients can enter their type of stroke, stroke severity and age in the model, which then shows the discharge location of comparable patients based on historical Santeon data (N > 4000).

Stroke decision aid

1. Stroke 2. About you 3. Where to rehabilitate? 4. Your current situation 5. Your preferences 6. Summary

3. Where to rehabilitate?

Which discharge destinations are available?	✓
What is the best discharge destination for me?	✓
Where did other patients with stroke rehabilitate after discharge from the hospital?	✓
What is required for rehabilitation at home?	✓
What can I expect from an inpatient rehabilitation program?	✓
Who can I consult after finishing my rehabilitation program?	✓
What are other important things to know for me and my caregivers?	✓

Where did other patients with stroke rehabilitate after discharge from the hospital?

Sometimes it can help to know where other patients go to after being discharged from hospital. Below you can see an overview of distribution between the different discharge destinations depending on diagnosis, age and stroke severity.

Diagnosis	Ischaemic stroke	Haemorrhagic stroke			
Age	younger than 30 years	30 - 49 years	50 - 64 years	65 - 79 years	older than 80 years
NIHSS*	0 - 4	5 - 15	16 - 42		



Of 100 patients:

- 51 returned home
- 37 temporarily moved to an inpatient rehabilitation facility
- 8 temporarily moved to an inpatient skilled nursing facility
- 4 permanently moved to a nursing home

This information is based on data from more than 5000 patients with stroke from OLVG, MST and St. Antonius during the period of 2017-2020.

* The National Institute of Health Stroke Scale (NIHSS) score quantifies stroke severity. A higher score indicates higher stroke severity.

Component 3: summary sheet

A digital summary sheet containing patients' values, preferences concerning discharge planning, and individual PROM scores to be used in the doctor-patient consultation.



Your summary

This is the summary about your situation and preferences. Discuss the summary with your healthcare professional. Together you will choose which discharge destination suits you best.

My situation before my stroke

What did I like to do before I was admitted to the hospital? Working as an artist, having an active and social life.		I was able to walk more than 30 minutes	Yes
What effects of my stroke do I notice? Weakness and numbness of my left arm.		I was walking with a walking aid	No
What would I like to do again? Returning home without help, being able to work and cycle again		I was able to get dressed without assistance	Yes
		I was able to do grocery shopping without assistance	Yes
		I had memory complaints	No

My current situation

I think that I can safely manage my routine activities at home, with help if needed		I don't think that I can safely manage my routine activities at home, not even with help
I am able to walk safely without help in my home		I need help to walk safely in my home
I can ask for help by telephone		I cannot ask for help by telephone
I can prepare a simple meal		I need help to prepare a simple meal

My situation at home

I have to use the stairs to reach my home or live at home

Social assistance with daily living

	I need help with basic activities of daily living, for example going to the toilet, bathing, dressing and eating	No
	I need help with household chores, for example shopping for groceries or preparing meals	Yes
	I need help with transportation to medical appointments	Yes
	I need help with planning and making medical appointments	No
	I have a family member or caregiver(s) who can support me in daily life	Yes

My preferences

I would like to make a (physical) effort to recover		I have troubles with making a (physical) effort to recover
I would like to create a rehabilitation program together with my healthcare professionals		I prefer that a rehabilitation programme is created for me by my healthcare professionals
I would like to rehabilitate at home		I would like to rehabilitate at an inpatient rehabilitation facility
My preference at this moment	Returning home with an ambulatory rehabilitation program in a rehabilitation facility or hospital.	
Explanation	I would like to go home, but also to make an effort to recover	
My questions	Who is my healthcare professional?	

Advanced kidney disease patient decision aid

Component 1: consultation sheet

The consultation sheet (printed or digital) contains a flowchart of the kidney failure care path, a graph that health care professionals can use to draw the patient's individual eGFR decline, and a table that health care professionals can use to mark eligible treatment modalities.

Kidney failure decision aid

Each treatment option for kidney failure impacts your life differently. Which treatment option ultimately suits you depends on your medical history and on what's important to you and your loved ones.

Your situation
When you should start a treatment for kidney failure depends on your medical history, the course of your kidney disease, the severity of your symptoms and your wishes.

Your options
Your nephrologist indicates what treatment options you are eligible for.

Kidney transplantation
 Peritoneal dialysis
 Hemodialysis
 Conservative care

Disclaimer: additional examinations may be needed to evaluate if these options are possible for you. If you are not eligible for an option your nephrologist will explain why.

Begin on time!
Educate yourself about your treatment options. Making a decision and the subsequent preparations take a lot of time. Prevent unnecessary pressure and give yourself time to make a well-informed decision.

Tip

MAASSTAD ZIEKENHUIS

Your nephrologist

name
 name
 name
 name
 name

If you have questions you can contact your social worker.

This decision aid will help you prepare for your future appointments

Use the online decision aid to:

- ✓ Read about your diagnosis and treatment options
- ✓ Think about your values and preferences
- ✓ Set goals for your treatment

Together with your healthcare provider you can:

- ✓ Discuss your goals, values and preferences
- ✓ Choose a treatment that suits you best

To use the online decision aid

Go to

Username Password


In collaboration with

©padTelen-v1

Component 2: online interactive PtDA

The online interactive PtDA contains information on SDM, kidney failure and treatment modalities (haemodialysis, peritoneal dialysis, kidney-transplantation and conservative care management). Written information is supplemented with videos of patients' experiences. As part of the PtDA, patients are asked to complete PROMs questionnaires on their physical condition and on whether they consider life as completed. Additionally, patients are asked to complete value-clarification exercises regarding kidney transplantation (when applicable), dialysis and conservative care management. The PtDA contains an interactive "patients-like-me" model: patients can enter their age in the model, which then shows the

median survival- and mean hospitalisation rates per treatment modality based on both Santeon and national data.

 Kidney failure treatment decision aid

1. Kidney failure 2. About you 3. Kidney transplantation 4. Dialysis and conservative care 5. Your preferences 6. Summary

4. Dialysis and conservative care

Information on dialysis and CC	✓
What is PD?	✓
PD: how often, how long and where?	✓
What to consider when choosing for PD?	✓
What is HD?	✓
HD: how often, how long and where?	✓
What to consider when choosing HD?	✓
What is CC?	✓
What is the impact on my daily schedule?	✓
What is the impact on my life?	✓

What is the impact on my daily schedule?

Dialysis and CC impact you daily schedule in different ways.

Work and/or hobbies

PD	HD	CC
<ul style="list-style-type: none"> PD is a daily treatment you can perform yourself. You can adjust your treatment schedule to your daily schedule. 	<ul style="list-style-type: none"> HD is treatment you undergo several times a week, at a fixed schedule on a fixed location. You have to plan your daily schedule around your dialysis treatments. 	<ul style="list-style-type: none"> Your treatment is not bound to any schedule so you are free to plan your days. As your condition deteriorates it will be increasingly difficult to work and/or do hobbies.

Commuting

PD	HD	CC
<ul style="list-style-type: none"> You do not have to commute to a treatment centre frequently. You will have check-ups in the hospital every 6-8 weeks. 	<ul style="list-style-type: none"> If you dialyze in a treatment centre, you need to commute for your treatment 3 times a week. If you dialyze at home you will have check-ups in the hospital every 6-8 weeks. 	<ul style="list-style-type: none"> You do not have to commute for your treatment. You can choose to receive your treatment from your nephrologist or general practitioner.

Rest and night schedule

PD	HD	CC
<ul style="list-style-type: none"> CAPD will not affect your rest and/or schedule at night. APD can affect you and/or your partner's rest and/or schedule at night. 	<ul style="list-style-type: none"> HD during the day will not affect your rest and/or schedule at night. HD during the night can affect you and/or your partner's rest and/or schedule at night. 	<ul style="list-style-type: none"> The treatment does not directly affect your rest and/or schedule at night.

Traveling and vacation

PD	HD	CC
<ul style="list-style-type: none"> You can travel and go on vacation on the condition that you can hygienically perform your treatment at your destination. If your supplier cannot deliver equipment and materials at your destination, you have to take them with you yourself. Ask your healthcare provider for help. 	<ul style="list-style-type: none"> You can travel and go on vacation on the condition that you can dialyze at your destination. Take 3 months of preparation into account when planning your vacation. Ask your healthcare provider for help. 	<ul style="list-style-type: none"> You can travel and go on vacation as long your condition allows you to do so.

Average rate of hospital admissions

Age	18 - 44 years	45 - 64 years	65 - 74 years	75 - 79 years	Older than 80 years of age

	PD	HD	CC
Average rate of admissions	2 times a year	1 time a year	2 times a year
Average length of admissions	7 days a year	6 days a year	4 days a year

Component 3: summary sheet

A printed or digital summary sheet to be used in a clinical consultation, containing patients' values, preferences concerning discharge planning, and individual PROM scores.

Kidney Failure treatment Decision Aid
pat12345

Your summary

This is the summary of your situation and preferences. You can use this summary at your next appointment to help you and your doctor make a treatment decision that suits you best.

About me

What do I enjoy doing in my daily life?
I enjoy working at my garage with my two sons and nephew. I would give anything to keep working for a couple of more years so one of them can mature and take over my responsibilities.

Who plays an important role in making this decision?
My wife and I are real team players. She's my personal consultant.

Can you continuously walk for 30 minutes or more? **Yes**

Can you dress yourself? **Yes**

Do you do groceries by yourself? **No**

What symptoms are currently bothering you the most?
The nausea and breathlessness.

Tell us what you think

There are things I still want to do with my life

I feel fulfilled with my life

I want a treatment that primarily focuses on extending my life

I want a treatment that primarily focuses on my quality of my life

Kidney transplantation

Do you have moral objections to receiving a kidney from a living donor?
No

Did you talk about living donation kidney transplantation with anyone you know?
I talked about it with my wife, but I don't want to put this burden on my kids.

Has anyone offered to donate you a kidney?
[Not yet]

Do you have any questions or comments about kidney donation?
Am I also eligible for a kidney from a deceased donor?

Dialysis at home or in a hospital?

I don't mind doing dialysis at home

I don't want to feel like a patient at home

I don't want to be in the hospital on a weekly basis

I don't mind being in the hospital on a weekly basis

I want to be flexible and plan my dialysis according to schedule

I don't mind being in the hospital according to a fixed schedule

I feel confident that I can perform dialysis on my own at home

I would rather have a healthcare professionals help me with my dialysis

Comments: **I would prefer doing PD treatment at home**

Dialysis during the day or night?

I want to sleep without having to deal with my dialysis

I accept that the quality of my sleep may worsen due to my dialysis

I can free time during the day to make time for my dialysis

I want to remain flexible during the day

Comments: **I would prefer doing my PD at night so I can freely manage my garage during the day!**

My preference

My preference at this moment: **Kidney transplantation from a deceased donor or APD**

What goals do I want to achieve with this treatment? **Extending my life while remaining flexible. I want to spend my golden years with my wife after making my sons owners of my garage. They still have a lot to learn though!**

What do I absolutely not want? **CC**

My questions: **no additional questions**