



OPT-ePRO

Optimising routine collection of
electronic patient-reported outcomes
(OPT-ePRO)

Specifications of software for receiving and
displaying ePRO data in renal unit EHR systems

Version 1.0 (29/11/2018)

Overview of software developments within OPT-ePRO

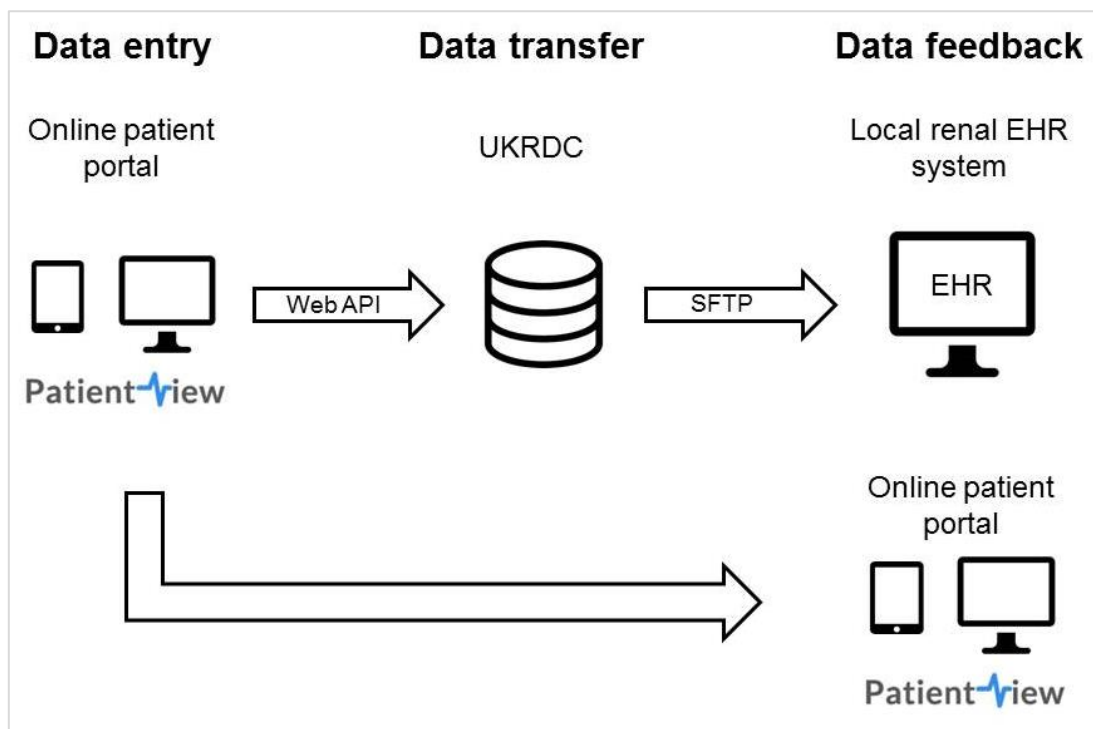
General purpose

The overall purpose of the software developed within OPT-ePRO is to enable kidney patients to self-report on their symptoms and quality of life through an online patient portal (PatientView), and to incorporate this information within renal services. The questionnaires for reporting symptoms (POS-S Renal) and quality of life (EQ-5D-5L) are included in Appendices 1 and 2. Patients will be asked to report their systems for every clinic visit, whereas quality of life will be reported annually.

For this, electronic patient-reported outcome (ePRO) data will be made accessible within the patient’s electronic health record (EHR) at the renal unit. This will facilitate review and discussion of symptoms and quality of life in clinic consultations, as well as during patient rounds and team meetings. Patients can view their own ePRO results within the patient portal to support them with self- managing their kidney disease. Lastly, all ePRO data will be stored alongside clinical data in the UK Renal Data Collaboration (UKRDC) data warehouse.

Description of the overall data entry, transfer and feedback mechanism

As shown in the diagram below, patients complete an ePRO questionnaire in an online patient-facing portal (PatientView) to which they have access via any desktop pc or tablet that is connected to the internet. Patients may enter data from home, while on dialysis, or in the waiting area of the outpatient clinic.



After completing a symptom and/or quality of life score in PatientView, the portal sends the ePRO data to UK Renal Data Collaboration (UKRDC) repository using a web API; the data file will be structured according to the UKRDC Survey schema (see below). Upon receiving a new ePRO file, the UKRDC pushes the file to the local EHR system via SFTP through the Trust's firewall. The EHR system will locate the ePRO file and process it. From then on, clinicians can access the ePRO data within the patient's EHR.

The time between patients entering ePRO data into the portal and the data being accessible within the local EHR should be as close to real-time as possible. This is required in outpatient settings, where patients enter their data in the waiting area before going into the consultation to discuss their results. Patients can access their own ePRO results within the online patient portal immediately after data entry.

Developments within renal unit EHR systems

Within renal unit EHR systems, there are two main software elements that require developing:

- A mechanism to receive ePRO files from the UKRDC and store it as part of the patient's EHR;
- Screens to display ePRO results within the patient's EHR.

Both elements are further specified below, including a description of the software's final end-to-end test.

Specification of elements within renal unit EHR systems

Mechanism to receive ePRO files from the UKRDC into the EHR system

As soon as the UKRDC receives a new ePRO file from the patient portal, they will push it to the local EHR system via SFTP through the Trust's firewall. The EHR system will locate the ePRO file and process it.

MUST-HAVES

- Trusted relationship between the UKRDC and the Trust's EHR system, which will give the UKRDC access through the Trust's firewall;
- EHR server location and folder for the UKRDC to write the ePRO files to;
- Mechanism whereby the EHR system monitors for new ePRO files. The frequency of monitoring should be in line with the aim to keep data transfer from the portal into the EHR as close to real-time as possible;
- Mechanism whereby the EHR system processes the ePRO file according to the UKRDC rda schema, specifically the survey elements:
(<https://github.com/renalreg/ukrdc/tree/master/Schema/Surveys>) and the required

elements from <https://github.com/renalreg/ukrdc/blob/master/Schema/UKRDC.xsd> and <https://github.com/renalreg/ukrdc/blob/master/Schema/Patient.xsd>. An example data file is included in Appendix 3.

ALTERNATIVE TRANSFER OPTION

An alternative option for transferring the ePRO files from the UKRDC to the EHR system may be that the EHR system uploads the files from sftp.ukrdc.org using an SFTP login, while frequently monitoring for new ePRO files that require uploading and processing.

Screens to display ePRO results within the patient's EHR

Once the EHR system has processed the ePRO file, results should be displayed within the patient's EHR. We developed recommendations for screen designs based on scientific literature and interviews with clinicians (full report available on request). Recommendations on which there was clear consensus have been categorised as must-haves. The research team at the University of Manchester will organise workshops with clinicians and patients in Jan-Feb 2019 where there is an opportunity to obtain user feedback on screen designs/mock-ups.

MUST-HAVES

In general, the ePRO data should be displayed primarily as tables and simple line graphs, and where possible in line with how clinical data (e.g. lab results) are currently presented. Screens should support clinical decision making, as well as patient-clinician communication (e.g. during clinic visits) and clinician-clinician communication (e.g. during team meetings).

Symptom scores (as reported through the POS-S Renal questionnaire; see Appendix 1)

Symptom scores should be displayed in an overview screen (that displays scores for all symptoms), complemented with symptom-specific screens. The latter were identified as essential for enabling discussion of symptom scores with patients in clinic. The value of symptom scores varies between 0 (not affected at all) to 4 (overwhelmingly affected).

Symptom overview screen

In Appendix 4, we have included a screenshot from an existing symptom overview screen to illustrate the recommendations below.

- The overview screen should display time-stamped scores for all symptoms individually in a table with even columns and rows, as well as the symptoms that patients identified as affecting them the most and that have improved the most (see Appendix 1).

- Colour coding should be used to differentiate low and high symptom scores; the use of green should only be used for symptom scores with value 0.
- For each instance of the symptom score, the table should display the total symptom score. The total score is calculated by adding up the individual symptom scores, including the scores for ‘any other symptoms’ (see Appendix 1); the value of the total score ranges between 0 and 80.

Symptom-specific screens

- Symptom-specific screens should be available to display scores over time for the 17 individual, pre-defined symptoms (see Appendix 1), as well as for the total symptom score.
- Symptom-specific screens should be presented as “pop-up” screens that are displayed on top of the overview screen; they should be moveable, and their size adjustable. Pop-up screens are preferred to displaying individual symptoms/total symptom score on a separate tab within the patient record.
- Symptom-specific information should be displayed as simple line graphs (see Appendix 5 for example).

Quality of life scores (as reported through the EQ-5D-5L questionnaire; see Appendix 2)

The design of the screens to display data from the EQ-5D-5L questionnaires should be similar to how symptoms are displayed. Each quality of life score consists of scores for six individual aspects: mobility, self-care, usual activities, pain/discomfort, anxiety/depression, and an overall health score. Values for the first five aspects can range from 1-5 (1, no problems; 2, slight problems; 3, moderate problems; 4, severe problems; 5, extreme problems); the overall health score is a value between 0 (worst health) and 100 (best health).

Quality of life overview screen

In Appendix 6, we have included an example of a table to present quality of life scores to illustrate the recommendations below.

- The overview screen should display time-stamped scores for all six quality of life aspects individually in a table with even columns and rows.
- Colour coding should be used to differentiate low and high scores; the use of green should only be used for symptom scores with value 0.

The quality of life overview screen could be either separate from the symptom overview screen, or combined into one ‘PROMs’ screen (see Appendix 7 for an example).

Aspect-specific screens

Aspect-specific screens should be:

- Available to display scores over time for the six aspects of quality of life individually;
- Presented as “pop-up” screens that are displayed on top of the overview screen; they should be moveable, and their size adjustable.
- Displayed as simple line graphs.

NICE-TO-HAVES

- It should be possible to display the total symptom score (calculated from the POS-S Renal questionnaire) and the overall health score (from the EQ-5D-5L questionnaire) in any overview screen within the EHR that is currently in use for listing multiple patients, e.g. lists to discuss patients during team meetings.

Symptom scores

Symptom overview screen

- Clinicians should be able to place a flag on symptoms of particular concern to the patient in order to track these over time. This will help satisfy clinicians’ need for customisable symptom displays, as well as the need to primarily focus on specific symptoms of concern.
- Total scores should be flagged if they are calculated from an incomplete questionnaire (i.e. if a score for one or more of the 17 pre-defined symptoms is missing). However, the data entry screen in PatientView is likely to be designed such that patients cannot submit their symptom questionnaire if not all pre-defined symptoms have been scored.

Symptom-specific screens

- To facilitate a degree of informal trend analysis and to aid clinical decision making, the line graphs that display individual symptom scores should be customisable to allow clinicians to:
 - Add lines to display scores of other individual symptoms;
 - Add lines to display lab results (e.g. estimated Glomerular Filtration Rate);
 - Select a specific time period to be displayed;
 - Flag specific data points in the graph, e.g. to highlight points where treatments have been administered, or for illustrative purposes during patient consultations.
- Clinicians should be able to attach notes to specific data points to enrich the presented symptom information. Notes may also act as a reference point when symptoms are discussed in clinic.

Quality of life scores

Quality of life overview screen

- Clinicians should be able to place a flag on quality of life aspects of particular concern to the patient in order to track these over time.

Aspect-specific screens

- The line graphs that display scores of individual quality of life aspects should be customisable to allow clinicians to:
 - Add lines to display scores of other individual quality of life aspects;
 - Add lines to display lab results (e.g. estimated Glomerular Filtration Rate);
 - Select a specific time period to be displayed;
 - Flag specific data points in the graph.
- Clinicians should be able to attach notes to specific data points.

End-to-end test

EHR system managers should conduct an end-to-end test of the software to assess whether and how quickly ePRO data entered into PatientView are correctly displayed within the EHR. Using a PatientView test account and dummy patient IDs, they will enter test data (as if they were patients) and monitor the (speed of) transfer, processing and displaying of results in the EHR. Tests should be planned in consultation with the UKRDC and the patient portal supplier to allow further investigations of the data transfer mechanism, should any problems be identified.

REQUIREMENTS

- Dummy patient IDs (i.e. NHS numbers), created by the clinic sites. Dummy IDs need to be available within the EHR system, as well as registered as PatientView users;
- PatientView test account
- Test plan, including use cases and success criteria; development will be coordinated by the research team at the University of Manchester

Timelines

<i>Deliverable</i>	<i>By</i>	<i>When</i>
Mechanistic test of trusted relationship between UKRDC and EHR system	Sites / UKRDC	Dec 2018
Design/mock-ups of ePRO screens	Sites	Jan 2019
User feedback on screen designs	UoM	Jan/Feb 2019
Mechanism for file transfer	Sites / UKRDC	Jan 2019
Mechanism for file processing	Sites	Feb 2019
Development of ePRO screens	Sites	Feb 2019
Development of test plan	UoM	Feb 2019
Completed end-to-end test	Sites	Mar 2019

- A detailed GANTT chart for OPT-ePRO IT developments will be provided separately.
- Go-live has been planned for April 2019 (i.e. start of data entry and transfer)
- After go-live, we will observe patients using PatientView for data entry in clinic during the first 12 months. **NICE-TO-HAVE:** opportunity to tweak ePRO screens in the EHR in case we identify any user requirements that need addressing.

Appendix 1: POS-S Renal questionnaire

POS-S RENAL – PATIENT COMPLETION

Below is a list of symptoms, which you may or may not have experienced. Please put a tick in the box to show how you feel each of these symptoms has affected you and how you have been feeling over the past week.

	Not at all No effect	Slightly but not bothered to be rid of it	Moderately limits some activity or concentration	Severely activities or concentration markedly affected	Overwhelmingly unable to think of anything else
Pain	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Shortness of breath	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Weakness or lack of energy	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Nausea (feeling like you are going to be sick)	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Vomiting (being sick)	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Poor appetite	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Constipation	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Mouth problems	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Drowsiness	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Poor mobility	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Itching	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Difficulty sleeping	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Restless legs or difficulty keeping legs still	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Feeling anxious	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Feeling depressed	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Changes in skin	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Diarrhoea	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Any other symptoms:					
	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

Which symptom has affected you the most? _____

Which symptom has improved the most? _____

Appendix 2: EQ-5D-5L

Figure 1: EQ-5D-5L (UK English sample version)

Under each heading, please tick the **ONE** box that best describes your health **TODAY**

MOBILITY

- I have no problems in walking about
- I have slight problems in walking about
- I have moderate problems in walking about
- I have severe problems in walking about
- I am unable to walk about

SELF-CARE

- I have no problems washing or dressing myself
- I have slight problems washing or dressing myself
- I have moderate problems washing or dressing myself
- I have severe problems washing or dressing myself
- I am unable to wash or dress myself

USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)

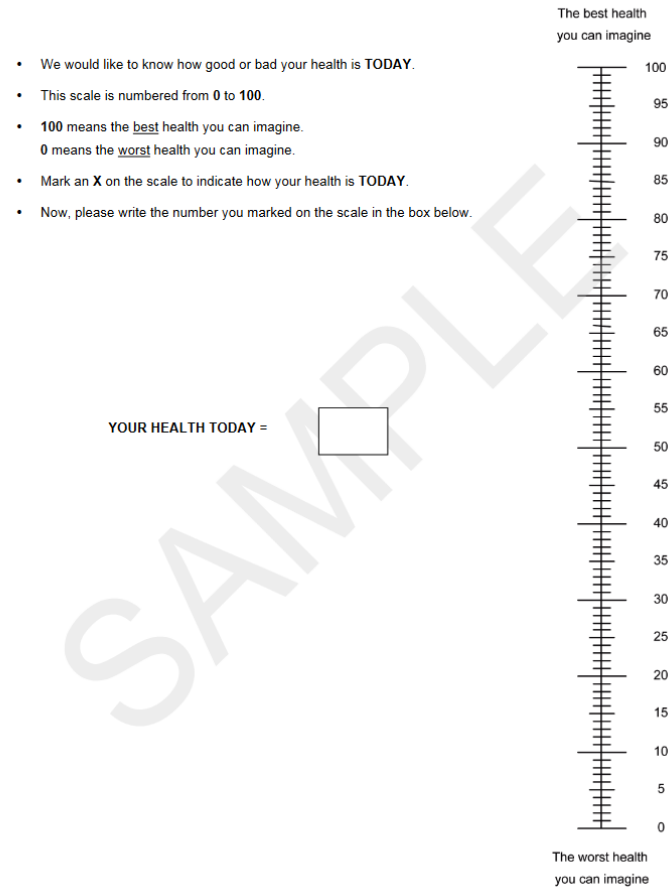
- I have no problems doing my usual activities
- I have slight problems doing my usual activities
- I have moderate problems doing my usual activities
- I have severe problems doing my usual activities
- I am unable to do my usual activities

PAIN / DISCOMFORT

- I have no pain or discomfort
- I have slight pain or discomfort
- I have moderate pain or discomfort
- I have severe pain or discomfort
- I have extreme pain or discomfort

ANXIETY / DEPRESSION

- I am not anxious or depressed
- I am slightly anxious or depressed
- I am moderately anxious or depressed
- I am severely anxious or depressed
- I am extremely anxious or depressed



Appendix 3: example data file as transferred from PatientView to the UKRDC

Notes

- The UKRDC will make a small amendment to the question schema by adding an optional extra field QuestionText. This is for returning values entered for the 'any other symptoms' in the POS-S questionnaire (see Appendix 1; Q18-20 in the schema).
- ExteralID (in ProgramMembership) is a unique reference for an individual patient's membership, which will be generated by PatientView based on the information that is already in the file. UKRDC can share the formula for creating this ID if needed.

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```




Appendix 4: example of symptom overview screen

Below an example of the overview screen as currently available within RenalWare, the renal unit EHR system at King's College London.

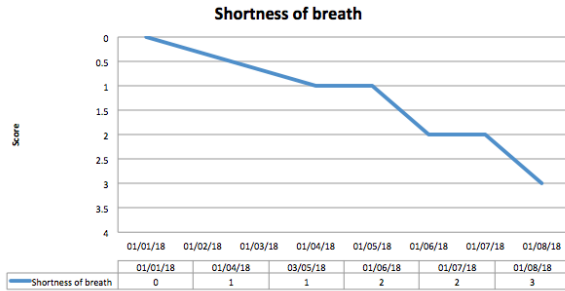
POS-5 Surveys (Most recent at top)

KEY: 0=Not at all 1=Slightly 2=Moderately 3=Severely 4=Overwhelmingly

Date	User	TOTAL	pain	SOS	weakn	N/V	Poor App	Const	Mouth	drowsy	mobility	itch	insomn	legs	anxiety	depr	skin	diarrh	other 1	other 2	other 3	affected most	improved most	
17/01/2018	soliveros	3	0	0	2	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0		weakness	
05/07/2017	soliveros	8	2	1	2	0	0	0	0	1	2	0	0	0	0	0	0	0	0	0	0		poor_mobility	
06/02/2017	sghimire	11	3	0	3	0	0	0	0	1	3	0	0	1	0	0	0	0	0	0		pain	poor_appetite	
30/09/2016	operalta	5	1	0	2	0	0	0	0	0	1	0	0	1	0	0	0	0	0	0		weakness	poor_mobility	
03/06/2015	operalta	17	3	1	2	0	0	1	0	0	1	2	1	2	2	0	0	0	0	0	0	pai at the back 2	pain	shortness_of_breath
13/12/2014	mneale	13	1	2	2	0	0	1	0	0	1	2	1	0	1	1	1	0	0	0	0			
28/06/2013	pmaglaque	4	0	0	1	0	0	0	0	0	1	1	1	0	0	0	0	0	0	0	0		poor_mobility	
03/10/2012	sstrestha	2	0	0	1	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0			
20/05/2011	kvinen	8	0	0	2	0	0	0	0	0	2	0	0	2	0	0	2	0	0	0	0	eye problem		other1 skinchanges

Appendix 5: Example of simple line graph for symptom-specific screens

Single symptom line graph



Appendix 6: example of presenting an overview of quality of life scores

Date	Overall health *	Mobility	Self-care	Usual activities	Pain/ discomfort	Anxiety/ depression
17/01/2018	70	2	1	1	2	1
05/07/2017	65	2	2	1	2	1
06/02/2017	45	3	2	2	2	1
30/09/2016	28	4	3	3	2	2

* Overall health reflects the value that patients entered in the 'Your health today' field (see Appendix 2)

Appendix 7: example of combined PROM screen

Below an example of an overview screen from the Ambuflex system (Denmark) that displays results for a range of patient-reported outcome measures (PROMs), including symptom scores and quality of life (SF-36 and WHO-5).

		HISTORY	SETTINGS	DEMOGRAPHICS	SHOW PRO
		WE 17 OCT 2012	TH 10 JAN 2013	SU 21 APR 2013	TH 08 AUG 2013
Seizures	Overall 12 months	Number of days: 0	Number of days: 0	Number of days: 0	Number of days: 0
	Absences 3 months	Number of days: 0	Number of days: 0	Number of days: 0	Number of days: 0
	Seizures 3 months	Number of days: 0	Number of days: 0	Number of days: 0	Number of days: 0
Symptoms	Headache	2	1	2	1
	Dizziness	3	3	3	1
	Shaking / tremor	4	4	4	2
	Double vision	1	1	2	1
	Loss of appetite	1	1	1	1
	Memory	3	1	3	2
	Concentration	2	3	4	2
	Aggressiveness	3	3	4	2
	Lethargy	2	2	3	2
	Sadness	4	3	4	1
	Anxiety attack	1	1	4	1
	Presence of side effects	1	1	1	1
	Eating too much	1	1	3	1
	Compliance	Forget medicine	4	4	4
SF-36	General health	2	2	4	3
WHO-5	Wellbeing index	52	60	56	80
	State of mind/mood	2	1	2	2
	Energy	2	2	4	2
	Interest	3	6	4	2
	Rested	5	5	4	2
	Relaxed	5	1	4	2