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## **RHAPSODY – Internet-Based Support For Caregivers of People with Young Onset Dementia: Program Design and Methods of a Pilot Study <sup>1</sup>**

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## **Abstract**

**Background:** Young Onset Dementia (YOD), defined by first symptoms of cognitive or behavioral decline occurring before the age of 65 years, is relatively rare compared to dementia of later onset, but it is associated with diagnostic difficulty and heavy burden on affected individuals and their informal carers. Existing health and social care structures rarely meet the needs of YOD patients. Internet-based interventions are a novel format of delivering health-related education, counseling and support to this vulnerable yet underserved group.

**Methods:** The RHAPSODY (Research to Assess Policies and Strategies for Dementia in the Young) project is a European initiative to improve care for people with YOD by providing an internet-based information and skill-building program for family carers. The e-learning program focuses on managing problem behaviors, dealing with role change, obtaining support and looking after oneself. It will be evaluated in a pilot study in three countries using a randomized unblinded design with a wait-list control group. Participants will be informal carers of people with dementia in Alzheimer's disease or behavioral-variant Frontotemporal degeneration with an onset before the age of 65 years. The primary outcome will be caregiving self-efficacy after 6 weeks of program use. As secondary outcomes caregivers' stress and burden, carer health-related quality of life, caring-related knowledge, patient problem behaviors and user satisfaction will be assessed. Program utilization will be monitored and a health-economic evaluation will also be performed.

**Conclusions:** The RHAPSODY project will add to the evidence on the potential and limitations of a conveniently accessible, user-friendly and comprehensive internet-based intervention as an alternative for traditional forms of counseling and support in healthcare, aiming to optimize care and support for people with YOD and their informal caregivers.

**Key words:** dementia, young, early, onset, caregiver, e-learning, education, guide

**Running title:** RHAPSODY: Internet-based support for young onset dementia caregivers

## **Introduction**

Caring for a person with dementia imposes a heavy burden on informal carers and is associated with negative effects on their health and quality of life (Etters et al., 2008). Several meta analyses and systematic reviews have concluded that well-designed support programs decrease burden and improve psychological well-being of informal carers, and enable them to provide at-home care for a longer period of time. Caregiver interventions are particularly effective if they go beyond medical information and teach behavior management skills, offer advice on available services, and provide strategies for self-care

(Huis in het Veld et al., 2015; Parker et al., 2008; Vandepitte et al., 2016). Interventions that target carers have been shown to provide benefits for the person with dementia as well (Brodaty et al., 2003; Schulz et al., 2002). The increasing use of computers and internet by older adults (Gell et al., 2015) opens novel opportunities for delivering information, counseling and support to informal caregivers, particularly when traditional formats such as face-to-face meetings or support groups are difficult to organize or are hindered by geographical or mobility related barriers. Advantages of internet-based e-learning and information programs over traditional formats of carer support include convenience of use, overcoming of geographical barriers, variety of information delivery formats and low cost (Goodwin et al., 2013; Serafini et al., 2007). Web-based (Boots et al., 2014) multi-component interventions for dementia caregivers have been reported by users to be educational, convenient, beneficial and interesting (Lewis et al., 2010). Such interventions have been shown to reduce caregiver depression (Blom et al., 2015) and stress (Kajiyama et al., 2013), improve illness-related knowledge and self-efficacy (Cristancho-Lacroix et al., 2015), and strengthen empathy and understanding (Hattink et al., 2015).

In the RHAPSODY project (Research to Assess Policies and Strategies for Dementia in the Young) a group of researchers from 6 European countries (France, Germany, The Netherlands, Portugal, Sweden, United Kingdom) aims to develop a comprehensive, multi-media, educational and skill-building program for informal carers of people with young onset (i. e. symptoms occurring before the age of 65 years) dementia (YOD) delivered via the internet, and to evaluate the e-learning program in a randomized, wait-list controlled, multi-center pilot study.

Carers of people with YOD were chosen as a target group for the web-based intervention for several reasons. Although the prevalence of YOD is much lower than that of dementia in later life (Harvey et al., 2003; Mercy et al., 2008), it has a more severe impact on affected individuals and their informal carers. This is due to: high frequency of problem behaviors (Sansoni et al., 2014); disruption of family relations (Svanberg et al., 2014) including partnership and intimacy (Harris, 2009), and often involving children (Millenaar et al., 2014); frequent conflicts between the caring role and other family or professional responsibilities (Ducharme et al., 2013); significant economic consequences due to early retirement or reduced working hours. People with YOD and their informal carers are an underserved group, because correct and timely diagnosis of YOD as well as appropriate

counseling and medical treatment may be difficult to obtain (Mendez, 2006). Furthermore, existing health and social care structures for people with dementia rarely meet the needs of this particular group of patients and family carers since they have been designed for older adults (Bakker et al., 2010). Services specifically designed for people with YOD and their carers are available at only a few centers across Europe (Goldberg, 2011; Hooghiemstra et al., 2012), and access to these services may be hindered by geographical and mobility-related barriers.

## **Methods**

### *Study design*

The pilot study has been designed as a randomized trial with a wait-list control group. It will be conducted in three countries (France, Germany and United Kingdom) and focuses on the acceptability of the e-learning program. It will also trial tests procedures (e. g. recruitment, randomization, programme utilization) and outcome measures (e.g., caregiving self-efficacy, perceived stress and burden, health-related quality of life, user satisfaction, caring-related knowledge) to help with planning a larger trial to investigate the efficacy and cost-effectiveness of the intervention (Craig et al., 2008; Thabane et al., 2010). After providing written informed consent and baseline assessment, participants will be randomly assigned to the e-learning program or to a wait-list control group without immediate access to the intervention. The immediate-start group will have access to the e-learning program and to technical support provided by the research team for six weeks. Throughout the study, both groups will continue to receive care as usual. After mid-point assessment, the control group will have access to the program including technical support for six weeks. The e-learning program will continue to be available to the immediate-start group during this second phase to determine whether prolonged access to the program increases usage and provides any further benefits to carers. Effect sizes of the outcome measures will be estimated and a preliminary health economic evaluation will be performed. Information on patients including diagnosis, symptoms, treatment and services received will be obtained from the carers at baseline. Approval for the pilot study will be obtained from the local ethics boards, and the trial has been registered at the German Registry for Clinical Trials (DRKS00009891). The trial flow chart is shown on Figure 1.

*Figure 1 goes here*

### *Participants*

The participants will be recruited by various means, including through memory clinics and post-diagnosis services having access to large YOD populations, and patient advocacy groups. Participants will be primary informal carers of people meeting diagnostic criteria for dementia in Alzheimer's disease (AD) (McKhann et al., 2011) or behavioral variant frontotemporal dementia (bvFTD) (Raskovsky et al., 2011) with symptom onset before the age of 65 years, diagnosis established before the age of 68 years, and diagnosis disclosed no more than three years prior to enrolment in the study. Carers of people with other causes of dementia, participants who do not have a minimum level of computer literacy, and those without access to the internet will be excluded. A sample size of 60 participants is considered to be adequate for the pilot study (30 per group, 20 in each country) (Lancaster et al., 2004; Teare et al., 2014).

### *Assessments*

Participants will be assessed at three time points: baseline (after consent, before randomisation), six weeks (the mid-point when the control group crosses over to receive the intervention); 12 weeks (the final endpoint). At baseline (week 0) information will be gathered from carers on socio-demographic background, history of the patient's illness and treatment, as well as use of existing support and information services. The selection of outcome measures was informed by practical factors including administration time, with a preference for self-report measures, validated scales and instruments available in the 3 working languages (English, French and German). Data will be gathered by face-to-face or telephone interview (Table 1).

### *Outcomes*

*Caregiving self-efficacy* was selected as the primary outcome. The Revised Scale for Care-giving Self-Efficacy (RSCSE) (Steffen et al., 2002) was identified as the most domain-specific tool to assess care-giving activities, offering optimum validity compared to more general measures. It contains 19 items covering the areas of obtaining respite, responding to disruptive behaviors and controlling upsetting thoughts about caregiving.

Secondary outcomes cover a range of targeted issues. *Caregiver stress* will be assessed using the 10-item version of the The Perceived Stress Scale (PSS) (Cohen et al., 1983), which is a quick to administer and widely used indicator of subjectively evaluated stress with well-established acceptable psychometric properties. *Caregiver burden* will be measured using the 10-item short form of the Burden Scale for Family Caregivers (BSFC) (Gräsel et al., 2003) which assesses carers' global subjective burden relating to the care of a chronically ill person. The extent of *problems dealing with behavioral change* will be indicated by The Revised Memory and Behavior Checklist (RMBC) (Teri et al., 1992). This is a carer-report measure of symptoms in YOD patients and one of few instruments that evaluates both cognitive and behavioral symptoms, and provides an indication of the extent to which carers feel impacted by symptoms. *Health-related quality of life* will be rated on the EQ-5D-5L (EuroQuol-Group, 2009), a standardized instrument for indicating health status at five levels in five dimensions (mobility, self-care, usual activities, pain/discomfort, anxiety/depression) which is used in health economic analyses for the calculation of quality-adjusted life years (QALYs).

*Program feasibility, user satisfaction and computer literacy* will be investigated using the Technology Acceptance Model (TAM) (Venkatesh and Bala, 2008). This assesses perceived usefulness, ease of use, intention to use, computer self-efficacy and computer anxiety. To assess acceptability of the intervention, qualitative information on user experiences and satisfaction with program content and mode of delivery will be obtained through individual interviews with all participants using a semi-structured interview guide after week 12. Since no appropriate and validated instrument is available for the assessment of dementia- and caring-related knowledge, a questionnaire was developed by RHAPSODY members with special expertise in education on dementia. Engagement with the intervention will be assessed through utilization data (e.g., number and duration of visits, click paths) that is logged for each user during participation in the e-learning program. In addition, the time spent in coaching participants, managing the website when it is live, and monitoring the online forum by site personnel, technical staff and project members, respectively, will be logged.

*Table 1 goes here*

## *Intervention*

The educational and skill-building e-learning program is being developed to assist informal carers in coping with YOD and managing the behavioral, interpersonal, organizational and financial problems encountered, and to provide a comprehensive resource of information. The design of the intervention adopts a multiple-component model of dementia carer support which has been successfully evaluated in the Resources for Enhancing Alzheimer's Caregiver Health (REACH) II Study (Belle et al., 2006; Burgio et al., 2009). It also takes account of the official policies and guidelines for health and social care professionals on the care of people with YOD, and the information available for patients and carers in the six countries involved, both of which were researched through open internet searches and by targeting the web sites of relevant organizations (government sector, professional bodies, health insurers, provider groups and patient advocacy organizations). Evidence on the care needs and access to services of people with YOD and their informal carers is available from a systematic review (Millenaar et al., 2016) and is complemented by findings from qualitative interviews conducted as part of the Needs in Young Onset Dementia (NeedYD) Study in the Netherlands (Millenaar et al., 2015) and from focus groups with family carers undertaken in five other European countries.

Based on this evidence the intervention will be organized into seven chapters addressing the major components of support for YOD carers, including medical information (with a focus on problem solving), dealing with behavioral change, coping with role shift in the family, and finding help. The program will be developed as a web-based, multimedia e-learning course, comprising of explanations by experts, case study examples as well as interviews with family carers and service providers. It will also include sections where participants can choose topics to work through in more detail. To meet the users' needs for interaction with fellow carers with whom they may share experiences, the program will also include a user forum. The forum will be monitored to eliminate inappropriate content. Similar online programs that included social functionalities have been successfully applied in other target groups, e. g. in overweight adults (Pressler et al., 2010).

### *Control group*

A wait-list control group will be used in order to enable all participants to benefit from the intervention and to enhance recruitment. Participants allocated to the control group will have access to the e-learning program for six weeks following the mid-point assessment.

### *Statistical analysis*

Data will be entered at each site into a common central database using an electronic case record form. The primary end point will be the six-week assessment. Descriptive statistics will be conducted to detail the study population characteristics at baseline. The impact of the intervention on each outcome will be assessed by comparing the change score (week 0 to week 6) between the intervention group and the control group using t-test or non-parametric tests as appropriated. An intention-to-treat procedure (ITT analysis) will be applied. The possible additional benefit of another six weeks of access to the program will be determined by a global ANOVA including the following fixed effects: group (intervention or control), period (period 1: weeks 0-6; period 2: weeks 6-12) and the interaction between group and period. This will indicate whether periods 1 and 2 differ in the intervention and / or control groups and whether the intervention group differs from the control group in period 2. Analysis of satisfaction and acceptability of the program will be conducted based on program analytics (back-end data), triangulated with findings from self-report questionnaires. Qualitative feedback will be analyzed using a content analysis. Subgroup analyses will explore whether particular participant variables at baseline are associated with program efficacy (such as diagnosis, time since diagnosis, patient gender, caregiver gender, country) are associated with program outcomes. The association between program usage and participant outcomes will also be tested. All quantitative analyses will be exploratory since this is a pilot study and no power calculations have been performed.

### *Health economic analysis*

An embedded health economic analysis will assess the costs and outcomes of the e-learning intervention in a cost-consequences framework at the six-week follow-up point. The costing exercise will focus on direct intervention delivery costs, including the time spent by technical staff in managing the website when it is live, and time spent monitoring

the online forum. The resources devoted to the development of the e-learning program and its translation will not be considered since these are fixed costs and costs per user will fall the more widely the program is accessed. An initial estimate of the incremental mean cost per QALY gained from access to the intervention will be performed using data collected from EQ-5D-5L in preparation for the full cost-effectiveness analysis in the larger trial.

### *Intervention refinement and dissemination*

The results of the pilot study, including both quantitative data and qualitative feedback from participants, will be used to refine the e-learning program and to produce a final product that will be made available to organizations supporting YOD patients and carers across Europe, providers, including insurers and medical boards. National and municipal authorities will be approached since the internet-based e-learning program is particularly suited for use in rural areas where few support structures and services are available. Selected content of the intervention will be used to create a range of educational materials addressing a variety of potential user groups including informal carers, healthcare professionals and service providers.

## **Discussion**

The internet and modern consumer electronics offer novel ways for delivering information and counselling to people with dementia and their informal carers as a complement or alternative to traditional formats of education and support. The RHAPSODY project takes advantage of the new media to provide an online information and skill-building intervention that is specifically tailored to the needs of carers of people with YOD for whom appropriate services are scarce and may be difficult to access. These informal carers are particularly vulnerable, highly burdened and underserved, but being younger than most dementia carers, may especially benefit from an online, computer-delivered intervention. The Rhapsody program builds on the existing evidence on dementia caregiver support, on surveys of the policy and information environment, and on an analysis of individual needs and access to care. Hence, it focuses on the areas that are most relevant to carers of people with YOD, including practical problem solving, dealing with psychological and interpersonal issues, finding help and looking after oneself.

In recent years, online programs of differing content, format and duration have been created for professional and non-professional dementia caregivers released by a number of institutions and organizations, including nursing schools (<https://www.coursera.org/course/dementiacare>), a research consortium funded by the European commission (<http://www.startraining.eu>), care education providers (<http://www.dementiaforum.org/education/e-learning/>) and patient organizations (<http://www.scie.org.uk/dementia/e-learning/>). Few internet-delivered e-learning programs for informal dementia carers have been evaluated in randomized controlled trials, demonstrating benefits regarding caregiver empathy (Hattink et al., 2015), depression and anxiety (Blom et al., 2015) and perceived stress (Kajiyama et al., 2013). It is not clear to date whether this type of intervention can increase behavior management skills, alleviate psychological and interpersonal problems, enhance help-seeking competence, or improve self-care. Another open question is which components of online programs including social functionalities such as discussion forums are particularly beneficial to dementia carers. To our knowledge, the only online information and support program that specifically targets YOD is offered by the Alzheimer's Association (<http://training.alz.org/products/1025/living-with-alzheimers-for-younger-onset-alzheimers>). This program does not address other forms of dementia.

The RHAPSODY pilot study will explore the usability and acceptability of the e-learning and support program, and indicate areas for refinement. It will provide measures of outcome for carers (self-efficacy, caring-related knowledge, subjective burden and stress, skills for dealing with patients' problematic behaviors, access to available services). Any improvements in these areas may translate into gains relating to patients' behavioral and functional status (Brodaty et al., 2003; Schulz et al., 2002). This information gathered will provide a basis for planning a fully powered, multi-centre, randomized and controlled trial evaluating the efficacy and cost-effectiveness of the e-learning program in a larger participant population. The pilot study will add to the evidence on the potential and limitations of internet-delivered educational and skill-building media in dementia care. It will also provide insight into the importance of specific program components for acceptance, adherence and user benefit and satisfaction. The evidence gained may have an impact on the development of digital learning in various segments of healthcare.

## **Conflict of interest**

None

## **Author's roles**

A. Kurz planned the study, wrote the grant application and contributed the main parts of the manuscript.

C. Bakker co-designed, coordinated and conducted the needs assessment analysis.

M. Böhm is a technical advisor to the study and is responsible for the online data collection and analysis.

J. Diehl-Schmid provided scientific input to the e-learning program and assisted in writing the article.

B. Dubois participated in designing the pilot study.

C. Ferreira contributed to several components of the e-learning program.

H. Gage leads the policy and information environment analysis and is responsible for the health economic evaluation.

C. Graff provided scientific input to the e-learning program and helped with writing the article.

T. Hergueta designed the pilot study and is responsible for the statistical analysis.

S. Jansen leads the development of the dissemination strategy of the project.

B. Jones has contributed to the English version of the e-learning program.

A. Komar is responsible for the online multimedia format of the intervention.

A. de Mendonça contributed to designing the pilot study and provided e-learning program components.

A. Metcalfe participated in the design of the pilot study and is responsible for the French version of the e-learning program.

K. Milecka is the project manager and coordinated the writing of the manuscript.

J. Millenaar contributed to the design and conducted the needs assessment component of the project.

A Orrung Wallin assisted with writing the manuscript.

J Oyeboode has contributed to the English version of the e-learning program.

H Schneider-Schelte designed the family issue and self-care parts of the e-learning program.

S Saxl was involved in the development of the interpersonal and self-care parts of the programme and contributes to the development of the dissemination strategy.

M de Vugt leads the needs assessment and contributed to the design of the study.

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Figure 1: Study flow diagram

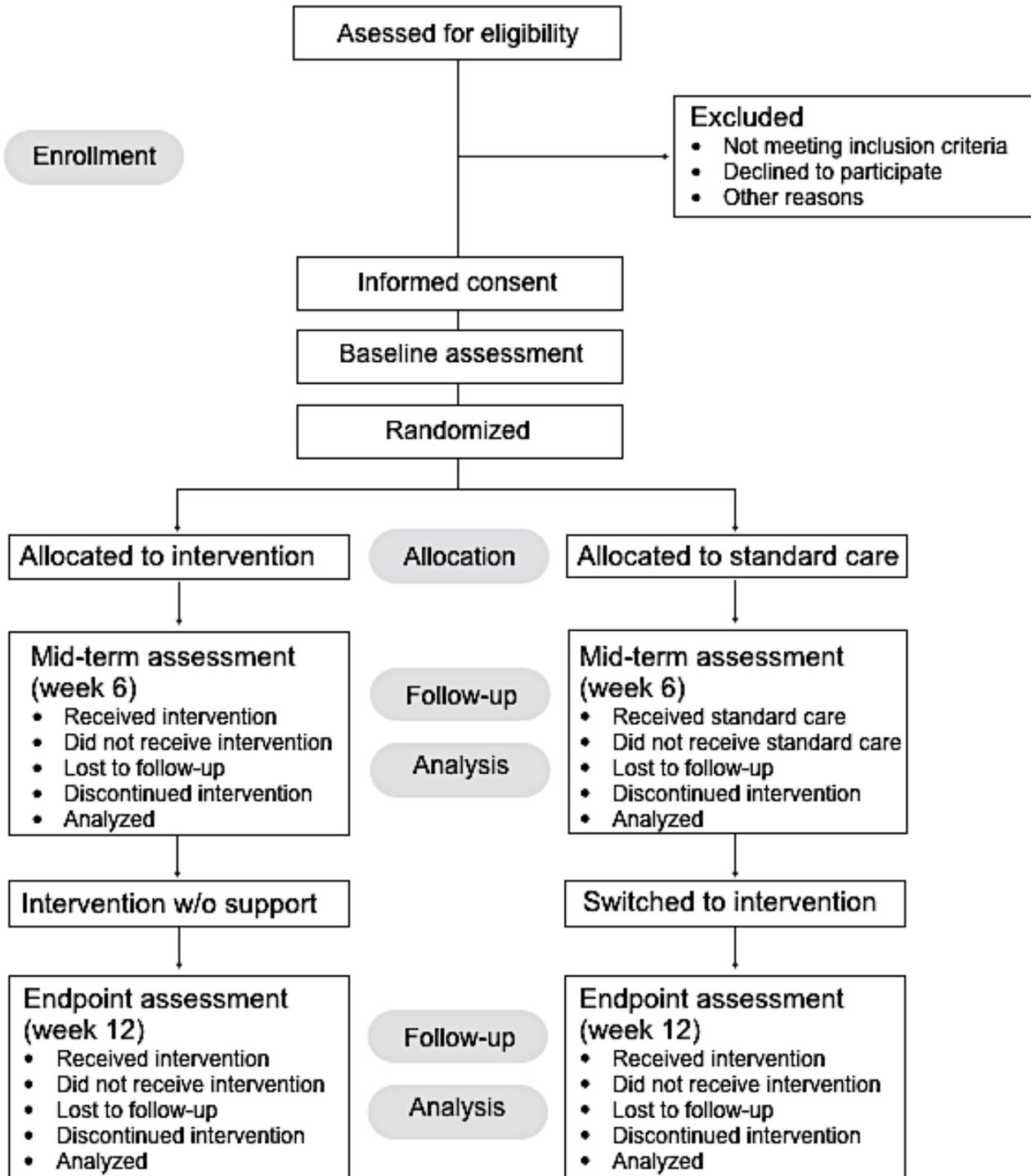


Table 1: Outline of the assessments and timelines of the pilot study

Assessment	Baseline (0 weeks)	Mid-term (6 weeks)	Endpoint (12 weeks)
Demographic information	x	-	-
Caring environment and support received	x	-	-
Care-giving self-efficacy (RSCSE)	x	x	x
Dementia and caring-related knowledge questionnaire	x	x	x
Perceived Stress Scale (PSS)	x	x	x
Burden Scale for Family Caregivers (BSFC)	x	x	x
Revised Memory and Behaviour Checklist (RMBC)	x	x	x
Technology Acceptance Model (TAM)	x	x	x
Health-related quality of life (EQ-5D)	x	x	x
User satisfaction	-	x	x
Programme user behavior	continuous online recording		