JPND research
EU Joint Programme – Neurodegenerative Disease Research

Joint Programming Neurodegenerative Disease

Joint Transnational Call for Proposals

European research projects for the evaluation of health care policies, strategies and interventions for Neurodegenerative Diseases

Final Report

Please submit electronically to:

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JPND Joint Call Secretariat
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I General Information

1. Acronym of the collaborative project: RHAPSODY

RHAPSODY

2. Full Title of the project

Research to Assess Policies and Strategies for Dementia in the Young

3. Project Runtime:

April 2014 to March 2017, extended to December 2017

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6. Amendments in the budget of the project

None.

7 Amendments in the composition of the consortium

Prof. Jan Oyebode (University of Bradford, UK) contributed to WP3 by facilitating focus groups, as well as to WP5, where she was involved in the English translation and filming. Prof. Oyebode was also involved in the qualitative analysis of the pilot study results and in the writing of the final report.

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II. Lay Abstract of the project and its achievements (200-400 words)

In the RHAPSODY (Research to Assess Policies and Strategies for Dementia in the Young) project researchers from six European countries (France, Germany, the Netherlands, Portugal, Sweden, United Kingdom) collaborated to improve care for people with young onset dementia (YOD, i.e. symptoms occurring before the age of 65 years) by providing an internet-based information and skill-building programme for their informal carers. People with YOD are an underserved group, because correct and timely diagnosis as well as appropriate psychosocial counseling and medical treatment may be difficult to obtain. Furthermore, existing health and social care structures for people with dementia rarely meet the needs of people with YOD and their carers since they have been designed for older adults. The project started with an analysis of the policy and information environment for people with YOD and their carers in the six countries. Next, the specific needs of this particular group and their preferences for an online programme were assessed. This information was used for designing the programme. This includes 7 modules focusing on medical information, managing problem behaviors, dealing with role change, obtaining support, and looking after oneself. The online programme is available in four languages (English, French, German and Portuguese). It was evaluated in a multi-national pilot study using a mixed randomized design with a wait-list control group. Participants were 61 carers of people with dementia in Alzheimer's disease or behavioral-variant Frontotemporal degeneration. The overall rating of the programme by the participants was favourable in terms of length, detail of information, usefulness and language style. Results suggest that use of the programme may be associated with improvements in caregivers' perceived stress and emotional reactions to memory problems after 6 weeks. However, a definitive trial is needed to validate these findings. On average, participants accessed the programme approximately once a week and consulted 31 % of the large entire content. After project termination the online programme will be made publicly available through dementia associations and other non-profit organisations.

III. Description of the project and its results

This section is for internal use by the JPND joint call partner organisations. Please also describe potential problems and highlights so we can shape our future call scheme. This information will not be published.

1. Structure of the project

1.1. Work packages of the project

The work packages, their content and the allocated partners are shown on Table 1.

Table 1: Work packages

WP	**Title** (subtitles, if applicable)	**Partner N°**
WP1	Coordination and project management	1 (lead)
WP2	Policy and information analysis	2 (lead)
WP3	Needs assessment	3 (lead)
WP4	Intervention design and product development	1 (lead)
WP5	Pilot study	4 (lead)
WP6	Dissemination	7 (lead)

1.2. Project report of goals, tasks and milestones

Work Package 1: Coordination, monitoring and quality management (P1)

Goals and tasks

1. To manage the Consortium, oversee timelines and deliverables, organise the group meetings
2. To coordinate efforts and to ensure information flow between participants
3. To provide data management and data sharing

Milestones: Consortium Agreement, General Assembly Meetings Q2/2014, Q2/2015, Q3/2016, Q2/2017.

Work Package 2: Policy and information environment analysis (P2 lead, P 1, 3, 4, 5, 6, 7 involved)

Goals and tasks

1. To analyse and compare the health and social care policies including means of financing and delivering health care in participating countries with regard to people with YOD and their carers
2. To review and compare policies, guidelines and information for health care professionals regarding the management of YOD in the six countries
3. To identify, describe and compare available information provided for people with YOD and their carers by national organisations

Milestones: Content input to WP4, report.

Work Package 3: Needs assessment (P3 lead, P 1, 2, 4, 5, 6, 7 involved)

Goals and tasks

1. To conduct a review of the literature on needs of people with YOD and their carers
2. To identify the needs of people with YOD and their carers at different stages of the disease
3. To explore differences in experiences, needs and access to services of people with YOD and their carers across 6 European countries

Milestones: Content input to WP 4, report.

Work Package 4: Intervention design and product development (P1 lead, P 2-8 involved)

Goals and tasks

1. To design an intervention for carers according to the identified healthcare policies, strategies and needs of people with YOD
2. To provide an internet-based, interactive convenient e-learning format of delivery

Milestones: Screenplays finalised Q4/2014, programme prototype ready for piloting Q4/2015, programme finalised Q1/2017

Work Package 5: Pilot Study (P4 lead, P1, 2, 8 involved)

Goals and tasks

1. To evaluate the e-learning programme in a pilot study with regard to feasibility, acceptance and user satisfaction
2. To compare and evaluate different outcome measures
3. To perform an economic evaluation of the intervention

Milestones: Recruitment complete Q1/2016; analysis finalised Q1/2017; final publication Q1/2017

Work Package 6: Dissemination, implementation and exploitation (P7 lead, P1-6 & 8 involved)

Goals and tasks

1. To communicate emerging scientific findings of the project
2. To develop a comprehensive dissemination and sustainability strategy

Milestones: Dissemination strategy ready Q2/2014; website launched Q3/2014; young researchers' workshop Q2/2015; final conference Q4/2017

2. Delivery of the project

2.1. Major achievements of each work package and of the overall project

WP1 (Coordination; leader: Technische Universität München)

1. Management of the Consortium

Four General Assembly meetings were organised:

- Munich, Germany, 28-30 April 2014
- Maastricht, The Netherlands, 22-23 April 2015
- Lisbon, Portugal, 22-23 September 2016
- Berlin, Germany, 19-20 June 2017

At the kick-off meeting a scientific delegation from Québec, Canada, was present and expressed interest in the development of the online programme and in future collaboration. Detailed protocols of the meetings were written and distributed to the group. A Steering Committee was appointed at the kick-off meeting. An *External Advisory Board* was set up and invited to the General Assembly meetings.

A *Consortium Agreement* was prepared, agreed and then signed on 30 April 2014.
For the time after the RHAPSODY-project an *Amendment to the Consortium Agreement* (regarding intellectual property, final version due in December 2017) was worked out.

Application for a cost-neutral extension (2 January 2017): The transformation of the screenplays into a user-friendly e-learning programme was unexpectedly complex. Also, there were delays in obtaining the ethics approvals for the pilot study in several countries as well as difficulty recruiting participants, with the effect that the pilot study started 3 months later than originally planned. Therefore, all project partners applied for a cost-neutral extension of the project until 31 October or 31 December 2017, respectively.

Follow-up projects: RHAPSODY-Plus: An important feedback from the participants of the pilot study was that an online programme that an online program is valuable, but might be extended with individual face-to-face counseling to meet carers‘ needs. Therefore, a project was started in collaboration of Technische Universität München and the University of Melbourne (Victoria, Australia) which complemented the e-learning programme by two counseling sessions provided by a social worker and a psychologist through video-conferencing. The project is funded by an Anna Boyksen Fellowship from Technische Universität München – Institute for Advanced Study.
RHAPSODY 2: Encouraged by the results of the pilot study the Consortium plans to apply for a large follow-up study powered to investigate the efficacy and cost-effectiveness of the e-learning programme in comparison to standard forms of support (e. g. group psycho-education, counseling). The University of Melbourne (Victoria, Australia) and the University of Montreal (Québec, Canada) are interested to participate as full partners.

2. Coordinating efforts and ensuring information flow between participants

Monthly telephone conferences were held to coordinate efforts and to ensure information flow between participants, to plan and agree on necessary steps and to keep track on timelines. All calls were documented and notes were distributed to the group. A project file sharing platform based on Seafile was provided by IMC to all RHAPSODY partners. This enabled convenient exchange of documents and constantly accessible project documentation.

3. Data management and data sharing

As part of TUM, Münchner Studienzentrum was in charge of data management. An electronic database was set up for the pilot study enabling remote data entry (WP5). After collection and cleaning the data were sent to UPMC for analysis. Study data will be stored at Münchner

Studienzentrum after project completion and will be made available upon request to other study groups.

WP2 (Policy and information environment; leader: University of Surrey)

1. Aim

The primary purpose of WP2 was to review the availability of information in the six countries that addressed the needs of families living with YOD, and identify gaps in order to provide guidance to the development of the online programme.

2. Methods

Searches for YOD information for patients and carers were conducted between September and December 2014. Standardised research procedures were maintained across countries via in-person and Skype meetings, teleconferences and email. Ethical approval was not required as no participants were recruited.

Websites of organisations with potential interest in dementia were targeted: national and regional government agencies; professional and provider associations; third sector (voluntary, charity) patient advocacy groups; and pharmaceutical companies. Lists of organisations were developed in consultation with local YOD experts. Lateral searching covered other potential sources.

Entire websites of YOD agencies were included. The YOD-specific content within websites of organisations with broader remits was identified using search terms (dementia, young/er onset, early onset, pre-senile, younger people, working age, carer) applied in local languages. YOD information was saved for analysis and links were followed. All accessible styles and media forms were relevant, including online text, printed copies (fact sheets, booklets, articles, books) and audio or audio-visual items (recordings, films, DVDs). Eligibility was based on source and content: sources had to be recognised organisations or authorities (government, public agencies, professional or provider organisations, industry, advocacy groups), and content had to be nationally relevant. Independent personal accounts, opinions, output from local meetings and blogs were excluded (content may not have been checked for accuracy).

Details were recorded in an Excel spreadsheet: title, author/agency/publisher, date, format of material, approximate size (pages/length), website address, date accessed. A brief description of YOD content was provided. Country reports (prepared in English) included the spreadsheet, material available and signposted information gaps.

Reports were subject to narrative synthesis and comparative analysis in England involving individual discussions with countries to clarify understanding and ensure consistency in the items that were included. This process resulted in some materials being dropped. The content descriptions of the retained items were reviewed and evaluated by two independent researchers in order to identify topics covered. These were discussed and refined to define eight key subject areas: general YOD background; types and symptoms; diagnosis; treatment and therapies; social and emotional (family perspectives, loss, bereavement); formal implications (employment, driving, legal, financial); residential (technology, home adaptations for independence, respite and long term care); resources (help and support). This provided a picture of the overall availability of information by country and gaps in coverage. Results were verified in each country at each stage of the synthesis. The continued availability of sources was checked in October 2016 and the search was updated to identify new resources.

3. Results

Initial searches identified 21 sources: six each in the Netherlands and England, three in France, and two each in Germany, Portugal and Sweden. Two years later, the same sources were still available, although some web addresses and content had changed. About half (11/21) the sources were from the third/voluntary sector. No professional associations or pharmaceutical companies provided

information. In the Netherlands, information was produced by a group of nursing homes and a tertiary Alzheimer's Centre collaborating with a University.

Four dedicated YOD websites were identified, three voluntary sector (Young Dementia UK (England), national Young Dementia Reference Centre in France and Alzheimer's Society in Portugal) and the tertiary Alzheimer's Centre/University collaboration in the Netherlands. Four books (two each in England and Netherlands) written for people with YOD and carers were identified from 'other resources' sections of websites. All other YOD information was provided as sub-entries within generic dementia sources, including Alzheimer's Societies in all countries except Sweden, the National Health Service and Social Care Institute of Excellence in England, public broadcasting channels in the Netherlands, two national government agencies in Sweden, a non-profit organisation producing training materials in Portugal, and a commercial health information service in France. Some sources provided multiple items on YOD. Videos were available in England (2), France (2) and the Netherlands (4).

Regarding the content of the materials: comprehensive information was provided by single sources in Netherlands, England and France (three websites, three books). Topic coverage elsewhere was piecemeal, but most frequently focused on medical aspects. In Germany, Portugal and Sweden, gaps related to implications of living with YOD, such as employment, finance, driving and legal issues.

4. Conclusions

Information for patients and carers in the six European countries was found to be variable, with the broadest range and most comprehensive coverage of topics in the Netherlands, followed by England and France. Searches suggested that access to information is less good in Germany, Portugal and Sweden. Overall, the focus was on medical aspects, rather than the implications of living with YOD, even though studies of information needs of carers of people with dementia indicate varied and changing needs, including anxiety related to disease progression, the dying process and psychosocial issues (Nichols et al., 2009, Wackerbarth et al., 2002, Washington et al. 2011, Prorok at al., 2013). Guidance on financial and legal matters (Wackerbarth et al., 2002), and help with practical problems and emotional, as well as physical, coping strategies (Nichols et al., 2009, Farran et al., 2004), are also paramount. Except in Sweden, the voluntary/charity sector plays a major role, while governments and provider organisations (other than in the Netherlands) have limited involvement.

5. Implications

Families living with long-term illness seek information as a coping strategy to ease continuous lifestyle and related psychosocial adjustment, for example with role transition and social stigma associated with dementia (Prorok at al., 2013, Lambert and Loiselle, 2007). In health and social care, information provision is important for enabling self care, thereby reducing demands on formal services, and support for family carers is viewed as an indispensable and effective component of dementia management, providing benefits to patients (Brodaty et al., 2003) and carers (Chien et al., 2011, Sörensen et al., 2006). Hence, European guidelines highlight carer support as an integral part of treatment (Sorbi et al., 2012). A comprehensive resource collating key information is likely to be the most helpful way to fill the information gap for families living with YOD. This was addressed through the development of the RHAPSODY online programme.

6. References

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WP3 (Needs Assessment; leader: Maastricht University)

1. Research questions

- What are the care needs and experiences with (access to) services of people with YOD and their informal caregivers, from the caregivers' perspective;
- What are differences and similarities in these findings across six European countries; and
- What do informal caregivers think about an online e-learning programme and which content do they believe is appropriate.

2. Methods

Systematic review: A search in the electronic databases PubMed, Psychinfo and CINAHL was performed. After appraisal of the methodological quality of the included studies based on a checklist for observational studies (Mallen, Peat et al. 2006) and a quality checklist for qualitative studies (Walsh and Downe 2006) studies were examined for their study and patient characteristics and main outcomes of interest with a standardized data extraction form.

Search terms:

- Dementia OR Alzheimer OR Frontotemporal (title or abstract)
- Young onset OR early onset OR presenile OR under 65 (title or abstract)
- Patient* OR carer* OR caregiver* OR child* OR family OR families OR
- relative* OR spouse* OR son* OR daughter* (title or abstract)
- support OR services OR care OR facilities (title or abstract)
- experiences OR satisfaction OR needs OR problems OR access (title or abstract)
- #1 AND #2 AND #3 AND #4 AND #5

Caregiver interviews: In the Netherlands, qualitative interviews with caregivers of YOD patients were performed during the Needs in Young-onset Dementia (NeedYD) study (van Vliet, Bakker et al. 2010) to examine their experiences with the use of available services and their care needs. Caregivers were selected from a total of 209 available participants. In order to capture differences and similarities between caregivers experiencing high levels of unmet needs as well as caregivers with low levels of unmet needs all 209 participants were ranked according to their number of unmet needs assessed with the Camberwell Assessment of Needs (Reynolds, Thornicroft et al. 2000). The audiotapes of all interviews were transcribed verbatim. Two researchers (JM and CB) independently analyzed the narratives using an inductive content analysis (Elo and Kyngäs 2008). Both researchers thoroughly read the interview transcripts and assigned open codes to depict all aspects of the content (Hsieh and Shannon 2005). Through the use of inductive reasoning these codes were grouped into categories if they referred to the same phenomenon and these categories were grouped into higher-order themes. Based on the analysis a theory was established.

Focus groups: Qualitative focus group interviews were conducted in each participating country (Germany, France, United Kingdom, Portugal, Sweden), except for the Netherlands to examine YOD caregivers' experiences with the use of available services and their care needs. All focus groups were taped or videorecorded (according to the countries specific regulations) and consecutively transcribed verbatim and analyzed with the Computer Assisted Qualitative Data Analysis Software (CAQDAS) programme 'Atlas.ti', version 6 or a similar qualitative analysis programme. In each country, transcripts were analysed according to a protocol developed by the WP3 leader. A deductive content analysis (Elo and Kyngäs 2008) was applied, in which the transcripts were first coded using an open coding system. After codes were assigned to quotes that had a relationship with the research questions, codes were systematically compared and grouped using a categorization matrix. The categories in the categorization matrix were derived from the above mentioned systematic review and the analysis of the caregiver interviews.

3. Results

Systematic review: Twenty-seven studies were included and a synthesis of the literature revealed six themes. The first theme concerned problems in the diagnostic period. Early recognition and referral was reported as an essential area which required improvement in order to obtain appropriate help in time. The second theme discussed the need for information about YOD and the availability of care throughout the caregiving trajectory. The third theme described barriers in access to care that hindered caregivers in finding the right services. The fourth theme showed the availability of appropriate services and specific unmet needs. The fifth theme illustrated that behavioural and personality changes pose a significant challenge for caregivers and other family members. The last theme showed the profound impact of YOD on caregivers.

Caregiver interviews: Findings revealed the following themes: (1) acceptance of the diagnosis (2) perception of the relationship (3) role adaptation (4) availability of services and tailored care (5) support system and communication, and (6) awareness in the person with dementia and acceptance of help. Several factors were more apparent in the caregivers who experienced few unmet needs opposed to the caregivers who experienced more unmet needs.

Focus groups: After open coding most codes could be placed in the categorization matrix, corroborating the results that were found in the Dutch interviews. However, additional topics emerged during the analysis, revealing some country specific differences. In France, caregivers explained that there were no typical grounds for retirement and that this caused legal and financial administrative complications when the professional life of the person with YOD abruptly ended. Also in Portugal and Germany it was mentioned that there was a lack of financial support and that the financial burden was high. Furthermore, caregivers in the German and Swedish focus groups mentioned that they needed help with bureaucratic and legal issues and felt that there was poor coordination and cooperation between the different care services. In the UK, Germany and Sweden the caregivers mentioned positive experiences as well. Based on the results of the analysis of the last part of the interview guide, recommendations were made for the structure as well as the content of the programme. Caregivers were asked what they thought were the advantages and disadvantages of an online course and whether they would consider using it. In addition, the caregivers gave feedback about important topics for the course.

4. Recommendations

Recommendations for the structure of the programme

- The intervention website should be highly accessible for caregivers and also be made available to health care professionals.
- The intervention website should act as the main portal for YOD families to access information on YOD. The website should be available straight after diagnosis and should also be accessible in the future.
- The website should clearly be linked to a trustworthy organisation and be actively promoted, i.e. through a media campaign
- The intervention should have a modular design, with separate modules for all the different family members (including the person with YOD, children) and should have an integrated search tool to easily access information across modules.
- There should be different modules for the different stages of the dementia.
- The intervention could be informative in nature, but should also provide a platform for personal contact with peers and health care professionals.
- The intervention should be regarded as a resource for YOD families, not so much as an educational programme
- The modules should be printable to allow for offline reading and be available as a book.

Recommendations for the content of the programme

- The information should appeal to the target audience and be easily comprehensible.
- The intervention should be complementary to the information that is already available and provide links to other places where this information can be found. The intervention is not a replacement for individual help and information.
- The intervention should offer an optimistic perspective on YOD, show users that they are not alone and everything is not hopeless.
- The intervention should provide country specific information (i.e. benefits) and information on available health care services.

5. Conclusion

The results indicate that there is still a lot of further development needed in the care for people with young onset dementia and their caregivers as they encounter a wide range of difficulties during the disease process specifically related to their younger age. The themes that were generated from the literature review and the interviews provided a good framework for the important topics to be included in the intervention. Furthermore the caregivers offered valuable feedback for the development of the intervention and the implementation.

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WP4 (Intervention design and product development; leader: Technische Universität München)

1. Programme design

The work on the intervention started by identifying key components of the intervention taking into consideration literature reviews, previous experiences (Deutsche Alzheimer Gesellschaft, 2015; Kurz et al., 2016), and results of the policy and information environment analysis (WP2) and the needs assessment (WP3). The core content was identified including the following seven topics:

- Chapter 1 (What is young onset dementia)
- Chapter 2 (A medical perspective on young onset dementia)
- Chapter 3 (Frequent problems and solutions)
- Chapter 4 (Dealing with challenging behaviours)
- Chapter 5 (Family issues)
- Chapter 6 (How to get help)
- Chapter 7 (Looking after yourself)

A programme outline together with a sample of the first chapter were presented to the Consortium at the meeting in Maastricht for discussion, and task assignments took place. The partners provided detailed feedback and agreed on the structure and content of the online information resource. A consistent design and structure of the programme were developed with the following features:

- A moderator plays a key role in the programme and guides participants through the chapters.
- Information is presented using a mix of short presentations by medical experts and therapists, video case examples, graphics, and interactive texts where carers can freely choose the information that is most relevant and interesting to them.
- In addition, carers can select from a variety of downloadable materials, such as written information, short videos or audio files.
- Throughout the entire programme, we adopted a language style that is comprehensible for lay people, precise but avoiding use of medical and other technical terms as much as possible.

2. Programme production

Chapter 2 was generated with scientific input from the Swedish team. Chapter 3 includes materials produced by the team in Portugal. The script for chapter 4 was written by the team in the Netherlands and chapter 5 was provided by the DAG team. The interactive section of chapter 6 is country specific and was produced separately in each country. In Germany, DAG provided content for this chapter as well. Drafting of over 200 pages of scripts for all chapters, choosing and drawing illustrations, charts and diagrams, numerous revisions and intensive editing of the materials took more than seven months to complete. For the production of videos, a small studio was set up, since cost of professional services was not in the budget and no other funding sources were identified. With the help of IMC, the WP4 team learned how to set up lighting, shoot videos and how to do audio recording. Production of all videos and audios in 3 languages involving over 20 people (ranging from actors/caregivers, medical experts and therapists, various service providers, etc.) took over two months to complete. All of the materials had to be translated to German and French by the respective teams, and the UK team provided extensive editing of the final versions of the scripts in English. Team members from France and the UK travelled to Munich for video productions, visits to several facilities took place and actors were used to film the case examples. Teams in France, Germany and UK also had to record voice-overs for specific sections in the programme. The metrics of the programme are shown on Table 2.

Table 2: Metrics of the programme (German version)

Chapter	Pages	Graphics / photos	Videos	Pages to download
Introduction	17	3	2	18
1	29	12	9	9
2	53	16	5	21
3	65	4	5	20
4	42	2	5	19
5	18	12	11	14
6	39	10	13	24
7	12	5	10	17
Total	**275**	**64**	**60**	**142**

The Consortium was kept informed about progress and materials were presented to the group as they bacame available for feedback. The group's views were taken into consideration and corrective actions were taken, texts and visuals were changed or modified as needed. It became apparent that the style of communicating ideas and information to people with dementia and caregivers in the English and French countries are different than in the German speaking country. It was a mutual learning opportunity for all in creating a truly European product.

In 2016 the online programme (collaboration platform as well as integrated content) had been finalized by IMC. The programme was then tested internally at TUM. Based on the internal feedback some changes had to be incorporated mainly regarding design and navigation. The structure of the programme with 7 chapters was maintained. The contents of all parts were reviewed to ensure compliance with ethics committee guidelines.

Within this workpackage IMC designed and realised the online modules (Task: Creation of Content). IMC also designed, configured and adapted the online platform to enable delivery of the chapters and monitoring of user behaviour in the pilot study. Finally, IMC performed the integration of all content into the online platform and prepared and administered the platform for the pilot study in three languages (Task: Collaboration platform). More specifically, within the task "Creation of Content" IMC technically realised 24 interactive online chapters (7 different chapters and 1 general introduction, each in three languages (English, French, German), each containing about 30 min learning time. IMC used the authoring software "Content Studio" to produce the online chapters as Web Based Trainings (WBT) complying to SCORM 2004 standard, and also made them available as HTML5 objects. This approach ensured that the online chapters can on the one hand be easily integrated and delivered in standard learning management systems (pilot use) as well as general Webpages (after project use). Moreover, Content Studio is an easy-to-learn software that enables straightforward post-processing by other partners after the project's end. The WBTs (online chapters) integrate media such as text, visuals, audio, video, animations, and interactions. The WBT structure is based on branching, skippable content, so the learner can choose how to explore the chapters. As part of the task "Collaboration platform", IMC implemented the collaboration platform to deliver the programme in three languages and integrated a forum software for powerful interaction functionalities. The platform to deliver the online program was based on the learning management system IMC Learning Suite (ILS) and was adapted to provide maximal usability and accessibility for RHAPSODY's users. Using ILS enabled the collection of complex usage data need for the evaluation in WP5.

For the pilot study the programme was provided to carers on the following webpages:

- www.ratgeber-junge-demenz.de (Germany)
- www.young-dementia-guide.org (UK)
- www.accompagner-alzheimerdftjeune.fr (France)

3. Portuguese version of the intervention

In early 2017 production of a Portuguese version of the e-learning programme started which took about 6 months to complete. The moderator videos were re-recorded with experts at UL. For the remaining videos subtitles were used instead of voice-overs. Chapter 6 containing country-specific content was completely redesigned. The Portuguese version does not include downloadable material thus far, however PDFs or booklets are planned. The programme will be provided by a Portuguese non-profit organisation (Grupo de estudos de envelhecimento cerebral de demencias).

4. Handover of the German programme version to DAG

Since October 2017 the German version of the program is available online to the public at the website of the DAG:

> https://www.deutsche-alzheimer.de/die-krankheit/demenz-im-juengeren-lebensalter/ratgeber-zu-demenz-bei-juengeren-menschen.html

or via the domain

> http://www.ratgeber-junge-demenz.de

4. References

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WP 5 (Pilot study; leader: Université Pierre et Marie Curie, Paris)

1. Tasks

The task of Work Package 5 was to design and conduct a pilot study of the online programme in three countries, focusing on:

- feasibility, user acceptance, and user satisfaction;
- a test of procedures and outcomes for caregivers to inform a future larger-scale efficacy study;
- a cost analysis to assess value-for-money.

The pilot study was carried out between June 2016 and March 2017 across three sites: Surrey (England), Paris (France) and Munich (Germany).

2. Methods

Study design: A randomised and controlled pilot study design was used in order to anticipate the methodology of a subsequent efficacy trial.

Ethical procedures: Ethical approval was obtained from the respective regulatory boards in each country, and a clinical trials registration was completed (German Clinical Trials Register, DRKS00009891).

Recruitment: In Germany and France, recruitment of participants took place at the memory clinics of partner sites. In the UK, the study was advertised via support organisations, including the Alzheimer's Society and Young Onset Dementia UK, and listed on the National Institute of Health Research (NIHR) Join Dementia Research database.

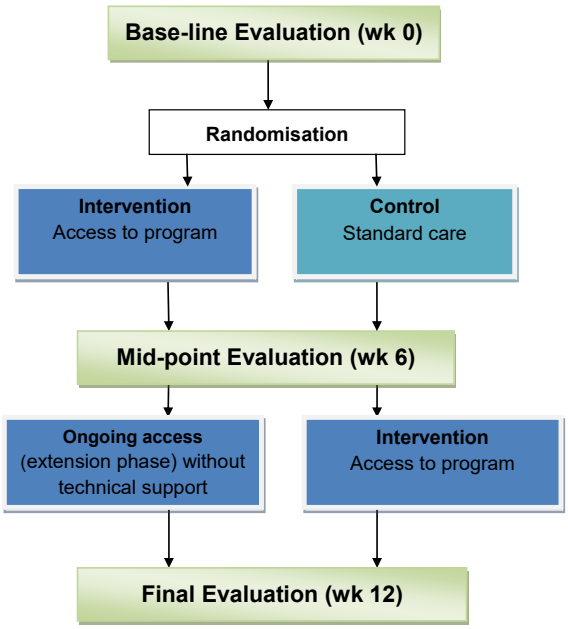
Inclusion and exclusion criteria: Participants were informal carers of a person diagnosed with Alzheimer's disease (AD) or behavioural variant (bv) Frontotemporal Degeneration (FTD) within three years of the point of inclusion and with onset of symptoms before the age of 65. Carers had to be over 18 years of age, have basic computer literacy and speak English, French or German (depending on study site). To ensure homogeneity of the sample, carers of people with dementia unrelated to AD or bvFTD were excluded from the study.

Intervention: The intervention comprised access to the programme (described in WP4 above) and a discussion forum, which was moderated by the junior researchers, for 6 weeks.

Study procedures: Participants received an Information sheet before providing informed written consent. Following baseline data collection (week 0), participants were randomly allocated to the experimental condition or a control condition (programme waiting-list). Both groups continued to receive standard care. Electronic randomisation was generated by TUM and a closed envelope allocation process carried out at each site.

Follow up assessments were carried out at week 6 (midpoint), after which both groups received access to the programme for a further 6 weeks (Figure 1). Final evaluations were completed at week 12. Evaluations were conducted either in-person or by telephone to accommodate participants' availability.

Figure 1: Pilot study flowchart



Database management: An electronic central database (eCRF) was developed by MSZ, who oversaw database cleaning and hard-lock procedures. Researchers at each site received training in order to complete data-entry and data queries remotely.

Outcomes

a) Programme *feasibility* and *acceptability* were assessed by participant retention rates, user activity measures (No. of log-ins, percentage of programme content reviewed), and an adapted version of the *Technology Acceptance Model* questionnaire which measures perceived usefulness, ease of use and behavioural intent to use the resource (Venkatesh & Bala 2008). Satisfaction questionnaires and semi-structured feedback interviews explored participants' views on content usefulness, aspects for improvement and likeliness to recommend to others.

b) Caregiver-related outcomes: A range of outcome measures was selected from existing validated instruments, to establish suitability for use in a larger follow-up trial:

- Caregiver self-efficacy was evaluated using the Revised Scale for Caregiving Self-Efficacy (RSCSE, Steffen et al. 2002 – higher scores indicate better self-efficacy);
- Carer stress was measured with the Perceived Stress Scale (PSS, Cohen et al. 1983 – higher scores indicate greater stress);
- Caregiver burden was assessed using the Burden Scale for Family Caregivers (BSFC short version, Graessel et al. 2014 – higher scores indicate greater caregiver burden);
- Patients' symptoms and carers' reactions to these were rated using the Revised Memory and Behaviour Checklist (RMBC, Teri et al., 1992 – higher scores indicate that symptoms are more frequent / more bothersome).
- Health-related quality of life was measured using the *EQ-5D-5L*, a five-dimension instrument (mobility, self-care, usual activities, pain, anxiety/ depression), scored on five levels, that provides a single utility index for use in economic evaluations (EuroQuol Group. 2009) – higher scores mean poorer quality of life.

c) Economic evaluation: Direct costs of delivering the intervention were estimated from study logs kept by investigators related to the time spent in induction of participants, provision of user-support, 'technical' requirements, technical resolution of platform-related incidents and moderator provision for the online forum. The following logs were prepared for recording information relating to these running costs:

- *Site log for technical support,* recording participant ID, additional induction/training, number of contact points, date, time spent, issue and follow-up actions.
- *IMC trouble-shooting log,* recording the site referring the incidents, participant ID, date, time spent, issue and action.
- *Site log for forum moderator,* recording date of alert, time spent checking, participant ID (relating to posting), brief summary (time providing this was not to be included in 'time spent checking') and decision on removal and retention of forum posting.

The costs of designing, constructing and setting up the online version of the programme were not included because these were one – off costs that would be discounted as the number of users increased.

Statistical analysis

Quantitative analysis: Socio-demographic data and measures of caregiver-related outcomes were analysed by two APHP statisticians. Technology acceptance and reported satisfaction were analysed by TUM descriptively. Technology acceptance, including perceived usefulness and perceived ease of use were examined for their impact on the intention for actual and future use (triangulation of log-in data) using partial least squares structural equation modelling (PLS-SEM). Differences between countries were examined with regard to culture-specific appraisal. Health-related quality of life and intervention-related costs were processed by the University of Surrey. Back-end data (actual use) from the online platform were provided by IMC and analysed descriptively by TUM to ascertain the number of logins and programme components accessed by participants.

Caregiver-related outcomes associated with programme use were analysed by comparing group score distribution changes from week 0 to week 6 in the two groups using the Wilcoxon rank sum test. No correction for multiple testing was applied. The possible additional benefit of a further six weeks of access to the programme was explored by comparing outcome measures between weeks 6 and 12 in the intervention group. Results were used to identify a potential primary outcome for a larger follow-up trial.

A mixed linear model was applied to analyse the interaction between treatment group (immediate intervention or waiting list) and the period (week 0 – week 6 or week 6 – week 12) on score

evolution. Associations between demographic variables (e. g. gender, diagnosis), user activity, and carer-related outcomes were also examined.

Qualitative analysis: Semi-structured interviews were carried out with participants post-intervention. The average duration of interviews was approximately 25 minutes. Interviews were transcribed or notated and translated into English for analysis. A thematic analysis procedure was used, taking a deductive approach to the data-set. Two researchers (1, 4) coded all interviews and identified potential themes, which were reviewed and refined in collaboration with a third researcher (2). A thematic map was developed demonstrating relationships between identified themes and sub-themes.

3.Results

Study population

A total of 61 carers (20 in England and Germany, 21 in France) were randomised either to the immediate intervention (n=30) or waiting list (n=31). 58 participants completed the study according to the protocol (one participant dropped out at each intervention site). Characteristics of participants assessed at baseline are shown in Table 3. There were no significant differences in socio-demographic variables between the two groups.

Table 3: Carer characteristics

Variable	Intervention	Waiting list
Age, mean (SD)	57.6 (10.5)	57.2 (9.9)
Caregiving years, mean (SD)	1.8 (1.1)	2.6 (1.7)
Females [%]	60.0	61.3
Higher education [%]	46.7	41.9
Full/part time employment [%]	50.0	67.7
Retired [%]	23.3	22.6

The characteristics of the people with dementia are shown in Table 4. There were no statistically significant differences between the two groups.

Table 4: People with dementia characteristics

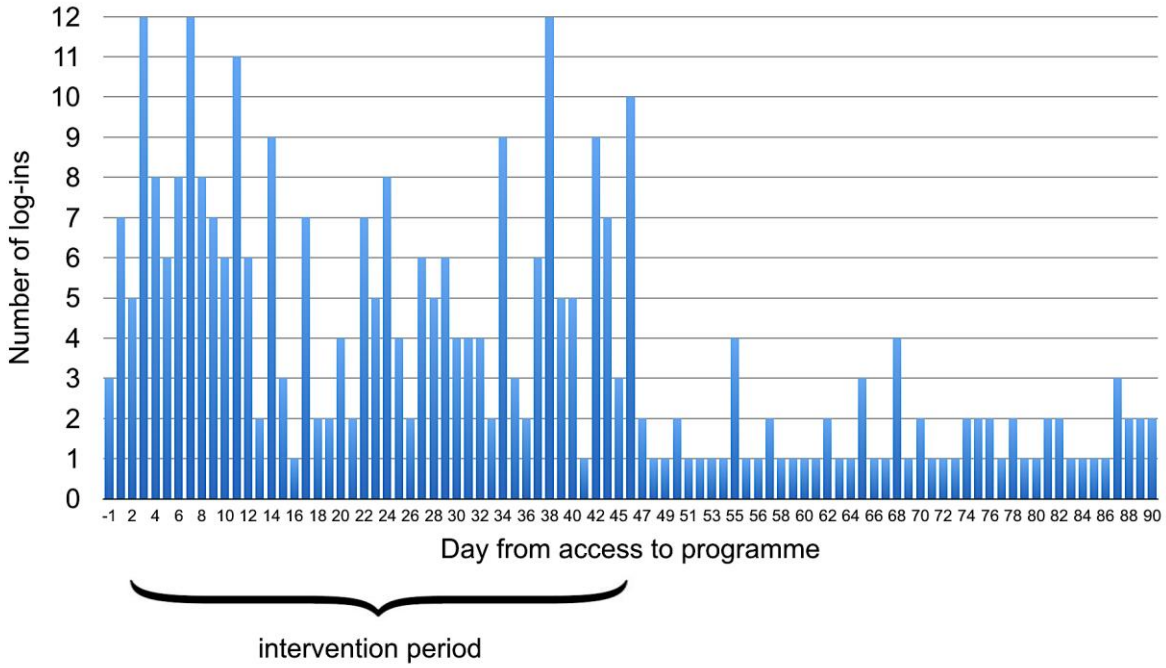
Variable	Intervention	Waiting list
Age, mean (SD)	61.6 (3,9)	61.8 (5.7)
Females [%]	43.3	45.2
Diagnosis AD / FTD / other	17 / 9 / 4	20 / 9 / 2
Years since diagnosis 1-2 / 3-4 / 5+	8 / 13 / 9	7 / 13 / 11

User behaviour

Frequency of programme access: On average, participants accessed the online programme once a week and consulted 31 % of its overall content (slides and videos). Over the two six-week intervention periods, user activity peaked at the beginning and end of the period. It may be that anticipation of a follow-up evaluation prompted users to log on online. Following the initial six-week usage period, approximately 60% of Intervention group participants continued to use the programme to some extent, though considerably less than from weeks 0-6 (Figure 2). The most popular time of programme use was late afternoon or early evening.

Consumption of programme content: No significant difference was found between the immediate intervention group and the waiting-list group concerning the number of programme sections consulted. A possible order effect was noted in that the number of chapter-views decreased progressively from chapter 1 (“What is young onset dementia?”) to chapter 7 (“Looking after yourself”). This suggests that self-care was not a priority subject for the participants.

Figure 2: Frequency of log-ins

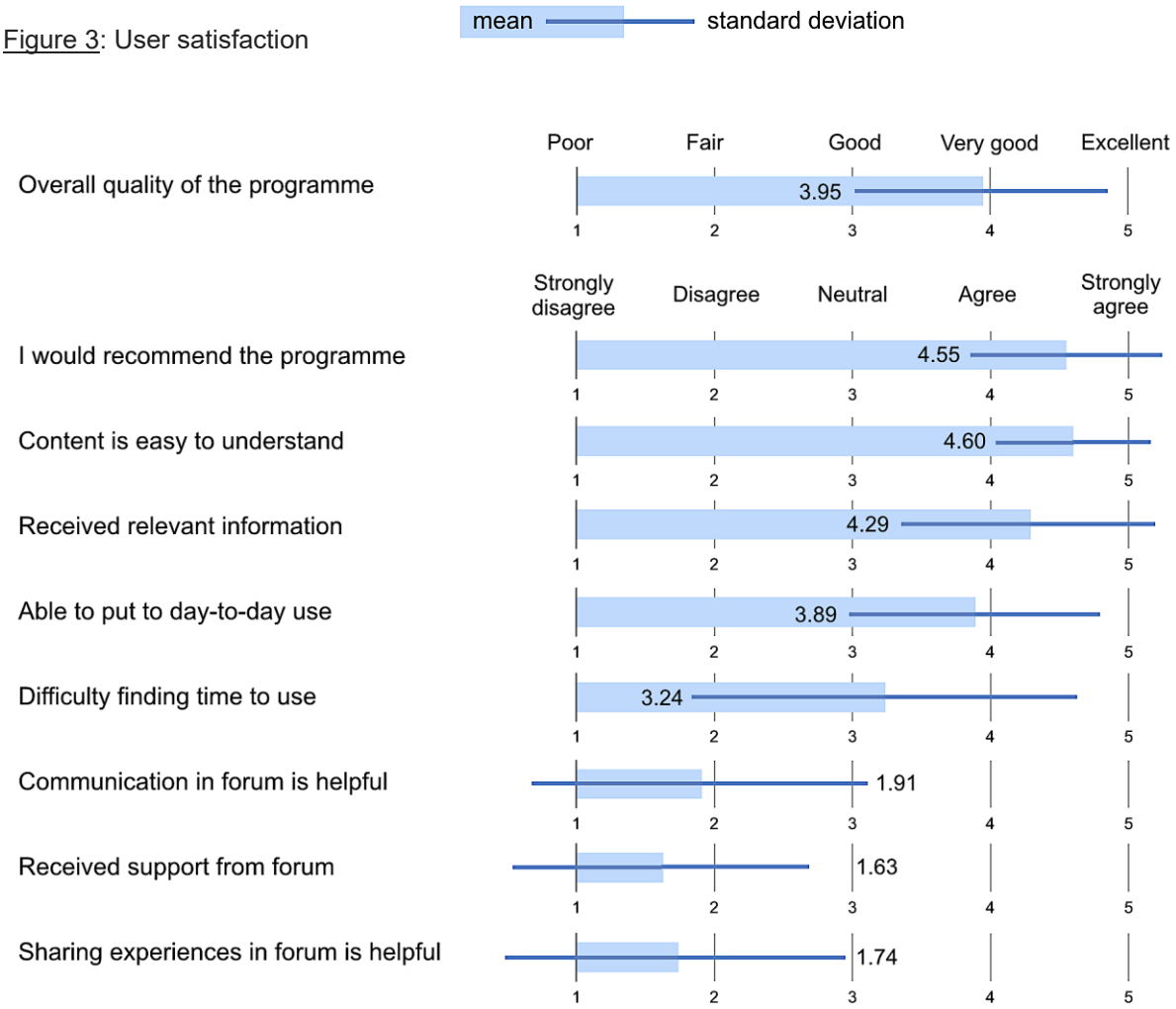


User satisfaction

The results of the questionnaire inquiring about the satisfaction of participants with the content and format of the programme showed an overall positive appraisal (Figures 3). There were no significant differences between the immediate intervention and the control group. The overall quality of the programme, recommendation to others, comprehensibility, relevance of information provided, and applicability of information to care practice were favourably evaluated. Also, the amount of detail of information, the number and duration of the single chapters and the overall length of the programme were rated as appropriate (Figure 4). The seven chapters were uniformly rated as helpful (Figure 5). This provides evidence that the programme was well conceived for the target audience. However, participants often had difficulty finding time to use the programme. The forum that had been provided for the exchange among participants was rarely used. This explains why the respective ratings were less positive.

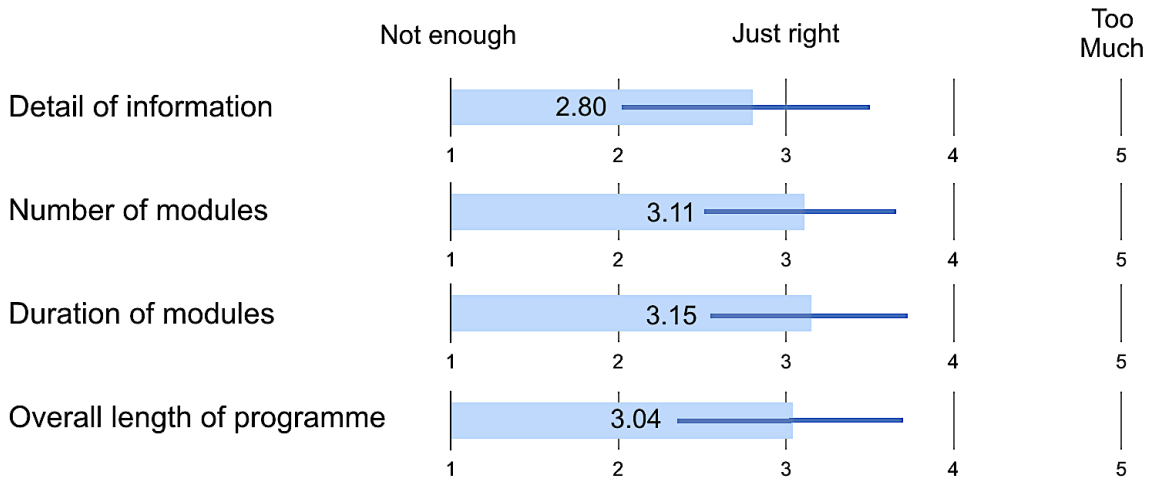
Among participants who completed the final evaluations (N = 57), 70 % stated that they would use the online programme for queries they would otherwise take to a professional. 86 % expressed the intention to use the programme again in the future. 68 % said they would consider buying the online program. One in four participants experienced technical problems. Most of these were related to forgetting the password or website address for the log-in, difficulty loading the videos or problems due to using a tablet rather than a desktop computer.

Figure 3: User satisfaction



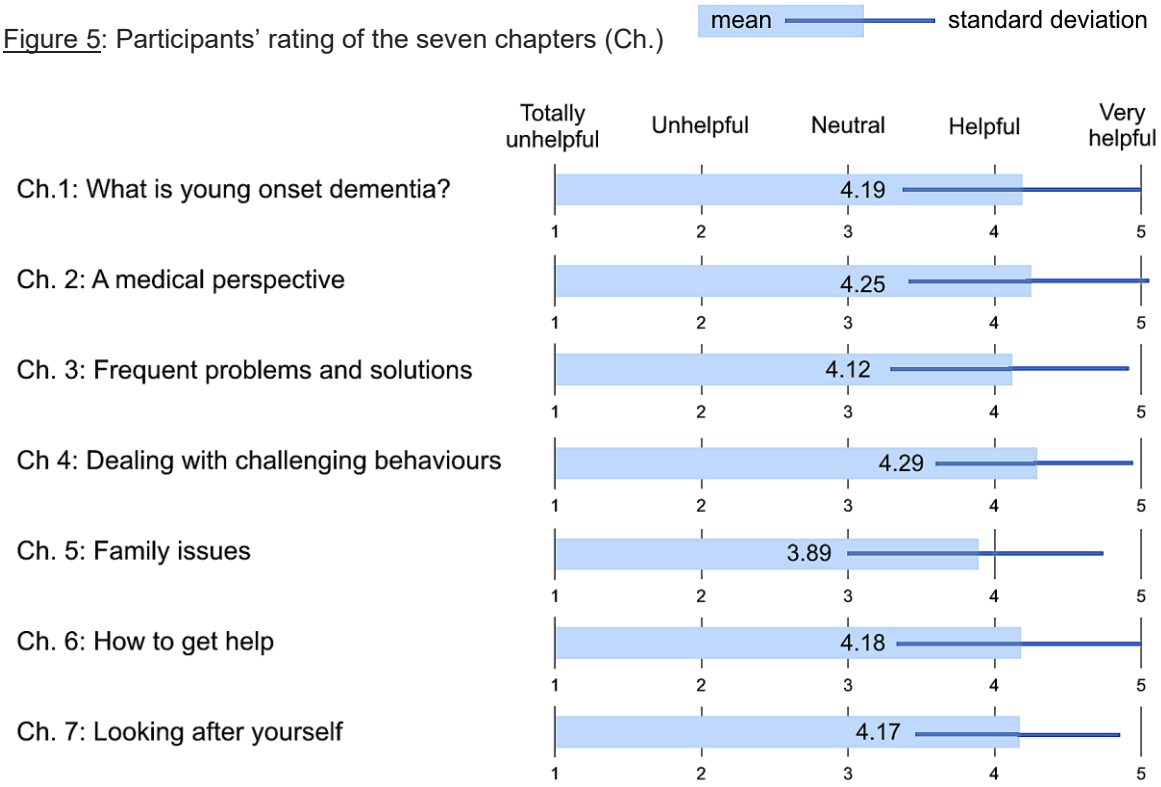
Overall rating of the programme: 39/55 (70.9%) rated it as very good/ excellent; 51/55 (92.7%) rated it as good / very good / excellent. The French participants were less positive than those in England and Germany. Similarly, for *recommending*, *ease of understanding*, *relevance of information* and *putting learning to daily use*, responses were generally positive but less so in France.

Figure 4: Participant's rating of information detail and length



Regarding *detail of information* in the programme, 38/55 (69.1%) thought the information was 'just right', 12 (21.8%) thought it was 'too general', 5 (9.1%) thought it was 'too detailed'. Around 80% thought the number of individual parts, duration of individual parts and overall length of the programme were 'about right'.

Figure 5: Participants' rating of the seven chapters (Ch.)



On *helpfulness* of the programme, there was general agreement between the countries. Over 80% of participants thought the information on YOD, medical perspective, dealing with challenging behaviours, looking after self, where to get help was helpful or very helpful. The least helpful chapter was that on family issues (68% rated this as helpful or very helpful).

Technology acceptance

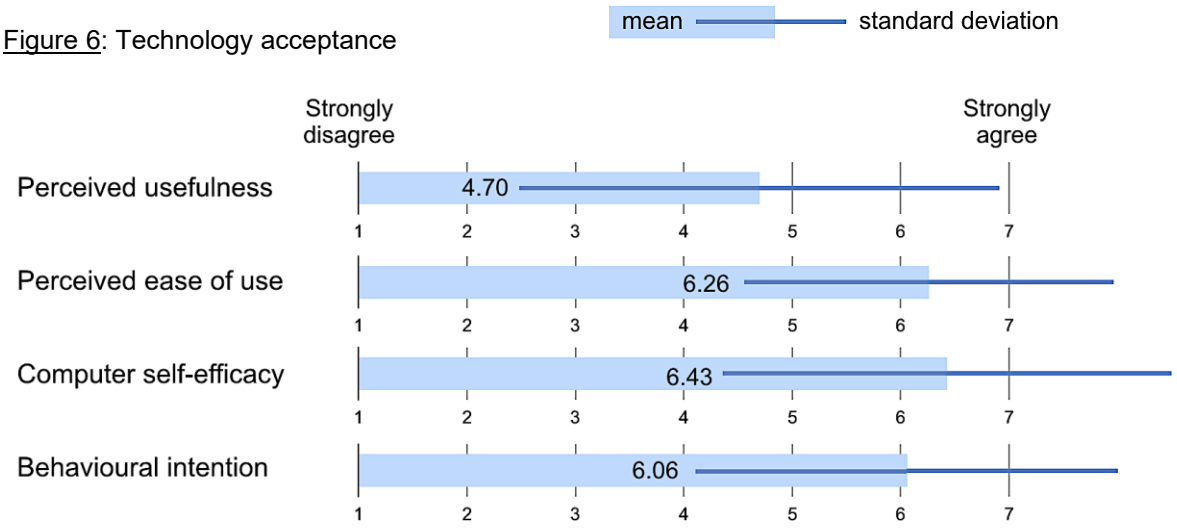
The four dimensions of the Technology Acceptance Model (perceived usefulness, perceived ease of use, computer self-efficacy and behavioural intention) are shown in Figure 6.

Perceived usefulness: This was rated higher in France and lowest in Germany on enabling management as a carer, being more constructive as a carer, and being more effective as a carer. Agreement that the programme was useful was 4.7 (mean of three countries) on a scale of 1 (totally disagree) to 7 (totally agree) (no significant difference between the countries).

Perceived ease of use: There was no significant difference between the countries, with general agreement that it was easy to use. The mean score was greater than 6 on scale of 1 to 7.

Computer self efficacy: Participants strongly agreed they were able to use the programme with no one around to tell them what to do. The mean score across the three countries was 6.43 on a scale of 1 to 7 (no significant difference between the countries).

Figure 6: Technology acceptance



Behavioural intention: There was no significant difference between the countries and general agreement amongst participants that they would use it again. The mean score was > 6 on scale of 1 to 7

A *triangulation analysis* was carried out on a sample of n=55 participants comparing log-in data to the dimensions of technology acceptance (Turner et al. 2010). The analysis revealed that the intention to use the programme was mainly driven by perceived usefulness. On the other hand, perceived ease of use was not significantly related to the intention of future use. The model has the power to explain approximately 32 % of the variance in behavioural intention. Conversely, behavioural intention is significantly related to the actual usage of the programme as indicated by the number of log-ins (Table 5).

Table 5: Associations between technology acceptance and intention to use

Association	Effect size	p value
Computer self-efficacy → Perceived ease of use	0.21	0.03
Perceived ease of use → Intention to use	0.02	0.43
Perceived ease of use → Perceived usefulness	0.06	0.35
Perceived usefulness → Intention to use	0.39	<0.01
Intention to use → Actual use	0.03	< 0.01

Willingness to pay

In addition to inquiring about user satisfaction and technology acceptance we also evaluated the willingness to pay for the programme. Among participants who would envisage buying the programme (N = 39), 15 % indicated less than 10 EUR as an appropriate price for the resource, 49 % thought that 10 – 20 EUR were appropriate, and 36 % were willing to pay more than 20 EUR. Two thirds of these participants said they would prefer a one-off payment model to subscription-based payment. Participants who preferred payment by subscription added that this form of payment would be most appropriate if content was regularly updated (e.g. on advances in research, new services, etc.).

Outcomes for carers and people with young onset dementia

While not designed to produce statistically significant findings on efficacy, the pilot study allows an indication of possible impact on caregiver psycho-social wellbeing. The properties of the various outcome measures tested inform the design of a follow-up study in two important ways: identifying sensitive psychometric scales to measure impact, and calculating an appropriate sample size.

The difference between the intervention and control groups in change scores from baseline to week 6 are shown on Table 6. Significant differences in favour of the intervention group were found on some indicators: self-reported stress, emotional reactions to memory problems, and the overall frequency of memory and behaviour symptoms. No differences between groups were noted regarding caregiving self-efficacy and carer burden. It is important to interpret these findings with caution as the study was not powered to detect effectiveness, and the clinical significance of these differences has not been ascertained.

Table 6: Outcome scores from baseline to midpoint evaluation

Variable	Intervention, mean (SD)		Waiting list, mean (SD)		N (NA)	p value
	baseline	mid-point	baseline	mid-point		
Caregiving self-efficacy (RSCSE)						
Obtaining respite	62.7 (28.4)	59.7 (30.4)	57.5 (31.2)	57.5 (31.7)	56 (5)	0.97
Responding to behaviour	67.5 (22.6)	66.9 (21.9)	73.2 (21.8)	69.3 (17.8)	54 (7)	0.08
Controlling upsetting thoughts	63.12 (23.5)	62.1 (22.7)	62.3 (21.9)	66.27 (21.6)	59 (2)	0.41
Perceived stress (PSS)						
Overall score	17.3 (6.3)	15.6 (8.03)	17.0 (6.3)	18.6 (6.3)	60 (1)	0.03
Carer burden (BSFC)						
Overall score	12.5 (7.8)	11.8 (6.69)	14.9 (7.8)	14.9 (7.3)	60 (1)	0.47
Patients' symptoms and carers' reactions (RMBC)						
Memory problems frequency	2.4 (1.0)	2.4 (1.0)	2.7 (1.9)	2.9 (1.0)	58 (3)	0.18
Memory problems reactions	1.3 (0.7)	1.0 (0.8)	1.5 (1.0)	1.5 (0.8)	57 (4)	0.04
Depression frequency	0.8 (0.7)	0.8 (0.7)	1.1 (0.8)	1.0 (0.7)	59 (2)	0.61
Depression reaction	1.8 (1.0)	1.7 (1.0)	2.2 (0.9)	2.3 (1.1)	47 (14)	0.72
Disruption frequency	0.7 (0.6)	0.7 (0.9)	0.6 (0.5)	0.9 (0.7)	59 (2)	0.01
Disruption reaction	1.99 (1.06)	1.84 (1.12)	2.19 (0.98)	2.22 (1.14)	42 (19)	0.66
Total symptom frequency	1.3 (0.6)	1.2 (0.6)	1.4 (0.6)	1.5 (0.5)	60 (1)	0.04
Total symptom reaction	1.6 (0.7)	1.3 (0.8)	1.9 (0.6)	1.9 (0.7)	59 (2)	0.11
Health-related quality of life (EQ-5D-5L)						
Overall score	0.82 (0.17)	0.84 (0.17)	0.87 (0.16)	0.86 (0.16)	61 (1)	0.28

Secondary analysis using a mixed model test revealed no significant results regarding the *impact of continued use of the programme* from week 6 to week 12 in the intervention group. Similarly, access to the online programme from week 6 to week 12 in the waiting-list group also showed some numerical but not statistically significant changes.

Sample size calculation: On the basis of identifying a standard deviation (SD) of 6.41 in the Intervention group (the SD in the Control group was 4.73) at 6 weeks for change in Perceived Stress score, and an observed effect size of 3.43, then to compare the 2 treatment regimens using a 2-sided test with size=5% and power=80%, in order to detect a difference of 3.43 in the change in Perceived Stress score at 6 weeks, a sample of at least 56 subjects will be required in each treatment regime. Rounding up, to detect 3.0, need 73 per group; to detect 3.5, need 54 per group; to detect 4.0, need 42 per group; to detect 5.0, need 27 per group. Additional participants would be required to allow for drop out.

Economic analysis

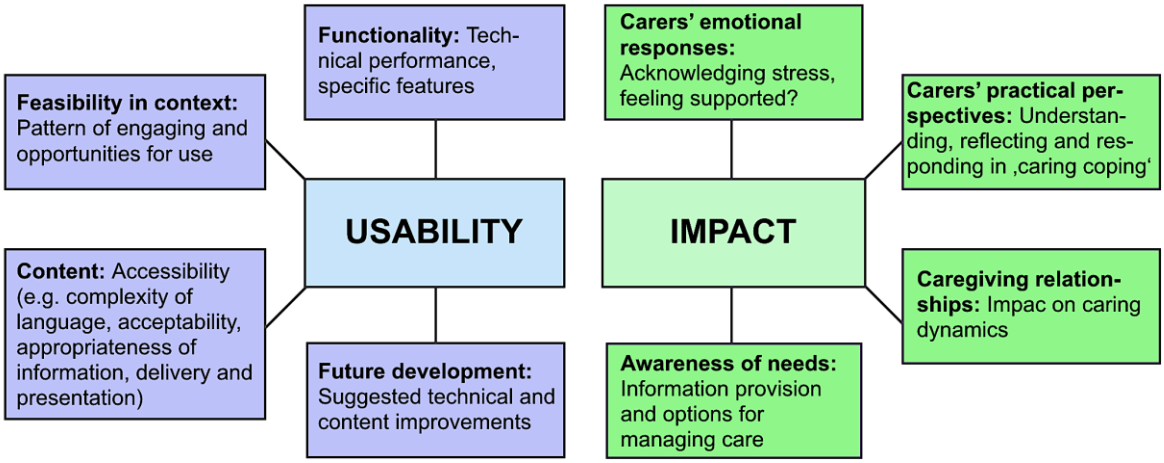
There were no significant differences in EQ-5D-5L scores between the intervention and waiting list groups at baseline, and no significant differences in changes from either baseline to mid-point evaluation (at 6 weeks) or final evaluation (at 12 weeks). The online programme is designed for independent user access and navigation without the need for individual inductions. Within the study context, researchers briefed participants on the research process, provided log-in details and highlighted the availability of information in the introductory chapter of the programme. The researcher time would not translate into service provision time and costs. With reference to the

maintenance costs related to the use of the program, the forum was minimally used, resulting in no moderator role other than setting up posting alerts. Similarly, the induction process provided for participants was sufficient for them to progress without needing further technical support during the study period. No technical problems were logged during the study period. Due to the short time period of the study, participants' reported use of health and social care was low or nil due to length of time between scheduled appointments, and no conclusions could be drawn about differences between groups.

Qualitative feedback from participants

A thematic map (Figure 6) was developed demonstrating relationships between identified themes and sub-themes. Thematic analysis identified two overarching themes relating to participants' experiences of the program: Usability and Impact.

Figure 6: Thematic Map of participants' experiences of using the Rhapsody programme



Theme 1

Within the overarching theme of *Usability,* subthemes of *feasibility* and *functionality* referred to participants' real-life experiences of using the programme in context. Overall qualitative feedback was very positive, stating that the programme was easy to use, featured accessible language, and that the online format was helpful.

> "It's particularly helpful not having to go somewhere (to receive information)"
> "I liked the convenience of being able to pick it up when I could".

The sub-theme *content* described this aspect as good, comprehensive and relevant, with many participants stating that they appreciated the practical focus on concrete situations, and the use of videos.

> "The case studies (videos) with explanations, instead of a theoretical speech, it's a concrete reality, more easy to relate to".

Several participants reported that not all content was relevant to them at the current stage in the condition as they had either already received such information, or it was not yet applicable. Grouped under the sub-theme *future development* were many suggestions for enhancing programme content and functionality, which should inform the future development of the programme. For example, having a search function and adding more videos, providing videos in the same language as written content, rather than using voice-overs would be helpful.

Theme 2

The overarching theme of *Impact* related to changes resulting from programme use for caregivers, the caregiving relationship, as well as for people diagnosed with YOD. Many participants reported *emotional responses* to the online resource, such as identifying with case studies, feeling understood or 'heard' and an alleviated sense of guilt and isolation. Expressions of negative emotional responses were also noted; for some participants certain aspects of the programme were stressful or worrying to read.

> "Confrontation with future stage of the illness was stressful".

Many participants described improvements in their *caregiving relationship*, due to enhanced understanding of their loved one's symptoms.

> "There is less conflict in our relationship… he is less anxious and I am less angry."
> "Finding explanations for things has helped".

While the programme appeared to respond to certain needs for many caregivers, barriers to use and limitations of the programme were also identified. Several participants communicated that while helpful, an online resource should not replace the individualised advice that face to face consultations with a professional allow. Barriers to programme use included lack of time, the presence of the person with YOD, and unwillingness to devote more time to the illness than was necessary.

4. Discussion

The findings demonstrate that the online programme is feasible, acceptable and generally well-received by carers of people with young-onset dementia. In qualitative feedback, over 90% of participants rated the programme as good, very good or excellent. Ease of understanding, relevance of the information and willingness to recommend was high in all three countries. Perceptions of benefits varied, however, with around one half reporting improvements in managing everyday activities, or improvements in mood.The intention to use the programme was associated with participants' impression of its usefulness but not with perceived ease of use. Hence, information about YOD and the need for help may be the major driver for an intended use of the programme in the future.

The average frequency and intensity of programme use were moderate, and little forum activity was observed. Reminder communications could be tested as part of a follow-up study design, to establish whether this can enhance programme use and impact.

On quantitative outcomes, the study shows encouraging initial indications of improvements for caregivers, following programme use. Statistically significant improvements were found in favour of the intervention group in stress and distress in reaction to memory problems in the person with young-onset dementia. In addition, the caregiver-rated overall frequency of patient memory and behaviour problems declined. These findings must be interpreted with caution as the study was not powered to show effectiveness, and statistically significant differences may not align with clinically significant changes. The findings suggest that the *Perceived Stress Scale* and *Revised Memory and Behaviour Checklist* are potentially sensitive measures, and may be considered as possible primary outcomes for a follow-up study. The sample size calculations based on the parameters of the Perceived Stress Scale from this pilot study suggest a sample size of around 60 per group would be sufficient.

There were no significant findings related to extended programme use (beyond 6 weeks) in terms of caregiver outcomes. However users continued to visit the programme after 6 weeks. This might suggest that the programme has ongoing utility for caregivers over time, which was not picked up by the measures applied. This observation also calls for enquiry in any follow-up study into the potential long-term benefits associated with continued in-depth use of the programme.

Qualitative data from semi-structured interviews provided some unexpected insights on caregivers' positive emotional experiences associated with programme use. This suggests there is important therapeutic potential to be harnessed, in the use of online interventions for this population. Qualitative feedback also revealed some weaknesses of the intervention. In particular, participants were critical of the use of voice-overs in several videos; others felt that the navigation could be improved to allow users to search for a specific topic. Some technical difficulties were reported, relating to logging on to the site and viewing video content.

5. Conclusion

The results of the pilot study suggest that the online educational programme is feasible, acceptable and rated as useful by informal carers of people with young-onset dementia. It is also inexpensive to deliver. The valuable participant feedback will be instrumental to enhancing the intervention. Experience from the pilot will inform the design of an appropriate follow-up study. Based on the encouraging findings a larger trial powered to demonstrate efficacy and cost-effectiveness of the online programme appears warranted.

6. References

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WP 6 (Dissemination; lead: Deutsche Alzheimer Gesellschaft, Berlin)

1. Activities

Internet presence

The first step in making information about the project and its emerging results available to the public was to set up a project website. The website provides information about RHAPSODY on six languages (http://www.rhapsody-project.eu). Information on the project was also launched on the website of German Alzheimer's Association. In August 2015 a Facebook page for RHAPSODY was created.

Conference appearances

A leaflet on the goals and study design of RHAPSODY as well as on the specific challenges of young onset dementia was published in English and German and handed out at several conferences. To standardise the presentations of project partners on RHAPSODY a PowerPoint

template was created. The project was presented in posters and scientific lectures at 14 scientific conferences, including three annual conferences of Alzheimer Europe (2014, 2015, 2017), the 10th International Conference on Frontotemporal Dementias (2016), two conferences of German Alzheimer's association (2014, 2016), and the Alzheimer's Association International Conference (2017).

Press releases, newsletters and other publications

As part of press relations, 7 press releases dedicated to the RHAPSODY project (five in 2014, one in 2015, one in 2017) were launched on an international level as well as on a national level in Germany. Reports on RHAPSODY were published in several articles in the Young Dementia UK (10/2014) and Alzheimer Europe (6/2017, 11/2017) newsletters and in other charity publications. The intensive press relations generated increased interest not only in the RHAPSODY project but also in young onset dementia as a medical and societal challenge. In Germany, a press agency published an interview with WP6 leader Sabine Jansen on YOD and RHAPSODY. This interview achieved broad spread throughout German media.

Information on "Young Onset Dementia" and its "Impact on Children and Teens" was published in the form of factsheets in English and German. Furthermore, a carer's brochure on Young Onset Dementia was developed and published in the publication series of the German Alzheimer's Association.

Adoption of the e-learning programme by non-profit organisations

Since October 2017 the German version of the RHAPSODY Carer's Guide has been accessible for free on the website of the German Alzheimer's Association as part of its regular services:

> https://www.deutsche-alzheimer.de/die-krankheit/demenz-im-juengeren-lebensalter/ratgeber-zu-demenz-bei-juengeren-menschen.html

The Portuguese version is also available free of charge. The publication of the English and French versions is in preparation and planned after termination of the RHAPSODY project. Additional national Alzheimer Associations are also interested to adopt the programme. For example, negotions are ongoing with Alzheimer Switzerland.

Starting in January 2018, IMC will make the German version of the programme freely available on its Open Online Course platform OpenCourseWorld (www.opencourseworld.de). IMC also considers to make the English programme public on this platform, however, several details will have to be finalized with UK partners beginning of 2018.

2. Sustainability study

In order to ensure the continuation of the RHAPSODY project, a sustainability study was conducted among the partners of the RHAPSODY Consortium in order to identify possibilities and prospects.

Methods

A qualitative survey using open questions was based on the Business Model Canvas (Osterwalder & Pigneur, 2010) and included all important aspects which are needed to identify and discuss possible future scenarios for continuing the RHAPSODY programme. The survey covered the eight topics: target groups, customer relationships, changes, key activities, key partners, key resources, revenue stream, intellecutal property rights. Answers were collected and evaluated to determine possible sustainability scenarios.

Results

Three groups: Four groups were identified who would benefit most from the programme: a) YOD carers and the people they care for, b) people in rural areas; c) people who experience difficulty accessing local services.

Customer relationships: Within this topic, the first question referred to the typical usage pattern of the programme. Most partners viewed the programme as a one-time course. It was also suggested that it might be used as a permanent reference resource that could be consulted repeatedly in the case of particular problems or knowledge gaps. The second question asked about possible ways to attract users. Propositions were references to the programme in folders or recommendations by physicians or psychologists at the time of diagnosis.

Channels: General physicians, other health professionals, memory clinics, patient organisations and Alzheimer Europe were suggested as optimal information channels. Patient organisations were also considered to be most appropriate for hosting the online programme and developing it further.

Key activities: These included regular review and update of the content, monitoring of the user forum, technical supervision and marketing the programme.

Key resources: To maintain and update the programme (by researchers and professionals) several days per year were considered to be required. Monitoring the forum and moderating the posts would take about 0.5 to 1 day per week.

Revenue stream: Partners were sceptical about whether users would be willing to pay for the service. Only a low one-time payment was considered feasible. Ethical issues were also raised against a fee for the programme.

Intellectual property rights: There was no final consensus among partners about whether the intellectual property rights should be given to a third party. The need to avoid unforeseen changes to protect the original contributors was mentioned. Commercial use was excluded.

Conclusion

Three potential paths for the dissemination of the programme were identified and discussed.

- to finance the project's future through a sponsor, e. g. Alzheimer Europe or national patient organisations. This was the preferred option and was pursued in WP6 activities (see above).
- to provide the programme as a Massive Open Online Course (MOOC) on an open platform in the form of pro-bono hosting; in that case updates and including a forum would be impossible
- to make the programme and its materials (texts, videos, graphics) open source. Regular updates could be provided by a community of volunteers, and the forum could be monitored by the active community.

3. References

Osterwalder A, Pigneur Y: Business Model Generation: A Handbook for Visionaries, Game Changers, and Challengers. New Jersey: John Wiley & Sons, 2010

2.2. Highlights of the collaboration (scientific and structural)

The style of collaboration and mutual understanding of all partners improved continuously during the lifetime of the project. The frequent conference calls and particularly the face-to-face meetings were instrumental in achieving this, as were the personal meetings during video filming. The project was a great opportunity to meet peers from other countries and share experience of work in the dementia field, noting similarities and differences in our working contexts.

The partners' different professional fields (academics, clinicians, IT specialists, patient organisations) as well as the cultural backgrounds provided the opportunity of tackling the project from many different angles. A lot was learned about the differences in health care and available services within Europe.

Moreover, there was a great deal of mutual learning on a scientific level, e. g. regarding the methods and importance of qualitative research, on how to present research data to carers and to the public.

2.3. Overall conclusions

Conclusions from WP1

The collaboration, engagement and mutual understanding of all partners was excellent during the entire duration of the project. Regular telephone conferences and especially face-to-face meetings were instrumental in achieving this.

Conclusions from WP2

The conclusion from WP2 is that the availability of information for people with YOD and carers varies greatly across the six European countries in this study. Some countries have no dedicated source, making it difficult to locate information. Specific issues differentiating the needs and concerns of people with YOD from those of people who develop older-age dementia are not comprehensively covered. The RHAPSODY online programme was developed to provide a holistic resource to support carers of people with YOD. The programme is also intended as an information-provision model for other conditions with poorly met needs.

Conclusions from WP3

The results from WP3 indicate that there is still a lot of further development needed in the care for people with young onset dementia and their caregivers as they encounter a wide range of difficulties during the disease process which are specifically related to their younger age. The themes generated from the literature review and the interviews provided a valuable framework for the key topics to be included in the intervention. Furthermore, the caregivers offered important feedback for the development of the intervention and the implementation.

Conclusions from WP4

The design, structure and contents of the e-learning programme were produced jointly by the partners. The programme was a low-budget production which was only possible because of the excellent collaboration and commitment of all members of the Consortium. The end product is a remarkably comprehensive online intervention that is available in four language versions including downloadable materials.

Conclusions from WP5

We successfully completed a multi-site randomised and controlled pilot study which established the feasibility and acceptability of the intervention for YOD caregivers. From the participants we received valuable feedback which will help to further enhance the programme and design a follow-up efficacy study.

Conclusions from WP6

The dissemination of information on the RHAPSODY project in each of the countries involved was a joint effort of the entire Consortium. This was done in the "scientific world" as well as for the general public. From the view of family carers it is positive that scientific work has led to practical support for the families of people with YOD.

2.4. Changes and amendments to the original work plan regarding each work package and the overall project and rationale for changes and amendments

Changes in WP1

In the second year of the project the project manager was unfortunately lost due to illness. Because of the unexpected complexity of producing the online programme, delays in obtaining approval from the ethics committees, and greater than anticipated difficulty in setting up the pilot study in the three countries involved a cost-neutral extension was applied for by all partners at their respective funding agencies. The extension period was 31st October for Germany (IM-C) and 31st December for France, Germany (DAlzG, TUM), Netherlands, Portugal and UK.

Changes in WP2

No changes or amendments were made regarding the original work plan of WP2. As planned, the findings on information availability for patients and carers in the different countries was provided to inform the development of the online RHAPSODY programme.

Changes in WP3

No changes or amendments were made regarding the original work plan of WP3. As planned, the results of the work package were presented at the mid-term meeting in April 2015 to provide input to WP4 and WP5.

Changes in WP4

First delays were already encountered in the phase of writing the screenplays due to multiple feedback loops. Team writing tools such as Google docs may have been an advantage but were not used by the group. However, the main delay occurred upon translating the linear screenplays into a multi-media e-learning format allowing users to navigate the content. Again, multiple feedback loops were required to harmonise the three language versions. Another unexpected problem was the cultural adaptation of the materials, particularly of the language style. After termination of the pilot study no major revision of the online programme was performed due to time constraints.

Changes in WP5

Delays were incurred in WP5 due to a number of factors: the work package started later than planned due to WP4 delays (see above), recruitment and ethics procedures took longer than anticipated, processes for the electronic database (development, testing, validation and hardlock) took several weeks longer than initially planned. Some necessary changes were made to the protocol during the course of the study:

- A reminder call or email was sent to participants approximately three weeks after being given access to the programme, to encourage user activity. Regular reminder communications should be considered in future distribution of the programme.
- It was not possible to measure user connection time per session, using the software platform provided. Therefore the average number of log-ins per user and a composite measure of learning progression were used as indicators of user behaviour.
- Many participants had difficulties in attending evaluation appointments in person at the research sites. Therefore some evaluations were conducted by phone where necessary, or sent and returned to the research centre by post. In a future study, a “distance evaluation” procedure such as online or telephone evaluation may be helpful.

Changes in WP6

The idea of creating an *exploitation* strategy was changed to a *sustainability* strategy due to the feedback of stakeholders. However, the sustainability strategy could not be designed in the beginning of the project because information was missing and only became clearer over time. For

example the costs of running the online programme could only be estimated after completion of the pilot study.

2.5. Problems faced and their solutions (scientific and structural)

It was a much greater than expected challenge to produce an online programme in three different languages. The screenplays originally drafted in formal English required extensive adjustments to meet the specific cultural needs in the different countries, including the translation process.

Designing and creating online self-study content for carers of people with YOD required much more caution and consideration than creating content in non-medical domains. The project partners felt that the online programme might be associated with adverse effects if the information provided is incomplete, misleading or otherwise harmful to people with dementia or carers. Therefore, particular care was taken regarding amount of information and language style.

The project manager was lost from the team due to illness. This unexpected challenge was met by enhanced collaborative efforts within the group and especially by the engagement of junior researchers.

2.6. End-user engagement

End-user participation was essential for the development of the content of the programme and for producing a user-friendly intervention. A thorough investigation was conducted of the needs and experiences of young onset dementia caregivers. Both individual interviews as well as focus group interviews were analysed to provide input for WP4. Caregivers were asked about their opinion regarding the advantages and disadvantages of an online course and whether they would consider using it. In addition, the caregivers provided feedback on the selection of key topics for the online course.

Another important resource for end-user input on the design and content of the e-learning programme was the routine consulting activity of German Alzheimer's Association. The coordinator of the Association's telephone hotline was involved in the development of the chapters "Family issues", "Dealing with challenging behaviours" and "Looking after yourself".

End-users were also engaged in the evaluation of the program. In the pilot study carers of people with YOD were asked about their experiences with the RHAPSODY programme. The feedback from carers will help to optimise the programme.

2.7. Patient and public involvement

In the beginning of the project the German Alzheimer Association held meetings with stakeholders including insurance companies and other patient organisations in Europe. These target groups were informed about the project and appraised of the special problems and needs of people with young onset dementia and their family carers. As part of the meetings there was a discussion on whether to charge a small fee for using the online programme. The project partners finally decided against this option. Stakeholder input also came from participants of congresses and public conferences where RHAPSODY was presented and discussed.

3. Outputs from the project

3.1. Publications

Number of publications and communications

Type of publication	Total N°
Peer reviewed articles	4
Books or book's chapters	0
Reviews	0
Articles dedicated to general public	2
Communications in scientific congresses	16
Dissertations	1
Communications in public conferences	6
Factsheets	2

List of publications and communications

Publication (authors, title, journal, year, issue, pp.)	Partner(s)	Impact factor
A Kurz, C Bakker, M Böhm, J Diehl-Schmid, B Dubois, C Ferreira, H Gage, C Graff, T Hergueta, S Jansen, B Jones, A Komar, A de Mendonca, A Metcalfe, K Milecka, J Millenaar, A Orrung Wallin, J Oyebode, H Schneider-Schelte, S Saxl, M de Vugt: RHAPSODY – Internet-based support for caregivers of people with young onset dementia: programme design and methods of a pilot study. Int Psychogeriatr 28: 2091-2099, 2016	**P1-P8**	2.423
J K Millenaar, C Bakker, R T Koopmans, F R Verhey, A Kurz, M E de Vugt: The care needs and experiences with the use of services of people wth young-onset dementia and their caregivers: a systematic review. Int J Geriatr Psychiatry 31: 1261-1276, 2016	**P1, P3**	3.018
B Jones: The development of an online information and support programme for informal carers of people with YOD: The RHAPSODY study. J Alzheimers Dis Parkinsonism 6: suppl 5.66. 2016	**P2**	3.03
J K Millenaar, C Bakker, D van Vliet, R T C M Koopmans, F R J Verhey, M E de Vugt: Exploring perspectives of young onset dementia caregivers with high versus low unmed needs. Int J Geriatr Psychiatry, Jun 23, 2017	**P1, P3**	3.018
B Jones, H Gage, C Bakker, H Barrios, S Boucault, J Mayer, A Metcalfe, J Millenaar, W Parker, A Orrung Wallin. Availability of information on young onset dementia for patients and carers in six European countries. Patient Educ and Couns, 13 Jul 2017	**P1, P2, P3, P4, P5, P6**	2.429

Communications (authors, title, journal, year, issue, pp.)	**Partner(s)**
2014	
RHAPSODY is a European research project aiming to improve care for people with young onset dementia." In: Young Dementia UK Newsletter, 1 Oct 2014	**P1, P2**
Saxl, S: "RHAPSODY - A European Project to improve support for young people with dementia." In: Info-Dienst für Gesundheitsförderung", 15 Dec 2014	**P7**
Jansen S, Saxl S: 8th Congress of Deutsche Alzheimer Gesellschaft, poster: „RHAPSODY - a joint European project to improve care for people with YOD"23-25 OCT 2014	**P7**
Jansen S, Conference of Alzheimer Europe, Glasgow, introduction about Rhapsody at the Annual General Meeting of Alzheimer Europe, 20 Oct 2014	**P7**
2015	
29th Meeting of Grupo de Estudos de Envelhecimento Cerebral e Demência (GEEDC), Aveiro, Portugal. Oral presentation: "Research and strategy for dementia in the young", 29-30 May 2015	**P5**
Jansen S: 25th Alzheimer Europe Conference Ljubljana, Slovenia. Poster "RHAPSODY -A joint European initiative to improve care and support for people with young onset dementia (YOD)", 2-4 Sept 2015	**P7**
Oral presentation at Journée Nationale des Équipes Pluridisciplinaires des Centres Mémoire 2015, Centre Mémoire de Ressources et de Recherche, Lille, France, 8-9 Oct 2015	**P4**
Oral presentation, Simpósio de Enfermagem de Neurologia, Lisboa, Portugal: "O défice cognitivo, funcional e comportamental e a decisão para a intervenção de Enfermagem- Apresentação do Estudo RHAPSODY", 11 Nov 2015	**P5**
Oral presentation, Escola de Outono de Medicina Geral de Famioliar, Peniche, Portugal: "Ensinar e aprender com o cuidador nas actividades de vida diária: Estudo RHAPSODY". 21 Nov 2015	**P5**
Poster, Congrès National des Unités de Soins, d'Evaluation et de Prise en Charge Alzheimer, at the Unités de Soins Alzheimer, Palais des Congrès d'Issy-les-Moulineaux, France: RHAPSODY, une initiative européenne pour développer un programme en e-learning à l'intention des proches de patients présentant jeunes une maladie d'Alzheimer ou une démence fronto-temporale, 16-17 Dec 2015	**P4**
2016	
Conference presentation: O apoio ao cuidador na demência de início precoce", February 20th 2016, Torres Vedras, Portugal	**P5**
German Alzheimer's Association: Fact sheet on Young Onset Dementia (YOD), German Alzheimer's Association Publication Series, Apr 2016	**P1-P7**
Kurz A, oral presentation: EU-conference "Living well with(out) dementia" Amsterdam, The Netherlands, 9-10 May 2016	**P1**
30th Meeting of Grupo de Estudos de Envelhecimento Cerebral e Demência (GEEDC), Lisboa, Portugal. Oral presentation: "Research and strategy for dementia in the young", 3-4 Jun 2016	
Saxl S, Schneider-Schelte H: poster at ICFTD 2016, Munich, Germany: „Care for people with Young Onset Dementia: A web-based intervention aiming to support family carers", 31 Aug-2 Sept 2016	**P7**
Saxl S, oral presentation: 9th Congress of Deutsche Alzheimer Gesellschaft, Saarbrücken, Germany: „RHAPSODY – ein europäisches Kooperationsprojekt zur Verbesserung der Versorgung von Menschen mit früh beginnender Demenz", 29 Sept – 1 Oct 2016	**P7**

Millenaar JK: oral presentation: Alzheimer Europe conference 2016: „Care needs and experiences with the use of services of people with young-onset dementia and their caregivers“, Copenhagen, Denmark, 1 November 2016	**P3**
De Vugt, M: oral presentation: Interdem meeting: „RHAPSODY“, Copenhagen, Denmark, 1 November 2016	**P3**
Oyebode J: oral presentation at 7th National Memory Services Forum, UK, 3 Oct 2016	**P2**
Kurz A, poster , Millenaar J, oral presentation, Alzheimer Europe Conference 2016, Copenhagen, Denmark, 31 Oct -2 Nov 2016	**P1, P3**
Millenaar J: Young Onset Dementia. Towards a better understanding of care needs an experiences, Doctoral Thesis, Universität Maastricht, The Netherlands. 22 Dec 2016	**P3**
2017	
German Alzheimer's Association: Fact sheet on "Young Onset Dementia - Impact on Children and Teens". German Alzheimer's Association Publication Series, Jan 2017	**P1-P7**
Saxl S: oral presentation "Das Projekt RHAPSODY – Ansätze zur Verbesserung der Versorgung von Menschen mit Demenz im jüngeren Lebensalter“ at conference of MDK Bayern, Fürth, Germany. 13 Mar 2017	**P7**
Millenaar, JK: oral presentation: "Developing an online intervention to support young onset dementia caregivers", Kyoto, Japan, 27 April 2017	**P3**
Mayer J,: oral presentation „RHAPSODY- An e-learning programme for carers of people with YOD“ at DANDEC meeting in Podgorica, Montenegro, 14 June 2017	**P1**
Metcalfe A et al: The feasibility of an internet-based support program for informal caregivers of adults with early-onset dementia: A multi-centric RCT study in England, France and Germany. Alzheimer's Association International Conference (AAIC), London, 18 July 2017. Published in: Alzheimer's & Dementia 13 (7) suppl, P1168	**P4**
Saxl S: oral presentation „Dementia in the middle of life", at Conference of Alzheimer's association Hamburg, Germany "I'll stay active!". 23 Sept 2017	**P7**
Metcalfe A et al: Un programme d'information et de soutien destiné aus aidants familiaux des malades jeunes (MA et DFT). Newsletter, Centre National de Référence des Démences Rares our Précoces, September 2017, No. 17	**P4**
Metcalfe A, Boucault S: Présentation du programme Rhapsody: outil d'information et de soutien en ligne destiné aux aidants familiaux des malades Jeunes. Oral presentation, IM2A clinical research meeting : September 2017, Paris, France	**P4**
Millenaar J: oral presentation "Developing an online intervention to support young onset dementia caregivers", Jansen S, oral presentation "Young Onset Dementia" at 27th Alzheimer Europe Conference, Berlin, Germany, 2-4 Oct 2017	**P3, P7**
Mayer J.: oral presentation "RHAPSODY & RHAPSODY-Plus – Examples for technology-based services for carers of people with YOD" at Dementia Master Class in Belgrade, Serbia, 11 October, 2017	**P1**
Diehl-Schmid J, Jansen S, Saxl S: RHAPSODY final conference "Dementia in the Young", Berlin, Germany. 17 Oct 2017	**P1, P7**
Jansen S,: oral presentation "RHAPSODY - an international project to support carers of people with YOD" at FrühLInk Conference "Dementia – Self-help - Empowerment", Münster, Germany, 18 Oct 2017	**P7**

3.2. Research tools / methods / models / datasets

The RHAPSODY pilot study has been registered at the German Clinical Trials Register (DRKS00009891)

3.3. Medical products, interventions, clinical testing

The e-learning programme has been evaluated in a randomised, controlled pilot study. It is ready to be further tested in terms of clinical efficacy and cost-effectiveness in a larger follow-up trial.

3.4. Software, devices, technical products

The following main digital outputs have been produced.

Components of the online programme

- *Media files* for each language version of the program (texts for scripts, written materials or other use, graphics and images, videos, audio files etc.). These can be re-used for further adaptations of the program.
- *24 Web-based training packages (WBTs)* as main interactive modules of the program**.** The WBTs have been composed with the authoring software "Content Studio". They are compliant to SCORM 2004 as well as HTML5 standard and are therefore universally applicable on many devices and platforms (offline, online, with or without a Learning Management System). All WBTs are available as Content studio source files, rendered SCORM packages as well as rendered HTML5 packages.
- The following existing software has been adapted, integrated or configured to the needs of the pilot study. Design, adaptation, configuration and hosting of the *IMC Learning Portal* as a platform to deliver the online program for the pilot study. The adaptations mainly concerned navigation, wording and several interactional design updates. These adaptations were required to ensure maximal ease-of-use for the pilot users. Design and realization of a "Content Studio" template to compose the WBTs. Design and integration of a powerful *discussion forum* into the IMC Learning Portal. The discussion forum is based on the open source *software "Vanilla Forum".*
- Daily *report files* have been generated to document the user behaviour of pilot users. These files were used in WP5 for the evaluation study.

All content components have been made available to the Consortium members before the project's end through a file-sharing server. Also, all project members could upon request receive a free license of IMC's authoring software "Content Studio" until the end of the project to be able to edit the WBT source files themselves.

The integrated RHAPSODY program in four languages

All parts have been integrated into four language versions of the RHAPSODY online programme. These are the major outputs of the project. The pilot versions of the online programme are delivered through the Learning Management System IMC Learning Portal. The versions of the integrated programme used for the pilots are available for at least one year after the project's end at the following URLs (passwords to be requested from the co-ordinator)

- http://ratgeber.rhapsody-project.eu (Germany)
- www.young-dementia-guide.org (UK)
- www.accompagner-alzheimerdftjeune.fr (France)

The public versions of the program are delivered through the standard Web Content Management System.

- www.ratgeber-junge-demenz.de (Germany, version adapted by Deutsche Alzheimer Gesellschaft for use in their existing CMS Typo 3, using HTML5 versions of WBTs)

- www.young-dementia-guide.pt (Portugal, adapted version not based on WBTs but on different compilation of source files, based on Wordpress as CMS)

3.5. Intellectual Property and licensing

In an amendment to the Consortium Agreement the partners stipulated that after determination of the project intellectual property rights of the programme should remain with the original partners of the project. The document also determines that each partner is entitled to use all foreground jointly produced and to grant non-exclusive licences to third Parties, particularly to non-commercial organisations.

Number of patents and licences

Type of patent or licence	N° Submitted	N° Obtained
International patents		
EU patents		
National patents		
Licences (of exploitation/cession)		
Creation of firm (enterprise)		
Other (specify)		

List of patents

Patent description	Partner(s) involved	Main partner (moderator)

3.6. Collaborations/partnerships formed during the course of the project

None.

3.7. Further funding gained as a result of the project

The experience gained in the project by TUM (P1) was helpful in obtaining funding from the European Institute of Innovation and Technology (E.I.T. Health, Grant No. 17510). In particular, the design of the pilot study has been adopted.

3.8. Policy influence

In September 2014 The German Federal Government launched the “Alliance for People with Dementia” (Allianz für Menschen mit Demenz). This initiative aims to improve the quality of life of people with dementia and their families, and preserve their prospects for the future. German Alzheimer’s Association (P7) as the representative of people with dementia and their families is co-chair of the Alliance. The Alliance set up an agenda identifying four fields of action. People with young onset dementia are addressed in the action field: “Structuring the support and health care system” which calls for ‘coordinated support at all stages and for all forms of the illness, i.e. for young and old people to be provided by the healthcare system. The target group of people with young onset dementia proved to be too small for establishing separate and specific measures as part of the implementation of the agenda. People with young onset dementia were also addressed by the motto

of the Week of Dementia 2017: “Demenz – Die Vielfalt im Blick” (Dementia – Diversity in View). This motto was branded by German Alzheimer’s Association and adopted by the Alliance for People with Dementia.

3.9. Capacity and skills development – staff mobility, next destination, qualifications/recognition gained

Partner #	Career stage	Academic dissertation (year, degree)	Name, Gender	Exchange from / to (country)	Duration of Exchange weeks / months
1	Professor	1981, Dr. med.	Alexander Kurz		
1	Professor		Janine Diehl-Schmid		
1	Research nurse		Katrina Milecka		
1	Research group leader	Dr. rer. nat.	Markus Böhm		
1			Johannes Mayer		
1		Dr. rer. nat.	Alfred Zollner		
2	Professor		Heather Gage		
2			Bridget Jones	Surrey - Munich	2 - 3 Dec 2015
2			Ramin Nilforooshan		
2			Wendy Parker		
3	Professor	2004, PhD	Marjolein de Vugt		
3	Postdoctoral researcher	2016 Ph.D.	Joany Millenaar		
3	Postdoctoral researcher	2013 Ph.D.	Christian Bakker		
	Professor	1986, MD 1993, PhD	Frans Verhey		
3	Professor	1985, MD 1994, PHD	Raymond Koopmans		
4	Professor		Bruno Dubois		
4			Thierry Hergueta	Paris - Munich	26 - 27 Nov. 2015
4			Sarah Boucault	Paris - Munich	24 Nov. 2015
4			Anna Metcalfe	Paris - Munich	23 – 24 Nov. 2015
4		M.D.	Stéphane Epelbaum	Paris - Munich	23 Nov 2015
4			Sophie Tezenas du Montcel		
4			Said Lebbah		
5	Professor		Alexandre de Mendonça		
5			Maria Graça Melo		
5			Tiago Mendes		

5			Catarina Ferreira		
5			Helena Bárrios		
6	Professor		Caroline Graff		
6			Anna-Karin Edberg		
6			Anneli Orrung Wallin		
6			Petra Lilja Andersson		
7			Sabine Jansen		
7			Helga Schneider-Schelte	Berlin - Munich	2 – 3 Nov and 14 Dec 2015
7			Susanna Saxl		
8	Research manager	2003, Dr. phil.	Uta Schwertel		
8	Research professional		Alexander Komar	From Saarbrücken to Munich	23 - 25 Nov 2015
9	Professor	1989, PhD	Jan Oyebode	From Bradford to Munich	3 – 4 Dec 2015

3.10. List of other outcomes

Outcome	Field in which the results will be applied	Partner(s)

4. Outreach

4.1. Public engagement activities

Press releases		
European research project aims at improving the management of people with young onset dementia	6/2014	Newsletter of Klinikum rechts der Isar der TUM, Germany
European research project aims at improving care for people with young onset dementia - RHAPSODY – research for a better life for young people with dementia	8/2014	International press distribution, EU Parliament - Health Department
Deutsche Alzheimer Gesellschaft beteiligt sich an Europäischem Forschungsprogramm - RHAPSODY – Forschung für jung an Demenz Erkrankte	8/2014	National press distribution (incl. Federal Ministry of Health and FM of Senior Citizens)
RHAPSODY: European research project aims at improving care for people with young onset dementia	8/2014	German and English
RHAPSODY: e-Learning zur Weiterbildung in der Demenzbetreuung	8/2014	Online, German
Germany's Alzheimer Association participates in the 41 European research project RHAPSODY: There's a big lack of awareness for dementia in the young	5/2015	National press distribution (German) (incl. Federal Ministry of Health and FM of Senior Citizens)
Press interview on YOD and RHAPSODY (**P7**)	5/2015	Published in several German newspapers and magazines
Neuer Online Ratgeber auf den Internetseiten der Deutschen Alzheimer Gesellschaft informiert zu Demenz bei jüngeren Menschen	10/2017	National press distribution (incl. Federal Ministry of Health and FM of Senior Citizens)
Networking and distribution of materials		
Raising awareness of project and networking as member of National Steering Group on YOD; distributing leaflets of RHAPSODY (**P2**)		
RHAPSODY leaflets sent to consultants for distribution at clinics at two NHS trusts in Surrey and Sussex South-East England. (**P2)**		
Raising awareness of RHAPSODY and networking at 'Younger People Living with Dementia Conference', University College London conference venue, in association with The Journal of Dementia Care (**P2**)		

4.2. Materials made available to the research community and how

The data of the RHAPSODY pilot study are available to researchers from TUM (P1, Münchner Studienzentrum) upon request.

IV. Recommendations

Dementia, most of which is caused by neurodegenerative diseases, represents an increasing challenge for societies and their health systems in Europe. The overall number of people living with dementia in the EU is expected to rise from 9.6 million in 2015 to nearly 15 million in 2035. However, the progress of pharmacological treatments for neurodegenerative disorders is slow, neglects the less frequent forms of dementia, and will most certainly not resolve the problem of dementia in the near future. Therefore, we would be grateful if the JPND remained to be a strong and efficient platform for research on psychosocial interventions, including the use of modern technology.