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# A self-management psychoeducational eHealth program to support and empower people with advanced cancer and their family caregivers: Development using the scrum methodology

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#### ABSTRACT

*Background:* eHealth programs could be a flexible and scalable resource to support and empower people with advanced cancer and their family caregivers. A face-to-face intervention that has demonstrated effectiveness is the "FOCUS" program, developed and tested in the USA. Recently the FOCUS program was translated and adapted to the European context as part of an international study in six European countries, resulting in the "FOCUS+" program. FOCUS+ served as the basis for development of the web-based iFOCUS program.

*Objective:* We aim to (1) describe the development process of the iFOCUS program, (2) outline the challenges we encountered and how they were overcome, and (3) present findings regarding the acceptability and usability of iFOCUS.

*Methods*: We used the four phased agile Scrum methodology to develop iFOCUS and applied set timeframes of rapid program development and evaluation (sprints). Five teams were involved in the development i.e. a core development group, a web development team, an international consortium, audio-visual experts, and potential end-users.

*Results*: Development followed seven steps, integrated across the four phases of Scrum: (1) concept design, (2) development of mock-ups, (3) Feedback from the international consortium, (4) technical development of iFO-CUS, (5) creating versions for the six participating countries, (6) preliminary testing of iFOCUS and (7)

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Abbreviations: CEO, (chief executive officer); DIAdIC, (dyadic psychoeducational interventions for people with advanced cancer and their informal caregivers); eHealth, (electronic health); FOCUS, (family Involvement, outlook, coping effectiveness, uncertainty reduction, symptom management); IT, (information technology); RCT, (randomized clinical trial).

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<sup>&</sup>lt;sup>1</sup> 'Evaluation of Dyadic Psychosocial Interventions for People with Advanced Cancer and their Informal Caregivers (DIAdIC): An international randomized controlled trial' – 'DIAdIC' (EU grant agreement No 825722)Group authorship: Kim Eecloo<sup>2</sup>; Agnes van der Heide, Judith Rietjens, Erica Witkamp<sup>8</sup>; Katherine Bristowe, Lydia Tutt<sup>12</sup>; Kevin Brazil, Joanne Reid, Gillian Prue<sup>10</sup>; Silvia Di Leo, Massimo Costantini, Monica Guberti<sup>7</sup>; Mogens Groenvold, Caroline Møller Arnfeldt, Ulrik Sørensen Schmidt<sup>5</sup>; Charles Normand, Peter May, Samantha Smith<sup>7</sup>; Suzanne Guerin, Philip Larkin, Paul D'Alton, Michael Connolly<sup>11</sup>.

implementing the final version in a randomized controlled trial. User testing included 42 participants (twenty patient-family caregiver dyads and two bereaved family caregivers) who reviewed the iFOCUS program. Users found the iFOCUS program to be acceptable and usable. Feedback mainly focused on text size and fonts. Minor changes to the content, tailoring, and program flow were required. During development we encountered program specific and general challenges. Using the Scrum methodology facilitated iterative development to address these issues. For some challenges, such as tailoring, we had to make pragmatic choices due to time and resource limitations.

*Conclusions/discussion:* The development of a tailored, self-managed psychoeducational eHealth program for people with advanced cancer and their family caregivers is an intense process and requires pragmatic choices. By keeping the emphasis on the target population during development, no specific remarks pertaining to advanced cancer were identified. Some challenges we encountered are common to eHealth development, others were related to program specific requirements. Using the Scrum methodology allows teams to efficiently collaborate during program development and increases the flexibility of the development process. Interpersonal contact between research staff and potential end-users is recommended during and after the development of eHealth programs.

#### 1. Introduction

Technological advancements, such as eHealth, are increasingly being recommended to address the challenges faced in healthcare (Hickey, 2020). eHealth refers to the use of technology, such as computers, to engage, inform, support, and empower users such as patients and family caregivers (Slev et al., 2016). By providing a cost-effective means of expanding the reach of clinical care and facilitating efficient patient communication and support, eHealth can improve quality of life in patients and family caregivers and reduce healthcare costs (Capurro et al., 2014), as well as reduce travel time and intrusive home visits for formal healthcare (Barbabella et al., 2017). Considering that most care for people living with serious illness is offered at home by family caregivers, eHealth could be considered as a potential way to provide psychoeducational support to patients with advanced cancer and their family caregiver (i.e. dyads) in how to cope with the impact of the disease on their lives (Saunders, 2006). However, a recent systematic review found that only nine psychosocial eHealth interventions have focused on dyads in which the care recipient had cancer (Shaffer et al., 2020). The review does not specify how many of these interventions have a specific emphasis on people with advanced cancer.

Emphasizing research into eHealth development for people with advanced cancer and their family caregivers is justifiable as people with advanced cancer and their family caregivers might have unique experiences related to the disease progression and treatment in comparison to patients and family caregivers involved in a non-advanced setting (Yong et al., 2023; Lee et al., 2021). Research shows that people with advanced cancer can experience reduced quality of life, which can worsen as the disease progresses (Sheykhangafshe et al., 2023; Zimmermann et al., 2014). Family caregivers of people with advanced diseases also experience higher levels of distress compared to other family caregivers (Van Goethem et al., 2022), and there is a positive correlation between distress levels in both cancer patients and their family caregivers (Hodges et al., 2005), affecting their overall quality of life (Northouse, 2012; Traa et al., 2015).

In order to cope with the unique experiences of patients with advanced cancer and their family caregivers the Transactional Model of Stress & Coping (Lazarus and Folkman, 1984) states that enhancing the dyad's self-efficacy, problem-solving, and communication skills can lead to a more favorable response to stressors related to the illness. Research supports this theory, showing that increasing knowledge about the illness, self-efficacy, coping skills, decision-making involvement, improved communication, and mutual understanding can help the patient-caregiver dyad to better manage illness-related stressors (Slev et al., 2016; Penedo et al., 2020). Research also shows that adopting a salutogenic approach towards dyads, which focuses on improving health and social coherence rather than reducing illness can reduce distress and increase their quality of life (Gustavsson-Lilius, 2010).

The FOCUS program, developed in the USA in the early 2000s, is a

nurse-led psychoeducational dyadic intervention designed for people with cancer and their family caregivers (Northouse et al., 2002) based on the Transactional Model of Stress & Coping (Lazarus and Folkman, 1984). FOCUS consists of five modules: Family involvement, Optimistic outlook, Coping effectiveness, Uncertainty reduction, and Symptom management. The program is simultaneously delivered to the patient and family caregiver by a nurse and has been shown to improve quality of life and self-efficacy, and reduce emotional distress in dyads in an advanced cancer trajectory (Northouse et al., 2002; Northouse et al., 2007). A self-managed web-based format of the "Family involvement" component of the FOCUS program was developed in the USA (Northouse et al., 2014). Development of content and program design happened simultaneously for the original FOCUS program. A multidisciplinary team was involved in the process of development encompassing three stadia namely ideation and prototyping (1), iterative design and development (2), and internal testing and final development (3). For usability testing four focus groups and four patient-caregiver dyads per session reviewed the sessions and found the programs structure, design and content favorable (Zulman et al., 2012). Dyads with advanced cancer who completed this web-based format as part of a phase II feasibility trial reported a decrease in emotional distress, improved quality of life, and more benefits from illness and caregiving (Northouse et al., 2014).

As part of the international DIAdIC project which involves six European countries (Belgium, The Netherlands, Denmark, Italy, The United Kingdom, and Ireland) we developed two adaptations of the US-based FOCUS program, namely a face-to-face program named FOCUS+ and a web-based program iFOCUS and will determine whether these two adaptations could effectively improve the emotional well-being and self-efficacy of people with advanced cancer and their family caregivers (Matthys et al., 2021). In the present article we specifically report on the development process of the iFOCUS program. Development of the FOCUS+ program has been reported elsewhere (van der Wel et al., 2022).

The aim of this article is three-fold:

- 1. To describe the process of development of the eHealth iFOCUS program.
- 2. To outline the challenges encountered during the development of the eHealth iFOCUS program and how they were overcome.
- 3. To present the results of the acceptability and usability of the eHealth iFOCUS program through user testing.

#### 2. Methods

#### 2.1. Study design

Predating the actual development of iFOCUS the FOCUS program and its materials were evaluated from both an etic (outsider; i.e. scientist) and emic (insider; i.e. user) perspective to identify necessary modifications and additional features for translation to the European context. In a next phase FOCUS was adapted and translated to a face-to-face program for people with advanced cancer and their family care-givers namely FOCUS+. This process is extensively described elsewhere (van der Wel et al., 2022). FOCUS+ served as the foundation for the development of the iFOCUS program.

We developed the iFOCUS program using the four phases of the Scrum methodology, which are: design, development, go-live, and maintenance & support (Hema et al., 2020) (Fig. A). To support agile software development, we utilized "sprints", which are periods of rapid program development and evaluation (Hema et al., 2020; Forsman and Sisak, 2020). During each sprint, the team responsible for the technical development decides on the deliverables and related tasks and meets on a daily base to synchronize their work, to discuss the progress and plan the next days. Each sprint is ended by a retrospective evaluation of that sprint (Morales Garzón, 2017). We applied sprints of two weeks throughout the process of design, development, and maintenance & support. During the go-live period, we had weekly sprints. Using the agile Scrum methodology allowed us to instantly and efficiently resolve emerging problems (Morales Garzón, 2017).

The core development group designed a seven-step development process (Fig. B). These steps can be integrated into the four phases outlined in the Scrum model. The seven steps are followed in a sequential, yet flexible manner, allowing for revisiting previous steps for continuous refinement and correction (Lawal and Chukwu Ogbu, 2021). During the Scrum phases of design and development (step one to six) an iterative process was used within each step. The iterative process of development involved cycles of brainstorming, development and evaluation within each phase. Multiple feedback rounds were conducted before concluding a particular phase. Each feedback round provided insights which shaped subsequent iterations of development. This approach allowed for continuous refinement and improvement based on user feedback and evaluation.

#### 2.2. Study procedure

#### 2.2.1. Groups involved in the development

Five groups participated in the development process (Fig. C). The core development group (1) consisted of academics, clinicians, and healthcare professionals who were actively involved in the daily development of program content and flow. The web development team (2) was made up of software developers, a user expert/cancer survivor, and the CEO of the IT firm who acted as the technical project manager

and handled all technical and administrative tasks. The international consortium (3) involved in the DIAdIC project comprising researchers and experts in palliative and supportive care provided oversight, input, and feedback on the program development. Experts on videos and visualization (4) were consulted as needed. Finally, potential end-users (5) from each participating country provided input and feedback during the feasibility and usability evaluation.

### 2.3. Step 1: concept design

Two earlier studies that modified one module of the original FOCUS program to a web-based format were analyzed to gain insight into the procedures and tailoring (Northouse et al., 2014; Ellis et al., 2017). Based on these findings, the core development group created a visual representation of the proposed web program using MS PowerPoint, with each slide corresponding to a screen of the intended program. They also identified the technical requirements. Justifications for the choices regarding program flow, slide design, and technical requirements were documented and added to the slides, referencing the philosophy of the FOCUS+ program. During the phase of concept design we continued to be aware of the intended end-users, being patients with advanced cancer and their family caregivers. In light of this, we conscientiously considered functionalities which could mediate program difficulties due to side effects resulting from the disease or treatment trajectory of patients with advanced cancer and their family caregivers. Feedback was sought from the international DIAdIC consortium.

#### 2.4. Step 2: development of mock-ups

The web development team created digital mock-ups based on the MS PowerPoint presentation as a first draft representation of iFOCUS. As part of the functional and technical analysis, there were several meetings between the web development team and the core development group to discuss the main functionalities required and the technical specifications. At the same time, the core development group, in collaboration with the video and visualization experts, prepared various materials, such as videos, written text, external resources, and references, to be included in iFOCUS.

# 2.5. Step 3: feedback from the international consortium

A workshop was held to gain more perspectives on the form and content of the program. During this meeting, the consortium members

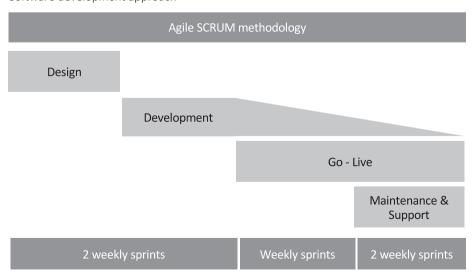
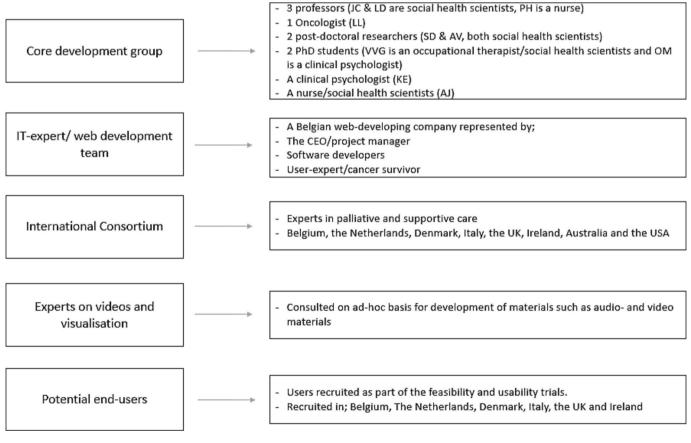


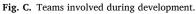
Fig. A. Scrum model.

Software development approach

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<u>SCRUM</u>	Steps taken Prior to iFOCUS development	Tasks performed	Teams involved
	Original FOCUS intervention	<ul> <li>Review of the original FOCUS intervention</li> <li>Conceptualization and operationalization, aims, theoretical framework, key components, materials</li> <li>Identification of teams necessary for development of the iFOCUS program</li> </ul>	International consortium Core Development group
	The European FOCUS+ program	Update materials and content to contemporary, European version     Write the intervention manual for the face-to-face version (FOCUS+)	
	During iFOCUS development		
Design	1. Concept design May '19 - Sept '19	Identification and translation of key components to features, principles and pedagogic techniques     Review of previous studies and consultation with development team of original FOCUS program     Result: First PowerPoint-based concept	Core development group International consortium
ă	2. Development of mock-ups Sept '19 – Oct '19	Present first PowerPoint based concept to web-development team     Development of various materials and functionalities <b>Result:</b> First digital mock-ups	Core development group Experts on video and visualisation Core development group Web development team
	3. Feedback from the international consortium Nov '19	<ul> <li>Organised moment where the international consortium can provide feedback</li> <li>Feedback on program flow and log-in procedure</li> </ul>	Core development group International consortium
t	4. Technical development of the iFOCUS program Nov '19 – Jan '20	Calculation on required time and cost of development     Development of a functioning back-end     Inputting materials in the iFOCUS program back-end     Result: IFOCUS V1.0 in one language available	Web development team Core development group
Development	5. Creating iFOCUS versions for the six participating countries Jan '20 – Aug '20	Providing international translations of core materials     Result: Fully functioning iFOCUS Version V2.0 in six languages	International consortium Core development group
ă	6. Preliminary testing of iFOCUS Aug '20 – March '21	National and international functional testing     Result: V2.1     User testing of iFOCUS (30 dyads spread over 6 countries – 5 dyads per country)     Result: V3.0	International consortium
Go-live & Maintenance	7. Implementing the final version in an RCT	- Onboarding procedure	International consortium
G	Feb '21	Fig. B. iFOCUS Development flow.	





discussed the proposed content, concepts, functionalities, and materials. The core development group presented the initial MS PowerPoint concept and the first digital mock-ups. Throughout the subsequent development steps, the international DIAdIC consortium was consulted to provide feedback on language, cultural significance, and additional materials.

#### 2.6. Step 4: technical development of the iFOCUS program

The web development team calculated the time and cost required for the technical development of iFOCUS. A digital platform was created which allowed the core development group to input videos, images, and certain functionalities, such as exercises and tailored feedback. This resulted in the first web-based version (V1.0) of iFOCUS in English.

#### 2.7. Step 5: creating an iFOCUS version for the six participating countries

To implement iFOCUS in each of the six participating countries, country-specific versions were created. The core development group asked the international consortium for translations of all written text, spoken text, and references to external local resources into their respective languages. This process involved both translators and professionals with experience in palliative and supportive care. The core development group then systematically added all translated information and materials to the digital platform, resulting in a viable version (V2.0) of iFOCUS in six languages: Dutch (Belgium), Dutch (The Netherlands), English (The United Kingdom), English (Ireland), Italian, and Danish.

#### 2.8. Step 6: preliminary testing of iFOCUS

To validate the functionality and user experience of iFOCUS, both professionals and end-users were consulted through functional and user testing. The results were used to identify and fix any bugs or errors and to further optimize the program to meet current technological standards and user requirements.

#### 2.8.1. Functional testing

Version 2.0 of the iFOCUS program underwent functional testing from August to October 2020. Functional testing evaluates the performance of a device across its various modes of operation and verifies that the application's features and operational behavior match its specifications (Shala et al., 2017). Initially, seven members of the core development group acted as dyads going through iFOCUS. Next, five teams from the international consortium (UK, Ireland, The Netherlands, Denmark, and Italy) accessed the web sessions in their respective language and performed functional testing in the same manner as the core development group. The procedure for analyzing the data can be found in Appendix A. Based on the feedback obtained from this functional testing, the core development group resolved all identified bugs and errors, resulting in Version 2.1.

### 2.8.2. User testing

User testing of Version 2.1 of iFOCUS took place between October 2020 and March 2021. User testing involves evaluating a program by its potential end-users (Cabañas and Rañosa-Madrunio, 2020). As part of the user testing, we wanted to assess the preliminary acceptability and usability of the iFOCUS program as well as control the program for bugs and look for potential improvements to the program as defined by potential end users. We considered a program acceptable when the content and the program structure were agreeable (Adrian et al., 2020) and satisfactory to the dyads after having engaged with the program (retrospective acceptability) (Nadal et al., 2020). We aimed to conduct online semi-structured interviews with people with advanced cancer and their family caregivers to assess their evaluations of the user-friendliness, content, and layout of iFOCUS. Interviews were conducted using an interview guide with questions and probes (Appendix B).

Questions such as "What was your experience logging in", "What are your experiences going through this chapter X" and "What did you think going through chapter X" were asked and participants were encouraged to think aloud and express their thoughts as they went through the program (Ghenai et al., 2020). The core development team analyzed the data and made necessary adaptations to the program.

Based on a diminishing return analysis model, a participant population of five to fifteen is considered sufficient to detect defects (Esteve et al., 2021). Considering that the technical functionalities are the same across countries we aimed to recruit five dyads (10 participants) per country participating in the international RCT, resulting in 30 dyads (60 participants) across six countries, through purposive sampling. Participants were dyads similar to those planned for inclusion within the international RCT. Patients were over 18 years old and had been diagnosed with advanced cancer, i.e. were no longer receiving curative treatment. Patients with brain cancer or non-solid cancer, a prognosis of fewer than three months, or without a family caregiver were excluded. Family caregivers were over 18 years old, were appointed by the patient as the main family caregiver, and did not receive a cancer diagnosis 12 months prior to study participation. We aimed to include a diverse range of participants in terms of sociodemographic characteristics such as age, sex, and patient-family caregiver relationship.

As the COVID-19 pandemic affected participant recruitment, we allowed some flexibility by 1) recruiting four dyads instead of five; 2) using alternative recruitment methods such as Patient and Public Involvement, self-referral, contacting dyads involved in the testing of FOCUS+, existing groups or networks of patients and family caregivers, 3) recruiting dyads where the patient was not in an advanced stage of cancer, and 4) recruiting bereaved family caregivers.

## 2.9. Step 7: implementing the final version in an RCT

Feedback gathered from the functional and user testing resulted in the final version of the iFOCUS program (V3.0).

# 2.10. Ethical considerations

This study is performed following the Declaration of Helsinki. The Ethics Committee of the Ghent University Hospital (UZ Gent), Ethics Committee of the North Emilia Wide Area (AVEN), Italy; St. Vincent's University Hospital Research Ethics Committee, Ireland; Medical Ethics Review Committee Erasmus Medical Centre Rotterdam, the Netherland; and NHS/HSC Research Ethics Committee, United Kingdom, approved the study procedure and materials. The Denmark Scientific Ethical Committee system determined that the protocol did not require formal approval.

All personal data were processed in accordance with the General Data protection Regulation (GDPR) (EU, 2016/679, in effect since May 25th 2018). All information is gathered confidentially. All data gathered was pseudonymized and accessible to researchers or physicians involved in the study only.

Informed consent was obtained from all participants. Participants did not receive any financial compensation for participating in the study.

# 3. Results

#### 3.1. Step 1: concept design (May 2019 – September 2019)

We identified seven key characteristics as part of the iFOCUS concept design (Table A). iFOCUS is a psychoeducational intervention (1) that addresses the five core components of the FOCUS+ program (2) in four sessions as opposed to three sessions in FOCUS+. The challenge of redistribution of the session content into four sessions was handled by the core development group by iteratively reviewing different renditions of the program structure. The increased number of sessions allows for

Key characteristics	Operationalization of key characteristics
2. iFOCUS should be a psycho-educational program 2. iFOCUS should address the five core components of the FOCUS+ program	Operationalization of key characteristics Modus operandi of providing information: To provide information, a logic flow was implemented based on the Stress Coping model from Lazarus and Folkman along with the evidence-based FOCUS program. We aimed to introduce a topic, and assess the needs, priorities, or situation of dyads, followed by providing tailored feedback. For example, as part of the iFOCUS program, in the part 'Symptom Management' both patient and caregiver individually get the chance to graded different symptoms. Based on the grading of the symptoms they are referred to pages with information or resources on the symptoms they graded higher. Most exercises and topics end with guiding questions, facilitating reflection or discussion. Long-term learning effect: To allow dyads to reflect in the long term on the information they received and entered into the web program, a reference work in the form of a personal workbook was implemented. This is generated as dyads complete their sessions. The personal workbook functions as a logbook in which the dyads receive standard information based on the content of the sessions and personalized information based on the answers they gave to the exercises and their choices on what additional references (existing information or brochures) they would like to add The personal workbook can be downloaded in pdf format upon completion of at least one sessior and can be viewed at any time. The different FOCUS + components are: "Mutuality and engagement in dyad communication" (F) "Resilience and meaning-making" (O), "Coping and Self-efficacy" (C), "Uncertainty reduction" (U), and "Symptom management" (S). These components provide the basis for both FOCUS + and iFOCUS. Since iFOCUS is based on the face-to-face FOCUS + program, they are similar both in content and order of presented topics. As part of the "F" component, dyads are encouraged to establish an alliance, assess their roles, analyze their communication patterns, and reflect on how they support
3. iFOCUS should have a varied pedagogic approach	duration of the face-to-face sessions was estimated at 1.5h per session, which we reduced to 1h fo the iFOCUS intervention. Extra attention was paid to obtaining a good program flow both within and between the different sessions by linking topics to one another and building on previous information. Didactically varying materials: Various materials such as written text, voice-overs, exercises, tailoring, animated PowerPoints and videos, testimonials, referrals to external sources such as pee support groups and a personal workbook are needed to increase engagement with the program content and to reduce fatigue in patient-caregiver dyads. Relatable content: For the content of the iFOCUS program, the international consortium was
	instructed to obtain culturally appropriate and contemporary information or resources. To find this information national scientific and grey literature used in healthcare related settings were used. Visually recognizable: Visually, we aimed to increase relatability for different types of dyads by providing diverse images regarding age, sex, ethnicity, and dyad relationship. Furthermore, we included testimonials to increase recognizability for dyads. Testimonial videos are played at the beginning of the session and depict a dyad that completed the session, reflecting on what they learned from it. Number of sessions and session duration: Increasing the number of sessions and the period in which the program is to be completed allowed us to reduce the length of each session. This decisio was based on the preliminary assumption that reduced session longer sessions. Program flow within and between sessions: To ensure a positive experience for dyads when goin through the iFOCUS program, it was necessary to obtain a good program flow within and between the sessions. All materials gathered for the FOCUS+ intervention on the five FOCUS component were analyzed. Firstly, an overarching structure per individual component was created to provid an overview of which topics per component were discussed in which sessions. The overarching content is divided in such a way that each session/topic builds on previous information related t
<ol> <li>the content of iFOCUS (information and exercises) should be tailored to identified needs, priorities and situation of the patient-caregiver dyads</li> </ol>	that session or topic. Having a good program flow across sessions meant that information retacted in upon, but not repeated. Once the topics and components were spread over the four sessions, we examined each session separately, identifying ways to link different topics together. This was achieved by changing the order of topics within a session in such a way that it allowed a coherer story. Tailoring: Tailoring allows programs to process the information they receive from users into an individualized reply. This means that tailored programs are likely to fit better to the individual context and needs of their end-users, in contrast to default programs in which content remains th same for all users. Although tailoring was well-received in the original web-based FOCUS program development of tailoring proved to be very time and resource consuming which resulted in onl
<ol> <li>FOCUS aims to facilitate dvadic communication between patients and their</li> </ol>	development of failoring proved to be very time and resource consuming which resulted in oni- the F-component being translated to a web-component (Northouse et al., 2014). Because of bas tailoring in the iFOCUS intervention, all components have been translated to a web-based forma Guiding questions: During the sessions, dyads are asked to reflect on themselves, one another, o

<sup>5.</sup> iFOCUS aims to facilitate dyadic communication between patients and their family caregivers

(continued on next page)

Guiding questions: During the sessions, dyads are asked to reflect on themselves, one another, or

the dyad. In doing so, they are encouraged to think about their strengths, problems and needs

Table A (continued)

Key characteristics	Operationalization of key characteristics
	related to various topics such as communication, goal setting or disease management. Following the tailored feedback, the dyads are presented with a page containing several guiding questions that encourage discussion amongst themselves. This is intended to steer the conversation in a certain way to allow both patient and family caregivers to develop further insight into the situation.
6. iFOCUS should be complementary to the regular care.	The iFOCUS program provides information to patient-caregiver dyads complementary to information from other resources. During the various sessions we refer to external resources or direct dyads to relevant organizations or peer support groups.
7. iFOCUS should be accessible to patient-caregiver dyads	Accessibility: The program is accessible through either a laptop, computer, or tablet as we expected most households to have at least one of these options available. The sessions should be completed by patient-family caregiver dyads, sitting side-by-side at a location of their choice. Intelligibility: To increase intelligibility, all content is written at a lower secondary education level (ranging from age 11-14 in accordance with the International Standard Classification of Education, education category ISCED 2) (Statistics, 2012), using principles of plain language, i.e. easy to read and understand. The program is also available in six languages. Program safety and accessibility: As participants share personal data and information throughout the program, we considered protection of user information to be a key priority during development. As such it was important that access to accounts remained limited to the user of the account. On the other hand, based on the assumption that not all participants are knowledgeable about technology, it was also paramount that the program remained easy to access, in a way that wouldn't be threatening to possible participants. To ensure a safe but uncomplicated way to gain access to the program, we implemented authentication by email. When logging in, users enter their email address. On this address they receive a mail which tremains viable for a limited duration and which they need to click on to access the program.

reduced time per session which might be beneficial for dyads who experience increased symptom burden at the end of life. Dyads can pause and resume at any time. Variation is needed in terms of pedagogic approach and technical functionalities (3) to enhance user engagement. The content of iFOCUS is tailored to the identified needs, priorities, and personal situations of the dyads (4). iFOCUS aims to facilitate communication within the dyad (5) and complement regular care (6). Finally, iFOCUS is accessible to dyads across participating countries on various platforms (desktop, tabletop, or tablet) and in their preferred language (7). A challenge we encountered was effectively convey the idea of the concept design to the web development team, which we resolved by using PowerPoint slides with imagery of the desired program pages and its related functionalities.

# 3.2. Step 2: development of mock-ups (September 2019 – October 2019)

The digital mock-ups had limited visuals and were based on the initial PowerPoint and the required technical functionalities (Table B). The functionalities included: information icons, written text, voice-overs to read large sections of text aloud, animated text presentations with guidelines, animated explainer videos for more complex topics, testimonials, referrals to external resources or contact information, exercises, and tailoring. Additionally, a personal workbook is created for each dyad as a reference tool for long-term information retention. The workbook can be downloaded and printed for convenience.

We experienced considerable limitations in available time and effort towards in-depth personalization through tailoring. Given the time and effort required to develop a fully tailored program, we focused on basic tailoring such as customizing the dyad names, patient-caregiver roles, and exercises. The personal workbook logs both general information as well as personalized information, including answers to exercises.

# 3.3. Step 3: feedback from the international consortium (November 2019)

The international consortium agreed on redistributing information across program sessions but had concerns with the proposed log-in procedure using two-factor authentication and the impact on program accessibility. To ensure data protection and program accessibility, it was agreed to use a log-in procedure linked to email addresses instead of two-factor authentication, as this could decrease accessibility for participants and reduce retention during the trial. No major issues with the proposed functionalities were identified. This feedback was relayed to the web development team for implementation.

# 3.4. Step 4: technical development of the iFOCUS program (November 2019 – January 2020)

We developed the iFOCUS program into an entirely new platform. The first fully functional English version of iFOCUS (V1.0) was developed featuring all required technical functionalities. The web development team uploaded a limited amount of information to the platform to present a front-end visualization to the international consortium. Table C shows which topics are presented in each session. We have added a few images from the program as Figs. D, E, F and G.

# 3.5. Step 5: creating an iFOCUS version for each of the six participating countries (January 2020 – August 2020)

iFOCUS is available in six languages. As it was developed based on FOCUS+, many materials to be used for iFOCUS had already undergone translation (van der Wel et al., 2022). New materials and information were translated by professional translators with input from palliative care experts who spoke the respective native language. All partners provided their translations, which were integrated into the program by the core development team. Since the information was added by nonnative speakers, some language errors were expected and were addressed by presenting the program in their respective language to each international partner for feedback. Any linguistic mistakes were reported to the core development team with a clear description, location, and suggested correction. These were addressed by the core development team.

### 3.6. Step 6: preliminary testing of iFOCUS

A ticketing system was established using an online platform for collaborative project development to manage and track bugs during and after the functional and user testing. Bugs were reported to the core development team with a description and location of the issue. Potential solutions were discussed in weekly meetings with the web development team.

#### Table B

Functionalities of the iFOCUS program.

Functionality	Description of functionality
Information icons	Upon encountering a new functionality for the first time, an information icon appears which can be clicked. When clicked on, an explanation of the functionality is presented.
Written text	Much of the information is delivered through written text using a large font to enhance readability.
Voice-overs	A "reading aloud" option was included for sections with a substantial amount of written text. This option allows participants to have the written text read out loud to increase intelligibility.
Exercises and tailoring	Several exercises are included across the sessions. Sometimes these exercises are simply open-ended questions e.g. "Talk about X with your partner" to allow the dyads to gain more insight into the presented topic. Based on the estimated cost in time and resources we included basic tailoring related to names, their position (if they are sitting left or right), patient-caregiver role, and tailoring to dyads' information needs, e.g. some exercises are tailored so that certain information is only provided if participants completed an exercise indicating a score below or above a pre-defined cut-off. Tailoring was implemented to make the shift from a more generalist support program to a personalized one and to increase the usefulness of the information for the dyad's specific situation. Pragmatic choices were made to allow us to create a web-based format for all sessions but with reduced tailoring to decrease the time and monetary effort.
Animated text presentations	Certain information, such as guidelines on how the program works is presented using animated text presentations. These are minimalistic videos in which basic guidelines or rules are presented with key messages appearing on screen, as well as spoken text clarifying them. We included these videos to make practical information more engaging.
Animated explainer video's	Complex concepts, e.g. advance care planning, are explained using animated explainer videos. These videos explain a concept in a story-like manner, with spoken text accompanying the animations. These videos were implemented to make complex concepts more understandable by representing them visually. Within each video, we aimed to represent different people/dyads in relation to age, gender, sexual orientation, and ethnicity to make the videos as inclusive as possible.
Testimonials	Each session begins and ends with a video testimonial of a patient-family caregiver dyad who completed the program. During the sessions, various written testimonials are also presented. These testimonials are intended to create a feeling of recognisability in participating dyads. The video testimonials are performed by actors reading a script developed by the research team.
Referral to external resources or contacts	During different sessions, patient-caregiver dyads are occasionally directed to external resources, peer support groups or contacts for additional information. This is to keep the webtool concise and to the point. These materials have been evaluated by experts involved in the DIAdIC project during the development of the FOCUS+ intervention.
Personal workbook	Since the webtool remains accessible for a limited time (one year after finishing the last session) we wished to include something that registers both the fixed and the dyad-specific tailored information that was entered by or presented to the dyads. The personal workbook functions as a reference and can be downloaded as a pdf file and printed. The personal workbook is considered a tailored result from participating to the iFOCUS program as it can contain additional supplementary materials, chosen by the dyad.

### 3.6.1. Functional testing

Bugs were classified as either major or minor. Major bugs completely hindered the program's functionality, while minor bugs negatively impacted the user experience. All major bugs were fixed, while minor bugs were evaluated based on their impact versus the effort required to resolve them.

Spelling and grammatical errors, primarily minor, were identified in all sessions and languages. In some exercises, the program logic failed, leading users to irrelevant information. Fixing certain bugs was difficult due to the interconnected nature of the program. Inconsistencies in layout, such as the use of different fonts or colors, were corrected by standardizing the text. Some national teams reported issues with images, such as the depiction of age, gender, or ethnicity, which were replaced. Issues with audio volumes, such as being too loud or soft, were not considered substantial enough to make changes due to the impact on time and budget.

Modifications were made by the responsible partner, research team, or web development team, depending on the situation.

#### Table C

iFOCUS components.

	Mutuality and engagement in dyad communication	Outlook, Resilience and meaning making	Coping and Self-efficacy	Uncertainty reduction	Symptom management
	F	0	С	U	S
Session					
1	Establish alliance	Normalizing emotions	Different coping styles	Different treatments	Side-effects of treatments
	Assess roles and teamwork	Maintaining a positive outlook			
	Identify additional needs for support				
	Communication patterns				
2	Reflection on previous session	Acknowledging difficulties	Communication towards others	Mapping uncertainties	Side-effect assessment
	Impact on family and friends	Setting goals		Acknowledging uncertainties	Information on side- effects
3	Reflection on mutual support	Impact on body image	Managing body changes	Talking about uncertainties to a healthcare provider	Intimacy and sexuality
			Tips to cope with stress	ľ	Evaluation of symptoms
			Encouraging a healthy lifestyle		
4	Reflection on previous sessions	Evaluate change in attitude	Coping with stress and energy management	Evaluate capability for managing uncertainty	Evaluate symptom development
	Refer to extra sources	Advance care planning			
			Refer to extra sources for help	Inform about help for uncertainty	
		Refer to extra sources			

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municatior

Chapters	
Introduction	Both
About you	Take a moment to consider how you usually talk to each other about the cancer. Read the descriptions below and choose the one which best matches how you communicate with one another.
Family involvement	
Communication	<ul> <li>Both of us are open about our feelings, we're comfortable talking about the cancer and how it affects our lives.</li> <li>One of us is more open about our feelings than the other. We are different in how comfortable we feel when talking about cancer.</li> </ul>
Emotions	Neither of us is very comfortable talking about our feelings. We like to keep our feelings about cancer to ourselves.
Coping	O None of these describe us.
Treatments and symptoms	
Let's recap	
Leave Session	
	PREVIOUS
	Fig. D. Example of single choice item from iFOCUS.
Chapters	Communication difficulties
Introduction	Both
About you	Good communication can be put to the test when someone is seriously ill. Emotions that are commonly linked to cancer, such as fear, grief, anger, can lead to problems in communicating clearly with one another.
Family involvement	Below we have listed some common communication issues experienced by families who are dealing with cancer. You can click

Below we have listed some common communication issues experienced by families who are dealing with cancer. You can click on any of the boxes for more details.

atments and	Being overprotective Some people try to hide their feelin		
	Some people try to hide their feeling		
's recap	and fears. They do not want to ups others. So, they try to protect their		
ve Session	friends by not talking about cancer changing the subject if it happens		
	Although their intentions are good,		
	P loved ones who share their feeling		NE
	better position to receive and provi		
	one another.		

Fig. E. Example of the option to receive additional information from the iFOCUS program.

3.6.2. User testing, preliminary acceptability and usability and points of improvement

Twenty dyads and two bereaved family caregivers reviewed the sessions. Patients and family caregivers use the program simultaneously and together behind the same medium (computer or tablet).

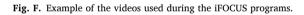
Participants were mostly female (57.1 %) and 55 to 74 years old (72.4 %), with most being spouses (81.1 %). Breast cancer (25 %) and prostate cancer (20 %) were the most diagnosed types of cancer among participants. The majority of participants (60 %) was in an advanced metastatic stage of cancer (Table D). After participation to the user testing, participants stated that the program structure and content was agreeable and no major issues with program acceptability were mentioned. The program was found to be useful and clear, but some participants felt that some information may not be relevant to them. The

session duration was considered appropriate, and participants were satisfied with the variety of videos, text, and exercises. Most comments related to text size and font, spelling errors, and bugs. Videos were well received, although some minor remarks were made about the testimonial videos and their ability to increase the sense of recognition among dyads. Patients with cancer had similar feedback as patients with advanced cancer. No difficulties pertaining to an advanced cancer disease trajectory or its treatment were identified.

"The fact that the videos are supported by text increases the clarity of the information and makes it so that you will remember it longer." (S, female, Patient, fourth session)

Two major bugs were reported by users: 1) The text was being automatically translated into English and back into their own language

Chapters	Lucertainty
Introduction	Both Click the video below.
Looking back	
Impact of the Illness	
Talking With Children	Read about what to expect,
Uncertainty	Increase your knowledge
Goals	
Symptom Management	What are the stages of cancer Whether are the stages of cancer Whe
Recap	Types of cancer
Leave Session	
	Cancer The hidden Truth 4
	Living with Cancer •
	VIDEO TRANSCRIPT



Chapters	Goals		
Introduction			
Looking back	An exercise for both of you! Try to think about 3 things that you still want to do (together) and don't want to do anymore, using the tips we've mentioned. This can be anything; certain activities (playing sports, walks), chores, trips, You can write them down		
Impact of the Illness	together in the scale below.		
Talking With Children	0		
Uncertainty	Our Goals		
Goals	Tip! Download this notepage with both your goals on it, print it out and hang it on your fridge or notice board!		
Symptom Management	We no longer want to do this		
Recap	We still want to do this		
Leave Session			
	6°6		

Fig. G. Example of exercises for the dyads during the iFOCUS program.

while trying to log in, causing the program language to be less than acceptable; 2) Some users were unable to log in due to using outdated software such as Internet Explorer. Most users found the login process to

be clear, however, some participants had difficulty navigating the webtool, particularly in starting the videos. Some exercises were also reported to be unclear.

#### Table D

Characteristics	Total	Patients	Family caregivers
	N = 42	N = 20	N = 22
	n (%)	n (%)	n (%)
Country			
Belgium	10 (23,8 %)	5 (25,0 %)	5 (22,7 %)
The Netherlands	8 (19,0 %)	4 (20,0 %)	4 (18,2 %)
The United Kingdom	7 (16,7 %)	3 (15,0 %)	4 (18,2 %)
Ireland	1 (2,4 %)	0 (0,0 %)	1 (4,5 %)
Italy	6 (14,3 %)	3 (15,0 %)	3 (13,5 %)
Denmark	10 (23,8 %)	5 (25,0 %)	5 (22,7 %)
Sex			
Female	24 (57,1 %)	9 (45,0 %)	15 (68,2 %)
Male	18 (42,9 %)	11 (55,0 %)	7 (31,8 %)
Age			
18-34	1 (2,7 %)	0 (0,0 %)	1 (5,3 %)
35-54	8 (22,2 %)	3 (17,7 %)	5 (26,3 %)
55-74	26 (72,4 %)	13 (76,5 %)	13 (68,4 %)
75+	1 (2,7 %)	1 (5,8 %)	0 (0,00 %)
Type of cancer patients	**		
Breast cancer	5 (25 %)		
Prostate cancer	4 (20 %)		
Oesophageal cancer	2 (10 %)		
Other types of cancer	9 (45 %)		
Cancer stadium patient	s**		
Stage IV	12 (60 %)		
In Remission	2 (10 %)		
Unknown	6 (30 %)		
Relationship***			
Spouses	17 (77,3 %)		
Parent/child	3 (13,6 %)		
Bereaved carers	2 (9,1 %)		
Issues logging in?***			
Yes	15 (68,2 %)		
No	7 (31,8 %)		

Missing values for Age: N = 6 (14.3 %). Percentages may not add up to 100 % because of rounding.

\* Percentages calculated on patient-caregiver individual level.

\* Percentages calculated on patient-level, N = 20.

\*\*\* Percentages calculated on dyad-level, N = 22.

"The exercises – yeah yeah, they could be useful, but we might not need them. Other people might have use for them, but we talk a lot, we have many friends- but there might be people who use them."

(C, Male, Patient, Third session)

Adaptations were made with a pragmatic approach. Time and resource constraints limited the ability to provide additional tailoring, but dyads were given the option to skip certain parts of the program. Major changes to functionalities, content, or form that would have a significant impact were deemed too costly in terms of time and budget. Instead, minor changes were made to improve the overall quality of the program. We included additional referrals to the "Help" or "Frequently Asked Questions" section to provide better support to dyads. We revised the written text for grammar and clarity and increased font size. Text was also emphasized using italics, bold and underlining to stress important information. The log-in procedure was amended to increase clarity and allow logging in through email. The bug regarding automatic translation was resolved by disabling the translation option provided by web browsers. Participants in the RCT were advised not to use Internet Explorer to access the program.

#### 3.7. Step 7: implementing the final version in an RCT (February 2021)

The final iFOCUS program consists of four sessions that patients and their family caregivers access together and simultaneously using the same device over a 12-weeks period, with a three-week break between sessions. Each session lasts approximately 60 min. The program has been implemented in six different languages for six European countries participating in an RCT to evaluate its effectiveness. To implement iFOCUS in the RCT, an onboarding procedure was deemed necessary to introduce participants to the program's timeline and goals and to gather the necessary information for enrolment. This information, including the participants' names and their relationship, will be entered into the system and used to tailor the program. The onboarding procedure was developed by the core development group in collaboration with data collectors and was approved by the international consortium. The process was written down in a guide to be used by data collectors during recruitment. After setting up a profile, both the patient and family caregiver will receive an email inviting them to complete the first session together on the same screen. The program automatically sends emails to participants at a set time for future sessions. Currently, iFOCUS is being evaluated as part of an international RCT to determine its effectiveness on the quality of life, emotional functioning, self-efficacy, healthcare resource use, and cost-effectiveness among patients with advanced cancer and their family caregivers (ClinicalTrials.gov Identifier: NCT04626349) (Matthys et al., 2021). The study will also gather information on participant satisfaction with iFOCUS and aim to uncover its underlying mechanisms.

#### 4. Discussion

#### 4.1. Main findings

The iFOCUS program consists of four sessions over a 12-week period, with a three-week gap between each session. During its development, seven steps were taken: (1) concept design, (2) development of mockups, (3) obtaining feedback from the international consortium, (4) technical development of the program, (5) creating country-specific versions for each of the six participating countries, (6) preliminary testing through user and functional testing and (7) implementing the final version for the RCT. Using the Scrum methodology allowed for flexibility and adaptability in the development process, as it included alternating periods of program development and evaluation. Collaboration between different teams and integration of different perspectives helped resolve issues related to program flow, content, language, layout, and bugs, but some pragmatic choices were necessary considering project limitations. User and functional testing showed that the program was acceptable and functional. By building on the philosophy of the FOCUS and FOCUS+ program for patients with advanced cancer and their family caregivers, and by keeping the emphasis on this population during development, no specific remarks pertaining to advanced cancer were identified, indicating the program's successful adaptation to address patients with advanced cancer and their family caregiver. The development process resulted in a self-management psychoeducational eHealth program for people with advanced cancer and their family caregivers that can be used autonomously by the patient-caregiver dyad. Currently, the effectiveness of iFOCUS is being tested in an international RCT. Various challenges were encountered across different steps of development (Table E). The challenges we encountered were related to transferring ideas into working functionalities, spreading of the content, tailoring, determining the log-in procedure, input of translated materials and determining an onboarding procedure.

#### Table E

Experienced challenges during development.

Specific or general challenges	Description of the challenge	Resolved how?
Specific challenges	The amount of information provided in three sessions made the session duration too long: Taking into account the impact of the disease progression on the dyad and related symptom burden the duration of sessions needed to be shorter.	Redistributing the session information across four sessions instead of the initial three was done by the core development group during an iterative process. Different renditions of the program structure were evaluated with attention to program flow within and between sessions. Increasing the amount of sessions allowed the duration of individual sessions to be shorter.
	The amount of tailoring: Tailoring could increase meaningfulness of a program for dyads but in-depth tailoring adds additional complexity to the program code and is a time and resource consuming process.	We focused on basic tailoring such as customizing the dyad names, patient- caregiver roles, and exercises.
	Information input in different languages: Partners provided translations of materials in their respective language. All information was put in by the core development team with knowledge of Dutch and English (limited). Issues in the input of translations was expected mostly in Danish and Italian.	During functional testing programs were presented in the local language to the respective teams. Based on these meetings language errors were filtered out. During user testing further language errors were also removed.
	Onboarding of participants: To provide participants the necessary information on the DIAdIC trial, to introduce them and to reassure them of support, an onboarding procedure needed to be developed to mitigate any challenges related accessing the iFOCUS program.	The onboarding procedure was developed in collaboration with an international consortium and carried out by a data collectors who received a guide with the necessary steps.
General challenges	As researchers conveying the idea of a concept to a web developer: While researchers have knowledge on topic substance they lack the technical knowledge that web developers have and vice versa. As such their ideas need to be translated to something visual in a way feasibility can be determined.	By using a PowerPoint presentation the researchers could use imagery and descriptions on the related functions, which facilitated the online meetings between the two teams.
	<i>Correctly estimating the time and effort for eHealth development:</i> Development of eHealth programs is prone to bugs and at the same time constantly evolving. This makes it difficult to correctly estimate the required time and effort beforehand.	Pragmatic choices were made on how much time and resources were available for the development of the iFOCUS program. During meetings with the web developing team and the international consortium endpoints of developmen were set.
	Log-in procedure: Developing a log-in procedure which is safe (protects the collected data) as well as easy to use is a balancing act, as safer log-in procedures such as 2-factor authentication often require higher digital skills.	During meetings with the international consortium we brainstormed on the potential safe and easy ways of logging in. Considering that participants needed to register with an email address the consortium assumed that participants could at least work with email and it would be safe and feasible to work with a log-in link being sent to the email address.

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# 4.2. Interpretation and implications of the findings

We encountered challenges common to eHealth development in general as well as specific challenges related to the requirements of the iFOCUS webtool. A general challenge was that despite being functional and usable, there is always room for improvement in eHealth web programs, as they are continually evolving (Pieterse et al., 2018). Estimating the effort and resources required to develop an eHealth program is challenging, as previous research has shown that eHealth development costs depend on specific program requirements (Wu et al., 2014).

Program-specific challenges during the development of iFOCUS included deciding on the level of tailoring to be implemented. Tailoring can ensure that the program is applicable to the dyad by increasing the perceived program relevance (Lustria et al., 2013). Moreover, it increases program engagement and improves outcomes (Penedo et al., 2020), but also adds complexity to the coding and can result in errors (Ryan et al., 2019; Cruz-Martínez et al., 2021; Islam et al., 2019). Additionally, although eHealth interventions might be more costeffective than face-to-face interventions, designing and developing tailored programs is a very resource-consuming endeavor (Abdelrazek et al., 2018) which explains why we limited the level of tailoring in iFOCUS. Another difficulty encountered during the development of iFOCUS and reported in similar studies is the rapid advancements in technology (Zulman et al., 2012). Since advanced cancer is more common in older adults (Estape, 2018) who often have lower digital competence (Antonio and Tuffley, 2015) it is also critical to be aware of challenges associated with age and the uptake of technological innovations which can be reflected in difficulties with onboarding, logging-in or working with the program in general.

iFOCUS is designed to be used outside of clinical settings, but still requires personal interaction as part of the registration process due to barriers to digital program participation such as limited access to the internet or data, low computer use, and low digital literacy (Czaja et al., 2013). Interpersonal contact is crucial in overcoming these barriers (Hernandez-Ramos et al., 2021) and enhancing the user experience and

program adherence by improving verbal and non-verbal communication, and building trust between clinicians and participants (Borgerink, 2016; Christie et al., 2018). Nevertheless, it is essential to be aware of the potential impact of personal interaction as part of the iFOCUS onboarding procedure (Banbury et al., 2021) without compromising the intended self-sufficient nature of the program.

# 4.3. Strengths and limitations

Other than the FOCUS program that iFOCUS was based on, there are to our understanding no other dyadic, self-managed, tailored eHealth programs for people with advanced cancer and their family caregivers. The iFOCUS program benefits from being built on the evidence-based face-to-face FOCUS program and its underlying conceptual framework, Lazarus and Folkman's Model of Stress & Coping, and a salutogenic approach. The development of iFOCUS was carried out through an iterative process that involved various teams with different areas of expertise, leading to a wider range of perspectives and access to a broad spectrum of skills. Using the Scrum methodology allowed for multiple feedback loops during development, both within and between teams, which allowed efficient contributions towards improving the quality of the program and its content.

This study also has some limitations. Due to limited time and resources, it was only possible to receive feedback from end-users in one of the later stages during the development process, i.e. during user testing. Ideally, we would have liked to involve end-users in all stages of the program development as end-users' experiences, insights, and interests are often better incorporated in a co-design process (Fuchs et al., 2010), which can contribute to long-term program availability and implementation (Higgins et al., 2018). Due to limitations in both time and resources, the development team was forced to make pragmatic choices. Furthermore, the COVID-19 pandemic made recruitment for the functional testing challenging. As such we also included bereaved caregivers and people with non-advanced cancer who might have different experiences than those in an advanced stage of the disease (Yong et al., 2023; Lee et al., 2021).

#### 4.4. Conclusions

Developing a tailored, self-managed eHealth program for dyads is a complex process and involves making pragmatic choices, particularly regarding the level of tailoring. By its nature, an eHealth program requires constant revision and updates. Communication between program developers and end-users is recommended during and after the development of the program, to improve program quality.

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#### Appendix A. Procedure for analyzing data of functional testing

We identified four categories ("language and translations", "logic", "layout" and "video and audio") that were subsequently divided into 1) applicable for all countries or 2) applicable for a specific country. To determine if, or in what order we would implement adaptations, the items within these categories were divided into two groups; "Simple solution identified" or "No simple solution identified". To grade whether a solution was simple

or not, questions were asked on: 1) the monetary burden on the national or international teams and 2) time consumption and its effect on planning and time management. All items where a simple solution was identified were adapted accordingly. For items with no simple solution on an international scale, pragmatic choices were made on what adaptations we could make. For all items with no simple solution on a national scale, the country reporting the issue was contacted to request if they would make these adaptations themselves.

#### Appendix B. Interview guide for user testing without probes

iFOCUS user testing: SESSIO	IN ONE
Starting your session	What was your experience logging in?
	Was the video with tips and tricks unclear?
Mutual support & family invo	olvement How was it to go through this chapter?
	What was/wasn't clear about the question on general support?
Communication	What are your experiences going through this chapter?
Emotions	What did you think going through the chapter on emotions?
Coping	How did you experience going through the information in the coping chapter
Treatments	What are your thoughts on the treatments chapter?
RECAP	What do you think about the recap video?
General remarks iFOCUS SESSI	ION 1
<ol> <li>Did you experience any bu</li> <li>How do you evaluate the r</li> <li>How was the use of picture</li> <li>How do you evaluate the t</li> <li>How do you evaluate the l</li> </ol>	read aloud option? res? What effect did this have on you? use of different exercises?
iFOCUS user testing: SESSIO	6
Starting your session	
	What was your experience logging in?
0,00	What was your experience logging in? Was the video with tips and tricks unclear?
0,7	Was the video with tips and tricks unclear?
Impact of the illness	Was the video with tips and tricks unclear? How was it to go through this chapter?
Impact of the illness	Was the video with tips and tricks unclear? How was it to go through this chapter? How do you evaluate the option to send information to friends or family?
Impact of the illness	Was the video with tips and tricks unclear? How was it to go through this chapter? How do you evaluate the option to send information to friends or family? What are your experiences going through this chapter?
Impact of the illness Talking with children	Was the video with tips and tricks unclear? How was it to go through this chapter? How do you evaluate the option to send information to friends or family? What are your experiences going through this chapter? Did you understand what the personal workbook was?
Impact of the illness Talking with children	Was the video with tips and tricks unclear? How was it to go through this chapter? How do you evaluate the option to send information to friends or family? What are your experiences going through this chapter?
Impact of the illness Talking with children Uncertainty	Was the video with tips and tricks unclear? How was it to go through this chapter? How do you evaluate the option to send information to friends or family? What are your experiences going through this chapter? Did you understand what the personal workbook was? What did you think going through the chapter on uncertainty?
Impact of the illness Talking with children Uncertainty Goals	Was the video with tips and tricks unclear? How was it to go through this chapter? How do you evaluate the option to send information to friends or family? What are your experiences going through this chapter? Did you understand what the personal workbook was? What did you think going through the chapter on uncertainty? How useful is it to you to write down your uncertainties in this chapter, why is or isn't this useful
0,7	Was the video with tips and tricks unclear? How was it to go through this chapter? How do you evaluate the option to send information to friends or family? What are your experiences going through this chapter? Did you understand what the personal workbook was? What did you think going through the chapter on uncertainty? How useful is it to you to write down your uncertainties in this chapter, why is or isn't this useful How was going through the information in the goals chapter?

### Declaration of competing interest

None.

# Data availability

The data sets generated and analyzed during the current study are available from the corresponding author upon reasonable request.

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VVG, SD, OM, LN, LD, LL, PH, ADV and JC contributed to conception and design of the study. VVG and OM acquired and analyzed the data. All authors contributed to the interpretation of the data. VVG, SD, ADV, and JC drafted the manuscript. All authors revised the manuscript critically for important intellectual content and approved of the version of the manuscript to be published.

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#### (continued)

#### General remarks iFOCUS SESSION 2

- 1. Did you experience any bugs?
- 2. How do you evaluate the read aloud option?
- 3. How was the use of pictures? What effect did this have on you?
- 4. How do you evaluate the use of different exercises?

5. How do you evaluate the length of the tool? *iFOCUS user testing: SESSION THREE* 

Starting your session

Mutual support Outlook Stress & Healthy lifestyle Uncertainty Symptom management RECAP General remarks iFOCUS SESSION 3 What was your experience logging in? Was the video with tips and tricks unclear? How was it to go through this chapter? What are your experiences going through this chapter? What did you think going through the chapter on Stress & Healthy lifestyle? How was going through the information in the uncertainty chapter? What are your thoughts on the symptom management chapter? What do you think about the recap video?

1. Did you experience any bugs?

- 2. How do you evaluate the read aloud option?
- 3. How was the use of pictures? What effect did this have on you?
- 4. How do you evaluate the use of different exercises?
- 5. How do you evaluate the length of the tool?

iFOCUS user testing: SESSION FOUR

Starting your session	What was your experience logging in?
	Was the video with tips and tricks unclear? (to be put in)
Communication & mutual support	How was it to go through this chapter?
Outlook	What are your experiences going through this chapter?
Coping	What did you think going through the chapter on Coping?
Uncertainty	How was going through the information in the uncertainty chapter?
	What did you think about the offered extra information on different healthcare providers?
Symptom management	What are your thoughts on the symptom management chapter?
	How was it to rate your symptoms? What would or wouldn't you change?
	How was the description on the different symptoms?
RECAP	What do you think about the recap video?
General remarks iFOCUS SESSION 4	

1. Did you experience any bugs?

- 2. How do you evaluate the read aloud option?
- 3. How was the use of pictures? What effect did this have on you?
- 4. How do you evaluate the use of different exercises?
- 5. How do you evaluate the length of the tool?

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