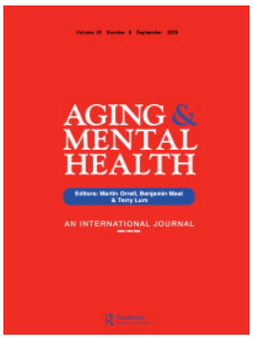

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Developing an intervention to support employment in younger persons with dementia using co-creation: lessons learned within the WorkDEM project

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ABSTRACT

Objective: To develop the WorkDEM Compass, a practical tool that supports continued employment for individuals with YOD.

Methods: A user-centered iterative design process was used to develop the Compass. Insights from previous research were used to develop the Compass in two co-creation sessions with stakeholders from the Dutch governmental ($n=3$), voluntary work supervisor ($n=1$), employees with dementia ($n=5$), caregiver ($n=1$), HR and employers ($n=6$), occupational physicians & labor experts ($n=4$) and healthcare professionals ($n=13$).

Results: Co-creation sessions guided the design of the Compass as a website including information and several tools. It was deliberately chosen to offer different types of information, both factual, evidence-based content and experiential narratives. The tools included a signal card to improve recognition of YOD in the workplace, an inspiration kit to support continued employment, a handout containing legal and financial information, and conversational aids to address communication. The Compass may therewith facilitate early recognition, improve communication between stakeholders, and promote shared responsibility among stakeholders.

Conclusion: The WorkDEM Compass offers a practical approach to support continued employment for persons with YOD. The Compass has the potential to reduce premature job loss and enhance work participation. Future research should evaluate its feasibility, usability, and impact in practice.

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Young-onset dementia; intervention development; workplace; co-creation; continued employment

Introduction

Dementia is often associated with older adults, however around 3.9 million persons worldwide are living with young onset dementia (YOD), where symptoms start before the age of 65 (Hendriks et al., 2021; van de Veen et al., 2022). In the Netherlands, it is estimated that 14.000–17.000 individuals are living with YOD, many of whom were still employed when symptoms started (Hendriks et al, 2021). The onset of YOD is often insidious and heterogenous. Young persons not only show cognitive symptoms, but also affective, behavioral and social symptoms including personality changes, language impairment, and depressive symptoms (Hendriks et al., 2022). Therefore, symptoms are difficult to recognize and are often overlooked or misattributed to other disorders, leading to delayed diagnoses. Given the high cognitive demands of many jobs, early signs and symptoms of dementia are often first noticed in the workplace (Thomson et al., 2019).

Due to the aging population, governments across Europe are increasing the age of retirement (Clemens & Parvani, 2017) to reduce the economic burden of aging. In the Netherlands, the government has increased the retirement age from 65 to 67, and from 2028 this will further increase based on the average life expectancy (Clemens & Parvani, 2017). With an increasing age in the workforce, health problems mostly associated with older age, such as dementia, will have an increasing impact on the workforce. This increased retirement age, and the prevalence of YOD show that dementia is becoming an increasing workplace concern.

The intersection of YOD and employment presents several different complexities. Diagnoses are

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frequently delayed, often resulting in extended sick leave or premature loss of employment (Egdell et al., 2021). Additionally, legal frameworks surrounding employment and dementia are often ambiguous, and there is limited awareness of how individuals with dementia might continue working in a meaningful way. These barriers contribute to early exit from the workforce. Early exit from employment can have substantial financial consequences for individuals with YOD and their families, particularly as many are still managing mortgages, supporting children, or planning for retirement (Page et al., 2025). In addition, caregivers may need to reduce their own working hours to provide care, further increasing financial strain and affecting family wellbeing (Page et al., 2025). Yet, many individuals with YOD express a desire to remain active in their jobs (Smeets et al., 2024). Work provides not only daily structure and social connections, but also plays a vital role in sustaining self-esteem, confidence, and personal identity (Issakainen et al., 2023; McCulloch et al., 2016). Additionally, continued employment can help alleviate some of the caregiving burden.

There is a lack of guidelines for employees, employers, occupational physicians and other stakeholders regarding dementia in the workplace (Egdell et al., 2021). In the Dutch context, an occupational physician is a medical specialist in occupational health who supports employees and employers in work-related health issues, including sickness absence management, return-to-work guidance, and workplace accommodations. Some workplace accommodations may be applied informally, but they are seldom based on systematic approaches or informed by best practices. In the UK, both Age Scotland (Scotland, 2016) and the Alzheimer's Society (Society As. Creating a dementia-friendly workplace, 2015) have developed an employer guide, including examples of adjustments, the importance of communication and the need for ongoing support based on the progressive nature of dementia. However, these guides are only tailored to the employer, and it is unclear to which extent they are used in the UK. Previous research showed that multiple stakeholders, including individuals with YOD, caregivers, employers, human resources (HR) professionals, occupational physicians and dementia healthcare providers, are enthusiastic about continued employment, but they often face barriers due to insufficient knowledge, limited guidance, and inadequate communication between sectors and stakeholders (Smeets et al., 2024; Smeets et al., 2025).

To address these challenges, we adopted a co-creation approach to develop a practical and sustainable tool: the WorkDEM Compass. In this paper, we describe the development of the WorkDEM Compass, a practical tool that helps navigating support for continued employment for individuals with YOD. Hereby, we have a special focus on the lessons learned from applying a co-creation approach in the development.

Methods

Development strategy

The development of the WorkDEM Compass followed a user-centered design (Gulliksen et al., 2003) as also incorporated in the Medical Research Council (MRC) Framework for the development of complex interventions (Skivington et al., 2021). This design method focuses on usability throughout the entire development process and emphasizes the importance of the needs of end users during the development. Throughout the development strategy, 'key principles' were applied. First, the process was 'user-focused', meaning it ensured that the development process was based on the stakeholder's experiences. This was addressed in step 1, where qualitative studies with the stakeholders were conducted (Smeets et al., 2024; Smeets et al., 2025). Next, stakeholder users (i.e. employees with YOD, caregivers, employers, HR professionals, occupational physicians and dementia healthcare professionals) were continuously involved in the development, enabling 'active user involvement'. In this case, co-creation sessions were organized at the beginning of the design and development process, and stakeholders were also involved throughout the development. Finally, 'evaluating use in context' and 'prototyping' will be applied by evaluating and testing the WorkDEM Compass in a follow up study. Figure 1 shows the iterative development process of the WorkDEM Compass.

For the development of the WorkDEM Compass, involvement of all relevant stakeholders was realized *via* the network of stakeholders already involved in this project. The project partners were researchers, experts by experience, and stakeholders engaged in the Dutch work context (e.g. employers and an occupational physician), as well as professionals and organizations involved in the care and support of individuals with YOD (e.g. dementia care professionals, the Dutch Alzheimer's Society, the Frontotemporal Dementia peer support network, and the Dutch Young-onset Dementia knowledge centre), allowing for a broad reach to engage relevant stakeholders. Throughout the different steps, recruitment included partners disseminating invitations within their organizations and the use of social media channels, newsletters, and other relevant contacts provided by the project partners. Most participants were recruited through one-on-one contacts, using a snowball sampling approach. This way, we were able to include persons with YOD and their caregivers, employers, occupational physicians, HR

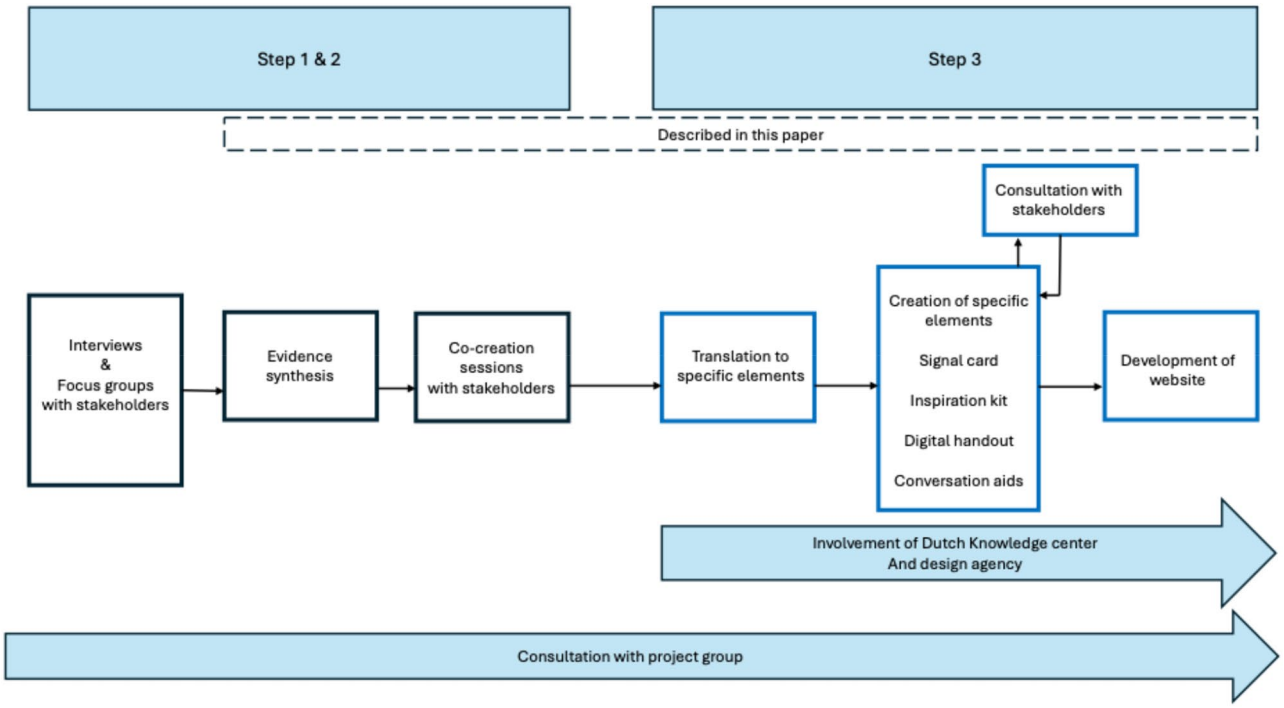

Figure 1. Development of the WorkDEM Compass.

professionals, dementia healthcare professionals and employees from the Dutch governmental agency responsible for benefits for employees throughout all phases of the development process. For participants with YOD, they were able to participate in the sessions if they could understand the study information, meaningfully participate in the sessions, and give informed consent. No additional exclusion criteria related to symptom severity were applied.

Step 1 – interviews & focus groups (user-focused)

In the first step 33 interviews and six focus groups were conducted to gain better insight in the experiences and needs of different stakeholders regarding working with dementia. All relevant stakeholders were represented (i.e. employees with YOD, caregivers, employers, HR professionals, occupational physicians and dementia healthcare professionals), leading to a comprehensive understanding of the situation. The methods and results of these interviews and focus groups have been published elsewhere (Smeets et al., 2024; Smeets et al., 2025). In this step, the results were synthesized and used to create personas and the work-related journey, which were input for the co-creation sessions in step 2.

Step 2 – co-creation sessions (user involvement)

During the period December 2023-February 2024 two co-creation sessions were organized. Through the recruitment methods described before we were able to include persons with YOD and their caregivers, employer perspective, voluntary work supervisors, occupational physicians and labor experts, HR professionals, dementia healthcare professionals and the Dutch governmental agency responsible for benefits for employees. During the second co-creation session, two advocates for people with YOD also joined. One was assigned to the group of employees and the other to the group of healthcare professionals.

First co-creation session

The aim of the first co-creation session was to identify the role and responsibilities of each stakeholder. It was based on the Personas co-creation method, a user-centered design that provides a vivid representation of the target users, making them concrete and life-like to achieve user insight (Pruitt & Adlin, 2010). Personas help deepen understanding of end users and ensure that the developed support is usable and relevant (Pruitt & Adlin, 2010). Another benefit of persona-driven design is its usefulness in clearly communicating design requirements to different stakeholders (Jansen et al., 2021).

During this session, researchers and stakeholders came together to explore and validate the personas' roles, needs, and prerequisites for supporting continued employment. The session consisted of three rounds. In the first round, participants reviewed the personas to assess recognition, relevance, and completeness, providing feedback *via* post-its. This process

validated stakeholder roles and clarified their needs in supporting employees with dementia.

The second round focused on developing concrete solutions for the different personas involved in work and dementia. Working in smaller groups, participants worked through the different phases of the work-related journey, identifying important priorities, stakeholders and responsibilities at each stage.

In the third and final round, findings were summarized, followed by an open discussion where all participants could reflect on the overall needs and requirements for continued employment. Here, the work-related journey was used, based on a co-creation method known as the *patient journey*, which visually represents the route an individual may follow, in this case within the context of work and dementia (Bulto et al., 2024). Given the context of this co-creation session, the use of a journey-based approach was considered a valuable complement to the Persona method. The gained insights were then used to inform the second co-creation session and further develop the WorkDEM Compass.

Second co-creation session

The second co-creation session aimed to get a holistic view of key support needs and the layout of the Compass. It built on the insights gathered during the first session and aimed to further develop the WorkDEM Compass in a concrete and practical way. The second co-creation session focused solely on the patient journey method (Bulto et al., 2024). For this, we used the work-related journey of a person with YOD mapped in step 1. In this co-creation session, we highlighted the stages in the journey that required support, and we identified for each stage which stakeholders were involved, and which needs they had. We visualized the concepts of the WorkDEM Compass, including which elements it should entail.

To prime participants, they received an assignment in the form of an inspiration booklet ahead of the co-creation session. This booklet provided background information on what is already known about working with dementia and outlined the objectives of the day. It also included four questions: 1. In your view, what is the most important problem we need to address when it comes to working with dementia? 2. What could be our shared goal in solving this problem? 3. What form of support do you think would be most helpful, and for whom? 4. What would you specifically like to know about working with dementia? These questions were designed to stimulate participants' thinking about the session topic and could serve as a starting point during the first round of the session (Supplementary 1). The session was again structured into three rounds, followed by a plenary closing session. Participants were divided into groups based on stakeholder perspective: employees, healthcare professionals, occupational physicians and labor experts, and HR and employer perspective.

The goal of the first round was to identify a shared focus or common problem regarding working with dementia within their stakeholder perspective. Participants had already considered this question in their inspiration booklet, and insights from previous phases of the research also informed the discussion. The booklet served as a guide for the conversation. By the end of this round, the group established a clear basis for the day's focus: finding concrete solutions and support for the identified problem or goal.

The second round explored participants' perceptions of support in the context of the WorkDEM Compass. Participants discussed what comes to mind when they think of the WorkDEM Compass, what it might look like, which options it could include, and who plays a key role in providing support. This round provided an initial, broad view of how each stakeholder group envisions the practical toolkit.

Building on the insights from round two, the third round focused on concretizing the ideas. This was the most intensive round. On each table examples of various forms of support were displayed, such as websites, brochures, or training modules. Miniature versions of these examples were placed on the table to allow participants to move and arrange them according to phases of the work-related journey or relevant stakeholders (Personas). Participants then collaboratively defined what kind of support is important, how it should be delivered, and which stakeholders are involved in providing it. The outcomes could be structured per phase of the work-related journey or in other ways participants found meaningful. At the end of this round, the final concept was summarized on a large blank sheet, including relevant stakeholders for each support option. This summary helped prioritize what each stakeholder group considered most important.

The second co-creation session concluded with a plenary round in which a recap of the three rounds was presented, followed by an open discussion. This allowed all participants to reflect on the overall insights and collectively prioritize the key elements for continued employment support. The outcomes from this session informed the development of the WorkDEM Compass.

Step 3 – designing and developing the WorkDEM compass

The results of step two were summarized and used to design and develop the WorkDEM Compass, in close collaboration with the Dutch Young Onset Dementia Knowledge Centre. First, the audio

recordings of the two co-creation sessions were reviewed and summarized by two researchers (SH & BS), after which the summaries were analysed and discussed to determine the specific tools and lay-out of the Compass. This was done by and expert team consisting of three researchers, two clinical experts, and two employees of the young-onset dementia Knowledge Center and resulted in specific tools and content for the Compass. For the styling, we collaborated with a professional design agency. Next, the tools were designed and developed in an iterative process, where various stakeholder groups were invited to review and comment on the materials both on lay-out and content. In total, seven individuals provided feedback: one former employee with dementia, one family member of an employee with dementia, one occupational physician, one employer/care professional, and three staff members from Alzheimer Nederland (the Dutch national Alzheimer's association).

For this study, ethical approval was obtained from the Medical Ethics Review Committee (METC) of Maastricht UMC+ (azM/UM) (METC 2023-0176).

Results

Step 1 – interviews and focus groups

Results of Step 1 have been published elsewhere (Smeets et al., 2024; Smeets et al., 2025). The results of this first phase shaped seven different Personas that were important for continued employment with YOD. These Personas were used in the first co-creation session. See supplementary material for the Personas that were created (Supplementary 2).

Additionally, the work-related journey of a person with YOD (Figure 2) was created with data from the interviews and refined in the focus groups, and used during the co-creation sessions.

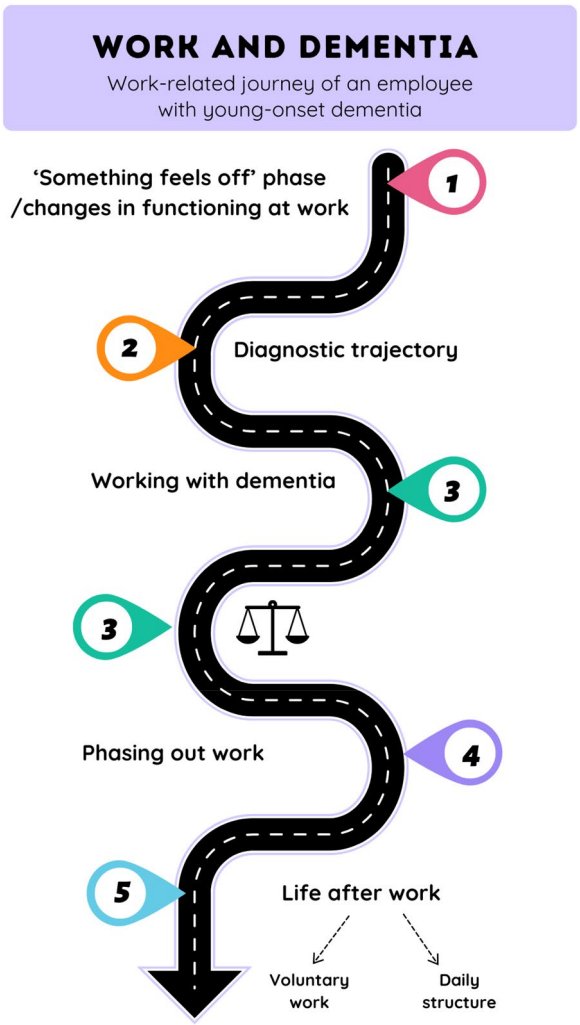

Figure 2. The work-related journey of a person with young-onset dementia.

Step 2 – co-creation sessions

Co-creation session 1

In this session, 14 individuals participated. The session included stakeholders from the Dutch governmental agency responsible for benefits for employees ($n = 3$), healthcare professionals ($n = 7$), voluntary work supervisor ($n = 1$) and HR and employer perspective ($n = 3$). Stakeholders that were missing during this session were employees with dementia and their caregivers and occupational physicians.

During the session, perspectives of the Personas were thoroughly discussed, resulting in clear and useful insights in their roles and needs and prerequisites. Table 1 shows the needs and prerequisites that were mentioned during the discussions of the Personas. The most important prerequisites included collaboration between the different Personas, and the most important needs included knowledge and understanding of the situation.

A final plenary discussion involved the roadmap of the work-related journey. Participants discussed the different journey phases and the difficulties and needs within these phases.

Discussion phase 1 – changes in functioning at work. Participants noted that this was one of the most difficult phases of the journey. First symptoms that emerge at the workplace were often first related to other causes such as depression or burnout. Therefore, participants found it challenging to recognize dementia in the workplace. They emphasized the importance to distinguish between stress related symptoms and dementia symptoms and identified a need for clear 'red flags' in the workplace.

Furthermore, participants indicated a need for communication and trust between employers, employees and their families and healthcare professionals. Communication and trust between the employer and the employee and his or her family are

Table 1. Needs and requirements of the different personas.

Persona	Needs	Prerequisites
Occupational physician	• Increased knowledge of YOD and its early symptoms • Awareness of work adjustment possibilities for employees with YOD	• Regular consultation with social insurance physicians* regarding benefits and compensation • Regular consultation with the General Practitioner to better understand the employee's overall condition
Dementia case manager	• Early involvement in the work-related support process, ideally before a formal diagnosis • Better integration into employment-related care • Understanding of work opportunities for people with YOD • Knowledge of relevant legislation and policy	• Collaboration with occupational physician and employer to identify sustainable work options
Employee with dementia	• Clarity about personal capabilities and limitations in the workplace • Understanding of financial consequences and support options • Knowledge on possibilities for continued employment or adapted roles	• Early application for disability benefits (e.g. Dutch early disability scheme) • Access to a trusted confidant or 'buddy' in the workplace
Employer	• Practical advice from occupational physicians on managing the employee with dementia • Education about dementia and its workplace implications	• Joint consultations with the employee and occupational physician • Transparent discussion of possibilities and limitations within the company/organisation • An open and flexible mindset throughout the process
Healthcare psychologist	• Knowledge of relevant legislation and policy • Insights in the needs and wishes of the person with dementia	• Consultation with occupational physician to discuss work possibilities
Caregiver of employee	• Recognition and validation of their role and stress • Financial security for the household • Education about dementia • Access to caregiver support services	• Involvement in work-related meetings, if desired by the employee • Access to financial counselling and caregiver support services
General Practitioner	• Improved understanding of YOD and its early presentation • Comprehensive view of the patient's situation, including workplace dynamics	• Structured consultation with occupational physicians • Timely referral to a dementia case manager (*In the Netherlands, the GP is responsible for initiating this support*)

*A social insurance physician assesses work capacity and disability in the context of social security legislation and determines eligibility for disability benefits.

crucial for openness about the situation and possibilities.

> Throughout the entire 'something feels off' phase, there should already be good communication between all parties involved. Why should the employer not also engage with the employee's family? This relates to building trust. – dementia case manager

Participants agreed that the occupational physician plays a crucial role in this phase, but he or she can only be included if consulted by the employer or employee, which often happens too late. Without the timely help of an occupational physician, participants believed employees were more at risk of premature sick leave or job loss. Additionally, once an occupational physician was involved, they should contact the General Practitioner and relatives of the employee to get a clear understanding of the situation at work and at home and acquire a holistic understanding of the situation.

> The occupational physician needs to be well informed with concrete examples from the workplace. What is happening at home? You have to involve multiple domains, a combination of the general practitioner and the occupational physician. – HR professional

An employee from the Dutch governmental agency responsible for benefits for employees emphasized that employers and employees are aided with an early diagnosis, because this gives them the opportunity to apply for disability benefits. This allows the employee to remain active in the workplace if they want without financial restraints, and the employer has no financial risks anymore.

> An employee's income can be supplemented with a benefit if he or she is still working or wishes to continue working. The employer bears no financial burden because the IVA [Dutch Invalidity Insurance] benefit is granted, while the employee gains financial security. – Employee of the Dutch governmental agency responsible for benefits for employees

Discussion phase 2 and 3 – diagnostic trajectory & working with dementia. Participants agreed that during phase 2 and 3 the needs of the employee are most crucial. Disability benefits should be applied for as soon as possible, and possibilities for continued work should be explored if this is the wish of the employee. Continued work should be supervised by an expert, who can inform employers on what to expect, and help employees find work that fits their needs and capabilities.

> The presence of a job coach is necessary to enable continued employment. – Welfare professional

Here, participants emphasized that communication between the employer, employee and his or her family and the occupational physician is crucial.

Dementia case managers were also seen as highly important in these phases, because they can aid in finding compatible work, as well as providing information on dementia for employers and colleagues. In the Dutch context, a dementia case manager is a specialized healthcare professional who coordinates care and provides practical and emotional support to people with YOD and their families. Their role includes navigating healthcare services, facilitating communication, and addressing age-specific challenges such as work and family life.

> The case manager accompanies the individual throughout the entire trajectory, from the diagnostic process to leaving paid employment, but also beyond that by supporting engagement in activities such as volunteering and continued participation in the community. – *dementia case manager*

Discussion phase 4 and 5 – phasing out work & life after work. Participants indicated that identifying opportunities within one's current job is particularly challenging in the absence of a formal diagnosis, placing a substantial burden on the employee. Once a diagnosis is established, it becomes easier to focus on remaining work capacities. In addition, financial arrangements are often addressed through disability-related benefits, providing employers with greater scope to explore options that support continued participation at work and preserve a sense of purpose and self-worth.

However, participants also emphasized that this requires additional workplace support for employees with dementia, as well as for colleagues and supervisors. This support may include increased guidance, adjustments in task allocation, and the redistribution of certain responsibilities. Participants suggested that this support could be provided by a case manager YOD in combination with a job coach.

> In this phase, work is no longer expressed in terms of wage value, but in terms of value; of meaning, of being of value. What sense of self-worth can you still offer someone? It is about looking at what still fits, which will likely not be within one's original job role. - employer

Participants agreed that when it is time for an employee with dementia to leave the workforce, a decent farewell is important. The decision to leave should be made together with the person with dementia.

> A farewell is also important… keep it dignified and respectful towards the person. – HR professional

After cessation of paid employment, participants suggested that volunteer work could be a new valuable daily activity. In the Netherlands, there are growing initiatives that help persons with YOD find volunteer work. For this, an expert is involved to monitor and evaluate how it is going. Participants thought this could be a good alternative for other dementia healthcare such as day care, a community-based daytime support service where individuals can participate in structured social, recreational, and therapeutic activities. Persons with YOD often feel not ready to start day care yet, or there are no appropriate day care options for young persons in the region.

> It is not only about the aspect of the illness, but also about wanting to do something together and the willingness to invest in that. I think this is just as important as knowledge, sensing the other person and truly seeing and hearing them. – dementia case manager

Co-creation session 2

In this session 19 individuals participated, all of whom did not participate in the first session. The session included employees with dementia ($n=5$), a caregiver ($n=1$), HR and workplace specialists ($n=3$), occupational physicians & labor experts ($n=4$) and healthcare professionals ($n=6$). The perspective of the employer was missing during this session, however, HR professionals and workplace specialists had enough knowledge to substitute for this perspective.

In this second session, the aim was to gather clear suggestions for the design and content of the WorkDEM compass. For this, stakeholders were grouped together, to discuss amongst peers what their thoughts and needs were. The participants used the roadmap of the work-related journey and the Personas in their discussions. The session resulted in several suggestions for the design and content of the WorkDEM compass.

Format. All stakeholder groups independently suggested a website including all relevant information regarding dementia and employment would be their preference. The website should tailor to the specific phases in the work-related journey but should also contain stakeholder specific information.

Additionally, participants mentioned the website could host different tools, including conversation aids, a signal card, leaflets with tips and tricks, and information on the legal framework.

Next to the WorkDEM Compass, dementia case managers suggested to develop specific training for direct co-workers and employers of persons with YOD. Additionally, they mentioned the WorkDEM Compass should be integrated in the young-onset dementia case manager training program that is already in place in the Netherlands for case managers working with people with young-onset dementia and their relatives.

Content. All stakeholders agreed that the compass should contain all the relevant information for every stakeholder. There were several specific topics suggested to be included in the WorkDEM compass. First, information about the financial and legal possibilities when a person with YOD wants to continue employment was mentioned by all stakeholder groups. This can be used by all stakeholder groups to help understand the possibilities. The Dutch legislation is complex, and no clear overview of possibilities is available. Employees, employers and healthcare professionals all expressed the need to be aware of possibilities they could explore. They also mentioned clearly described scenarios of possibilities within the legal framework could help occupational physicians find the best solutions for individuals with YOD. Next, information on red flags or early signs and symptoms related to dementia in the workplace was mentioned as a need to recognize dementia earlier. Also, HR professionals mentioned the need for information on measures that could be taken in the workplace that help a person with YOD continue employment.

In all cases, the emphasis remained that although generic information is needed, every individual is different, and every trajectory can therefore be different. Additionally, it was emphasized how important collaboration between stakeholders is for successful continued employment throughout the whole journey.

Step 3 – designing and developing the WorkDEM compass

In this step, all the information from step one and two were accumulated, and together with an expert team different elements were created. They drafted the content of the tools, after which different stakeholders (an employee, a caregiver, an occupational physician and a healthcare professional) were asked to comment on and improve the content.

The different elements that were created were; i) a signal card to aid the early recognition of YOD specifically in the workplace, ii) an inspiration kit on how to support dementia in the workplace with practical tips and tricks, iii) a digital handout describing various scenarios about all the regulations and financial options in the Dutch context, and iv) conversational aids for different target groups (see Table 2). The elements were designed by a professional design agency. Purpose of the styling was to be elegant, peaceful and optimistic. The elements were specifically designed to address positivity and underline possibilities in the context of working with dementia, with an emphasis in all elements on collaboration between relevant stakeholders.

The results of the co-creation sessions also showed a strong desire for a website which accumulates all information on working with dementia and can be used by all stakeholders. Therefore, the next step was to build the website with the design agency, again using the same design as previously used in the different elements. The website included all the different elements, but also the work-related journey of a person with dementia as a roadmap, with specific information tailored to the specific phases of the journey. Additionally, specific information was also tailored for different stakeholders. Finally, to increase the positive approach for this topic, we included positive experiences of working with dementia from the perspectives of different stakeholders. The website and the elements were then integrated on a digital environment, hosted by the Young-onset Dementia Knowledge Centre to ensure longevity of the digital environment beyond the end of the project.

Table 2. Tools included in the WorkDEM compass.

Website
Tips and insights in every phase of the work-related journey
General information, including all the developed tools
Information for specific stakeholders, including employees and their caregivers, employers, occupational physicians and healthcare professionals
Positive experiences
Tools
Signal card
This is an easy-to-use product including 10 early signs or signals that could help recognize YOD at the workplace
Inspiration kit
Includes information on the decision to continue employment, tips to remain active in the workplace, who to involve in this process, examples of work adjustments and tips on communication throughout the process
Digital handout
This handout focusses on legal and financial information. It contains different scenarios, important notes regarding the disability scheme and tips regarding financial consequences
Conversation aid
There are two conversation aids included, one for the employee and one for the employer. Both are tailored to the first phase, to help conduct open and respectful conversations when first symptoms and suspicions start to arise.

Discussion

The development of the WorkDEM Compass was guided by a co-creation approach, in which relevant stakeholders were actively involved throughout the design process. It was aimed at supporting continued employment for individuals with YOD, resulted in an online platform providing extensive information and guidance on working with dementia for all relevant stakeholders. It includes a signal card, inspiration kit, digital handout and conversation aids as tools. It addresses an important gap in dementia care, namely the lack of accessible, practical resources to support continued employment for persons with dementia (McCulloch et al., 2016). Within the developed WorkDEM Compass, the combination of a phase-based work-related journey, practical tools and stakeholder specific information offers a novel way to

support employment for persons with dementia. The Compass promotes and facilitates shared responsibility and communication between stakeholders, which are key determinants for successful continued employment.

The WorkDEM compass closely aligns with the International Classification of Functioning, Disability and Health (ICF), both emphasizing what a person can still do, rather than focusing solely on limitations. The ICF is widely recognized as the most established conceptual framework for structuring vocational rehabilitation, developing interventions, and assessing work capacity (Escorpizo et al., 2011). It provides a biopsychosocial perspective, in which health conditions interact with personal factors, activity limitations, participation restrictions, and environmental influences. The emphasis on positivity closely aligns with the positive approach of the WorkDEM compass and the concept of positive health (Huber et al., 2011).

By identifying possibilities and using a positive tone, the WorkDEM Compass encourages stakeholders to find suitable solutions for continued employment. The ICF model highlights that the ability to continue working depends not only on medical factors but also on personal and external factors (Heerkens et al., 2017). In the case of YOD, external factors include the workplace environment, opportunities for adjustments, supportive colleagues, and HR support. Personal factors encompass motivation to work, awareness of limitations, coping strategies, and work identity. The WorkDEM Compass specifically addresses these personal and external factors by promoting collaboration between stakeholders and offering guidance on workplace adjustments. With this, the Compass can reduce stigma and improve the work-related journey by improving coordination and knowledge on which steps to take. By acknowledging the importance of different stakeholders, the Compass encourages timely involvement of all relevant stakeholders, thereby reducing the amount of sick leave or early job loss due to YOD. Moreover, the handout will also help minimalize early job loss or financial restrictions, as it gives insights in legal possibilities such as disability benefits. In the Netherlands, persons with YOD can apply for a benefit scheme, preventing them from financial despair.

Finally, as highlighted in the ICF framework, a person's medical condition affects their ability to work and participate, and if not addressed, cause (extended) sick leave or job loss. Many individuals with YOD face a prolonged period before receiving a diagnosis, during which symptoms gradually develop and affect their work performance. Often, by the time the condition is diagnosed, employees are indeed already on sick leave or have lost their jobs, making early recognition critical (Damsgaard et al., 2025). To support timely identification, the WorkDEM Compass includes a signal card specifically designed for the workplace. This tool helps managers, colleagues, and employees recognize early signs of work difficulties allowing for the initiation of support or appropriate adjustments, potentially reducing sick leave and preventing premature job loss.

Beyond supporting continued employment, the WorkDEM Compass may contribute to a more inclusive society by promoting equal opportunities for people with YOD to remain engaged in meaningful work. By increasing stakeholder awareness, facilitating communication, and providing practical guidance, the Compass aims to reduce barriers that may otherwise lead to unnecessary exclusion from the workforce.

During the development process, it became clear that the employment journey of persons with YOD is highly individual. Nevertheless, there is a common work-related journey that many people with dementia follow while still in the workplace. Using this journey as the foundation for the WorkDEM Compass made it easier to identify which stakeholders should be involved in every phase of the journey, and what their specific needs were within these phases. This approach ensured that the Compass was tailored to the needs of all stakeholders, with an emphasis on the most important stakeholders; persons with dementia and their caregivers, employers, occupational physicians and dementia healthcare professionals. This phase-based approach also reflects the dynamic of the ICF framework, where functioning and participation evolve over time and interact with changing personal and external factors (Escorpizo et al., 2011).

Previous research has shown that effective collaboration between stakeholders is a key factor in supporting employment among persons with dementia (Smeets et al., 2024; Smeets et al., 2025). Within the ICF framework, such collaboration constitutes a key external factor that can either enable or hinder continued participation in work. While the WorkDEM Compass includes information and tips to facilitate such collaboration, its success ultimately depends on stakeholders' awareness and willingness to access the platform and engage in joint efforts. An important ethical consideration within this collaboration is the disclosure of a dementia diagnosis to employers and other stakeholders. Disclosing the diagnosis should always be guided by the person's autonomy, eventhough it may facilitate support and workplace accommodations, it can also carry risks of stigma or unintended harm.

Sustained collaboration remains challenging due to factors such as time constraints, limited awareness of available resources and differences in workplace culture or organization. During the implementation

of the WorkDEM Compass, as well as in future research, efforts should be made to enhance these collaborations.

As is clear from the literature, persons with dementia who are still in a working age often desire to continue employment, because it sustains self-esteem, gives them daily structure and social connections (Ritchie et al., 2018). However, barriers such as delayed diagnoses, a lack of guidelines and ambiguous legal frameworks make continued employment difficult. The extensive WorkDEM Compass has integrated these barriers in its content, thereby aiming to reduce the barriers and increase likelihood of continued employment. It builds on existing initiatives from the UK and Scotland (Scotland, 2016; Society As. Creating a dementia-friendly workplace, 2015), but differs by targeting all relevant stakeholders, and by being co-created with these stakeholders. This multi-stakeholder, co-creation approach offers a more comprehensive and practical way to overcome employment challenges.

Reflection on methods and lessons learned

A key strength of this project is the active involvement of users throughout the development process, which helps ensure that the intervention meets the user's needs (Dabbs et al., 2009). Yet, studies providing a detailed description of user involvement are scarce (Göttgens & Oertelt-Prigione, 2021). This study therefore contributes by demonstrating continuous involvement of users in all phases of the WorkDEM Compass development. The development strategy of the WorkDEM Compass was based on a user-centered design (Skivington et al., 2021), which was regarded the most appropriate design, as user involvement is associated with significant benefits such as gaining insight in the user's perspective, generating new ideas and improving feasibility (Shah & Robinson, 2007).

The co-creation sessions of phase two were particularly successful. As co-creation is an increasingly used method in research, benefits and challenges become increasingly clear. A systematic review from 2025 (Agnello et al. 2025) showed that there are many common challenges when conducting co-creation sessions. Many of these, including amongst others poor engagement and participation, low transparency and low trust were not applicable to our experiences. Below, we describe some lessons learned regarding these common challenges.

First, there is a risk of lack of representativeness. In our case, all relevant stakeholder groups participated in either the first or second co-creation session, leading to a holistic view of the content and design of the WorkDEM Compass. Nevertheless, representativeness across stakeholder categories may have been limited. Participants were primarily recruited through project partner networks, likely narrowing the range of perspectives included. However, collaboration with the Dutch Young-Onset Dementia Knowledge Centre provided broader contextual insight through the accumulated experiences of their network partners, which appeared to align with the findings from our co-creation sessions, suggesting that the perspectives captured were broadly reflective of the main stakeholder groups. A specific lesson from this study concerned the inclusion of persons with YOD in the second co-creation session. Participants with YOD were highly motivated to contribute and expressed appreciation for having their perspectives acknowledged. To minimize distraction and optimize engagement, group discussions were organized in separate rooms, an approach that was positively received by participants with YOD.

Although poor engagement is commonly cited as a challenge for co-creation sessions (Göttgens & Oertelt-Prigione, 2021), our experience showed that the use of Personas and the work-related journey map emerged as particularly powerful tools for engaging stakeholders. These visual methods translated abstract processes into concrete, relatable scenarios that stimulated reflection and creativity. Participants reported that they found the visual tools particularly helpful in the co-creation discussions. Incorporating visual design methods into co-creation not only enriches the process but also enhances the interpretability of results. Future projects addressing complex, multi-stakeholder issues may benefit from systematically integrating such tools. Participants also appreciated the priming assignments, which made them feel prepared for the session and helped in engaging during the discussions. These assignments can also help preventing topic drifting, a known challenge in co-creation sessions (Agnello et al., 2025). Managing expectations during the co-creation sessions is essential to reach the goal of the co-creation sessions. We learned some participants had different expectations, including using the session to discuss personal situations or seek advice. This experience highlights that setting a clear goal and clear expectations at the start of the session is recommended.

Last, a key lesson from the co-creation sessions was that bringing together diverse stakeholders fostered in depth discussions and understanding of each other's perspective. This helped stakeholders understand their own role but also other stakeholder's role much better. The co-creation session can therefore be seen as a way to enhance collaboration between stakeholders and result in a product that enhances this collaboration.

Future research and implementation for practice

The next step in this research is the evaluation of the WorkDEM Compass amongst all stakeholders. Here, the feasibility, usability and impact of the Compass should be tested in a large group of different stakeholders.

The WorkDEM Compass has been developed particularly for and with persons with YOD, as they face unique challenges in the context of employment. Nevertheless, the Compass may also be useful for other populations with neurodegenerative disorders that occur in working age such as Parkinson's disease, Huntington's disease or Multiple Sclerosis. Future research should explore which elements of the WorkDEM Compass can be transferred or require condition-specific tailoring to other diagnostic groups.

Although the WorkDEM Compass provides resources to foster collaboration, the platform's effectiveness still depends on stakeholders' awareness, motivation, and digital access. Implementation of the WorkDEM Compass should therefore exist of easy access to the online platform and widespread communication of the existence of the Compass. The online platform is already freely available (www.werkendementie.nl), and next steps should be tailored to increasing awareness and generating easy to use pathways for the Compass.

Conclusion

This study aimed to develop a co-created, user-centred intervention to support continued employment among persons with young-onset dementia. The WorkDEM Compass meets this aim by integrating stakeholder perspectives into a practical, digital platform and by demonstrating the feasibility of applying co-creation principles in a multi-stakeholder context.

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References

Agnello, D. M., Anand-Kumar, V., An, Q., de Boer, J., Delfmann, L. R., Longworth, G. R., Loisel, Q., McCaffrey, L., Steiner, A., & Chastin, S. (2025). Co-creation methods for public health research—characteristics, benefits, and challenges: a Health CASCADE scoping review. *BMC Medical Research Methodology*, *25*(1), 60. https://doi.org/10.1186/s12874-025-02514-4

Bulto, L. N., Davies, E., Kelly, J., & Hendriks, J. M. (2024). Patient journey mapping: Emerging methods for understanding and improving patient experiences of health systems and services. *European Journal of Cardiovascular Nursing*, *23*(4), 429–433. https://doi.org/10.1093/eurjcn/zvae012

Clemens, J., & Parvani, S. (2017). *The age of eligibility for public retirement programs in the OECD.* Fraser Institute Vancouver.

Dabbs, A. D. E. V., Myers, B. A., Mc Curry, K. R., Dunbar-Jacob, J., Hawkins, R. P., Begey, A. L. E. X., & Dew, M. A. (2009). User-centered design and interactive health technologies for patients. *CIN: Computers, Informatics, Nursing*, *27*(3), 175–183. https://doi.org/10.1097/NCN.0b013e31819f7c7c

Damsgaard, L., Pedersen, J., Laursen, T. M., Nabe-Nielsen, K., Hendriks, S., Jensen-Dahm, C., Waldemar, G., & Janbek, J. (2025). Patterns of sick leave and unemployment prior to a diagnosis of young onset Alzheimer's disease. Alzheimer's. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, 2025 *21*(2), e14607. https://doi.org/10.1002/alz.14607

Egdell, V., Cook, M., Stavert, J., Ritchie, L., Tolson, D., & Danson, M. (2021). Dementia in the workplace: Are employers supporting employees living with dementia? *Aging & Mental Health*, *25*(1), 134–141. https://doi.org/10.1080/13607863.2019.1667299

Escorpizo, R., Reneman, M. F., Ekholm, J., Fritz, J., Krupa, T., Marnetoft, S.-U., Maroun, C. E., Guzman, J. R., Suzuki, Y., Stucki, G., & Chan, C. C. H. (2011). A conceptual definition of vocational rehabilitation based on the ICF: Building a shared global model. *Journal of Occupational Rehabilitation*, *21*(2), 126–133. https://doi.org/10.1007/s10926-011-9292-6

Göttgens, I., & Oertelt-Prigione, S. (2021). The Application of Human-Centered Design Approaches in Health Research and Innovation: A Narrative Review of Current Practices. *JMIR mHealth and uHealth*, *9*(12), e28102. https://doi.org/10.2196/28102

Gulliksen, J., Göransson, B., Boivie, I., Blomkvist, S., Persson, J., & Cajander, Å. (2003). Key principles for user-centred systems design. *Behaviour & Information Technology*, *22*(6), 397–409. https://doi.org/10.1080/01449290310001624329

Heerkens, Y. F., de Brouwer, C. P., Engels, J. A., van der Gulden, J. W., & Kant, I. (2017). Elaboration of the contextual factors of the ICF for Occupational Health Care. *Work (Reading, Mass.)*, *57*(2), 187–204. https://doi.org/10.3233/WOR-172546

Hendriks, S., Peetoom, K., Bakker, C., van der Flier, W. M., Papma, J. M., Koopmans, R., Verhey, F. R. J., de Vugt, M., Köhler, S., Withall, A., Parlevliet, J. L., Uysal-Bozkir, Ö., Gibson, R. C., Neita, S. M., Nielsen, T. R., Salem, L. C., Nyberg, J., Lopes, M. A., Dominguez, J. C., … Ruano, L, Young-Onset Dementia Epidemiology Study Group. (2021). Global prevalence of young-onset dementia: A systematic review and meta-analysis. *JAMA Neurology*, *78*(9), 1080–1090. https://doi.org/10.1001/jamaneurol.2021.2161

Hendriks, S., Peetoom, K., Tange, H., van Bokhoven, M. A., van der Flier, W. M., Bakker, C., Papma, J. M., Koopmans, R., Verhey, F., Köhler, S., & de Vugt, M. (2022). Pre-diagnostic symptoms of young-onset dementia in the general practice up to five years before diagnosis. *Journal of Alzheimer's Disease: JAD*, *88*(1), 229–239. https://doi.org/10.3233/JAD-220215

Huber, M., Knottnerus, J. A., Green, L., van der Horst, H., Jadad, A. R., Kromhout, D., Leonard, B., Lorig, K., Loureiro, M. I., van der Meer, J. W. M., Schnabel, P., Smith, R., van Weel, C., & Smid, H. (2011). How should we define health? *BMJ (Clinical Research Ed.)*, *343*(jul26 2), d4163–d4163. https://doi.org/10.1136/bmj.d4163

Issakainen, M., Mäki-Petäjä-Leinonen, A., Heimonen, S., Nedlund, A.-C., Astell, A., Boger, J., Rissanen, S., & Nygård, L. (2023). Experiences of influencing one's own life when living with working-age dementia. *Ageing and Society*, *43*(8), 1934–1953. https://doi.org/10.1017/S0144686X21001525

Jansen, B. J., Jung, S-g., Salminen, J., Guan, K. W., & Nielsen, L. (2021). *Strengths and weaknesses of persona creation methods: Guidelines and opportunities for digital innovations*.

McCulloch, S., Robertson, D., & Kirkpatrick, P. (2016). Sustaining people with dementia or mild cognitive impairment in employment: A systematic review of qualitative evidence. *British Journal of Occupational Therapy*, *79*(11), 682–692. https://doi.org/10.1177/0308022616665402

Page, L., Meredith, P., O'Reilly, M., Donohue, G., & Stanley, M. (2025). Understanding employee experiences of developing younger onset dementia within the workplace: A scoping review. *Work (Reading, Mass.)*, *80*(1), 24–60. https://doi.org/10.3233/WOR-230469

Pruitt, J., & Adlin, T. (2010). *The persona lifecycle: Keeping people in mind throughout product design*. Elsevier.

Ritchie, L., Tolson, D., & Danson, M. (2018). Dementia in the workplace case study research: Understanding the experiences of individuals, colleagues and managers. *Ageing and Society*, *38*(10), 2146–2175. https://doi.org/10.1017/S0144686X17000563

Scotland, A. (2016). *Dementia and the workplace*. A guide for employers in Scotland Edinburgh: Age Scotland.

Shah, S. G. S., & Robinson, I. (2007). Benefits of and barriers to involving users in medical device technology development and evaluation. *International Journal of Technology Assessment in Health Care*, *23*(1), 131–137. https://doi.org/10.1017/S0266462307051677

Skivington, K., Matthews, L., Simpson, S. A., Craig, P., Baird, J., Blazeby, J. M., Boyd, K. A., Craig, N., French, D. P., McIntosh, E., Petticrew, M., Rycroft-Malone, J., White, M., & Moore, L. (2021). A new framework for developing and evaluating complex interventions: Update of Medical Research Council guidance. *BMJ (Clinical Research Ed.)*, *374*, n2061. https://doi.org/10.1136/bmj.n2061

Smeets, B., Janssen, N., Peetoom, K., Boots, L., Bakker, C., & de Vugt, M. (2024). 'Too young to sit at home': A qualitative study conducted among employees with young-onset dementia and their relatives. *Aging & Mental Health*, *28*(8), 1119–1128. https://doi.org/10.1080/13607863.2024.2345132

Smeets, B., Peetoom, K., Janssen, N., Boots, L., Bakker, C., de Vugt, M., & Hendriks, S. (2025). Supporting continued employment for individuals with young-onset dementia: Insights From a qualitative study into key stakeholders' roles and perspectives. *Dementia*, 14713012251409436. https://doi.org/10.1177/14713012251409436

Society As. Creating a dementia-friendly workplace. (2015). *A practical guide for employers*. London: Alzheimer's Society.

Thomson, L., Stanyon, M., Dening, T., Heron, R., & Griffiths, A. (2019). Managing employees with dementia: A systematic review. *Occupational Medicine (Oxford, England)*, *69*(2), 89–98. https://doi.org/10.1093/occmed/kqy161

van de Veen, D., Bakker, C., Peetoom, K., Pijnenburg, Y., Papma, J., de Vugt, M., & Koopmans, R, PRECODE study group. (2022). Provisional consensus on the nomenclature and operational definition of dementia at a young age, a Delphi study. *International Journal of Geriatric Psychiatry*, *37*(3), GPS5691. https://doi.org/10.1002/gps.5691