

MS@Work in Flanders: The Development of a MS Toolkit for a Stable Employment

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Abstract. Persons with MS have the highest unemployment rates compared to other chronic diseases. We want to develop a MS Toolkit with several aids for persons with MS to help them gain a sustainable employment with sufficient and permanent attention and guidance for the daily obstacles in the workplace. Therefore, the opportunities and bottlenecks were mapped through a survey with persons with MS and employers, a diary and expert interviews. There were 3 major problems identified: Persons with MS find it difficult to ask for help in time; they have little or no concrete knowledge about who they can turn to for support and healthcare professionals do not always possess the expertise to guide their patients through problems experienced on the work floor. These problems were used as fundaments in a cocreation session to create the content of the MS Toolkit: a screening tool and dashboard. The screening tool ensures an annual reflection of the work situation. The dashboard links each problem to the most appropriate service.

Keywords. Multiple sclerosis, employment, MS toolkit, screening, prediction, dashboard

1. Introduction

Multiple Sclerosis (MS) is a chronic, inflammatory and neurodegenerative disease that affects the central nervous system by forming plaques. In Belgium, more than 12.000 inhabitants suffer from MS and it is one of the most common neurological disorders in working adults with ages between 20 and 50 years old [1-3]. People with MS are a vulnerable group in our society. On the one hand, their condition is chronic. The symptoms, progression and severity of the disease have an unpredictable character and vary per person. On the other hand, people with MS encounter many problems to stay at work. 60-90% of this group effectively has a job at the time of diagnosis or has worked in the period before diagnosis [4-6]. However, 10 years after diagnosis, only 30% are

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still actively working [1,7,8]. MS patients have the highest unemployment rates compared to other chronic diseases [9]. These high rates are a consequence of complex interactions between health status (physical, cognitive and psychological function, type of immunomodulator, ...), work environment (temperature, accessibility, parking, ergonomics, support from colleagues/employer, ...), job requirements (job content, hours, flexibility, ...) and personal factors (education level, health perception, personality, ways of coping with illness, age, ...). However, it is proved that a stable, long-term employment has a positive impact on patients with MS. It is associated with higher quality of life, higher well-being, better disease management, higher self-confidence, higher social participation and fewer problems in the workplace [7,10,11]. In contrast, losing a job or an unstable professional future has a negative impact on health. It is associated with lower quality of life (both physical and psychological) and higher mortality rates [12].

Aside the fact that persons with MS are a very vulnerable group in our society due to their chronic and unpredictable disease character, they are very motivated to (continue to) work. They want to contribute to the society, want to remain useful, still have career goals and have a great perseverance. In addition, to maintain a decent standard of living, they need a decent financial return. Our society currently does not provide enough answers to give vulnerable groups with such a diverse course of illness a stable place in the labour market. There are no simple tools or well-known support channels specific to this group that could help them continuing work. This makes them a population with high labour potential, but with reduced opportunities and higher health costs.

To find a solution for this fundamental problem, it is, in first instance, necessary to precisely identify the opportunities and bottlenecks on the work floor for persons with MS in Flanders. In the second place, based on the results, we want to develop a MS Toolkit including several aiding tools for persons with MS and their network to help them (re)gain a sustainable employment.

2. Methods

2.1 Part 1 “Opportunities and bottlenecks”

To map the opportunities and bottlenecks, 4 methods were used:

1. an online survey for working persons with MS.

Prior to the development of this survey, inspiration was sought from (international) literature on relevant questions and themes. This formed the basis for a questionnaire that was thoroughly reviewed and revised by the entire project team in order to arrive at a final version. The final survey consisted of four parts: current and previous work experiences, detailed information about working with MS, disease characteristics and background information. The survey was composed in Qualtrics and the link was distributed via social media channels. In order to achieve the widest possible inclusion, no predetermined selection criteria were imposed on the basis of work status or working age. The themes which were particularly important at a later stage of the investigation were:

- The impact of MS on current or past employment
- The biggest challenges in current or past employment
- Helping factors to stay at work

- The desired vs. the made adjustments
- Level of information on support measures

2. **an online survey for employers of persons with MS.**

The survey was created in the same way as described above. This survey also consisted of four sections: background information, opportunities for adaptations on the work floor, concerns and current knowledge. The dissemination of this survey was a lot more personalised: (1) through the network of MS-Liga Flanders, (2) direct demand for employer contact data in the survey and reflection study of persons with MS and (3) via social media. Here too, the survey was composed in Qualtrics and distributed via a link.

The inclusion criteria included 1 condition: at least one person with MS had to be actively employed. The issues that were taken to the next stage were:

- What disadvantages they experience of employing someone with MS
- What benefits they experience in employing someone with MS
- What impact the company has already experienced
- What adjustments have already been made
- What are the main barriers to keep someone at work for a long time
- Knowledge support measures

3. **a 5-day online reflection diary for working persons with MS.**

To get a deeper insight in persons with MS, an online reflection study was done. 5 days in a row, 5-6 questions were asked within a particular theme. The themes were: illness and impact on daily (work) life, working experience, communication, support, social network/context. Once again, inspiration was drawn from (international) literature to pick the themes, together with the themes of the survey. On the one hand, the search for potential participants took place via social media, on the other hand persons with MS were recruited through the participating rehabilitation centres. Here too, Qualtrics was used as a medium to send out the short diary surveys on a daily basis. The inclusion criteria were working persons with MS, jobseekers, persons on sick leave or retired persons.

4. **semi-structured in-depth interviews with multiple experts.**

As the surrounding network is also very important, the opinion of a wide range of experts in the field was also taken into account. These expert profiles (medical insurance advisor, occupational doctor, job coach, disability case manager, occupational therapist, general practitioner, social assistant, MS nurse, neurologist, psychologist, rehabilitation doctor, care manager, employer) were specifically searched for within the existing network of the project partners. The inspiration for the interview guide also came from (international) literature and was of course closely related to the themes that were already covered by previous methods: their role, bottlenecks, opportunities, important measures, level of communication, knowledge of employment pathways and support measures.

A descriptive analysis was done for the questionnaires and a thematic analysis was applied on the diaries and interviews.

2.2 Part 2 “Co-creation”

The results of part 1 were used to create personas and customer journeys as input for 2 cocreation sessions with multiple experts (Director of MS-Liga Flanders, occupational therapist, care manager, professor, social worker, researcher) in the MS domain. For the personas, the International Classification of Functioning, Disability and Health (ICF) model was used as the basis for objective mapping of each participant. The personas were categorised according to the degree of limitations: no-light-moderate-serious. One of the five personas eventually disappeared, as it included the population who retired early and no longer had any job motivation. Furthermore, the following themes were included in the personas: demographics, goals, type of work, work motivation, communication with employer, acceptance, support, used support measures, contacts with healthcare professionals and participation in the society.

For the creation of the customer journeys, suitable time points were sought (diagnosis, first interview with employer, symptoms at work, etc.) within the results of part 1 and ordered in a realistic timeline. This timeline was expanded with information on positive or negative experiences and current bottlenecks. Subsequently, a process analysis was done during a co-creation session, where each participant had to indicate 5 priorities. The elements that received the most attention were used as fundament to formulate 5 concluding opportunities. These opportunities were the starting point to brainstorm about new ideas (short individual process). After this individual brainstorm phase, each participant indicated the 5 most innovative ideas. The idea with the highest score became the fundament of the group brainstorm to further refine the concept.

Afterwards, this concept idea was then developed, prototyped, investigated and further refined and received the name “MS Toolkit”.

3. Results

A total of 118 working persons with MS, 2 job seekers, 16 persons in sick leave, 12 retired persons, 5 students, 4 work volunteers and 19 employers finished the questionnaire, 24 persons with MS participated in the diary study and 23 experts cooperated in the in-depth interviews. This data was used to create 5 personas and 4 customer journeys to support the co-creation process and idea generation.

The generated idea from the co-creation session is eventually a solution for 3 major problems (identified from the customer journeys): (1) Persons with MS find it very difficult to ring the alarm bells in time and ask for help; (2) they have little or no concrete knowledge about who they can turn to for support or advice and (3) healthcare professionals do not always possess the expertise to guide their patients through questions or problems experienced on the work floor. This means that potential problems often drag on and usually result in a relapse, attack or flare-up, forcing the person with MS to quit his/her job for a while (or permanently) to recuperate.

In the cocreation session, these 3 elements were used as the fundaments to brainstorm about the MS Toolkit content. Two online aiding tools were the result:

A **screening tool** ensuring an annual reflection of the work situation and motivates a faster detection (**Figure 1**). The content was based on an extensive literature search, where an overview was created about all the existing screening tools to discover work problems. Based on certain criteria (availability, validation, scoring system, collection time, purpose, language, etc.) this list was screened. The current screening tool became

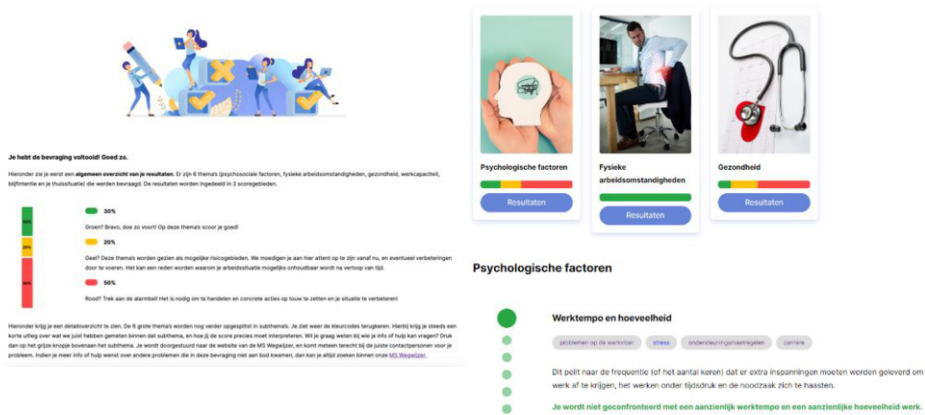


Figure 1. Print screen from screening tool (in Dutch)

a combination of 2 validated dutch workability questionnaires (Vragenlijst over Werkbaarheid (VOW) [13] and Vragenlijst Arbeidsreintegratie (VAR) [14]), which assesses how the employee experiences the balance between his own characteristics and the demands he is confronted with in the workplace. Results are calculated in diverse levels: psychosocial factors, physical working conditions, health condition, work capacity, the intention to stay and stressful home situations. All these levels are subdivided into different subdimensions. The choice of VOW and VAR was decided by a small test group ($n=14$) of persons with MS and experts (Director of MS-Liga Flanders, occupational therapist, care manager, professor, social worker, researcher). To start the screening, each patient receives a unique weblink. Only the persons who have this link, can enter the screening or the results (for GDPR reasons). Each test is automatically saved, so that current or previous results rest available.

In addition, a **dashboard**, functioning as a user-friendly supporting online platform, which is either accessible from the screening results, or by surfing to www.werkenmetms.be (Figure 2). It can be consulted by the person with MS itself or a healthcare professional. This dashboard is a website which guides a person with MS immediate to the desired source of information in a quick and easy way, if they encounter problems in their work situation. The development was done in 2 phases: 1) based on literature research and a questionnaire for persons with MS ($n=36$) and experts ($n=13$), all possible work problems were gathered. This was followed by 2) desk research and 19 in-depth interviews with diverse experts (social worker, job coach, MS nurse, occupational physician, disability case manager, occupational therapist, HR, labour union, career coach, psychologist, return to work coach) were done to find out which service(s) exist in Flanders per reported problem. This information became the blueprint of the dashboard. Each link was double checked afterwards with the concerning instance. Eventually, the dashboard provides 10 main themes (“most common problems”): Communication, Problems on the work floor, Energy, Reintegration, Career, Psychological factors, reorienting, mobility, education, laws & duties. Under each main theme, there are multiple subthemes. Each subtheme is subdivided into 4 categories: aids on the work floor, external aids, trajectories, tips & tools. Under each category, a summary is found of the existing (Flemish) solutions (e.g. service, professional, organisation, ...). The goal of the dashboard is to provide a simple and straightforward guidance for each problem or question concerning work towards the right solution.



Figure 2. Print screen of dashboard, available at www.werkenmetms.be (in Dutch)

Through this medium, we want to create instant lines to an immediate and correct referral per problem/question, so that interventions could be initiated faster and the person with MS is immediately advised or helped by the right person. In Flanders many solutions exist, but healthcare professionals and patients do not know where to find them.

The screening tool and dashboard were developed as online tools. Both tools are stepwise prototyped in a small group of persons with MS ($n=3$ to 4) with attention to layout, guiding texts, figures, fonts, size, user friendliness, etc.

4. Discussion

This study reaches 2 easy and applicable aiding tools for persons with MS and their surrounding network to help them with a sustainable place in the labour market with sufficient and permanent attention and guidance for the daily obstacles in the workplace. With 430 new cases per year in Belgium, without intervention, the problem of unemployment and sickness will only increase, with an ever-lasting negative impact on the economy, patient well-being and businesses.

Our ultimate goal is to implement this MS toolkit in each Flemish hospital and in services who work with persons with MS (e.g. patient associations like MS-Liga Flanders) in order to reach annually and automatically as many as possible working persons with MS. A stable employment will not cure MS, but seen it is associated with a better disease management, higher quality of life, higher wellbeing, etc. this toolkit might be seen as an indirect, non-invasive assistance in the treatment of MS.

In the long term, this project will have a positive impact on society, for the well-being of the individual MS patient and for society through the growth towards a more inclusive society, but also economically, for government through cost savings, for employers and businesses by maintaining their experienced workforce and associated expertise and for the person with MS through a better financial condition. For the policy areas, it is initially very relevant for the Flemish labour market: the more people with MS that are actively working, the higher the contribution to the efficacy rate of the Flemish population. This also has an advantage to preserve the knowledge-based economy, which is based on the presence of sufficient human resources: Almost half of the Flemish population between 25 and 44 years old are highly educated [15], but also a large number of people with MS are included in this group. If they continue to participate,

they can help maintain the high level of knowledge in Flanders. But a lasting expertise of the technically skilled is also an added value for the knowledge economy. They are the bridge between innovation and practice.

Between May-July 2023, the MS Toolkit will have its first try-out in Flanders. We aim to evaluate, improve and validate the MS Toolkit. In addition, we will check which steps are necessary to be able to implement it easily in the current health care sector, so we can prepare the MS Toolkit for further distribution and validation. This will be done by organizing a focus group with different profiles inside the healthcare sector (managers, therapists, etc.). The NASSS (non-adoption, abandonment, scale-up, spread, sustainability) framework will be used in this focus group to help predict and evaluate the possible success of this MS Toolkit [16].

In the future, the MS Toolkit also need to be complemented with a flyer, given at the moment of diagnosis, which informs persons with MS about the possibilities to stay at work with MS. Also different kinds of aiding materials to facilitate communication about MS to avoid misunderstandings are welcome to support this population. These were 2 other aiding tools that were discussed in the co-creation session but are not developed yet. The MS Toolkit is the first step towards a better support for patients with MS, but certainly not the last.

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