

MULTIPLE SCLEROSIS CARE PROCESS DIGITALISATION

A multi-actor approach

Fundació HiTT
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Multiple Sclerosis Care Process Digitalisation

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Issue: Multiple Sclerosis Care Process

Multiple sclerosis (MS) is a degenerative, chronic, autoimmune disease of the Central Nervous System that affects the brain and spinal cord.

- It is the second leading cause of disability in young people, after traffic accidents.
- Every year in Spain 1,800 new cases are diagnosed.
- 55,000 people are currently diagnosed with MS in Spain.
- 8,000 people diagnosed in Catalonia.
- 700,000 people diagnosed in Europe. And more than 2.5 million worldwide.^[1]

MS has particularities in the care system due to its **chronic nature**, the **diversity of manifestations** in which it occurs and the cross-cutting implications in terms of **social, health and psychological needs** that it entails in patients.^[2]

Improving the care that people with MS receive throughout the disease goes beyond clinical work, it also involves **the organization of care** and the **tools and solutions** offered to patients.

Solution: Digitalisation of multiple sclerosis care process

The digitalisation of the healthcare system has the transformative potential to introduce improvements in the management of healthcare processes. The introduction of digitization in the different phases of the care process in multiple sclerosis is seen as a formula to improve:

- Patient care experience.
- The quality of life of people with multiple sclerosis.
- The efficiency and sustainability of the healthcare system.

Approach: Definition of the healthcare process and digitization solutions

A multidisciplinary team made up of professionals from the sectors involved in the care process for multiple sclerosis jointly delimits the MS care process in a day of co-creation with the aim of introducing proposals for improvement through the introduction of digitization solutions throughout the process.

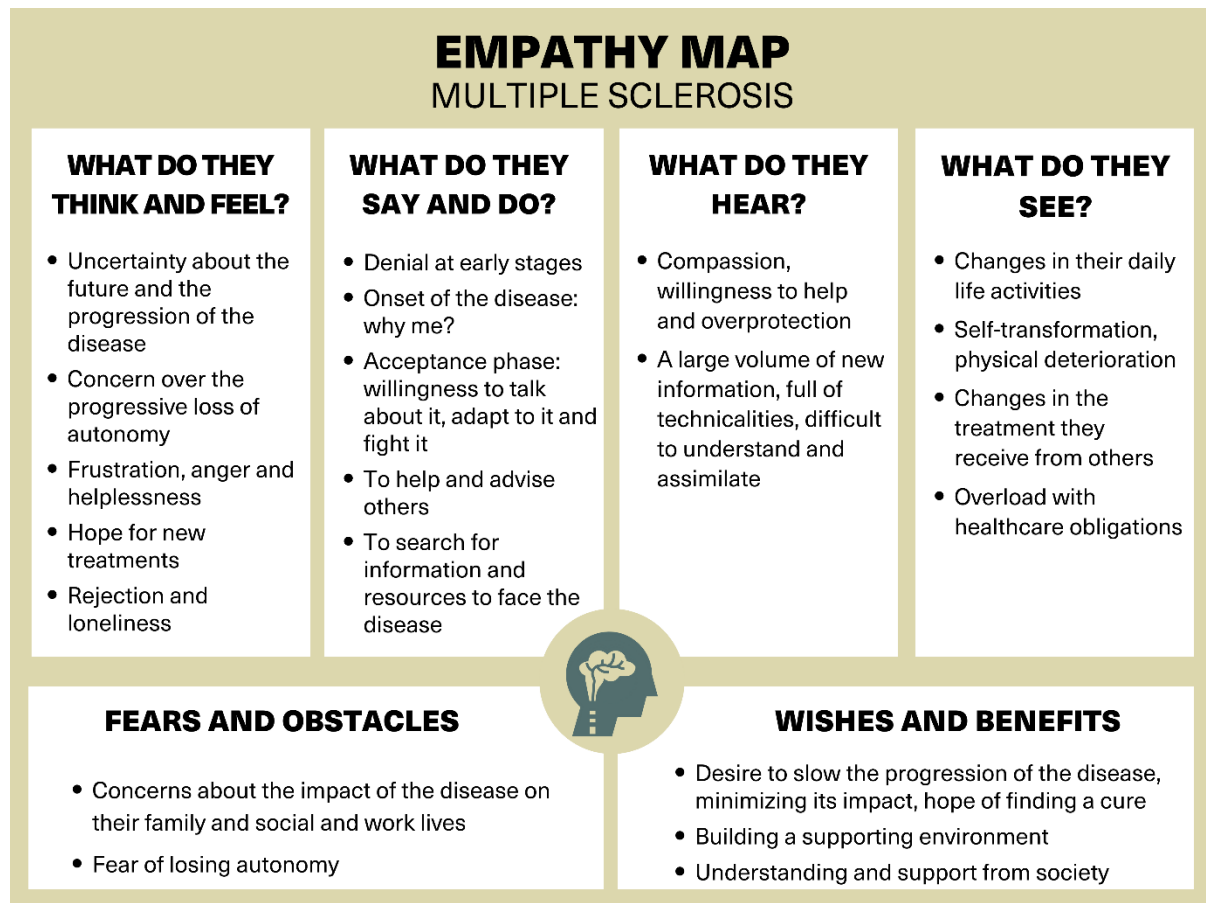
Sectors: Nursing, Business, Neurology, Psychology, Health System and Patients.

Phases:

1. Map of empathy.
2. Definition of the care process.
3. Identification and classification of digitization points.
4. Indicators for the standardization of information systems.

Empathy Map

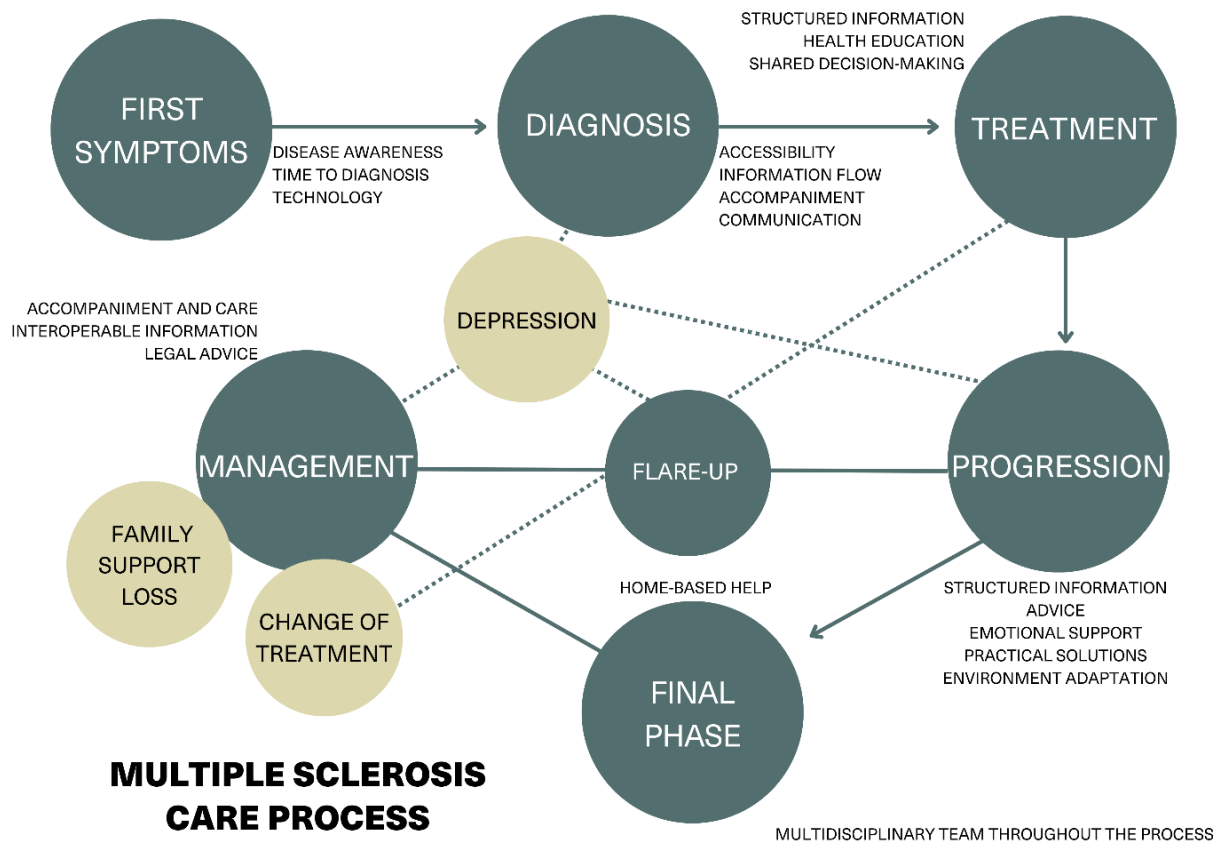
The purpose of the empathy map is to offer a global and cross-sectional view of the patient's experience in multiple sclerosis through the contributions of the different agents involved in their care process. A shared building where representatives of the patients also take part.



Collection of the most representative contributions regarding the patient's experience:

- Uncertainty about the future and evolution of the disease. How personal and work life will be affected and the ability to manage the disease are a source of concern.
- Fear of the loss of autonomy caused by the disease.
- Frustration, anger, and helplessness when thinking why the disease is affecting them.
- Receiving a large flow of information, an abrupt exposure to a high volume of new information to be assimilated, with lots of technicalities, poorly adapted to the situation.
- Contributions regarding acceptance, indicate the willingness to explain the new situation, to adapt, and move forward, also to help and to advise others in the same situation.

Definition of the care process and areas for improvement



1. Onset of Early Symptoms and Initial Studies

Location: Primary Care and Emergency Department.

- The ability of the professionals involved to identify the disease. It is important that they have the knowledge of multiple sclerosis to approach it with in the best way possible.
- Technology and time to diagnosis when facing early symptoms of the disease happens to be key elements to dispel the uncertainty that the patient may experience and address the disease efficiently in the early stages.

2. Diagnosis

Location: Specialist Care at the Hospital.

- It has been identified as relevant when it comes to diagnosis: facilitating accessibility to the system; providing comprehensive and integrated care; the intervention of a

multidisciplinary team; the strengthening of communication skills and the guarantee of an adequate flow of information, task in what patient associations can contribute.

- Providing the patient with support on the understanding and correct management of the information transmitted to him. As well as the provision of psychological care that equips the patient with the skills to face new challenges.

3. Treatment

Location: Health Center and the patient's home.

- Structured information, necessary for decision-making, as well as health education are considered.
- A comprehensive, multidisciplinary, approach and a process based on shared decision-making where the patient gets involved.

4. Disease progression (functional and cognitive)

Location: Home, place of work or other spaces.

- To provide the patient with structured information and tools to identify a flare-up. To empower them and guaranteeing their accessibility to the healthcare system by speeding up contact with it.
- To offer emotional support as well as legal and community guidance is key. Progression involves growing needs that may require practical solutions to face the functional challenges involved, as well as adjusting their environment to their needs, adapting the spaces they inhabit such as home or their workplace.
- In some cases, the help of a caregiver may, also, be required.

5. Disease management

This phase includes regular check-ups, stages of depression, changes of the treatment, adapting the environment, and the loss of family support. Those are issues connected with each other intertwined with the rest of the stages, where it is valuable to bring together a multidisciplinary team.

Location: Health Center, home, and environment of the patient.

- Periodic check-ups and changes in treatment. Make it necessary to have an interoperable information system.

- Stages of depression may be experienced in different stages by the patient. It is necessary to provide legal and employment advice, and to accompanying the patient's relatives in this situation.
- Phases of loss of family support, either due to the death of the caregiver or the separation of the partner. Phase where it is also essential to ensure patient care with a person in charge of care.

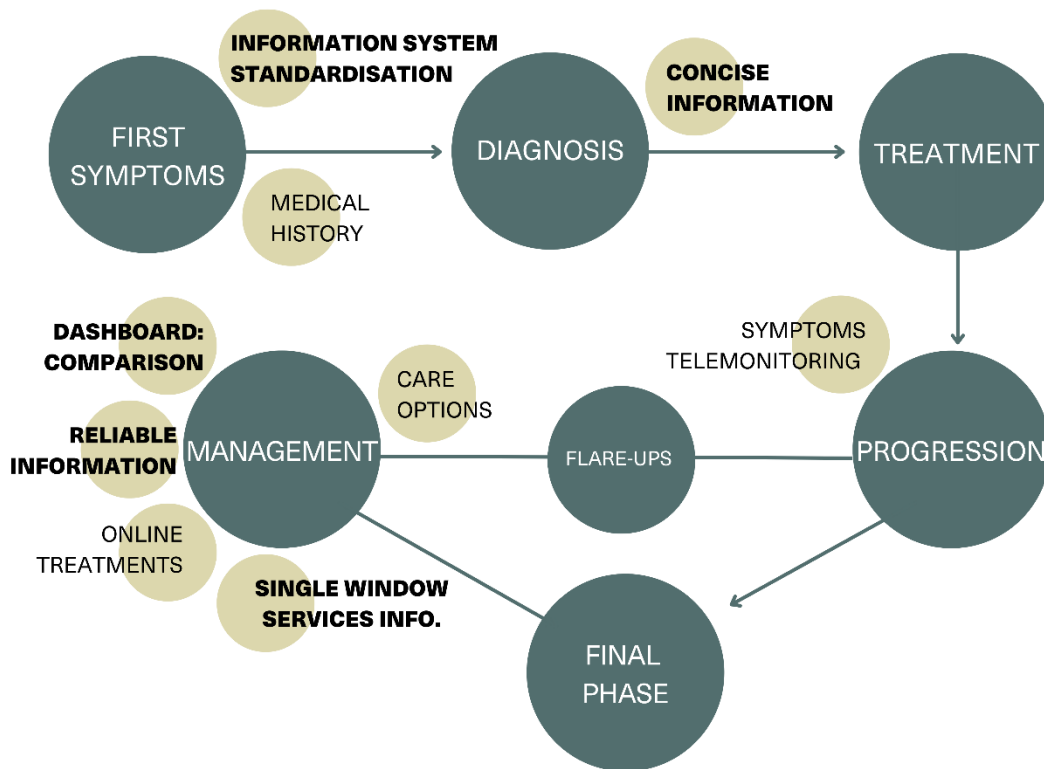
6. Final phase: Advanced disability and end-of-life

Location: your usual address or residence.

- It is key to ensure support and home help, integrating palliative care as well as establishing advance wills.

Digitisation solutions

Once the stages of the healthcare process and the areas for improvement have been identified, the proposal of potential digitisation solutions located in the different phases of the process is considered.



- When facing the onset of early symptoms, digitalisation is aimed at the engagement in terms of access, navigation, and links. Through the centralization of information through a universal access source, that considers a prioritisation according to the level of severity through a prior triage.
- The standardisation of information systems is taken into account in the diagnostic phase, through the digitalisation of information, which is presented in a unified, centralized, structured and accessible way for both healthcare professionals and users. Facilitating the patient's access to their medical history via a smartphone.
- In a phase of periodic controls, the digitalisation is geared towards telemonitoring symptoms before or between visits and the options of visits adapted to the needs of the patients: face-to-face, non-face-to-face, video call, e-consultation.

- The digitalisation of procedures, services, management, and resources and the access to a one-stop window to structured, contrasted and reliable information is contemplated in a phase of disease management, so that are online accessible.
- The need to provide an overview of the situation is also noted. Through a dashboard with complete visual information that provides a comparison between the population.
- When it comes to advanced stages of the disease where patients could find themselves in a state of advanced disability, digitalisation becomes necessary for the geolocation of services and the provision of a library of resources.
- From the onset of the disease to its treatment, digitalisation becomes relevant for the management and flow of information that is received by the patient, so the information provided is concise as it has been previously selected.

Proposal of indicators for the standardization of information systems

Building standardized information systems where information is concise, reliable, comparative, and universally accessible is fundamental to the digitalisation of the multiple sclerosis care process. The standardisation of the information system necessarily involves the prior selection of relevant data. Through a cross-sectional perspective of the care process for multiple sclerosis, mediated by agents from different areas of this process, we propose a list of indicators.

- **Demographic Information:** Knowing the gender and age of the patient provides relevant information to know which population group it is. It is especially relevant in a disease that, like multiple sclerosis, has biases in terms of incidence in terms of sex and age, affecting more young women than men.
- **Onset of the first symptoms:** Indicator that may coincide with a first visit to the emergency room or care centre, which does not necessarily lead to an initial diagnosis. It allows us to know not only the first recognized manifestation of the disease, but also the relationship between it and the age of diagnosis. It is important to identify whether the time of diagnosis is optimal and whether it varies according to others, such as geographical location.
- **Treatment Lines:** The identification of the different types of treatment that have been involved in the care process of the patient's multiple sclerosis and the dates of each one, allow us to know the evolution of the disease.
- **Expanded Scale of the State of Disability (EDSS^[3]):** Indicator designed for the assessment of disability in people with Multiple Sclerosis. It allows us to know the functional situation of the patient on a motor scale and monitor their evolution, which does not present or evolve uniformly in different patients.
- **Function Independence Measure (FIM^[4]):** An indicator that assesses the ability to develop functionally and their degree of autonomy to perform different motor and cognitive tasks.
- **Hospital Anxiety and Depression Scale (HADS^[5]):** Assessment of the emotional dimension of the disease acquires relevance in multiple sclerosis, a multidimensional disease that is characterized by psychological implications. The HADS scale determines the emotional impact of the disease on the patient in terms of depression and anxiety. Other non-hospital indicators, such as the Beck Despair Scale (BHS) indicator or the Hamilton Depression Scale, are also considered.
- **Recognized degree of dependency:** Relevant indicator in the field of social benefits, however, may have a skewed fit for the assessment of diseases such as Multiple

Sclerosis, as being oriented to the most visible symptoms, may not reflect the degree of actual disability of people with multiple sclerosis.

- **MsQoI-54^[6]**: The intervention and services for patients with multiple sclerosis aim to ensure their quality of life. This indicator, designed for the evaluation of multiple sclerosis, assesses life quality regarding health. This questionnaire offers a broad view that includes issues such as physical function, psychological state, pain, social function, fatigue, and sexuality.

The following are other aspects to consider in defining information systems to build a more complete view of the care process, including indicators capable of assessing the following dimensions:

- **Type of multiple sclerosis**: It allows us to know in which stage of the disease is the patient, according to the following phenotypes^[7], relapse-remission, progressive secondary, progressive primary, and progressive relapse. So the evolution of the disease could be evaluated, however, the symptoms are very variable and groups of people with the same type can experience the disease in different ways.
- **Level of social support**: Measuring the social support of a person with multiple sclerosis allows us to get closer to their relationships and their trust and degree of support. Indicators such as Oslo-3 (OSSS-3^[8]) may be useful in this dimension because of their comparability, brevity, and ability to complement other indicators in terms of quality of life, emotional state, or degree of dependency.
- **Patient satisfaction with the care process**: Provides information on the quality of health care and its adaptation to the needs of the patient. Likert scale offers a pathway to the perception of the quality of the services patients received, regarding their disease, on a scale of 1 to 5, where 5 indicates the higher degree of satisfaction.
- **The degree of knowledge of the disease**: It has been shown that disease awareness facilitates the patient's adaptation to a chronic disease ^[9]. Information is a resource that the patient has, it offers autonomy. Indicators such as MSKQ-25^[10] they allow us to know the degree of information that the patient has to deal with the disease.
- **Habitual physical activity**: There is a beneficial relationship between physical activity and the improvement of the symptoms of multiple sclerosis. Indicators such as the International Physical Activity Questionnaire, in its simplified form (IPAQ-SF^[11]), helps us to know the physical activity related to the health of people with multiple sclerosis in their daily lives.

DEMOGRAPHIC INFORMATION gender and age	ONSET OF EARLY SYMPTOMS	TYPE OF MULTIPLE SCLEROSIS	LINES OF TREATMENT
QUALITY OF LIFE MsQoI-54	EMOTIONAL DIMENSION HADS	SOCIAL SUPPORT OSSS-3	HABITUAL PHYSICAL ACTIVITY IPAQ-SF
PATIENT SATISFACTION likert scale	KNOWLEDGE OF THE DISEASE MSKQ-25	DEGREE OF DEPENDENCY	DISABILITY EDSS and FIM

Conclusions

Through the shared approach to the patient's experience, the definition of the care process, the key elements in each phase and the proposal of digitization solutions, it was determined that the digitization of the care process of multiple sclerosis must consider the following points:

- The value they provide based on two axes: patients and professionals of the health system. It is necessary to consider the value that the solutions provide for the patient and also the value that they build for the agents of the health system. In this way, the goals of improving the patient experience and the efficiency and sustainability of the healthcare system are pursued.
- The importance of information management emerges throughout the care process. The information and its flow emerges as a cause for concern of patients in the face of the high volume of information they are exposed to, and at the same time a desire to have the necessary knowledge to deal with the disease and reduce the uncertainty. The management, selection and transfer of information emerges as a challenge of digitalisation, it is necessary to know what information should be measured to build efficient information systems.
- Putting the patient at the centre involves including their participation in the process that involves them, not only as beneficiaries, but also taking into account their active role in the process. Where it has access to information, streamlining its contact with the health system, improving accessibility, and enhancing autonomy.
- In the standardisation of information systems, it is necessary to take into account the need to obtain a cross-sectional approach to the needs of the patients. Therefore, a selection of indicators capable of picturing the reality of people with multiple sclerosis should be considered, indicators that provide measured, reliable, comparative and universally accessible information.

As a result of these key points, the digitalisation solutions that have been identified in the healthcare process should be led by the following points:



From early stages, where the first studies are performed on the patient, the standardisation of information systems becomes important. Making concise and structured information available allows us to establish what information should be measure and build a dashboard with visual and comparative information of the population.

From there, create a universal access point, a one-stop window accessible for both patients and healthcare professionals involved in the healthcare process, to ensure a reliable source of information.

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