

MUSICALISE

MULTIPLE SCLEROSIS, HOW TO INSTIGATE CARE INTEGRATION ACROSS NATIONAL CONTEXTS VIA PATIENTS ENGAGEMENT?

KEYWORDS

multiple sclerosis, integrated care, MS care unit, gradation of care, mixed methods, patient engagement

DURATION

36 months

ABSTRACT

Multiple Sclerosis (MS) is a chronic lifelong neurological disease starting in young adulthood with diverse symptoms and unpredictable evolution. Consequently, it necessitates a high degree of coordination to guarantee continuity of care and to answer as much as possible the specific patients needs. In recent years, to face the increasing therapeutic arsenal and the unmet needs from patients with MS, the concept of MS care units (MSCU) emerged. The main mission of MSCU is to gather a MS-expert multidisciplinary team in order to offer a seamless and efficient management of the disease, leading to an improved patient experience and outcomes. These structures are an interesting form of innovation and a potential means for care integration, as a key player in the care process. Indeed, integrated care is a potential solution to avoid care discontinuities that are associated with negative consequences for patients, and to ensure that individuals receive the care services they are in need of. Such an approach relies on a quintuple aim, i.e. get a simultaneous focus on improving population health, improving patient experience, reducing costs, improving healthcare providers' work experience and health equity. In this perspective, MUSICALISE aims to develop a patient-centered model of care based upon MSCU that will be relevant and declinable in different contexts to better answer needs from all the stakeholders (patients, health care providers, policy makers) and ensure integrated care. The project consortium brings complementary expertise and will facilitate access to different models of care management and different schemes regarding MSCU implementation. The projects methodology fits with the realist evaluation paradigm, using mixed methods (combination of qualitative and quantitative data analysis) in an interdisciplinary approach (epidemiology, political and management sciences). Furthermore, MUSICALISE will adapt and integrate the MULTI-ACT digital framework that represents a holistic management model encompassing mission-driven governance, patient engagement and impact assessment. More specifically, the Master Scorecard provides a collection of indicators, classified under five impact dimensions: excellence, efficacy, economic, social and patient-reported outcomes. Results will come both from data that are already available (patients data in MS registries and medico-administrative databases) and data that will be collected during the project (online questionnaire, semi-structured interviews and focus groups). In particular, data collection will focus on: 1. existing models of MS care, 2. perceptions of stakeholders (patients, health care providers, health care authorities, policy makers) regarding the models of care required to fully meet the needs of the person with MS, and 3. innovative solutions proposed by MSCU in order to promote integrated care and care coordination with health care providers outside MSCU. This will allow us to assess at what points the care to patients with MS differs from the most desired situation, what are the impeding and facilitating factors, how

to correct the deviation, and how MSCU are a lever to promote care integration. The comparative perspective across countries and care settings will offer the opportunity to learn lessons that may be relevant throughout EU member states. With a strong interest from patients perspective, MUSICALISE aims to propose a sustainable concept of care and a personalized approach, built upon the benefits and meaningful impacts of all the stakeholders. This will provide health care authorities and policy makers access to evidence-based strategies supporting the transformation towards people-centred services. MUSICALISE will first benefit to people living with MS (2.8 million in the world, including 1 million in Europe) but can also be a case study for other chronic diseases.

PARTNERS

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Robert-Seilaniantz	Ecole des Hautes Etudes en Sante Publique	France
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