



Computational Models for new Patients Stratification Strategies of Neuromuscular Disorders

D 8.1 Communication and Dissemination Plan

Dissemination and communication strategy, advisory board and guidelines (First Plan)

PROJECT DETAILS AND DELIVERABLE INFORMATION

PROJECT DETAILS

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GLOSSARY OF ACRONYMS

Acronym	Extended Definition
AI	Artificial Intelligence
CA	Consortium Agreement
C&D	Communication and Dissemination
CDE	Communication Dissemination Exploitation
CDL	Communication and Dissemination Leader
CDI-WG	Communication, Dissemination and Impact Working Group
CeGaT	Cegat GMBH
CERBM	Centre Europeen de Recherche en Biologie et Medecine
DBL	Deep Blue
DoA	Description of Action
EC	European Commission
EU	European Union
FINC	FINCONS Group
FSM	Fondazione Stella Maris
GA	Grant Agreement
GDPR	General Data Protection Regulation
HNMDs	Hereditary NeuroMuscular Diseases
ICT	Information and communications technology
KPI	Kei Performance Indicators
KUM	Klinikum der Universität Munchen
LMUM	Ludwig-Maximilians-Universität Munchen
MoM	Minute of Meeting
MRI	Magnetic Resonance Imaging
PC	Project Coordinator
RND	Rare Neurological Disease
R&D	Research & Development
SFF	Samfundet Folkhalsan i Svenska Finlandm
SMART	Specific, Measurable, Attainable, Relevant and Time-bound
SUT	Politechnika Slaska
TECNALIA	Fundacion Tecnalia Research & Innovation
UNEW	University of Newcastle
UNIMORE	Università di Modena e Reggio Emilia
WG	Working Group
WP	Work Package

DISCLAIMER

Views and opinions expressed in this document are those of the author only and do not necessarily reflect those of the European Union or European Commission. Neither the European Union nor the granting authority can be held responsible for them.



1. EXECUTIVE SUMMARY

This document contains the CoMPaSS-NMD plan for its dissemination, which provides internal guidance on planned C&D activities and tools foreseen to achieve the specific objectives of the CoMPaSS-NMD project. The plan will also establish accountability for C&D actions as well as means to measure the results of the planned activities and to track progress towards the dissemination goals.

CoMPaSS-NMD is a 4-year European-funded project started in May 2023 and aims to develop new tools for diagnosing, monitoring and treating patients with Hereditary Neuromuscular Diseases (HNMD) in a more accurate and personalised way. To achieve this goal, clinical, genetic and histopathological data, as well as those derived from MRI scans, provided by members of the CoMPaSS-NMD Consortium, will be processed by advanced clustering techniques to identify group of patients with similar clinical characteristics.

CoMPaSS-NMD concerns a wide range of stakeholders, from HNMD patients to different roles in the healthcare providers' system and faces highly sensitive topics. In this context, the communication and dissemination activities play a key role in achieving the project goals, and they are crucial for CoMPaSS-NMD to provide clear explanations of the complex aspects characterising the project to facilitate the acceptance and the adoptions of the proposed solutions in the daily medical routine.

Finally, the plan also aligns with the stakeholders' engagement and consultation, the release of Recommendation and Guidelines and the exploitation strategy (WP8).

A second update of the communication and dissemination plan (D8.1) will be released at M24, and the final version of the plan will be delivered at the end of the project (M48).

2. PROJECT ABSTRACT

The CoMPaSS-NMD project creates novel and universal tools for the diagnostic stratification of patients suffering from Hereditary NeuroMuscular Diseases (HNMDs) aiming at personalised treatments.

HNMDs often occur in young people, causing long-term disability and early death; these conditions bring lack of participation, need for permanent assistance, and may require long-term institutionalisation. Multidimensional HNMD data - clinical, genetic, histopathological and MRI – will be provided by third-level clinical centres in Italy, France, Germany, Finland, and the United Kingdom as part of the European Reference Network for Rare Neurological Diseases. Computational tools for high-dimensional clustering will be applied in an unsupervised learning approach using the internal structure of data to define groups of similar patients. Classification model averaging and integration techniques for federated learning-inspired model building and novel HNMD-specific descriptors of histopathological images will be implemented. The adoption of this multidimensional view has the potential to increase the diagnostic rate of HNMDs by 30% and foster effective actions by European national health systems. As the main project outcome, the CoMPaSS-NMD Atlas Platform will be a cost-effective AI-based application providing precise clinical characterization and diagnosis, with data remaining publicly available for anyone in the research and health community to use.

The project will deliver Recommendations and Guidelines for stratification-based patient management to offer superior standard-of-care for diagnosis and prognosis and assist in planning clinical trials. It will follow a user-centred, co-design methodology with a strong stakeholder engagement and networking with other project consortia.

The project engages partners with clinical, biotechnological, ICT, computational, ethical and legal, communication and exploitation competences: 6 clinical/academic centres, 1 academic, 4 industrial partners.



3. INTRODUCTION

3.1 Scope and structure of the document

This document contains the CoMPaSS-NMD Communication and Dissemination Plan, identifying the appropriate channels and tools/methods to be utilised to spread the CoMPaSS-NMD concept to a wider audience. This is the first release which will be continuously refined, adjusted and completed as the project evolves, on the basis of the project's evolution, the feedback received by the target audience and the changes in the project's communication and dissemination needs.

The upcoming versions of this deliverable (i.e., first update due at M24 and the second update at M48) will gather and report all the project's dissemination actions, conclude on the impact generated and define the post-project dissemination and communication actions plan to support the exploitation strategy (delivered in WP8, D8.2 at M26).

The following main session represents the C&D plan itself (Chapter 5) and contains the C&D:

- objectives
- strategy
- tools and channels
- enhancing and increasing the impact and the visibility of the project
- evaluation criteria

Finally, in Chapter 6 the conclusions of this deliverable are provided.

4. COMMUNICATION AND DISSEMINATION PLAN

This section describes the WP8 objectives, strategy, defining goals, target audience and approach for the communication, the dissemination of the project results and outcomes, and the engagement of key stakeholders of CoMPaSS -NMD.

4.1 Objectives of the Communication & Dissemination Plan

The main objective of the dissemination and communication plan of the CoMPaSS -NMD project is to offer partners a set of guidelines, responsibilities, and timelines on how/when/where disseminate the project, as well as to encourage them to use their channels (institution's websites, social media channels, their networks, etc.) to support the dissemination, with the main goal of gathering the ideal conditions to:

- **Raise awareness** of the project topic, importance, activities and events. This means circulating information about the project, its objectives, its expected results, and its activities, in order to make all the potentially interested parties aware of CoMPaSS -NMD. This phase begins in the early stages of the project and continues for all its duration. It may be considered achieved when a wide audience has received information on the project and is aware of it to some extent.
- **Generating understanding.** This goal regards transferring key messages to specific stakeholders, enhancing their knowledge and comprehension of the project itself. This phase



is a follow-up step of the raising awareness one: its achievement can be validated through the generation of follow-up discussions on CoMPaSS -NMD, requests for further information, or use of project materials (documents, reports, or dissemination material) for other research activities. This activity will be constant during the length of the project to ensure constant dissemination of its progress and achievements.

- **Engaging stakeholders.** Specific dissemination measures will promote interaction and active participation of the stakeholders in CoMPaSS -NMD. Through a variety of initiatives, CoMPaSS-NMD aims to attract and engage innovators (mainly hospitals and service providers, as well as healthcare related organisations) and potential customers and users from all over Europe. Again, this phase is a step ahead in the communication process. Its success is reflected in stakeholders' actions and interactions with the project.
- **Ensuring impact.** The dissemination objectives will ensure the long-term impact of the project results on the target audience. This is the most ambitious target of dissemination: it focuses on delivering key messages to key decision maker and policymakers so that the CoMPaSS -NMD findings and results are taken up and have an impact on future policies or practices.

The achievement of the Communication and Dissemination Plan objectives will be ensured by the complementarity of its component activities. These will ensure both project dissemination and constant and/or specific feedback from stakeholders. Feedback collection will be developed on an ongoing basis (through website and social media as well as events) and may concern a specific issue or a particular project stage (through communication activities).

4.2 Strategy

4.2.1 Internal Communication

The communication activities within the CoMPaSS -NMD Consortium have the two-fold objective of coordinating the dissemination effort and keeping the Consortium aware of the progress of the project.

More specifically:

- A shared workspace has been established on Unimore365.sharepoint platform. In this space, all CoMPaSS-NMD partners will share documents and inputs useful to coordinate and schedule the dissemination activities.
- Shared documents and direct contacts will be used to coordinate the activities related to the production of website contents and news on the social channels.
- Periodic e-mails from DBL, the WP8 leader, will be used to send reminders and elicit specific contributions from CoMPaSS-NMD partners.
- Regular CDI-WG meetings will be scheduled to coordinate the C&D activities, share updates about the different tasks of WP8 and discuss proposals from the partners.

4.2.1.1 Communication, Dissemination and Impact Working Group

The Communication, Dissemination and Impact Working Group (CDI-WG) includes one representative per each WP and has been set up at the beginning of the project to steer, manage and monitor the communication, dissemination and exploitation activities, ensuring the project sustainability. In particular, this WG will lead the co-production and promotion aspects of the ATLAS and



recommendations, supervising the organisational aspects as well as the implementation and monitoring of the CDE activities. Each partner appointed a member of the group and communicated her/his name during the kick-off meeting. A complete list of CDI-WG members is in the CoMPaSS-NMD SharePoint folder.

4.2.1.2 Synergies between WP8 and the other WPs

The communication & Dissemination strategies will serve the needs of different WPs:

- providing assistance during event promotion, organisation and management
- sharing of project results and products
- supporting the networking with relevant stakeholders
- Set-up and management of Scientific Advisory Board (SAB)
- launching call for action (e.g., CDI-WG and SAB members)

The C&D plan will take into consideration all the work packages, i.e., publishing articles and social media posts with the main results and takeaways of each WP. This will be done in collaboration with the WP leaders, who will be in charge of selecting and supplying the publishable material to the WP8 leader.

Results from selected deliverables will be extracted to create communication materials.

Moreover, following the procedures of learned neurological societies CoMPaSS-NMD Recommendations and Guidelines on the best use of the AI-based clinical tools will be co-produced stemming from the results of WP 2, 3, 4, 5, 6 and 7.

4.2.2 External Communication

External communication targets all the stakeholders not involved in the CoMPaSS-NMD project. Therefore, the main purpose of external communication is raising their awareness of the project's activities and achievements, and later engaging them in using the CoMPaSS-NMD solutions.

The external communication relies on many different means to promote the project: the website and other media communication (detailed in 4.3.2 section), attendance of conferences and events by the CoMPaSS-NMD consortium, the use of targeted dissemination products, and direct contact within selected organisations. CoMPaSS-NMD will contact these relevant organisations to collaborate, obtain expertise and provide outputs.

These actions aim at stimulating discussions and exchange of information with professionals and experts in the field, to both support the refinement of the project based on the feedback received and, at the same time, foster the future exploitation of the project results.

The following sections present details regarding the groups of stakeholders to reach, the key messages to each group and the means of external communication.

4.2.2.1 Identification of target groups

The first step is the identification of categories of stakeholders and some specific key actors relevant to CoMPaSS-NMD. Correctly identifying the characteristics and requirements of the audience targeted



by CoMPaSS-NMD is fundamental to tailor the communication, and thus increase the possibility to reach the dissemination goals.

At the beginning of the project the relevant target audiences (a preliminary list is presented below) has been identified and key messages for each of those have been defined as well as specific communication channels and customised materials and activities.

The community of stakeholders will be involved in the co-design process right from the first phases of the project thus allowing for the early identification of the project exploitable results, the increase of the social acceptance of CoMPaSS-NMD outcomes and the spread of the project results and possible replication Europe wide.

Relevant categories of stakeholders for the CoMPaSS-NMD project are categorised in three clusters:

- **Specialised Audience:** this audience is composed by people who may directly use or be impacted by the project results, e.g. in their work, study, research, or life. They constitute the main target audience for CoMPaSS-NMD. This target audience can be further split into several stakeholders' segments:
 - health professionals in the project's key locations and local/national health agencies/authorities: potential users of the CoMPaSS-NMD solutions, outputs and services. Physicians (especially neurologists, geneticists, and general practitioners) are crucial potential demanders of a solution that may affect patients' survival rates or disabilities and have a key role in justifying the clinical validity and utility for hospitals' uptake of the CoMPaSS-NMD tool.
 - the research community (including the coordinators of other relevant R&I actions and sister projects, as well as large national and international initiatives working in similar areas where synergies can be found)
 - technology providers: large and SMEs specialized in AI, IoT, Cloud & Big Data; key innovators in healthcare systems; data management; software developers
 - pharmaceutical industries
 - Interested groups: the [European Alliance of Neuromuscular Disorders Associations](#) (EAMDA) which works to support and improve the quality of everyday life of people with NMDs, [Muscular Dystrophy Association](#) (MDA), [Muscular Gystrophy UK](#), [French neuromuscular network](#) (FILNEMUS), [Unione Italiana per la Lotta alla Distrofia Muscolare](#) (UILDM), [Deutsche Gesellschaft für Muskelkranke e.V.](#) (DGM).
 - HNMD patients and their families: patients association for myotubular and centronuclear myopathies ([Myotubular Trust](#), [Zusammen Stark](#), [MTM-CNM family connection](#)).
 - **Scientific Advisory Board (SAB):** a group of seven experts in the CoMPaSS-NMD field, with an active role in ensuring the methodological quality, as well as the best transfer of research results.
 - **Ethics Advisor** who has the competencies in the involvement of humans in research projects and in the protection of personal data, to monitor the following ethics issues of particular concern:
 - development of an incidental findings policy, considering the analysis of genetic data and the possibility of unexpected findings,



- compliance with the GDPR in view of the processing of large scale of special categories of personal data.
- **Policy Makers, Governmental and International bodies:** these comprise public authorities defining societal health, social and economic priorities, as well as entities aligning the allocation of resources and investments with these priorities. Since they can contribute orientating research in the field of Artificial Intelligence usage for medicine, CoMPaSS-NMD will contact these relevant organizations to collaborate, obtain expertise and provide outputs. This category includes:
 - Political and governmental organisations, at local, national and international level, including the [European Commission](#), the [World Health Organization](#) (WHO), international networks and associations, such as the [European Reference Network for Rare Neurological Diseases](#) (ERN-NMD), and the [European eHealth Stakeholder Platform](#) (EHTEL) , [Agency for Healthcare Research and Quality](#), [National Institute of Health](#), [World Federation of Neurology](#), [Institut National de la Santé et de la Recherche Médicale](#) (INSERM French NIH), [Istituto Superiore di Sanità](#) (ISS, Italian NIH).
 - Regulatory bodies and ethical committees
- **General public:** this cluster includes people and groups interested in the general topics pertaining CoMPaSS-NMD, such as civil society groups, patients associations, or citizens interested in the potential of the project. This kind of audience recognizes the importance of the project topics and the benefits that may derive from the project research.

These three clusters of audience are expected to use the information and knowledge that CoMPaSS-NMD provides in different ways.

The general public will mostly make conceptual use of information, which will impact their levels of knowledge or attitude towards CoMPaSS-NMD. The specialised audience will use CoMPaSS-NMD project communication in an instrumental way, with a change of behaviour and practice. Finally, effective dissemination will produce a strategic use of the information by the policy makers, affecting the definition of policies and broad research topics.

As a result, different roles within the same organisation may require the use of different dissemination means, languages, content types and levels of detail for each specific target. In the following way the dissemination and networking strategy will ensure that the dissemination effort reaches the different target audiences and produces a specific type of utilisation of information.

4.2.2.2 Key Messages

The early definition of the key messages to transfer is crucial in the effort to support the dissemination of the project.

The key messages will change during the project duration to adapt to the evolution of the project and to take into consideration the different phases the project is in. In fact, in the initial phase the focus of the communication will be on promoting CoMPaSS-NMD and raising awareness around the project; later, it will shift to highlighting its progress; and finally, to spreading its results. Therefore, the key messages to convey will have to reflect these changes in focus.

Nevertheless, it is possible to identify from the beginning some key aspects of CoMPaSS-NMD to highlight for the entire duration of the project, as they are key to comprehending CoMPaSS-NMD. It is



particularly important to communicate them clearly in the initial phase of the project, to ensure proper understanding of the project.

These pertain to both technical and non-technical aspects, such as:

What is CoMPaSS-NMD? CoMPaSS-NMD - Computational Models for new Patients Stratification Strategies of Neuromuscular Disorders – is a project funded by the European Commission's HORIZON EUROPE programme. The project aims at developing new and universal tools for diagnosing, monitoring, and treating patients affected by hereditary neuromuscular diseases (HNMDs) in a more accurate and personalised way. Thanks to advanced clustering techniques, CoMPaSS-NMD will identify groups of patients with similar clinical characteristics and generate a valid methodology to be applied in clinical practice. The creation of the CoMPaSS Atlas platform will make all collected data and metadata available to the stakeholders' community.

Why is the project needed?

Loss of independence for HNMD patients: HNMDs cause long-term disability impeding the full participation of affected people in society with an added social burden since HNMD often occurs in young people (Turner JA et al. Prediction of chronic disability in work-related musculoskeletal disorders: A prospective, population-based study. *BMC Musculoskelet Disord.* 5:24, 2004) and the loss of independence implies lack of participation, assistance by family members or caregivers, and may lead to long-term institutionalisation. Remarkably, 30% of HNMD patients are wheelchair bound and/or home ventilated after the age of 50.

Lack of accurate diagnosis: 60% of patients presenting neuromuscular disease symptoms either receive a molecular diagnosis that does not explain their whole clinical phenotype or do not receive any molecular diagnosis at all (Savarese M et al. The genetic basis of undiagnosed muscular dystrophies and myopathies Results from 504 patients. *Neurology* 87:71-76, 2016).

There are no adequate tools to define and classify the specific clinical Gestalt of patients with HNMDs. The CoMPaSS-NMD project aims at enacting an advanced AI-based system for the stratification of HNMD patients starting from multidimensional information.

Lack of proper prognosis: the lack of understanding hinders the definition of a proper prognosis, with a devastating impact on patients' life, and prevents the development of efficacious treatments for most of these diseases (Voet NBM et al. Strength training and aerobic exercise training for muscle disease. *Cochrane Database of Systematic Reviews* 2019 12:CD003907): currently, only a few therapies, highly costly and difficult to scale up, have been generated based on known hereditary defects.

Which will the project impact be?

CoMPaSS-NMD will create a new approach to HNMD patients by integrating four fundamental aspects of the patient Gestalt (Cook C. Is clinical gestalt good enough? *J Man Manip Ther.* 2009;17(1):6-7. doi: 10.1179/106698109790818223. PMID: 20046560; PMCID: PMC2704346). The adoption of a multidimensional view, leading to a paradigm-shift, will increment the diagnostic rate by 30% and promote effective actions by European national health systems, ameliorating the quality of life of patients and caregivers and reducing needless expenses.



How does CoMPaSS-NMD work?

CoMPaSS-NMD includes six clinical centres present in Italy, France, Germany, Finland, United Kingdom, all present in the framework of the European reference network for rare neurological diseases, one technological university centre (AI) and four industrial partners (biotechnological, ICT, ethical and legal).

These centres will provide the multidimensional data (clinical, genetic, histopathological and MRI), which will be processed and used as input data patterns and distributions to identify groups of similar patients by high-dimensional computational tools based on clustering algorithms.

How does CoMPaSS-NMD deal with privacy?

In order to comply with the data privacy regulations such as GDPR, the extraction of the patient superclusters will be done without sharing the sensitive parts of clinical data. To do so, CoMPaSS-NMD makes use of a system, which protects the data of individual patients. Indeed, Federated Learning is a machine learning technique that trains a model across multiple decentralised devices holding data samples locally and therefore without exchanging them.

It is important to convey the message that **CoMPaSS-NMD will analyse patients' data whilst fully respecting their privacy.**

These key messages constitute the core of the communication in every phase of the project. Therefore, they will have to be taken into consideration when elaborating the specific messages related to the project progress and results in the later phases of the project.

Considering the different clusters of audiences identified, the messages above will be delivered to the three audiences differently.

1. **Communication towards the General Public** will focus on high-level content about the CoMPaSS-NMD solutions and benefits, with particular attention to privacy aspects to stimulate the acceptance of ICT solutions for health management.

2. **Communication towards the Specialised Audience** depends on the stakeholders' segments:

- **Hospitals, healthcare providers and value chain stakeholders, and patients** will receive mainly information regarding the CoMPaSS-NMD ecosystem, services, and products. In addition, they will receive technical details on framework support, security, and interoperability of its solutions, as well as functional and technical requirements. Finally, they will be targeted with content on market and financing opportunities, business models, product/services lifecycle, and innovative and sustainable solutions for healthcare management.
- **ICT industry** Large and Small and Medium-sized Enterprises specialised in AI, IoT, Cloud & Big Data; key innovators in healthcare systems; data managers; software developers: content regarding the CoMPaSS-NMD ecosystem, services and products; and, in addition, technical details about ecosystem support, security and interoperability, platform maintenance and usage, IoT devices used in CoMPaSS-NMD, functional and technical requirements, end users (pilots) needs. Finally, they will be made aware of market opportunities, business models, financing opportunities for related health 4.0 technology.



- **Academic and scientific community** in the field of healthcare, AI, IT, and Big Data will be informed of the knowledge, results and research advancements produced by CoMPaSS-NMD that can be transferred to academic environments, colleagues, scientific committees, scientific journals, Internet Forums, and other working groups.
- **Other EC projects** will receive project information, results and outputs, and evidence, good practices and recommendations.

3. **Communication towards the Policy Makers, Governmental and International bodies** will highlight successful or exemplary activities and results. CoMPaSS-NMD will also underline the cost effectiveness of its health solutions and approach, and in addition the current and potential value-based benefit of IoT, Big Data and AI/ML for health. Overall, CoMPaSS-NMD will promote content that supports and fosters the adoption of IoT, AI and Big Data solutions for management of health. This will be particularly important if CoMPaSS-NMD could prove that early identification/intervention can decrease the cost of downstream care by preventing healthcare utilisation in HNMDs' patients.

4.2.2.3 Engagement and Consultation of target groups

Defining the dissemination goals and the target audience of communication, and identifying the key messages to deliver, is the first step of the dissemination strategy. The next step consists of an accurate matching between the goals of the communication, the target audiences' characteristics and needs, and the identification of the proper means, formats, and language style to achieve the desired outcomes from the target audiences.

Effective and efficient engagement starts from the personalisation of contents, format and means for the different categories of stakeholders. The goal is to use platforms and communication channels best suited to target stakeholders. For example, policy makers will be engaged through existing networks and direct contact through letter, phone call and e-mail (abiding with GDPR). Moreover, more broad measures such as social media and the website will support messaging. Here the goal is to establish a credible position in the domain and attract interested parties via strategic content that is relevant, engaging and informative. Therefore, the team will release articles, newsletters and reports that can be found by those searching for materials related to e-health and NMD diagnosis and treatment. Doing so will provide followers of CoMPaSS-NMD with additional value and more reason to be engaged. Of course, the tangible actions of the project will also provide opportunities to attract the right audience members. Consequently, it is imperative that all partners are active and consistent with the communication efforts, especially attracting and encouraging the relevant stakeholders to join/follow the project.

The main steps considered in drafting the CoMPaSS-NMD dissemination strategy concern:

- The analysis of the peculiarities and interests of the three main clusters of stakeholders presented in the target audience section, and the identification of the reactions CoMPaSS-NMD intends to achieve through the project communication. This will help the Consortium in tailoring the information to deliver to the stakeholders based on their characteristics, since the communication aims at both technical and non-technical people. Therefore, the project will make available promotional material in various forms, to ensure that each different category of stakeholders can access them in the most suitable format, without CoMPaSS-NMD losing consistency and credibility in the communication.
- The definition of the contents to disseminate, which will evolve during the project, as will the means supporting the communication. In the initial phase, the focus will be on the promotion



of CoMPaSS-NMD; the focus will later shift to communicating the progress of the project; and finally, to spreading its results. Therefore, initially CoMPaSS-NMD will mainly rely on general informative means, while the communication of its progress and of the achievement of results will be supported later by more specialized means. Based on these premises, the map of stakeholders has been matched with a set of products considered as the most effective for each group of stakeholders.

Below is a preliminary table (Table 1) summarising the most appropriate communication means for each group of stakeholders and the changes that CoMPaSS-NMD expects to see in the targeted stakeholders' categories:

Table 1 C&D means and expected impacts for each group of stakeholders

TARGET GROUP	ACTIVITY/TOOLS/CHANNELS	EXPECTED RESULTS
Specialised audience		
Health professionals	<ul style="list-style-type: none"> ● website & social media ● mailing list ● videos ● graphic materials (flyers, brochures, and others) ● press releases and interviews ● presentations and posters ● scientific articles ● articles in magazines ● CoMPaSS-NMD webinars and reports 	<p>acquisition of patterns to support precise clinical characterization and diagnosis of people living with HNMDs</p> <p>acceptance of ICT and digital solutions for health management</p> <p>as primary users and early adopters, become advocates of the CoMPaSS-NMD system because of the diagnosis-facilitating approach</p>
Research community	<ul style="list-style-type: none"> ● workshops and exhibitions ● demonstrations and open days ● CoMPaSS-NMD public events cooperation with other EU projects 	Exploitation of a wide set of data from the CoMPaSS-NMD Atlas for further studies
Industries and companies		Adoption of software solutions developed within the project, which will be further distributed to the



		B2B health market, creating new business opportunities
Decision- and Policy- Makers, Governmental and International bodies		
Local and national health agencies/authorities and policy makers	<ul style="list-style-type: none"> ● website & social media, ● <i>ad hoc</i> graphic materials (flyers brochures, and others) ● policy briefs and benchmarks ● presentations and posters, ● CoMPaSS-NMD webinars and reports ● workshops and exhibitions ● demonstrations and open days ● conferences and brokerage events ● CoMPaSS-NMD public events 	Acquisition of new systems and interactive Guidelines to face HNMDs
General public		
civil society groups, patients' associations, and citizens interested in the potential of the project	<ul style="list-style-type: none"> ● website & social media ● mailing list ● videos ● graphic materials (flyers, brochures, and others) ● press releases ● presentations and posters 	<p>Raise awareness of CoMPaSS-NMD topic, importance, and societal, medical, economical and life impact for the HDNM patients and their families</p> <p>acceptance of ICT and digital solutions for health management</p>



Figure 1 A preliminary schedule of the stakeholder engagement and consultation activities

Type of action	WHAT	WHEN	WHO	WHY
CONSULTATION	1° Workshop	M5 - M15	health professionals technology providers pharmaceutical industries caregivers and patients + policy- and decision- makers regulatory bodies and ethical committees and SAB	Collection of requirements
	2° Workshop	M26-M30		Feedback on suitability, usability and acceptability of preliminary outputs
	3° Workshop	M48		Validation of the final outcomes, recommendations, and feedback on ethical and legal issues
COMMUNICATION	1 campaign	tbd	All above + general public	Raise awareness
	4 webinars	from M12		Raise awareness
DISSEMINATION	First diss. event	M24	CoMPaSS community	Public disclosure of CoMPaSS results
	Final diss. event	M48		Popularization of CoMPaSS outcomes

4.2.2.4 Dissemination towards the Scientific Advisory Board

The CoMPaSS-NMD project will avail the support provided by a Scientific Advisory Board (SAB) to help with the project direction, its research and to ensure that the project outcomes are really useful and effective.

The SAB acts as an independent body, consisting of a group of key stakeholders (external to the project) who have expertise in the field CoMPaSS-NMD explores. CoMPaSS-NMD has appointed seven members to form the SAB, keeping in mind the gender balance. The details about the SAB and Ethic Advisor are reported in deliverable D1.1 Appointment of an External, Independent Ethics Advisor.

Specifically, its members will:

- promote and raise awareness of CoMPaSS-NMD both within and beyond their organisation and projects
- offer guidance and feedback on the approach CoMPaSS-NMD is taking
- provide CoMPaSS-NMD with information and guidance concerning synergies with the relevant activities of their ongoing work in the healthcare areas
- monitor how ethics issues are handled during the lifetime of the project

The overall aim of engaging the SAB is to ensure that the project delivers real valuable results and gains exposure for a wider market interest. To obtain this goal, the steady communication with the SAB is of primary importance. CoMPaSS-NMD will periodically update the SAB on the project progresses and main results, both through yearly face-to-face meetings (such as workshops and demonstrations), and via teleconference and remote communication (including reports and deliverables).

CoMPaSS-NMD SAB will be a fundamental role in the co-design approach proposed by the project, which shifts the view from technology-driven solutions to user-driven ones, by integrating practices from human factors, usability, ethics, and law. CoMPaSS-NMD will use standard methods of active stakeholders' participation such as consultation workshops (three are foreseen along the project implementation), interviews, questionnaires, to collect needs and requirements and at the same time to assess the stakeholders' awareness level and their perception with respect to the introduction of new innovative technologies in their daily practice. The results of these workshops will feed the technological work packages and provide suggestions and support to the design process. The aim would be to have user-centred solutions that would allow for a smooth collaboration in the human-



machine teams and to early identify potentialities and showstopper to the full exploitation of the project outcomes.

4.3 Channels and Tools

DBL will manage and ensure the continuous synergy between activities to make the most out of the content produced within the project, by communicating knowledge in different platforms (website, social networks, etc.), using different styles (infographics, videos, images, etc.). In this section, the channels and the tools used to support the communication of the right messages to the targeted audiences will be presented.

4.3.1 Website

The public project website is a key element in the communication of CoMPaSS-NMD, facilitating the interaction with specialists and potential users, as well as the general public. It represents a virtual showcase where CoMPaSS-NMD will display information about the project and share its results, the events CoMPaSS-NMD will attend or organise along the project, and more generally the news of the project. The website will also be the virtual space where CoMPaSS-NMD will collect promotional material, public documents, scientific papers, posters or presentations and videos. It will be updated regularly with public information about CoMPaSS-NMD progress, the status of the activities and any other relevant communication. It will integrate the project's social profiles, so to easily share the latest project developments or relevant news related to the research field and relevant external links to project partners, contributing to build a solid network.

In this direction, each partner of the CoMPaSS-NMD Consortium will contribute to create a back-link to the CoMPaSS-NMD website on its organisation website, in order to maximise the project visibility and the ranking on search engines.

DBL is responsible for the graphical layout, the information architecture, the implementation and maintenance of the website. The website architecture and contents will be discussed internally with the partners to select the most appropriate and appealing ones for the website.

The partners of the Consortium will contribute to the website by providing information, documents, or any other material they consider useful to disseminate the progress of the project.

The website is implemented using the WordPress Content Management System platform, which grants the integration of different functionalities and tools, also allowing easy changes in the structure and characteristics of the website.

The final version of the official website will be launched in October 2023 (M6) at www.compass-nmd.eu, and officially delivered with the D8.6 on 31st October 2023.

The final website is currently in the design phase. A "coming-soon" page informing that the project website is under construction is available at the website link.

As responsible of the C&D task, DBL will propose information architecture and a contents draft, which the partners will then review and discuss.

The website structure according to the tentative table of content, consists of the following sections:

- **Home page:** presenting the project's overview and main purpose, its objectives, the timeframe and a call to action to subscribe the project mailing list;
- **About:** this page provides further details on the project, such as the concept and the approach, the consortium's composition and the CoMPaSS-NMD network;



- **Resources:** a container of the public deliverables, scientific publications, technical products and the communication material;
- **Training & Learning** contains the learning material and opportunities;
- **News & Events:** at the top of this page there is a Call to Action that invites visitors to register to the CoMPaSS-NMD mailing list, a single page with the news, and a further single page reporting the events.

The project's website will incorporate the proper dissemination format of the results and shall provide a "customised" link to make them visible to stakeholders, and each specific target group. Importantly, the reference to EU funding will be properly emphasised further under a specific section of the CoMPaSS-NMD website.

4.3.2 Social Media Channels

CoMPaSS-NMD will use social media channels to enlarge its group of followers and ensure a broader outreach of its findings and results. Social media are useful for maximising the visibility of the CoMPaSS-NMD project. Using social networks, CoMPaSS-NMD activities and progress may also be valuable for people who are not direct part of the CoMPaSS-NMD immediate professional environment, allowing to easily connect with a wide range of people and facilitate the creation of a widespread community, addressing both the general audience and the specialised one, also depending on the social channel used.

LinkedIn and Twitter are the social channels chosen for the CoMPaSS-NMD communication. Both channels allow people to stay in touch with the project; however, LinkedIn is ideal to share content in a business context, targeting specialised audiences and institutional bodies. You can write posts, share your article, and book homepages, photos, links and videos. A specific user for CoMPaSS-NMD will be created in both social media channels. The user will be managed by DBL.

LinkedIn allows finding other professionals/projects with similar interests and taking part in the online discussions in the CoMPaSS-NMD subject area.

Twitter targets both specialised audiences and the general public. CoMPaSS-NMD will use it to share information, opinions and news in less than 280 characters and to stay up-to-date on news and events in the same area of interest.

The activation of a project specific YouTube channel will be considered during the project in case it is convenient for sharing videos. The channel will be managed by DBL.

Together with the project news, the social media profiles will share relevant news related to the project's domain and that help placing the accounts into specific discussions. At least one social media campaign will be launched to increase the awareness of the project's benefits and to spread the project's results in the second part of the project (M24-M48). CoMPaSS-NMD aims to reach the overarching goal of 500 LinkedIn followers and 300 Twitter followers by the end of the project. Teaming up through coordinated communications on each partner's official communication channels will be paramount to reach this goal.

Some news and posts about the launch of the CoMPaSS-NMD project in May 2023, from the project coordinator and other partners' social media and websites, are listed below:

Press review:

<https://www.magazine.unimore.it/site/home/notizie/articolo820066776.html>



- American academy of neurology @american-academy-of-neurology

4.3.4 Dissemination towards the European Commission

Institutional EU websites will be used to promote the project results at European level to policy makers, researchers, and a vast variety of experts. The Consortium plans to appear at least twice on one of the following channels:

- Horizon Magazine: the EU research and Innovation Magazine spreading the latest news and features about science and innovative research projects funded by the EU.
- Research and Innovation Success Stories: a collection of the most recent success stories from EU-funded Research & Innovation
- CORDIS (Community Research and Development Information Service): European Commission's primary public repository and portal aimed at disseminating information on EU-funded research projects and their results. The website includes editorial content to support communication and exploitation (news, events, success stories, magazines, multilingual "results in brief" for a broader public).
- The CORDIS News and Events: it allows to browse and find the latest news from EU-funded research projects and forthcoming events;
- CORDIS Wire: it allows the research community to publish their own news and events (access to Wire requires a CORDIS account). CoMPaSS-NMD aims to make use of this channel to promote its events.
- CORDIScovery: it is the official CORDIS platform of podcasts dedicated to EU-funded projects. CORDIScovery is a monthly podcast that dives into some of the key scientific solutions being developed by EU-funded researchers to address the major societal challenges that we all face today.

The use of these channels will be coordinated with the European Commission, asking for support – if needed – to reach and interact with the channel “owners”.

4.3.5 Promotional Supports

The promotional supports aim to support partners in their informal communications in those events where they will represent the CoMPaSS-NMD project (i.e., brochure/flyers/roll-up).

Flyers are one of the main products to promote both the project and its activities, such as participation in public events, workshops and fairs. They are short documents (1 or 2 pages) with a strong graphical identity; usually, they provide a brief project description, the crucial points of a conference, and its programme. Both digital and printable versions will be produced and uploaded on the website.

During the whole span of the project, the Consortium will produce at least 8 promotional materials (e.g. brochures, social media cards, concept image, project timeline) as better specified in Table 4 CoMPaSS-NMD Key Performance Indicators among in connection to public events (e.g., conferences, workshop, sector meeting, joint dissemination events), including most recent project results.

Other material like posters and roll-up could be also considered depending on the needs of the specific event. To ensure a homogeneous visual identity, a preminent graphical poster template will be shared with all partners, leaving them a large degree of freedom in selecting and adding contents, depending



on their needs. Posters and roll-up banners will also provide access to the project website through a QR code when in physical format, whereas it will include active links to the website and social media when digital. These materials will be available on the project's website and distributed to the people interested in the project's topic as soon as they are released.

4.3.6 Promotional Videos

Promotional videos will play an important role in the CoMPaSS-NMD dissemination strategy. They will provide highly engaging and added-value contents that will be collected on the CoMPaSS-NMD Youtube channel and shared via the project's communication channels. The videos will introduce the challenges at hand and how CoMPaSS-NMD is addressing them.

A final video will be created where all the results achieved by the project will be presented.

Where possible (in the presence of staff available and directives from GDPR), videos during events will be recorded for dissemination activities (social media, news, etc.).

Finally, we will organise very short video interviews with the partners / Advisory Board members / relevant stakeholders to be disseminated on the social channels of the project and with the patients and their families to create awareness.

The steps for maximising visualisations are listed below:

- If relevant, the creation of subtitles
- Post on social media the relevant videos published on partners' platforms, define the segments of the addressees and promote the publications for the identified targets
- The use of relevant hashtags and tags that might interest CoMPaSS-NMD targets, in order to appear in suggested search results
- The videos will be gathered on the CoMPaSS-NMD Youtube channel and shared by partners and through all the project's social media, allowing the monitoring of views and the number of sharing of each video

4.3.7 Press Releases and interviews

Press media includes the preparation of press releases, dossiers information, interviews management, press conferences and media events. Overall, CoMPaSS-NMD will diffuse at least three press releases (the first one about the launch of the CoMPaSS-NMD project has been released at M2 via the DBL press office and through the partners' channel and contacts).

A preliminary list of media outlets the Consortium intends to target is provided below:

1. (e-)Magazines dedicated to NMD/disable patients:
 - a. About People Magazine
 - b. DISABILI.COM
2. (e-)Magazines dedicated to NMD research, healthcare and e-health:
 - a. Healthcare-in-Europe
 - b. Healthcare IT news (European edition)



- c. HealthITAnalytics
 - d. Healthscient
 - e. ReachMD
 - f. MEDICO E PAZIENTE
3. (e-)Magazines dedicated to the technologies related to CoMPaSS-NMD:
- a. Silicon Republic
 - b. Smart Industry
 - c. TechRadar
4. General (e-)newspapers and media:
- a. LE SCIENZE.IT
 - b. SALUTE NATURALE
 - c. RAI - TGR LEONARDO
 - d. FOCUS
 - e. SALUTE24.ILSOLE24ORE.COM
 - f. RICERCA & PRATICA
 - g. ADNKRONOS SALUTE

4.3.8 Mailing list and Newsletters

In line with the GDPR, CoMPaSS-NMD will implement a mailing list, open for subscribers, in order to gain contacts interested in the project. CoMPaSS-NMD will use call-to-action on the project's website and social media as well as through signed consent forms distributed during events and meetings organised or attended by CoMPaSS-NMD. Partners will explore the possibility of leveraging their customer relationship management systems, inviting relevant contacts to subscribe to the mailing list, provided that this is done in accordance with the GDPR.

The emails collected in the mailing list will receive periodic project updates in the form of newsletter at least twice a year starting from M18 as well as invitation to CoMPaSS-NMD workshops and dissemination events. Free online tools such as MailerLite or Mailchimp may be used to monitor the engagement generated by the newsletter.

4.4 Enhancing and increasing the impact and visibility of the project

4.4.1 Communication Toolkit for Partners

The materials provided in the toolkit will be shared with the consortium at the start of the project to ensure consistent presentation and to strengthen the visibility of the project and its activities.

The toolkit will be composed by the following elements:

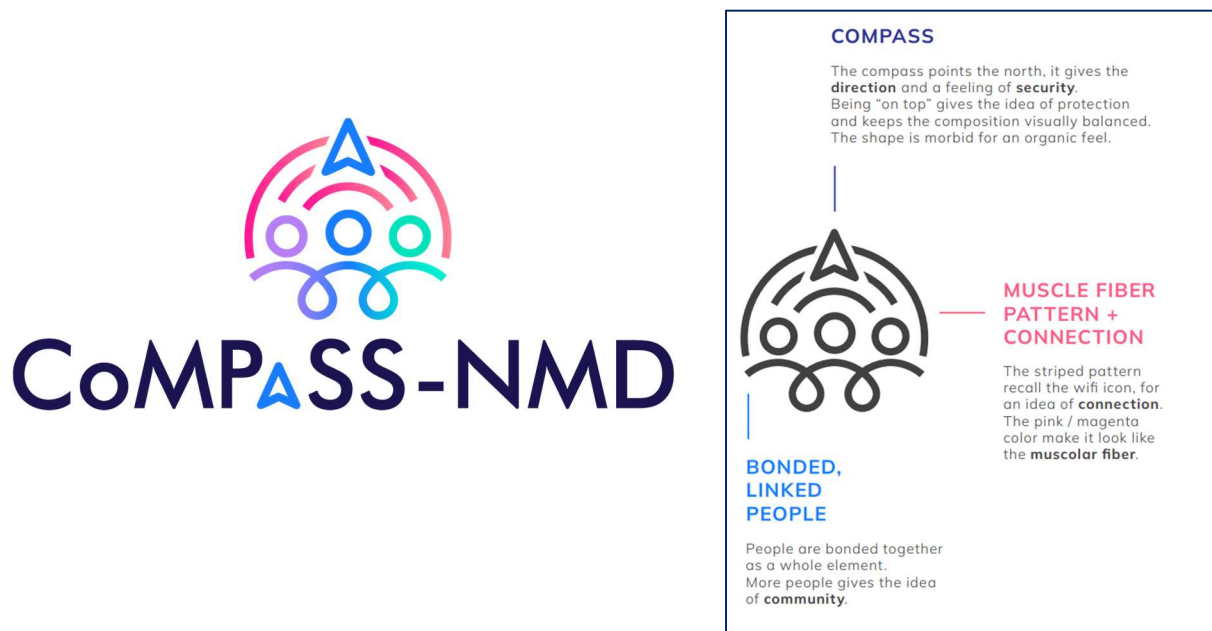
- Brand Identity and Graphical elements



The design and development of a logo is a central task in the communication activities. The project logo should be graphically appealing, manageable, and meaningful with respect to the project goals and activities. The logo works as the project graphical identity base. Through the choice of colours and fonts, it represents the frame that embodies every communication activity. It is the “trait d’union” of the project, which makes each element of the graphical identity immediately ascribed to the project and help communicate and disseminate the project purpose.

In Figure 2 we report the approved logo and its significance.

Figure 2 The CoMPaSS-NMD official logo and the significance of its elements



- Stationary

Templates for presentations or public technical documents are essential to reinforce the consistency of the project identity, uniform the style of the produced material and immediately refer the document to the CoMPaSS-NMD project. The design of these tools should be coherent with the project visual representations (e.g., CoMPaSS-NMD logo, typography, etc.). At the same time, templates should be clear, useful and adaptable to the specific needs of the Consortium members.

The various templates created for CoMPaSS-NMD are shown in the following figures as follows:

- Deliverable Template (Figure 3)
- Agenda template and MoM Template (Figure 4)
- PowerPoint Template (Figure 5)



Figure 4 Official template of the Agenda and Minutes of the CoPaSS-NMD internal meetings



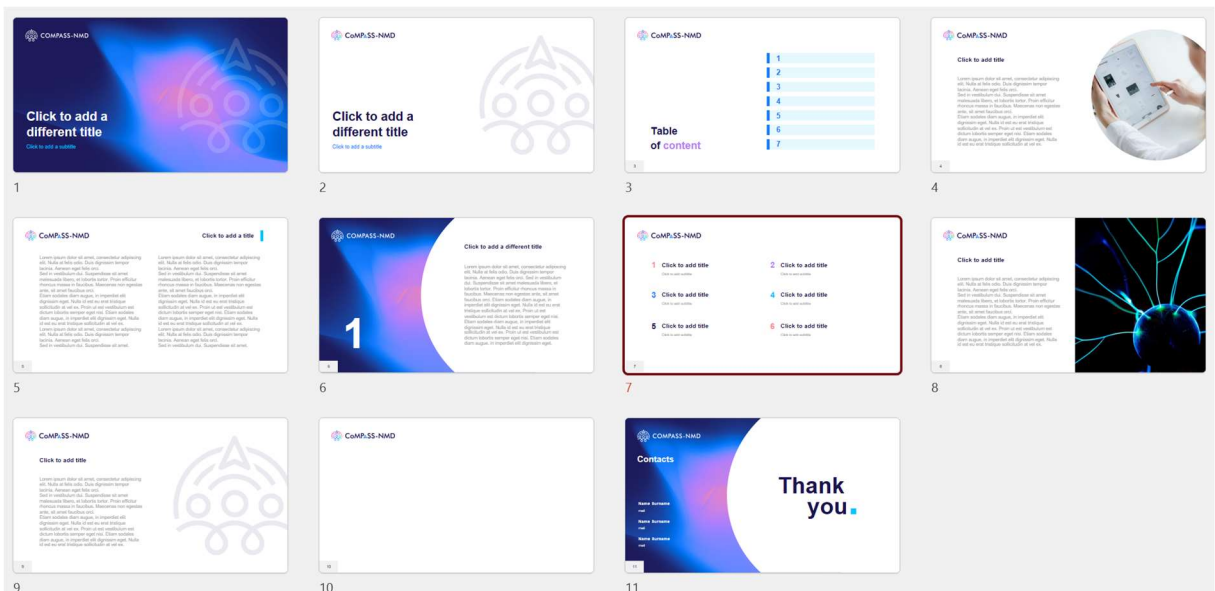
<div style="display: flex; justify-content: space-between; align-items: center;">  CoPaSS-NMD </div> <h3 style="text-align: right; margin-top: 10px;">Meeting Title</h3> <p>Meeting Details</p> <p>Location <input style="width: 100%;" type="text"/></p> <p>Date and time <input style="width: 100%;" type="text"/></p> <p>Host <input style="width: 100%;" type="text"/></p> <p>Work package <input style="width: 100%;" type="text"/></p> <p>Attendance</p> <table border="1" style="width: 100%; border-collapse: collapse; margin-top: 5px;"> <thead> <tr> <th style="width: 30%;">Invited</th> <th style="width: 30%;">Present (Y/N)</th> <th style="width: 40%;">Expected preparation</th> </tr> </thead> <tbody> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> </tbody> </table> <p>Agenda</p> <table border="1" style="width: 100%; border-collapse: collapse; margin-top: 5px;"> <thead> <tr> <th style="width: 15%;">Time</th> <th style="width: 60%;">Topic</th> <th style="width: 25%;">Leading partner</th> </tr> </thead> <tbody> <tr> <td>00:00-00:00</td> <td> </td> <td> </td> </tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> </tbody> </table> <p style="font-size: 8px; margin-top: 20px;">The information contained in this document is the property of the CoPaSS-NMD Consortium and should not be reproduced, disclosed, modified, or communicated to any third parties without the prior written consent of the abovementioned entities.</p>	Invited	Present (Y/N)	Expected preparation										Time	Topic	Leading partner	00:00-00:00									<div style="display: flex; justify-content: space-between; align-items: center;">  CoPaSS-NMD Meeting title DD-MM-YYYY </div> <h3 style="margin-top: 10px;">1 MINUTES</h3> <p>1.1 TOPIC 1</p> <p>Body text</p> <p>1.2 TOPIC 2</p> <p>Body text</p> <h3 style="margin-top: 10px;">2 ACTION POINTS</h3> <table border="1" style="width: 100%; border-collapse: collapse; margin-top: 5px;"> <thead> <tr> <th style="width: 25%;">Action point</th> <th style="width: 20%;">Work packages</th> <th style="width: 20%;">What</th> <th style="width: 35%;">Responsible partner</th> </tr> </thead> <tbody> <tr><td> </td><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td><td> </td></tr> </tbody> </table> <p style="font-size: 8px; margin-top: 20px;">The information contained in this document is the property of the CoPaSS-NMD Consortium and should not be reproduced, disclosed, modified, or communicated to any third parties without the prior written consent of the abovementioned entities.</p>	Action point	Work packages	What	Responsible partner												
Invited	Present (Y/N)	Expected preparation																																							
Time	Topic	Leading partner																																							
00:00-00:00																																									
Action point	Work packages	What	Responsible partner																																						

Figure 5 Official template of the CoPaSS-NMD slides



4.4.2 Scientific publications

CoPaSS-NMD will publish articles in peer-reviewed journals and conference papers, guaranteeing at least 20 scientific publications in Open Access scientific journals.

The CoPaSS-NMD Consortium agreed on the following procedure for new scientific publications:



1. The partner inform the consortium about the proposal to submit a new scientific paper to a specific journal
2. The partners should answer in 10 days after the notification
3. Silence would be considered as acceptance

A list of publishers and scientific journals relevant to CoMPASS-NMD is reported below:

[PLOS](#)

[Frontiers](#)

[Neurology](#)

[JAMA Network Open](#)

[The Lancet Neurology](#)

[Orphanet Journal of Rare Diseases](#) (Springer Nature)

[Machine Learning](#) (Springer)

[Applied Intelligence](#) (Springer)

[Knowledge-Based Systems journals](#) (Science Direct)

4.4.3 Networking with other external projects and initiatives

An important aim of C&D is the networking and the creation of synergies between the CoMPASS-NMD project and other relevant R&D initiatives - EU research projects similar to CoMPASS-NMD relevant networks. CoMPASS-NMD will support liaison activities, which might possibly lead to the organisation of joint events between different projects, significantly improving the effectiveness of the dissemination and communication efforts spent by the involved consortia.

The collaboration will include joint workshops and dissemination events, the exchange of knowledge, the development and adoption of best practices, or joint communication activities.

A non-exhaustive list of similar projects follows:

- Sister Projects:

COMFORT - COMPUTATIONAL MODELS FOR PATIENT STRATIFICATION IN UROLOGIC CANCERS – CREATING ROBUST AND TRUSTWORTHY MULTIMODAL AI FOR HEALTH CARE

METASTRA - COMPUTER-AIDED EFFECTIVE FRACTURE RISK STRATIFICATION OF PATIENTS WITH VERTEBRAL METASTASES FOR PERSONALISED TREATMENT THROUGH ROBUST COMPUTATIONAL MODELS VALIDATED IN CLINICAL SETTINGS

Microb-AI-ome - Federated artificial intelligence for privacy-preserving international stratification of colorectal cancer patients

PREPARE - PERSONALIZED REHABILITATION VIA NOVEL AI PATIENT STRATIFICATION STRATEGIES

Recon4IMD - Reconstruction and Computational Modelling for Inherited Metabolic Diseases

SPIDeRR - Stratification of Patients using advanced Integrative modeling of Data Routinely acquired for diagnosing Rheumatic complaints



STRATA-FIT - Stratification of Rheumatoid Arthritis: CompuTational models to personalise mAnagement strategies for diffiCult-to-Treat disease

STRATIF-AI - Continuous stratification for improved prevention, treatment, and rehabilitation of stroke patients using digital twins and AI

- Project and activities related to CoMPaSS-NMD:

ReCognitiON - (JTC 2018) (LMUM) Oversight committee

RD-Connect (FP7, 2012- 18, GA 305444) <https://rd-connect.eu> (UNEW, SFF)

MYO-MRI (COST Action BM1304, 2013) (UNEW)

MYO-Share <https://myoshare.ohri.ca>

INRF (Italian National Registry for FSHD) UNIMORE

NeurOmics (FP7, 2012, G.A.305121) <https://rd-neuromics.eu/> (UNEW)

SeqNMD (UNEW, SFF)

MYO-SEQ <https://myoseq.org/>

Solve-RD (H2020, 2018- 2022, GA 779257) <https://solve-rd.eu/> (UNEW, SFF)

InGene2.0 - Data set related to LGM and congenital myopathies (<http://www.ingene.eu/>) (FSM, UNIMORE)

PROSPAX First EJP RD Joint Transnational Call for Rare Diseases Research Project (EJPRD19-193) (FSM)

MYOCAPTURE (France Génomique and Fondation maladies rares) (CERBM)

IDOLS-G European Joint Programme on Rare Diseases (SFF)

4.4.4 Project events

The main results of the project will be presented and disseminated through CoMPaSS-NMD dedicated events. The type of events will vary in style, depending on the aim and the target group. The partners will disseminate the project results within organised internal or public events, and external ones, organised by third-parties.

4.4.4.1 Organised Events

CoMPaSS-NMD will organise public events serving as networking opportunities where all or specific target audiences will be invited. The project goals, results and findings will be presented during such events accordingly to the project evolution: in the early phases to raise awareness about the project and share knowledge, gradually shifting towards disseminating results (dissemination events and workshops), engaging stakeholders and collecting their feedback (consultation webinars). In particular, the workshops and consultation webinars aim at co-designing the project solutions and at collecting feedback on the ethical/legal aspects from the stakeholders involved.

Consensus meeting on Recommendations and Guidelines will be organised to meet the SAB and Ethics Advisory members, and at the end of the project the achieved results will be shown during the final dissemination event.



In this section will be presented a preliminary schedule of the public events organised by CoMPaSS-NMD (Table 2).

Table 2 CoMPaSS-NMD Internal events

Event	WP / Task	Location	Month
Dissemination Workshops	WP8/T8.3	TBD	M24/M48
Consultation Webinars for stakeholders	WP8/T8.3	Online	M1-M48 (in line with WP4)
Consensus meeting on CoMPaSS-NMD Recommendations and Guidelines	WP8/T8.4	Online	M44
Project final event	WP8	TBD	M48

4.4.4.2 External Events

Partners will participate in conferences, fairs, workshops to provide information and interact with relevant stakeholders to promote and disseminate CoMPaSS-NMD projects, including its activities and results. A non-exhaustive list of some international events relevant to CoMPaSS-NMD is reported in Table 3. The table will be updated every year and the event attended will be reported in the dedicated files in the sections Reporting and Monitoring.

Table 3 Scientific Conferences relevant to CoMPaSS-NMD

SCIENTIFIC CONFERENCES			
No.	Conference Title	Date/Location	Short description
1.	ENMD-EHealth and Innovation to overcome Barriers in Neuromuscular Diseases	2 - 4 November 2023 Munich, Germany	e-Health and innovation to overcome the barriers in neuromuscular diseases
2.	European Society of Human Genetics	1 - 4 June 2024 Berlin, Germany	ESHG is a hybrid 4-day event which covers all aspects of human genetics, from the cutting-edge research into the human genome and individual genetic or chromosomal conditions, right through to the practical issues of organising genetic services.
3.	European Pediatric Neurology Society	20-24 June 2024 Prague, Czech Republic	The main theme of the congress is “From genome and connectome to cure”. The congress field has traditionally focused on precise diagnostics; however, curative



			treatments remained unavailable for a long time. This trend has been changing rapidly and novel therapeutic options in this field have brought hope to even such families whose children need to cope with the most severe neurological conditions.
4.	EAN - European Academy of Neurology	29 June – 2 July 2024 Helsinki, Finland	EAN is a non-profit, independent organisation aiming to promote neurological excellence and working closely with 47 European national societies.
5.	WMS - International Annual Congress of the World Muscle Society	8 - 12 October 2024 Prague, Czech Republic	Topic 1: Understanding phenotypic and genetic diversity in neuromuscular disorders Topic 2: Pathobiology of neuromuscular repeat expansion diseases Topic 3: The effect of lifestyle, exercise and nutrition on neuromuscular pathology and outcomes
6.	ICNMD - International Congress on Neuromuscular Diseases	25 - 29 October 2024 Perth, Australia	The aim of the ICNMD Congresses is to offer attendees an updated view on neuromuscular disorders and that networking opportunities increase their international experience and collaborations.
7.	American Society of Human Genetics	5 - 9 November 2024 Denver, CO	The meeting provides a forum for the presentation and discussion of cutting-edge science in all areas of human genetics.
8.	Researchers' Night	Variable/ each participating country (European researchers' night: 29 September 2023)	The Researchers' Night is a world-wide public event, which displays the diversity of science and its impact on citizens' daily lives in funny, inspiring ways.

4.4.5 Training sessions and summer schools

We will organize a multidisciplinary Summer School in 2024 (or 2025) entitled "**Omics technologies and their application in the clinical practice**". CoMPaSS-NMD will offer a high level, intensive educational program carried out by an excellent international faculty to up to 20 Ph.D. students, postdoc fellows and residency's students in genetics, computer sciences, and child or adult neurology. The main aim of the program is to bring together junior European fellows and expert investigators working on different aspects of Rare Neurological and Neuromuscular Diseases, from



clinical perspectives to multiomics approaches, and to provide a forum for new directions and ideas in RNDs field. The meeting will combine research lectures by leading scientists from CoMPaSS-NMD team and other European Colleagues (e.g., SAB in CoMPaSS-NMD) and aims to encourage active discussions and exchange of information and ideas between seniors and young fellows.

Additionally, we will organize biannual virtual teaching seminars for expert training of computer scientist and mathematicians on the clinical use of data analysis, deep phenotyping, muscle MRI investigations and patterning, and additional expert tools generated in CoMPaSS-NMD.

4.4.6 Recommendation and Guidelines

In accordance with the practices of learned neurological societies, Recommendations and Guidelines on the best use of the AI-based clinical tools will be delivered. It will be a generalizable guidance regarding the use and the evaluation of the AI application to the diagnosis and prognosis of HNMDs. It will include an evaluation matrix to illustrate the applicability of the CoMPaSS-NMD proposed cross-domain methodology. These guidelines will be further translated into a framework of concrete recommendations for specifying, developing, evaluating, and deploying technically, clinically and ethically trustworthy AI solutions into clinical practice so that will be shared within the research community, health professionals and researchers, health authorities, technology providers, pharmaceutical industries, caregivers and patients' associations, regulatory agencies.

4.4.7 Summary of the C&D activities

This chapter reports in Table 4 a preliminary schedule of the WP8 activities according to the management plan.

Table 4 A preliminary schedule of the WP8 activities

Activity	Objective	Target audience	Activity
Project website	Provide a public online showcase of CoMPaSS-NMD, including an overview of the project, up-to-date information on results, public reports and publications; events, etc.	All targets	Project website
Promotional material (brochures, roll-ups, videos, visual identity)	Create awareness and also exploit viral marketing effects	All targets	Promotional material (brochures, roll-ups, videos, visual identity)
Social media (LinkedIn, Twitter, Youtube)	Create interest around the project and involve relevant stakeholders	Specialised audience and SAB	Social media (LinkedIn, Twitter, Youtube)
Press media	Raise awareness on the project results	All targets	Press media
Newsletter			Newsletter



Participation in conferences	Spread project results among the scientific community	Regulatory bodies and ethical committees Research community Technology providers	Participation in conferences
Publications	Spread project results among the scientific community	Specialised audience	Publications
Raising awareness webinars	Contribute to building and strengthening the community of stakeholders and promote the project outputs to the interested audience	All targets	Raising awareness webinars
Dissemination events			Dissemination events
Stakeholder consultation events	Support co-design of the project outputs and gain a consensus on them	Specialised Audience and SAB	Stakeholder consultation events

4.5 Evaluation Criteria

To ensure an effective assessment of the achievement of the expected results for the communication and dissemination of the project, all the D&C activities will be reported and monitored, with the aim of reaching the established key measurable success indicators.

4.5.1 Key measurable success indicators

Key measurable success indicators will be defined and reported in this section to measure impact in community building and engagement, also, the uptake of the project outcomes within and beyond the consortium. Such indicators will be defined to be robust, clear and SMART (Specific, Measurable, Attainable, Relevant and Time-bound).

The following Table 5 will show a quantitative overview of the dissemination and communication Key Performance Indicators that the project will set.

Table 5 CoMPaSS-NMD Key Performance Indicators

Key Performance Indicators for Dissemination & Communication					
KPI	Year 1	Year 2	Year 3	Year 4	Overall
C&D KPI					



No. of unique visitors to the Website (based on Google Analytics)	500	1000	1500	2000	5000
Brochures	1		1		2
Roll-up	1				1
Promotional video					1 (> 1000 views)
LinkedIn contacts	100	100	150	150	500
Twitter followers	50	50	100	100	300
Press releases	1	0	1	1	3
Newsletters	0	1	2	2	5
Participation in conferences representing the project	1	3	4	4	12
N° publications in Open Access Journals	0	6	6	8	20
N° Dissemination events	0	0	1	1	2 (> 200 participants)
N° Raising awareness webinars	0	1	1	2	4 (> 400 participants)
N° consultation workshops	1	1	1		3 (> 30 participants)
N° synergies/joint actions	2	2	3	3	10

4.5.2 Reporting

CoMPaSS-NMD will report the activities made by the Consortium using C&D inputs' sheets shared in the workspace of the project. The CoMPaSS-NMD partners will integrate the sheet with all relevant information about the actions taken or planned at any time during the project.

The collaborative spreadsheets will include:

- **Community building sheet** where the Consortium will add the names and contact details of stakeholders that belong to relevant target groups.



5. CONCLUSIONS

DBL, the CoMPaSS-NMD Communication and Dissemination Leader is responsible for the production and implementation of the CoMPaSS-NMD Communication and Dissemination plan. The C&D leader works closely with the PM and the CDI-WG to ensure the project is adequately communicated internally and externally. The CDL shall remain conscious of all opportunities to raise awareness of the project; thus, they will engage all WP leaders and the Exploitation and Innovation Manager to uncover additional opportunities for interacting with stakeholders relevant to the project.

To successfully accomplish the main objectives of this Impact, Communication and Dissemination Plan, we will need to promote a consistent brand with a strong mission, supported by a useful set of tools, fed with professional and attractive content messages, and driven by fully committed partners.

All partners will be actively involved in the dissemination and communication actions implementation and are highly committed to ensure a satisfactory dissemination of the project's results. In general, the expected contribution from partners is to:

- Implement publicity and dissemination through their channels in their own countries and at European level
- Exploit their contacts and networks
- Supply news and updates for the web portal and newsletter
- Help to keep the project's Social Media Accounts alive and active
- Participate in relevant events to promote the project and its outcomes

The successful communication and dissemination of the project highly depends on the content, therefore DBL will proactively encourage all partners to contribute and share information about the CoMPaSS-NMD project.

The Communication and Dissemination Plan will be updated regularly during the project and a first report on the C&D activities and results will be delivered on M24.

