



Project acronym: HealthData@PT

Project full title: Setting up a Health Data Access Body in Portugal and laying the national foundations for EHDS2

WP2 – Dissemination, Training and Support

D2.2– Dissemination, Education and Training: Website

Project Coordinator	Shared Services of Ministry of Health, E. P. E. – SPMS, E.P.E (Portugal)		
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Executive Summary

This document constitutes the deliverable 2.2 referring to the Website of the action HealthData@PT - Setting up a Health Data Access Body in Portugal and laying the national foundations for EHDS2.

This deliverable provides an overview of the website's structure, which will act as one of the main channels of communication and dissemination during the project's four-year timeframe.

On the work package 2 – Dissemination, training, and support – it is expected a set of initiatives to raise awareness and to provide information on European Health Data Space (EHDS) matters to specific target groups: citizens, data holders, data users and the HealthData@PT team. This work package also entails training activities. The HealthData@PT website will be an important communication, dissemination, education and raise awareness channel of HealthData@PT outcomes and of EHDS-related matters. Particularly, the website will be a channel to i) provide all the information regarding the stages of the project, ii) disseminate the webinars and workshops organized, iii) provide the prepared documents and educational/training materials, and iv) to make publicly available other relevant contents related with the HealthData@PT, WP2 or with the EHDS for the secondary use of health data to the HealthData@PT team, data holders, data users, and citizens. This document includes the link to the current version of the publicly available website as well as the general layout of the current version.

Document Revision History

Version	Date	History/Summary main changes	Author(s)
0.1	20/12/2023	Creation of the document and content	Marta Caria
0.2	03/01/2024	Revision	Sara Marques
0.3	22/02/2024	Final version draft	Marta Caria
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0.5	06/03/2024	Final version of the document	Marta Caria

Table of Contents

Terms and Abbreviations	v
List of Figures	vi
1. Introduction	1
2. Visual Identity	2
2.1. Logo	2
2.2. Colours	3
2.3 EU co-funding logo and project disclaimer	3
3. Project Website Structure.....	4
3.1. Homepage	5
3.2. About.....	5
a) Sub-section HealthData@PT	6
b) Sub-section Work Packages.....	7
3.3. Results	8
3.4. Communication.....	8
a) Sub-section News & Events	9
3.5. Educational.....	10
a) Sub-section Documents.....	10
b) Sub-section Acronyms	11
c) Sub-section FAQs	11
3.6. Contacts	12
4. Conclusion and Next Steps	13

Terms and Abbreviations

Acronym/Term	Full name/Definition
D	Deliverable
EC	European Commission
EHDS	European Health Data Space
EU	European Union
M	Month
MS	Milestone
SPMS	Shared Services of Ministry of Health
WP	Work Package

List of Figures

Figure 1. HealthData@PT logo.	2
Figure 2. HealthData@PT brand colours.	3
Figure 3. European Union co-Funding Logo and disclaimer included in website’s footer.	3
Figure 4. HealthData@PT website structure.	4
Figure 5. HealthData@PT website homepage.....	5
Figure 6. HealthData@PT website “About” menu section.....	5
Figure 7. HealthData@PT website “About” section: HealthData@PT sub-section.....	6
Figure 8. HealthData@PT website “About” section: Work Packages sub-section.	7
Figure 9. HealthData@PT Website "Results" menu section.....	8
Figure 10. HealthData@PT Website "Communication" section.....	8
Figure 11. HealthData@PT Website: "News & Events" sub-section.	9
Figure 12. HealthData@PT website: “Educational” menu section.....	10
Figure 13. HealthData@PT website: “Acronyms” sub-section.	11
Figure 14. HealthData@PT “FAQS” sub-section.	11
Figure 15. HealthData@PT “Contacts” sub-section: contact form.....	12
Figure 16. HealthData@PT “Contacts” menu section.	12

1. Introduction

The main objective of the HealthData@PT project's Work Package 2 (WP2) - Dissemination, training, and support is to raise awareness among citizens, data holders, and data users of the functions and responsibilities of the health data access body, as well as to conduct educational initiatives related with the secondary use of health data and orchestrate support initiatives for health data access body staff, data holders, and data users.

The communication and dissemination initiatives will have the following primary goals:

- a) to raise awareness, inform and generate interest among data users and data holders in the services provided by health data access body in terms of providing national and cross-border access to health datasets in a secure and regulated way;
- b) to educate citizens on the secondary uses of their electronic health data, its benefits, and their privacy rights.

Furthermore, communication activities will involve educational and training initiatives, as well as the coordination of support initiatives for the health data access body team, data holders, and data users.

As detailed in WP2, SPMS will create and make use of differentiated communication channels, such as a website, to provide all project-related information, provide access to educational materials, raise awareness, and promote engagement with data users, data holders, and other stakeholders of the health data ecosystem.

Throughout the four-year project's duration, specific communication and educational sessions will be organized to inform and train data users, data holders, and members of future national health data access body, via the website. The website will act as the primary platform for disseminating and providing all necessary information. Workshops, webinars, meetings, training sessions and public events are examples of the activities planned in the scope of WP2 that can be actively disseminated through the website.

The website will also serve as an important channel to communicate EHDS-related initiatives to target specific stakeholder groups (such as potential data users, data holders, citizens, researchers, and public health entities, among others), in order to maximize engagement, impact and collaborative endeavours.

HealthData@PT website, which is a subpage within the website of SPMS, the beneficiary and coordinator of this action, can be reached through the following link:

<https://www.spms.min-saude.pt/healthdatapt/>

2. Visual Identity

The visual identity of the website was created using the action's logo colours of red and black (Figure 1), with the red representing life, health, and strength, and the black having the impact of attention and motivation.

The primary goal of the logo created for these endeavours was to represent health data by utilizing dots as a linking point (Figures 1 and 2).

The website footer additionally includes a disclaimer regarding the action and the co-funding logo of the European Commission (Figure 3).

2.1. Logo

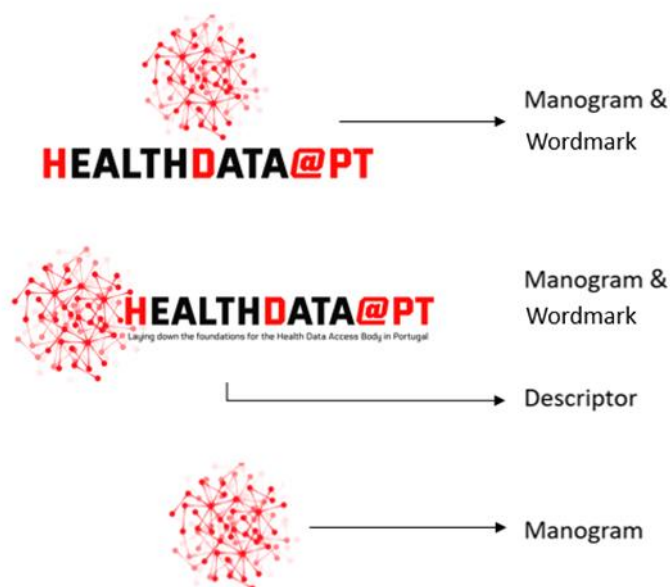


Figure 1. HealthData@PT logo.

2.2. Colours



Figure 2. HealthData@PT brand colours.

2.3 EU co-funding logo and project disclaimer

The European Union co-funds the HealthData@PT action. The grant agreement regulates the European Union elements that must be provided in any communication, dissemination and training activities related to this action, to highlight EU support. As stated in the grant agreement, these include the EU flag (emblem) accompanied by the funding statement *“The HealthData@PT action is co-funded by the European Union, EU4Health Program 2021-2027 under Grant Agreement Nr 101128332. The views and opinions expressed are those of the author(s) and do not necessarily reflect the position of the European Union or HaDEA. Neither the European Union nor the grant-awarding authority can be held responsible for these opinions”*, as depicted in Figure 3. Therefore, all pages of the website include this information on the website footer.

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Figure 3. European Union co-Funding Logo and disclaimer included in website’s footer.

3. Project Website Structure

One of the main objectives in developing this website was to ensure that this is user-friendly in addition to providing all the information related to the action, so that any user, whether a citizen, a health professional, a data holder, data user, or a researcher, can easily navigate through the website and find the information they are searching for.

It should be noted that the website's menu components can be modified when necessary for achieving the communication and dissemination objectives. Sections, for instance, may need to be added or deleted to guarantee that the information provided on the website is easily fully understood by all users, regardless of age or degree of knowledge.

The website's menu remains visible during navigation, allowing users to swiftly return to and/or explore additional sections.

Figure 4 depicts the current structure and main sections of the navigation menu bar:

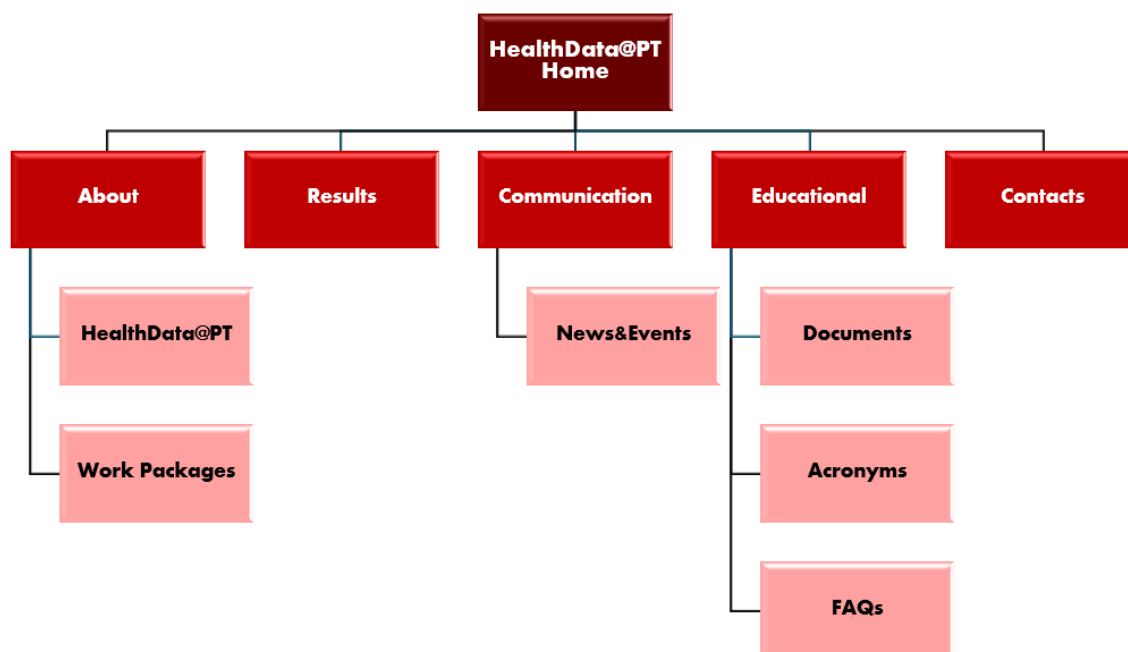


Figure 4. HealthData@PT website structure.

3.1. Homepage

Figure 5 represents the current structure of the website. This homepage will be adjusted thought the project’s lifetime.

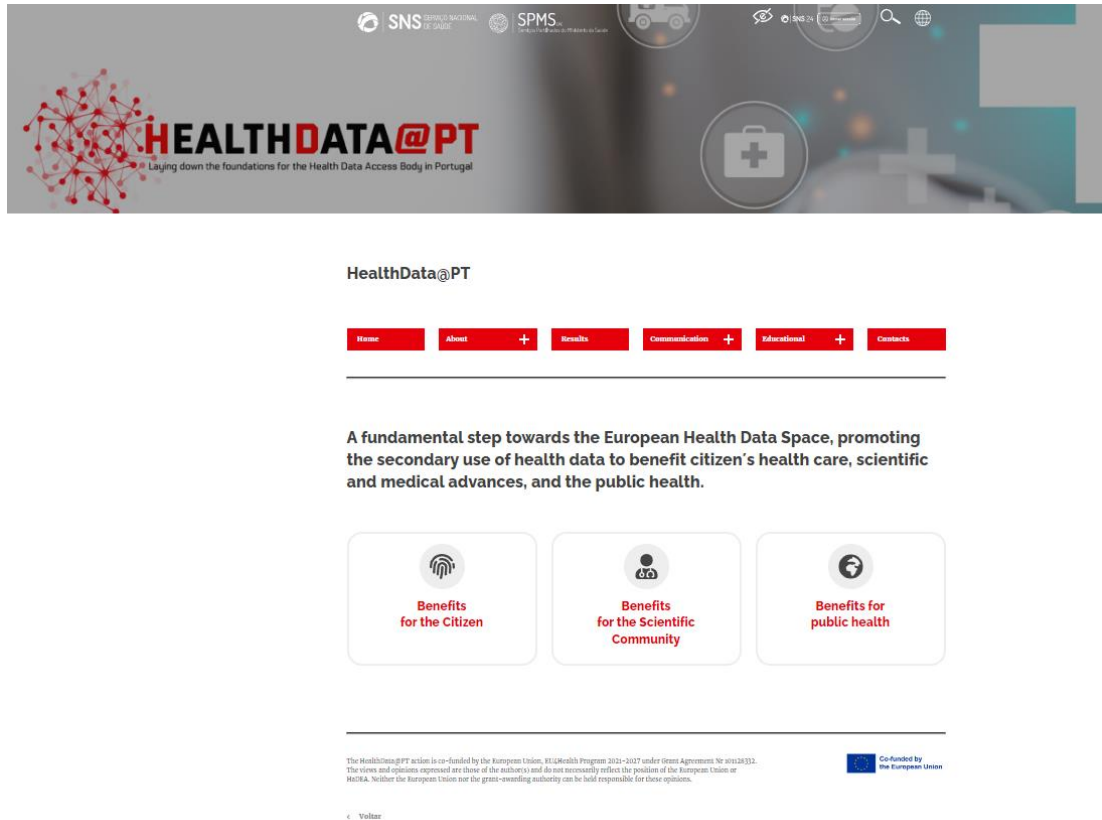


Figure 5. HealthData@PT website homepage.

3.2. About

The section About is divided in two sub-sections (Figure 6):

- HealthData@PT: which provides an overview of the action and highlights its objectives (Figure 7).
- Work Packages: which describes the nine work packages of HealthData@PT action (Figure 8).

HealthData@PT



Figure 6. HealthData@PT website “About” menu section.

a) Sub-section HealthData@PT



HealthData@PT

(go to PT website)

Home About + Results Communication + International + Contact

About

The HealthData@PT - Setting up a Health Data Access Body in Portugal - action aims to establish the national infrastructure, network and the foundational elements necessary to ensure secure access and use of health data for the purposes of research, medical innovation and health policymaking (secondary use of health data). Additionally, HealthData@PT seeks to provide tools to improve the overall quality of health data for secondary use.

Through its concerted efforts, HealthData@PT aims to prepare the national ecosystem for the intra- and cross-border secondary use of health data, with the main goal of improving therapeutic outcomes and strengthening the healthcare system. The establishment of these national foundations is crucial for ensuring the successful future integration of Portugal into cross-border infrastructures, such as HealthData@EU.

This action will advance the technical implementation of the Health Data Access Body in Portugal, crucial for the future national integration into the HealthData@EU infrastructure for the cross-border sharing of electronic health data.

This four-year initiative was approved by the European Commission in the scope of the EU4Health programme 2021-2027, and started officially in November of 2023.

National infrastructure for the secondary use of electronic health data

A data access management system able to receive, process and provide an answer to health data requests in < 2 months.

A publicly available National Dataset Catalogue with 25 datasets.

Groundwork for a Future Secure Decentralized Environment for nonclinical research / innovation / policymakers to access health data.

Cross-border access to electronic health data

Develop the software stable product to connect the Portuguese infrastructure with the mandatory infrastructure for the cross-border exchange of electronic health data for secondary use, the HealthData@EU.

Improving the quality of electronic health data

Provide recommendations and guidelines to foster the improvement of the quality of electronic health data at data holder's level. Enhancing the quality of data available for secondary use will lead to better results in enhancing the quality of health care for citizens and by strengthening the national health system.

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Figure 7. HealthData@PT website “About” section: HealthData@PT sub-section.

b) Sub-section Work Packages

HealthData@PT

Home About + Results communication + International + Contacts

Work Packages

 <p>Work Package 1 Management and coordination</p> <p>Establishment of a national governance and management framework to guarantee the execution of the proposed plan. This work package encompasses the production of a Sustainable National Governance Model for HealthData@PT, along with monitoring, reporting and other related coordination activities. Furthermore, participation in the activities of the HealthData@EU community of practice is also envisioned within the scope of this work package.</p>	 <p>Work Package 2 Dissemination, training and support</p> <p>Raise awareness among citizens, data holders and data users of the health data access body function and responsibilities. Conducting training initiatives and orchestrate support initiatives for health data access body staff, data holders and data users.</p>	 <p>Work Package 3 Evaluation</p> <p>Conduct performance monitoring and evaluation activities to assess the effectiveness of the implementation of the digital business capabilities in scope of this project.</p>
 <p>Work Package 4 Sustainability</p> <p>Ensure that the digital business capabilities implemented in the scope of this project have a sustainability plan and business continuity plan beyond the duration of the grant.</p>	 <p>Work Package 5 Data Access Applications management solution</p> <p>Development of a solution (a data access applications management solution) capable of receiving and processing data access requests.</p>	 <p>Work Package 6 National Dataset Catalog for Health Data</p> <p>To enable HealthData@PT to provide data users a way to discover and assess the suitability of existing health datasets for the data users' intended purpose.</p>
 <p>Work Package 7 Secure Processing Environment for Health Data</p> <p>Establish the foundations for creating a secure process in accordance with the security specifications for the processing of electronic health data.</p>	 <p>Work Package 8 Cross-border gateway to connect with the HealthData@EU infrastructure</p> <p>Develop a minimum viable product to connect with the future HealthData@EU infrastructure for the secondary use of health data at EU-scale.</p>	 <p>Work Package 9 Health Data Quality Enhancement</p> <p>To enhance the quality of electronic health data and to provide specifications to advance data semantic and technical interoperability. This work package will contribute with specifications for improving the quality of the raw data and metadata, as well as datasets descriptions, at data holder level. This will foster more easily discoverable and interoperable data in accordance with European specifications, and will provide a better education for researchers, innovators, and policymakers on the suitability of a dataset for their research/work endeavors.</p>

[← To go back](#)

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Figure 8. HealthData@PT website “About” section: Work Packages sub-section.

3.3. Results

This section (Figure 9) will provide all the information related to the deliverables, milestones, and important public documents made available throughout the project.

HealthData@PT



Figure 9. HealthData@PT Website "Results" menu section.

3.4. Communication

All events, including workshops and webinars, and news about the project will be published in this section (Figure 10). Moreover, important information on advances that impact this project will be also made available. For example, information on important deliverables from HealthData@EU Pilot, documents related with the future European Health Data Space Regulation and from other European actions devoted to the advance of secondary use of Health Data will be made available in this section of the website.

HealthData@PT

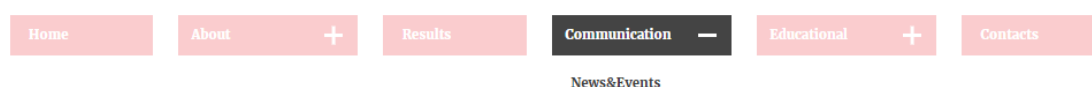


Figure 10. HealthData@PT Website "Communication" section.

Currently, this section is composed by the sub-section “News & Events”, where the news to disseminate the launching of the HealthData@PT action in November 2023 was published (Figure 11).

a) Sub-section News & Events

News&Events



HEALTHDATA@PT
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HEALTHDATA@PT
SPMS launches the HealthData@PT action to advance the European Health Data Space
16 Novembro, 2023

SPMS coordinates the HealthData@PT action, which will be an important milestone for the implementation of the European Health Data Space in Portugal.SPMS coordinates the HealthData@PT action, which will be an important milestone for the implementation of the European Health Data Space in Portugal.

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Figure 11. HealthData@PT Website: "News & Events" sub-section.

3.5. Educational

The educational section (Figure 12) is one of the most valuable areas of the HealthData@PT website, as training and dissemination information are the primary goals of the WP2 of this action. This section includes 3 subsections: i) Documents, ii) Acronyms, and iii) FAQs.

Throughout the four years (2023-2027), all essential communication, education, and information materials prepared in the scope of this action will be made available in the sub-section “documents”. Additionally, this sub-section will contain graphical material, brochures, videos, and other documents, as soon as they are available.

A list of the most important acronyms/most used terms related to this action was made available in the sub-section “Acronyms” (Figure 13). This list will be updated throughout project’s lifecycle. Moreover, a list of the most relevant FAQs, to provide information on HealthData@PT “FAQS” was also made available (Figure 14). Please keep in consideration that the content will be published alongside the project's outcomes.

HealthData@PT



Figure 12. HealthData@PT website: “Educational” menu section.

a) Sub-section Documents

[To be published]

This section will include the reports and deliverables that will be produced during the duration of the project, if categorised as Public.

b) Sub-section Acronyms

Acronyms

BDNP	National Prescription Database
CNPD	National Data Protection Commission
DAAAMs	Data Access Applications Management solution
DEM	Electronic Dispensing of Medicines
EHDS	European Health Data Space
EHDS2	European Health Data Space 2
EHS	Electronic Health Summary
EHR	Electronic Health Record
eHDSI	eHealth Digital Service Infrastructure
eHN	eHealth Network
eD	eDispensation
eP	ePrescription
HDAB	Health Data Access Body
nHDS	National Health Dataset Catalogue
PT	Portugal
SPE	Secure Processing Environment
NHS	National Health Service

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Figure 13. HealthData@PT website: “Acronyms” sub-section.

c) Sub-section FAQs

FAQs

What is the European Health Data Space (EHDS)?	^
<p>The digital transformation of healthcare in the European Union is greatly aided by the European Health data space (EHDS). The EHDS puts citizens first by granting them complete control over their data, free of charge, so they can benefit from better healthcare delivery throughout the European Union. Additionally, the EHDS aims at providing a consistent and regulated framework for leveraging health data to accelerate health innovations and improve research studies, to ultimately lead to better live-saving medicines, healthcare policies and healthcare outcomes to all EU citizens. The EHDS has a regulation proposal, currently being debated and negotiated. For more information on EHDS regulation proposal, please consult the provided Link.</p>	
How is my personal health data protected?	v
What is meant by secondary use of health data?	v
How is my personal health data protected?	v
What is HealthData@PT project and the main objectives?	v
Who will have access to the national dataset catalogues?	v

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Figure 14. HealthData@PT “FAQs” sub-section.

3.6. Contacts

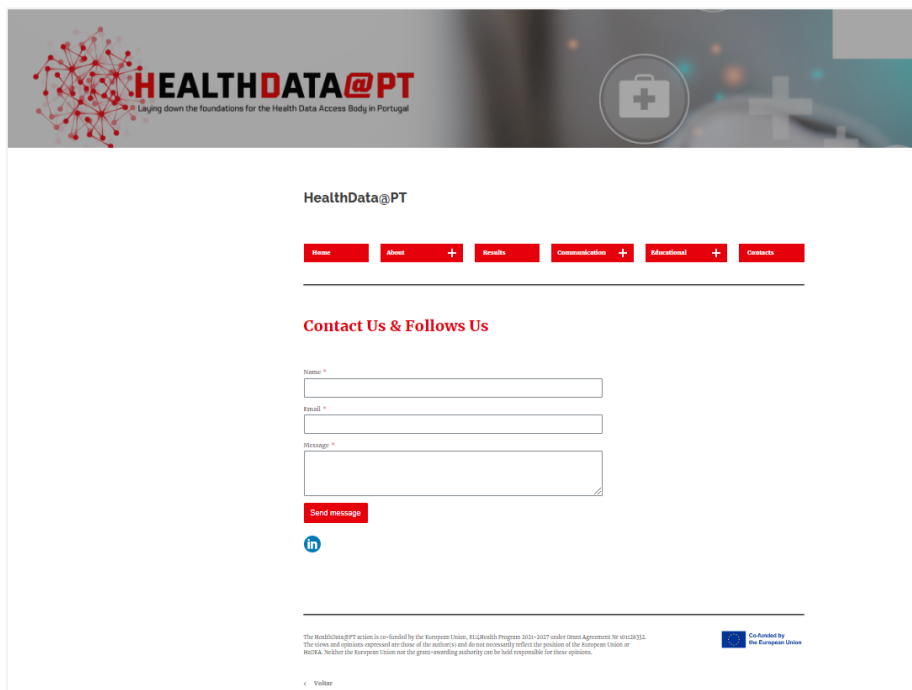
This section (Figure 15) contains a form that users can fill out with their name, e-mail address, and any queries or comments they may have about the HealthData@PT project (Figure 16). This way, the HealthData@PT team can respond to individuals who are interested in contacting directly.

To increase engagement with the project's development and outcomes, in this webpage the link to connect with the SPMS LinkedIn, though the icon of the platform, has been provided, which will be used to disseminate results and outcomes of the HealthData@PT during the course of the action.

HealthData@PT



Figure 15. HealthData@PT “Contacts” sub-section: contact form.



HealthData@PT

Home About + Results Communication + Educational + Contacts

Contact Us & Follows Us

Name *

Email *

Message *

Send message



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Figure 16. HealthData@PT “Contacts” menu section.

4. Conclusion and Next Steps

The next phases in the website's development will be to add all the project's updates, deliverables and produced documents as the project progresses and milestones are reached.

At initial months, there will be no significant information available, as the project development will be in early stages. Nevertheless, important information on other EHDS2-related activities or on EHDS regulation will be published on the website as soon as it is available, to disseminate and engage with stakeholders of the health data ecosystem. Moreover, throughout project lifecycle, the goal is to feed the website with content for data holders, data users and citizens towards inform, disseminate, and provide training, whether in webinar, workshops, or in the form of informative documents/contents, open to the public.

In addition to the current english version of the website, depicted in previous figures in this report, this website will also be translated into Portuguese, the official language of the country coordinating HealthData@PT action. This is fundamental for citizens engagement and information, one of the main goals of the WP2 of HealthData@PT.

Regarding the website's structure, it should be noted that the website's menus/sections and sub-sections are subject to changes, as required towards achieving communication and dissemination objectives.



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