Deliverable 10.1

Dissemination strategy plan and preliminary material

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## Document History

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## List of Contributors

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## List of reviewers

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<td>Mirko De Maldè</td>
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Introduction

This document is aimed at illustrating the communication and dissemination strategy that will be followed throughout the MHMD project to achieve the most effective disclosure of the project objectives and principles, as well as the technologic innovations that are going to be implemented and their potential impact on the EU society. It also provides some preliminary communication and dissemination materials produced within the first three months of the project.

MHMD outcomes are capable of profoundly modifying the EU citizens’ approach towards individual privacy data issues and the healthcare system, allowing a direct participation of individuals into the production and management of health data, fostering a mutual interaction among patients and between patients, patients’ associations and healthcare providers, favoring confrontation among clinicians themselves, and raising interest in R&D in healthcare on a EU basis, all this possibly contributing to substantial improvements in the quality of healthcare and in the advancements in public and private scientific research. This socioeconomic “revolution” will equally involve different groups of stakeholders, including patients, patients’ associations, clinicians, healthcare public researchers, as well as R&D and healthcare service provider businesses. This network will constitute a solid basis for subsequent development of relevant business opportunities (i.e. exploitation activity), which will be the object of separate dedicated tasks (T10.6-8) and deliverables (D10.4-5, D10.8-9).

For these reasons, the communication and dissemination strategy is intended to utilize the most comprehensively accessible language to make easily understandable to the widest audience the technological solutions implemented, their innovation potential, implications and outcomes, as well as to possibly raise further interest on these topics and push EU citizens to directly inform and engage themselves in the use of the newly implemented systems, which are potentially going to exert a powerful impact on their everyday life, with the ultimate goal of creating and fueling a community of people and organizations animating the MHMD platform.
The overall strategy

According to the project proposal, the main objectives of this task will be to

1. **Communicate project rationale, overall objectives and methodology** to the different stakeholders and the general public;

2. **Disseminate the technical and scientific project outcomes**, focusing on the key stakeholders, also through specific dissemination event and fostering the creation of the community of people and organizations that will animate the MHMD platform.

To achieve these major objectives, the Consortium conceived a unified strategy for communication and dissemination tailored to maximize the potential of cross-fertilization between these activities, fostering the combined effects of general communication, delivery of specific peers’-driven messages, and ultimately the presentation to the public and potential end-users of advanced technological solutions. These activities will be carried on continuously throughout the project, with a focus on communication of the project mission and principles from the very beginning, and later dissemination of the results to the different groups of stakeholders, promoting direct engagement in the MHMD system along with the respective competences, goals and interests.

This will go through a range of parallel activities at various communication levels, including the following:

1. **Set up of different communication channels** *(website, twitter, LinkedIn, YouTube)*;
2. **Prepare and publish various dissemination materials** *(e.g. annual newsletter, flyer, press releases)*;
3. **Organise the attendance to relevant conferences, seminars, workshops, and public events, collaborations and cross-fertilization with other EU projects**.

In performing the above-mentioned activities, the Consortium will apply the best practices indicated by the EC and proven effective in a series of ongoing EU-funded projects *(e.g. MD-Paedigree, Cardioproof, Health-e-Child, Sim-e-Child)*, adequately refined to the project peculiarities, including:

- **Definition of the key audiences** (in relation to different stakeholder groups) and **conception of specific messages and appropriate communication strategies** for each of them, promoting their engagement and contribution to the Action;
- **A bi-directional and knowledge sharing approach**, to mostly exploit the feedback and interaction with the future end users (through workshops, dissemination events, and direct interaction) to enhance the overall usability of the implemented solutions;
- with the only exception of materials tailored to specific groups, dissemination channels and materials will **make use of everyday language** rather than academic or industrial language, to maximize the public comprehension of the project mission and outcomes, and ultimately the effectiveness of the communication activities;
- **Extensive use of multimedia content** to most effectively explain concepts and outcomes;
- **Involvement of further institutions, relevant associations and cross-fertilization with other relevant projects**, to favor the expansion of the reference network and widen the stakeholder community.

MHMD will always request as much support as possible from the EC, to disseminate its vision and results,

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1 European Commission, *Communicating EU research and innovation guidance for project participants*, 25 September 2014.
and by informing well in advance the EC with regard to its major forthcoming dissemination activities. Furthermore, a clear acknowledgement of EC funding will be included in all dissemination activities (materials, media or event), in compliance to the Communication guidelines.
MHMD messages

Along with the project proposal, main project scopes, to be properly conveyed through the established communication channels, are the following (as reported in the project website). These messages have been defined in relation to specific key audiences, and identification of the most suitable means of communication and dissemination have been made accordingly.

CITIZENS’ ENPOWERMENT

- Development of the dynamic consent interface, aimed at enabling data subjects to allow, refuse and withdraw access to their data according to different types of potential usage.
- Build-up of a blockchain-based software infrastructure in which individual data exchanges are governed by peer-to-peer relationships between all the stakeholders.
- Implementation of the personal data account, a personal cloud allowing data subjects for direct access to their whole clinical data from any personal device through the blockchain.
- Use of smart contracts to assist data subjects in their right to access, erase, modify delete or even “be forgotten”.
- Analysis of the current legislation applicable to the processing of health data and other personal information, definition of a proper legal and regulatory framework and creation of new rules and best practices for uncovered processes, solutions and methodologies.

This message is primarily addressed to individual data subjects, i.e. patients. Unlike the current system, for the very first time patients will be given the possibility to be aware of which use is made of their own data, but mostly they will be able to fully control it through a dedicated user application, all within a proper legal framework that will regulate the transactions and safeguard their rights, in a safer way than ever. Most of all, they will be able to become an active part of the process, capable of turning to different professionals for clinical opinion, asking for advice from other people with the same disease, or getting informed over scientific research projects. These, in particular, will be the messages conveyed through the different communication channels, particularly the social media (i.e. website, twitter, You Tube) to the potential future users of the MHMD platform.

DATA PROTECTION

- Application of the blockchain model, a resilient and decentralised secure control system to monitor and assess the legitimacy of data transactions and detect fraudulent activities in real time.
- Identification and system implementation of the most suitable and robust de-identification and encryption technologies needed to secure different types of information.
- Evaluation of the overall security of the system architecture by testing it through dedicated re-identification and penetration self-hacking simulations and public hacking challenges.

This message is chiefly directed to hospitals, i.e. clinicians, research and IT directors, and secondarily to patients, for the same reasons. Indeed, also given the frequent and dangerous occurrence of identity thefts and data breaches in current local health data repositories, achieving a full trust of hospitals represents an unavoidable step to the successful development of the project, for which the disposal of large data sets from hospitals is essential to develop and test advanced analytics and encryption and de-identification technologies, develop new models and tools for clinical prediction (clinical decision support systems - CDSSs), and make the MHMD information marketplace as “ecumenical” as possible. This message will be delivered through the general communication channels, but mostly by the dedicated academic publications (and related dissemination materials, i.e. newsletter, press releases) that will be produced throughout the project,
and public institutional events on health data privacy and security the Coordinator and other members of the Consortium will attend to, particularly in regard to the application of the blockchain technology, which represent the driving project novelty in health data management.

**DATA VALUE ENHANCEMENT**

- **Profiling and classification of sensitive data based on their informational, scientific and economic value.**
- Implementation of **normalisation services** able to process, harmonize and semantically consolidate all authorized data allowing rapid merging of heterogeneous sources.
- Creation of a unique application programming interface (API) to facilitate **lawful data access to all registered stakeholders with a user-friendly registration process**, supporting development of a proper **Big Data analytical framework**.
- Exploring potential ways to make use of **anonymised or pseudonymised data** with **advanced data analytics and patient-specific model-based prediction applications**, accelerating discoveries, fostering technological innovation and improving clinical care.

This message primarily applies to the scientific research community, at both academic and business level. As heterogeneity of data formats and sources, considerable difficulties (in terms of time and costs) in acquiring patients’ data considerably impairs research outcomes, a straightforward and functional access to high-value normalised clinical datasets would be essential in motivating public and private research centres to get involved and contribute to the project, as well as, in later stage, to be part of the MHMD platform. This will not only foster an increase in scientific research activities, but also an improvement of the quality of research outcomes, severely impaired by scarcity and homogeneity of isolated small datasets. The involvement of the research community will be engineered particularly with the use of academic publications made within the Consortium, which will be promptly disseminated through the project newsletter, press releases, twitter posts, but also through dedicated scientific events on the themes of Data Science, Information and Communication Technology, Bioinformatics.
Stakeholder involvement

According to the project scopes, there are four groups of stakeholders that are likely to be involved and should be addressed by appropriate means:

1. **Patients**, including individual subjects and patients’ associations;
2. **Hospitals**, including physicians, clinical research coordinators, IT directors, clinical researchers;
3. **Research centres**, including experimental researchers, data scientists, bioinformaticians;
4. **Businesses**, including industrial research enterprises or commercial enterprises such as health management organisations, accountable care organizations and health tech companies.

**Patients**

Patients constitute the real project basis, representing both the health data providers and, as future users, the ultimate recipients of the project outcomes. Hence, their involvement will be fostered with the greatest attention, by raising awareness on controversial issues of health data privacy and security, presenting the solutions implemented and illustrating the opportunities provided by the new MHMD platform. As patients will be fundamental in defining the user requirements, their feedback will be crucial for a continuous update and improvement of the proposed solutions, and their contribution will be elicited throughout the project.

In first place, besides the wide use of web and social media-based **direct communication channels (e.g. website, daily twitter activity, You Tube channel)**, patients’ attention will be drawn through the direct involvement of patient associations, which will contribute to raise awareness on data privacy and security issues, and in turn provide their feedback on the system requirements implementation. In a second phase, when digi.me applications will be ready, direct involvement of new patients will be also obtained by the direct engagement of clinicians within the Consortium, who will explain to their patients the potential benefits of the new applications. At this stage, **video tutorials**, to be spread through the various communication channels, and appropriate **informative material (i.e. flyers)** will be designed to illustrate the new solutions, both in terms of usability and potentials, to the possible end users.

**Hospitals**

Hospital repositories represent the primary data source for the development of the project, particularly for the development of advanced analytics, privacy preserving and encryption technologies. Most importantly, physicians constitute as an intermediary to engage patients in the MHMD network, as themselves an essential category of end-users, who will possibly provide useful insights to refine the platform use cases and functionalities. Hence, gaining their trust in crucial for a successful development of the project.

In order to attract the attention of the healthcare community, the Consortium is going to organize attendance to **public events dedicated to health data privacy and security**, to **contact associations** in regard to the topics, while producing **dissemination materials (posters, flyers, newsletter)** that will be distributed in related contexts. Later on, a dedicated video tutorial will be produced to illustrate potential uses and benefits on the MHMD platform and idig.me application to hospitals, physicians and patients.
Research centers and businesses

Research centers and business role will be particularly crucial for the possible insights to be provided throughout the analytics solution development phases, while academic and private researchers would also constitute one of the major group of interest in the MHMD platform, with the possibility to access large datasets of biomedical records for research purposes.

To this regard, the Consortium should be effective in disseminating the biggest technological innovation of the project, with specific attention to the simplified lawful data access that will be granted through the MHMD platform, through scientific workshops and seminars, particularly focused on the themes of big data and blockchain technology, academic publications and dissemination materials (flyers, posters, newsletter) conveniently spread out through social media (twitter) and the project website. In the final project stages, a dedicated promotional video tutorial will be produced to communicate project outcomes.
Communication channels

Website
The project website is intended to primarily serve as a showcase to present the rationale, objectives, methodology and accomplishments of the project Consortium to the general public, in first place to individual subjects, but also clinicians, researchers and business representatives, to be potentially involved into the MHMD platform. Together with the Twitter account, it is meant to contribute in raising interests on the project key innovation themes (#health data, #data security, #data protection, #blockchain technology, #data science, #big data, #cyber security, #Internet Of Things) fostering the creation of a dedicated community of people and organizations, including (besides the above mentioned) data scientists, cyber security experts, blockchain developers, technology service providers and consumers, public and private institutions (e.g. ICO., Information Commissioner’s Office) devoted to information and data rights.

Twitter
The twitter account will serve as the “armed branch” of the project website, as it will actively contribute in the spread of news and contents on relevant issues, as well as updates on the project (e.g. project meetings, attendance of public events) in real time. It will have a role in creating links and groups of interests, spreading news and contents, and fueling the community of stakeholders.

You Tube
A you tube channel dedicated to the project will be created and filled with a series of videos with different purposes and potential audiences:
- an introductory video, to serve as a “manifesto” of the project, which will explain in simple words the rationale, goals, methodology and expected outcome of the projects, to be addressed to a general audience, and spread through the website, social media account and public dissemination events;
- a “end user-tailored” video tutorial, which will explain the novelties of the MHMD platform and digi.me application, as well as instructions to an end users’ audience;
- a “clinicians-tailored” video tutorial, explaining project novelties, advantages for patients and hospitals, and reasons for inviting patients to the platform;
- a “researcher-tailored” tutorial, directly addressing the healthcare researcher, with a more “business” approach to engage the academic and business community.

All these videos will have common features, including shortness (5 minutes maximum), large use of animations, spaced out by fragments of interviews to the Consortium Leaders. Besides the dedicated channel, these are going to be spread through social media (including websites of engaged patient association or hospitals), and at relevant public events.

LinkedIn
A LinkedIn page dedicated to the project will be designed and filled with project information and contacts, as well as articles and news relevant to the project scopes, all this contributing to the growth of a relevant community of stakeholders.
Dissemination materials

The production of dissemination material will address both communication and dissemination scopes: as first step, to raise awareness on MHMD overall vision, scopes and methodology, and in later stage to disseminate the project scientific results within and beyond the relevant scientific community.

Novel developments will be submitted for publication in relevant scientific journals, with the following list being a preliminary list of potential targets:

- Journal of information security and Privacy.
- International Journal of Computer Application.

In order to ensure the widest possible availability of the publications stemming from MHMD, Open Access gold or green solutions will be adopted, also relying on centralised platforms such as ZENODO or OpenAIRE. In addition, specific duly anonymised dataset will be made available for re-using (with proper credits) or reproduction/validation of the scientific results in an Open Science environment, in compliance with Open Access and Open Data EU policies.

Academic publications will be disseminated through materials such as

- **Press releases**, which will come along the main academic publications and will be spread through news agencies like EurekAlert!, Alpha Galileo, Esna, Agence Europe, ANSAméd; press releases will also be produced in relation to the MHMD dissemination- or other major events;

- **MHMD newsletter**, to be produced at M12, M24, M36 with the direct collaboration of involved researchers; articles will deal with scientific results, implemented tools, project vision and future outcomes, in a captivating and comprehensible language.

To achieve more general communication purposes, dedicated **flyers** will be prepared to reach different potential audiences: while a former business-addressed one has been already prepared (see following section), in a later stage others will be directed to patients and to clinicians, to explain MHMD vision, potentials of the MHMD platform and provide a brief use guide to potential users. Besides, **posters** might be prepared when relevant to the participation of scientific workshops and seminars.
Scientific and dissemination events

Participation of the Project Coordinator or other Consortium partners to public events, scientific symposia and workshops is meant to address the relevant scientific stakeholders, contributing to lay the groundwork for creating a dedicated network of businesses and research centers, by both presenting the project scopes and methodology and, in a later stage, scientific outcomes and implemented tools.

At present, MHMD has been preliminarily presented at the following events:

- the Big Data Value Association Summit held in Valencia on November 30 - December 2, 2016, convening more than 350 experts from Industry, Academia, Public Administration, data owners and users from all Europe;
- the Information and Networking Days on Horizon 2020 Big Data Public-Private Partnership topics 2017, taking place in Luxembourg on January 17–18, 2017, where MHMD was presented with a specific effort to start networking activities with the Coordination and Support Action of the Big Data PPP call ICT-18 (Privacy-preserving big data technologies), which has the mandate to explore the societal and ethical implications and provide a broad basis and wider context to validate privacy-preserving technologies.

Other relevant conferences likely to be attended in 2017 are reported in the table below, while other events would be identified in the next months.

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<td>WSDM 2017 - 10th ACM International Conference on Web Search and Data Mining</td>
<td>February 6–10, 2017</td>
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<tr>
<td>ICBDAIS 2017: 19th International Conference on Big Data Analysis of Images and Signals</td>
<td>February 16-17, 2017</td>
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<td>Big Data &amp; Analytics Innovation Summit</td>
<td>March 1–2, 2017</td>
<td>Singapore</td>
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<td>CHIIR 2017 - Conference on Human Information Interaction &amp; Retrieval</td>
<td>March 7-11, 2017</td>
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<tr>
<td>BigData Congress 2017 - 6th IEEE International Congress on Big Data</td>
<td>June 25-30, 2017</td>
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Besides, the Consortium will organize two public dissemination events (M18, M30). The former will be primarily directed to present the overall goals and methodology and the state of the art of the project, contributing to enlarge the community of affiliated research and clinical centres and possibly providing useful insights for the subsequent project developments; the latter will be addressed to the presentation of final scientific results and implemented tools, aimed at further engagement of business, research and clinical centres into the network, as well as in search of further opportunities of R&D collaborations within the project objectives.
Management of the dissemination activities

Communication and dissemination activities will be leaded by Lynkeus (LYNK), which will be responsible for the conception and development of the general strategy, while all other partners will be involved to a minor extent, contributing in content draft (i.e. newsletter, conference papers), presentation of the project at scientific events, and circulation of the project contents and materials through their organization websites and social media accounts throughout the project.

In the following table, the effort for each partner is shown.

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Preliminary Materials

**MHMD Logo**

The project logo is currently displayed in the project website, twitter account and project presentations, and will be included in every dissemination document and deliverable.

**RGB version**

![RGB version](image)

**Black version**

![Black version](image)

The *white version* (not visible in this document) has also been produced and is available in case of need.
Presentation template

This template will serve as basis for every presentation that will be held by the Project Coordinator at relevant conferences, seminars, workshops, and public events, when presenting the project for networking, collaboration and cross-fertilization purposes.
Project Website

The first version of the project website has been already implemented and released online (www.myhealthmydata.eu) and will be launched with a dedicated press release on February 1st 2017.

The website was conceived and structured innovatively, to exhaustively illustrate the key aspects of the projects, while parallely motivating the user to further reading being as intuitive and straightforward, appealing and interactive as possible, using different features:

- large use of images, diagrams, infographics and icons to illustrate project key concepts besides or (whenever possible) in place of texts;
- high level of interactivity with insertion of image animations responsive to the scrolling of the mouse on the screen, displaying contents flowing right-left or down-up, or allowing to navigate across different page portions by mouse click;
- content organization via keywords, moderate use of texts (not exceeding 1.100 words per page, but about 600 on average), organized and divided in text boxes or short paragraphs;
- different navigation options: possibility to navigate the pages either through the upper menu or among pages by interactive shortcuts (arrows or word links) connecting consequential pages;
- a mixed structure, both including a traditional upper navigation menu to access the different pages as well as a landing responsive main page to be viewed by mouse scrolling.
The website layout is overall organized as follows:

- **Home Page**: a responsive landing page briefly illustrating rationale, objectives and key innovation elements, mentioning the project consortium, the coordinator’s contacts and providing a partial view of the news, events and twitter pages;

- **Project section**: providing a detailed description of project rationale, objectives, structure and (public and confidential) achievements, including the following pages:
  1. **Why MHMD?**, stating the problems of data privacy and security, as well as data subjects rights;
  2. **Objectives**, describing the main goals of the project and how the consortium is going to achieve them;
  3. **Structure**, illustrating the project articulation into work packages and related tasks;
  4. **Public Deliverables**, containing the public deliverables distributed along the project timeline to be downloadable as soon as submitted to the European Commission (EC);
  5. **Restricted Area**, as private page that will be made accessible only to the EC and will serve as additional archive for the confidential deliverables;
• **Consortium page**, providing details about the different consortium partners and their respective role in the project;

![Consortium Page]

• **News & Events section**, containing the pages
  1. *News*, regarding news and articles on data privacy and protection issues, as well as internal events (e.g. project meetings);
  2. *Events*, dealing with public events, workshops and seminars regarding the project topics and having seen the project coordinator’s attendance and/or project presentation;
  3. *Publications*, a space for publishing the annual project newsletter, as well as academic related Consortium publications and other dissemination materials;

![News & Events]

• **Contact us**, a page containing a form to be filled in to request further information on the project; the e-mails will be delivered to info@myhealthmydata.eu, and taken care of by a dedicated communication officer.

Throughout the project, the structure of the site may evolve according to communication needs. Particularly, dedicated spaces will be established for additional dissemination material (i.e. multimedia) produced in later stages.
Twitter account

The twitter account has been created and is already active on a daily basis posting and retweeting news regarding the core project issues (e.g. health data, personal data privacy, blockchain technology) as well as news on the project, such as project meetings or attendance to relevant public events by the Project Coordinator or other partners of the Consortium presenting the project.
Press release #1

The first press release was dedicated to introduce the project at a broader level and launch the website. Other one will be specifically devoted to disseminate definite project outcomes or academic publications made within the Consortium.

MyHealthMyData: Blockchain and Smart Contracts enhance utmost privacy and security in healthcare
An EU project to empower citizens with regard to the usage of their own health data

MyHealth-MyData (MHMD), a H2020 EU-funded research and innovation project, is poised to be the first open biomedical information network centred on the connection between organisations and the individual, aiming at encouraging hospitals to start making anonymised data available for open research, while prompting citizens to become the ultimate owners and controllers of their health data. MHMD profiles and classifies sensitive data based on their informational and economic value, and assesses the most suitable and robust de-identification and encryption technologies needed to secure different types of information, while still allowing advanced knowledge discovery through analytics and deep learning applications running on a growing amount of anonymised or pseudonymised data.

MHMD develops new mechanisms of trust and of direct, value-based relationships between people, hospitals, research centres, and businesses, by making use, for the very first time in healthcare, of a blockchain system, i.e. a digital ledger where information relating to the distributed storage of the health data is trimmed in hash-based language code, making it possible to describe exactly what type of data are available, referring to what cohorts of patients, and data transactions are continuously validated to the entire network of stakeholders, avoiding any possibility of fraudulent usage.

A dynamic consent interface will allow users to grant, deny and revoke data access for different uses according to their preferences through personal data accounts, storage clouds enabling individual access from any personal device. In this way, patients will be able to fully leverage the value of their clinical information, turning to different healthcare professionals for second opinion, or searching for profiles of similar patients and contact them upon their permission. Physicians, in turn, will have the possibility to retrieve medical annotations or execute queries to identify patients with analogous features to find cues about a specific clinical case. Smart contracts, self-executing contractual states in digital form, will regulate data transactions between users, allowing the permission to access, and stakeholders, who will be enabled to make direct requests and offer incentives in exchange of access rights. This system will be checking its applicability as an operational Infostructure, and will represent an innovative challenge within the EU General Data Protection Regulation entering in force in 2018. On this basis, MHMD has the ambition to foster the development of a true information marketplace for healthcare.

MHMD will also analyse users’ behavioural patterns alongside ethical and cultural orientations, to identify hidden dynamics in the interactions between humans and complex information services, and will assess the overall security of its multi-modular architecture by testing it through dedicated self-hacking simulations and public hacking challenges, performed on synthetic data sets.

“MyHealthMy Data is an exciting project which aims at fundamentally changing the propensity to share sensitive data between clinical institutions while facilitating the transition towards a patient-centric approach based on the direct engagement of citizens” declared Edwin Morley-Fletcher, the Project Coordinator. “Blockchain and Smart Contracts will play a key role in providing the maximum degree of privacy protection and security by making trust digitally self-enacted when accessing health data”.

MHMD officially started on 1st November 2016, and is now online at www.myhealthmydata.eu. The project, is coordinated by Lynkeus (an Italian SME, based in Rome), and involves 4 other SMEs (from Austria, France, and the UK), 4 research centres and academia (Greece, Italy, Romania, Switzerland), 4 clinical centres (Germany, Italy, UK), a legal firm (Belgium/Italy), and 1 industry (Siemens).

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http://www.myhealthmydata.eu/
Flyer

This first flyer is aimed at prospective customers willing to get involved into the MHMD platform. It contains a general rationale and very brief explanation of the project key challenges and innovation aspects, and was conceived for preliminary general communication purposes.

Flyer

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MY HEALTH
MY DATA

A NEW PARADIGM
IN HEALTHCARE DATA PRIVACY
AND SECURITY

Shortage of biomedical data is rapidly becoming a thing of the past as wearable devices, integrated hospital IT systems and full scale genome sequencing become the norm in medical and wellbeing care, all this leading to an expected 40 exabytes of data produced every year in 10-year time. The challenge is now storing and securing patients data, in an industry were data breaches and identity thefts are rampant, but in which, at the same time, availability of extensive, multidimensional data sets is crucial to foster innovation and improving clinical outcomes. Reducing costs and liabilities, by reducing ‘by design’ the risk of identity theft and privacy breaches, while accelerating discoveries and technological innovation, is the fundamental goal of MyHealth-MyData.

5.0 BILLION DOLLARS/YEAR
SPENT IN THE US TO PROTECT
HEALTHCARE DATA

27.8/67.7
MILLIONS OF MEDICAL RECORDS
BREACHED SINCE 2009

Black market prices 10x higher for medical records in respect to other industries

THE PROBLEM
IN FIGURES

More than 193 million personal records open to fraud and identity theft in 2015

Today’s health IT landscape is a constellation of isolated, locally hosted data repositories, managed by diverse ‘data owners’, which take on the cost and the risks of this still ill-defined prorogation. Punitive but unclear regulations make for high regulatory risks, while patients remain disenfranchised, without an actual understanding of or control over who uses their personal information and for what purposes. MyHealth-MyData (MHMD) aims at fundamentally changing these assumptions by introducing a new way to share private information and to empower their primary owners, the patients. This new model implements Dynamic Consent to drive data exchanges in a proactive, secure, open and decentralised manner. Personal Data Accounts empower the individual over who accesses his/her data and for what purposes, while Smart Contracts automate the execution of legitimate data transactions under constantly evolving conditions. In the MHMD architecture, a Blockchain system is used to distribute control and detection of fraudulent activities to the entire network of stakeholders, from patients to businesses and institutions. Peer-to-peer data transactions are allowed based on explicit access rights set by individuals (not by policies that are seldom understood or properly implemented) and monitored by the entire community. The project also wants to develop a new methodology to design and apply identity protection provisions, to solicit, for instance, Multilevel De-identification and Encryption technologies based on data value and intended use, while allowing analytics applications to leverage the information. In this way, MHMD will foster the development of true information marketplaces, in which individuals can exercise full control on their personal data and leverage their value, implementing new mechanisms of trust and direct, value-based relationships between people, hospitals, research centres and businesses.
PARTNERS:

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