IDEA4RC

Intelligent ecosystem to improve
the governance, the sharing, and the re-use
of health data for rare cancers

Deliverable 10.2

Stakeholder Engagement Plan

February 2023

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Revision History

Revision no.	Date of Issue	Author(s)	Brief Description of Change
0	27/12/2022	DICOR/ACC	Preliminary Table of Content
1	26/01/2023	DICOR/ACC	Advanced Table of Content
2	22/02/2023	DICOR/ACC	Advanced draft
3	28/02/2023	DICOR/ACC	Document submitted for internal peer review
4	06/03/2023	UU	Internal peer review
5	14/03/2023	DICOR/ACC	Final version following internal peer review. To be submitted to EC.

Addressees of this document

This document is addressed to the whole IDEA4RC Consortium. It is an official deliverable for the project and shall be delivered at the European Commission and appointed experts.

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ABBREVIATIONS AND DEFINITIONS

CoEs	Centres of Excellence
DIGICORE	DIGital Institute for Cancer Outcomes REsearch
EC	European Commission
EDPB	European Data Protection Board
EFPIA	European Federation of Pharmaceutical Industries and Associations
ERNs	European Reference Networks
ESMO	European Society for Medical Oncology
IDEA4RC	Intelligent ecosystem to improve the governance, the sharing and the re-use of health data for rare cancers
NLP	Natural Language Processing
OECI	Organisation of European Cancer Institutes
RCE	Rare Cancers Europe
RWD	Real World Data
RWE	Real World Evidence
SEP	Stakeholder Engagement Plan

1 EXECUTIVE SUMMARY

Stakeholder Engagement is generally recognized as a critical activity for project success. However, in order to make it relevant and impactful, it is very important to define upfront who are the actors involved, which are the objectives and the approach in relation to a specific project.

Defining the boundaries of stakeholder engagement in the context of IDEA4RC is the aim of the first chapters of this plan.

In particular, chapter 3 introduces DIGICORE, leader of WP10 and specifically of the stakeholder engagement activity, and why its expertise has been considered strategic for leading this task.

Chapter 4 outlines the engagement strategy, starting from the aims in relation to IDEA4RC objectives, and introducing the concept of 'engagement cycle' as a *modus operandi* for implementing and reviewing the strategy, in order to refine it and make it more and more effective.

From paragraph 4.2.1 to 4.2.13, the document goes into the detail of which are the categories of stakeholders that we consider instrumental to the project success, which is their interest in the project and the message we should deliver, and which will be the channels/ways we plan to pursue to effectively engage them.

Finally, chapter 5 illustrates the mechanisms that will be put in place to effectively monitor and evaluate the engagement activity, and to review the strategy in due course.

2 ABOUT THIS DOCUMENT

This document corresponds to Deliverable 10.2 of the IDEA4RC project and aims to describe the strategy that will be adopted for engaging and managing the stakeholders identified as being strategic for reaching the project’s objectives.

Moreover, this document aims to provide guidance for project partners on how to effectively engage with the above stakeholders, in order to maintain an harmonic, coordinated approach throughout all the activities.

Finally, the document sets up the framework for monitoring and evaluating the work done for stakeholder engagement, both during and at the end of the project.

This deliverable is related to “Task 10.2 - Community of interest” and is inscribed within the work of Work Package 10: “Rare Cancer Data Ecosystem enlargement and liaison”.

3 INTRODUCTION: WHY DIGICORE?

Stakeholder engagement in IDEA4RC is managed by Work Package 10, led by DIGICORE (DIGital Institute for Cancer Outcomes REsearch). In the next paragraphs we will shortly describe DIGICORE's expertise and field of action, as well as its strategic position in the context of European data sharing initiatives to support cancer research.

3.1 The network

DIGICORE is a pan-European research network built to accelerate the Implementation of precision oncology in Europe.

DIGICORE promotes and equips cancer centres in their use of routine electronic health records (EHR) and molecular diagnostic information (MDX) for trial automation, real world outcomes research, digital diagnostics and care quality management.

The ultimate goal is to shape a digital research infrastructure based on digital interoperability between its members. Network membership supports them to improve data quality and completeness, develop new data sources and tools, share digital best practices and promote novel, digitally enabled research methods.

DIGICORE is set-up as a European Economic Interest Grouping including 34 prominent European cancer centres, two cancer networks, UNICANCER and Alleanza Contro il Cancro, and two commercial partners allied in this challenge.

3.2 The strategic projects

DIGICORE support with its own budget strategic projects and training activities strictly linked with its objectives and mandate. It is also involved in several European actions as part of the European Cancer Mission of Horizon Europe and of Europe's Beating Cancer Plan.

PARTICIPATION TO EUROPEAN COMMISISON ACTIONS

IDEA4RC - *INTELLIGENT ECOSYSTEM TO IMPROVE THE GOVERNANCE, THE SHARING AND THE RE-USE OF HEALTH DATA FOR RARE CANCERS* - *HORIZON-HLTH-2021-TOOL-06*

The main objective of IDEA4RC is to establish a Data Space for rare cancers (RC) that will make possible the re-use of existing multisource health data (cancer registry data, national registries, data from biobanks etc.) across European healthcare systems leveraging emerging interoperability technologies and AI approaches.

The realised "Rare Cancer Data Ecosystem" is expected to improve the quality and the organisation of RC patients care, and to increase knowledge on rare cancers advancing health research, so that all patients have equal access to high quality specialist care.

The project approach will be experienced in the framework of the European reference network for rare adult solid cancers (EURACAN). DIGICORE is asked to participate to the creation of the Data Space with its experience on the internal Digi-ONE project.

CAN-HEAL - ***BUILDING THE EU CANCER AND HEALTH GENOMICS PLATFORM -<u>EU4H-2021-JA</u>***

Genomics plays an emerging role in clinical and public health research. Cancer is strongly driven by genomic modifications, and wide-profiling of these modifications with new technological approaches has become a major asset for (early) diagnosis, prognosis and therapy in regard to personalised medicine.

The CAN.HEAL consortium recognises that prevention, diagnosis and treatment should be approached in a concerted way for optimal benefit of patients and citizens. The CAN.HEAL clinical arm, responding to the 'Cancer Diagnostic and Treatment for All', will focus on applying 'next generation sequencing' technology and identify implementation paths in order to:

- extend the application of genetic profiling of patients and tumour cells to allow harmonized data interpretation and facilitated treatment decisions,
- apply the same or similar diagnostic and therapeutic approaches to patients with comparable cancer profiles across the EU,
- take up the molecular tumour profiling biomarkers that estimate cancer predisposition to allow better counselling of family members regarding cancer risk.

In the arm of 'Genomics for Public Health', the application of novel insights on estimating cancer risks in healthy populations by polygenic risk score analysis within population wide interventions as well as strategies of remote genetic counselling and telegenetics will be further developed.

Finally, CAN.HEAL wishes to set the framework for integrating and aligning the Genome of Europe biobanking initiative into public health genomics for cancer.

EUonQoL - ***QUALITY OF LIFE IN ONCOLOGY: MEASURING WHAT MATTERS FOR CANCER PATIENTS AND SURVIVORS IN EUROPE*** - ***<u>HORIZON-MISS-2021-CANCER-02</u>***

EUonQoL aims to develop, pilot and validate the EUonQoL-Kit, a patient-driven, unified system for the assessment of quality of life (QoL) based on evaluations and preferences of cancer patients and survivors.
The EUonQoL-Kit will be developed from a patient perspective, administered digitally, available in the EU27 and Associated countries languages, and applicable in future, periodic surveys to contribute to the EU's Cancer Mission.

At the core of the EUonQoL there is the adoption of a multistakeholder, co-design methodology, engaging patient representatives, healthcare professionals, administrators, policymakers, and citizens in all project related activities.

This review will be used in the context of the co-design consensus with stakeholders' and patients' preferences to identify gaps and establish all QoL dimensions that are relevant from the perspectives of patients, clinicians, and society.

A multidisciplinary research panel, composed by the most talented experts, will develop the EUonQoL-Kit that will be validated in a pilot survey using digital data collection within month 24 of the project. A total of 4,000 cancer patients and survivors will be enrolled through a network of EU cancer centers. An analysis of factors potentially impacting on cancer patients and survivors QoL, will also be

performed.
Implementation and exploitation strategies, as well as the linkage with other Cancer Mission projects and actions will be explored to develop future periodic surveys.

EUonQoL is composed of research institutions, cancer centres, as well as scientific, professional, and patient representative organisations, all with extensive experience and robust scientific background in the development of self-report QoL measures.

This partnership fuels the ambition of EUonQoL to translate QoL information into future changes in cancer care policy and clinical practice.

DIGICORE leads the WP5: Digital tools for data collection.

CCI4EU— *STRENGTHENING RESEARCH CAPACITIES OF COMPREHENSIVE CANCER INFRASTRUCTURE - HORIZON-MISS-2022-CANCER-01-02*

There is a large variability among (and within) MSs in the presence, functioning and performance of Comprehensive Cancer Infrastructures (CCIs).

CCI4EU solution: this Coordination and Support Action (CSA) will support MSs and ACs in improving or developing their existing or future CCIs, focussing on developing their research innovation and digital-related capacities and their integration with cancer care. A tailored Capacity Building (CB) programme should achieve that 90% of cancer patients are treated in CCIs by 2030.

CCI4EU’s main objective is to improve or develop existing or future (CCIs). This will be achieved within 3 years, through the following specific objectives:

1. To finalize a standardised matrix of cancer research/care performance indicators, and a CCI Maturity Model (CCI MM), to be used to analyse the maturity of CCIs across the EU.

2. To map the maturity of CCIs across all EU MSs according to the agreed matrix of cancer research/care performance indicators; thereby clustering CCIs according to maturity.

3. To plan a CB programme tailored to each identified CCI, and further customising tailored interventions (in agreement with the relevant public authorities), giving precedence to those MSs and ACs with absence of, or a low maturity of, CCIs.

4. To identify and coach CB subject experts to deliver the onsite tailored interventions (‘Deep Dives’) and for online lectures and 3 F2F regional conferences.

5. To execute the CB programme, covering all EU MSs and ACs at various levels of tailored intervention (all having access to online interventions, and some having onsite interventions according to a co-creation model1, reporting on the impact and recommended sustainable follow-up actions for each CCI site.

6. To disseminate and communicate to the relevant stakeholders (i.e., research and healthcare professional, policymakers, citizens including patients, patients’ associations, and informal caregivers) the CB lessons learned and best practices, to further exploit the CB beyond the project.

DIGICORE will be involved in all training activities related to its expertise in data storage and retrieval and dissemination actions.

DIGICORE SUPPORTED PROJECTS:

DIGIONE

DigiONE aims to create a federated digital research network that links routine, high quality clinical data with routine molecular data information. DigiONE started including 6 prominent cancer centres in 6 countries and will attract other cancer centres to enlarge the "mature" network.

The underlying digital infrastructure provides a minimal description of every patient's cancer diagnosis, biomarkers, treatment and outcomes in near real time relying on a Minimal Essential Description of Cancer (MEDOC) built upon consensus and aligned with international standards. It provides a minimal description of cancer from diagnosis to outcome, and includes all major research inclusion/exclusion criteria, to create a unique resource for high-quality real-world evidence (RWE) and care quality management.

DigiONE is an open innovation programme leveraging interoperability technologies (OMOP) improving primary data capture with NLP or Natural Language processing solutions. New research services will follow with high quality structured real-world data (RWD) from routine cancer care with privacy-preserving data analytics (federated AI) addressing some urgent clinical research questions that require scale.

Currently, stakeholders and researchers of DigiONE are working on infrastructure-related solutions to support federated data sharing approaches to make the data, models, or digital objects smart in their original silos.

IDEAL4RWE Leadership Training 2022-20-23

Equipping the real-world evidence research leaders of the future Outcomes research has never been more important in healthcare, and in particular in cancer care. Survival variation across countries is well documented through epidemiological registries, but the identification of actionable solutions is more challenging. Clinical trials remain of central importance but are rarely possible at a scale to address all questions of risk, prognosis, treatment and personalised care. These restrictions on research are reflected in the European Cancer Mission priorities and the funding programmes to support them. The efficient and scalable generation of evidence derived from existing data within routine electronic medical records (real-world evidence (RWE)) has a key role to play in highlighting and driving changes in clinical practice. But there is a critical skills gap - a lack of clinical researchers with the skills to scale digital methods into care systems and so transform care quality management internationally. To equip young research leaders with the skills they will need to drive RWE research in the future, including accessing funding, we have developed the IDEAL4RWE Programme, designed based on years of academic and commercial experience in delivering outcomes research in cancer.

The IDEAL4RWE training programme combines:

- An overview of the opportunities, challenges and practice of RWE in cancer
- Technical skills to realise "the art of the possible", including novel study designs and technologies.
- Strengths and weaknesses of RWE study design
- Effective hypothesis generation and preparation of funding proposals
- Research leadership skills, including self-awareness, forming teams across diverse functions and geographies, influencing systems and managing projects and budgets

4 STAKEHOLDER ENGAGEMENT IN THE CONTEXT OF IDEA4RC

The main objective of the IDEA4RC project regards the design and implementation of an EU-wide Data Ecosystem, that enables the use and reuse of quality health datasets in the rare cancers' field where – considering its specific data scarcity - the need for better data interoperation is particularly urgent.

The path towards such a complex objective has been designed throughout the project as a gradual process with two main developments:

a) In the short-term, the idea of a common Data Ecosystem will be pursued within the EURACAN network, also in consideration that 11 out of the 75 EURACAN's CoEs are already part of the IDEA4RC consortium;

b) In the medium term, the project – and in particular WP10 – will create a 'Community of Interest' (CoI), aiming at extending the Data Ecosystem beyond EURACAN to other relevant stakeholders.

Both these developments require a carefully planned engagement of relevant stakeholders, partly to actively advocate for the Data Ecosystem, but also to promote people participation in the definition and building of the architecture of the platform, in a bottom-up effort that is crucial to the success of the initiative.

Therefore, we are planning a 'two-fold' engagement strategy that will consist of both a proactive promotion of the Data Ecosystem and an ongoing feedback request about it.

Figure 1 – Stakeholder engagement strategy in the context of IDEA4RC

4.1 General aims

As a consequence of the approach above illustrated, the general aims of the stakeholder engagement activities planned within this project will be essentially two:

1) Enlargement of the Data Ecosystem

This aim will be pursued by promoting the project – its objectives, mode of operation and future benefits – with stakeholders who can potentially join the Data Ecosystem by feeding their data into it. This means, as explained above, starting with members of EURACAN and moving beyond to other CoEs.

2) Create a Community of Interest (CoI)

This aim will be pursued essentially by creating a community of stakeholders (CoI) who could be users of the Data Ecosystem in the future. These potential beneficiaries can provide an all range of feedback on different aspects of the database, offering precious insights for making it more functional.

These two aims have provided the direction to identify and prioritise the most relevant stakeholders' categories, as well as the most appropriate level of engagement for each of them.

Equally, according to the two aims highlighted above, it is possible to visualize how the identified stakeholder categories will interact with the Data Ecosystem, depending on whether they will be data suppliers, data users, or both (see Fig. 2).

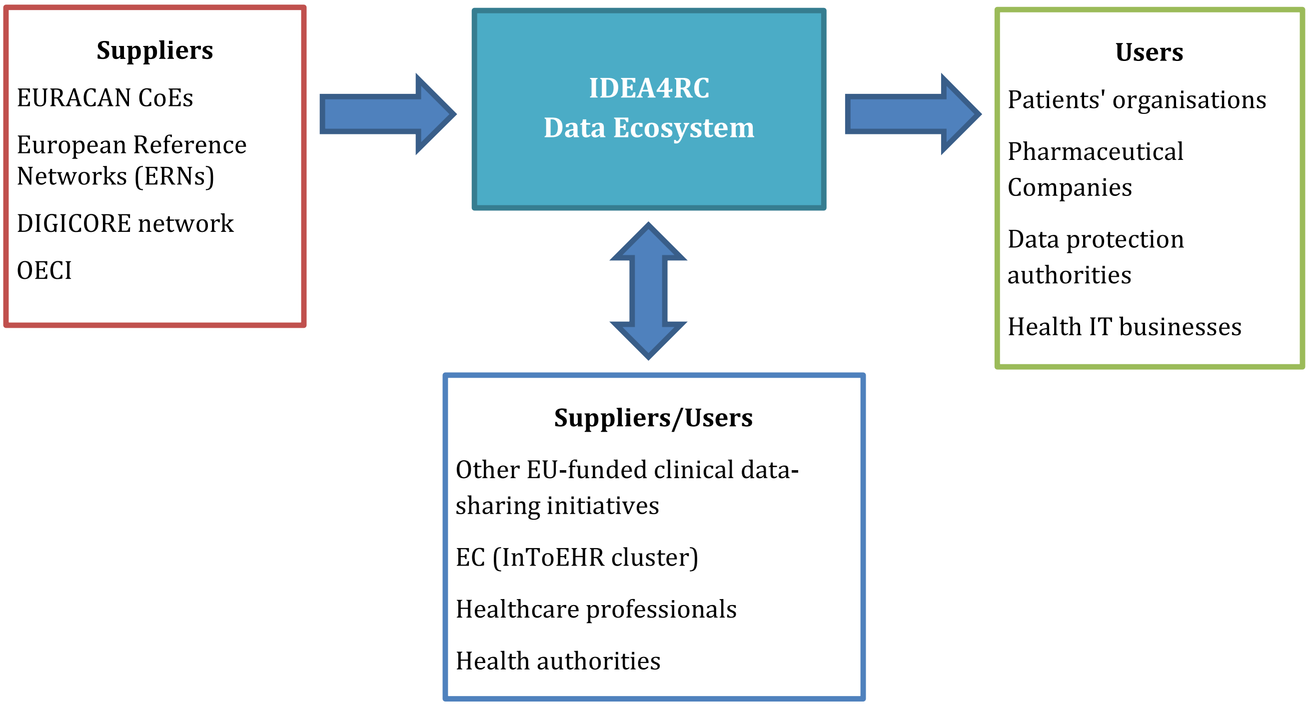

Figure 2 – Stakeholder categories' distinction between suppliers and users.

4.2 Stakeholder identification and levels of engagement

Since the beginning of the project, it has been very clear that – given the potential impacts of the Data Ecosystem, and the multi-disciplinary elements of it – the stakeholder engagement activities require a collective effort, with each partner of the Consortium providing input and undertaking their own part of engagement.

Moreover, given the structure of the project, it was also evident that stakeholder engagement has cross-cutting implications across different Work Packages' activities.

For these reasons, WP10 has started its work by gathering all the relevant feedback across the project, primarily among WPs more involved in stakeholder engagement (WP2 and WP11), but also with the rest of the consortium.

This initial effort won't remain an isolated initiative. Rather, we plan to build a 'Stakeholder engagement cycle', being conscious that our strategy will need to be verified and reviewed from time to time. In fact, it might be necessary to fine-tune the strategy in order to respond to an emerging need, to include new stakeholder categories, to narrow-down the existing one or dismiss an engagement channel in order to open a new one.

There is a further consideration that makes it necessary to establish a follow-up mechanism for this strategy: as it will be clear in the next paragraphs, some of the stakeholders we have identified are grouped in broad, complex networks. Being effective in reaching these networks requires a gradual approach, starting from engaging with those who have the responsibility to coordinate/lead the network, and agreeing with them about the opportunity and the best modality to reach the members.

Therefore, bearing in mind the above, we will follow a four-step approach:

1. Stakeholders' categories identification: we will agree with relevant WPs which are the most relevant categories of stakeholders to be approached.
2. Stakeholders mapping: within each category, we will identify the most relevant stakeholders and the most effective channels/modalities to involve them.
3. Engagement: the actual engagement will be undertaken as planned.
4. Verify and review: also in light of the feedback received, we will verify the relevance and effectiveness of our engagement, and we will refine our strategy as required.

We have represented this approach in Figure 2:

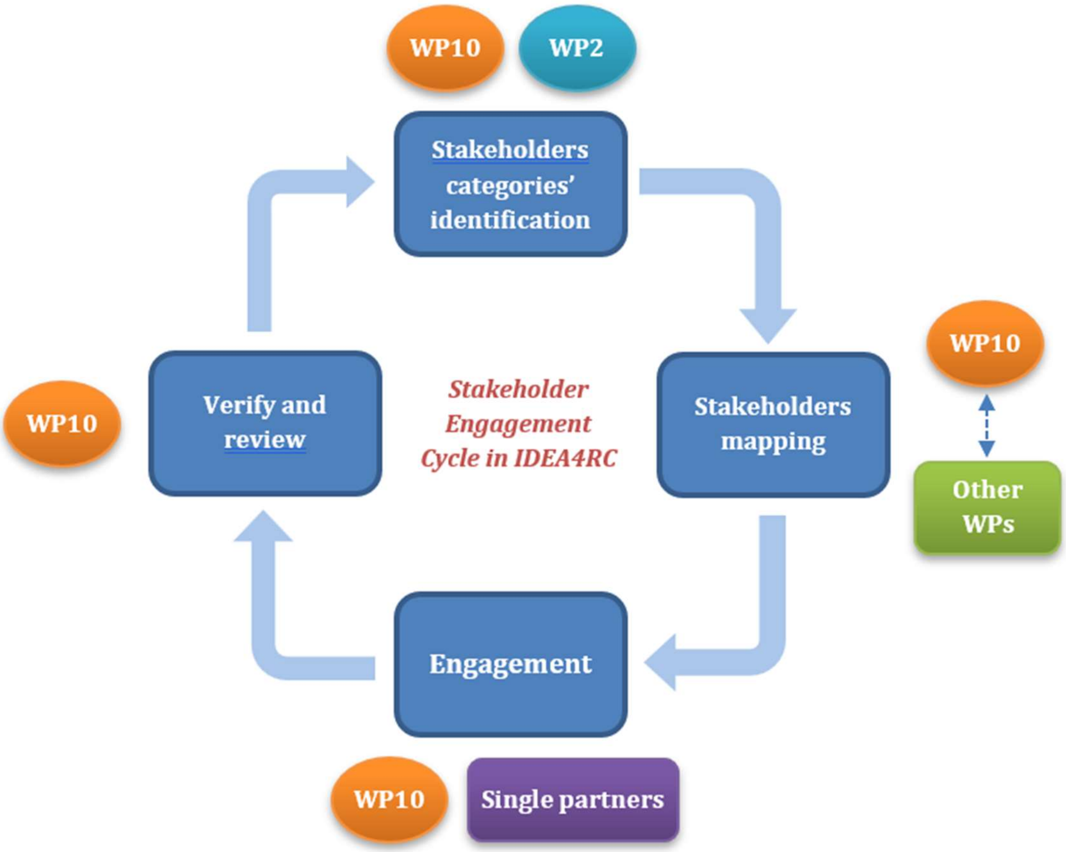

Figure 3 - Stakeholder engagement cycle within the IDEA4RC project.

As we write this plan, we have gone through the first two steps, and have also started some early engagement with stakeholders, primarily through the work undertaken by WP2. The next months will be dedicated to actually undertaking the engagement activities.

In the following paragraphs, we will go through the single stakeholder categories identified, illustrating for each of them the following aspects:

- Who they are.
- Which should be their interest in the project.
- Which will be the main message to be conveyed through our engagement.
- What type of input we might need or what we are planning to ask.
- What channels/initiatives we think might be more effective for engagement.

4.2.1 EURACAN Centres of Excellence (CoEs)

As described above, and as clearly stated in the DoA, the EURACAN Network represents the first and most logical place where to start engaging new CoEs. Partly because of the field of action of the EURACAN Centres (rare adult solid cancers), partly because 11 of them are already partners of the IDEA4RC consortium.

Through the engagement with EURACAN members, we aim at making IDEA4RC the interoperability platform of election for this ERN, that would represent the first bed test to create an EU-wide Health Data Space for rare cancers, which will collectively intercept more than 30,000 cases/year across Europe.

Who

EURACAN includes 75 cancer centres across 24 European countries. The Network also includes Associated Partners, which are European/international scientific societies, national networks and patient organisations/ePAG advocates.

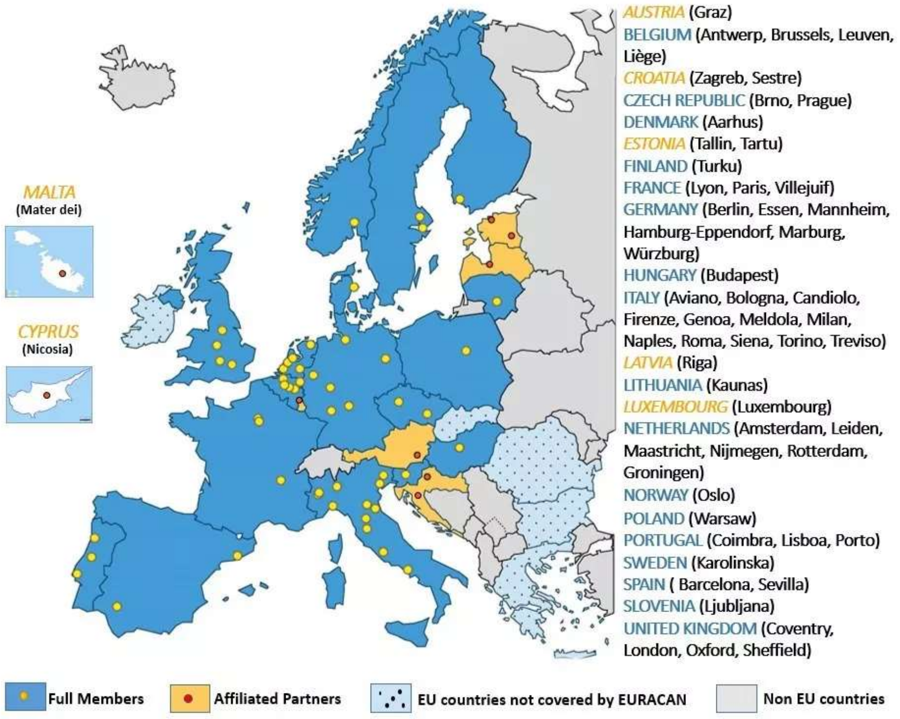

Figure 3 - EURACAN members distribution (EURACAN website);

Interest in the project

By becoming part of the project, the EURACAN CoEs would have access to a critical mass of quality data on rare cancers. In addition, their involvement with IDEA4RC could represent the occasion to strengthen the links between various CoEs, prompting new synergies to emerge, or even encouraging new collaborations between these CoEs and other stakeholders involved in the CoI.

Message to be conveyed

The engagement with this particular category of stakeholders will be two-faced. On the one hand, it will be oriented to convince them to be part of the Data Ecosystem as data providers, participating in the design of it from scratch.

On the other hand, we will focus on the advantages that such an ecosystem will bring and to the benefits for the Cancer Centres as future users.

Type of input that might be requested

Feedback on the initiative/Assessment of the level of readiness to implement the proposed model. As potential users, their feedback will be also very useful to implement the architecture of the Data Ecosystem in a direction that is more user-friendly.

Channels/initiatives

We have easy access to the general communication channels in place within EURACAN, with potential to reach all members.

However, we plan to explore with the coordinators of the network which is the best option for reaching the network members, both in terms of impact and engagement capacity.

4.2.2 European Reference Networks (ERNs)

The European Reference Networks (ERNs) are virtual, cross-border networks involving healthcare providers across Europe. The aim of these networks is to facilitate discussion and ensure better care on complex or rare diseases and conditions that require highly specialised treatment, and concentrated knowledge and resources.

If the ERN EURACAN represents the ideal starting point for enlarging the Data Ecosystem (see. §4.2.1), the other rare cancer ERNs represent the natural continuation of this enlargement effort, aiming at disseminating the usage of the tools that will be developed and experimented within the project.

In other words, through EURACAN we will test a model which will be hopefully replicable in other rare disease networks, possibly starting from other rare cancer networks: ERN PaedCan (paediatric cancers), ERN EuroBloodNet (which includes myeloid malignancies; and lymphoid malignancies), ERN GENTURIS (on genetic tumour risk syndromes).

We are aware that the willingness of the other ERNs to collaborate cannot be taken for granted, as they may have competitive interests (and this is one of the reasons why other WPs of IDEA4RC will explore incentivisation mechanisms). From a stakeholder engagement point of view, one of the goals of our initial engagements will be to better understand such competitive interests and what informs them. This will allow us to adjust our strategy for the follow-up engagement, either so as to speak to both types of interests or to highlight that those that can be achieved through collaboration will be more substantial and long-lasting.

This stakeholders' category is also relevant as the inclusion of datasets from at least one of the three other ERNs that deal with rare cancers is one of the project's KPIs for measuring the IDEA4RC impact.

Who

There are currently 24 ERNs, 4 of which are cancer related. These involve more than 900 highly-specialised healthcare units from over 300 hospitals in 26 Member States.

Interest in the project

The ERNs might be interested in the project as it has the ambition to make all available data sources on rare cancers interoperable and available, to inform the care of each rare cancer patient with the best clinical evidence contained in any available dataset.

Therefore, both accessing and contributing to the data ecosystem developed under IDEA4RC will be stressed as important opportunities to be taken.

Message to be conveyed

We will tailor separate communications to the cancer-related ERNs and to the rare disease-related ERNs. The core of the messages will regard the potential benefits both for research and for clinical practice of being providers as well as users of the IDEA4RC data ecosystem.

Type of input that might be requested

Engaging with CoEs that are part of other ERNs is potentially of great interest for the project, as they could offer insights about the actual exportability and replicability of the data ecosystem developed within IDEA4RC.

Channels/initiatives

Given the scale of these networks and in order to be effective, we envision to organise dedicated meetings with the coordinators of the ERNs and of projects in which these are involved (e.g. EJPRD, ERICA). This high-level approach will help us to understand the best strategy in terms of:

1 How/whether to reach for network members
2 Which ERNs/members to prioritise.

During the planned follow-ups of this strategy, we will consider the outcomes of these meetings and integrate them in the strategy as required.

4.2.3 European Reference Networks (ERNs)

As explained in §3, DIGICORE's core business is very consistent with the IDEA4RC objectives. This makes quite immediate the idea of involving the DIGICORE network members into the CoI of IDEA4RC.

Who

DIGICORE includes in its membership 34 among some of the most prominent European Comprehensive Cancer Centres, other than the French and Italian cancer networks, Alleanza Contro il Cancro and UNICANCER.

Interest in the project

DIGICORE is the WP10 leader within the IDEA4RC consortium.

Furthermore, the cancer centres which are members of its network can be potential users as well as providers of RC data in the IDEA4RC context. DIGICORE is also developing a core network of digitally mature cancer centres through the execution of a large project called "DigiONE", grouping six Institutions in six different European countries. DigiONE aims at establishing a federated network for interoperability of EHR, has defined a minimal data set inspired to French OSIRIS to define cancer patients, and will adopt an OMOP-based common data model for data standardization of interoperability of clinical data based on the use of OMOP for data standardization.

Message to be conveyed

The project is in line with DIGICORE's scope. In this context it will be important to assess the level of compatibility of the technical solutions adopted by DigiONE and by IDEA4RC.

Type of input that might be requested

DIGICORE members, in particular members of the Clinical Informatics Working Group and those participating to DigiONE initiative will be requested to provide their feedback about the compatibility of the architecture adopted by IDEA4RC data ecosystem, its future usability and accessibility with that of other emerging data ecosystem at the European level.

Channels/initiatives

Each institutional channel will be used, including the monthly newsletter and the social media channels, in order to promote a future active participation of the DIGICORE members to the IDEA4RC Community of Interest. In addition to this, the DIGICORE Board and General Assembly will be invited to discuss the progress of the technical development of IDEA4RC in order to verify if the outcomes could be applied to perform academic or commercial studies on non rare cancers and, in particular, if RWD could be used to produce evidence.

4.2.4 Organisation of European Cancer Institutes (OECI)

The OECI is a non-governmental Organisation founded in Vienna in 1979 and remodelled in 2005 into OECI-EEIG, an European Economic Interest Grouping.

The OECI aim is to accelerate the application of multidisciplinary personalised care approaches to reduce mortality and to guarantee an equitable access to care to all cancer patients and supporting parallel initiatives outside the EU and in other continents.

This goal is being achieved by promoting and enhancing the concept of “comprehensiveness” and “multidisciplinarity”, supporting quality in cancer care and dynamically working in crosscutting expertise.

The OECI is currently geared towards improving quality and the internal organisation of its members, supporting basic, translational & clinical research, collaborating for good practices with patients, improving molecular pathobiology approaches, performing studies on cancer economics and on real world data to produce evidence.

Who

OECI comprises 123 Members, including some of the most prominent European Comprehensive Cancer Centres.

In addition, several major cancer centres from Chile, Colombia, Jordan, Russian Federation, Tanzania, Turkey, Ukraine and Viet Nam are members of OECI.

Interest in the project

As Cancer Institutes, the interest in both contributing and accessing the data ecosystem will be self-evident. As OECI includes some of the most prominent European Comprehensive Cancer Centres, these can be very interested in the possibility of accessing a critical mass of data on rare cancers for research purposes.

Message to be conveyed

OECI members will be invited to join the CoI of the project, in particular by stressing the importance of contributing to the development of this data ecosystem and of being part of this effort from the early stages.

We will leverage the overlap between the different networks we are planning to engage with (OECI, DIGICORE, EURACAN and other ERNs) to achieve a positive 'contamination effect', thereby encouraging the participation of hitherto less active network members.

Type of input that might be requested

We will engage OECI members in order to understand whether the Rare Cancer ecosystem we are developing is of interest to join for them and which improvements we should implement to make it more appealing.

Channels/initiatives

Ad hoc contents for the OECI internal newsletter and for the OECI magazine will be created.

Furthermore, WP10 has good connections within the organisation and could potentially get some space for presenting the project during the OECI Annual Conference held in June every year. However, we'll explore together with OECI leadership whether there are strategic/more appropriate boards to get in touch with.

4.2.5 Other EU-funded clinical data-sharing initiatives

Currently, discussion about genomic/clinical data sharing (and associated ethical, legal, political, and technical challenges) is very lively within the EU scientific community.

Who

The San Raffaele Hospital - member of ACC/DIGICORE - is involved in several EU-funded genomic and clinical data sharing initiatives, namely Beyond 1 Million Genomes (B1MG)/Genomic Data Infrastructure (GDI), UNderstand CANcer (UNCAN), and European Open Science Cloud (EOSC)4Cancer. The B1MG project provided support to the 1+Million Genomes (1+MG) initiative, which set to create a network of genetic and clinical data across Europe, by establishing ad hoc infrastructures, legal guidance, and best practices, to allow cross-border access to one million sequenced genomes, including cancer genomes. The GDI project builds upon B1MG to realize the promise of 1+MG. The UNCAN initiative aims at achieving advanced cancer knowledge, and ultimately, improved cancer prevention, diagnosis, and treatment by creating a European federated cancer research data hub. The main goal set by the EOSC4Cancer consortium is to ensure transnational accessibility of various types of cancer data via federated and interoperable systems.

Interest in the project

The above-mentioned EU initiatives and projects are all linked by a fil rouge that is also shared by IDEA4RC–i.e. to ease health (especially, cancer) data sharing across Europe for improved patient care. Moreover, two of them are specifically focused on cancer. Given the common ground, this stakeholder category should be unquestionably interested in contributing to (and accessing) the IDEA4RC data ecosystem.

Message to be conveyed

If multiple ongoing efforts aim at a common objective, strategy alignment would be advisable to avoid unnecessary duplicated efforts. By sharing experiences, discussing problems and finding solutions together, we will learn from each other and move at a faster pace towards our, specific and general, goals. To this end, B1MG/GDI, UNCAN, and EOSC4Cancer representatives will be invited to join the IDEA4RC Community of Interest (CoI). Likewise, IDEA4RC would welcome the opportunity to participate in activities organized by the other parties.

Type of input that might be requested

The insights of this stakeholder category will be especially valuable in defining (and adjusting, if needed) the IDEA4RC model for the creation and accessibility of the data ecosystem.

Channels/initiatives

Alignment will require repeated opportunities for (virtual and in-person) discussion. Notably, awareness of the multiple concomitant and partially overlapping endeavours within the European Union has prompted a series of ‘synergy meetings’, specifically designed to build a map of the various data sharing-focused EU projects and initiatives. The next meeting will be held in Heidelberg on Feb 28 and Mar 1. It will be a unique opportunity to promote the IDEA4RC project thus laying the groundwork to future cross-fertilization.

4.2.6 European Commission (InToEHR cluster)

As the funding authority of this initiative, the EC is by definition one main stakeholder to be engaged.
In addition to the usual institutional channels that are in place for monitoring a EU project, including project reporting and deliverables, there is an additional channel to be considered: the “Innovative Tools for Electronic Health Records and patient registries” (InToEHR) cluster.
This cluster includes the projects that were funded under the Horizon Europe Call for proposal: “Innovative tools for use and re-use of health data (in particular of electronic health records and/or patient registries)”. It aims to harmonise the work of the funded projects towards the European Health Data Spaces and other European controlled initiatives such as 1 Million + genome, BBMRI, Elixir, EOSC, TEHDAS among others.

Who

Together with IDEA4RC, the following projects are represented: **IDAVA** (AI powered Data Curation & Publishing Virtual Assistant), **DataTools4Heart** (A European Health Data Toolbox for Enhancing Cardiology Data Interoperability, Reusability and Privacy), **eCREAM** (Enabling Clinical Research in Emergency and Acute care Medicine through automated data extraction), **RES-Q PLUS** (Comprehensive solutions of healthcare improvement based on the global Registry of Stroke Care Quality).

Interest in the project

The EC - as well as the other projects included in the cluster - have a clear interest in exchanging lessons learnt and best practices about how health data - from multiple countries - can be stored, shared, analysed and interpreted in a safe and legally compliant manner. Furthermore the EC is interested in sharing knowledge among the projects while they are running, mainly looking at proof of concept and recommendations for further detail of the EHDS regulation.

Message to be conveyed

Our participation in the cluster will be important to bring our experience and possibly to learn how particular issues are being dealt with in other projects.

Type of input that might be requested

We will participate in and monitor the work of the cluster, in order to get any useful insight that might be useful for the IDEA4RC development. We are also aligning our work with existing initiatives, especially the TEHDAS project from which we are following the initial findings on how EHDS should work and should be designed.

Channels/initiatives

The cluster is structured in four Working Groups (WG): "data quality and labelling", "data governance", "natural language processing and platform architecture" and "privacy preserving processing environments".

Channels for engagement will be the meetings organised on demand by the EC. At the moment there have been several online kick-off preparation meetings, a kick-off meeting in Bruxelles, an online meeting with EC and ERDRI Spider representatives to discuss possible collaboration, cooperation and data integration among ERDRI and IDEA4RC.

4.2.7 Healthcare professionals

This is perhaps the broader category we are planning to address, and the one where a careful prioritisation will be mostly needed.

However, as we'll see below, there are a whole range of reasons why this category needs to be engaged with from the very beginning of the project, first of all because they are among the main future beneficiaries of it.

Who

As they are a cross-cutting stakeholder category, we will engage with healthcare professionals by dealing with most of the other stakeholder's categories listed in this plan. We will encounter healthcare professionals while engaging with EURACAN, with other ERNs, with OECI and DIGICORE (e.g. the DIGICORE newsletter reaches on a monthly basis hundreds of healthcare professionals).

In addition to the above, we will also look at scientific societies which convene oncology healthcare professionals working in cancer at European level. Following the usual approach, we'll start from the federated level (e.g., we'll engage with ECO, ESMO, EACR) and proceed to narrow down the engagement area.

Interest in the project

One of the main benefits of the project for healthcare professionals will be the possibility, when the data ecosystem will be developed, to leverage "big data" AI and ML techniques for supporting clinical decision-making, as it is already happening for other diseases (including more common forms of cancers).

Moreover, healthcare professionals will also have access to quality information on rare cancers, as well as to patient data across EU centres of excellence for referral.

Message to be conveyed

The engagement with healthcare professionals will be based on enticing them to join the CoI to participate in the development of the Data Ecosystem, which will become a powerful tool for answering clinical research questions and supporting clinical decision making on RCs.

Type of input that might be requested

It might be possible to get feedback about the usability of the system and the user interface. It might also be interesting to understand how much they would trust data coming from such a system and the value they give to observational evidence in their clinical practice. This insight would be relevant in order to develop appropriate strategies to ensure/heighten the acceptability of IDEA4RC among this stakeholder category down the line, when it will be introduced into clinical practice.

Channels/initiatives

Healthcare professionals are already being engaged through the co-creation work developed by WP2. At the moment, WP2 is setting up interviews with healthcare professionals, to develop a preliminary understanding about their needs and concerns regarding IDEA4RC. The insights thus acquired will be used in the development of the activities of the first co-creation workshop in Venice (April 2023), where clinical and technical partners of the consortium will participate. We envisage conducting a number of follow-up co-creation workshops with more diverse groups of healthcare professionals from the CoEs that are currently involved to collect rich insights about their main values, needs, and incentives regarding IDEA4RC.

Finally, as WP10 will proceed with prioritising the most effective forums/boards, we will aim at engaging face-to-face with project presentations in dedicated occasions. Prioritisation will also regard the most useful categories within the broader category of healthcare professionals. For example, in the future we might decide to address nurses in particular, as they may be the ones manually inserting the data/overseeing some of it.

4.2.8 Patients' organisations

The IDEA4RC ambition is to "*leverage on rare cancer data, and on emerging interoperability technologies and AI approaches,* ***in order to improve the delivery of care, facilitate patients' information*** *and advance clinical and epidemiological research in rare cancers. [...] The 'Rare Cancer Data Ecosystem' realised in the project will improve the quality of care, patients' access to optimal diagnosis and treatment, and will increase knowledge on rare cancers, advancing clinical and epidemiological research, so that* ***ultimately all patients have equal access to high quality specialist care all over EU***"[1].

Following this ambition, which positions rare cancer patients among the main beneficiaries of the project, it comes quite naturally to include them within this plan as one of the main stakeholders' categories to engage with.

Who

Following a similar approach as the one described for other categories, we will target broad, EU-level organisations, refining the strategy in due course to reach more specific and relevant organisations. In the first instance, we will get in touch with umbrella organisations such as the European Cancer Patients Coalition (ECPC) - more than 300 cancer patients' associations throughout Europe - and EURORDIS-Rare Diseases Europe - over 1000 rare disease patient organisations from 74 countries.

We will also look at rare cancer-specific patients' groups, such as SPAEN (Sarcoma Patient European Network).

Interest in the project

Rare disease/cancer patients have a clear interest in the success of the project. Potentially, the data ecosystem developed could give them access to information regarding which/where are the best

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[1] IDEA4RC DoA, §1.1, p.3 - "*Objectives and ambition*";

Centres of Excellence for rare cancers, which is the quality of care, plus a whole range of additional information about their condition.

Message to be conveyed

Rare disease/cancer patients are very aware of the difficulties that dealing with a rare condition can generate, including the lack of easily available and high-quality information. Therefore, it will be necessary to stress the potential benefits of this initiative (i.e., finding all these information in one place), making it clear that their participation in it represents an essential condition for its success.

Type of input that might be requested

Engagement with patient organisations and representatives will be crucial to ensure that the wider data ecosystem end-user community is actively involved (and their voices heard) from the onset. We will aim to gather their feedback and recommendations – e.g., in regard to the types of data that they would find relevant to be shared, used, and re-used via IDEA4RC – and consider them into the design and development work.

Essentially, our engagement with patients will aim at answering this question: how can the data ecosystem we are putting in place help patients to better understand their disease and overcome barriers in diagnosis and treatment?

Channels/initiatives

As said above, we will look at getting into the institutional communication channels of umbrella organisations. We will also look at meetings/assemblies of cancer patients' organisations (e.s. the ECPC Annual Meeting), with a particular focus on understanding whether there are strategic boards to prioritise. In addition, once we have identified more proactive/strategic patient organisations, we will organise dedicated workshops/webinars in order to get their feedback and recommendations.

We will also look at developing specific/tailored information materials – such as flyers, website sections, videos, etc. – which hopefully will overcome potential barriers to patients' participation.

4.2.9 Pharmaceutical Companies

Given their critical role in designing clinical trials, as well as developing new treatments for rare diseases, pharma companies need to be among the stakeholders who will be engaged to be part of the Community of Interest.

Who

Initially, we will look at federated organisations, such as The European Federation of Pharmaceutical Industries and Associations (EFPIA) and EuropaBio.

We will also look at Rare Cancers Europe (RCE), a multi-stakeholder partnership coordinated by ESMO, that brings together scientific societies, patient and research organisations, healthcare and education providers, and the industry.

Finally, we will also target specific companies who develop rare cancers-related drugs.

Interest in the project

Pharma companies are potentially very interested in the project, as often - especially in the rare cancer area - they do not have the information necessary to study new drugs and/or recruit the right patients for clinical trials.

Also, the Data Ecosystem could be potentially interesting for them in view of post-authorization safety studies of orphan drugs to be developed.

Message to be conveyed

IDEA4RC can enable pharmaceutical companies to access large datasets and to develop long-term partnerships with researchers from the various CoEs involved. This will enhance their ability to develop new and effective forms of treatment for rare cancers potentially within a shorter time frame.

Type of input that might be requested

The engagement with this category will seek to get feedback on whether and how the IDEA4RC data ecosystem could enhance collaboration with industry on real world studies.

Channels/initiatives

We'll build on our good connections in order to understand which are the critical stakeholders/forums to engage with, so that we can organise face-to-face, explanatory meetings.

4.2.10 Data protection authorities

Data protection authorities monitor and supervise the application of data protection laws. Given the different types of data that will be shared, used and reused in IDEA4RC, it is important to include them in the CoI.

Who

We are currently employing a double strategy, as we are seeking to establish contacts with the European Data Protection Board as well as with representatives of national data protection authorities in the countries of the CoEs that are part of the consortium.

Interest in the project

Data protection authorities may be interested in the project, as it would enable them to understand how rules and regulations are applied on the ground, and to become aware of potential misalignments between/ challenges to align national legislation and European data protection laws in regard to different types of data.

Message to be conveyed

IDEA4RC is a pioneering effort, aligned with the proposed EHDS regulation, that can provide invaluable information on the real-world privacy and data protection issues that arise when Centers of Excellence of the EURACAN ERN make an effort to share data in order improve research and advance knowledge on the care of rare adult solid tumours (sarcomas and HNC).

Type of input that might be requested

They might give feedback about the ways in which EU data protection laws are interpreted and applied in IDEA4RC and make relevant suggestions as to changes that may be necessary or about additional aspects that should be taken into account in view of upcoming EU legislation/changes to current legislation (a main drawback is that the EDPB do not provide individual consultancy, so we'll have to frame it differently).

Channels/initiatives

We will seek to organize face-to-face meetings to engage in a dialogue with the EDPB and the national data protection authorities about the harmonization of the interpretation of relevant European and national laws and regulations and their adequate application. We are also considering inviting members of such data protection authorities to participate at broader IDEA4RC events, to have them engage in conversations with other important stakeholders, in order to facilitate a constructive and meaningful exchange.

4.2.11 Health IT businesses

Health IT businesses may have a commercial interest in contributing to the uptake and continuous improvement of the IDEA4RC technical platform.

Who
Mainly Health IT business involved in supporting interoperability of health data, including (but not limited to): data modellers, ETL script developers, database developers, providers of EHR systems, system integrators, etc.

Interest in the project
At the time of this writing, we can specify the general interests of this category of actors. Health IT businesses may find it interesting to engage with IDEA4RC, as this may allow them to develop additional components that would improve on what will be deployed during our project. They may also be interested to contribute to the development of additional technical components that ensure the interoperation of the IDEA4RC data ecosystem with existing systems for health data management, such as leading EHR systems already present in the market. Health IT businesses may also find it beneficial to develop components that further extend the capabilities of the IDEA4RC data ecosystem (e.g. ETL scripts, data navigators, AI application pipelines, NLP language models addressing more languages beyond those targeted in the project, etc.). Furthermore, they may also want to cooperate with relevant IDEA4RC partners to deploy the IDEA4RC technical approach into other contexts, with similar data sharing needs as EURACAN (e.g. other ERNs, as mentioned in other parts of this document).
Further detailing of this list will be achieved while working in the project, as the technical architecture of the project will be established in T2,3, and as first technical components are developed and demonstrated.

Message to be conveyed
Follow up the technical advancement of the IDEA4RC project, in order to spot opportunities to offer your products, services and/or expertise to the service of health data interoperability for rare cancers, also in view of the future development of EHDS.

Type of input that might be requested

They might be consulted about the technical demonstration of project components and of the data ecosystem technical platform as a whole. They may also provide feedback about the components' API documentation and help in the identification/selection of relevant use cases for further technical improvement of the IDEA4RC data ecosystem.

Channels/initiatives
Channels to get in contact with Health IT businesses include Industry's specialised press, specialised trade fairs, professional social media channels (as LinkedIn), workshops with promising prospects.

4.2.12 Health Authorities

Health authorities are involved as managers and/or policy makers in healthcare provision.

Who

Health authorities that manage healthcare provision on a certain territory and are tasked with health policy making, including healthcare resource allocation. In light of the inclusion of pharmaceutical companies in our community of interest and given the potential of (re-)using data via IDEA4RC to develop in time new forms of treatment or to repurpose existing ones, we are also planning to engage with the EMA. We deem this fruitful given the upcoming regulation on Health Technology Assessment, which requires the EMA to closely collaborate with regional and national HTA bodies when making decisions about financing and reimbursement.

Interest in the project

Depending on the type of health authorities and their responsibility in health management and policy making within the regulatory context of their country - which has to be investigated in the frame of WP2 co-creation activities - interest in the IDEA4RC endeavour may be multifarious. The health authorities' engagement with IDEA4RC may contribute to the promotion of data sharing in the territory of their remit. It may also help them assess the potential future impact of the EHDS regulation, to which IDEA4RC is striving to align. Health authorities may further be interested to use data from the IDEA4RC data ecosystem to support the assessment of quality of care, the optimal allocation of resources, healthcare provision policies and planning (particularly in the area of rare cancers and rare diseases). They may also find it relevant to know more about the practices and approaches of their homologues in other countries, as this may allow them to improve their own strategies and approaches.

Message to be conveyed

Corresponding to the specific interests above mentioned, different types of messages can be delivered to health authorities. It will be highlighted that IDEA4RC provides a context conducive to fostering health data sharing, which can improve healthcare on each health authority's territory. IDEA4RC also provides a platform that can be used to inform data-driven decision making and policy making. It also offers a window on what the future application of the EHDS may entail in their territories.

Type of input that might be requested

Mostly, the results of the co-creation activities conducted in WP2 will provide the fundamental input that is needed to effectively address this stakeholder category. We aim to identify what incentives are necessary for health authorities to adjust the distribution of human and material health resources in ways that better do justice to the different types of research, technical, clinical, and data work conducted via IDEA4RC and that can enhance the sustainability of this data ecosystem. We would also like to identify the types of data health authorities would find most useful for the development of health policies focusing on rare cancers (and rare diseases). In due course, the input of relevant health authorities on the new statistical methods and models which may be developed by researchers using IDEA4RC and which are bound to perform better on small populations and these health authorities' willingness to engage with evidence thus generated will be highly valuable. It would also be useful to better understand if and under what conditions health authorities may be willing to allow some of the relevant population data they hold to become accessible via IDEA4RC.

Channels/initiatives

We will engage with health authorities via the specialized press and trade fairs. We will also participate in workshops and other events dedicated to healthcare policies and management. We are also considering organising a dedicated IDEA4RC forum 1-2 per year with representatives of health authorities, pharmaceutical companies, data protection bodies, health IT businesses, ERNs, legislators, etc., in order to update them about the progress made, and to invite them to give presentations on aspects of their work that may be relevant.

4.2.13 Additional stakeholder groups

Whereas the stakeholder groups discussed above are necessary to first include in the IDEA4RC CoI, we are also considering categories for inclusion at a later stage, such as NGOs, trusts, and foundations, which sponsor research and/or the development and maintenance of data registries.

These stakeholders may be interested in IDEA4RC as it would allow them to identify relevant researchers in the field of rare cancers, and to become faster aware of research opportunities they could contribute to. Those who focus on data registries could learn from the data governance approaches used in the project and from the practices of data collection, standardisation and secure storage.

Decisions about when and how to engage with these stakeholder groups will be made in future follow-ups of the strategy.

5 STRATEGY REVIEW: EVALUATION AND MONITORING

As clearly represented in the previous paragraphs, we have approached our stakeholder engagement strategy by considering first of all our strengths in relation to our objectives. We started from the consideration that we already have 11 out of the 75 EURACAN Centres within our consortium, therefore looking at EURACAN as the first, more natural place to start enlarging our CoI.

We also considered the strategic position of DIGICORE as a network of institutions that consider data sharing and re-use as a crucial priority (see § 3). This strategic placement allows us to take advantage of many good connections at EU level, especially with broad, cross-border organisations with whom DIGICORE get in touch quite frequently.

However, this is to some extent also a potential risk for the work we have to do. We are very conscious, in fact, that the type of commitment we hope to obtain from our stakeholders - to take part in the CoI both as users and contributors - requires a type of engagement as specific and personalised as possible. In other words, using high-level institutional communication - such as conferences, newsletters or magazines - might be useful but it is not enough. It is also important to set up chances for a ‘live engagement’ - webinar, workshops, face-to-face meetings - possibly with a relatively small number of people involved. It is clear that such an engagement is very time and resource-consuming, and that is why we consider crucial a progressive prioritisation in order to understand who are the most important stakeholders to engage with directly.

This is the reason why, for each stakeholder category, we envisage an initial contact with relevant networks/high-level organisations, with the aim to explore which are the best/more strategic forums to be prioritised, where the engagement is more likely to be effective and to produce a real commitment.

This progressive refinement of the approach will be reflected in the periodic strategy follow-ups, that we plan to carry out at least on a six-monthly basis (Fig. 4).

Following the logic of the “engagement cycle” (see § 4.2), these follow-ups will be also useful to evaluate the work done and improve the approach as required. This might mean, for example, to identify a new category, or to change/add a new engagement channel, taking also into account the feedback that we receive from the stakeholder that we engage as well as the potential problems or complexities that might arise from initial engagements..

This way, the strategy review and the actual stakeholder engagement implementation will feed each other, so that - from cycle to cycle - we envisage to improve the efficacy of our engagement strategy: the Gannt chart represented in figure 4 visually illustrates this approach, and we anticipate we will be populating it more and more as the project progresses.

Furthermore, in order to support the strategy delivery, we have also established a set of KPIs - reported in Table 1 - to help an effective monitoring and evaluation of our work.

Finally, this continuous monitoring of the strategy will feed into a series of stakeholder engagement progress reports, to be issued at the end of each year of activity, where we will capture both quantitative and qualitative information. The reports will include the account of the work done, as well as reflections about the activities that seem meaningful for those engaged, the feedback/insights received, the strategy changes agreed and the status of the KPIs.

Table 1 - Stakeholder engagement KPIs:

KPI	Target
No. of SE reports issued	4 by the end of the project
No. of SE strategy follow ups	Minimum 6 by the end of the project
No. of webinars/workshops with strategic stakeholders (e.g. healthcare professionals, cancer patients, etc.)	6 by the end of the project
No. of strategic meetings with network coordinators/senior leaders of cross-border/umbrella organisations	At least 6 by the end of the project
No. of IDEA4RC-related news included in newsletters/internal comms of target organizations	10 by the end of the project
No. of IDEA4RC-related contents (web pages, flyers, information materials) - tailored for specific stakeholder categories - produced.	5 in total by the end of the project

Figure 4 - IDEA4RC Stakeholder Engagement Gannt chart