

BOOKLET

Best Practices on Health Data

A SHOWCASE OF EXAMPLES,
APPROACHES AND PLANS FROM
REGIONAL AND LOCAL HEALTH
AUTHORITIES IN EUROPE



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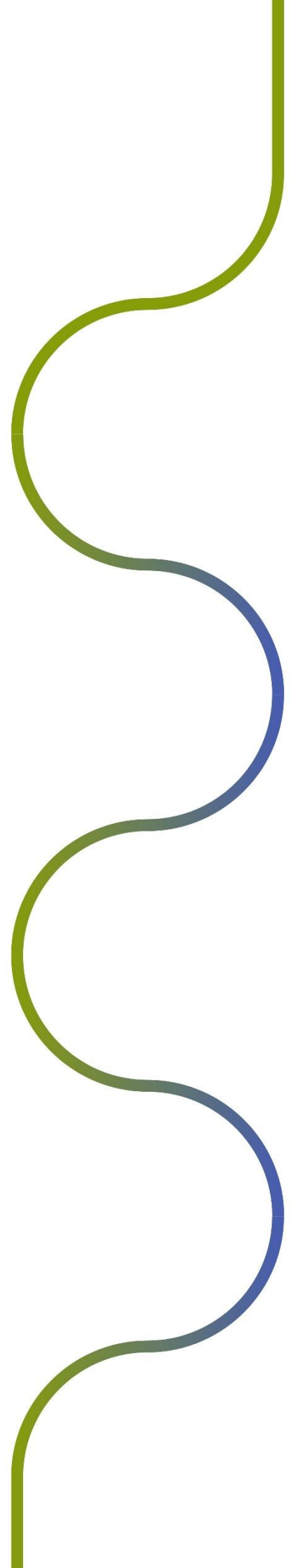
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INTRODUCTION

The health and care systems are in constant evolution, and the digital transition represents a crucial component of this transformative process. Fast-tracked, put under a spotlight during the COVID-19 pandemic, and further driven forward by initiatives such as the [European Health Data Space](#), digitalisation is front and center in the planning and implementation activities of all actors involved in the organisation of health and care, with regional and local health authorities at the forefront of this process in several countries across Europe.

With this booklet, published in its first version in December 2023, EUREGHA – the reference network for regional and local health authorities across Europe –, intends to collect and present a series of 13 important practices from its members, covering different levels of implementation and target areas in the field of health data and digital health. The booklet showcases how regional and local health authorities have been already extremely active to tackle digital health and health data challenges and highlights once again the importance of learning from their experience to further build other local, regional, national and European frameworks.

To this end, the booklet is organised in three key clusters of practices depending on their target and approach:

- **National and regional strategies**
- **Practices on telemedicine / telehealth**
- **Practices on health data use and/or collection**

For each practice, in the booklet it is possible to retrieve key information such as summary recap, description of the practices' key components, methodologies and processes, core challenges, transferability potential to other regions and local authorities, and sets of key learnings from the implementation of the different initiatives.

To know more about the practices, for each contribution it is also possible to retrieve key contacts and additional reference, through which you will be able to gather further insights.

NATIONAL AND REGIONAL STRATEGIES

BASQUE COUNTRY

E-Health strategy of the Basque Country



Implementation status:

The Basque Country has fully implemented the strategy for health data use.

Summary:

The Basque E-Health Strategy Care intends to improve health and quality of life of the population, enhance the health system quality, efficiency and sustainability and the collaboration with social services and the Community. The approach focuses on digitally enabled integrated care and patient/citizen empowerment, by means of new organisational models and processes supported by digital tools and analytics.

Description:

Deployment of integrated communication and information systems

The Basque Healthcare Service, *Osakidetza*, has made great investments in digitalization and E-Health. As a result, several services to **support integrated care and interoperability** between communication and information systems have been implemented that enable non-face-to-face care focused on prevention, monitoring, and health advice.

The Information and Communication Technology (ICT) platforms and communication channels align actions, avoid duplication of efforts and bridge gaps in patient care. Nowadays, in the Basque Healthcare System various relevant tools that support integrated care are implemented, see *Figure 1*.

The Unified Electronic Health Record (*Osabide Global*)

Osabide Global is a single electronic health record (EHR) that provides unified and shared clinical information and is accessible to all HCPs. 100% of *Osakidetza* centres have implemented and deployed the EHR (including hospitals and primary care centres). The tool contains **all health-related information of patients** such as: appointments, fact sheets, recommendations, informed consent forms, social care history, pending tasks, reports, stratification scores, clinical data, diagnostic tests, etc.

It greatly facilitates the care service, and it enables the provision of new forms of healthcare such as tele-consultation between primary and specialized healthcare. In addition, *Osabide Global* interoperates with hospital Healthcare Information Systems.

The EHR was introduced in the Basque Healthcare Service around 1998 thanks to two strategic projects: *Osabide-AP* aimed at Primary care and *e-Osabide* for hospitals aimed at erasing all existing barriers between the organization of services, centres, and care levels at that time.

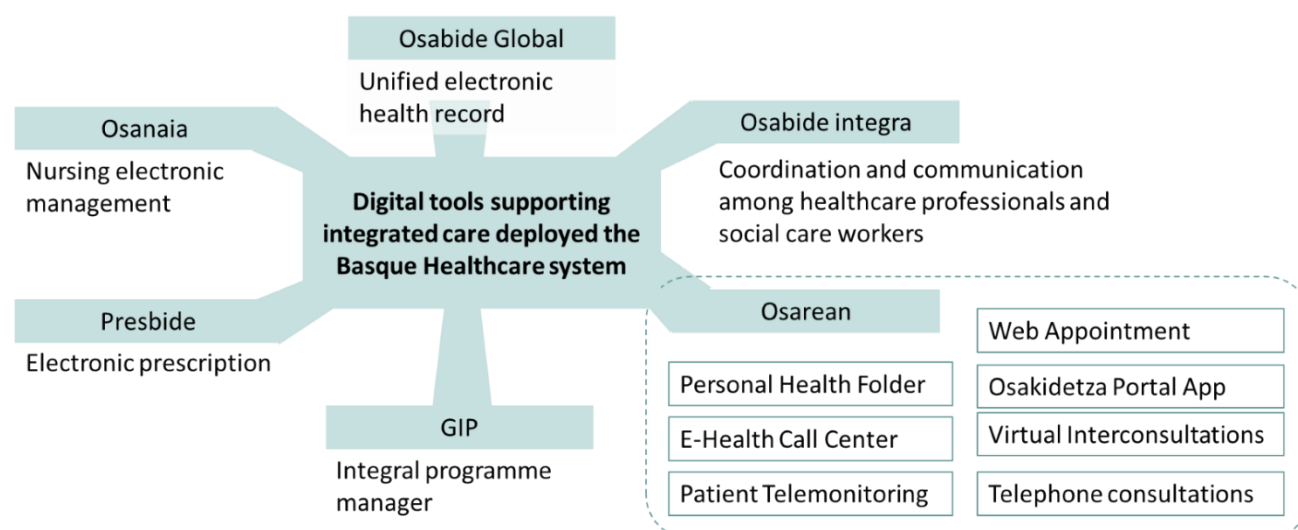


Figure 1

Once all systems were renewed, both at the Primary care and Hospital level, in 2009 it was decided to move a step forward regarding EHR in the Basque Country. This new era increased greatly the quality of the existing systems and works mainly in two areas:

- The **elimination of all existing organizational barriers**, so that all professionals involved in care share all the existing information of patients supplied by communication mechanisms in real-time.
- The **development of patient interaction mechanisms** beyond face-to-face consultations: telephone consultation, email, videoconference, etc.).

The patient-centred approach of *Osabide Global* has significantly contributed to the care continuum and allowed to overcome the previously existing barriers between different areas and levels of care. *Osabide Global* interoperates permanently and very intensively with hospital healthcare information systems (HIS), called *e-Osabide*.

Nursing electronic health record – *Osanaia*

Osanaia is the tool created for the management of nursing care, allowing to set and manage personalized nursing care plans for patients. It integrates information from primary care, specialized care, and mental health.

Electronic prescription (*Presbide*)

The electronic Prescription service, *Presbide* has also been deployed and integrated as a module within the EHR systems (*Osabide*) and is operating in all the pharmacies in the Basque Country. The e-prescription involves the integration of all pharmaceutical supply procedures: prescription, permission, dispensing and invoicing, based on information technologies. It allows switching from the old concept of the pharmacist's prescription to the establishment of **integrated pharmacotherapeutic plans**, particularly relevant for chronic illnesses due to the existence of multimorbidity, complexity and long duration of pharmacological treatments. Both primary and secondary care health professionals have access to the same information about the patient's pharmacological treatment, which improves drug management. This system has been implemented in 100% of *Osakidetza* centres as a module within the EHR system.

Virtual *Osakidetza* (*Osarean*)

It is the multi-channel Healthcare Service Centre of the Basque Country that increases the number of interaction channels of the Basque citizens with the health system. It includes the following services: Personal Health Folder, Call Centre, Patient Telemonitoring, Web Appointment, *Osakidetza* Portal App, Virtual Interconsultations, Telephone Consultations.

Personal Health Folder (PHF)

The PHF allows patients to have safe access to their medical records and enables communication with HCPs, thus providing new non-face-to-face communication channels and allowing patients themselves to enrich their medical records. The PHF services can be grouped into four main areas:

1. Consult and retrieve information

- Filiation data. The basic data of the patient is shown as well as the HCP assigned. Fields that can be updated by the user are also shown, such as telephone and e-mail.
- My clinical history. This includes discharge reports, primary care reports, laboratory reports, radiological tests and surgical reports, the vaccination history, dosimetry (radiation received from Computed tomography (CT) scans) and active treatment sheet (from where the Sintrom dosage pattern can be accessed in case of use). A QR code with a summary of the medical history can be also downloaded.
- Upcoming appointments. The patient can consult the pending appointments at both Primary and Hospital Care.
- Surgical waiting list. Once included in the waiting list, information is displayed. This information can also be directly asked to the Patient Care Service by e-mail directly from the PHF.

2. Enrich the medical history

- Self-tracking programmes. Tobacco and alcohol consumption, weight control and blood pressure.
- Uploading of documents. Patients can upload health reports in their EHR after validation of the HCP.

3. Interaction with the healthcare system

- Patient diary. This is a one-way channel where patients can write down information about their state of health on a daily basis when HCPs ask them to do so. This information is automatically included in their EHR. HCPs scan monitor patients' status thanks to the information included and by means of dedicated forms.
- Messages to the patient. This is another one-way channel, in the opposite direction to the above, where the professional contacts the patient to send information, recommendations and adjustments to the treatment. It enables a closer relationship between the HCP and the patient.
- Doubts with your doctor. This is a two-way non-face-to-face channel. The HCP must authorise the patient to solve his/her doubts through the Health Folder for primary and/or specialised care. The patient writes down his/her doubt and the HCP sends the answer after accessing the virtual appointment created and visualising the data. Later, the patient receives an email confirming the answer from the HCP.

4. Allow access of third parties to the Health Folder: Parents, Legal Guardians and Authorised Persons.

The initial aim of the PHF was to give access only to the holder of the folder, who is over 16 years of age. However, as a consequence of several requests for access from duly accredited and authorised third parties, a new function was developed to allow these accesses directly from the PHF itself in the following cases:

- Parents and Legal Guardians. Given that the parents have the parental authority or the document of guardianship, as appropriate.
- Representatives of legally incapacitated patients that hold the corresponding document.
- People of legal age when authorised by the holder of the Folder.

In 2021, the number of accesses to the PHF was 570 which meant a 26,18% increase over the previous year. The number of people using the PHF in 2018 was 62,28, a 20,73% increase over the previous year¹.

e-Health Call Centre

It is a non-face-to-face care service provided by nursing professionals (approx. 23 nurses) 24 hours a day, 365 days a year) that includes:

- Direct telephone attention for people calling the free telephone number 900203050. These services include recommendations for common health problems that do not require the intervention of a HCP, solving doubts and offering the most advisable guidelines according to the symptoms. The professional answering to the call has access to the Clinical History of the caller to individualise the advice.
- Monitoring of chronic patients included in various ICT-based programmes (Tele HF, Tele COPD, Pluri-pathological patients, Palliative patients)
- Patients with Teleassistance (*Beti ON* programme, explained later). This is a socio-healthcare collaboration.
- Various health programmes:
 - Monitoring of Major Outpatient Surgery patients
 - Support for Advanced Practice Nurses
 - Support for Home Hospitalisation
 - Follow-up of patients on discharge from hospital
 - Suicide prevention
 - Monitoring of Palliative Care Patients at home
 - Monitoring of patients in the ICHOM program- Quality of Life STROKE and Prostate Cancer Programme.
 - Notification of deaths to the health centre out of their working hours or on public holidays

Patient Telemonitoring

At-home Patient Telemonitoring is a new form of healthcare that integrates the information of all telemonitoring devices and sensors that measure patients' clinical parameters at home, facilitating patient follow-up, care adherence and enhancing patient-professional communication. In 2020, there were around 14,306 patients² in *Osakidetza* included in the following Telemonitoring Programmes:

- Telemonitoring of patients with Defibrillators, Pacemakers and Holters
- Telemonitoring of HF patients
- Telemonitoring of HF patients 72 hours after discharge from hospital
- Telemonitoring of COPD patients
- Telemonitoring of Pluri-pathological patients
- Telemonitoring of patients with oral anticoagulation (OAT) treatment. This is done through two sub-programmes: nursing homes and self-monitoring at home.

Osakidetza Portal APP

The *Osakidetza* App is a digital tool focused on citizen empowerment. The following apps can be found and downloaded from the *Osakidetza* Portal app:

- Accessing to PHF

¹ Osakidetza Transparency portal, available at: <https://www.osakidetza.euskadi.eus/transparencia-buen-gobierno/-/presupuestos-y-contabilidad/>.

² Osakidetza: Balance of activity and waiting lists 2020. Available at: https://www.osakidetza.euskadi.eus/contenidos/informacion/osk_corp_informacion_sanitaria/es_def/adjuntos/listas_de_espera/Balance-de-actividad-y-listas-de-espera-2020.pdf

- Access to My Treatment-Electronic Pillbox
- *Osasun Eskola* (School of Health, explained later)
- Messages to the patient
- Recruitment lists
- Cardiopulmonary reanimation
- Web Appointment

Virtual Interconsultations between General Practitioners and hospital doctors

Nowadays professionals can consult each other about a patient's case through Virtual Interconsultations avoiding the need of patients going to the hospital. In 2020, 62% (351,338) of the 565,620 Interconsultations between GPs and hospital doctors were non-face-to-face³.

Telephone consultations

This is considered as a highly value-added service for the population. In Primary Care, patients can request telephone consultations on their own at the health centre, by telephone and online through the *Osakidetza* website. In 2018, general practitioners made 1,647,403 telephone consultations and paediatricians did 207,738. In Hospital Care, telephone consultations are indicated by HCPs for the follow-up of chronic patients. In 2018, 300,040 telephone consultations were made in hospitals.

Interoperability between social and health information systems (*Osabide integra*)

A coordination model between health and social institutions has been developed, based on the harmonisation of the policies of both fields.

InterRAI-CA started in 2011 as a research project with the aim of identifying and validating an instrument to establish a common language for the social and health sectors and enable the joint assessment of people with social and health needs. The deployment of InterRAI-CA started in January 2016 led by Basque Country Social-Health Coordination Team. It had a **multidisciplinary approach** as its use was focused on professionals of primary care and social services, mainly doctors, nurses and social workers. It involved the deployment of a **coordinated action** of Social and Healthcare professionals, 48 Municipalities, 92 Health Centres, 3 Provincial Councils, 1 Private Entity and 3 regional organizations dependent on the Basque Council of Social and Healthcare. Nowadays, 458 InterRAI-CA licences are implemented throughout the health and social system of the Basque Country (primary care centres, hospitals, City Halls, nursing Homes, etc).

The coordination of Social and Health at local level in the Basque Country is also promoted by linking Social and Healthcare teams and allowing the access of Nursing Homes to the *Osabide Integra* platform, including EHR.

In this framework, it must be also mentioned that the Ministry of Employment and Social Policies of the Basque Country implemented in 2011 the telecare service called **BetiON**. It integrates the information of **all telemonitoring devices and sensors** that measure patients' clinical parameters at home, facilitating patients' follow-up and care adherence and enhancing the communications between patients, HCPs, and social care professionals. Furthermore, it has a central call centre that received 321,408 calls and made 969,664 calls in 2018. Operators can activate services entrusted to the eHealth Call Centre, such as telemonitoring or emergency department. Finally, as mentioned in the chapter above, the main evaluation tool of the Basque Healthcare system is the Framework Contract. The Health and Social coordination of the IHOs are also assessed through this tool.

³ Osakidetza: Balance of activity and waiting lists 2020. Available at: https://www.osakidetza.euskadi.eus/contenidos/informacion/osk_corp_informacion_sanitaria/es_def/adjuntos/listas_de_espera/Balance-de-actividad-y-listas-de-espera-2020.pdf

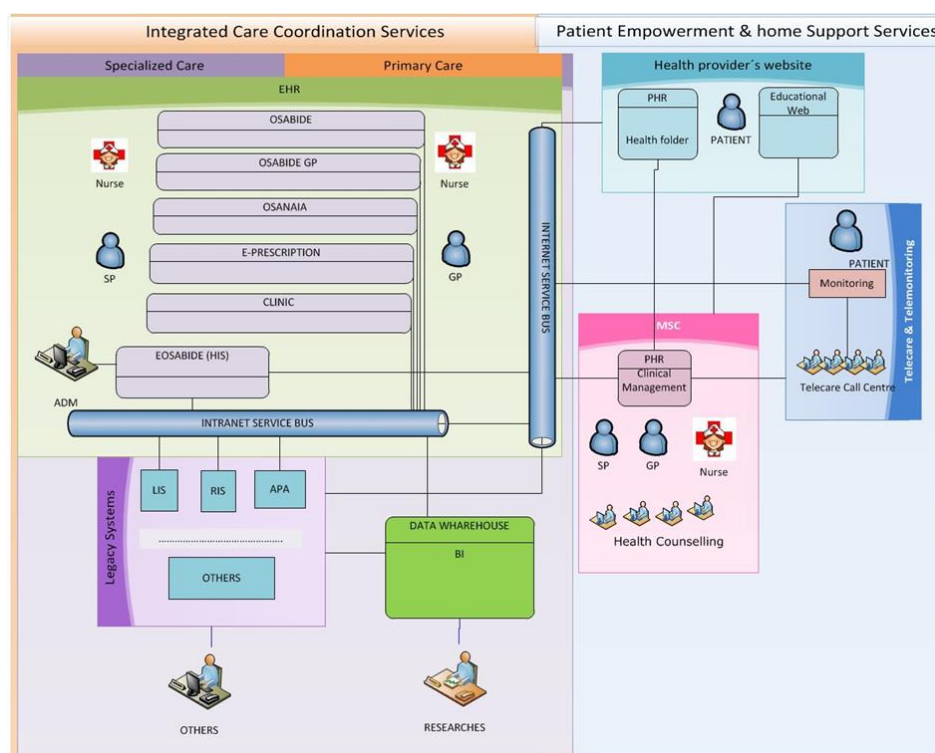


Figure 2 - The Basque Healthcare System architecture

Methodology and processes:

Problem/challenge description

The response to the needs of people with chronic illnesses has become the principal challenge faced by the Basque Healthcare System. These pathologies have multiple impacts: they represent a considerable restraint on life-quality, productivity, and the functional state of patients; they exert a strong influence on morbidity and mortality rates; and they accelerate the increase in health and social costs, which compromises the medium-term sustainability of the healthcare system.

Progressing in this area demands a change in the existing conceptual frameworks where curing and caring take place and that are clearly outlined in the current health and social policies. The individuals and their environment, their health and their needs have become the central focus of the System at the expense of merely treating the illness.

Chronic conditions generally lead to a greater risk of incapacity and mortality in individuals. Moreover, some chronic pathologies are notoriously disabling. This close relationship between chronic illnesses and dependence is the determining factor when prioritizing and identifying the most suitable health and social policies.

In addition, chronicity implies a challenge to the quality of care provided, as people with chronic illnesses are more likely to not receive optimum care and to suffer adverse pharmacological side-effects.

Furthermore, the challenge of chronicity requires proactive measures to combat the health factors that cause them. Hence, the **importance of anticipation**, set up a framework of action which reduces its emergence and progression employing awareness and preventive actions.

To summarize, chronicity is a global challenge for the systems and consequently requires a systematic response. Beyond particular illnesses of specific groups of patients, it is a challenge which must consider the structural conditions and the lifestyles that cause them and the social and health requirements of the chronic patients and

their carers: from the initial stages up until the care provided during the final phase of life, including all aspects of care, convalescence, and rehabilitation.

Chronic patients tend to slip under the radar of the health system because for decades the system has been focused on rescuing and saving lives, thus, concentrating on acute illnesses. The increase in chronic illnesses makes it necessary to **consider caring as well as curing**, having a system that offers continuity of care throughout a person's life, with the added potential of preventing unnecessary hospitalizations and thus reducing costs.

The key factors in the interventions in chronic procedures are different to those for acute illnesses, whatever the particular illness. They are the following:

1. They require a complete diagnosis of the patient including their social situation and their role as opposed to a traditional diagnosis focused on the illness and the acute symptoms.
2. Proactive, preventive (primary and secondary) and rehabilitation interventions are more important than a typically curative focus on the acute illness.
3. The patient and the carer play a much more important role in the successful outcome of the intervention. They need to change lifestyles and adhere to these over long periods in contrast to the traditionally passive role of the care receiver.
4. They require a coordinated approach to care with an "individual vision" at all levels of care (primary, specialized, medium stay, mental health, emergencies, social services, health at work, etc.) throughout the duration of the illness as opposed to a rapid action of a limited number of specific departments.
5. The needs and priorities (medical but also emotional, social, material and even spiritual) of each patient are given more importance considering that we are often dealing with continual interventions over the remaining lifetime of an individual compared to a specific intervention which has a limited impact on a person's quality of life in the mid-term.

These differences in the focus of the interventions are such that the phenomenon of chronicity requires a model of care different to that typically used for acute illnesses⁴.

General purposes of implementation

Having a clear strategic vision⁵ to face the challenge of ageing, chronicity and dependency has provided explicit support, leadership, and capacities to transform the health system towards integrated care in the Basque Country.

An integrated care strategy has been deployed, focusing on clinical and functional organizational integration. It deploys an **integrated care model** capable of providing **continuity of care both at the health and social care levels**. To this purpose, several processes and tools have been developed and implemented.

The aim of the new provision model in the Basque Country is to meet the current needs of the population, more efficiently with a **population-based approach**. To this end, it has been necessary to reconfigure and redistribute resources, gradually shifting them towards the home/community level and to primary care, whose decisions and proposals must be formulated locally.

This model is possible thanks to the tools already implemented and deployed over the years, which allow for the monitoring of complex and stratified patients in places other than the hospital, thus promoting personalized care for patients and their families in their environment. Incorporating follow-up activities, monitoring, and stabilizing the patient at home promotes the avoidance of admissions and, as a consequence, frees up hospital space. Likewise, over the years, alternatives or new modalities of hospitalization have been promoted, that are more cost-effective and satisfy both patients and HCPs (e.g., home hospitalization).

⁴ Strategy to Tackle the Challenge of Chronicity in the Basque Country, 2010

⁵ http://www.euskadi.eus/web01-s2osa/es/contenidos/plan_gubernamental/xleg_plangub_13/es_plang_13/index.shtml

This type of decision, which mostly affects the **organization of processes** and the **redistribution of resources** (gradually transferring activity to the community) were defined and implemented by the professional teams and local managers of the Basque Country's Integrated Health Organizations (IHO).

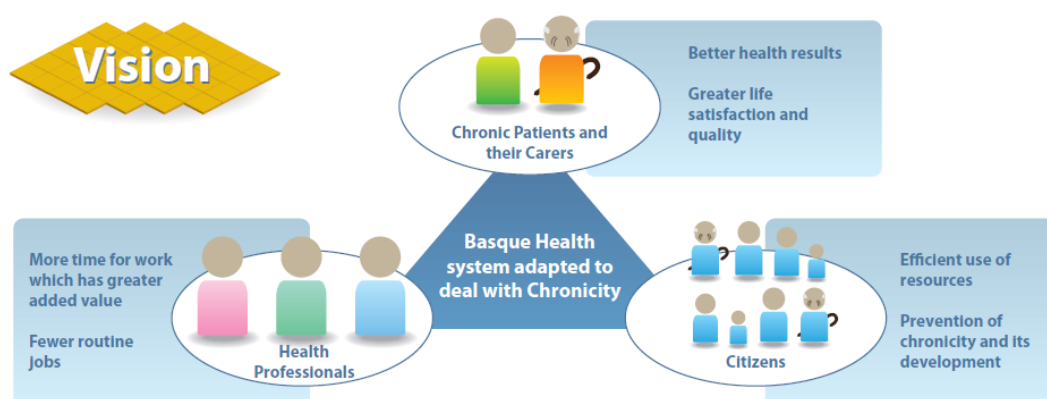


Figure 3 - Vision of the Basque Country to tackle chronicity

Involvement of other organisations/actors:

The main actors in the deployment of the integration model are the Ministry of Health of the Basque Government, represented primarily by its councillors in the last decade, and *Osakidetza* (the Basque healthcare public provider), represented by its general directors.

In addition to these two main actors, the good practice has been promoted and sustained by four main figures:

- Basque Foundation for Healthcare Innovation and Research (BIOEF, for its acronym in Spanish), through the Innovation and Management Department,
- *Kronikgune* Institute for Health Services Research and
- Basque Foundation for Social and Healthcare Innovation

The aim was to reach the necessary alignment between local and corporate levels, seeking a better distribution of leadership where the central management created the conditions to promote organizational innovations inspired by local management and health professionals themselves. The local arena will be the place to find the necessary innovations⁶. A major effort was made to **encourage a different type of leadership and to engage HCPs and staff**⁷. Optimal collaboration and coordination between professionals in the delivery of integrated care have become essential requirements for the provision of high-quality care⁸.

Funding source(s) of the initiative:

The Basque Country's e-health strategy has been a national commitment for more than 10 years and the source of funding has been the Basque public health service - *Osakidetza* and the Department of Health of the Basque Government. This approach ensures the sustainability and evolution of the strategy, which does not depend on specific project funds.

Innovation, Impact and Outcomes:

The greatest impact to be mentioned is that the technological solutions that make up the Basque Country's eHealth strategy have a wide reach, i.e., around 30,000 healthcare professionals use the tools (EHR, e-prescription) in their

⁶ Department of Health. A strategy to tackle the challenge of chronicity in the Basque Country. 2009. <http://cronicidad.blog.euskadi.net/descargas/plan/ChronicityBasqueCountry.pdf>

⁷ Bengoa R. Transforming health care: an approach to system-wide implementation. *International Journal of Integrated Care*. 2013;13(3): None. DOI: <http://doi.org/10.5334/ijic.1206>

⁸ Mays GP, Au M, Claxton G. Convergence and Dissonance: Evolution in Private-Sector Approaches to Disease Management and Care Coordination. *Health Aff* 2007. 26(6): 1683–1691.

daily practice and 2.2 million citizens can benefit from the solutions aimed at society according to their particular needs (Personal Health Folder, phone consultations, virtual consultations, apps, etc.).

The great innovation of this strategy is that sophisticated, cutting-edge technology has been incorporated into the healthcare provider as it became sufficiently mature in the market to respond to the perceived needs of professionals and citizens. At present, we are still analysing where we need to move forward and we are working on further and greater development of services and solutions, always hand in hand with the corresponding organisational changes. A **key factor** in the success of this strategy is that it has been **driven from a macro level (top-down)** with the backing of the health authorities, while at the same time bringing together **bottom-up initiatives**.

One of the great challenges we are working hard on now is to use what has already been built to create the Basque Country's health data lake, in order to be able to participate actively and with sufficient solidity in the European Health data Space. The work we are carrying out is not only technological, but also addresses ethical-legal issues and organisational changes and professional roles.

Legal and/or ethical issues:

All the technological developments that have been carried out over the years to shape the Basque Country's eHealth strategy have complied with current laws regarding privacy, confidentiality, and ethics.

Transferability to other regions:

The good practice has been transferred in the framework of the Joint Action [JADECARE](#) to the teams of the University Hospital of Olomouc in the Czech Republic and USL Umbria 1 in Italy. The Basque Country's eHealth strategy is of great scope and complexity, so within the framework of the JA JADECARE an approach was designed to facilitate the transfer and adoption of specific elements of the strategy, but not all of it in its entirety.

Key learning points on barriers and enablers to the practice:

- The above-mentioned good practice constitutes a solid basis a more effective work with data in the future in the field of communication with patients, scientific and clinical studies.
- The numerous projects, models and programs proposed over the years to tackle digitalization of health, have promoted a fertile ground for the development and implementation of innovations in the field.
- However, concerns related to GDPR are very high and they may slow down development due to fears about privacy breaches, data loss, etc.
- Moreover, the lack of time of professionals or their natural resistance to use the new digital tools has sometimes impeded a more rapid and gentle transition.

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Health/AI Programme: Programme for the promotion and development of artificial intelligence in the Catalan Health System.

Implementation status:

Catalonia has fully implemented this programme.

Summary:

The purpose of the Health/AI Programme is to create an enabling environment for innovation in the field of health through the development and implementation of artificial intelligence solutions to improve citizens' health, which prioritises prevention, leads the implementation of AI solutions and contributes to improving the quality of care and the sustainability of the health system, making use of the knowledge generated by Catalonia's comprehensive health system for public use.

Description:

The Health/AI Programme is a human-centred initiative with a strong ethical foundation, in line with the European Union's guidelines, to promote AI innovation in the healthcare sector. Its main objectives are to involve the entire Catalan healthcare system, ensuring access to the most advanced solutions, standardising the quality of this technology in healthcare applications, and reducing inequalities. By promoting this innovative healthcare environment, the programme will develop and deploy AI solutions to improve care for citizens and support healthcare professionals. The final objective is to lead the implementation of AI solutions that improve the quality of healthcare and support the healthcare system, while increasing the value of the knowledge generated by SISCAT.

The functions of the programme cover several critical aspects. It aims to strengthen the AI ecosystem in healthcare by **enhancing SISCAT's AI development capabilities** through knowledge transfer. It promotes the adoption of innovation as a fundamental aspect of AI implementation, emphasising rigorous evaluation methods across clinical, ethical, legal, and technological dimensions.

In addition, the Health/AI Programme ensures that AI serves the public interest and promotes **long-term public value** by discouraging the use of non-optimal technologies. It aligns with SISCAT policies and priorities, promotes the adoption and integration of AI in the health sector, and supports innovative public systems. Collaboration is a pillar, encouraging the involvement of the entire Catalan health system.

The programme ensures that AI solutions are accessible throughout the Catalan health system, avoiding inequalities and standardising the quality of care. The programme also promotes **collaboration between the public and private sectors**, fostering an innovation ecosystem capable of addressing the challenges facing the healthcare sector. In summary, the Health/AI Programme is a holistic and ethical approach to AI in healthcare, aiming to improve the **quality, accessibility, and efficiency** of care, while maintaining rigorous standards and fostering collaboration.

The implementation of this programme aims to strengthen the knowledge generated in SISCAT in the form of digitalised data to improve the quality of care and the sustainability of SISCAT, while seeking to position Catalonia as a leader in the spread of innovation in healthcare towards the concept of the four Ps medicine (Preventive, Predictive, Participative and Personalised).

Methodology and processes:

The Health/AI Programme encompasses the entire life cycle of AI tools, from conceptualization to implementation, with a focus on people-centred systems. It operates across three main axes: Innovation, Evaluation, and Implementation.

Innovation:

The programme is structured around three main actions. The first is to **launch challenges**, initiated by the government, to address specific health problems that can be solved through the application of AI tools. These challenges will be implemented through research calls aimed at promoting collaborative research projects.

Secondly, the programme will provide **support to research groups** wishing to carry out pioneering AI projects in the field of healthcare. This support will act as a motor for innovation and facilitate the development of innovative solutions for the benefit of the healthcare sector and the well-being of the population. Additionally, it involves defining MAPES a set of requirements for AI in Health and creating accessible best practice guides on topics like data protection, CE marking, explicability in artificial intelligence, and best practices for AI solution development in healthcare.

Finally, the programme will establish an observatory to **monitor innovative trends** in AI in healthcare. The role of the Observatory is to promote highly innovative yet safe advances, ensuring a constant focus on the evolution and progress of technology in healthcare. Together, these three distinct actions are putting Catalonia at the forefront of the international healthcare AI sector.

Evaluation:

The evaluation of AI solutions in healthcare involves clinical, ethical, legal, and technological assessments before they are implemented. This evaluation revolves around two key concepts: **Reliability of outcomes** (legality, ethics, and robustness) and **Improvement of efficiency**, where measuring the potential impact of implementing the tool in the healthcare system is essential.

Continuous evaluation and monitoring of implemented solutions will maintain their quality throughout their life cycle. The programme also supports the retraining of implemented tools, if required.

Implementation:

The main advantage of the Health/AI programme lies in its final objective: the implementation of AI solutions in the health system of Catalonia in case that all the aforementioned requirements are met. This model aims to achieve excellence in Catalonia's healthcare system, strengthening the **four Ps model** of medicine (Preventive, Predictive, Participatory and Personalised) with the individual at the centre, ensuring the security and privacy of citizens' data. The implementation of such tools at a systemic level ensures that all citizens of Catalonia have access to new applications that contribute to their well-being and guarantee equity throughout the region.

The Health/AI programme sets a wide adoption and deployment of a specific **AI Skills training Programme Framework** for Healthcare professionals in Catalonia, in order to ensure engagement from stakeholders and a digitally prepared healthcare workforce.

A well-planned **communication strategy** increases the program's impact, encompassing the design of a new Health/AI Program website, the development of visual identity, creation and distribution of supportive materials, participation in congresses, and organization of events, all serving to ensure effective outreach and engagement with stakeholders.

Involvement of other organisations/actors:

The Health/AI programme involves several actors.

Firstly, the Department of Health of the Generalitat de Catalunya, the main administrative body of the Generalitat de Catalunya in health decision-making.

It also involves CatSalut, an institutional public body dependent on the Generalitat de Catalunya and attached to the Department of Health of the Generalitat de Catalunya. It is responsible for guaranteeing public, comprehensive, and quality health care coverage for the citizens of Catalonia.

The Fundació TIC Salut Social is a body of the Department of Health, working to promote the development and use of ICT and networking in the field of health, acts as an observatory of new trends, innovation, and monitoring of emerging initiatives, and offers standardization and product certification services.

The Health Quality and Assessment Agency of Catalonia (AQuAS) is a public law entity attached to the Ministry of Health of the Generalitat de Catalunya that acts in the service of public policies and is subject to private law.

Funding source(s) of the initiative:

The programme has been funded by Catalan Government: Since 2020, the Catalan Government, through the Ministry of Health has contributed to the AI/Health Programme deployment with 750K per year.

Innovation, Impact and Outcomes:

The programme is an asset to the healthcare sector, promoting innovation and excellence in a variety of ways. Its main goal is to drive the healthcare system to adopt innovative and safe AI solutions. This innovation comes from our continued commitment to transforming the healthcare landscape. We promote innovation by introducing **cutting-edge technologies and methodologies** that not only improve the quality of care, but also enhance the resilience and sustainability of the healthcare system. Our commitment to innovation is evident in our approach to AI, where we are continually pushing the boundaries of what is possible; to benefit both healthcare professionals and the citizens they serve. Our programme serves as a benchmark for the entire Catalan healthcare system, setting a high standard for best practice.

To ensure that our results have a tangible impact on the sector, communication plays a key role. The primary outcome of our efforts is a significant improvement in the quality of care for citizens, as well as a stronger and more sustainable public health system. In addition, our technical guidance initiatives are actively working to establish a **secure framework for government-to-government and business-to-business data sharing**, in full alignment with the EU Data Strategy and the EU Artificial Intelligence Strategy.

In terms of success criteria, a multiple approach can be used to measure the effectiveness of the initiative. For example, tracking the number and impact of the evolution of detected solutions in the healthcare environment, ensuring that our programme results, including guidelines and training, are successfully created. We also monitor the level of interest and participation of healthcare professionals by assessing factors such as interest in registration, attendance at information sessions and participation in needs assessment surveys, as well as how healthcare organisations integrate our results into their workflows. In addition, we measure the performance improvement of AI solutions in the system and actively collect feedback from stakeholders to understand their expectations, preferences, and the usability of our results.

As we consider the future of the European Health Data Space, our adaptability is unquestionable. Our values and goals are perfectly aligned with the core objectives of the EHDS, which include empowering individuals through increased digital access and control over their personal health data, fostering a single market for electronic health record systems, medical devices, and high-risk AI systems, and providing a trusted and efficient setup for the use of health data for research, innovation, policy-making and regulatory activities. In all aspects, we are fully prepared to contribute to and thrive in the evolving European Health Data landscape.

Legal and/or ethical issues:

The programme raises several ethical and legal challenges for its application in health care. Specific guidelines and mechanisms are needed to ensure the ethical quality of AI in this field. In addition to monitoring by ethics committees, it is essential to involve citizens from the beginning and to promote transparency and accountability.

These ethical and legal challenges include the quality of data, the fairness of algorithms and the responsibility of all stakeholders in the integration of AI tools into healthcare decision-making. It is also crucial to ensure that market rules do not apply to health research contexts, given the sensitivity of personal data. Strict security measures and ethical guidelines are needed to ensure data privacy and security. The use of AI in healthcare will reshape the

relationship between patients and healthcare professionals, requiring new ethical roles and legal frameworks adapted to this new model.

The programme follows European guidelines, including:

- The *White Paper on Artificial Intelligence*, which focuses on promoting a European ecosystem of excellence and trust in AI by proposing cooperation, investment, and regulation, especially for high-risk applications.
- The *European Data Strategy*, which presents ideas and actions to drive a digital transformation that benefits everyone and reflects European values of openness, fairness, diversity, and trust, promoting a society driven by digital solutions and reliable technology in a dynamic and sustainable economy.
- The *Report on the Safety and Liability Implications of Artificial Intelligence*, the Internet of Things and Robotics stresses the importance of investing significantly in these technologies and establishing a clear and predictable legal framework to make Europe a world leader in these fields.
- The *Report on Ethical Guidelines for Trustworthy AI* provides a set of recommendations for those involved in the design, development, deployment, application, or use of AI to promote trustworthy AI. The Health/AI Programme ensures that the requirements to ensure compliance with ethical principles for legal, ethical, and robust AI are met.

The Health Data Protection Officer is required to supervise the entire process to ensure compliance with GDPR principles, which is crucial given that the data comes from treatments carried out by the Catalan Health Service and the Ministry of Health.

Transferability to other regions:

The good practices of the Health/AI programme can be of great interest to other regions and organisations due to its alignment with European values and active participation in standardisation activities. By adhering to established European standards and actively contributing to European projects, this programme can serve as a model for other regions and organisations looking to implement AI in healthcare.

A key aspect of its transferability is its participation in European initiatives such as **FUTURE-AI**, a dynamic framework that is constantly evolving to adapt to the latest developments in AI in medical imaging. The programme's involvement in FUTURE-AI and its adherence to the principles established by FUTURE-AI, such as fairness, universality, traceability, explicability, robustness, and usability, ensures that the AI solutions developed under the Health/AI programme are in line with best practice and ethical guidelines.

This will not only ensure the ethical and responsible use of AI, but also facilitate collaboration and standardisation efforts on a wider scale. The Health/AI programme's commitment to these principles and its involvement in European projects make it a valuable example that can be replicated by others seeking to use AI in healthcare while maintaining high ethical and quality standards.

Key learning points on barriers and enablers to the practice:

Barriers:

- **Ethical and Legal Complexity:** Deploying AI in healthcare involves navigating complex ethical and legal challenges, such as data quality, algorithm fairness, and the responsibility of all stakeholders.
- **Data Privacy and Security:** Maintaining strict security measures and ethical guidelines to protect patient data is a significant challenge.
- **Resistance to Change:** Integrating AI tools may require healthcare professionals and patients to adapt to new models of healthcare, which can face resistance.
- **Market Rules in Health Research:** Ensuring that market rules do not apply to health research contexts due to the sensitivity of personal data is a challenge.
- **Patient-Provider Relationship:** The use of AI in healthcare will reshape the relationship between patients and healthcare professionals, requiring new ethical roles and legal frameworks.

Enablers:

- **European Guidelines and Collaboration:** Alignment with European guidelines, such as the White Paper on Artificial Intelligence, the European Data Strategy, and the Ethical Guidelines for Trustworthy AI, ensures a strong ethical foundation.
- **Transparency and Accountability:** Promoting transparency and accountability through mechanisms like ethics committees and involving citizens from the beginning is a key enabler.
- **Collaboration and Standardization:** Actively participating in European projects and initiatives, such as FUTURE-AI, promotes collaboration and adherence to ethical standards.
- **Government Support:** Funding from the Catalan Government and its commitment to innovation create a supportive environment for AI in healthcare.
- **Stakeholder Engagement:** Involving multiple key stakeholders, including the Department of Health, CatSalut, the Fundació TIC Salut Social, and the Health Quality and Assessment Agency of Catalonia, ensures a holistic approach.
- **Communication Strategy:** An effective communication strategy, including a dedicated program website, visual identity, and participation in events, enhances outreach and engagement with stakeholders.
- **Transferability:** The program's alignment with European values and active participation in standardization activities make it a valuable model for other regions and organizations looking to implement AI in healthcare.

Further information:

- <https://iasalut.cat/en/>
- <https://iasalut.cat/en/suport-a-iniciatives/>

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COMPDIG-Health/Challenge 4 FDP project - Digital Skills of Health Professionals

Implementation status:

Catalonia is in the process of implementing a project on Digital Skills.

Summary:

One of the challenges uncovered by the “Fòrum del Diàleg Professional” (Professional Dialogue Forum) was the “necessity to improve the digital competences of healthcare professionals” in the Catalan health sector. Digital Skills for Healthcare Professionals (COMPDIG-Salut)” project arose with the aim of meeting this challenge.

Description:

COMPDIG-Salut has three main objectives: (1) **defining a specific digital competence framework** for HPs; (2) **creating a specific evaluation and accreditation model** for HPs; and (3) **drawing up actions to train and qualify** HPs in digital competencies. With respect to objective 1, the Fundació TIC Salut Social relied on the ACTIC certificate, an existing certification model of DCs for Catalan citizens, which features 3 competency levels: ACTIC Basic Level (ACTIC-1); ACTIC Medium Level (ACTIC-2); and ACTIC Advanced Level (ACTIC-3). This model is based on the European Commission’s DigComp framework and was the first certification developed in Europe for citizen’s DCs. Other relevant frameworks such as the NHS’ “A Health and Care Digital Capabilities Framework” were also taken in account. The result was the production of a DC framework for Healthcare Professionals. In this process, Fundació TIC Salut Social counted with the collaboration of sector experts, as well as the validation of the members of Challenge n.4 of the Fòrum de Diàleg Professional.

In parallel, and in order to design an evaluation, certification and training model that adequately adapted to the real situation of healthcare professionals in terms of their digital skills, *Fundació TIC Salut Social* also established the necessity to determine the current digital competence level of workers in the sector. To do this, a complete study that included the participation of 803 healthcare professionals was carried out, with its results determining that two thirds (66,7%) of the participating healthcare workers showed a digital competency level below ACTIC-2 (Medium Level). Moreover, COMPDIG-Salut developed an evaluation model for the developed Digital Competences framework specific for healthcare professionals. The model was tested in 2022 with health professionals. The results showed that the evaluation model is valid but confirmed the need to reinforce training.

The results of these studies have served Catalonia as a guide to reformulate the accreditation and training strategy for healthcare professionals.

Currently, COMPDIG-Salut continues its path with a new two-year project funded by the Technical Support Instrument of the European Union.

The results expected for 2024 are:

- To define a Catalan strategic training plan to upskill all healthcare workforce.
- To define education and training itineraries.
- To develop training content and materials for health professionals.

These results will help to **standardise, assess, and improve the digital skills** of healthcare professionals throughout Catalonia.

Methodology and processes:

Several methodology and processes have been used along our project, namely:

1. Mapping European or International DC frameworks.
2. Surveys and pilots with active healthcare professionals.
3. Validation with members of Challenge n.4 of the Fòrum de Diàleg Professional.
4. Focus groups and interviews of relevant stakeholder.
5. Validation with other relevant stakeholders from the Catalan healthcare ecosystems.

Involvement of other organisations/actors:

Professional associations, Scientific Societies, Universities, Healthcare Providers

Funding source(s) of the initiative:

Directorate-General for Structural Reform Support (DG REFORM), Catalan Ministry of Health, Department of the Vice-Presidency and of Digital Policies and Territory and Fundació TIC Salut.

Innovation, Impact and Outcomes:

Innovation: Development of a digital competence test which combines both skills and self-assessment and it is contextualized in the clinical environment of the professionals.

Impact: 803 healthcare professionals participated in a survey to assess their current digital competence level and to identify the areas needing improvement. 122 healthcare professionals completed the Pilot of the Digital Competences evaluation model.

Outcomes:

- Digital competences framework for healthcare professionals.
- Digital competence test.

Transferability to other regions:

The Digital competences framework for healthcare professionals could be easily transferred to other regions.

Key learning points on barriers and enablers to the practice:

Ensure that there is continued funding for implementing the strategy to upskill Catalan healthcare professionals.

Further information, if any:

- <https://ticsalutsocial.cat/competencies-professionals/>
- <https://salutweb.gencat.cat/ca/departament/eixos-legislatura/forum-dialeg-professional/grups-treball/d/>
- <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9752462/>

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SCOTLAND



Scotland's Data Strategy

Implementation status:

Scotland has fully implemented its strategy for health data.

Summary:

The vision of Scottish Data Strategy is “to improve the care and wellbeing of people in Scotland by making best use of data in the design and delivery of services.” It is underpinned by three ambitions:

- To empower the people of Scotland by **giving individuals** clear and **easy access** to, and **control** over, their own health and social care data where it is safe and appropriate to do so.
- To empower those delivering health and social care services to have the confidence and **ability to gather, safely use, and share** data to sustainably improve services and ensure outcomes are being met.
- To ensure fit for purpose data is readily accessible through secure and safe means for **planning, research, and innovation**. Data will be used for the benefit of individual wellbeing and the public collectively, including the development of new and innovative ways of working, improving care, developing new treatments.



Description:

As part of Scotland's refreshed Digital Health and Care Strategy, we committed to publishing Scotland's **first ever Data Strategy for Health and Social Care**. The Data Strategy builds on the refresh of our digital health and care strategy by delivering a strategy for greater access and ability to manage health and social care data. It also brings Scotland in line with the work ongoing in our partner nations across the United Kingdom.

Scotland's Data Strategy supports the aims of the NHS Recovery Plan, work to improve population health outcomes, social care reform and the proposed delivery of a National Care Service. By supporting the transformation of our health and care system using data, we will be better able to identify and address the gaps in data and the challenges of data quality.

The Data Strategy will ensure that health and social care data supports the delivery of health and care services, and that it does so in a way that empowers citizens and staff and supports innovation and research.

Methodology and processes:

The Data Strategy was developed through **analysis of evidence**. A literature review was undertaken to identify gaps for further collection of information through bespoke engagement and formal public engagement.

The outputs of engagements were analysed, and the results used to identify key themes for the Strategy. Following this workshop were held with stakeholders exploring suitable commitments and key narrative points for the Strategy.

Deliverables of the Strategy were refined in **conversation with stakeholders and delivery partners**. Once refined members of the Scottish Government's Digital Health and Care senior team took part in a matrix plotting exercise to further refine and create timescales around principles and deliverables.

Following publication of the Strategy. Engagement was undertaken with stakeholders to identify who would lead, how they plan to deliver, milestones and key risks for each deliverable to further develop the 2023/24 delivery plan. This initial delivery plan is being used to **monitor delivery status and risk** of each of our delivery priorities.

Involvement of other organisations/actors:

The Data Strategy was developed in line with the principles of the Scottish Approach to Service Design. Extensive engagement with stakeholders and the public was undertaken to inform the development of the Data Strategy.

Engagement was undertaken with delivery partners to develop a baseline understanding of how and when deliverables will be delivered. The Scottish Government will regularly engage with delivery partners to monitor progress and update the Data Strategy delivery plan.

Government officials held multiple workshops and engagement sessions with a variety of health and care stakeholders. The Scottish Government also commissioned bespoke public engagement (linked below) and linked in with key partners, including the [ALLIANCE](#) and Inclusion Scotland.

A public consultation was launched on Citizen Space from 16 May 2022 –12 August 2022. There were 162 responses received of which 101 were from organizations. The [analysis of the consultation responses](#) alongside the stakeholder engagement that has been undertaken was used to inform the development of the Data Strategy and the associated delivery plan.

Funding source(s) of the initiative:

The Health and Social Care Data Board has been set up to provide oversight and governance of the Data Strategy and its associated delivery plans. Membership has been drawn from a wide and diverse community representative of health and social care to ensure the ambition and reach of the Strategy is achieved in a timely way. This governance board sets and assigns priorities. Funding of the ambitions of the Data Strategy is through existing funding routes, no set additional funding accompanies the strategy.

Innovation, Impact and Outcomes:

Success indicators are currently being developed; the Scottish Government would be happy to update upon completion.

Legal and/or ethical issues:

Scotland's Data Strategy sets out our approach to using health and social care data in an ethical manner. It explains that e- wants to embed an ethical, open, and human rights-based approach to the use of health and social care data in Scotland which maintains public trust and confidence. To do so we set out eight principles:

1. **Beneficial:** Start with a clear articulation of need, public benefit, and risks.
2. **Responsible:** Recognise the need to behave in a trustworthy way with the use of data and digital technology across systems and processes
3. **Accountable:** Be accountable and transparent to independent scrutiny and oversight, use reliable practices and work within our skillsets.
4. **Insightful:** Our health and social care data contain insights that can help us improve services. However, we must identify where there are limitations in the data and digital technology being used, and recognise unintended bias, while identifying and ensuring that approved mitigations are in place.
5. **Inclusive:** Ensure that data is accessible in formats that are appropriate for everyone, and that access to data is not limited to digital means.
6. **Necessary:** Identify reasonable and proportionate requirements to meet the need.

7. **Observant:** Implement all relevant legislation and codes of practice.
8. **Widely Participatory:** Embed the view of the public, through the routine use of public participation and co-design.

Transferability to other regions:

The vision, ambition and key priority areas of this strategy are predicated on engagement with people in Scotland and Scotland's health and care professionals, however, its core messaging is very similar to that of health and care Data Strategies internationally. For instance, those of four nations partners or that of Australia. The learnings and principles of our strategy are expected to be largely true of and applicable to similar sized nations, respecting that each national will have unique areas of strength and challenges that will vary from those we have in Scotland.

Key learning points on barriers and enablers to the practice:

This information is currently being collated; the Scottish Government would be happy to update upon completion.

Further information:

- [Greater access, better insight, improved outcomes: a strategy for data-driven care in the digital age \(www.gov.scot\)](https://www.gov.scot/publications/greater-access-better-insight-improved-outcomes-a-strategy-for-data-driven-care-in-the-digital-age/pages/introduction.aspx)
- <https://www.digihealthcare.scot/app/uploads/2022/03/FINAL-Data-Dialogues-Report-compressed-1.pdf>
- <https://www.digihealthcare.scot/app/uploads/2022/05/Data-Strategy-HSC-Engagement-Summary-March-2022-pdf.pdf>

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WALES

Wales's Data Strategy



Implementation status:

Wales is in the process of implementing its strategy for health data.

Summary:

The refreshed Digital and Data Strategy for Health and Social Care in Wales is designed to help people in Wales to lead happier, healthier, and longer lives through user-centred digital services built on better digital skills, partnerships, data, and platforms.

We want to develop services which support people to stay well, not just treat them when they become ill. Developed in partnership with health and social care services, the refreshed Strategy provides clear policy direction to help shape internal decisions and prioritisation of digital innovations and improvements. Placing citizens and staff at the heart of the Strategy, its six missions set out themes of digital inclusion, digital economy, interoperable systems, standardisation to support efficiencies, optimisation of patient data to support care and innovation and empowering our staff to engage with digital confidently.

Description:

This strategy acts as a pivotal guide for all health and social care organisations in Wales to follow and align with when they undertake health and social care service design, care model improvements and better ways of meeting people in Wales needs.

The Strategy is designed to operate on a **three-year review cycle**, to ensure priorities remain current and to take account of any new and developing technologies. Delivery plans will be developed in partnership with the system and will align with our key digital partners strategic and annual plans. Key to success will be the wider involvement and input from partners and linking to recovery plans within the health and social care systems, along with embedding **alignment into the NHS Planning Framework**. The Strategy is designed to integrate learning from previous experiences, recognises digital transformation as key to successful and improved health and social care outcomes, recognises the value of strategic leadership and highlights benefits realisation are core priorities that should underpin all initiatives.

Methodology and processes:

In 2021, a delivery partner was commissioned to assess learning from exploratory work e.g., a Digital Architecture Review, and undertake extensive engagement with representatives across the health and social care environments through a variety of approaches. This culminated in the development of agreed principles and broad themes that a modern health and social care service should have in place to meet the needs of its populations.

The recent appointment of a **Chief Digital and Innovation Officer for Health and Social Care** has triggered a move towards strengthened system-wide governance and centralisation of Government-funded digital initiatives. Embedding and ensuring digital transformation is part of national policy and programmes is the initial step in developing a managed approach to digital transformation amongst a challenging financial landscape. Delivery will be overseen by a National Board as part of improved funding and governance arrangements.

Involvement of other organisations/actors:

- Health boards.
- NHS Trusts.
- NHS Strategic Health Authorities.

- Digital Directors / Digital Leads (Health and Social Care).
- Association of Directors of Social Services.

Funding source(s) of the initiative:

- A mixture of local funding of core services and national transformation type funding.
- Focus on collaborative and partnership working, with a reduction of duplication and cross-sector working.

Innovation, Impact and Outcomes:

The refreshed Strategy has recently been launched and background work is currently underway as part of providing the structural governance changes required to support a system-wide approach to digital transformation initiatives.

Legal and/or ethical issues:

Maintaining equity of approach for those less confident to engage with digital services, and support interactions for those less able to engage.

Transferability to other regions:

- National strategic approach to digital transformation.
- An emphasis on local delivery and delivery partners, collaboration and partnership working.

Key learning points on barriers and enablers to the practice:

- Competing and increasing demands on health and social care services.
- Changing demographics, rise in long term condition and health inequalities.
- Challenging financial position.

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TELEMEDICINE / TELEHEALTH

APULIA REGION

CORēHealth: Operating Centre of Telemedicine for Chronic Diseases and Clinical Networks of Apulia Region



Implementation status:

The Apulia Region has fully implemented an initiative for health data. The focus is the setup of the Centre of Telemedicine for Chronic Diseases and Clinical Networks of Apulia Region.

Summary:

The healthcare innovation by telemedicine in Apulia starts a long time ago with the POR Puglia 2014-2020 projects from which CORēHealth directly derives, set up at AReSS. CORēHealth offers: HL7-FHIR interoperable web-cloud platform; televisit, teleconsultation, telemonitoring, telecooperation and teleconference; Device tracking system; patient synoptic; central alarms; Mobile App; Integration with the Regional Health Information System, the EHR and others. The APP promotes the **patient's involvement in the care process**: keeping in touch with doctor; consult the agenda of the televisits programs with care team; view care plan; enter the vital parameters in real time; manage the clinical diary and share it with the care team; facilitate the measurement of compliance with the treatment path. AReSS has launched a virtuous path of training, change management and digital literacy for all users of the system and for patients to promote continuous training and the consolidation of digital skills.

Description:

Thanks to CORēHealth patients can be cared for from home, accompanied by self-management of their chronic disease, thus reducing hospitalizations and visits to hospitals clinics and doctors.

The Central provides the care team (doctors and nurses) a cloud platform (Backoffice) for the **telematic management of their patients** by offering, among the main services: personalized patient monitoring paths (telemonitoring), teleassistance, Televisit, teleconsultation and telehealth teleoperation services, digitized services for taking charge, personalization and management of patient care plans, logistics/warehouse management of medical device kits. The medical team, based on the specific need, provides the **patient with the medical device kit** (tablet, pulse oximeter, multi-parameter, balance, etc.) suitable for detection and monitoring in real time of the salient parameters, which allow constant detection and monitoring and possible intervention by virtue of the automatic alarm system with which the control unit is equipped.

An **app**, available for Android and iOS, allows the patient to stay in touch with the their specialist doctor and with the caregiver (video calls, diary and chat), to consult the agenda of Televisits scheduled with their team of treatment, to visualize their own therapeutic plan and the insertion of the vital parameters that are communicated to the doctor in real time; it also facilitates the measurement of compliance to the care pathway (taking drugs, style of life).

The objectives of the Operating Centre, therefore, are:

- **To refine**, through the digitization of processes, the **regional organizational model of prevention, care, and treatment** of its frail citizens and/or those with chronic diseases in accordance with the provisions of the "National Plan of Chronicity" which identified the adoption of telemedicine models, techniques, and tools as opportunities for improvement and benefits.
- **Centralize citizens' epidemiological data** on a single platform, as well as the entire process of taking charge and managing the defined prevention, assistance, and treatment plans.

- **Promote the cooperation and collaboration** of all the structures and professional figures involved in the process of prevention, assistance, and care of citizens according to the various levels of responsibility and action.
- **Integrate the entire network of regional services** with particular reference to the "clinical networks of rare diseases" and the "Oncological Orientation Centres (COro)".
- **Make the telemedicine network more efficient** (definition of the operational processes of the Service Centre and the Delivery Centres) for the management of data, reports and reports acquired through Telemonitoring, Televisit, Teleconsultation and Telecooperation healthcare tools.
- Have full health, organizational and economic governance of the interventions and plans activated.
- **Strengthen the relationship with the citizen** and improve the citizen's perception of services.

Methodology and processes:

The Apulia Region in a pioneering way, by DGR n. 1088 of 2020/07/16, established the Regional Operating Centre of Telemedicine of Chronic Diseases and Clinical Networks within AReSS (Regional Agency for Health and Social Care of Apulia), also providing the operational guidelines for the promotion and dissemination of the telemedicine in the health service and authorizing the financing of the information-technological infrastructure for the first start-up phase of the Operation Centre.

The Agency followed up on the mandate conferred by the Region and, through acceptance of the Consip SPC Cloud Lot 1 Framework Contract (RTI Telecom Italia S.p.A./Enterprise Services Italia S.r.l./Postecom S.p.A./Poste Italiane S.p.A./Postel S.p.A.), developed the infrastructure, the platform, and the Mobile APP (available on the Android and iOS stores) of the Operating Centre, called CORēHealth. Subsequently, with Resolution of the CEO n.65 of 07/04/2021, AReSS Puglia published the Guidelines for the Management of Outpatient Services in Telemedicine, transposing the "National indications for the provision of services in Telemedicine" approved by the Conference standing for relations between the State, the Regions, and the Autonomous Provinces in the session of 2020/11/17. The document defines and regulates the procedures (recipients of the service, services, delivery methods, etc.) aimed at the creation of some specific telemedicine services for people who need remote health checks, such as, for example, Televisit/health video call, remote control of devices in specific areas e.g., cardiology, diabetes, specialist teleconsultation, territorial health, and social teleservices.

CORēHealth is part of the Regional Health Services Network by dialoguing and cooperating with the various institutional and operational stakeholders of the area and is the **institutional and operational reference for all e-Health initiatives implemented by Apulia**. The Regional Operating Centre, in its full operational mode, provides for central coordination of the various e-health solutions implemented region wide, guaranteeing **technological interoperability** and plurality of services; so, it works as a Service Provider for regional e-Health services. To this end, periodic working tables have been organized to involve, compare, and implement operational plans for new services to be developed.

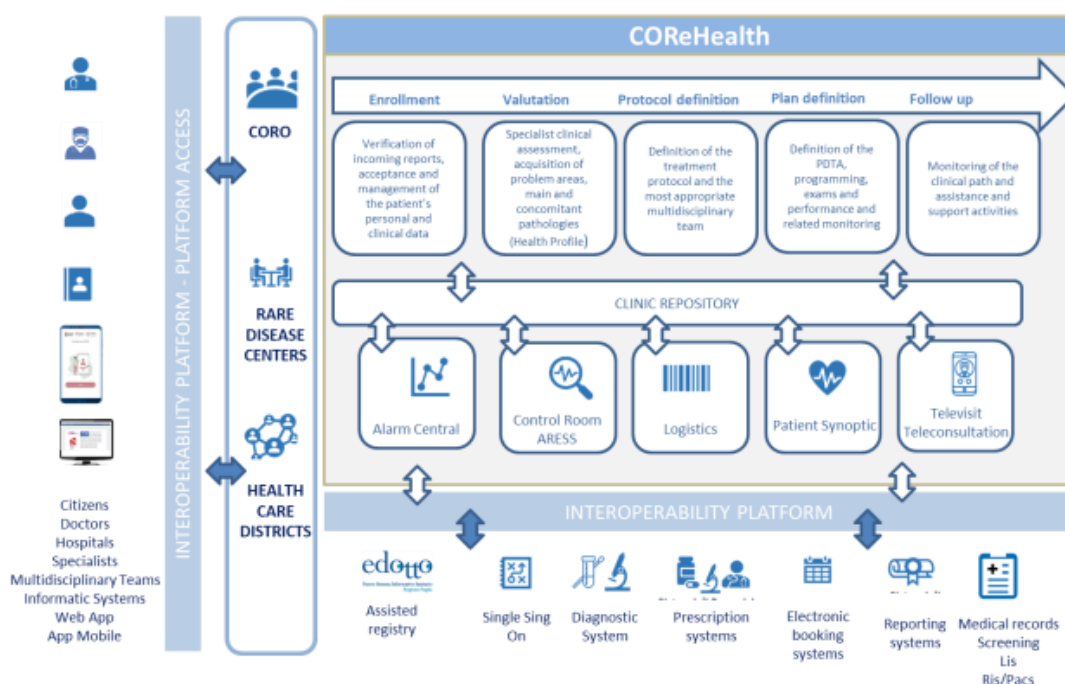


Figure 4

The figure schematically represents the logical model of CORēHealth. The various stakeholders can access the platform (back office and/or mobile APP) for patient enrolment, clinical assessment, protocol and treatment plan definition, and subsequent follow-up plan. The platform makes all the information available in the clinical repository and through interoperability tools it interacts with the services of alarm centre, logistics platform, patient synoptic, Televisit/telemonitoring as well as with third-party systems (e.g., diagnostic systems, reporting systems, prescription systems, electronic booking systems, etc...).

CORēHealth can be summarized in three macro-blocks:

- **ARESS Service Centre:** the facility responsible for the management and maintenance of the entire information system.
- **Dispensing Centres / Clinical Networks:** the structures of the Health Service (authorized or accredited, public, or private, GPs / PCPs, specialist clinics, etc.) who manage the relationship with citizens through the management of all phases of the process of taking charge and providing the services provided by the Diagnostic Therapeutic Care Plans.
- **The telematic platform.**

From a more strictly technical point of view, the platform implements an application solution that enables the model at a regional level, implementing the **technological transformation towards a cloud environment**, as well as the re-engineering and migration of its application systems on the Cloud infrastructure of the Service Centre of InnovaPuglia (in-house provider of the Region). Next figure shows the interoperability of the CORēHealth, with standard protocols.

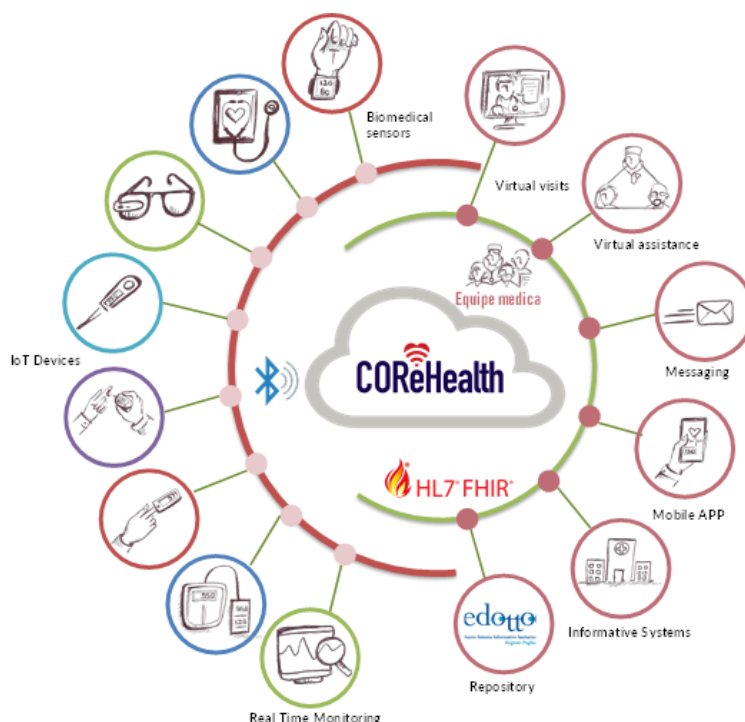


Figure 5

Involvement of other organisations/actors:

From an institutional point of view, the DGR 1088/2020 has identified the regional coordination for telemedicine with the following composition:

- the pro tempore Director of the Department of Health, Social Welfare and Sport for All of the Apulia Region.
- the pro tempore CEO of AReSS Puglia.
- the pro tempore Manager of the Technological and Instrumental Health Resources Section of the Apulia Region.
- the pro tempore Medical Director of the e-Health Area of AReSS Puglia.
- a representative of each Local Health Authority, University Hospital and public IRCCS (scientific research and care institute) of the Apulia Region, with expertise in the matter, appointed by the respective CEOs.

The main stakeholders belonging to the network of regional health services are therefore:

- The Regional Department of Health Policies, which constitutes the technical body of the executive, which coordinates and manages the Regional Health.
- AReSS Puglia, regional health and social care strategic agency that deals with healthcare evaluation and planning.
- The Local Health Authorities and their Departments and Services which govern the territorial services following the regional directives of the Department.
- The Health Districts that deal with territorial healthcare (home care, specialist medicine, non-residential type activities and other).
- General Practitioners (GPs) and Primary Care Paediatricians (PCP) who have an agreement with the SSR for taking charge of users in connection, as far as their respective competence is concerned, with the other components of the health system.
- The “USCA”, Special Unit for Continuity of Care, born specifically to deal with the Covid-19 emergency and made up of specially selected doctors, with an hourly relationship in the agreement, who take charge of the

management of patients on the recommendation of the GPs belonging to it by territory to which the management of cases falling under the Covid 19 categories (suspected, confirmed, discharged) in home isolation is entrusted.

- The 118 Emergency-Urgency Network, for the management of emergencies, with the activation of the 118 centres, the pre-triage in the centres, dispatch of ambulances equipped for the therapeutic diagnostic approach at home or in the area, and accompaniment of the critical patient in a hospital environment in relation to the availability of beds and the types of assistance methods activated.
- The Regional Civil Protection, for health care support activities, including all pandemic emergency management activities, as the logistics of Covid-19 hotels, the procurement and distribution of PPE, the procurement of other equipment or consumables for which obvious difficulties emerge from the market, support for the carrying out of swabs, general assistance of the population for the distribution of drugs and groceries, management of OSS for prisons and Extended Care Units and more.
- Pharmacies, analysis laboratories and local outpatient facilities that provide specialized diagnostic, therapeutic or pharmacological services in the area.
- The Local Oncological Orientation Centres ("CORO") that treat and monitor oncological patients in the management of chemotherapy treatments over time.
- The "COT" (Territorial Operations Centres), "CdC" (Community Houses) and "OdC" (Community Hospitals) are being established.
- The Rare Diseases Centres, which are also territorial health centres to guide and follow patients and family members in identifying the most appropriate diagnostic therapeutic assistance path.
- Extended Care Units (RSA), Social and Health Care Homes (RSSA) and Hospices that take care of elderly and/or long-term patients with Healthcare and Social-health services.

Furthermore, these stakeholders are flanked, depending on the topic of discussion at the board and on the basis of specific interests, also by: Patients' associations, health trade unions (e.g., FIMMG), private healthcare associations (e.g., clinics, studios multi-specialist, etc.), manufacturers of medical devices and healthcare information systems and other stakeholders.

The involvement is extended to almost all subjects belonging to the regional social-health sector.

Funding source(s) of the initiative:

The telemedicine Centre of Apulia Region was established at the end of a long process that involved several private partners in co-financing (PPP), up to the creation of an interoperability platform inside the Talisman project. Then the regional council resolution No. 1088/2020, which established the telemedicine Centre of the region in AReSS, allowed the use of AReSS funds already available for the start-up phase including the customization of the Talisman platform and the coverage of the first two and a half years of management. Then ordinary funds will be used for the continuation.

Innovation, Impact and Outcomes:

Through CORēHealth we want, first of all, to promote the centrality of the citizen-patient and this requires that the entire social assistance and protection network, the various actors who are involved in it, cooperate effectively and assiduously, with the aim of protecting their well-being and health, guaranteeing the satisfaction of their main needs and their active inclusion as a conjunction.

CORēHealth, therefore, operates as an enabling factor for the realization of this basic prerequisite, guaranteeing:

- an extensive digitalisation of processes, consistent with the reference organizational models (regional and corporate, district and clinical networks) in the local area, aimed at maximizing the adoption of the new system by operators by focusing on **usability aspects** (simplicity of use, carrying out operations with "a few clicks", etc.) and optimizing the feeding activities of the new system (operators will only have to enter the

data necessary for the specific process they are carrying out and not those that are already available in other systems, which can be retrieved via, for example, integration mechanisms);

- the **interaction between all the actors** involved (e.g., GPs, pathology networks, accredited care providers, third-sector entities, etc.) and therefore, a "unified" taking care of the patient's needs, with reference to complex needs.
- a **monitoring** of processes, of the clinical-epidemiological and economic aspects to support both the continuous improvement of services offered and regional social-health planning.

It is also necessary to always be aware that e-Health is not the end, but the tool to achieve the goal to meet the health and well-being needs of citizens.

A prerequisite is the guarantee of the interoperability of healthcare systems so that all Regions can speak a single language and share a single view of patients: technological standards, data, homogeneous processes, and systems that cooperate with each other can really provide an advantage as they evolve over time based on the best experiences of the territories. Critical success factors need to be addressed for the realization of this transformation: citizen-patient centrality, data centrality, overall system governance, digital skills enablement, and finally, innovative financing methods.

Another key element is the **systematic approach in continuous training and digital skills** building to enable informed access of all the actors involved to the new digital technologies: among the enabling factors of digital health, the digital skills spread to all professionals are undoubtedly an essential strategic element. And it is for this reason that AReSS, by joining the Consip Framework Contract «DIGITAL HEALTHCARE - Clinical-Assistance Information Systems» - Lot 6 "Support services for Public Administrations in the National Health System - CENTRAL-SOUTH" has designed a **path of change management, training and digital literacy** of all users of the system (medical, administrative teams) and patients, so that CORēHealth does not remain a mere tool, albeit technologically advanced, but represents a real organizational shift toward a new way of caring for chronic patients with benefits for both patients and caregivers.

The necessary skills that should be strengthened are above all digital managerial skills, to plan, govern and optimize the digital transformation process.

The change management activities began with the support for healthcare operators in the management of the application software and in taking charge of patients, on one hand, and with the involvement of patient associations, on the other, to help patients in managing of their disease with the new technological tools.

So, it was decided to give a continuous boost to the change management phase by sending weekly contextual news to healthcare professionals (**Smartpills Newsletter**) and inserting training videos in the app for citizens. Furthermore, a digital contest was created to stimulate healthcare professionals to use the platform and to take care of patients virtuously:



Figure 6



Figure 7

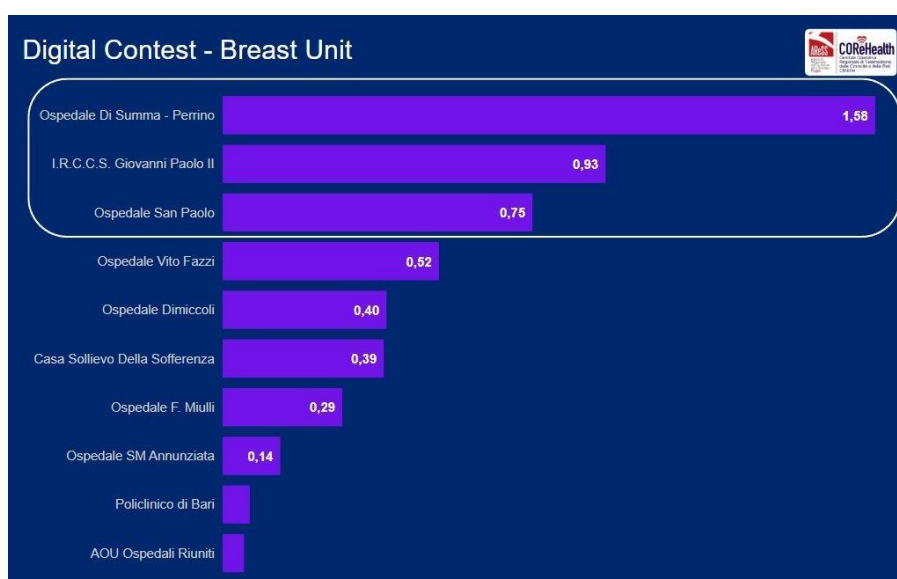


Figure 8

Legal and/or ethical issues:

The legal aspects faced for the implementation of the project were different. However, compliance with the GDPR was of particular importance, when dealing with health data.

The first activities carried out were the assessment of the risks related to data processing following which the formal steps and activities to be implemented for data protection were identified using COReHealth. Before the project was put into operation, the co-ownership agreements were signed between AReSS and the Apulian healthcare companies.

Subsequently, the information and consent documents for data processing were drawn up, which each facility submits to the patient's authorization signature before being treated with the help of the digital platform. Since the

platform is interoperable with other IT systems of the SSR, this implies the need to inform the patient about the exchange of his data between these systems.

In collaboration with the other bodies ARESS is working for the technical-legal resolution of these aspects.

Transferability to other regions:

Digital investments in healthcare must be commensurate with the needs to enable Digital Transformation and a deep renewal of the sector according to the logic of Value Based Healthcare. In this scenario, increased funding for eHealth is a necessary condition to start the digital transformation of the NHS and make it capable of facing the challenges of our times: this must become a primary objective of all actors in the health system at the ministerial, regional, and territorial levels. In this direction, the Apulia Region (during the Presentation at the Permanent Conference for relations between the State, the regions, and the autonomous provinces, last 2 March) was identified by the Minister for Technological Innovation and Digital Transition to develop, together with the Lombardy region (Flag Regions), the applications for the provision of Telemedicine services nationwide under M6C1 of the Italian National Recovery and Resilience Plan (NRRP).

Telemedicine, now considered one of the key components for improving citizens' health, is a historic opportunity to be seized thanks to the NRRP which intends to create a real ecosystem in this regard, through a national enabling platform (implemented by the National Agency for Regional Health Services -AGENAS-) and vertical regional implementations.

Key learning points on barriers and enablers to the practice:

- new organizational model.
- integration of medical devices and technologies.
- change management.
- digital literacy.
- patient empowerment and involvement.

Further information, if any:

CORēHealth overturns the traditional patient care pathways, bringing, for the first time, digital innovation directly into their hands (App Mobile) enabling them to have their own medical history, their care plan and maintain a constant, regulated dialogue with their doctor, medical team, and care giver, as well as being able to take the most appropriate measurements for the management of pathology/ies. Doctors can manage the clinical history of their patients in an integrated environment, optimizing care time, reducing inappropriate access to hospital facilities, developing their professional skills, including digital skills, according to a multidisciplinary approach to care taking with a single common point of access, reducing the distance between hospital and territory, and moving the care activities of chronically ill patients to an environment as close as possible to the patient's home. In November 2022 the Apulia Region received the "Innovation in Digital Health" award, organized by AGENAS, the National Agency for Regional Health Services, and Sics, publisher of the journals *Quotidiano Sanità* and *Popular Science*, for the regional telemedicine platform CORēHealth. Other numerous awards have come, including Best Practices Award in key thematic Area 4 "Innovation Flow in the Healthcare" by Regions4perMed, in March 2023; DT4Regions award in June 2023. CORēHealth was also included among the best practices of the AGENAS's PON GOV chronicity (2014-2020) as a simultaneous investment to improve the use of and access to ICT Technologies and strengthen the institutional capacity of public authorities.

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Media (photos, videos (link), etc.):

- <https://aress.regione.puglia.it/en/aree-tematiche/sanita-integrata-e-digitale/corehealth>
- <https://www.youtube.com/watch?v=plPWFu7V4jk>
- <https://www.youtube.com/watch?v=hpM3TxAnGO8>
- <https://www.youtube.com/watch?v=iSKhFVVyOgU>
- <https://www.youtube.com/watch?v=8aT2AEL96C4>
- <https://www.youtube.com/watch?v=A4n2A6dcwUw>
- <https://www.youtube.com/watch?v=zj6PcTG0fIk>
- https://www.youtube.com/watch?v=f-O_XWTj7gl
- <https://www.slideshare.net/VitoPetrarolo/premio-forum-pa-sanita-2022-corehealth-aress-pugliapdf>
- <https://www.startupbusiness.it/i-vincitori-del-premio-agenda-digitale/121896/>
- <https://www.lagazzettadelmezzogiorno.it/news/in-salute/1398613/telemedicina-gia-6-200-pugliesi-monitorate-per-i-tumori-al-seno.html>
- <https://www.regione.puglia.it/web/press-regione/-/premio-alla-puglia-con-aress-per-le-buone-pratiche-di-medicina-personalizzata-nella-conferenza-finale-a-bruxelles-della-partnership-regions4permed?redirect=%2F>
- <https://www.youtube.com/watch?v=s9JJqNkgpx4>

SCOTLAND



Digital Remote Monitoring: Primary Care Hypertension Management Pathway

Implementation status:

Scotland is in the process of implementing this programme/strategy.

Summary:

The Scottish Scale up Best Practice programme was originally launched in 2019 with funding of £1.2m distributed across 11 health boards to implement remote monitoring of blood pressure in primary care. This followed the successful test of change and evidence from research using an SMS platform. The national programme team supported the expansion of a comprehensive learning network enabling the development of national resources and clinical engagement. NHS NES is supporting the skills and workforce aspects essential for supporting large scale adoption. The experience and knowledge of implementing a national approach to adoption informed the procurement and implementation of the new national platform in 2021.

This pre-COVID programme sought to establish remote monitoring as the mainstream method for diagnosing, titrating medication and controlling Hypertension in Primary Care as a key priority. Recruitment to the original programme continues using a new and updated pathway on the national platform.

Description:

Around 30% of adults in Scotland have high blood pressure. The number is set to increase as the population ages. Around half are undiagnosed and of these only 40% is fully controlled (worse in poor populations). It is the second commonest reason for attending a GP in Scotland (more than 1.2 million appointments per year).

The programme contributes to National Strategic delivery plans such as the Digital Health & Care strategy, Realistic medicine, Health & Well-being portfolio, Data strategy and the Preventative and Proactive workstream and is a priority area within Winter planning deliverables.

Using the solution, patients are registered by Primary care clinicians to receive **regular reminders** to submit blood pressure readings. They can choose between **app/online**, **SMS** or **automated telephone call** (mobile or landline keypad) to access the pathway.

The **digital pathway** provides options for both standard and lower-level parameters (adhering to clinical guidelines), days and times to suit individual preferences and an automated option to progress from diagnosis through medication titration to long term monitoring. This progression can also be controlled by the clinician to suit individual clinical need.

Currently over 75,000 people have been activated to use digital blood pressure monitoring with all 14 Territorial health boards in Scotland engaged. The aim is to reach at least 90% of all primary care GP practices by March 2025. It should be noted Scottish GPs are independent contractors therefore retain individual preference not to participate.

The infographic below shows current progress and outcomes/impacts and is cumulative from legacy system and new national platform.

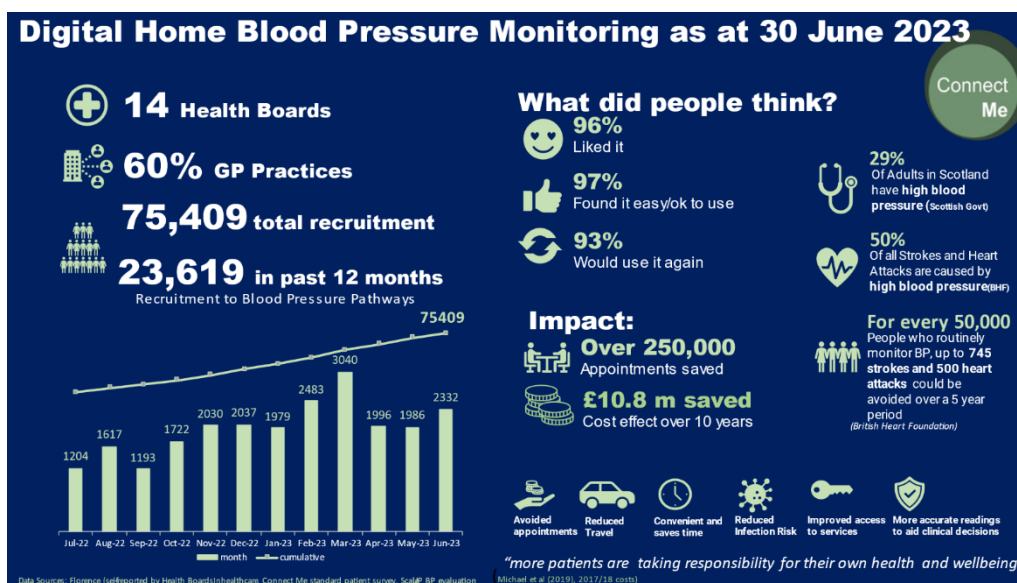


Figure 9

Methodology and processes:

Patients asked for a system which they could use with an APP and online as well as with SMS. They also wished to see their own results displayed graphically. Clinicians wanted, if possible, to widen participation to those who were not tech-savvy.

NHS Scotland DHaC commissioned a system (**InHealthcare**) which achieved provided multiple means of access to patients including touch-tone phone for those without smart mobiles.

The national programme has developed a streamlined process for the development of digital pathways enabling collaboration and co- production at every step.

This included data collection (national and regional) and evaluation planning.

Improvement methodology has been utilised throughout the process of developing, testing, and implementing the new pathway.

Integration with national CHI (NHS personal ID number) ensures individual reports are sent to GP system (Docman).

It is planned to integrate BP data from the legacy SMS system and the new national platform into a cloud-based data warehouse (SEER, hosted by NSS) to enable better access for performance reporting, evaluation, and future research both nationally and regionally.

The volume of blood pressure physiological readings data being generated using digital pathways will provide a comparison with readings obtained using traditional face to face or paper-based methods. **Territorial health Boards** will be provided with **direct access to their data** for further **linkage/integration with other local or national health and care datasets**. An improvement on the current standalone dashboards available from the system supplier.

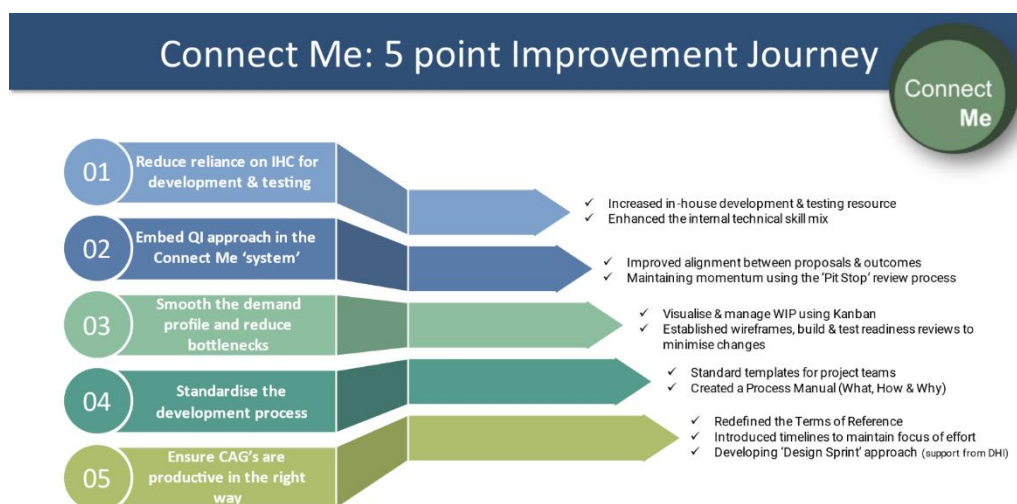


Figure 10

Involvement of other organisations/actors:

- **Connect Me:** This is the “brand” name used for the Remote Health Pathways programme in Scotland. Co - designed with Alliance Scotland to provide a public facing identity.
- **Scottish Territorial health Boards:** All 14 Health Boards are engaged with 12 boards already live using the pathway. The expectation is all boards will be live by December 2023.
- **InHealthcare Ltd:** national supplier of the platform and viewed as a technical partner in the development and build to agreed specification including enabling testing and the baseline integrations with each partner board. Contract signed November 2021 for 3+1+1 years.
- **NES (National Education Services):** Provision of design support and web-based materials for clinician and organisational education/guidance. Design support for patient literature.
- **NSS (National Services Scotland):** Provision of technical services (integration), account management and Programme management/administrative support services.

Funding source(s) of the initiative:

Scottish Government has funded the procurement of the national asynchronous monitoring solution contract for up to 5 years (3+1+1).

It is available to all Scottish Territorial NHS Boards in terms of licence and usage costs. Participating boards are responsible for implementation and local management of services using the solution.

Provision of Blood pressure monitors has been partially funded by Scottish Government through on recurrent budget. A paper is being prepared for submission to Chief Medical officer for a substantive national provision to enable ongoing sustainability and remove the current inequitable access for citizens.

Innovation, Impact and Outcomes:

Multiple RCTs including the CSO funded HITS study in Scotland showed telemonitoring resulted in 4mm BP reduction (much bigger in poorly controlled patients). This would result in at least a 18% reduction in stroke and 14% in MI/angina if sustained.

Cost effectiveness

The mean societal and clinical costs in the first 12 months after a stroke have been estimated at £45,409 and £24,003 respectively underlining the potential gains from lowering BP. A health economic analysis, applying modelling of potential health gains using data from the TASMINH 4 randomised controlled trial, showed that telemonitoring was likely to be cost-effective at a cost of £17,424 per quality-adjusted life year gained.

Recent research from NHS England shows evidence of a reduction over 5 years in the incidence of Heart Attacks and Stroke if hypertension is effectively managed.: avoidance of 750 strokes and 500 heart attacks per 50,000 people.

Evaluation is mainly based on contributory analysis and logic models as shown in the papers linked in the section *Further Information*.

Legal and/or ethical issues:

- Data Protection and Privacy Impact Assessment (DPIA) for the programme is in place as a nationally approved template.
- Each Territorial board requires to have this validated by their Information Governance Officer prior to implementation.
- The changes to Medical Device regulations (due to both EU and subsequent UK amendments) were taken into consideration during the contract negotiations and continue to be reviewed to ensure compliance.

Transferability to other regions:

The provision of large-scale data from Scotland and the evidence of impact using digital remote monitoring measured against traditional clinic appointments or non-digital management could be used to encourage similar programmes at scale in other regions.

Key learning points on barriers and enablers to the practice:

Barriers	Enablers
Culture shift for clinicians and patients	Pandemic impact: shift in digital adoption
Budget constraints (local and national)	Clear evidence of impact
Staffing resources /clinical capacity	Supplier relationship
Local systems diversity	Clinical leadership
Information Governance/MDR regulations	National programme support and facilitation
Supply of peripheral devices (BP monitors)	National Procured platform and pathway

Further information, if any:

Papers for Evaluation's contributory analysis:

- [Evaluation Report for NHS Scotland's Scale-up Blood Pressure Programme | TEC Scotland](#)
- [TEC Home and Mobile Health Monitoring Economic Case Studies | TEC Scotland](#)
- [Telemonitoring at scale for hypertension in primary care | TEC Scotland](#)

Other information: [Blood Pressure | Turas | Learn \(nhs.scot\)](#)

Media (photos, videos (link), etc.):

[Connect Me for Patients | TEC Scotland](#) Animation describing Connect Me and video clips from clinicians and patients using digital remote monitoring and what it means for them.

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HEALTH DATA USE and / or COLLECTION

CATALONIA



Health Data to share – Blue Button

Implementation status:

Catalonia has fully implemented a programme for health data use and collection.

Summary:

The Catalan public healthcare system has introduced an innovative tool, 'Health Data for Sharing-Blue Button,' the first of its kind in the European Union. This tool empowers users to securely download their clinical data for sharing with other healthcare systems or research endeavours. Users can access this feature through the 'Personal Data' section on the **La Meva Salut** (LMS) platform, where they can obtain documents in XML format, including diagnoses, treatments, vaccinations, test results, and allergies. Additionally, medical discharge reports are currently available in Catalonia, with plans to expand the range of information in the future. The Blue Button initiative, originating in the United States in 2010, aimed to provide war veterans with digital access to their medical records. Furthermore, the 'European Patient Summary' is now operational in collaboration with several European countries, allowing for the seamless exchange of medical information across borders to ensure appropriate care and mitigate language barriers.

Description:

The Catalan public healthcare system stands as the pioneer in the European Union, having developed a groundbreaking tool that enables users the ability to securely download their clinical data for sharing purposes with other healthcare systems or research entities. This innovative tool is known as 'Health Data for Sharing-Blue Button.'

Individuals seeking access to this invaluable data can conveniently **download the requisite documents in XML format** via the 'Personal Data' section within the La Meva Salut (LMS – Personal Health Record) platform. LMS is a **digital, non-transferable query space** that allows citizens to store all their personal healthcare information and use it in a secure and confidential manner. Furthermore, through this platform, citizens can perform electronic transactions.

In this manner, the functionality of the Blue Button has been integrated into LMS, offering Catalan citizens the opportunity to retrieve their **International Patient Summary**. The International Patient Summary (IPS) is a standardized health document that contains essential patient health information. It is designed to facilitate the exchange of patient information across borders and between different healthcare systems, with the goal of improving the quality and continuity of care for individuals who receive medical treatment in different countries.

The collated patient summary comprises critical medical information, including diagnoses, treatments, vaccinations, test results, and allergies. In Catalonia, the offering extends to the inclusion of medical discharge reports. Furthermore, there are plans to expand the range of available information in the future.

For individuals seeking unscheduled medical assistance abroad, there is no active involvement required to provide healthcare professionals with access to their medical summaries. **Authorization** only becomes necessary at the time of treatment. This service is set to facilitate the determination of the most suitable course of action, mitigate allergy-related risks, and overcome language barriers.

Methodology and processes:

The methodology for the implementation of the Blue Button good practice within the Catalan Health System has been as follows:

1. Definition of the data model in accordance with EU standards for data encoding.
2. Definition of the proof of concept.
3. Development of the necessary software.
4. Pilot testing.
5. Implementation into the system.

Involvement of other organisations/actors:

- CatSalut

Funding source(s) of the initiative:

This project has been entirely funded by CatSalut. Additionally, Tic Salut Social will allocate funds for the evolution of the Blue Button towards data sharing with the private sector. Furthermore, the EC will contribute to the BB project through the xShare initiative (starting in 2024).

Innovation, Impact and Outcomes:

Innovation

The Catalan public healthcare system has pioneered a transformative and forward-thinking solution known as 'Health Data for Sharing-Blue Button.' This innovative tool redefines the European healthcare landscape by empowering individuals to securely access and download their clinical data in a structured XML format. While the 'Blue Button' concept originated in the United States, the Catalan adaptation takes innovation to the next level, as it not only grants citizens control over their health data but also fosters **cross-border collaboration** through the **'European Patient Summary.'** This unique initiative sets new standards by enabling the seamless exchange of medical information across borders, bridging language barriers, and ensuring efficient, patient-centric healthcare services in collaboration with multiple European nations. It represents a groundbreaking leap towards the realization of the European Health Data Space's vision, embodying the ideals of data accessibility, privacy, and interoperability.

Impact and Outcomes:

The impact of the 'Health Data for Sharing-Blue Button' initiative has been profound, with several noteworthy outcomes:

- **Enhanced Patient Empowerment:** Citizens now have immediate, easy, and electronic access to their health data, granting them unprecedented control over their medical information.
- **Improved Healthcare Delivery:** The exchange of International Patient Summaries (IPS) enables healthcare professionals to make informed decisions, especially when treating patients from different countries, thereby enhancing the quality and continuity of care.
- **Mitigated Allergy-Related Risks:** With access to critical medical data, including allergies, the risk of allergic reactions during treatment is significantly reduced.
- **Language Barrier Overcome:** The tool addresses language barriers by providing standardized patient health information for healthcare professionals.
- **International Collaboration:** The 'European Patient Summary' collaboration with other European countries, and plans for future expansion, demonstrates Catalonia's commitment to pioneering cross-border healthcare data sharing.

- **Legal and Ethical Compliance:** The initiative adheres to the General Data Protection Regulation (GDPR) and aligns with the European Health Data Space (EHDS) standards and specifications, ensuring ethical and legal compliance.

Success Criteria:

The success of the 'Health Data for Sharing-Blue Button' initiative is determined by several key criteria:

- **Citizen Utilization:** The adoption and usage rate of the Blue Button tool among citizens, signifying the extent to which individuals are empowered to manage their health data.
- **Cross-Border Collaboration:** The extent of collaboration and adoption of the European Patient Summary among European member states.
- **Ease of Use:** The ease and accessibility of the tool for both citizens and healthcare professionals.
- **Data Security:** The successful safeguarding of patient data to maintain privacy and data security.

Impact on the European Health Data Space:

The 'Health Data for Sharing-Blue Button' initiative aligns with the principles of the European Health Data Space (EHDS) by providing immediate access to health data, adhering to international standards, and promoting cross-border data sharing. This initiative sets a precedent for the potential widespread adoption of similar practices across Europe to enhance healthcare data accessibility, quality, and interoperability.

Legal and/or ethical issues:

Access to the International Patient Summary (IPS) is typically granted to authorized healthcare providers and organizations involved in a patient's care. The primary goal of the IPS is to facilitate the exchange of essential health information across different healthcare systems and settings. On the other hand, the Blue Button (BB) promotes the secure sharing and access to personal health information by patients. It allows individuals to have easy and convenient access to their electronic health records (EHRs) and health-related data.

The Blue Button initiative has been developed to empower patients and promote patient engagement in their own healthcare. The Department of Health has developed the Blue Button (BB) as a feature of La Meva Salut (LMS), which allows a citizen to download their information in accordance with the HL7 C-CDA and Blue Button 2.0 standards and specifications, in conformity with the EU implementation guides certified by the Integrating Healthcare Enterprise (IHE).

In this way, Catalonia is committed to digital portability based on international standards, allowing citizens to move towards control of their health data: immediate, easy, free, and in an electronic, structured, and reusable format, becoming the first nation to enable BB outside the United States. This initiative is in line with the General Data Protection Regulation (GDPR) and advances toward what is established in the European Health Data Space (EHDS).

In the initial version, citizens will be able to download the summary of their electronic health record, the EU Patient Summary (EUPS), which follows the standard format established by the EU and aligns with the International Patient Summary.

Transferability to Other Regions:

The 'European Patient Summary' collaboration extends to several European countries, making it a transferable model for other regions. The European project **xShare** further aims to deploy and adopt a new version of the Blue Button in additional countries, fostering cross-border health data sharing and improving patient care across Europe.

The 'European Patient Summary' is now operational in collaboration with France, Portugal, Croatia, Luxembourg, and Malta, and will be available for 25 member states, that could potentially adopt the good practice.

Additionally, through the European project xShare (funded by Horizon Europe Programme), it is planned to work on the evolution, deployment, and adoption of a new version of the Blue Button in 8 countries (Italy, Greece, Portugal, Cyprus, France, Denmark, and Ireland).

Key learning points on barriers and enablers to the practice:

Barriers:

- **Data Privacy Concerns:** Addressing concerns related to data privacy and security, ensuring that citizens trust the system with their personal health information.
- **Interoperability Challenges:** Overcoming technical barriers and achieving interoperability with diverse healthcare systems and formats used by other countries within the European Patient Summary collaboration.
- **Legal and Ethical Compliance:** Ensuring compliance with evolving legal and ethical standards, including GDPR, and ensuring that data sharing remains in line with national and European regulations.
- **User Awareness:** Overcoming the challenge of raising awareness among citizens about the availability and utility of the Blue Button tool.

Enablers:

- **Strong Government Support:** Ongoing support from the Catalan Health Ministry and other government entities in terms of funding, policy, and regulatory framework development.
- **Collaborative Partnerships:** Effective collaboration with organizations like Fundació TIC Salut Social and SalusCoop for project development and implementation.
- **Standardization:** Adherence to international standards such as HL7 C-CDA and Blue Button 2.0, facilitating data exchange and interoperability.
- **Cross-Border Collaboration:** Collaboration with other European countries through the European Patient Summary, fostering international partnerships to overcome language barriers and facilitate data sharing.
- **Funding Sustainability:** Plans for sustainable funding, including contributions from Tic Salut Social and the European Commission through the xShare project, ensuring the continued evolution of the Blue Button tool.
- **Adoption of Best Practices:** Learning from the success of the United States' Blue Button initiative and adapting it to the European context, demonstrating the power of international knowledge sharing.

Further information, if any:

- <https://web.gencat.cat/es/actualitat/detall/Compartir-dades-cliniques-de-forma-segura>
- <https://catsalut.gencat.cat/ca/serveis-sanitaris/la-meva-salut/>
- <https://govern.cat/salaprensa/notes-premsa/502842/catalunya-posa-marxa-projecte-dades-salut-compartir-blue-button-que-permet-ciutadania-disposar-dun-resum-dades-seva-historia-clinica>

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FLANDERS

ALIVIA

Implementation status:

Flanders is in the process of implementing a tool for health data use.

Summary:

Alivia is a communication and planning tool developed to structure the organization of care to make it more person-centred. This tool supports **goal-oriented care**, organized around the patient together with the involved citizens. For data sharing, Alivia uses the data sharing and collaboration platform Vitalink (linked below), where data sharing takes place according to international information standards (HL7 FHIR). Alivia will facilitate collaboration between different care providers by improving digital data exchange. It is not an electronic health record, nor does it intend to replace one. Rather, the focus is on **data sharing for care planning within the care team**. This care team includes the patient as well as informal caregivers and professionals. In doing so, Alivia contributes to the primary care reform in Flanders by integrating health and social care. It is currently still under development, with its roll-out foreseen for 2024.

Description:

People with long-term or complex care and support needs often have several care providers from different disciplines and sectors, such as GPs, home nurses, psychologists, social workers, family support workers and specialists. Good cooperation is key. Alivia offers an easier and safer way for **task arrangements, planning, coordination, and communication between all parties involved** in the care and support team. In addition, the person with a long-term or intensive care need gets a better and complete overview of their care and support plan. They will also receive access to all information and will have an active and decisive voice in the choices made. This way we will achieve integrated, person-centred care.

Methodology and processes:

Four work packages have been developed. The first work package prepares a regulatory framework concerning the organization of care and support. It will form the **legal basis** for the care environment within which the digital care and support plan will be used. The second work package determines exactly what components (**functionalities**) will be included in the digital care and support plan. In short, what you will (and will not) be able to do with it. This is important for the IT subcontractor as they need to know exactly what the application will have to do and thus what needs to be created. A third work package is technical in nature and establishes the "**FHIR standards**." These are standards for exchanging data digitally between healthcare providers supported by Vitalink. The fourth work package defines the **pilot** projects that began in the spring of 2023. For each of these work packages, we involve stakeholders to give their input. There is also a broad stakeholder advisory board group to whom we provide regular feedback. By 2024 we want to be ready to roll out the digital care and support plan in Flanders.

Involvement of other organisations/actors:

The Department of Care¹ is the responsible entity for the overall start up and roll out of the instrument and is involved throughout all the steps of the process, from development to implementation to monitoring and evaluation. In addition, for each of these steps, the department works together with different partners, the most notable being the Digital Flanders Agency. The development of the IT tool itself is being outsourced to external partners.



Funding source(s) of the initiative:

The project is being funded as part of the “Flemish Resilience” COVID-19 recovery programme (linked below). It receives multi-year funding of 4 years, from 2022–2026.

There are a number of levers for further long-term sustainability, such as future financing for care coordination and case management, and the integration with other packages and solutions such as BelRAI (linked below), electronic patient records and electronic medical records. Care coordination packages focusing on the exchange of data within care teams themselves are still a niche in the sector with so far, no known available commercial alternatives, making Alivia an innovative and unique project in the care sector.

Innovation, Impact and Outcomes:

The innovative aspect of Alivia lies in the fact that it brings together the various **care providers**, both **formal and informal**, including healthcare and social care, as well as the person with a long term or intensive care need on one platform. They all work together focused on the wants and needs of the person. This allows for the implementation of goal-oriented, person-centred integrated care.

The final impact and outcomes are yet to be observed, as the tool is still under development.

Legal and/or ethical issues:

Some of the challenges within the project include the legal base and its alignment with the European General Data Protection Regulation (GDPR) and the integration of Alivia into the current ecosystem. The current ongoing legal process involves:

- a temporary legal basis for the pilot projects.
- an amendment of the primary care (parliamentary) Decree to allow the use/linkage of data with the eHealth services and national register.

In a later phase, there will be a (parliamentary) Decree on data sharing covering the whole health and social care sector.

Transferability to other regions:

Alivia could be of interest to any region looking for a digital communication tool aimed at fostering integrated care around the patient, facilitating a goal-oriented, person-centred approach, and integrating both health and social care.

Being a digital tool, Alivia takes into consideration interoperability with other systems. **Vitalink**, is the backbone of Alivia. It is a platform for data sharing in health and care that offers citizens the necessary guarantees that all health data exchange is done with respect for their privacy and that the shared information is always accessible to them. The idea is to offer the same functionality for direct collaboration between care actors. As such, the Alivia case could serve as a good practice to other regions on interoperability and data sharing while keeping the aforementioned aspects into consideration.

Key learning points on barriers and enablers to the practice:

Some of the barriers we are facing at this stage in the project include:

- the integration of Alivia into the existing eHealth ecosystem.
- strict rules on privacy (cf. GDPR legislation).
- finding the right technical solutions takes time.
- the duration of the legal process (amendments to existing decrees).

Some of the main enablers at this stage in the project are:

- co-creation with stakeholders.
- sufficient human and financial resources (cf. Flemish Resilience).
- clear and shared vision on goal-oriented and integrated care within the Department.

Further information, if any:

[Alivia in English | Zorg en Gezondheid \(zorg-en-gezondheid.be\)](https://zorg-en-gezondheid.be)

[Vitalink | data sharing & collaboration platform for health & care in Flanders](#)

[Vitalink | Vitalink](#)

[Vlaamse Veerkracht | Vlaanderen.be](#) / [Flemish Resilience | Flanders.be \(vlaanderen.be\)](#)

[BelRAI](#)

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GGD ZUID LIMBURG



Euregional Health Atlas (EHA): A dynamic platform for collecting, sharing, and visualizing health-related data within the Euroregion Meuse-Rhine (EMR)

Implementation status:

GGD Zuid Limburg has fully implemented a platform for Health Data use and collection.

Summary:

The Euregional Health Atlas (EHA) is a dynamic platform for collecting, sharing, and visualizing health-related data within the Euroregion Meuse-Rhine (EMR), where Dutch, German, and Belgian border regions converge. The EMR includes South Limburg, Aachen, Limburg, Liège, and Ostbelgien. The EHA provides data on population health, healthcare resources, demographics as well as project related data. It expanded during the COVID-19 pandemic to include a dashboard detailing COVID-19 cases, testing rates, hospitalizations, and deaths.

The EHA's methodology employs **transparent data sourcing**, utilizing Eurostat for regional statistics, supplemented with national sources as well as project related information. Collaborative partners ensure data reliability and comparability and enhance cross-border insights. Sustainable funding from the ERDF and project partners backs the initiative. The EHA addresses **data gaps** in the EMR, supporting professionals, policymakers, researchers, and the public to engage with localized health data. Its methodological blueprint is transferable, offering an adaptable framework to address cross-border health challenges elsewhere.

Description:

The EHA is a platform for collecting, creating, and sharing knowledge on residents of the Euroregion Meuse-Rhine (EMR) through visualizing statistics, figures, and information on various geographical levels. The EMR is an area where border regions of the Netherlands, Germany and Belgium come together. The EMR consists of the Dutch region South Limburg, the German Zweckverband Aachen (Städteregion Aachen, districts of Düren, Heinsberg, Euskirchen), and the Provinces of Limburg, Liège, and the region of Ostbelgien, also known as the German-speaking Community, on the Belgian side.

The topics of the EHA include **healthcare, lifestyle, demographics, and quality of life**. During the Corona pandemic, the EHA was extended with a COVID-19 dashboard. Until February 2023, this dashboard provided a visualized and up to date overview of COVID-19 cases, tests (positivity rate), hospitalizations and deaths.

The EHA is intended for anyone with an interest in the health and well-being of EMR inhabitants.

Methodology and processes:

Sources and methods often differ between countries; therefore, the source of every indicator is presented on the website in the tab 'Justification'. Data presented on the EHA originates from regional statistics (register data) or projects conducted in the EMR.

At the heart of regional statistics is NUTS — the EU's classification of territorial units for statistics. This regional classification for EU Member States is based on a hierarchy of regions and subdivides each Member State into regions that are classified according to three different levels, covering NUTS levels 1, 2 and 3 from larger to smaller areas.

The most important source of regional statistics presented on the EHA is Eurostat. Eurostat is the statistical office of the European Union. Eurostat collects, compiles, and publishes statistics for the EU and euro area, as well as national, regional, and other subnational data. Most regional statistics presented on the EHA originate from Eurostat. However,

several statistics are only available on NUTS 2 or NUTS 1 level. Therefore, data from the national statistical offices (such as Statbel, LZG NRW or CBS) were used to supplement the figures when available on NUTS 2 or NUTS 3 level.

Belgium:

The Belgium regional statistics were retrieved from the following data sources:

- SPMA tool (Standardized Procedures for Mortality Analysis) developed by Sciensano.
- Statbel.

Germany:

The German regional statistics were retrieved from the following data sources:

- Landeszentrum Gesundheit Nordrhein-Westfalen (LZG NRW).
- Information und Technik Nordrhein-Westfalen (IT.NRW)

The Netherlands:

The Dutch regional statistics were retrieved from the following data sources:

- Open data portal from the National Statistics Bureau (CBS).

Moreover, data on euroregional projects is presented on the EHA. These projects gathered quantitative data in the EMR. Through collaboration between different partners, the euroregional projects provide reliable figures and statistics which are comparable across borders in the Euroregion Meuse-Rhine at the lowest geographical areas. Comparability is especially enhanced within these projects because data is retrieved from participants in the three countries in the same way – with for instance the same questionnaire.

Involvement of other organisations/actors:

The EHA is a product of the collaboration between different partners.

Those partners are:

Partners in Data:

Interreg Euregio Meuse-Rhine (<https://www.interregemr.eu/>)

euPrevent (EMR) (<https://euprevent.eu/>)

Sciensano (BE) (<https://www.sciensano.be/en>)

Dirk Philippsen (Gesundheitsamt Düren) (DE) (<https://www.kreis-dueren.de/gesundheitsamt>)

GGD Zuid Limburg (NL) (<https://www.ggdzl.nl/>)

Project related partners:

Partners euPrevent SFC project (<https://euprevent.eu/sfc/>)

Partners euPrevent SNA project (<https://euprevent.eu/project-social-norms-approach/>)

Partners euPrevent YES project (<https://euprevent.eu/yes/>)

Partners euPrevent COVID-19 project (<https://euprevent.eu/covid-19/>)

Funding source(s) of the initiative:

The Euregional Health Atlas is carried out within the framework of the Interreg V-A Euregio Meuse-Rhine project(s), euPrevent SFC and euPrevent SNA, and currently within the project euPrevent PROFILE (linked below) and the project YES 2023 (linked below). The EHA is thus supported with means from the European Regional Development Fund (ERDF), co-financing and project partners contributions.

Innovation, Impact and Outcomes:

On a national level, available data about the border regions are insufficient. The current data are not entirely representative and the ways in which data are collected differ between countries. However, 40% of all European Union citizens live in 360 land border regions according to Eurostat. In everyday life, European citizens generally perceive borders as virtually non-existent as they cross borders for everyday activities for visiting friends and family, for work, study, leisure, healthcare or for groceries and gasoline.

Studies show that European border regions suffer from higher unemployment rates, worse health outcomes, ageing problems, and greater poverty. Above that, living in a border region means fewer possibilities of employment, mobility, and healthcare.

To change this, a knowledge-based approach is inevitable and analyzing data at a subnational or regional level is often more meaningful since such an analysis may highlight disparities between different (border) regions.

Professional can use the EHA to:

Compare data on a local and (EU)regional level so that they can better understand each other's work across borders. Therefore, the EHA also contributes to better cross-border collaboration among health professionals.

Policy makers can use the EHA to:

Develop policy tailored to the interest of the population of the border region, based on local and (EU)regional knowledge. Furthermore, the EHA enables databased knowledge sharing and can promote cross-border policy development.

Researchers can use the EHA to:

Improve comparison of data. Lacking harmonised data across countries hinders the health research on the population. To study and collect data on the border region population is a task of large scale and requires collaboration of various stakeholders, for continuous years. For a regular or small research institute, this would be almost impossible. Therefore, the EHA constitutes a good basis for researchers to pursue further research on relevant topics.

General Public:

In addition, the data in the EHA is visualised in an easy-to-understand and appealing way. Therefore, the general public can have a direct view and straightforward impression of the situation. The EHA is furthermore easy to use and globally accessible, guaranteeing fast and uncomplicated access to the data.

Below, a selection of impressions from the EHA website:

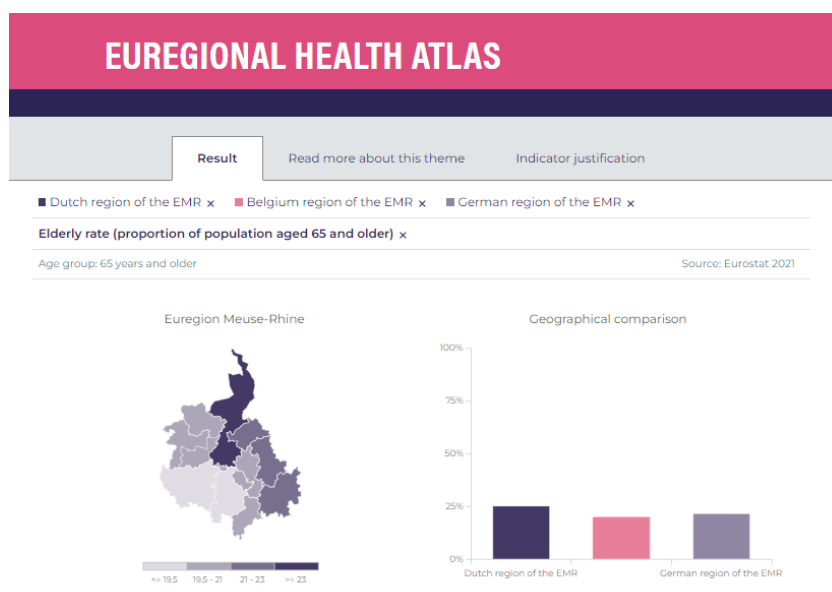


Figure 11 - EHA – Demographics: Elderly rate (proportion of population aged 65 and older) (13.09.23)

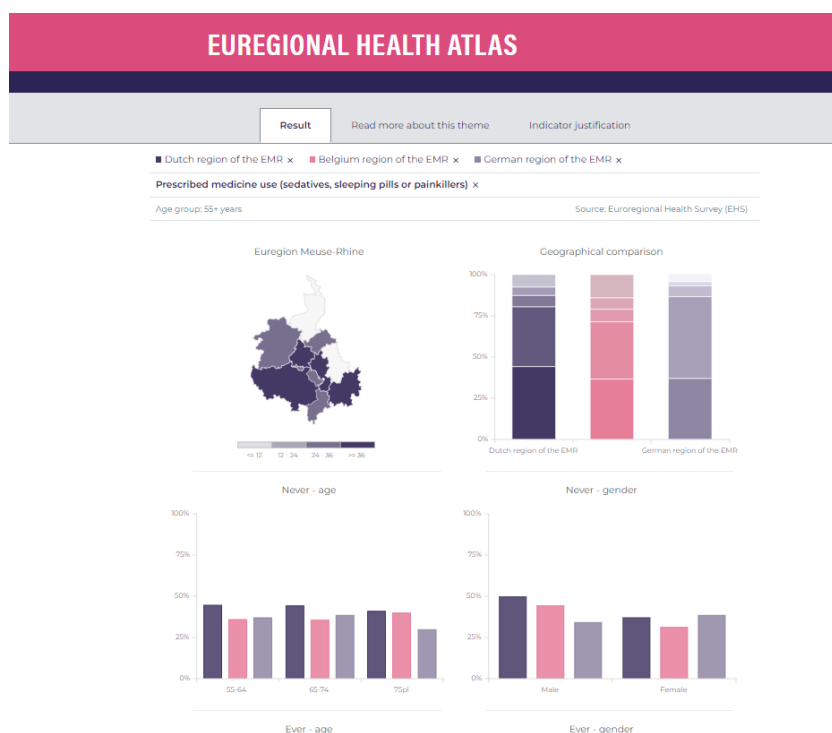


Figure 12 - EHA – project related data from the Interreg EMR funded project euPrevent Social Norms - Approach: Prescribed medicine use among senior citizens (55+) (13.09.23)

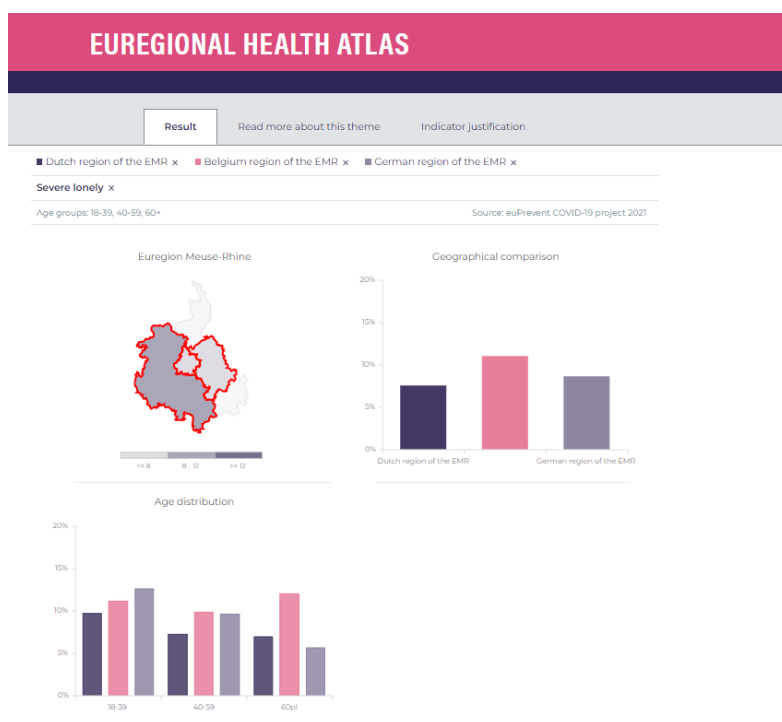


Figure 13 - EHA – project related data from the Interreg EMR funded project euPrevent PROFILE: Severe loneliness among adults in the EMR (13.09.23)

The traffic on the EHA website has seen a significant growth between 2020 and 2022.

Legal and/or ethical issues:

The EHA provides data for all three countries after addressing various legal and privacy-related challenges. This includes obtaining required ethical approvals, especially for medical projects, and ensuring strict compliance with privacy regulations such as GDPR (General Data Protection Regulation).

Transferability to other regions:

The EHA could be of interest for other organisations and regions for various reasons:

- **Cross-Border Health Insights:** Border regions often share similar health challenges and dynamics due to geographic proximity and interdependence. A health atlas tailored to such regions can offer valuable insights into common health concerns, enabling collaborative solutions as well as informed decision making among policymakers.
- **Collaborative Data Sharing & standardization:** As Health issues often transcend political boundaries, making cross-border collaboration essential. A collaborative atlas allows diverse stakeholders from different countries to share data, fostering joint efforts to tackle health disparities.
- **Resource Allocation and Subsidy Applications:** Accurate health data is crucial for securing resources and subsidies. An atlas can serve as a valuable resource for substantiating subsidy applications, supporting resource allocation, and attracting funding for regional health initiatives.
- **Research and Academia:** Researchers and academics can benefit from a centralized source of health data for cross-border studies. The atlas facilitates collaborative research projects that leverage shared data and expertise.

- **Public Awareness:** A user-friendly health atlas platform can empower residents to understand their region's health landscape better. Accessible information encourages proactive health behaviors and community engagement.

Transferability Key learning points on barriers and enablers to the practice:

Barriers

- **Data Discrepancies:** Variances in data collection methods and standards across different countries complicate the creation of a harmonized and comparable dataset. Discrepancies in terminology and definitions need to be considered for data interpretation.
- **Legal and Privacy Concerns:** Sharing health data across borders can raise legal and ethical issues related to data privacy, protection, and compliance with different national regulations, potentially hindering data sharing.
- **Socio-cultural and Language Differences:** Different cultural attitudes towards health, lifestyle, and data sharing can lead to national differences between health data from the participating countries and need to be considered.

Enablers

- **Cross-Border Collaboration:** The existing strong collaboration in the EMR among regional partners, regional governments, healthcare institutions, and research organizations fosters data sharing, expertise exchange, and joint initiatives to overcome health challenges.
- **Technological Advancements:** The use of data visualization tools and a user-friendly interface makes the platform engaging and accessible to a wider range of users.
- **Funding Opportunities:** The various funding sources, such as regional development funds, grants, and partnerships, ensure the sustainability of the EHA.

Further Information:

- Website: <http://euregionalhealthatlas.eu/>
- Project Yes: <https://euprevent.eu/yes/>
- Euprevent profile: <https://euprevent.eu/profile/>
- Introductory video of the EHA: <https://www.youtube.com/watch?v=GDFx7aR35kA>
- Results of the EHA with regard to the Interreg project euPrevent PROFILE: <https://euprevent.eu/profile/profile-euregional-health-atlas/>

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GGD ZUID LIMBURG



Collaboration between research, policy, and practice to monitor and improve the health of our citizens.

Implementation status:

GGD Zuid Limburg has fully implemented and initiative for health data use.

Summary:

To make good health policy, municipalities, provinces, and the government need insight into the health and well-being of citizens. Therefore, the health, social situation and lifestyle of the Dutch population is examined with questionnaire surveys called the **Health Monitors**. With these monitors all regional GGDs (Public Health Services) in the Netherlands collect data in the same way. This makes data available at national, regional, and local levels.

The health monitors have two different target groups: Youth (aged 13–16 years) and (Older) Adults (aged 18 years and older). These monitors are both conducted every 4 years. The Youth Health Monitor is a collaboration between the GGDs (united in GGD GHOR Nederland) and RIVM. The Adult & Senior Health Monitor is a collaboration between the GGDs (united in GGD GHOR Nederland), RIVM and CBS. Both Health Monitors are commissioned by the Ministry of Health, Welfare and Sport (VWS) and municipalities.

Description:

Municipalities in the Netherlands have a legal obligation to monitor the health of their residents. This statutory task is carried out for the municipalities by the Regional Public Health Services (GGD). The monitor results form an important basis for the development and implementation of local, regional, and national health policy. For example, the results may show that more help is needed for certain groups or that extra facilities are required in a municipality or neighbourhood.

Youth Health Monitor (ages 13–16 years)

The Youth Health Monitor provides insights into the health, well-being, and lifestyle of secondary school students. The survey takes place every 4 years and is carried out by all GGDs in the Netherlands in collaboration with GGD GHOR Nederland and RIVM. All regional GGDs in the Netherlands collect the data in the same way and publish results at the national, regional, and local level. Moreover, school results provide input for prevention activities at individual schools.

The Adult and Senior Health Monitor (ages 18–64 years and ages 65 years and older)

The Adult and Senior Health Monitor provides insights into the health, well-being and lifestyle of Dutch people aged 18 years and older. The survey normally takes place every 4 years and is carried out by the GGDs, GGD GHOR Nederland, RIVM and CBS (Statistics Netherlands). All regional GGDs in the Netherlands collect data in the same way and publish results at the national, regional, and local level.

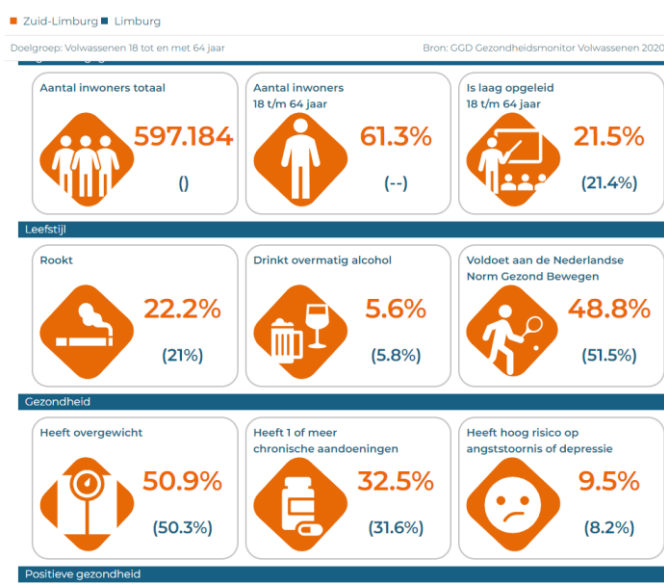


Figure 13

Methodology and processes:

The processes for both monitors are the same: preparation is done jointly at the national level. National working groups determine which themes and questions will be included in the questionnaire. Apart from national questions there is room for some local questions per GGD. GGD South Limburg and GGD Limburg North prepare this local part together to have a regional questionnaire for the Province of Limburg.

Youth Health Monitor (ages 13-16 years)

All secondary schools are asked to participate in the Youth Health Monitor. A digital questionnaire is administered to second (ages 13/14 years) and fourth (ages 15/16 years) graders. The questionnaire is completed in class under the supervision of a teacher. The questionnaire consists of **basic information** such as age, gender, height, weight, and postal code. To determine the health situation, questions are asked about basic living conditions, family situation, self-assessed physical health, mental health, stress, bullying, nutrition and exercise, risk behaviour and substance abuse, gaming and social media, sexuality, school, leisure, and friendship.

The results and trend figures are published at an online dashboard per target group, per theme, per region and per municipality. Furthermore, individual reports are put together for all schools and municipalities.

The Adult and Senior Health Monitor

The target population for the monitor is persons aged 18 and older who are residents of the Netherlands. Statistics Netherlands (CBS) selects people through random sampling from the Personal Records Database (BRP) for participation in the GGD Health Monitor. The selected persons together provide an average representation of the Dutch population. The people in this random sample will receive an invitation to fill in a questionnaire from the regional GGD, and this can be filled in either online or on paper. The questionnaire consists of **topics** such as: age, sex, household composition, education, work, financial situation, mental health, stress, loneliness, resilience, chronic disorders, health limitations (65+), height and weight, exercise, smoking, alcohol, social support, volunteer work, social activities (65+), and informal care.

The results and trends are published at an online dashboard per target group, per theme, per region and per municipality. Furthermore, data are published in health profiles at a district level. Additionally, individual reports are put together for all municipalities.

Involvement of other organisations/actors:

The Youth Health Monitor Youth is a collaboration between the GGDs (united in GGD GHOR Nederland), RIVM and the local schools. The Adult and Senior Health Monitor is a collaboration between the GGDs (united in GGD GHOR Nederland), RIVM and CBS. Furthermore, the GGD South Limburg collaborates with the GGD Limburg North.

The collaborations focus on:

- aligning questions and research methodology.
- aligning outcomes.
- exchanging knowledge.
- reducing survey pressure among citizens.

The parties collect and publish all data jointly.

Both Health Monitors are commissioned by the Ministry of Health, Welfare and Sport (VWS) and municipalities.

Funding source(s) of the initiative:

Municipalities in the Netherlands have a legal obligation to monitor the health of their residents every four years, this is stated in the Public Health Act (Wet publieke gezondheid). This statutory task is carried out for the municipalities by the regional Public Health Services (GGD).

Innovation, Impact and Outcomes:

To know what to do and what to prioritize when it comes to public health issues, data on the health situation of the population are needed for agenda setting, decision-making, implementation, and evaluation of a policy. The prevention cycle is an example of how policy cycle works in practice:

The Public Health Act stipulates that every four years the national government draws up a memorandum with the national priorities in the field of public health. The priorities in this memorandum are based on the Public Health Status and Forecast Report (VTV) of RIVM. This VTV describes the health situation in the Netherlands every four years on the basis of epidemiological data, from among others the GGDs. The national priorities offer municipalities starting points for local policy. On the basis of local epidemiological data, the **GGDs advise municipalities on local health policy**. Local governments can add local priorities to their policy plan, like drug abuse or school absenteeism among adolescents. The municipalities lay down the local health policy in a four-yearly municipal health policy memorandum. The Inspectorate for Healthcare (IGZ) monitors and reports on policymaking. This creates a cyclical process in which the VTV, the national policy and the municipal policy build on each other. Within this process, the data of both health monitors are an important source of information.

Additionally, the Youth Health Monitor provides information for individual schools. Together with a health promotion advisor from the GGD, schools can initiate preventive health policy and initiatives based on their school data.

Legal and/or ethical issues:

The health monitors are carried out in accordance with the General Data Protection Regulation (GDPR).

Transferability to other regions:

Building on the success of the national Youth Health Monitor, the initiative is already being transferred to neighbouring regions in the EMR (Euregio Meuse–Rhine) and ERMN (Euregio Rhine–Meuse–North) as “Youth Euregional Scan (YES)”. This collaboration exists in the EMR since 2001 and in the ERMN since 2023. This project is led by the GGD South Limburg and is financially supported by Interreg VI A Deutschland–Nederland. By pooling and analysing cross-border data, public health professionals in the EMR and ERMN can work together to develop targeted policies and improve overall health outcomes locally and for the region.

Key learning points on barriers and enablers to the practice:

- By collaborating on the Health Monitor on the national as well as the regional level, you can align questions and research methodology and align outcomes, which makes your data comparable at a national, regional, and local level.
- Collaboration on the Health Monitors enhances exchanging knowledge.
- Collaboration on the Health Monitors reduces survey pressure among citizens. Survey pressure is a general problem in epidemiological research.
- Collaboration on the Health Monitors determines the process on a national level, which may limit your regional influence. However, a lot of work is also done nationally, which could save up time for your regional efforts.
- Because of the many cooperating parties, it is not possible to include all individually preferred themes at the national level.

Further information, if any:

More information about the Health Monitors and regional health policy of the GGD ZL

- <https://www.ggdzl.nl/burgers/gezondheidsmonitors/>
- <https://www.ggdzl.nl/professionals/advisering-gemeenten/advisering-gezondheidsbeleid/>

Data of the GGD South Limburg Health Monitors:

- <https://www.gezondheidsatlaszl.nl/>

National data of the Dutch Health Monitors:

- <https://www.monitorgezondheid.nl/>

Euregional data of the YES project in the EMR:

- <https://euregionalhealthatlas.eu/>

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LOWER AUSTRIA



Digital nursing documentation in Lower Austria

Implementation status:

Lower Austria has fully implemented a programme for health data use and collection.

Summary:

Lower Austria has 50 public care homes, all operated by the Health Agency of Lower Austria. The care homes are spread throughout the region and provide barrier-free, multi-professional nursing and care for around 10,500 residents per year. Lower Austria has developed a person-centred model of care that emphasizes the promotion of independent life skills, self-determination, and a high quality of life for residents.

This care model is supported via an entirely digital nursing documentation that is centrally stored. In this one system, all medical and nursing processes are recorded, including master data, medical history, medical documentation, medication, nursing documentation, and (rescue) transports for each resident. All health professionals can easily access the nursing documentation, fill with new findings via portable laptops and stand PCs on each ward. The system is the same in each care home and allows time and location-independent access to data to provide best possible care.

Description:

Lower Austria implemented in all public nursing homes a **fully digitalized nursing documentation system**. From admission to care and support to discharge, all care processes and resident related data are documented paperless in one system. **All interdisciplinary occupational groups**, from administration to those involved in the care process, can **access** the resident file, and feed it with up-to-date nursing and medical data. They can access the digital nursing documentation via portable laptops and stand PC on each ward. In the near future, the documentation system will also be available from staff smartphones. The system connects with various external systems like 144/Notruf Niederösterreich (rescue transports) or eMedic (drug master data).

Benefits

Benefits of the digital nursing documentation are twofold. For the operation, it is a **uniform system for all care facilities** in the federal state of Lower Austria. Relocations or transfers run smoothly, and every stakeholder “speaks” the same language. Moreover, the system is well found by the Austrian Court of Auditors.

Regarding the users, the system allows a **time- and location independent access to health data**. Both administration and interdisciplinary health professionals work in the same system. The range of functions is wide and is expanded steadily. All in all, it is a user-friendly, technically stable documentation system for all occupational groups in nursing medicine.

New feature

The latest feature is **telemedicine wound care**. Via smartphones of employees or new communicative cameras, the nursing staff can take pictures of wounds to either trace the recovery process or in case send them to a wound manager in the hospitals via NÖBIS connection (see below). The expert who replies with a recommended treatment or with a possible prescription assesses the wound. The communicative camera (“**XotoCam**”) explains the nursing staff exactly how to make the right photo (distance, high-resolution, lighting) and independently measures the size.



Figure 14 - © XOTOTEC, retrieved here: OP-Kamera - XOTOCAM 1.0 - XotonicsMED - digital / Full HD / LED (medicalexpo.de)

Connections

The digital nursing documentation **connects to the Austrian Electronic Health Record** called ELGA (Elektronische Gesundheitsakte), which is used consistently throughout Austria. Data and medical documentation that is stored in ELGA can be retrieved and saved in the local patient documentation (e.g., medication, medical and nursing discharge letters, laboratory findings, findings of imaging diagnostics). In the near future, the latest nursing situation report (long-term care) can be added to the ELGA system and be retrieved from health professionals who have current access rights (e.g., hospitals/nursing homes/health professionals/GPs/pharmacy). The ELGA system however has an **opt-out option** for patients.

The nursing and IT department work on a **connection** of the regional nursing documentation system **to NÖBIS** (=NÖ Befundinformationssystem), a system that connects the 27 Lower Austrian hospitals with each other and where medical findings, laboratory reports, radiology findings and discharge letters are being exchanged without opt-out option for the patient. The nursing documentation system works within Lower Austria and is not yet connected to other federal states.

The nursing documentation system is in full operation, and all data is stored on an own data centre provided by the federal government. The data centre comprises around 70 servers, which are supervised by external IT companies that ensure highest security standards.

Methodology and processes:

The digital nursing documentation system works on the common standard HL7 and comes from a producer on the European market. A success criterion for implementing this new IT system was definitely the involvement of health professionals/staff from the field. For the tender, a comprehensive specifications book was written by the department of Strategy & Quality Care in close cooperation with interdisciplinary experts from the field to ensure that all necessary prerequisites from day-to-day care were pictured for the new digital documentation system.

Once a suitable supplier was found, a sporty timetable of 2 years for the introduction was chosen. In a first piloting phase, the system was introduced in a couple of nursing homes. Afterwards, it was rolled out to all remaining homes. Indeed, it was quite challenging to train 5.000 nursing professionals and around 1.000 other health professionals on the system, but with a well organised **train-the-trainer approach** it worked. A key-user group was introduced, each of them responsible for around 5 nursing homes, as a first contact point for questions and training. If a bigger support problem came up, they interacted with other key-users and the implementation partner. The key users are also involved in the further development process. Each three months, a mixed group from the field meets in a 'nursing forum' to discuss current topics related to the nursing documentation in order to make it piece by piece better.

Involvement of other organisations/actors:

Producer: Connex Communication GmbH (produces and develops standard software)

Sales and implementation partner in Austria: x-tention Informationstechnologie GmbH (direct support, tailors the software for Lower Austrian realities)

Other external links of the nursing documentation system:

- To 144/Notruf Niederösterreich for rescue transports (incl. live-mapping of the next ambulance).
- To residents' representations (ethical interests), in case of measures that restrict the freedom of a resident a notification is made, and direct communication is possible.
- To eMedic, every three months the drug master data is automatically updated in the system.
- To Eco-check, the prescribed doctor sees side effects, cheapest prices and have an interaction check (in case of multi-medication) of considered medicines.

Funding source(s) of the initiative:

The ongoing operation (including the data centre) is paid from the budgets of the nursing homes, the budget for further development and maintenance of the system lies within the headquarter of the Health Agency of Lower Austria. The digital nursing documentation system is thus financially secure.

Innovation, Impact and Outcomes:

- Include evidence on the impact and outcomes, if available.
- Outline the key innovative elements of your good practice, if available.
- What success criteria are used to determine that your initiative is working well?
- If applicable, please do also consider impact related to the upcoming European Health Data Space

The digital nursing documentation enables all care facilities in Lower Austria to carry out the medical and nursing documentation completely digitally and thus saves paper and time. The train-the trainer approach ensures that all staff has the required competencies to use the system similarly. As the system is used by 50 nursing homes and collects large amounts of uniform data, the evaluation possibilities e. g. in quality assessment are extensive. The data is also used in the company's **Balance Score Card**.

Legal and/or ethical issues:

The resident's contract in Lower Austrian nursing homes regulates all parts of nursing homes. It includes the full use of the nursing documentation system, which works anonymised. Due to the highly sensitive data of around 6.000 current residents, IT security and compliance with the Austrian data protection regulation is a top priority.

Transferability to other regions:

The digital nursing documentation is definitely a game changer to paper-based documentation systems. The benefit that its one uniform system in nursing homes all over Lower Austria weighs up the costs and efforts of implementation. Once technical, ethical and usability concerns are solved one can rely on a technically stable IT system that allows best and up-to-date nursing documentation for all residents. The system runs on HL7 standard and can be expanded according to wishes and needs for everyday nursing and care in Lower Austria.

Transferability Key learning points on barriers and enablers to the practice:

- close collaboration with the implementation partner is essential to tailor-made the software to local realities
- a well organised train-the trainer approach helps introducing a new IT system
- regular 'nursing forums' help to maintain and improve the quality of the documentation system

Further information, if any:

ON nursing and care homes in Lower Austria (only in German): [Niederösterreichische Pflege- und Betreuungszentren](#)
[| Niederösterreichische Betreuungszentren \(noebetreuungszentren.at\)](#)

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VENETO REGION



REGIONE DEL VENETO

The experience of the secondary healthcare data usage platform in Veneto Region

Implementation status:

Veneto has fully implemented a programme for health data use and collection.

Summary:

The **Veneto Region has established a platform for secondary health data usage**, strictly adhering to GDPR requirements. This initiative focuses on comprehensive stakeholder engagement within the healthcare ecosystem, employing a principled data governance approach that emphasizes standardization throughout the data lifecycle. The platform, crafted as a **serverless cloud solution**, ensures scalability, cost efficiency, resilience, real-time data processing, security, and collaboration. Secondary data usage serves diverse purposes, enhancing healthcare administration, evaluating service quality, monitoring healthcare expenditure, and contributing to bio-surveillance. The approach aligns with the big data 5Vs and has successfully empowered healthcare institutions in Veneto to make informed decisions based on real-time insights.

Description:

In the Veneto Region, a platform has been established for the secondary utilization of health data in strict accordance with national and international data regulations (e.g., GDPR). This data is primarily gathered for healthcare purposes, particularly within the framework of FSEr (the Regional electronic Health Information Exchange system) and is subsequently employed for governance-related matters in an anonymized or pseudonymized manner. The primary objectives of this initiative revolve around fostering a **comprehensive and holistic approach** that engages all stakeholders within the healthcare ecosystem.

Methodology and processes:

For the creation of this platform, we adopted a principled approach to data governance, encompassing the entire lifecycle of data, with a strong emphasis on **standardization**. Our approach begins with the collection of data, followed by metadata governance, data processing within workflow procedures, and the retrieval and utilization of data. Ultimately, we transform data for secondary uses. This standardization effort spans both semantic and syntactic aspects. Furthermore, we take great care in managing data access controls and implementing rigorous **data quality checks**. Our approach aligns with the fundamental characteristics of the **big data 5Vs**, namely veracity, volume, variety (comprising diverse documents, e.g., structured, and unstructured documents, and data types), velocity, and value (reflecting the intrinsic worth of health data). This comprehensive strategy ensures that secondary data usage in the Veneto Region adheres to the highest standards of quality, privacy, and regulatory compliance.

This data governance approach has empowered the establishment of a robust secondary data management system, underpinned by knowledge-based ontology, ensuring the integrity and quality of data. This approach is instrumental in enabling real-time data provisioning and access, thereby facilitating immediate data analysis. The objectives of secondary data usage within the healthcare institutions, including the Veneto Region Institution, the Regional Agency for healthcare (Azienda Zero), and all the Local Health Authorities and Hospital Trusts, encompass a wide spectrum of functions. These functions play a pivotal role in enhancing the effectiveness and efficiency of healthcare delivery. For instance, they include the **planning, management, control, and assessment of healthcare services**. This involves monitoring the level of digitization within healthcare organizations, as well as assessing the quality of clinical and socio-health information. Moreover, secondary data usage serves as an invaluable tool for evaluating the quality and effectiveness of services provided, such as the management of waiting lists. Furthermore, it plays a significant role in monitoring **healthcare expenditure and consumption trends**. Additionally, it contributes to bio-

surveillance systems, such as the monitoring of antibiotic resistance. In summary, the utilization of secondary health data within the different healthcare institutions serves a multifaceted purpose, from optimizing healthcare administration to safeguarding public health through real-time data-driven insights and informed decision-making. Moreover, the adoption of a serverless cloud architecture for secondary data usage not only leverages the advantages of cloud computing but also aligns with the dynamic and data-intensive nature of healthcare, empowering institutions to better serve their communities and enhance the quality of care provided.

Involvement of other organisations/actors:

The inclusive perspective acknowledges the essential role played by various actors in the healthcare sector: from data producers (including primary care, public and accredited private hospitals, as well as individual citizens and pharmacies) to data users, and service beneficiaries (comprising healthcare professionals, citizens, and healthcare institutions).

Funding source(s) of the initiative:

Regional health fund.

Innovation, Impact and Outcomes:

The secondary data usage platform has been meticulously crafted as a fully serverless cloud solution, capitalizing on the myriad advantages offered by cloud computing. This approach offers a host of benefits/impacts, including:

- **Scalability:** The cloud-based architecture provides elastic scalability, allowing the system to effortlessly expand or contract in response to changing data demands. This flexibility is paramount in handling the vast and variable volumes of healthcare data effectively.
- **Resilience and Reliability:** Cloud solutions come with robust redundancy and failover mechanisms, ensuring high availability and reliability. This resilience is vital in maintaining continuous access to health data, a mission-critical requirement for healthcare institutions.
- **Cost Efficiency:** A serverless approach minimizes infrastructure overhead, ensuring that resources are utilized efficiently. This cost-effective model is particularly crucial for healthcare institutions aiming to allocate their budgets judiciously.
- **Collaboration and Accessibility:** Cloud solutions support seamless collaboration among various stakeholders, allowing authorized individuals to access and analyse data from diverse locations.

Outcomes

- **Real-Time Data Processing:** The cloud-based architecture facilitates real-time data processing, enabling healthcare professionals and institutions to access up-to-the-minute information for timely decision-making, including in emergencies and critical patient care scenarios.
- **Security and Compliance:** Cloud providers often adhere to stringent security and compliance standards, offering strong data protection measures and ensuring that health data remains confidential and in accordance with regulatory requirements.
- **Futureproofing:** Cloud solutions provide an avenue for continuous technological updates and enhancements, ensuring that the system remains relevant and adaptable to evolving healthcare data needs and regulatory changes.

Legal and/or ethical issues:

The platform has been established for the secondary utilization of health data in strict accordance with national and international data regulations (e.g., GDPR). This data is primarily gathered for healthcare purposes, particularly

within the framework of FSEr (the Regional electronic Health Information Exchange system) and is subsequently employed for governance-related matters in an anonymized or pseudonymized manner.

Transferability to other regions:

Some possible steps to transfer this practice could be:

- Continuing sharing the best practices
- Identifying relevant key stakeholders and fostering their engagement;
- Understanding data governance requirements;
- Designing a serverless cloud solution;
- Customizing further platforms;
- Monitoring and evaluating the impact.

Key learning points on barriers and enablers to your practice:

Enablers

Privacy concerns; data security; technical challenges; Data quality and standardization.

Enablers

Adoption of a principled data governance approach, standardization, and the implementation of a serverless cloud solution.

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BOOKLET

**Best Practices
on Health Data**

