FROM BIG DATA TO SMART HEALTH

PUTTING DATA TO WORK FOR THE PUBLIC´S HEALTH

Data Strategy for Next Generation Portuguese National Health Service

Advanced Analytics and Intelligence Unit
Information Systems Department

Shared Services of the Ministry of Health

REPÚBLICA PORTUGUESA SAÚDE
40 SNS SERVIÇO NACIONAL DE SAÚDE
SPMS Serviços Partilhados do Ministério da Saúde

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FOREWORD

The World Health Organization's health policy for Europe, Health 2020, recognizes the strengthening of health information systems as one of the fundamental steps of health systems transformation to face current challenges: ensure universal health coverage, improve healthcare quality and reduce costs.

Fourteen years after the adoption by the Fifty-Eighth World Health Assembly of the eHealth Resolution, which advised Member States to adopt e-health for health systems strengthening, Portugal has made considerable progress in the digital transformation of the National Health Service. We are, now, well placed to proceed with the development of cost-effective models, led by information, to improve the quality and safety of healthcare and to strengthen public health surveillance and response capacity.

Realizing the promise of eHealth, the "safe use of information to support health and health-related factors" will require robust governance and leadership, multisectoral collaborations to establish the technical-scientific base and definition of shared models to improve quality, while ensuring respect for the principles of data protection, privacy and fairness.

The best available evidence indicates that data science and artificial intelligence, as well as the extension of telehealth networks, supported by high-quality data, will improve quality of care, management of resources and sustainability.

The National Health Service holds an ever-increasing, comprehensive data on people´s health across their life time that is a unique source of value for Portugal. To realize its potential for public health is a national policy imperative. Data governance will shape the future direction of healthcare management, accountability, precision medicine and public health intelligence for Portugal´s next generation National Health Service.

I believe that exploring this new "HEALTH DATA SPACE" is a national priority, but not in isolation, rather alongside other EU Member States, with whom we can learn, share and explore data value for health together, using common tools and common approaches in the wider EU space.

Henrique Martins, Lisbon 29th August 2019

SCOPE AND STRUCTURE

"From big data to smart health: putting data to work for the public´s health" is the Data Strategy for Next Generation Portuguese National Health Service. It sets out the vision, key areas and principles for secondary use of data, advanced analytics and artificial intelligence to improve Portuguese population´s health. This strategy is an integral part of the wider eHealth National strategy 2020- 2022, ENESIS 20|22 (National Strategy for the Health Information Ecosystem | *Estratégia Nacional para o Ecosistema de Informação da Saúde 2020- 2022*).

It calls all healthcare professionals, health organizations and relevant national and international partners, as well as the civil society, for collaboration.

I**t is structured in seven chapters. Chapter I** describes the regulatory background for secondary use of health data and artificial intelligence technology across the healthcare and public health sectors; **chapters II and III** define the vision and core values underlying a national health data strategy; **chapter IV** identifies key areas for achieving a data-driven National Health Service (stakeholder engagement, legal and ethical framework, advance primary healthcare-oriented analytics, enhance public health intelligence and develop a culture of innovation and collaboration); **chapter V** establishes the backbone principles for secondary use of data to the next generation National Health Service (robust governance, customer-centered approach, privacy and security, standards-based data, interoperability, use of new data sources, flexibility, openness to change, research and development); **chapter VI** outlines the journey of operational steps to be initiated and continued in the short, mid and long term; and finally, **chapter VII** describes the Health Intelligence Lab framework for innovation, allying secondary use of data and artificial intelligence in the National Health Service and ongoing flagship projects.

LIST OF ABBREVIATIONS

AI	Artificial Intelligence
IT	Information and Technology
OECD	Organization for Economic Co-operation and Development
NHS	National Health Service
WHO	World Health Organization
SPMS	Serviços Partilhados do Ministério da Saúde
EU	European Union
ECUs	Emergency Care Units

LIST OF FIGURES

CONTENTS

1 BACKGROUND

This document sets out the vision, strategic goals and roadmap of health data governance for secondary use, advanced analytics and artificial intelligence (AI) for the Portuguese National Health Service (NHS).

The overall objective is to provide guidance on handling big data in health within the existing legal and regulatory framework, advance secondary use of health data and foster innovative use of data science and artificial intelligence technology across the healthcare and public health sector for the benefits of society, individuals and the performance of the NHS.

Considering that, the success of adapting to new technologies and innovation depends on the way the enormous potential health data offers for improving people's health and health systems' performance is designed and used, this strategy builds on national and international recommendations and guidance, namely:

- Organization for Economic Co-operation and Development (OECD) Health Ministerial Statement *The next generation of health reforms* (OECD Health Ministerial Meeting, 17st January 2017) that underlined the commitment to tackle important challenges facing health systems around the world. These challenges include: improving the delivery of high-quality care for all while eliminating ineffective care; addressing how to pay for effective health technologies; measuring health system performance on the basis of what it delivers to people, as well as making better use of health data, and making health systems more people-centered. It also endorsed a new OECD Recommendation for governments to establish and implement a national health data governance framework that encourages the availability and use of personal health data (1).

- OECD Recommendation of the Council on *Artificial Intelligence*, OECD/LEGAL/0449 (OECD Ministerial Council, 22nd May 2019) the first intergovernmental standard to foster innovation and trust in AI, while ensuring respect for human rights and democratic values. This recommendation defined value-based principles for AI implementation and recommended policy makers to invest in AI research and development, to promote a digital ecosystem for AI, to enable a policy environment and human capacity building and to strengthen international collaboration for trustworthy AI (2).

- European Commission, Directorate-General for Health and Food Safety, Health Programme *Study on Big Data in Public Health, Telemedicine and Healthcare* (Final Report, December 2016) that covers recommendations for big data use on awareness raising, education and training, data sources, open data and data sharing, applications and purposes, data analysis, governance of data access and use, standards, funding and financial resources, as well as legal aspects and privacy regulation(3).

- European Commission Communication on *Artificial Intelligence for Europe* (European Commission, 25th April 2018) that recommended

development and use of AI for good and for all, building on European Union (EU) values and strengths. It urged European leaders to: put AI at the top of their agendas and seize the opportunities that come both from developing innovative AI solutions and applying them to a range of fields, including the healthcare sector, where AI has disruptive potential; capitalize on research and public sector data, which can be unlocked to feed AI systems; to make data sharing easier and to open up more data – the raw material for AI – for re-use. This should include data from the public sector as well as research related health data (4).

• European Commission, High-Level Expert Group on *Artificial Intelligence, Ethics Guidelines for Trustworthy AI* (European Commission, 8th April 2019) that established a framework for trustworthy AI. A trustworthy approach was set out as key to enable "responsible competitiveness" and the foundation upon which all those affected by AI systems can trust that their design, development and use are lawful, ethical and robust. These guidelines intended to foster responsible and sustainable AI innovation on the assumption that all legal rights and obligations that apply to the processes and activities involved in developing, deploying and using AI systems remain mandatory and must be duly observed, which is particularly relevant in the healthcare sector and personal health data (5).

• European Commission Communication on *Enabling the digital transformation of health and care in the Digital Single Market: empowering citizens and building a healthier society* (European Commission, 25th April 2018) that recognized digital solutions for health and care can increase the well-being of millions of citizens and radically change the way health and care services are delivered to patients, if designed purposefully and implemented in a cost-effective way. Data is a key enabler for digital transformation and EU should support action of member states to improve data quality, to promote research, disease prevention and personalized health and care, enable better health interventions and more effective health and social care systems (6).

• World Health Organization (WHO) Report by the Secretariat on *eHealth* (Document EB115/39, 16th December 2004) which recognizes that strengthening health systems through eHealth reinforces fundamental human rights by improving equity, solidarity, quality of life and quality of care. These benefits should apply not only to healthcare delivery, but also to public health, governance, finance, education, research, and health-related economic activities. It recommends fostering exchange of data and information for the promotion of health, health systems, and training of health-care workers, as well as, faster and more comprehensive epidemiological surveillance (7).

• WHO, 58th Health Assembly resolution on *eHealth* (WHA58.28, 24th January 2005) that noted the potential impact of advances in information and communication technologies have on healthcare delivery, public health, research and health-related activities. This resolution recommends member states to consider establishing and implementing national electronic public-health information systems and to improve, by means of information, the capacity for surveillance of, and rapid response to, disease and public-health emergencies (8).

• Portugal INCoDe 2030, Coordination Office of INCoDe.2030 guidance on *AI Portugal 2030*, Portuguese National Initiative on DIGI (4th June, 2019) that established a national strategy for AI considering that AI is already a powerful transformative technology driving all sorts of changes and with a wide-ranging effect in different domains, including health. It sets the basis of the national strategy for development of the Portuguese economy and society through the use of AI in public and private activities, and the consolidation of fundamental and applied research on AI. Portugal must foster strong investment in AI at national and European terms, mobilize key actors, identify key areas for development and mitigate risks for citizens and society (9) .

Together, these recommendations underpinned the development of this strategy and its guidelines reflect the most important expectations of big data and AI for health, as well as the foundational principles for ethical use of data, for privacy protection, safety, fairness and inclusion.

The Data Strategy for Next Generation Portuguese National Health Service is fully aligned with the national strategy for AI, AI Portugal 2030 (9) and is a strategic aim of ENESIS 20-22, the National Strategy for the Health Information Ecosytem (see Annex 1). It calls for a comprehensive approach to strengthen the digital transformation of the NHS, through strong national health data governance and uptake of the foreseeable benefits of AI technologies, for the public´s health.

II VISION

Portugal health policies must be guided by reliable health status indicators that measure efficiency of allocation of scarce public resources to improve health. Strong, data-driven health policies assure that Portuguese citizens receive high-quality and coherent care from a modern and efficient healthcare system.

Digital transformation in the Portuguese National Health Service has advanced significantly. Currently, our country has a *Digital* National Health Service (*e*NHS, e-National Health Service) that coexists with the traditional NHS encompassing healthcare provider institutions (hospitals, primary care units, continuity of care networks) and central agencies. The *e*NHS is composed by a network of multiple telehealth services and health information systems that collect and communicate data on people´s health and healthcare delivery.

One of the rapidly growing areas of innovation in the health sector lies in the use of data science and artificial intelligence, namely machine learning, computerized vision and natural language processing. The European Commission in 2018 (4) stated that the EU needs a sense of urgency to address emerging AI trends while, at the same time, ensure a high level of data protection, digital rights and ethical standards. It urged European countries to put AI at the top of their agendas to take hold of opportunities that come from innovative AI solutions applied to a range of fields, including the healthcare sector where AI has disruptive potential (4). As such, development of a health data strategy for secondary use, both for population health management and personalized medicine, is now a central cornerstone for the next generation NHS.

Like in other sectors, there is now more data stored about the health of the Portuguese population than ever before. Data stored in the *e*NHS is a unique source of value for Portugal and for health protection of the population. Furthermore, it is now possible to store and analyze this big volume of data much more cheaply due to intelligent computer processing skills which can quickly interpret large volumes of stored data. This aspect, in and of itself, has a recognized potential to transform all aspects of the health system as we know it (3).

The success of digital transformation of the Portuguese NHS is built on the promise of *big data to transform healthcare, public health and medical practice* to become more efficient and of higher quality through the intelligent operation of information systems: an evolution of the current digital national health service, *e*-NHS, to an intelligent National Health Service, *i*-NHS, that is data-driven by default and measures performance on the basis of what it delivers to the health of the population. Robust data – the raw material for advanced analytics and AI - is key to this achievement because the NHS can only be as *intelligent* as the quality of the data it holds.

The new, *electronic* data on population health, technical processing power and advanced telemedicine and communication platforms offer innovative opportunities to address the fundamental health system challenges of universal coverage, high-quality of care and financial sustainability. A transformation is more than needed for the Portuguese NHS that faces considerable pressure on human and financial resources to a disproportionately ageing population with multiple comorbidities. It is also well recognized that reforming health systems to face current challenges cannot be done with traditional interventions alone (10) (11).

The meeting of opportunity and need makes the present moment crucial to invest in information technology, data science and artificial intelligence in the Portuguese National Health Service.

Strengthening the collection, storage and reuse of health data will improve the capacity of the Ministry of Health to develop health policies informed by the best available evidence and strengthen national public health surveillance and response capacity, in favor of long and healthy lives for the Portuguese population. Advanced analytics and AI can be a major force driving national health policy.

Data must be used to leverage the NHS focus towards "health for all"(12) and primary health care through *precision* primary care services and *precision* public health(13).

Digital transformation and big data renewed the potential of sharing anonymized information with citizens, universities and civil society associations to develop health intelligence which emerges from national and international collaboration and collective effort (10).

Our vision highlights the use of data collected by national health information systems to enforce accountability and maximize the impact of information on health policy, healthcare and public health. As so, health information services must be viewed as a health service per se, more relevant than ever before and data governance and AI a key investment for sustainability of the NHS in Portugal. Success can only be limited by financial barriers, resources, flexibility and availability of trained health workforce.

CORE VALUES OF THE NATIONAL HEALTH SERVICE TRANSFORMATION LED BY *SMART* INFORMATION

FIGURE 1. Core values of National Health Service transformation led by smart information

For secondary use of data and AI to be foundational of a meaningful, responsible and ethical digital transformation of the NHS, the overarching values of trust, quality, efficiency and innovation must be placed at the core and accessed throughout the process.

1. MAINTAIN TRUST

Ensure the public´s trust in safe and confidential use of personal information is essential to the development of complex data analysis tools and artificial intelligence in the healthcare sector(14). Personal health information is a paradigmatic example of sensitive data and recent surveys indicate that data breaches influence people´s trust in digital services (15).

There is also increasing public´s interest in opportunities to exercise influence over and manage own´s data (15). The EU´s General Data Protection Regulation (16) that entered into force in May 2018 also improves individual's opportunities to influence the use of data about them.

Maintaining the public´s trust is strictly dependent on unequivocal commitment to develop and implement cybersecurity mechanisms, personal data protection, audits to data access and availability, trustworthiness, accountability and transparency in the use of advanced analytics and AI.

High-levels of people´s trust in governmental agencies around the secondary use of health data are one of the critical factors to succeed in the long term(15). Portuguese citizens need to know that their privacy rights are safeguarded in secondary use of data and to understand how and when data about them is shared, so that they can feel reassured that their data is being used for the public good, fairly and equitably (17).

2. DELIVER HIGH-QUALITY INFORMATION

The quality of information is paramount to its usefulness. Information must be reliable, up to date, independent and trustworthy for financial, clinical or population health purposes(18).

It is not possible to develop a reporting system or calculate indicators if there is no confidence in data quality from the beginning. Validity of data collection, adequate data quality management procedures ensuring high accuracy and adequate bias identification are specially challenging in the big data era and must be a central requirement of the NHS transformation led by information.

Implementation of a circular process of data quality assurance, not only at the time data is stored in the data warehouse, but at the source system – that is backed up by continuous data analysis - is the first requirement of data quality.

Investments are needed in professional training and development of a regulatory framework for data management, analysis and communication to deliver high-quality information, as part of a comprehensive ecosystem of data and related added value services. A well-functioning data ecosystem requires simple, cost-efficient and easy-to-use procedures to disclose data for knowledge generation on people´s health.

Data quality also includes appropriate selection of relevant health measures and standard indicators.

A range of data sources is available including administrative and health facility data, vital registration, personal health records and national health registries.

Matching the data item or indicator with the most appropriate and cost-effective tool for generating it is an essential function of the health information system but is not always straightforward (19). A complete review of the knowledge generation process is needed to make sense of big data for clinical decision support systems and population health.

There is no universal formula for a precise combination of data sources that will be optimal in every setting. Much depends on existing systems, that are themselves the products of history and social development, and so, multidisciplinary teams with adequate skill mix on how to interpret the data must be the basis to build smart inference chains that expand our understanding of health and care. Data alone, no matter how high quality, does not create better treatments or health outcomes (15).

This strategy endorses data quality as central asset of secondary use of data for health, including the necessary steps to ensure the right information, in the right hands, at the right time. High - quality information is a basic requirement to create a data-driven culture and stakeholder engagement. Therefore, trust in data must be extended to end-users to ensure they understand what they see and believe that it reflects reality.

3. EFFICIENCY THROUGH DATA INTEGRATION AND INTEROPERABILITY

The historical background of health information systems´ development, based on the "project" approach, resulted in scattered and differently codified data that does not yield a complete picture of a person's health (either for clinical practice or population health).

The word "system" implies a connected whole or organized process. In practice, like most countries, Portuguese health information systems lack such cohesion, having developed in a piecemeal way, fashioned by administrative, economic or legal pressures and invariably highly complex.

Thus, the development of a data governance framework in parallel with a central data repository (data warehouse) is the most important step towards efficiency (20). Making sense of big data for health planning and research needs a "secondary patient record" framework, a comprehensive assembling of data that includes relevant, prospective and updated, pseudonymized individual data for advance analytics and intelligence services operation. The data warehousing must be flexible to ensure easy access to information at the time of decision-making. Data extraction, cleaning and analysis has to evolve to increasingly simplified user-interaction platforms, with imbedded intelligent software applications that empower health professionals using the approach: People first – Process second – Technology third.

Likewise, health professionals and organizations in the Ministry of Health must be equipped with adequate skills to use data for identification of priority health problems, policy development, performance measurement and clinical and population health decision making.

4. DATA-DRIVEN INNOVATION IN HEALTHCARE

Innovation refers to transforming healthcare operations into data-driven processes, using technology and artificial intelligence to reshape management and accountability of healthcare service delivery and public health.

Healthcare innovation in the digital era is a national health policy requirement to support all the above-mentioned core values for secondary use of data and AI.

Digital transformation can boost innovation in the NHS by generating an increased supply of health data from multiple sources that can be assembled for a comprehensive picture of healthcare pathways and outcomes. Data-driven innovative solutions have the potential to change the face of healthcare making it adaptive, flexible, responsive to citizens, health professionals and the community(11).

AI-embedded IT solutions are being increasingly identified and adopted to support analysis and improve insights from research initiatives and translation of health research evidence into policy and practice. Many examples are already proving valuable in realizing the promise that AI holds for health systems. AI can be used to scale telehealth services and add value to communication platforms for home-based and integrated care; to develop self-learning algorithms that recognize patterns in data for clinical decision support systems; to develop computerized vision/Image recognition systems to extract information from images to increase sensitivity and specificity of diagnostic methods; to develop natural language processing algorithms that extract information from free text to decrease time spend in reviewing information for clinical and management purposes; to create early warning systems to detect public health emergencies, other risks of public health concern, and several other applications.

It is therefore important for the NHS to build a dedicated research environment for health intelligence, in partnership with private companies and relevant academic partners (for example through joint projects of applied research) and to have an active role in international AI research environments (21) to foster healthcare innovation in the national public sector.

IV

KEY AREAS FOR A DATA-*DRIVEN* NATIONAL HEALTH SERVICE

The substantial waste in health care systems, stemming from failure to coordinate and execute health policy to underuse of effective treatments and overuse of ineffective treatments, has given rise to value-based healthcare as a policy making priority (11). Effective use of big data can transform healthcare systems into value-based systems, but will require extensive commitment from all stakeholders, a strong legal and ethical framework, and a culture of innovation and collaboration. For data and AI to improve efficiency, the NHS needs a trusted environment to widen the realm of data reuse in health planning and primary healthcare, a focus on high-quality data for clinical decision support systems and use of new data sources for public health intelligence.

KEY AREA 1:

STAKEHOLDER ENGAGEMENT

Stakeholder engagement is a critical requirement to achieve data-driven transformation in the NHS. Data needs of citizens, health professionals, healthcare Institutions and central agencies must be accounted for since the beginning through a customer-centered approach to secondary use of data.

To achieve wide consensus for a data-driven transformation across the NHS, stakeholder engagement must include a communication and leadership strategy that creates flexibility and openness to change.

Communication, in a clear and proactive manner, information to healthcare professionals about the data and AI system's capabilities and limitations can enable realistic expectation setting about the manner in which the requirements are implemented. Communication channels should also be ensured with the public and/or public oversight groups, sharing best practices and discussing ethical concerns. As it cannot be expected that everyone is able to fully understand the workings and effects of AI systems, consideration should be given to organizations that can attest to the broader public that an AI system is transparent, accountable and fair(5).

Data must be used to keep people healthy and help patient empowerment in disease prevention, provide insightful information to health professionals for clinical decisions and improve management of healthcare institutions.

FIGURE 2. Key areas for a data-driven National Health Service

Involvement of stakeholders throughout the data life cycle also needs training and education so that all stakeholders are aware and have the appropriate skills to integrate data-driven technologies into daily operations (5).

CITIZENS

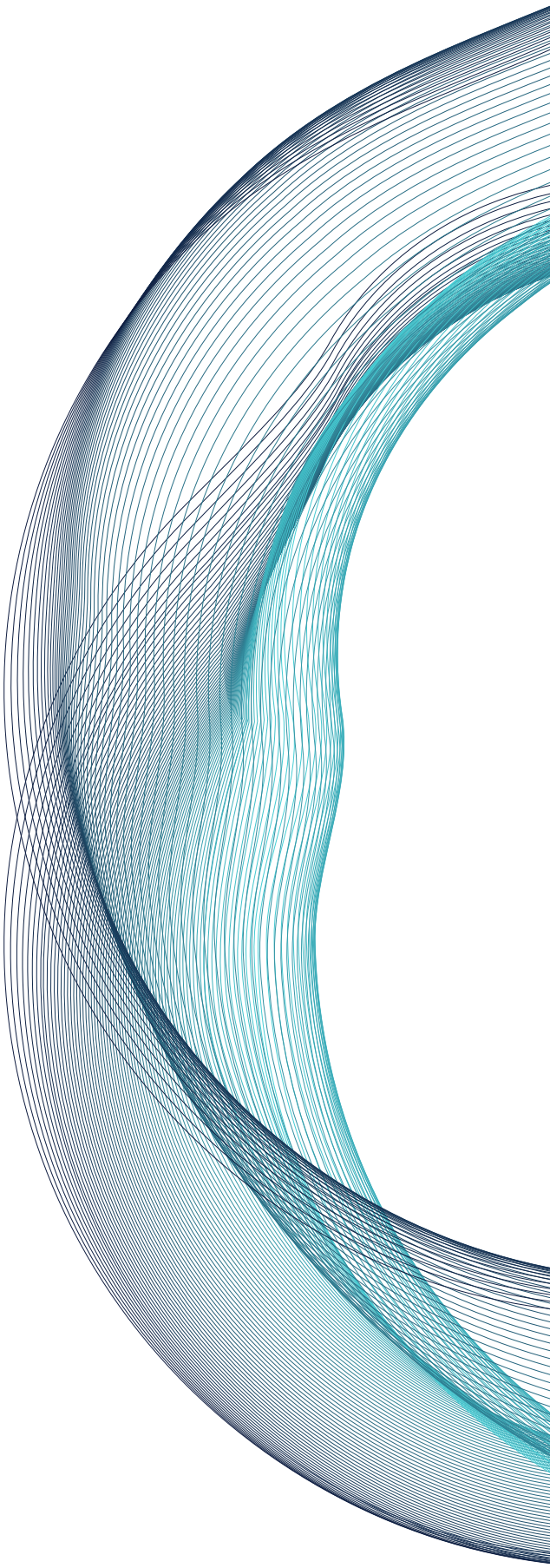
Supporting citizens to become active participants in managing their healthcare and wellbeing underpins the shift from reactive to preventive healthcare and can be reinforced by meaningful reuse of data along all citizens interactions with the NHS. Empowering citizens to make the right healthcare choices through access to relevant information ensures access to better value care. Robust data management provides faster access to information for personal healthcare management and targeted prevention that encourages participation in all health decisions.

Benefits of secondary use of data for citizens include:

- Reinforced accountability for personal health information management and data protection, privacy and security standards in the NHS;
- Transparency in decisions related to access and data sharing policies at all levels of healthcare;
- Personalized healthcare interactions and integrated models of care, using citizens´ own data to improve accuracy of disease prevention.

Citizens needs must drive the design, development and deployment of IT systems that share and analyze data to support healthcare related decisions, either for public health or clinical care.

Placing citizen at the core, ensures that investments in health data, advanced analytics and AI support an integrated health system that captures the complete range of needs from acute treatment to wellness management and that relevant NHS guidelines are incorporated since the beginning.



HEALTH PROFESSIONALS

Health professionals are all NHS workers, including clinical and non-clinical staff. Data-driven solutions will benefit health professionals transforming healthcare operations through intelligent IT tools to support decision-making, patient safety and improved information sharing across the NHS.

For clinical staff, delivery of consistent, accurate and real-time information can create better clinical outcomes, improve quality and integrated care, and safer and more effective treatment decisions based on high-quality, *smart* information.

For non-clinical staff, including NHS managers and administrators, data can improve financial outcomes through accurate resource planning based on high quality performance indicators.

High-quality data will also allow an holistic overview of the NHS that links financial and health outcomes ensuring evidence-based policy making and management decisions to improve overall efficiency.

HEALTHCARE INSTITUTIONS AND CENTRAL AGENCIES

A data - driven NHS can identify needs and tailor solutions for healthcare institutions and central agencies more efficiently, particularly for management of resources according to supply and demand.

Data-driven healthcare institutions can use analytic insights to drive improvements in service delivery and planning, safety, quality, prevention and appropriateness of care through timely access to linked data from a wide range of sources. Financial efficiency can also be improved through better operational management, based on high quality data for resource planning and performance monitoring.

KEY AREA 2:

LEGAL AND ETHICAL FRAMEWORK

To ensure the best possible ethical framework for secondary use of data and sustainable AI, our strategy endorses strong commitment to the foundational values of the NHS and the rule of law, as well as to the ethical principles set out in the European Commission "Ethics Guidelines for trustworthy AI" (5).

Health data analytics and AI are not an end in itself, but an opportunity to improve health, thereby enhancing individual and societal wellbeing and common good (5).The positive impact that big data and AI systems already have and will continue having, both in public health and healthcare must ensure that the risks and other adverse impacts with which these technologies are associated are properly and proportionately handled(5).

Citizens and health professionals will only have confidence in information and technology development and its applications if a clear and comprehensive framework for achieving trustworthiness is in place.

Trust in the development, deployment and use of data analytics and AI systems concerns not only technologies inherent properties, but also the socio-technical systems involving its applications(5). It requires a systemic approach, encompassing the trustworthiness of all actors and processes that are part of the system's socio-technical context throughout its entire life cycle(5).

Trustworthy secondary use of data and AI must ensure compliance with all applicable laws and regulations, ethical principles and values and *robustness* both from a technical and social perspective (5). Development, deployment and use of health information technologies and AI systems must be made in a way that adheres to ethical principles (respect for human autonomy, prevention of harm, fairness and explicability); pays attention to situations involving more vulnerable groups such as children, persons with disabilities and others at risk of exclusion; and acknowledges that these systems pose risks that may be difficult to measure or anticipate (5).

Technical and non-technical methods must be in place to ensure the implementation of those requirements in the design, development and deployment processes. End-users and the broader society should be informed about these requirements and able to request that they are upheld.

For data governance frameworks in the NHS to ensure accountability for the ethical dimensions of decisions associated with the development, deployment and use of AI systems. An internal **Health Information and Technology Ethics Board** should be appointed to provide oversight and advice (5). The *Health Information and Technology Ethics Board* would address the tensions between different principles and requirements and continuously identify, evaluate, document and communicate these trade-offs and their solutions.

Information systems and AI-backed information systems must guarantee privacy and data protection throughout a system's entire lifecycle. This includes the information initially provided by the user, as well as the information generated about the user over the course of their interaction with the system. It must be ensured that data collected about individuals will not be used to unlawfully or unfairly discriminate against them(5). The overall principle of user autonomy must be central to the system's functionality. Key to this is the right not to be subject to a decision based solely on automated processing when this significantly affects the user´s behaviours or decisions (5).

Operationalize ethical standards for trustworthy information and AI will require the incorporation of an assessment process into existing governance mechanisms, or implementing new processes, as needed, to be used throughout the systems' entire lifecycle. Accountability frameworks, including disclaimers as well as review and redress mechanisms should be facilitated by traceability and auditability procedures, particularly when dealing with AI systems in critical contexts or situations (5).

BOX 1

THE CASE FOR DATA DONATION

With the advancement of digital technology, large amounts of personal data are being recorded and retained by third parties, constituting an invaluable asset to both governmental and private organizations. There is now increasing interest in whether such data might also generate public good, and recent research work indicates that most people would be willing to donate their data for altruistic purposes. More so, the decision to donate personal health data depends on for what purpose the data will be used – as well as assurances on how securely it will be stored.

Data donation could be an important way to increase the availability of health-related data for researchers, scientists and policy-makers to analyse and translate data into meaningful reports and knowledge.

While donation schemes with dedicated regulatory frameworks have made relatively easy to donate blood, organs and tissue, it is virtually impossible to donate one own´s medical data. The lack of appropriate framework to govern such data donation makes it impossible to give away one´s medical data, even when this would be within the current limits of law. The importance of physical donations in the medical field is no longer questioned, but there is a lacking debate on the individual´s right to donate their health data.

Data sharing agreements can be made between health organizations/NHS and citizens to allow the later to donate/share their anonymized personal health information (i.e. a limited data set that is stripped of direct identifiers) for research, public health or healthcare planning purposes, to contribute to the common good by allowing that their data is used for other purposes that the initial data collection could not contemplate.

In such an arrangement, citizens would be able to donate data through a data-sharing agreement, i.e. a formal contract that clearly documents what data they want to share and how the data can be used. This agreement could serve two purposes. First, it could protect the individual providing the data, clarifying the purposes and means of data sharing and ensure data would not be misused. Second, it could prevent miscommunication on the part of the agency receiving the data by making certain that questions about secondary use of data were discussed and consented.

A *data sharing agreement* framework could improve trust and transparency in how the NHS uses citizen's data by ensuring that the citizen has detailed information to decide on how the data collected by healthcare organizations will be used. Legal and ethical considerations of secondary use of data and AI must access how personal health data is shared and used, and consider data donation as potential regulatory basis for increasing the value of data for the public's health.

KEY AREA 3:

ADVANCE PRIMARY HEALTHCARE-ORIENTED ANALYTICS

Comprehensive preventive, curative, rehabilitative, and palliative care throughout the life course, strategically prioritizing key healthcare services aimed at individuals and families (through primary healthcare) and the population (through public health functions) are central elements of national health policy (22) and a core value of the NHS.

Big data, advanced analytics and AI can have a major role in addressing the broader determinants of health (including social, economic, environmental, as well as people's characteristics and behaviours) through evidence-informed public policies and actions across all sectors. Secondary use of data for prevention-oriented health analytics aimed at population health monitoring, *precision prevention* and public health interventions will ultimately support the policy imperatives of primary care for all and universal coverage.

Primary healthcare also includes the key elements needed to improve health security and prevent health threats such as epidemics and antimicrobial resistance, through measures as community engagement and education, rational prescribing, and a core set of essential public health functions, including surveillance (22).

Systematically, consideration of big data potential to improve health is placed on personalized treatments and precision medicine. Secondary use of data must be aligned with core health policy objectives of strengthening primary health care and achieve the Sustainable Development Goals, as such, whenever possible, prioritize primary healthcare-oriented analytics. Information must be in line with implementation of knowledge-based health promotion and prevention strategies that can help address current limitations in healthcare delivery.

Digital health technologies provide innovative solutions to collect and process a massive amount of real time data. This has great potential to expand the capacity of primary healthcare to reduce risks and reveal unseen patterns or sensory features in a ubiquitous, personalized and continuous manner(23).

Advanced analytics and AI have a major role to play in generating "Smart Primary Care Environments" which can be defined as an ecosystem of interacting objects, e.g. sensors, devices, embedded systems, health professionals, patients, that have the capability to seamlessly provide services and manipulate complex data in a self-organize manner(23). In smart environments, technological devices and intelligent computing systems are adopted to analyse and manage daily activities of people. Transforming primary healthcare services to smart environments will help to solve issues related to ageing and dependency, for example monitoring chronic diseases and reducing medication administration error. It will also contribute to improve patient engagement and promoting cross-sector integration to realize the whole-person care(23). The quality, persistency and responsiveness of services in "Smart Primary Care Environments" will require handling the vast amount of data generated from interacted objects and big data analytics methods to support health professionals to use data integrated across the continuum of care (24).

Intelligent Health information systems will have a key role in next generation NHS commitment to further shift the focus of healthcare from treatment to prevention, ultimately leading to reduced expenditure on acute care, and improving quality of living and wellbeing of the population.

KEY AREA 4:

ENHANCE NATIONAL PUBLIC HEALTH INTELLIGENCE

Public health surveillance systems monitor trends in disease incidence, health behaviours, and environmental conditions in order to allocate resources to maintain healthy populations. "Big data" has unlocked novel opportunities to understand public health and data science and AI offer new methods for core public health functions(25).

Big public health datasets include new sources of data in major measurement domains of health: biology (as in genomic or metabolomic data sets); environment (as in Geospatial Positioning Systems data); medical record data that incorporate more participants than would be feasible in a study limited to primary data collection; biomarkers, taken automatically at extremely frequent intervals as by sensors and measures compiled from the data effluent created by life in an electronic world, such as search term records, social media postings, or cell phone records. All these categories of big data may contribute to inform authorities about the state of public health.

As the big data revolution continues, public health practice must continue to incorporate new data sources and emerging analytical techniques, while contributing to knowledge, infrastructure, and methodologies and retaining a commitment to the ethical use of data. Big data holds considerable potential to answer previously unanswerable questions, especially with the use of modern data science and AI/machine-learning techniques. Such successes may arrive more quickly and more rigorously to the extent that the public health services can embrace a specialized, team science model in training and practice (25).

However, the scale of these new sources of data poses analytic challenges as well. Some, like the "curse of dimensionality" associated with wide datasets, can be alleviated through the adoption of machine learning models, particularly in contexts where prediction or hypothesis generation rather than hypothesis testing is the analytic goal (ex. health surveillance).

PUBLIC HEALTH CORE FUNCTIONS

Advanced analytics and AI approaches can be applied to public health core functions in two broad types of opportunities: using AI to improve upon existing methods to answer a question; and address a novel question or challenge using AI (that could not be done before using traditional methods). Several areas of opportunity have been identified(26):

Tools to Support Interventions and Healthy Behaviours: AI can be used for predictive analytics to identify and predict segments of a population at risk or to predict temporal or spatial patterns of risk.

Understanding Pathways to Effect: Population health interventions can be enhanced using AI approaches, to better understand why some interventions work, in different contexts, and others do not. Analytic and explanatory AI tools offer the potential to better understand pathways that drive intervention outcomes and to capture more complex and comprehensive models.

Cross-sectoral Data Applications: AI tools increase the potential for applying cross-sectoral analysis to datasets related to the broader social determinants of health, such as education and social services. This information can then be used in decision-making by health and social service sectors to identify at-risk cases that need further support.

Learning from Observed Patterns in Complex Systems: Leveraging machines and techniques such as natural language processing to find patterns and make connections and linkages across multiple datasets offers advantages to obtain evidence that can help inform decision-making for policymakers and public health organizations.

Understanding Bias and Social Inequities: Public health can play a role in trying to understand bias and where it is coming from in AI. Public health is also in a position of identifying key examples of what AI could be used for, and examples of when either its use may not be effective or potentially could introduce inequities.

Population-level Social Interactions and Behaviours: At the intersections of systems science and data science, innovative AI approaches may allow for the ability to address broader social and global issues such as climate change, conflict, and instability, from a discovery perspective using computational approaches.

BIG DATA PUBLIC HEALTH SURVEILLANCE

To realize the potential that big data offers to public health surveillance there is a need to shift the focus form big data to “big indicators”—highly detailed, continuously produced, national indicators that track change in population health, in real time(27). “Big indicators” will form an important mechanism for guiding public health action, allow us to track the impact of our collective actions and interventions and enable better and more timely decisions, transform reporting, and empower new kinds of policy and financing instruments. “Big indicators” will address major current public health surveillance concerns as they improve traditional surveillance approaches in key features:

Precision and resolution: “big indicators” are based on real-time information and can monitor what is happening in a system with much greater spatial and temporal resolution, precision, and sensitivity. they might inform about a city or a particular neighbourhood with equal precision.

Frequency: Since they can be continuously recalculated, “big indicators” will tell us how a system is doing day to day, not just year over year.

Scale and Reach: “big indicators” can take advantage of the reach of new sensors and datasets to capture the state of systems previously too large, too remote, or too expensive to monitor effectively.

Predictive Capacity: As more data is collected in different domains, we can have indicators not only as markers of past change, but also the early warning signs of future change.

Sophistication: health systems behave in complex and sometimes counter-intuitive ways. “Big indicators” will provide understanding of these connections so that we can create more effective, comprehensive, and long-lasting interventions.

Comparison: “big indicators” will allow to compare patterns and processes across space and time that were not measurable before. They will, in effect, become new measurement and reporting standards.

Developing “big indicators” will be a complex undertaking—both technically and organizationally. First, the underlying data and insights that power them must be accurate, transparent, reliable, and widely accessible, as well as independently auditable and verifiable (27).

KEY AREA 5:

DEVELOP A CULTURE OF INNOVATION AND COLLABORATION

Data-driven innovation is about transforming ways of working and requires strong management and leadership. The fast change in the way technology can be used requires agile and iterative skills around governance and cultural shift in line with the move to digital, data-driven services.

The NHS must learn to adopt, iterate and continuously improve innovative solutions(24).
It will be necessary a collaborative approach that encourages local and national organizations to cooperate. Innovation in secondary use of data must be a shared process between data providers, data users, national health organizations and research partners throughout the healthcare system for safe and effective innovation that meets user needs.

Partnerships with universities and other research organizations, will help accelerate research, innovation and continuous learning on how to better inform health policy. Partnerships for research are also important to enable training of health data scientists for a highly skilled workforce.

To achieve the full potential of big data and AI for health the NHS must create a culture of innovation and collaboration that (21):

- Enables a specialized research and testing environment to develop innovative AI projects in the public sector, prototype and test solutions adapted to real world conditions in a safe and responsible manner;
- Guarantees the best innovations can be put into practical use so that the healthcare system, people and community can benefit;
- Improves tools to share knowledge and create structures to routine collaboration at national and international levels;
- Ensures stakeholders play key leadership roles in the development of new ideas and are empowered to support innovative technologies when they arise;
- Informs healthcare professionals and citizens about digital transformation and the "data to knowledge" pathway in a transparent and comprehensive manner.

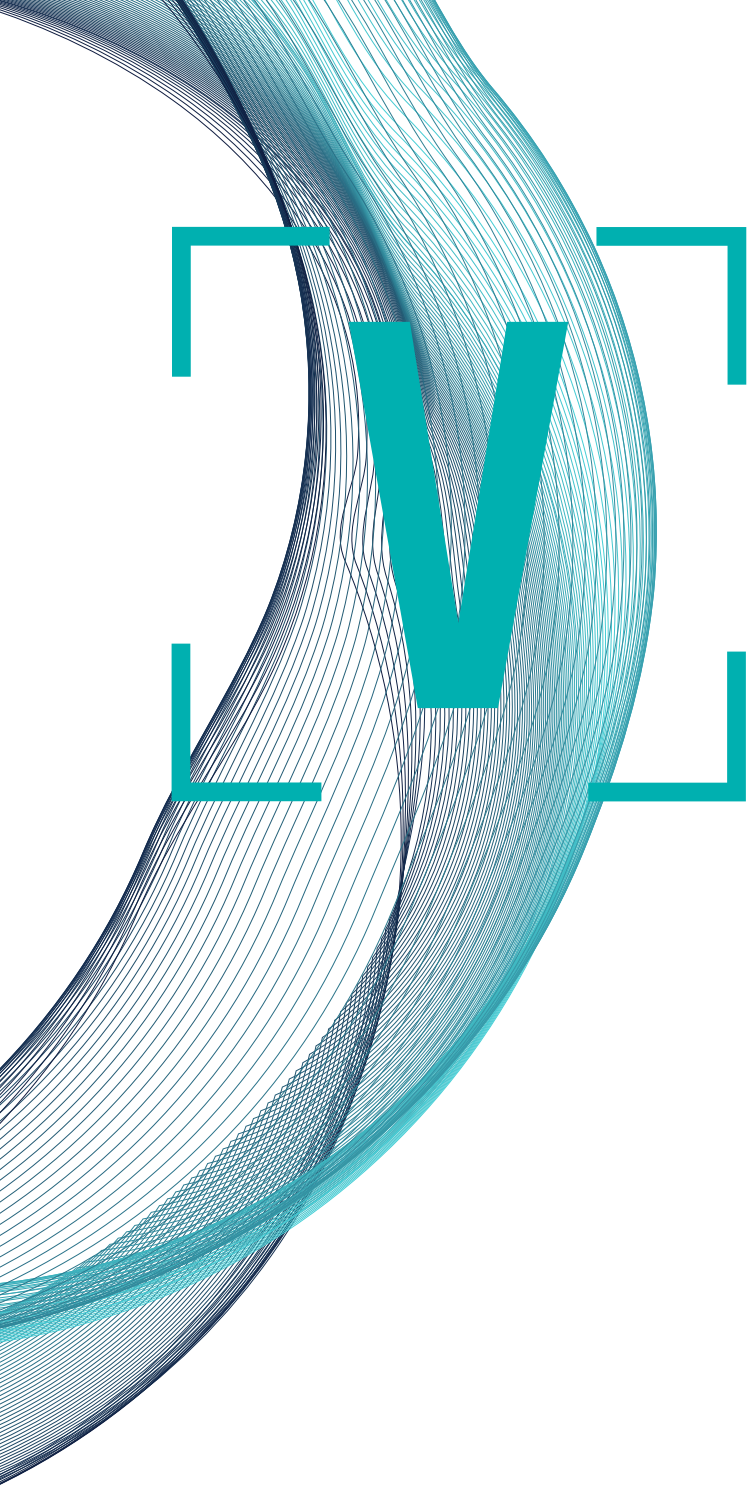
Public sector innovation projects in which advanced analytics and AI tools are developed and used, and where skills enhancement takes place, can have a significant impact on the effectiveness and quality of healthcare services (21).

BOX 2
STRENGTHENING INTERNATIONAL COLLABORATION FOR HEALTH INTELLIGENCE

In the rapidly changing technological field the importance of global cooperation to find the best solutions and long-term success is paramount. Throughout this strategy we want to bring a new coherence and sharper focus to Portugal's international research and innovation effort to reinforce the technical framework of secondary use of data and AI for health.

We propose to build strategic government and institution level partnerships for deep and long-term applied research and innovation. We also intend to engage national universities and other research organisations in international collaboration as an integral part of our approach to address shared challenges of secondary use of data and AI. One of our core objectives is to continue to collaborate with European partners on major health science, research, and technology initiatives. We want to deepen association to EU research and innovation programmes, including Europe´s Horizon 2020, research and training networks.

We want to expand SPMS4research centres of excellence across the country and assure that innovation in secondary use of data and AI technology can improve local health plans and health management at sub-national levels.



V

BACKBONE PRINCIPLES FOR SECONDARY USE OF DATA TO NEXT GENERATION NHS

An efficient, data-driven transformation of the National Health Service must be operationalized based on clearly defined structural principles, applicable to all action plans that encompass data management and reuse: robust governance, customer-centered approach, privacy and security, standards-based data, interoperability, use of new data sources, flexibility and openness to change and research and development.

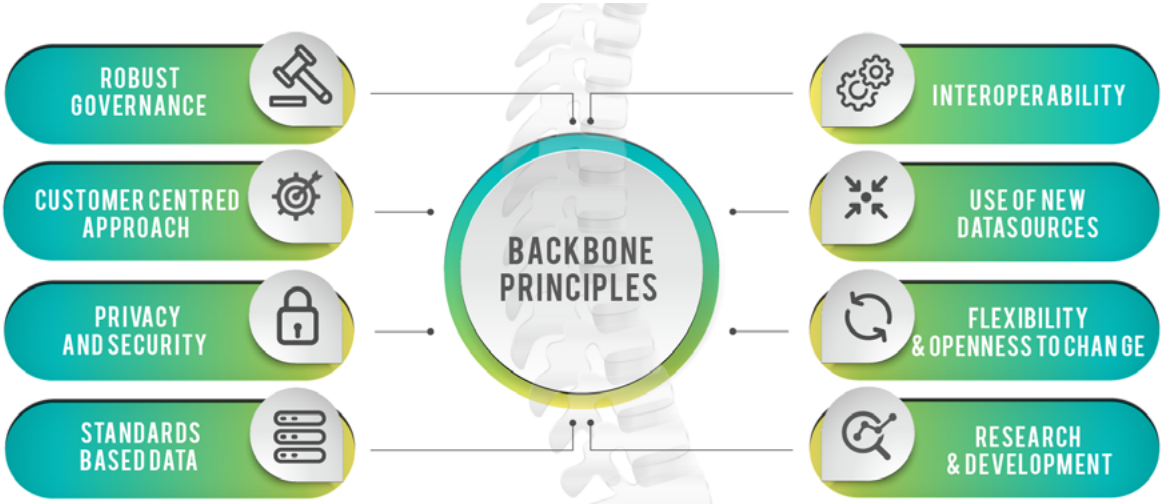


FIGURE 3. Backbone principles of secondary use of data for National Health Service data-driven evolution

ROBUST GOVERNANCE

Effective and timely implementation of secondary use of data and AI in the NHS will require robust governance. Data governance defines how the NHS manages its data assets, and, in a digital world, how improved decision-making should be operationalized(28).

A well-defined governance structure must be in place for a data-driven approach to next generation NHS that matches people (healthcare professionals), processes (care delivery) and technology needs. As such, a **Health Data Governance Board** should be appointed to oversee and coordinate national, regional and local activities (15,29). The *health data governance board* should be established within the existing national frameworks in cooperation with data protection authorities and ethics committees that are already in place at national level.

The Health Data Governance Board should be responsible for:

- Definition, approval and communication of national strategies for secondary use of data;
- Definition of roles, responsibilities and pathways regarding the access and processing of data;
- Legal and operational frameworks for data sharing;
- Development of core technical definitions for data management;
- Enforcing data policies and standards in data collection, storage and retrieval for secondary use;
- Ensuring accountability for data management through a network of *chief data officer´s* with specific roles, vertically and horizontally;
- Creating a framework to help health institutions and central agencies sponsor, track and oversee the delivery of data applications;
- Management and resolution of data related issues, to assure end-users that the data is accurate.

Defining a national data policy is vital to ensure trust and promote understanding of the value of secondary use of data, a core element for a data-driven NHS. Success will also require governance models that continually adapt to new data requirements as the NHS embraces integrated and home-based care and healthcare delivery evolves to telemedicine and remote monitoring with sensors and the “Internet of Things”. It is also a critical requirement to support research and innovation.

Data governance mechanisms need to be transparent and fair. The processing and linkage of data sources for access and secondary use should be approved by independent review to ensure non-discriminatory and timely data access and use. The national *Health Data Governance Board* should coordinate the governance process, by supporting the cooperation between different database owners, and stakeholders, and should have an active role in data-driven digital transformation and clinical process redesign, so that health outcomes can be measured by useful and high-quality data.

FIGURE 4. Health data governance Board responsibilities

CUSTOMER-CENTERED APPROACH

Potential customers of health data and AI technologies are diverse, including citizens, health professionals, health institutions and central agencies and research parties. Different customers demand for different requirements, but ensuring easy access to data, in an interpretable manner and fit-for-purpose, has common features that must be met.

Customers of data for secondary use must have a smooth service process, into a single "one-stop-shop", enabling one centralized operation process that generates a clear workflow for data customers to perceive a fragmented field of data sources as a uniform hole, across the NHS (15).

Changing the mindset from production-centricity (data stores and their handling) to customer-centricity is a necessity to a modern, data-driven NHS (15).

A customer centered approach ensures that investments in secondary use of health data, advanced analytics and AI support a digital health system that captures the complete range of customers' needs for data-driven decisions and innovation to improve people´s health.

PRIVACY AND SECURITY

Next generation NHS needs to maintain a trusted digital environment where information security and privacy is an integral principle for delivering value and protect healthcare services, citizens and the community.

Our ability to unlock the benefits of big data across care settings relies on the public having confidence in our appropriate and effective use of data. To strengthen public trust in how we store, share and use data it is essential to have the right foundation of policy, cybersecurity and management rules around privacy and data sharing. Secondary use of data and data-driven services must have clear guidelines based on the General Data Protection Regulation (GDPR) and related regulatory and ethical frameworks as well as cybersecurity standards.

A strong national cybersecurity department and the digital architecture of data repositories must be supported by clear and commonly understood data management standards, mandated across the NHS to ensure security by default and that data breaches monitoring is effective in protecting citizens' privacy. There are already several important safeguards in place, including the NHS cybersecurity department that defines data security standards.

Commitment to safe use of data, enables data to flow in a lawful, secure and appropriate way to improve health. Privacy at the forefront is a core requirement for secondary use of data.

STANDARDS-BASED DATA

Information Standards (including data standards, data collections and extractions) are an agreed set of rules, a consistent method or process for capturing, processing, managing and sharing of data and information. The term Information Standards also cover the specifications used to Collect and Extract data from information systems. Collections and Extractions are defined data sets that can then be used to measure or conduct analysis of particular areas of interest(30).

Data standards are the rules by which data are described and recorded. To share, exchange, and understand data, we must standardize the format as well as the meaning. Data standards support the consistent capture and use of data, and ensure all users have the same understanding of the data(30). Minimum information standards need to be in place for key tasks such as consistent identification of individuals and data integration while allowing innovation and specialization of the technology environment.

Adoption of data standards facilitates data integration and expands knowledge extraction, reduces integration costs and improves the overall quality of data in source information systems. Implementation of common standards, particularly for data specifications, will support information exchange and data analysis across disparate systems and different institutions, both within and outside the health sector (e.g. social services, justice).

Information standards address health professionals and people´s needs along the NHS in several ways:

- Citizens are reassured that the NHS can assemble all their personal relevant information, across the healthcare pathway, to improve safety and quality of care in a secure technological environment;

- Health professionals can use decision support tools based on all available and accurate data, that is context specific;

- National organizations and the Ministry of Health can improve planning through comprehensive performance indicators based on high quality data;

- Research institutions can reuse data easily for research purposes.

A strong commitment with information standards implementation across the NHS will improve healthcare by allowing data sharing across different health information systems and/or organizations. It will also improve the procurement and deployment of technology-based solutions with greater efficiency and at lower cost.

INTEROPERABILITY

Interoperability and technical standards (along with information standards) are key to deploy the full potential of data.

Interoperability is the ability of different information systems, devices or applications to connect, in a coordinated manner, within and across organizational boundaries to exchange and cooperatively use data amongst stakeholders (31).

Health data exchange architectures and technical standards allow relevant data to be shared effectively and securely across the complete spectrum of care, within all applicable settings and with relevant stakeholders (including with the person whose information is being shared). Optimally, interoperability facilitates connections and integrations across these systems to occur regardless of the data's origin or destination or the applications employed, and ensures data is reusable and readily available to share without additional intervention by the end user.

In the health system, interoperability furthers the goal of optimizing health by providing seamless access to the right information needed to further comprehensively understand and address the health of individuals and populations. Interoperability covers structural, semantic and organizational interoperability meaning that technical and non-technical components need to be in place and integrated into end-user processes and workflows (31).

However, there are still interoperability problems in the healthcare sector as data is often fragmented or generated from information systems with incompatible formats.

Data gathered from electronic health records, clinical activities, hospital services and administrative services are organized in silos and, often, each silo maintains its own separate organizational (and sometimes duplicated) data and information infrastructure.

This is a barrier to integrate and analyze data from different sources. Interoperability demands for technical standards to enable the big data value chain. As such, the creation of open, interoperable technological environments that promote rapid advances is necessary as well as the promotion of open standards.

Standards organizations are actively working, and a vast number of sources has been created in the realm of health care. Hence, there is a need for: (i) tools to process and integrate these knowledge sources in the healthcare framework that can be deployed in different health data workflows; and (ii) guidelines and best practices to inform providers and users of health data on processes and workflows, for handling data-driven systems in health care.

Since healthcare recommendations, standards, and policies are constantly evolving; flexibility should be built into the new technology to allow for rapid response to change.

USE OF NEW DATA SOURCES

Medicine and public health have always been data-driven sciences, however due to constant advances in technology, medical imaging, electronic health records and smart devices, public health as well as clinical practice are changing into *big data*-driven fields. Large volumes of health data will not only drive deeper insights in both public health and clinical applications within the system, but also in benchmarking, as known from the current experience of the public benchmarking site for the Portuguese NHS' institutions.

Therefore, the healthcare domain as a whole – healthcare professionals, citizens, managers and policy makers - can significantly improve data-driven approaches from current advances in big data technologies and artificial intelligence.

The most significant added value is generated by the increase in data usefulness when a high volume of data from several registries is combined(15). Knowledge generation opportunities in healthcare can improve with access to comprehensive data sources and new services around high-quality registered data. New sources of data are arising from medical and technological advances such as genomics, wearables, ingestibles, implantables and the "Internet of Things".

Datasets for advanced analytics and AI must also increasingly combine NHS data with data from many other public and private sector generated data. New data sources outside the health system are being generated, for example, by social services, education or justice.

It must be noted that measurable data variables related to health changes outside the public sector does not accumulate in public registers, so more consideration must be given about all factors that influence people´s health and identify opportunities for secondary use through adequate regulatory frameworks(15).

As new data sources are identified and can be integrated into the NHS data holdings there will be increased demands on improved data acquisition, storage and data integration solutions. Therefore, requirements to develop specialized methods and approaches for data analytics and artificial intelligence in healthcare must consider(19):

- **Multi-modal data**

Optimally in data analytics there is a set of well-curated, standardized, and structured data – for example found in electronic health records and administrative registries. However, a high percentage of health data is a diversity of unstructured data that is not being fully used (32). Much will come in the form of real-time sensor readings such as ECG measurements in intensive care, text data in clinical reports, medical literature in natural language or image data. Furthermore, the use of external data such as lifestyle information, e.g. for disease management, or geo-spatial data and social media for epidemiology will become increasingly common.

The goal is to obtain valuable information from such heterogeneous data, make relevant information available to health professionals, and incorporate knowledge into the clinical history of individual citizens.

- **Complex background knowledge**

Medical data describes very complex systems, from patient level data on medical treatment and procedures to lifestyle information. Hence, medical data needs complex *metadata* in order to optimally analyze the data, draw conclusions, find appropriate research hypotheses, and support clinical decisions.

- **Complex decision-making**

The analysis of image data, intensive care monitoring or the treatment of multi-morbidities are examples of areas in which medical decisions must be taken from noisy data, in complex situations, and possibly with missing information. Neither humans nor algorithms may be guaranteed to always deliver an optimal solution, yet they may be required to take important decisions or specify options in minimal time.

Advanced analytics and AI can support complex decision-making in healthcare processes by applied research investments to solve specific problems, through strong relationships between research, training and responsible application of innovative solutions in the NHS.

FLEXIBILITY AND OPENNESS TO CHANGE

Flexibility and openness for a data-driven NHS is a mainstay of effective change management.

To gain the greatest benefits from data science and AI technologies, support for change management needs to be embedded into systems, policies, practices and education across all NHS. *e*-literacy initiatives should be developed and targeted to all stakeholders, including citizens, their families and healthcare professionals to promote a universal approach to the redesign of healthcare.

Change management is critical for uptake and integration of decision support tools into management and clinical workflows and ensure seamless transition and sustainability.

Fostering an open mindset that is flexible to change will also be essential to meaningful secondary use of data, to investigate new technologies as they become available and to adopt AI-embedded technology.

RESEARCH & DEVELOPMENT

Many current healthcare applications would significantly benefit from the processing and analysis of multi-sources data. Artificial intelligence such as advanced machine learning systems can be used to uncover information from multiple sources and identify hidden correlations, not visible when considering only one source of data. Similarly, major progresses in personalized medicine, public health surveillance and telecare are expected to make use of this technology along with others such as deep learning, text analytics, and natural language processing that will be key in leveraging the full potential of the multiple sources of big *health* data.

The successful achievement of the enormous value kept in NHS data for AI will ultimately rest on the ability of the NHS to create trusted research environments through well-established partnerships with academic institutions, public and private sector organizations and other research parties. Furthermore, the uptake of data-driven solutions and AI in healthcare may be hindered by unforeseeable questions. To address these challenges a ***Health Intelligence Laboratory*** for research, within the NHS, will be key to translate the needs of health professionals and citizens into usable products.

Key areas for development of flagship AI projects, that translate stored data into useful and insightful tools in healthcare, have already been identified to establish the ground of future work encompassing healthcare management, clinical care and public health within the NHS (see also section VII. Health Intelligence Lab: actionable data using artificial intelligence). Further work will be needed using policy-level strategies to ensure sustainability of a specialized Health Intelligence Laboratory to continuously test and scale up opportunities offered by these research projects and other research and technological developments to improve people´s health.

A Health Intelligence Laboratory is a necessary step to a solid foundation of the evolution the *e*-NHS into an *i*-NHS, the one in which *intelligent* information systems will be an integral part of health decision-making at all levels.

VI

THE JOURNEY: FROM RAW DATA TO HEALTH INTELLIGENCE

Transformation of the NHS to a data-driven system requires a solid stepwise path to achieve a mature data ecosystem while ensuring support for health institutions to drive innovative progress using data and integrate data and analytics into daily work (33). To make sure information is accurate and truly actionable, it also requires an adequate technical and regulatory framework, bringing together relevant expertise across all aspects of technology, law and health to successfully build a value-based environment.

Digital health is not just a computer science or an engineering science— it's a social and behavioural science (33).

The NHS must seek to align all stakeholders on value, bring predictive and prescriptive analytics to personalized care, and further engage and educate patients in their own care. Truly personalized medicine and public health intelligence share the same population-base foundation that relies upon the creation of complete longitudinal patient records, and requires health analytics that moves beyond the descriptive capabilities of the past to predictive analytics and AI, not just unlocking health data, but reinventing how such data should be collected and applied (33).

We propose a continuum of steps, to be achieved in short, mid and long term, that will enable a responsible and functional data ecosystem for the NHS.

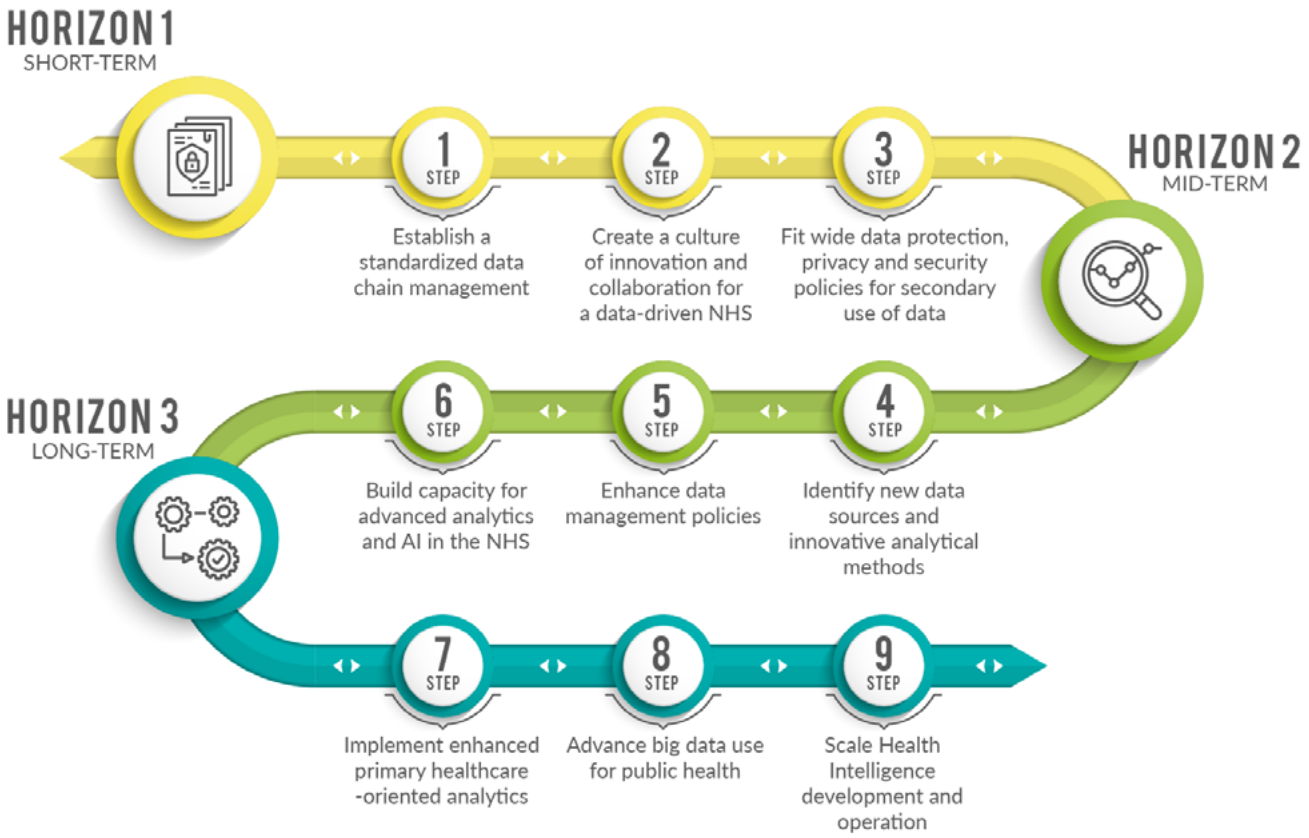


FIGURE 5. The short, mid and long-term steps from raw data to health intelligence

HORIZON 1
(SHORT-TERM)

STEP 1
Establish a standardized data chain managment

• Establish a "Health Data Governance Board" legal and operational framework;
• Define policy and related regulatory procedures for secondary use of data;
• Standardize values and definitions used in reporting systems to allow uniform understanding of data stored in the NHS information systems;
• Publish an integrated, accurate and consistent set of master data for use by other applications.
• Create and operationalize metadata standards for health information systems:
• Enforce compliance with metadata quality requirements in national health information systems;
• Implement a data supply chain concept to broaden the traditional information life cycle and include several data sources and the technological and logistical activities required to manage big data;
• Build a standard data repository and distribution system (data warehouse) where standardization occurs at the source;
• Define technical requirements for development of "secondary patient records" that capture clean and reliable individual data for optimization of data analytics and artificial intelligence activities;
• Eliminate middleware, ETL[1] and writing of custom code to standardize, clean and integrate data;

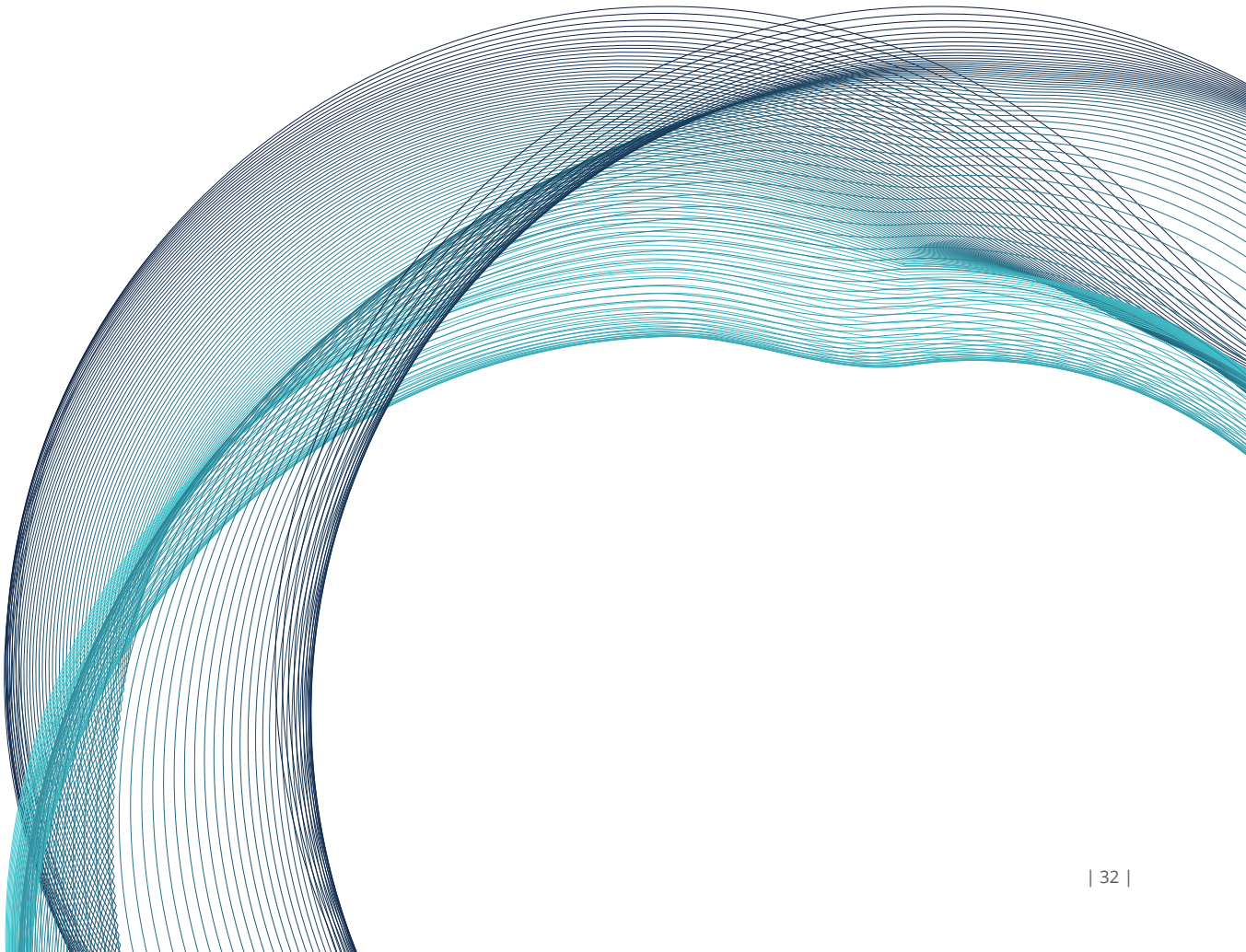
[1] Extract/load/transformation

STEP 2
Create a culture of innovation and collaboration for a data-driven NHS

• Develop a communication strategy for stakeholders (citizens, health professionals, health institutions and national organizations) to ensure understanding of the added-value of a data-driven NHS strategy;
• Develop a communication strategy for the public on AI for health to ensure wide discussion and understanding of AI main capabilities and implications and to leverage greater public awareness to incentivize policymakers' participation;
• Develop an action plan to enable participation of citizens, healthcare organizations and medical experts in all stages of the advanced analytics and artificial intelligence development and deployment;

STEP 3
Fit wide data protection, privacy and security policies for secondary use of data

• Establish a *Health Information and Technology Ethics Board* to support a legal and ethics consultation process for data management procedures for secondary use, design, development and deployment of advanced analytics and AI-backed solutions;
• Define privacy and security goals and objectives for data storage, management and sharing that incorporate national laws and relevant ethical standards;
• Define procedures for audit mechanisms of cybersecurity, data protection and privacy guidelines;
• Identify risks and critical systems in the data management life cycle;



HORIZON 2
(MID-TERM)

STEP 4
Identify new data sources and innovative analytical methods

• Develop an information assessment plan to identify NHS gaps in information, specially focused in primary healthcare and public health intelligence;
• Expand existing and explore new data sources according to national health system priorities and national health plans;
• Identify target-oriented innovative analytical methods and uses for big data in health;
• Integrate data from wearable devices, online diagnostic tools and genetic sequencing services in national health databases;
• Develop a plan to integrate unstructured data to current data management schemes;

STEP 5
Enhance data management policies

• Enforce policies, procedures, applications and other relevant technologies for harmonizing and managing systems of data workflow for secondary use;
• Develop a plan to progressively eliminate data redundancy and data inconsistency in national health information systems;
• Integrate information extraction, machine learning and semantic web technologies to enable context-based information interpretation.

STEP 6
Build capacity for advanced analytics and AI in the NHS

• Enhance policy-level training for data science and AI, improving technical knowledge of policymakers and government officials in data science and AI for effective policy level formulation;
• Implement life-long learning resources for health professionals in advanced analytics and AI technologies and reskilling strategies to deal with current and future technological transitions;
• Implement specific technical AI training programs (applied to health) in partnership with academia for data scientists, software engineers and health professionals to ensure diverse skill mix in health workforce;

HORIZON 3
(LONG-TERM)

STEP 7
Implement enhanced primary healthcare -oriented analytics

• Explore new data sources for improved prevention, diagnostic and treatment decision-making;
• Deploy AI based technology to foster innovation in primary healthcare based on wide-range of data sources;
• Deploy AI based technology for clinical decision support, risk scoring and disease monitoring focused on primary care needs;

STEP 8
Advance big data use for public health

• Engage policymakers and the public health community across the country in interdisciplinary groups of researchers and practitioners to identify public health challenges that could be effectively addressed using AI approaches;
• Identify knowledge gaps within public health core functions that are urgent and transformative and are not adequately addressed using traditional public health research methods;
• Create specialized technical teams of public health experts to support responsible interpretation of knowledge generated through AI models to ensure policy uptake and implementation is relevant and beneficial to public health;

STEP 9
Scale Health Intelligence development and operation

• Identify policy level and regulatory mechanisms for a dedicated Health Intelligence Laboratory for research within the NHS.
• Develop and train clinical decision support systems, progressively backed by artificial intelligence models, aligned with national health priorities;
• Integrate AI-backed support systems at user level to build better patient profiles and predictive models for clinical care and patient safety;
• Integrate AI-backed tools in public health surveillance to support early warning systems to manage public health risks and emergencies;

VIII

HEALTH INTELLIGENCE LAB: *ACTIONABLE DATA* USING ARTIFICIAL INTELLIGENCE

In parallel with the digital transformation in the Portuguese NHS, secondary use of health data from several NHS information systems began with development of integrated business intelligence systems that extract information from a wide range of datasets for assessment of NHS indicators and provide insights on "day to day" operations of healthcare institutions.

These systems merge data from disparate, disperse and heterogeneous sources into central data warehouses, and provide users in healthcare organizations of the Portuguese NHS analytic and reporting abilities.

The most complete business intelligence systems developed so far using NHS data are (i) SIMSNS[2] which aggregates hospital and primary care data at the national level and supports information needs of national organizations; (ii) SIARS[3] , a business intelligence system for data analysis at the regional level, available for regional health administrations; and (iii) BICSP[4] a Business Intelligence system for data analysis at the local level, available for primary healthcare centers. Other business intelligence systems have been developed to deliver information in specific domains, such as service contracting and monitoring between the Ministry of Health and healthcare providers (SICA[5]), hospital admissions (SIMH[6]), financial management (SIGEF[7]) and human resources administration (BIRH).

These systems use a large volume of stored data and a wide range of analytical tools, however, they are still underexploited in terms of data aggregation and analytic features.

The success of adapting health systems to new technologies and innovation depends on the way the enormous potential that health data offers for improving people's health and health systems' performance is designed and used and one of the rapidly growing areas of health care data secondary use lies in the advanced use of data science and artificial intelligence, specially machine learning, computerized vision and natural language processing.

[2] SIM@SNS - Sistema de Informação e Monitorização do Serviço Nacional de Saúde
[3] SIARS - Sistema de monitorização das Administrações Regionais de Saúde
[4] BICSP - Bilhete de Identidade dos Cuidados de Saúde Primários
[5] SICA - Sistema de Informação de Contratualização e Acompanhamento
[6] SIMH - Sistema de Informação da Morbilidade Hospitalar
[7] SIGEF – Sistema Informático de Gestão Económico-financeira

BY 2050 ONE PERSON COULD DIE EVERY 3 SECONDS IF AMR IS NOT TACKLED NOW

To fill the gap between existing opportunities and risks and extract knowledge of clinical, administrative, and other types of data being generated in the NHS, we identified flagship projects to shape the background of health data governance for AI and a solid foundation for the AI – backed evolution of healthcare in Portugal.

Flagship artificial intelligence projects are being developed in partnership with public and private research partners, focused on AI applied to NHS data and external data sources, ensuring a high level of data protection, privacy and ethical standards.

The goal is to advance the secondary use of data for priority areas in the healthcare sector: public health, hospital and primary healthcare service planning, clinical decision support and telehealth, enabling simultaneous development of procedures to anticipate and manage the risks associated with AI. They intend to create AI-backed solutions, operational for health professionals and citizens´ interaction with the NHS, evolved in a safe, secure and responsible manner.

FLAGSHIP PROJECTS

In this section we describe some of the currently ongoing AI projects funded by the Portuguese Government and EU funds. These aim to help the reader of this strategy to clealy understand the meaning of the "intelligent NHS" concept. They illustrate the power and usefulness of AI tools in providing novel solutions to existing and very important health problems in the Portuguese NHS, which are concerns in many other countries.

IDENTIFYING AND REDUCING ANTIBIOTIC UNDER AND OVER PRESCRIPTION[8]

The rise of antimicrobial resistance represents one of the major threats to human health, food safety, and the economy. The factors behind its emergence and maintenance are known and the widespread societal use of antibiotic treatment is very likely to be one of the major drivers of such resistance. Thus, it is fundamental to set clear guidelines for antibiotic use and prescription, implement methods to identify inappropriate prescribers, and monitor such prescriptions to standardize behaviors.

This project focuses on the implementation of methods to identify inappropriate prescribers, monitor such prescriptions to standardize behaviors and then devise a strategy to: identify outliers in prescription patterns, after controlling for a wide range of variables; devise a simple mechanism to reduce outliers, using a gentle "nudge" strategy.

Several strategies to increase prescription compliance have been documented and a combination of providing information about guidelines and showing prescribers where they stand, in comparison with their colleagues, has proven the most effective. Overall, this approach will tackle over and/or under inadequate prescription of antibiotics, contributing to the reduction of antimicrobial resistance.

[8] Partnership with Fundação para a Ciência e a Tecnologia and Instituto Gulbenkian de Ciência.

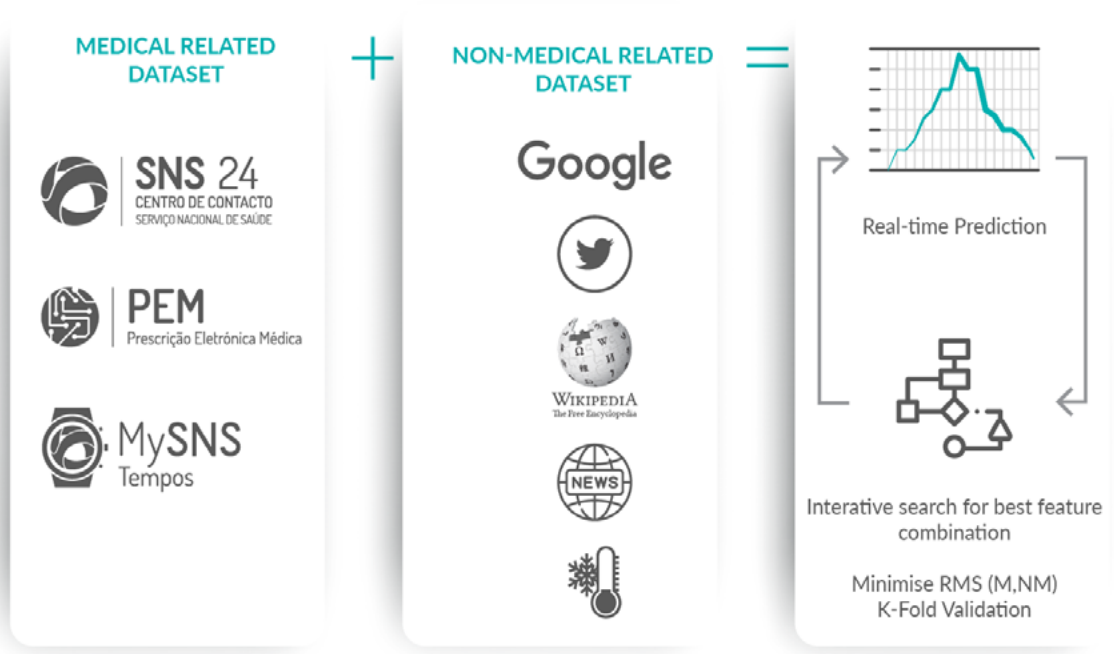
IDENTIFYING AND PREDICTING EMERGENCY ADMISSIONS[9]

Emergency Care Units (ECUs) are medical facilities that deal with unplanned patient turnout, for a very large range of conditions, often urgent or acute, and frequently life-threatening. Therefore, ECUs need to find a difficult balance between having enough resources (human and logistic) to deal with an unexpected surge in patients, while reducing wasteful practices that use more resources than required. Thus, timely information regarding possible variations in patient inflow is fundamental for adequate planning and service quality.

As a broad spectrum of reasons lead people to ECUs, hospital admissions vary significantly. From acute events, to lack of alternatives, or just out of concern, different reasons have different underlying dynamics, are guided by different factors, timings, and motivations. Thus, a combination of uncertainty and large variability, makes the problem of emergency forecasting a very complex challenge, with great impact on quality of care.

This project focuses on identifying top drivers of ECUs demand and uses a data science and machine learning approach to study variations in emergency peaks and possible factors that might predict them, using health data mining, social media analysis, network science, text miming, in order to develop a simple prediction algorithm, that can be used by decision-makers and reduce uncertainty in ECUs demand, to support planning and management.

Thus, this project tackles a very relevant problem and is particularly timely as it takes advantage of upcoming ways of approaching it, including state of the art data mining and machine learning. It will advance our knowledge on disease dynamics, Big Data management, data integration and privacy, and offer decision-makers fundamental information to properly prepare ECUs to variation of patient inflow.



[9] Partnership with Fundação para a Ciência e a Tecnologia and Instituto Gulbenkian de Ciência, Associação do Instituto Superior Técnico para a Investigação e o Desenvolvimento (IST-ID).

DERMA.AI: ARTIFICIAL INTELLIGENCE TO TELEDERMATOLOGICAL SCREENING[10]

Skin cancer is responsible for approximately one-third of all cancers detected annually in Portugal, affecting one in seven people throughout their lifetime. There has been a growing interest in telemedicine and other technological solutions to improve efficiency and decrease the burden on health services, but a significant potential still lies unexplored.

This project aims to improve current teledermatology solutions for skin lesions diagnosis, used in Primary Care Units and Hospital Dermatology Departments in the NHS, using artificial intelligence. The AI-backed framework will support both: general practitioners in primary care units, through a computer vision-based mobile application integrated with the electronic referral system (SIGA-VAI); and dermatologists, in hospitals, through a machine learning algorithm for risk score and decision support, embedded in the electronic referral system.

On the one hand, computer vision-based mobile application will guide general practitioners in the upload of macroscopic skin lesion images via an easy and intuitive workflow, specifically adapted to this referral procedure - autonomous image quality control will be performed by using image processing algorithms in real-time to control image focus and camera parameters, coupled with fast skin lesion segmentation methods to visually guide the user and select the correct region of interest for further analysis. On the other hand, machine learning and computer vision approaches will be explored to create an AI module for automatic risk scoring and prioritizing patient referral.

In addition to contributing to early diagnosis and survival rates improvement, this project foresees a fundamental contribution to the area of AI and m-Health technologies' integration and impact assessment in real NHS operational environment.

[10] Partnership with Fraunhofer Portugal.

SNS 24 PATH_SCOUT.AI: IMPROVE NHS CONTACT CENTER USING ARTIFICIAL INTELLIGENCE[11]

SNS 24 is a telephone and online-service of the Portuguese National Health Service. It is intended to help citizens who need advice for acute, non-emergent health complaints. It also offers a set of services that allow citizens to solve health-related issues that otherwise would need a primary care unit or hospital visit. SNS 24 offers both clinical and non-clinical services. Clinical services are all provided by healthcare professionals – non-clinical services by administrative staff.

Clinical services include: screening, counselling and referral in acute non-emergent disease; counselling about over-the-counter medicines, information about public health issues, information about and referral to specialized HIV, HBV, HCV care associated with point-of-care tests (Tests in pharmacies, laboratories or at home) and "Proximidade Sénior" Programme. Non-clinical (administrative and information) services include: scheduling a primary care appointment at your primary care facility; support on using the Electronic Health Registry – Citizen's Portal; information about blood donation and transplants; information about oral health and dental care providers in primary health care facilities; claim for exemption from "Moderation Fees" because of economic insufficiency among others.

This project aims to use machine learning and natural language processing to Support NHS 24 nurses in clinical pathway selection according to patients' audio reported information (automatic writing and registry of patient reported symptoms during phone calls) while taking advantage of all previous similar events and the collective experience of all nurses. The AI-backed algorithm is expected to decrease time to patient referral and care and improve service quality, through consistency of application and better use of standardized referral pathways.

[11] Partnership with Universidade de Évora.

VIII GLOSSARY

Artificial Intelligence
Systems that display intelligent behaviour by analysing their environment and taking actions – with some degree of autonomy – to achieve specific goals. AI-based systems can be purely software-based, acting in the virtual world (e.g. voice assistants, image analysis software, search engines, speech and face recognition systems) or AI can be embedded in hardware devices (e.g. advanced robots, autonomous cars, drones or Internet of Things applications)." In this document we use this definition to clarify certain aspects of AI as a scientific discipline and as a technology, to achieve a shared common knowledge of AI that can be fruitfully used also by non-AI experts, and to provide a broad definition that can be used in the discussion on both the AI ethics guidelines and the AI policy recommendations[12].

AI system's life cycle
Encompasses AI systems development (including research, design, data provision, and limited trials), deployment (including implementation) and use phase[13].

Auditability
Ability of an AI system to undergo the assessment of the system's algorithms, data and design processes[14].

Big data
Very large data sets that exceed the storage capacity or processing power of traditional tools. Big data "represents the information assets characterized by such a high volume, velocity and variety to require specific technology and analytical methods for its transformation into value[15].

Database
Collection of interrelated data stored (often with controlled, limited redundancy) according to a schema. A database can serve single or multiple applications.

Data-driven development
Approach to development that centres around identifying the commonality of data through a data model and building programs that have a broader scope than the immediate application. Data driven development differs from classical application-oriented development.

Data Science
The methods, processes and systems used to analyze, understand and draw insights from large and complex data sets[16].

Data warehouse
A collection of integrated, subject-oriented databases designed to support the decision support system function, where each unit of data is relevant to some moment in time. The data warehouse contains atomic data and lightly summarized data[17].

ETL
The process of taking legacy application data and integrating it into the data warehouse[18].

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[12] Communication from the Commission to the European Parliament, the European Council, the Council, the European Economic and Social Committee and the Committee of the Regions on Artificial Intelligence for Europe, Brussels, 25.4.2018 COM(2018) 237 final.
[13] European Commission High-Level Expert Group on Artificial Intelligence. Ethics guidelines for Trustworthy AI [Internet]. 2019.
[14] European Commission High-Level Expert Group on Artificial Intelligence. Ethics guidelines for Trustworthy AI [Internet]. 2019.
[15] Colclough G, Dorling G, Riahi F, Ghafur S, Sheikh A. Harnessing Data Science and Ai in Healthcare [Internet]. 2018.
[16] Colclough G, Dorling G, Riahi F, Ghafur S, Sheikh A. Harnessing Data Science and Ai in Healthcare [Internet]. 2018.
[17] Inmon WH. Building the Data Warehouse [Internet]. Wiley Computer Publishing; 1995
[18] Inmon WH. Building the Data Warehouse [Internet]. Wiley Computer Publishing; 1995

External data
Data originating from other than the operational systems of the Ministry of Health or data residing outside the central processing complex.

Governance
The institutional configuration of legal, professional and behavioural norms of conduct, conventions and practices that, taken together, govern the collection, storage, use and transfer of data and the institutional mechanisms by and through which those norms are established and enforced[19].

Integrity
The property of a database that ensures that the data contained in the database is as accurate and consistent as possible.

Primary use of data
Use of data for the purposes for which it was originally collected and registered. In healthcare context this generally means collection, processing, and display of data which is specific to an individual person for providing care and services to that person[20].

Secondary use of data
Processing and aggregation of data for uses other than primary use. In the healthcare context secondary uses may include planning and reporting duties of authorities, supervision, statistics, public health reporting and research[21].

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[19] Colclough G, Dorling G, Riahi F, Ghafur S, Sheikh A. Harnessing Data Science and Ai in Healthcare [Internet]. 2018.
[20] Adapted from A finnish model for the secure and effective use of data [Internet]. 2019.
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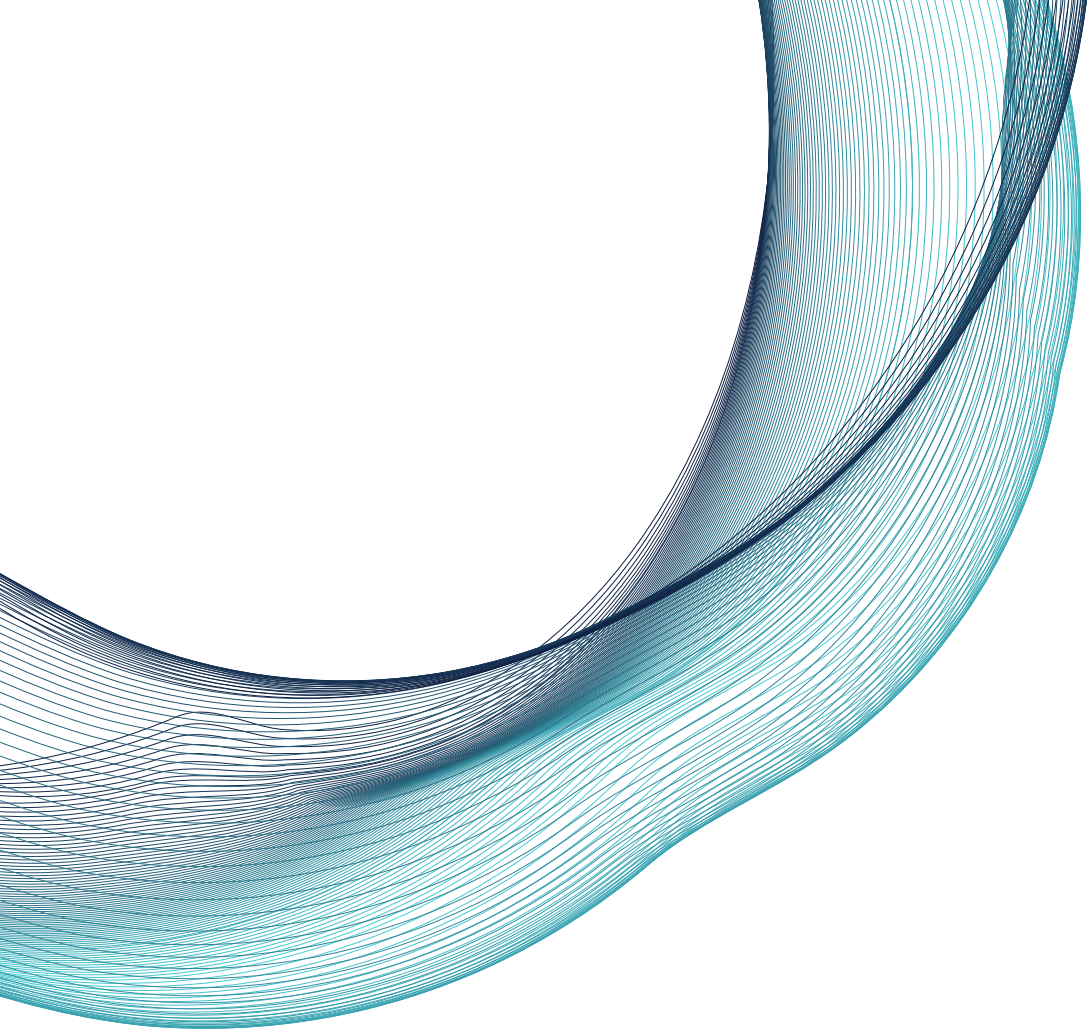

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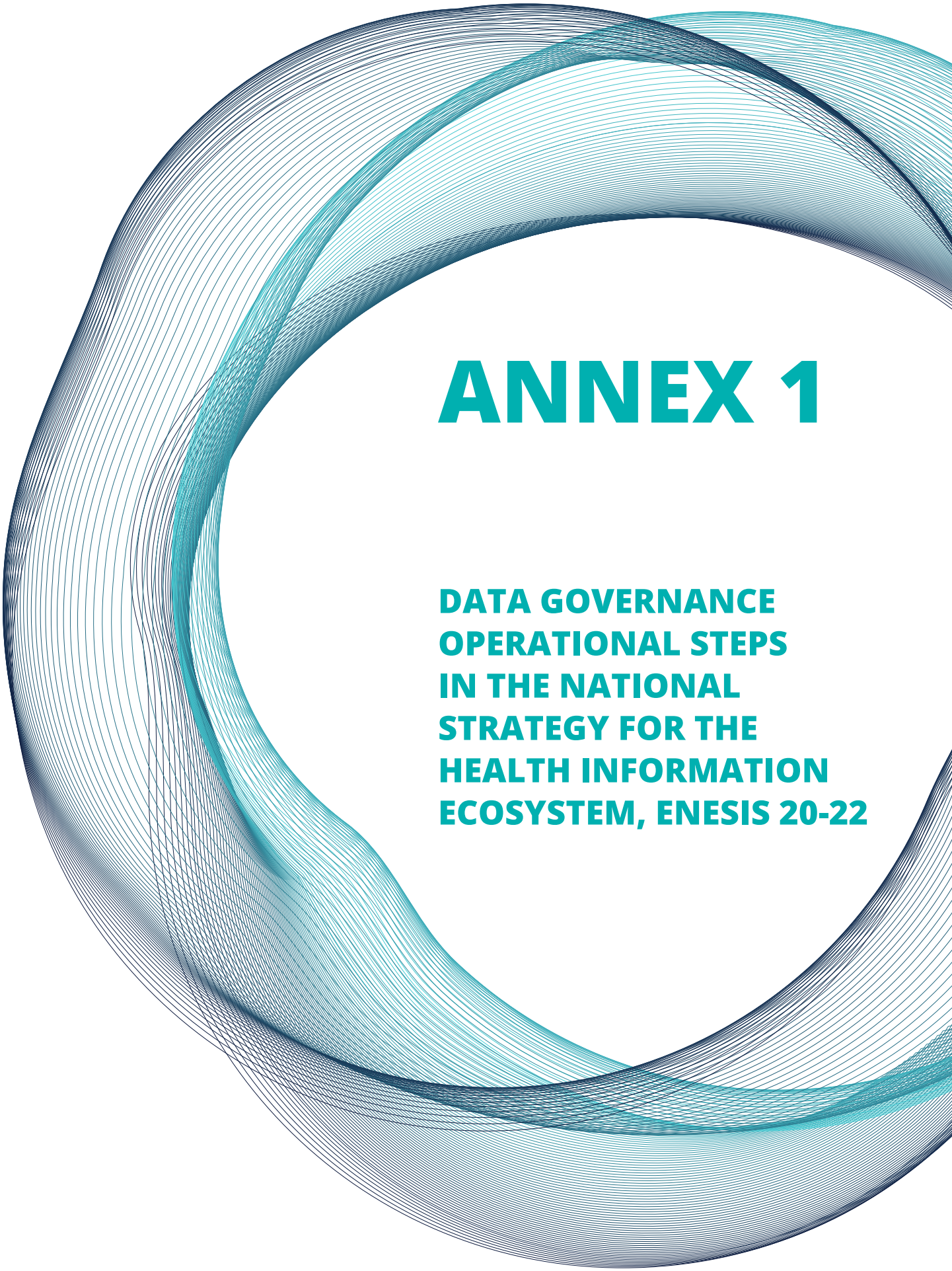

ANNEX 1

DATA GOVERNANCE OPERATIONAL STEPS IN THE NATIONAL STRATEGY FOR THE HEALTH INFORMATION ECOSYSTEM, ENESIS 20-22

			DATA STRATEGY OPERATIONAL STEPS / STREAMS ENESIS 20-22	Establish a standardized data chain management	Create a culture of innovation and collaboration for a data-driven NHS	Fit wide data protection, privacy and security policies for secondary use of data	Identify new data sources and innovative analytical methods	Enhance data management policies	Build capacity for advanced analytics and AI in the NHS	Implement enhanced primary healthcare -oriented analytics	Advance big data use for public health	Scale Health Intelligence development and operation
STREAM 1	ACESS TO HEALTH SERVICES AND CARE	1.1	Information Systems Accessibility									
		1.2	Health Access in Mobility				X					
		1.3	Communication between Information Systems within and among organizational	X								
		1.4	Provision of plataforms that promote the provision of distance care					X				
STREAM 2	CITIZEN EMPOWERMENT	2.1	Health literacydevelopment through the creation of shared solutions									
		2.2	Introduction of citizen experience as a mean of Health Services improvement									
		2.3	Promotion of improved usability of Information Systems trough citizen engagement mechanisms		X							
		2.4	Promotion of a 360° view of health condition									
STREAM 3	EFFICIENCY AND SUSTAINABILITY OF HEALTH	3.1	Evolution of Clinical and Administrative Information Systems									X
		3.2	Optimization of clinical and administrative processes					X				
		3.3	Optimization of network infrastructure and servers									
		3.4	Centralized Information Systems purchasing process optimization									
		3.5	Optimization and dissemination of Business Intelligence to support management decision making									X
		3.6	Definition of Data Governance model	X		X		X				
		3.7	Shared management services and health resources									
		3.8	Use of technological tools to support health professional practice					X		X		X
		3.9	Value management model									
STREAM 4	QUALITY AND SAFETY OF HEALTH CARE	4.1	Confidentiality, integrity and availability protection of the health information			X						
		4.2	Promotion of cybersecurity practices in Information Systems			X						
		4.3	Guarantee of Business Continuity									
		4.4	Assurance of Information Systems Conformity	X								
		4.5	Implementation of clinical decision supportmechanisms and patient safety							X		X
STREAM 5	HEALTH PREVENTION, PROTECTION & PROMOTION	5.1	Gamification concept application									
		5.2	Prevention in public health through data analysis and Artificial Intelligence	X	X			X		X		X
STREAM 6	ORGANIZATIONS AND PROFESSIONALS	6.1	Stakeholders involvement for continuous improvement of Information Systems		X							
		6.2	Improvement of digital skills of non-technological health professionals						X			
		6.3	Improvement of digital skills of health						X			
		6.4	Improvement of information and communication technology skills for top management						X			
		6.5	Boosting Innovation in Information Systems									
		6.6	Promoting a culture of knowledge sharing									X

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40 ANOS

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