

VSNU **Di**gital **So**ciet

Health & Well-being

Impact Map



- CREATING SUSTAINABLE NETWORK
- LOBBYING WITH GOVERNMENT
- LOBBYING WITH HEALTH INSURANCE COMPANIES
- IDENTIFYING RELEVANT STAKEHOLDERS

NETWORKING &  
LOBBYING

RESOURCES

PRIVACY & ETHICS

**DiSo**  
HEALTH & WELL-BEING

CREATE AN INVENTORY OF DECISIONS BY ETHICS BOARDS REGARDING THE APPROVAL AND NON-APPROVAL OF DIGITAL TOOLS AND DATA-SHARING TECHNIQUES IN RESEARCH

DEVELOPING BALANCED GUIDELINES FOR PRIVACY AND BIG DATA ON EU LEVEL

DEVELOPING GUIDELINES AND TOOLS TO IDENTIFY AND TO TACKLE DATA GAPS AND DATA BIASES (DATA WISDOM)

WRITING PROPOSALS (TOGETHER)

IDENTIFYING SUITABLE FUNDING SYSTEMS

# IMPACT MAP

STANDARDIZATION

BRIDGING CITIZENS,  
SCIENCE & INDUSTRY

KNOWLEDGE  
DISSEMINATION  
& EDUCATION

IDENTIFYING THE RELEVANT METHODS & PROCEDURES IN CONDUCTING RESEARCH WITH CITIZENS' DATA

SPECIFYING AND IMPLEMENTING FAIR DATA PRINCIPLES IN EHEALTH

CREATING A STANDARD FOR MEASURING SOCIETAL IMPACT

CREATING A STANDARD FOR MEASURING COST EFFECTIVENESS, BASED ON E-HEALTH IMPLEMENTATION

WORKING CLOSELY WITH THE EUROPEAN UNION (EU) INITIATIVE ON THE DIGITAL TRANSFORMATION OF HEALTH AND CARE (DIGICARE)

DIGITAL HEALTH & WELL-BEING INITIATIVES WITH COMMUNITY

IDENTIFY RELEVANT TOPICS AND PARTIES FOR COLLABORATION IN OUR ACTIVITIES AND PROJECTS

INVENTORY OF RELEVANT PATIENT ORGANIZATIONS

GET INVOLVED WITH PUBLIC/PRIVATE KNOWLEDGE INSTITUTIONS

IDENTIFYING BEST PRACTICES & TOOLS IN EHEALTH IMPLEMENTATION

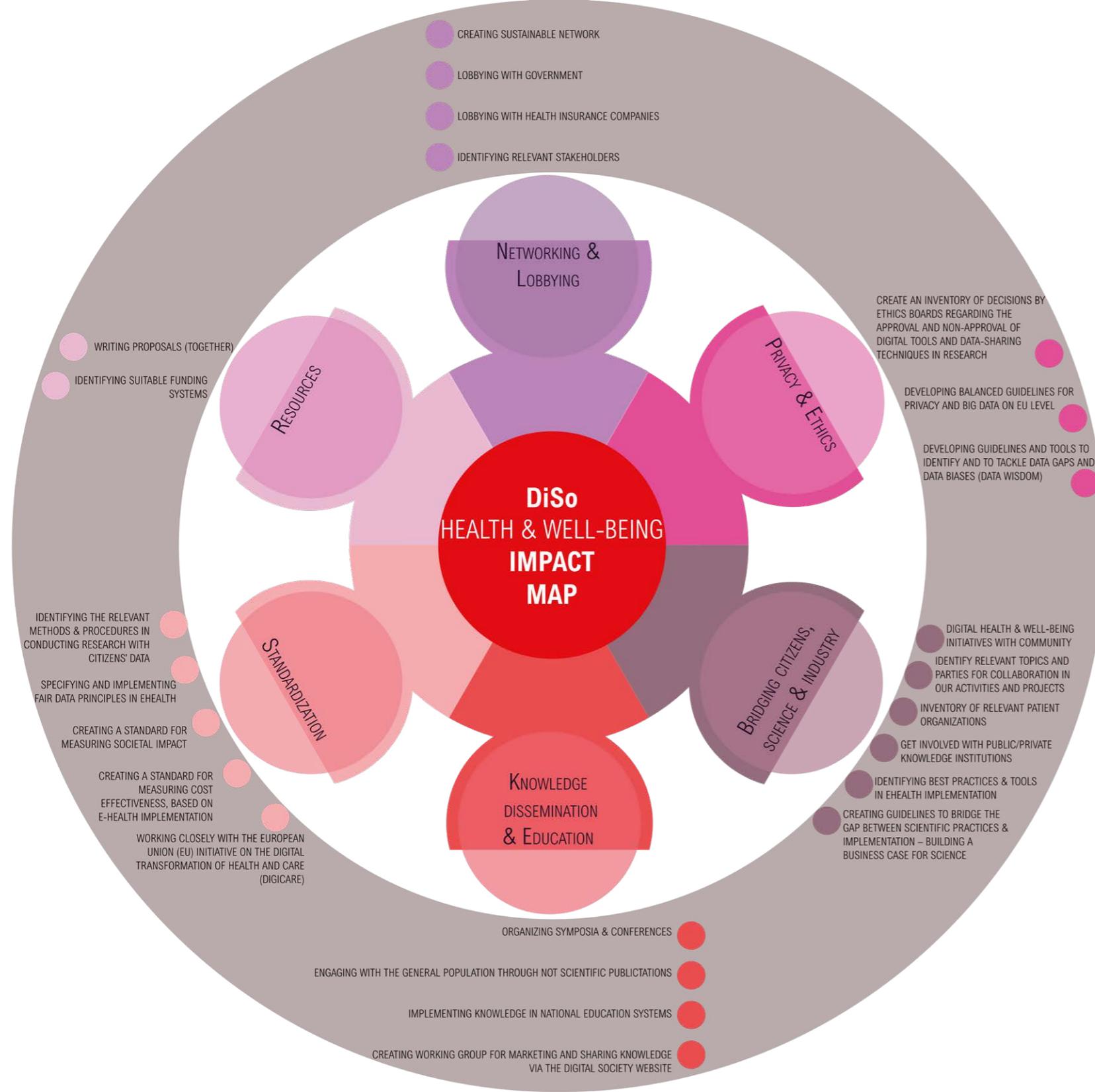
CREATING GUIDELINES TO BRIDGE THE GAP BETWEEN SCIENTIFIC PRACTICES & IMPLEMENTATION – BUILDING A BUSINESS CASE FOR SCIENCE

ORGANIZING SYMPOSIA & CONFERENCES

ENGAGING WITH THE GENERAL POPULATION THROUGH NOT SCIENTIFIC PUBLICATIONS

IMPLEMENTING KNOWLEDGE IN NATIONAL EDUCATION SYSTEMS

CREATING WORKING GROUP FOR MARKETING AND SHARING KNOWLEDGE VIA THE DIGITAL SOCIETY WEBSITE



**VSNU Digital Society (DiSo) Health & Well-being Vision:**  
*the Digital Society Health & Well-being network aims to **design, evaluate** and successfully and sustainably **implement** digital health interventions.*

To successfully implement this vision, our actions are needed in at least six strategically relevant areas: Resources; Networking & Lobbying; Privacy & Ethics; Bridging science, citizens and industry; Knowledge dissemination & Education; and finally, Standardization. To structure our approach, increase the efficiency of our work, and to be able to track and communicate the progress of our activities towards achieving DiSo Health & Well-being vision, we derived an Impact map. The Impact map provides an overview of our network's core activities and expected outcomes in each of the strategically relevant areas. The Impact map consists of two layers. The first layer, closest to the red nucleus, illustrates the strategic areas of our activities (e.g., Resources, Bridging citizens, science and industry), while the second layer depicts the activities that are taking place in each of the strategic areas (e.g., writing of the proposals, initiatives with community). The following paragraphs explain in detail each of the strategic areas, as well as relevant activities and expected outcomes within these areas.

## Privacy & Ethics

New developments in digital healthcare raise ethical and privacy concerns that need value-based (i.e., human rights and culturally sensitive), balanced (i.e., on personal and societal benefits and costs), flexible and FAIR solutions. Firstly, national and local university and hospital ethics boards ensure that ethical aspects (e.g., informed consent) and privacy aspects (e.g., who has access to the patient's data and where the data is stored) of innovative scientific studies are safeguarded. Accelerating developments in digital care, data security, artificial intelligence (AI), and research methods pose challenges to ethics boards, as decisions on ethical aspects require thorough deliberation. Yet, at the same time, innovative studies can be slowed down by lengthy ethical procedures and a lack of understanding of changing processes (e.g., online consent) and societal values (e.g., in cases of medical emergencies, digital data sharing of a patient's medical history has become the norm). To join this debate, we will first **create an inventory of approved by ethical boards digital tools and data sharing techniques in research** (METC/CCMO/LCDRM/ELSI desk). Based on insights from these cases we will publish a white paper concerning pathways to solving ethical aspects of digital tools, data sharing and innovation, and create awareness and understanding of digital tools, data sharing and ethical decisions surrounding new innovations. Secondly, ethical attention is also required for the development and use of artificial intelligence in the healthcare sector. Here, access to data, knowledge of data gaps and tools to deal with biased data are crucial to build inclusive and equity-based healthcare solutions and to avoid potential pitfalls. For example, for the development of reliable smart algorithms, access to large quantities of data is necessary and these prerequisites need to be balanced with the **protected privacy rights** of citizens and patients (e.g., analyzing data of 30.000 cancer patients may help identify common, previously unknown risk factors, but asking consent of each individual patient may be infeasible). In addition, historical data sets are

currently riddled with crucial **data gaps**. For example, in medical studies, a gender bias has led to an under-representation of women and their medical needs, resulting in less effective medical treatments for women. As algorithms learn based on the data sets they are fed with, a lack of diversity in data can create biased, ineffective or harmful treatment decisions for under-represented groups (e.g., women, people with low socio-economic status or an immigration background). As such measures to create awareness of gaps and biases in data as well as tools to mitigate these are necessary. Such data-wisdom will ensure the responsible development of tailored treatments and the customization of health care for each patient. In conclusion, it is our aim to promote responsible, inclusive, personalized healthcare.

## Bridging Citizens Science & Society

In this strategic area we are aiming to bridge citizens, science and industry in the context of development and implementation of eHealth technologies and systems to advance European healthcare. Our goals are to implement a human centred approach to our research and design practice, as well as to encourage and support transdisciplinary collaboration, thus involving multiple stakeholders in our initiatives and projects. To do that successfully we take the following actions: **organize digital health and well-being initiatives within communities** representing our target groups, we **identify relevant topics and parties for collaboration** in our activities and projects, we make **an inventory of relevant patient organizations**, we **get involved with public/private knowledge institutions** (e.g., the NIVEL eHealth monitor), we **identify the best practices and tools, nationally and internationally, in eHealth implementation**, and finally, we **create guidelines which will help us to bridge the gap between scientific practice and outcomes**

**and implementation of these outcomes** – a business case for science. These abovementioned activities span a wide range of milestones (e.g., active city labs, round table meetings) and outcomes (national community and implementation programs). It is important to note, that some of these milestone and outcomes may require multiple actions, spread out through a period of time and co-dependent with activities taking place in different strategic areas\*. For example, to initiate active city labs, funding is necessary, thus these milestones depend on outcomes in at least one of the strategic areas – Resources.

## Knowledge dissemination & Education

The key to successful and inclusive digital healthcare is knowledge dissemination and education. Knowledge here entails not only scientific output produced within the Health & Well-being academic cluster, but also the knowledge which will emerge from outcomes in different strategic areas, such as Bridging Citizens, Science & Industry, e.g., recent innovation and best practices in healthcare innovation and adoption of AI technologies in eHealth. Our objective is to engage all stakeholders using digital healthcare tools (with scientific peers, citizens, health care professionals, health insurers and regulators). The following activities will advance our goals: we will **organize symposia and conferences to reach out to scientific peers, engage with the general population through non-scientific publications** (e.g., blogs, interviews), **influence the national education program on various levels** (i.e., high schools, universities) through implementing knowledge in relevant courses, and we will **create a working group for marketing and sharing knowledge via the channels of the digital society** (e.g., the website of the Digital Society) to provide regular, structured and effective outreach and communication.

## Standardization

Standardization in several core areas of digital healthcare will speed up innovation and implementation. To reach our vision of successfully and sustainably implementing digital health interventions and to do this with cross-disciplinary collaborations we have identified the following action points and outcomes: we will **identify relevant methodologies and procedures in conducting research with citizens** and **implement FAIR data principles** in our projects across the Netherlands. This will result in **a legal template** that can be used for research with patients, as well as a foundation for **standard data and ICT infrastructure for eHealth practice in science and industry**. In addition, we will focus on **creating standard procedures** for measuring societal impact and cost effectiveness based on eHealth implementation to produce standard guidelines for measuring and reporting these key societal concepts. Last but not least, we will **work closely with the European Union** (EU) initiative on the Digital Transformation of Health and Care (Digicare) on projects such as the Health Research and Innovation Cloud (HRIC).

## Resources

Resources, and in particular funding, are crucial for creating change and moving towards outcomes in our other strategic fields. In this strategic area, our primary goals are to **acquire funding for the projects** identified in the areas of Networking & Lobbying; Privacy & Ethics; Bridging science, citizens and industry; Knowledge dissemination & Education; and Standardization. At the same time, successfully obtaining funding will be partially dependent on our lobbying activities, knowledge dissemination and scientific activities and results. In order to obtain funding, we need to **identify suitable funding streams and stakeholders**, write interdisciplinary projects proposal together (i.e., experts in data science, human centred design, health and wellbeing, biomedical sciences, valorization) and create flexible and dynamic consortia (see Networking and Lobbying). Specific actions will be directly, and temporally linked to activities and expected outcomes in the other strategic areas.

## Networking & Lobbying

Building a strong community to create change in digital healthcare requires active networking and lobbying. To build this community and to ensure our voice is heard, we have identified the following four ongoing activities: **creating a sustainable network** involving scientific, public and private partners, **identifying relevant stakeholders** including patient organizations, companies and industrial partners (e.g., medical devices, tech companies, pharmaceuticals) and health care organizations, **lobbying with the government** to inform about the impending societal changes and opportunities that arrive with digital and AI-based solutions in the healthcare sector and **lobbying with health insurance companies** to create financially sustainable change. We expect that these activities will result in flexible and dynamic consortia, influence at the policy level, and partnerships with health insurance companies. In addition, through these networking activities and the activities within the strategic area for resources, we will build a stakeholder platform for collaboration and secure early involvement in (research-) projects and business and startup incubators to support business case development in ehealth R&D.

\*The limitation of this insightful Impact map is that the codependencies between activities and outcomes in different strategically relevant areas cannot be easily picked up by exploring the Impact map. A more dynamic tool is necessary. Therefore, to understand the relationship between different strategic areas, and to obtain temporal perspective on the impact that DiSo Health & Well-being network delivers, we derived DiSo Roadmap.

