# Consultation on Digital Health Society

Deadline: 30 August.

Access here: http://echalliance.com/?page=digitalhealthsociety

*CHF: references/sources are available in the previous version*

**The Digital Health Society** enabled by the **Free Flow of Data** will create opportunities for all stakeholders.

In your opinion, what are the main ones for each category of the following stakeholders?

**Citizens**
**Health & Social care professionals and providers**
**Governments & policy-makers**
**Companies**
**Payers & Insurers**
**Research**

Digitalisation of health offers prospects of transformative approaches towards sustainable, integrated preventive health and care systems. This may include reorientation from excessive in-patient care to inclusive out-patient care and gradual but radical shifts from acute care to effective health promotion and disease prevention.

Better digital health applications provide some opportunities for increased emphasis on patient empowerment, which is a key factor in health promotion as set out in the Ottawa Charter, updated in the 2016 Shanghai Declaration. Taking into account rises in non-communicable diseases, aging populations in all EU states offering opportunities and challenges; the consequences of the economic, financial and social crises of the past decade in health and care systems, and increasing unsustainability of aspects of public systems, health promotion and disease prevention is the effective direction forward for digital health in modern economies and societies.

Digital health is a potential set of tools and instruments within processes to tackle inequities. Digital health offers the advantage of increasing access to disadvantaged populations. However this is not only about access to services, but also an opportunity for empowerment, balancing collective rights (to organise systems for States, Authorities and providers) with individual rights (rights to care, treatment, protection and prevention as set out in the EU Treaty, Charter of Fundamental Rights and potential EU Pillar of Social Rights).

In that context digitalisation of health and care systems could be a key trigger for removing health inequalities, as foreseen in the 2009 EU Communication Solidarity in Health; in the UN Agenda 2030 and Sustainable Development Goals (SDGs) and in the evidence and recommendations of the WHO Commission for Social Determinants of Health (SDH).

EuroHealthNet, the European Partnership for sustainable health promotion, wellbeing and social equity, has identified technological changes as one of the ten greatest priorities to be embraced and applied by public health and health promotion sectors towards 2030 objectives. EuroHealthNet is working with its national and regional members, EU Institutions and WHO Europe on sustainable health systems, health information systems, data use, health determinants and health literacy.

The approach of this Consultation within the EU Presidency of Estonia to identify key overall challenges and opportunities, then to make sustainable progress on specific tasks to seek solutions is welcome. EuroHealthNet, and in particular its members within our Thematic Working Groups on Health Promoting Health Systems and NCDs will be pleased to contribute on aspects within our remit, authority and expertise.

## Citizens

Digital Health can almost certainly enhance and potentially transform health promotion and disease prevention for European citizens. For instance, mhealth has the potential to prioritise integrated health promotion, disease prevention, provision of care and monitoring for people from vulnerable groups and disadvantaged areas identified by numerous health, social and economic metrics; thereby reducing health and social inequalities. Emerging technologies can empower patients and carers by giving them more control over and understanding of their health and making them less dependent on health care professionals for health information – if it is authoritative, reliable and accurate.

Potential measures are becoming well known in trials and development, including digital technology to research information online, share experiences, and identify risks, prevention and treatment options.

Applications providing access to information and education can be an important driver of literacy and citizen or patient engagement. However, digital, media and health literacy and technical skills become imperative for both the citizen and the healthcare professional in order to yield the potential benefits of Digital Health Society and avoid a widening of health inequality across Europe, both among and within countries.

### Health and Social Care Professionals and Providers

The proximate relationship to the health professional or care giver should not be substituted for only digital solutions. The digital revolution calls for new definitions of responsibility, competence and authority before implementation, including across borders as a key EU role. Healthcare professionals can be enabled to engage more closely with citizens in prevention of disease and health promotion. A key barrier at present is time and access limitation at primary care level. Greater integration could be possible in new ways through enhanced monitoring, secure and authorised data flows and sharing, risk awareness and treatment regimes.

An inclusive digital health society could involve improved interoperability and compatibility between actors in society, for example the wider public health workforce for physical and mental wellbeing across all generations and communities a key component in reducing health inequalities by addressing the social determinants of health. The partial substitution of conventional consultations, however, calls for a significant reorientation of existing health and social systems, thus it is imperative that all relevant stakeholders – cultural, social, economic as well as health – are engaged in design as well as implementation of new systems.

### Governments & policy makers

Better availability and use of health data can be transformative, depending on appropriate transparency. However, comparability and benchmarking within or between systems and states relies on interoperability, cultural and others sensitivities also set out within the TEU. For example, improved health data and ehealth systems can demonstrate and visualise levels of integrated care, a key factor in tackling social and behavioural determinants and towards the objectives of health promotion.

Improving the comparability of Health Systems Performance Assessments (HSPA) among Member States can improve transparency in policy and programme making. While the HSPA is developed to fit each individual country, the EU could have a suitable role in improving the availability and comparability of indicators – but one-size-fits-all approaches are not appropriate within Europe.

Clearly there are variations and inequalities within and between Member States on digital health solutions; this should be seen as an opportunity, not for competitive public services, but for co-operative partnership working in the EU context as a clear added value.

### Companies, including Insurers

EuroHealthNet operates a Code of Conduct which empowers cooperation with all bodies working transparently towards common goals: specific partnerships in work programmes regarding digital health and wellbeing will be welcomed. INHERIT, a current project within Horizon 2020 is one example of public-private partnership working towards sustainable systems for moving, consuming and living where digital solutions and learning is fundamental. See www.inherit.eu

### Research

Better identification, flows and use of data can potentially facilitate better prevention and promotion as well as diagnoses and effectiveness of current treatment methods. Datasets from finished studies could upon anonymization be made available and reused by allowing wider research communities access. Furthermore, sensors in smart devices collect datasets, which are more objective, cost-effective and potentially larger than traditional questionnaire exercises.

There are great potential benefits for the research field, yet the rise of new actors brings about the question of who benefits and owns the data; it is important to underline the safety and privacy of patients' and citizens' health data.

The statement rather suggests it is a matter of blame for citizens not to appreciate and understand complex technological matters. We disagree.

Conversely we have found that many entities seeking to provide digital health solutions are insufficiently aware of priorities, complexities and sensitivities for physical and mental health and wellbeing. In addition our studies have shown that different ethical and transparency rules and models between public and private systems are real barriers, not easily overcome. Resources are of course also a serious issue.

The complex truth is that genuine partnership working and involvement in design as well as implementation has been shown consistently to be the most effective approach. Far from stifling innovation, a precautionary principle better avoids costly and harmful risks and failures.

EuroHealthNet has been part of a consortium IROHLA regarding health literacy for older people in Europe (www.irohla.eu) which has put forward multiple steps and solutions towards improving citizen and system engagement and empowerment in these fields. EuroHealthNet is also part of the EU Joint Action CHRODIS on tackling chronic diseases and multi-morbidities (www.chrodis.eu) which has identified numerous steps in prevention and systematic application involving digital innovations.

Reassurance, trust, and transparency of information are fundamental for awareness and meaning for the citizen.

Proper legal frameworks at all levels from local to international are essential to protect citizens' and patients' personal data and define clear conditions for the ownership, licensing and use of the data.

There is good reason for these concerns, highlighted in numerous examples of problems within and beyond health systems where personal data has been at risk. Clearly block chain developments hold potential, but for an equitable digital single market to be created and sustained these concerns cannot be dismissed.

An example expressed to EuroHealthNet concerns data held in primary care environments, crucial for integrated approaches for mental and physical wellbeing, public health, disease prevention and health promotion, plus pathways to acute and ambulatory care. Data held by an authoritative practice may be secure; but if it is accessible to a third party provider, for example of online facilities or services, is it also guaranteed to be permanently secure? When business transfers occur, how is sustainability and security guaranteed? Doubtless solutions may be developed, but until they are tested a precautionary principle should apply.

Similarly rights to personal data must be clarified and clear: a vague, general opt out which may not apply to third parties and is insufficiently explained would be insufficient and is not welcomed by many professionals and practitioners.

The provisions of the potential EU Pillar of Social Rights and the highest standards of global data and health protection approaches should be incorporated.

Nevertheless, the work of EuroHealthNet with research institutions and WHO demonstrates that greater access to anonymised and ethical data offers great potential benefits for public health, and should be explored innovatively in the context of digitalisation of health and care systems.

eHealth is not yet a major component in most health systems. If it is to fulfil its potential, policy-makers need to address variation and discrepancies in regulations and increase standardization in the national and European contexts. This, in terms of interoperability means defining standards for and regulation on interoperability of eHealth solutions for remote consultation, monitoring and care as well as improving and implementing a concrete road map for compatibility and standardization of e-referrals, ePrescriptions and health information systems within and between EU Member States.

Meanwhile, it is necessary to recognise national differences in health systems. The EU could have a valid role in improving the availability of indicators in order to achieve better comparable data. Further, the EU could support initiatives like the ECHO Project; the European Collaboration for Health Optimization (ECHO) project is an international effort to bring together administrative datasets from several European countries and inform decision-makers on unwarranted variations in health care performance (www.echo-health.eu). Moreover, the EU could facilitate more shared learning initiatives between Member States in benefitting from shared data and digitalisation of health data.

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It is important that a potential legal framework for the use of health data should take stock of all of the different types of data, e.g. information gathered through internet search, social media, and smart devices. Limits should be clearly defined in terms of which data that should be allowed to be used and by whom. The consent procedure as well as ownership and licensing of health data should be clearly defined.

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Comprehensive training and educational campaigns will be important in improving the digital health literacy of patients, informal carers and health and social care professionals.
To stimulate European health care systems to move forward in health promoting initiatives through digital health solutions, e.g. related to the improvement of care for people with multimorbidity through eHealth tools, national policy-makers need to address the trust and literacy issue among citizens and healthcare professionals.
The health workforce (defined widely to include cultural, social and environmental actors as well as specifically in health systems) and informal carers lack digital skills and would benefit from improving their digital health literacy. National and sub national health promoting campaigns and shared learning on these among Member States could alleviate this. Healthcare professionals are often perceived to be reluctant to engage with technology, partly due to the scale and pace of changes, and partly through lack of education and training, and concerns over liability and

funding. The inclusion of attractive and inclusive eHealth modules in education and training would be beneficial for students in health and caring sciences, and professionals in the health care sector.

Furthermore, professional medical organizations could employ consensus-driven processes to define guidelines for the integration of digital health into care delivery, including but not limited to determining which clinical scenarios should involve in-person encounters and which are appropriate for virtual encounters.

EU funding instruments have key potential roles in vocational and professional training, notably ESIF and cohesion funds. It is important that EU Semester, Annual Programme and Multi Annual Financial Framework approaches take this fully into account.

**Some challenges** remain to fully implement the **Digital Health Society**. Please, comment the challenge mentioned below and share some concrete examples of solutions or actions to overcome it.

**Lack of change management strategy in healthcare systems**
As in all sectors, the implementation of digital technologies is not only equipping the on-going work process and organisation. It requires a re-think and re-organisation of the whole system, the role of the stakeholders and the approach for the healthcare service delivery. Digital brings a complete transformation.

As stated above, digital transformations offer potential opportunities to reorient health and care systems in favour of sustainable preventive and promotional approaches, which is long overdue. Health ministries should be encouraged and stimulated to develop new approaches and business models of the health sector to lead the way for a digital transformation. Currently, most mobile technology services are not reimbursed in many EU countries nor are there specific budgets for it. This business model should also provide the financial incentive for eConsultations in order to avoid a disincentive from the health professional's side. Shared learning between Member States in this progress is pertinent to ensure improved solutions.

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**Lack of meaningful and integrated solutions**
Simple rough and general data information is not impacting behaviours. The citizens need to understand the meaning of each set of data, to have a view on the impact of their actions and choices on their health status and so on. The basic *quantified self*, thanks to all personal devices and wearables currently on the market, are not triggering the expected behaviour changes, because of the lack of meaningful information and the lack of integration within the healthcare systems.

The UK (Scotland and Northern Ireland) example below provides a good example in establishing a body such as the Digital Health Institute to foster and encourage the growth of digital healthcare while combining it with existing experience and attention to integrated care. Such example could aptly be showcased in mutual learning initiatives between the ministerial, regional and local level in Member States. Notably, it is important to encourage collaboration between various levels in order to achieve effective digital solutions in integrated care:

Healthcare systems in Scotland and Northern Ireland, which traditionally had a much more integrated approach to health and social care, are at the forefront of exploiting the opportunities for technology enabled care (TEC). In Scotland, technology enabled care is central to integrated service delivery and, in March 2015, the Scottish Government announced a further GBP 30 million of funding over three years to increase the number of people receiving support, diagnosis and treatment at home. The TEC programme builds on the success of previous programmes of national support such as the Telecare Development Programme which ran from 2006-2011, and increased access to telecare services for almost 44,000 people in Scotland. Evaluation showed around 2,500 hospital discharges were expedited as a result of the programme, while at the same time around 8,700 unplanned hospital

admissions and over 3,800 care home admissions were also avoided. The TEC Programme is aimed at increasing choices and control in health, care and wellbeing for an additional 300,000 people. The Scottish Government has also established the Digital Health Institute to foster and encourage the growth of digital healthcare in Scotland.

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**Lack of innovation in funding models**

Lack of money is also often indicated as one of the main barrier factors but it is debatable. If we observe the allocation of resources in the area of digital health, and particularly related to electronic health data deployment at the EU or at the Member States level, we realise that large sums have been or are being invested. The issue seems to identify creative and innovative funding models. Because EU systems are widely based on fee-for-services models, the added-value of data-based systems and solutions focused on integrated care, services quality, prevention and outcomes of the interventions don't find their place in current purchase processes and contracts model. The challenge is then to break down the budget silos between health and social care or between secondary and primary care, to incentivise the stakeholders, to deploy more widely, innovative public procurement models, and new types of contracts, outcomes-based and involving risk sharing between the parties (suppliers-buyers-care providers).

As mentioned in connection with management strategies, financial incentive structures ought to be reformed to encourage increased use of digital solutions in integrated care as well as public health. Average public health budgets are not fit for purpose in most States and regions as a proportion of health and social care expenditures, despite evidence of sustainable cost-effectiveness for systems, societies and economies. This change necessitates public drivers at national level. Public procurement as well as authorisation and certification processes connected to involvement of third parties are necessary. Both should be alleviated through mutual learning between Member States and accompanied by comprehensive data protection regulation at EU level. Furthermore, the EU has an important role in encouraging this process through EU projects revolving around such strategies.

**The Digital Health Society** has set up **Task Forces** around specific **challenges** which need be moved forward in the next months. Please share with us your comments, ideas and initiatives that could generate progresses around the following challenge.

**Task Force 1**
is targeting
a **convergence roadmap for European member states and regions on interoperability standards and Digital Tele healthcare protocol**

It is important to address the local, regional, and national level in order to take integrated approach as well as research perspectives into account from the beginning. This also means taking actors involved in the social determinants of health into account. EuroHealthNet is a not for profit organisation encompassing responsible bodies (national and regional authorities and health departments) and research institutes. The added-value is strong in incorporating these actors in the shaping a convergence roadmap for interoperability in order to ensure a holistic, realistic and implementable deliverable.

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**Task Force 2**
is targeting to
**create Data donors campaigns and tools for EU member states and regions in order to raise awareness of the Europeans about the benefits in sharing personal health data to improve health services and contribute to the European Research**

It is important to take the health inequalities perspective into account in awareness raising as disadvantaged and vulnerable groups are  citizens who may  benefit particularly from health promoting measures such as enhanced literacy, mhealth and ehealth solutions. Conversely, such people may also be most at risk of abuses and failures. It is important to have all key stakeholders, including health care professions, health authorities, civil society organisations and wider public health stakeholders from environmental, cultural, community and social sectors involved in design through to implementation and evaluation in all integrated and inclusive initiatives. EuroHealthNet has a track record over two decades of such learning and engagements.

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**Task Force 3**
is targeting to
**collect the best practices and design the principles of a legal framework, including the GDPR and local regulations, facilitating the free flow of data and the 2nd use of data**

EuroHealthNet has two decades of experience of working on key issues around safe and effective use of data and information within health and care systems at all levels from local to international.

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**Task Force 4**
is targeting to
**collect the best practices and publish recommendations for the digital transformation & change management in healthcare organisations**

EuroHealthNet has two decades of experience of working with health and care partners on the ground in states and regions to identify, collect, evaluate and share promising, good and effective practices for practical implementation and change approaches from local to international levels, including significant online facilities and sources in addition to EU co-funded studies. See www.eurohealthnet.eu

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**The Digital Health Society** has set up several **Task Forces**, gathering high-level experts and 1st implementers on specific topics.

You will be invited in September to express your opinion on the pre-conclusions of these Task Forces. Please indicate which topic interest you.

☐ Convergence roadmap on interoperability standards and Digital Tele healthcare protocol
☐ Data donors campaigns
☐ Principles of a legal framework facilitating the free flow of data and the 2nd use of data
☐ Recommendations for the digital transformation & change management in healthcare organisations

COMPLET « Previous or Review Answers

✓ Tick all boxes