



The Digital Health Society

Join the movement!

www.thedigitalhealhsociety.com



Background

The Digital Health Society (DHS) movement:

- Born during the Estonian EU Presidency in 2017;
- Focused on the development of a digital society in Europe;
- Enabled by the free flow of data, as the 5th freedom right in the European Union;
- Launched by the Ministry of Social Affairs of Estonia and the ECHAlliance as a call for action;
- First objective - to bring together all stakeholders of the digital health ecosystem to drive the agenda of the EU Presidency.



What is the DHS?

The Digital Health Society, an open multi-stakeholder movement, is both:

- A Digital Health thought leadership platform to:
 - Generate innovative ideas;
 - Exchange knowledge, experiences, best practices, success stories
 - Design a route for large-scale deployment.
- An Innovation and Implementation Factory, enabled by Task Forces, able to accelerate and deliver innovation “on the ground”.



Strategic view

- DHS has an **ongoing strategic link with subsequent Presidencies;**
- The current link is with **Finnish Presidency** and their work centred on the **Wellbeing Economy**. E.g. the **Digital Health event in Helsinki;**
- There will be a **half day session devoted to DHS** and its activities;
- Emphasis has been on scaling existing innovations and work.(due to 6-month nature of EU Presidencies);
- Another important development in 2018/19 has been the development of the **strategic partnership with the Commonwealth Centre for Connected Health** bringing expertise and opportunities across its **developed and developing countries**. The opportunities to scale digital health is very substantial and furthers the aims of the DHS.



How do we work?

- Periodic Board Meetings with its Directors and Observers (every 3 months)
- Task Forces: open collaborative working and exchange groups arranged across four core topics

TF1 Standards and Interoperability

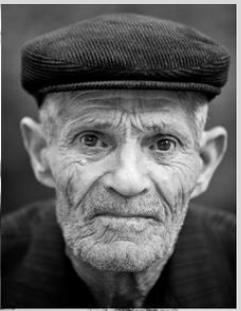
TF2 Citizen-controlled Data Governance & Data Donation

TF3 Legal & Regulatory Framework

TF4 Digital Transformation

- Meetings, calls and webinars of the Task Forces
- Cross-fertilization with relevant EU Projects
- Participation in other initiatives such as the [EU Health Summit Recommendations and Conference](#) as the lead on the Data and Digital work stream incorporating recommendations on dynamic consent, measuring wellness, digital skills training and a European Data institute and the [All Policies for a Healthier Europe](#) initiative
- Articles, ECHAlliance newsletter and social media communications





What is the DHS Mission?



100 million

Digitally Connected Healthier Citizens by 2027

The [mission](#) aims to develop a series of support activities and research & innovation projects, driving to **collect the data** (relevant for health purpose) of **100 million citizens, by 2027**, and **make them available** (under conditions) for the purposes of:

- **Research**
- **Improvement of health and care services enabling both personalised health and population health management**
- **Citizens' empowerment and self-management for a better health and wellbeing**
- **Innovation and development of innovative infrastructures, products and services.**



The four components



Research &
Innovation

Enabling
Environment

Citizen
Engagement &
Empowerment

Digital Health
Infrastructure

Instrumental to the DHS mission:
100 million Digitally Connected & Healthier
Citizens by 2027



The DHS Mission: Status and Next Steps

- The Mission needs to be adopted and funded.
- Recommendation - a **European Health and Care Data Convention for individual Member States and/or Regions to sign. No Member State supported to date so recommendation is to focus on dynamic consent.**
- Possible programmes include the creation of a **dynamic consent platform** - the idea is people/patients manage healthcare consent on-line in a secure platform and this could include both research and treatment consent and people would be able to vary consent from time to time in real time. This would create a substantial base of patients for research - would potentially make a serious contribution to the 100m Lives Mission and facilitate European Research and economic activity.
- Link with other relevant EU initiatives e.g. the [DigitalHealthEurope](#) project, the DataSavesLives promoted by EPF, All Policies for a Healthier Europe, EU Health coalition and international initiatives such as the WHO GCM on NCDs.



Task Force 1 – Standards and Interoperability

2019-2020 Action Plan (1 of 2)

Objectives:

- To consolidate the knowledge and awareness of all members and involved stakeholders around the state of the art of European initiatives, publications and projects in the domain of interoperability and standards in the context of digital health.
- To identify concrete use cases and facilitate the sharing of exemplary practices and knowledge around implementation strategies, drivers and barriers
- To facilitate peer-to-peer advise and exchange towards transfer and adoption

Activities carried out:

- Selection of the first use case: Maternal and child care
- Identification of three good practices in different EU countries (Ireland, Netherlands and UK)
- [Webinar](#) arranged by the Dutch Ministry of Health



Task Force 1 – Standards and Interoperability

2019-2020 Action Plan (2 of 2)

Next steps:

- Publication of infographics or a report gathering lessons learnt from the exchange
- Call for additional practices to be engaged in the Dissemination of exemplary practices across DHS and ECHAlliance relevant events e.g. DHWS19
- Launch of a consultation among the TF1 contributors to identify next use case to focus on
- Across 2019-2020, leverage/strengthen synergies with other projects (e.g. [Trillium II Community of Practices](#), DigitalHealthEurope, etc.)
- **For approval:**
 - New TF leadership



Task Force 2 - Citizen-controlled Data Governance & Data Donors (1 of 3)

Objectives:

- **To bring together European initiatives where citizens are directly in control of their personal data**, such as health data cooperatives models.
- **To analyse the governance models in use**, examining in particular how they assure the security and the privacy around citizens' data in order to build trust, as well as the incentives models used to engage with citizens
- **To create a European forum of relevant organisations** having developed citizen-controlled data governance models and digital empowerment models, analyse and benchmark good practices, similarities and differences, and present Europe with an options appraisal of successful candidate models to be widely promoted and adopted.



Task Force 2 - Citizen-controlled Data Governance & Data Donors (2 of 3)

Objectives:

- **To investigate existing donation programmes** (health-related - blood, organs - or not) and their components incl. how donation is incentivised by monetary and non-monetary means and how transparency of data use is provided back to citizens
- Based on the knowledge acquired, to **drive the design of a prototype of a health data donation campaign**, e.g. raising awareness about the benefits of data sharing, including creating key messages and channels for such campaigns, exploring incentives models to engage EU citizens in this societal ambition. **Synergy with DataSavesLives**



Task Force 2 - Citizen-controlled Data Governance & Data Donors (3 of 3)

Activities carried out in the first half of 2019:

- Setup of an initial working group at the DigitalHealthEurope Workshop @Lisbon eHealth Summit 2019

Next steps:

- Scoping review of existing knowledge and health data innovative citizen controlled data governance models and experiences across EU
- Follow up to Lisbon and call for experts to enlarge such forum
- Prepare and administer an in-depth interview protocol to gather information about innovative citizen controlled data governance models
- Perform desk search around donation programmes
- Arrange a workshop with key experts on donation and promoters of innovative models
- Release recommendations and guidelines on citizen-controlled data governance models and data donation campaigns for health



Task Force 3 – Legal and Regulatory Framework

Background:

- The conclusions reached at the end of the Estonian Presidency and presented in October 2017 were to create a European Health and Care Data Convention.
- In order to develop the concept of the Convention a lot of legal work would be necessary and DHS ability to drive progress is limited because this needs to be a government level led initiative.

Proposal:

- Switching our focus onto dynamic consent which had been one of the subjects TF3 had discussed. The idea is people manage healthcare consent on line in a secure platform and this could include both research and treatment consent and people would be able to vary consent from time to time in real time → **DHS Mission enabler**

For discussion:

- TF3 could be:
- Absorbed and dynamic consent moved into TF2
- focus itself on dynamic consent
- simply form part of the implementation of the Mission not a specific TF.



Task Force 4 – Digital Transformation

Objectives (elaborated from the website):

- Create a forum for health and social care managers for sharing internationally promising solutions and practices of Digital Transformation and identify champions and game-changers.
- A possible topic to focus on: **skills development** → Bring together existing EU initiatives for digital literacy and skills development of health/social care professionals (such as NHS Digital Academy and the ERASMUS+ DISH project as an example) and exchange experiences and promising practices in change management and programs fostering innovation readiness of health and social care workforce.

For discussion:

- TF leadership
- Where we are: work done so far
- Overlap or synergy with the newly relaunched: [EHTEL Digitally Integrated Care Task Force?](#)



Critical points for making DHS operational and other issues to be discussed with the Board

- **Establish clear TF leadership with organizations & people who can allocate resources**
- **Setup collaboration links with other parallel initiatives**, e.g. #DataSavesLives from European Patient Forum: they are going to build a platform meant to be an *“online portal on health data to improve awareness, dispel myths and inaccuracies, and promote the importance of Real-World Data to the public and to create a trusted environment for dialogue about the use of health data”*. The platform will be one of the assets of DigitalHealthEurope.
- **Requests coming from people who expressed interest in joining the DHS about having the list of participants published: thoughts?**
- **How can we operationalize the DHS 100 million mission and transform the task forces in its enablers?**
- **Consolidation of a permanent list of Official Observers**
- **Strategic link and collaboration with DigitalHealthEurope** as an example (see next slides)
- **Planned activities for TFs? How do we engage partners?**



The new [DigitalHealthEurope](#) project

New Coordination and Support Action (1/2019 – 12/2020) providing centralised support to the digital transformation of health and care (DTHC) priorities of the Digital Single Market.

Strategic value for DHS: **actionable strategic vision and recommendations for EU policy beyond 2020.**



Digital tools for citizen empowerment and for person-centred care – large scale deployment and scaling up across Europe

DTHC Priority 3

Citizens' secure access to and sharing of health data

DTHC Priority 1

Better data to promote research, disease prevention and personalised health and care

DTHC Priority 2

Centralised, continued support to scaling up and deploying digital solutions for chronic diseases and integrated care

Promotion of enabling factors and building blocks towards reference frameworks for DTHC scale-up

Collaboration with stakeholders to analyse DTHC challenges, solutions and agree common strategic agendas and commitments

Fostering the policy vision for EU's co-ordination and support on Digital Transformation for Health and Care topics beyond 2020

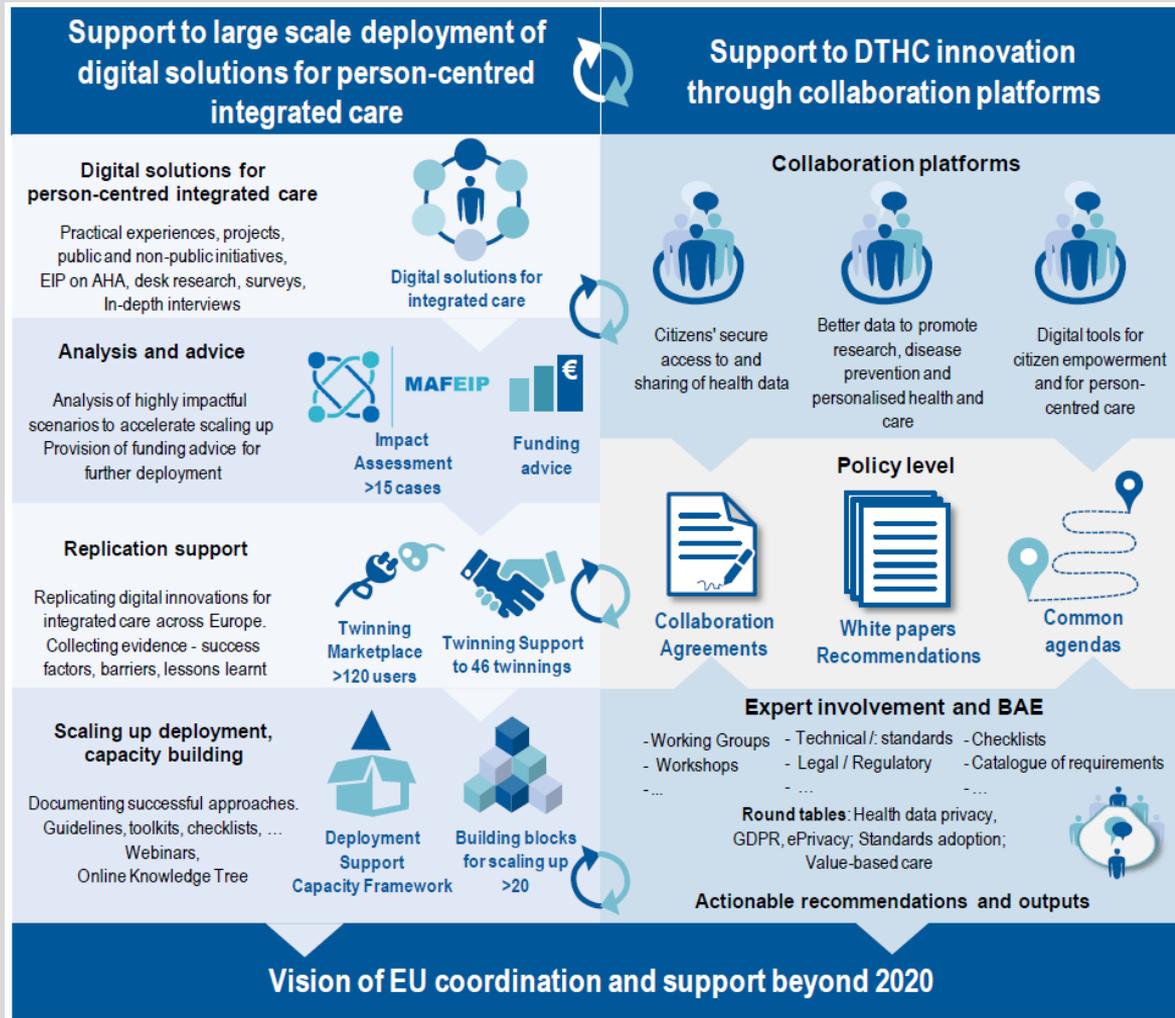


ECHAlliance is partnering the DigitalHealthEurope H2020 Consortium:

- Empirica
- SPMS
- EIP on AHA RSCN
- ERRIN
- AGE
- EPF

ECHAlliance (in collaboration with DHS)

- EUROREC
- Open Evidence
- FZJ
- EAPM
- EHTEL
- IFIC
- Lisbon Council
- ICE
- COCIR



How to join

Follow:  [@TheDHSociety](https://twitter.com/TheDHSociety)

Website: www.thedigitalhealthisociety.com

LinkedIn:  [The Digital Health Society](https://www.linkedin.com/company/the-digital-health-society)

Email: DHS Management Team, dhs@echalliance.com

