

Imagining 2029 webinar series: Building health data ecosystems for integrated care

An EHTEL factsheet:

Deep diving into health data ecosystems for integrated care: sustainability and governance



This second Digital Integrated Care Taskforce (DICT) factsheet delves into the principles for developing health data ecosystems for integrated care in two different health systems: NHS Scotland and Israeli health care. It draws on the lessons learned related to ecosystem governance and long-term sustainability of two different, and – at first glance – apparently opposite, approaches. By examining, however, the two services’ strategies and implementation approaches, some **common key elements** emerge as enablers of digital health innovation and integration of health and care. This factsheet is the second in a series produced by the DICT. Each factsheet reflects the content of a **dedicated webinar or workshop**. This document is based on virtual workshop discussions hosted by EHTEL on Thursday, 1 October 2020, with contributions from EHTEL DICT members. They included the DICT chair, Rachele KAYE of **Assuta Medical Centres** (Israel), together with Nessa BARRY of **Technology Enabled Care and Digital Healthcare Innovation** (Scotland, United Kingdom), and the further support of five European projects – **Digital Health Europe, InteropEHRate, European mHealth Hub, SCIROCCO Exchange, and vCare**. The discussions were enriched by expert insights offered by the workshop

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Introduction

Back in 1991, Peter B. Vail coined the concept of **permanent white water** in his book *“Managing as a performing art. New ideas for a world of chaotic change”*. He contrasted the liveliness of this dynamic metaphor to a scenario of calm lake waters, which most managers were taught to consider when they planned the future. Since then, the accelerated path of digital innovation has been constant and a number of disruptions have changed what and how managers manage health systems and services.

In this context of **rapid technological change**, health systems have developed and adopted digital infrastructures. This has led to initial steps being taken that have facilitated the digital transformation of health and care.

Health data ecosystems are a step forward that capitalise on the data spaces generated by past investments and new data sources, namely **people-generated data** through mobile applications and third-party data produced by medical devices and wearables. Altogether, this creates **new data ecosystems** that health systems can use to progress towards a data-driven care optimisation, thereby leveraging governance, legal frameworks, infrastructures, and incentives (Figure 1).

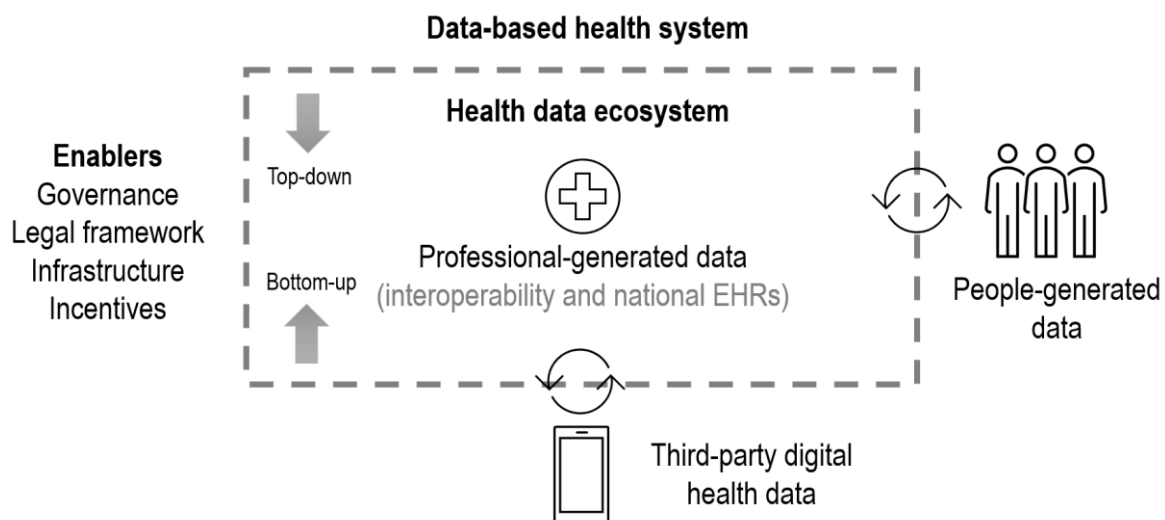


Figure 1. Development of health data ecosystems

Along these lines, a working paper [“Towards trustworthy health data ecosystems”](#) published in October 2020 by the Finnish innovation centre, Sitra, states that **a human-driven, fair data economy** – which creates new data-based, privacy-protected well-being and health services – will guarantee a transformation towards next-generation health-service systems: these will be based more solidly on integrated care. Data must be made more easily available, thus enabling the production of **more personalised services** (data cannot remain in silos). This shift will require extensive co-operation among public and private entities together with a wide

range of actions (from soft regulation and rules for a new infrastructure), and the **integrated use of smart devices** in healthcare processes.

Description of the workshop

Continuing a work programme on health data ecosystems initiated in 2020, the EHTEL Digital Integrated Care Taskforce (DICT) organised the workshop “*Deep diving into health data ecosystems for integrated care: sustainability and governance*” on 1 October 2020. It delved into the **development of health data ecosystems for integrated care** by comparing the journeys of two health systems with apparently opposite approaches. Keynote presenters were Nessa BARRY from Technology Enabled Care and Digital Healthcare Innovation (Scotland, United Kingdom (UK)) and Rachelle KAYE from Assuta Medical Centres (Israel).

Objectives of the factsheet

There are three objectives to this document:

- Illustrate how digital health and **data ecosystems are shaped** at country level.
- Identify **the governance principles** that drove successful implementations in the past and review them in view of the **current development of health data ecosystems**.
- Compare **national approaches** to the sustainability of digital health innovations that can enable **health and care integration**.

Digital health and care ecosystem in Scotland

Scotland maintains its own jurisdiction in health and care service delivery organisation since 1999, and its citizens have a strong sense of ‘ownership’ of the system. NHS Scotland serves 5.4 million citizens through 14 Regional Health Boards, 7 Special Health Boards, and one Public Health body. It has more than 900 general practices, employing around 140,000 health professionals. Governance is set by the Scottish Parliament through 32 Local Authorities. Scotland stands out as a **digital health front-runner** with a special focus on health and care integration with telehealth and telecare services.

A **top-down approach** has been followed in the development of digital health and care implementations. The approach has benefitted from a consistent government endorsement of the role of information and communication technologies in health. Since 2008, digital health and care strategies have been reinforced centrally, embedded in policy recommendations and actions, and received sustainable funding. **Key policy priorities** today are the integration of health and care, improved accessibility to health services, and support at home and in the community.

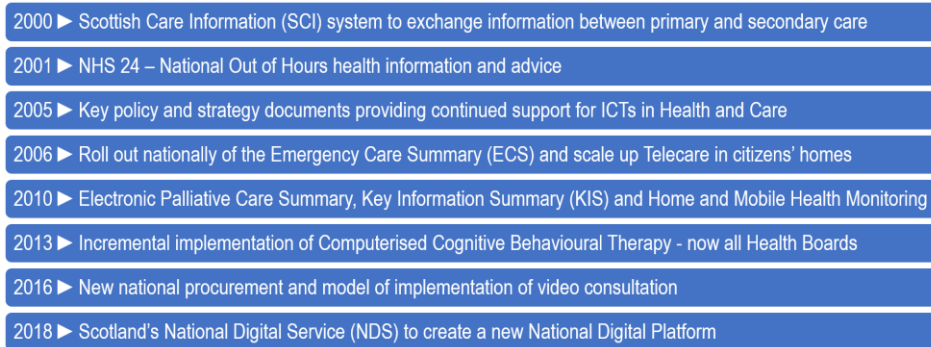


Figure 2. Timeline of Scottish digital health development

Key governance features for ecosystem generation

NHS Scotland has developed digital health services aligned with a **defined strategy** and clarity of roles and responsibilities. In 2010, the Healthcare Quality Strategy set forth the principles to provide safe, effective, and person-centred care across all policies. Quality improvement methods, leadership, and partnerships working across health and care settings, are **well established practices**.

In 2018, the Digital Health and Care Strategy identified **six key areas of focus** (Table 1).

National direction and leadership	A national Board and supporting governance mechanisms to rationalise and clarify decision making processes for investment, prioritisation and policy setting.
Information governance, assurance and cyber security	New national arrangements to support appropriate information sharing for delivery of care, research and innovation, give people choices in how they access and manage their information and maintain trust that information is used and managed safely and securely.
Service transformation	New processes to support the spread and adoption at scale of proven digital technologies within services and the promotion of methodologies that support local service change and redesign as part of pathways of care.
Workforce capability	A programme of work to promote leadership and workforce development in digital skills and capabilities in order to underpin the successful uptake and use of digital technologies.
Digital platform	The development at a national level of a digital platform that facilitates the availability and exchange of information and interoperability of existing and new health and care systems and applications.
Transition process	Agreeing a roadmap over time to rationalise different local, regional and national systems to converge on to the digital platform, without impacting existing service provision and delivery of care

Table 1. Six key areas of focus for health and care integration

Health and care integration and citizen participation are fundamental **drivers** for digitally-enabled services. The Scottish approach to service design seeks to build person-centred services, and the user perspective leads to insights for a more sustainable service delivery.

Scotland's Programme for Government 2020-2021 focuses on **scaling up the use of digital health services** so as to ensure more people can get the care they need in a suitable way. It addresses **mental health and wellbeing** as a means of overcoming existing health inequalities caused by the COVID-19 pandemic, and establishes an independent review to **reform adult social care** that can lead to a National Care Service.

Building grassroots from the bottom-up: the Israeli health data ecosystem

Israel's **national health insurance system** is based on integrated Health Maintenance Organisations (HMOs), acting as insurers and providers. HMOs are accountable for the health of their members as well as healthcare expenditures, and are relatively autonomous in a context of strong competition between the four main players – Clalit, Maccabi, Meuhedet, and Leumit.

Health information technology (IT) in Israel is driven by competing HMOs on digital excellence. In the 1990s, Electronic Medical Records (EMRs) were comprehensively implemented and shared organisation-wide. By 2000, clinical and management systems, patient portals, telehealth and virtual care were consolidated together with the HMOs health data ecosystem supporting integrated care, making Israel a **digital health system champion**.

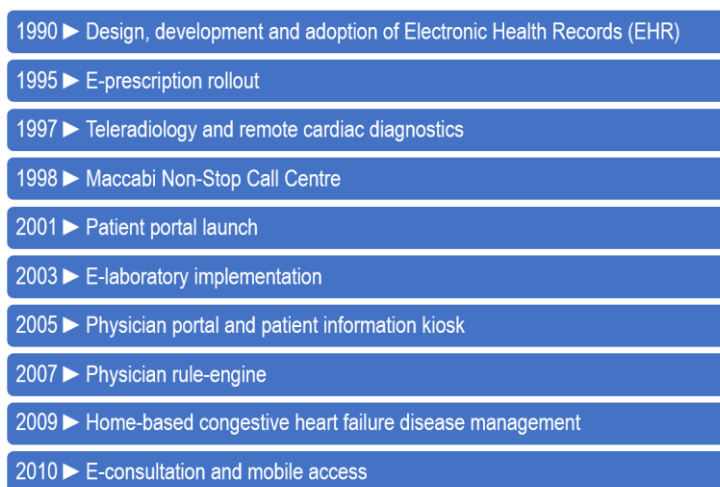


Figure 3. Timeline of Israeli digital health development

During the past decade, the Ministry of Health has assumed **increasing leadership at the national level**, articulating **a national strategy for digital health** and developing the National Electronic Health Record Exchange that preserves the local autonomy of HMOs and hospital data systems.

Governance principles, ongoing management, and assurance of sustainability

The development of health data ecosystems in **Maccabi Healthcare**, the second largest HMO in Israel, has followed three stages: initiating and establishing the foundation; providing ongoing management and continuous development; and building the future and assuring sustainability.

In the **first stage** of the three, visionary executives **led the transformation** by partnering with pioneer doctors involved in designing EMR user interfaces. Financial incentives to attract patients created a critical mass that led to mandatory EMR use.

Seven governance principles underpinned change:

- Innovative leadership.
- Active involvement of key stakeholders.
- Assessment of context and needs.
- Identification of compelling needs and immediate benefits.
- Political, financial, and professional incentives.
- Integrated responsibility of multidisciplinary teams.
- Continued training and support.

In the **second stage, consolidation** of digital health initiatives were supported by an ongoing management characterised by solid supportive leadership that fostered strategic planning and innovation. Mechanisms such as a permanent budget, clear process and organisational structures for setting priorities, and the evaluation of new technologies contributed to cement change. Building strong relationships between management, clinicians and IT became key.

In the **third stage**, the goal was to assure **sustainability** through the generation of a climate that fosters innovation and welcomes disruption. This stage included a large number of activities: embedding IT in ongoing organisational processes, balancing competition and collaboration, learning to partner with the technological industry, securing commitment and leadership at the top levels of governance, and providing ongoing training and support to all

users. The rapid pace of technological change and the advances in medical care have demanded **a process of ongoing transformation and openness**.

Learning from both approaches

Scotland and Israel have differed in their **implementation approaches and priorities** to digital transformation. Scotland has followed a national strategy that has driven the prioritisation of telehealth and telecare for integrating health and care (i.e., it occurred **top-down**). The competitive context of the Israeli health system drove **bottom-up** implementation that focused on deploying shared electronic health records (EHRs) and clinical decision support systems to improve care integration. Despite the differences between the two, however, both approaches share **five common governance elements**.

Their **five data governance principles** are:

- **Commitment and shared leadership** of innovators and senior managers.
- **Focus on compelling needs**. Scotland focused on accessibility and integrated care, and Israel on clinical coordination.
- **Collaboration and communication** between different stakeholders and sectors in Scotland and, through a multidisciplinary steering committee in Maccabi (Israel) and end-users' involvement in system design.
- **Embedding of IT in organisational processes** was reflected in the national digital health and care strategies in Scotland, and in integrated clinical processes in Maccabi (Israel).
- **Provision of training and ongoing support** occurred through online resources, exchange networks and training opportunities in Scotland, and onboarding training and regular updates for clinicians and managers in Maccabi (Israel).

The **workshop presentations showed that, whether the country's approach is top-down or bottom-up**, it is important to concentrate on these **five basic principles of governance**. These principles have also been identified in other digital health and integrated care development frameworks like the **Scirocco Exchange Maturity Model** or the **European Momentum for Mainstreaming Telemedicine Deployment in Daily Practice**.¹

Essentially, they relate to: leadership; the identification of compelling need(s); the embedding of IT in organisational processes; collaboration and communication; and the provision of

¹ Scirocco Exchange Maturity Model: <https://www.sciroccoexchange.com/maturity-model>
European Momentum for Mainstreaming Telemedicine Deployment in Daily Practice: <http://telemedicine-momentum.eu/>

training and ongoing support. Ultimately, the solutions chosen can be very different, the one from the other, in terms of their detail.

Outcomes from the expert discussion

The virtual workshop discussion with the audience was guided by a **five-question live poll**. It set the ground for debate among speakers and a 'front row' of experts from different countries: Meghan BRADWAY (Norwegian Centre for eHealth Research), Zhaklina CHAGOROSKA (eHealth Directorate, Ministry of Health, North Macedonia), Donna HENDERSON (SCIROCCO Exchange), Reut RON (Assuta Medical Centres), and Margaret WHORISKEY (Technology Enabled Care, Scottish Government). Twenty-five experts from seven different countries participated in the poll.

A first 'icebreaker' question inquired about **health systems approaches**. Forty per cent (40%) of respondents considered that their own country followed a top-down approach similar to that of NHS Scotland, 25% followed a bottom-up approach like in Israel, while 35% considered that their health system followed an intermediate approach.

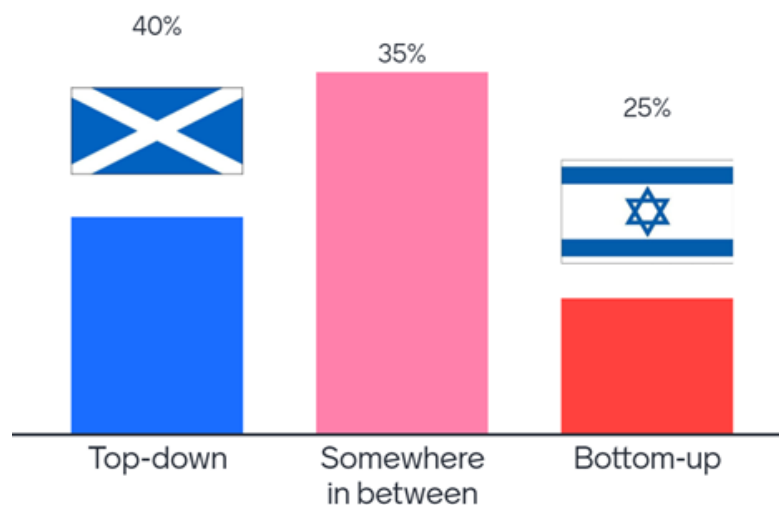


Figure 4. Live poll results on health system approaches (top-down vs bottom-up)

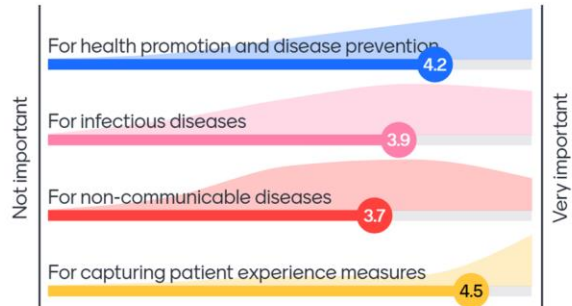
The poll then continued around questions relating to other **challenges** like obstacles/barriers; opportunities for increasing health data flow; and future governance features.

The poll results inspired the ensuing discussion. Culture, financial constraints, and rigidity stood out as the **main barriers** to increasing the innovation absorptive capacity of health systems.

What is the main obstacle to helping health systems absorb more digital health innovation?



How important for person-centred care is to increase the flow of data generated by patients?



Are the governance features that ensured progress in the past decades valid for integrating third-party health data?



Figure 5. Live poll results on health data ecosystems for integrated care

Highlighted in the discussion, as **enablers**, were the **training of health professionals** related to handling patient-generated data and how data is structured.

In general, participants considered that the **flow of data** generated by patients was important to develop person-centred care. Capturing patient experience measures and the use of patient data for health promotion and disease prevention received higher scores (this was underlined by the Scottish representatives as the need to incorporate a **patient-centred approach**). The Scots also expressed concerns about the **consequences of digital exclusion** in terms of lack of equity of access, especially for people with reduced or limited incomes. Not surprisingly, given the current importance of COVID-19, **patient data for managing infectious diseases** was slightly prioritised ahead of non-communicable diseases (a response of 3.9 in contrast to 3.7).

Delving into the integration of **third-party health data**, including patient-generated data, more than 75% of the experts responding declared that a **major adaptation of governance features** is needed. Twenty per cent (20%) demanded a new form of governance. Israeli representatives underlined the need for change, as the current eHealth interfaces in their country were created without patient input.

Finally, to make digital health investments sustainable in the present context, participants pointed out a **myriad needs**. These needs included: integration, public-private partnerships, efficiency, positive patient experience, flexibility, incentives, accessibility, new business models, redesign, political commitment, and effective collaboration.

The future is all about **making societies more sustainable**, by changing the model of care, embedding innovation in existing systems and adapting governance features, not simply about financial viability.

Conclusions and next steps

In agile and disruptive times, **adaptive organisational principles** are needed in order to deal with a new and complex reality. Building trust and relationships with key stakeholders, and understanding what citizens require and how their insights can impact services, are vital and yet time-consuming activities.

There is **not a single valid approach** to foster digital health innovation and consequently develop health data ecosystems. The examples of Scotland and Israel show how both top-down and bottom up approaches have succeeded, by **sharing five similar governance principles for long-term sustainability**. A review of supportive governance mechanisms was pointed out to enable and steer multi-stakeholder ecosystems, fostering collaboration between all actors. Nurturing a digitally-enabled workforce and increasing the level of engagement with stakeholders, including patients, are **key building blocks** that underpin this entire endeavour.

Ultimately, **health data ecosystems have two roles** in the way that they can lead to improved health and care: they provide not only a space for data sharing but also for knowledge and information exchange among a myriad entities. Integrating new players in health data ecosystems and collaborating across sectors can open up **a new environment where diverse business models may co-exist** if and when the appropriate incentives are in place.

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For more information about EHTEL's Digital Integrated Care Task Force and its work on health data ecosystems:
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