

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

**An EHTEL factsheet:  
Health data ecosystem for integrated care  
– A new “blue ocean”**

This factsheet concentrates on how integrated care can exploit **health data ecosystems** to provide renewed value to patients and professionals. It offers a brief outline of what health data ecosystems are, how they can be built, and how they can underpin **integrated care** initiatives. The factsheet is the first in a series for the Digital Integrated Care Taskforce. Each factsheet will reflect the content of a **dedicated webinar or workshop**. It is anticipated that several factsheets will culminate in a more **formal Briefing Paper** towards the end of 2020. This factsheet is based on discussions hosted by EHTEL on Monday, 22 June 2020, with the contributions of EHTEL Digital Integrated Care Taskforce chair, Rachelle KAYE of **Assuta Medical Centres** (Israel) and Saara MALKAMÄKI of **Sitra** (Finland), and the support of three European projects – **InteropEHRate**, **Digital Health Europe** and **SCIROCCO Exchange**. The discussions were enriched by expert input from the virtual workshop attendees.

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## Introduction

Improving health and care integration is a continuing journey. Over the last two decades, digital technologies have played a critical role in supporting higher levels of coordination and integration through data collection and exchange. Lots of progress has been made on Electronic Health Records (EHRs) and people's access to them, health information exchanges, and new eHealth services. The time has now come, however, for **developing health data ecosystems to enhance integrated health and care**. As a first step, these health data ecosystems are combining data captured by patients and health professionals to develop clinically sound and personalised digital health services.

Against this backdrop, the EHTEL Digital Integrated Care Taskforce (DICT) decided to focus on building health data ecosystems for integrated care as **the key topic for 2020**, and defined a work programme of online events.<sup>1</sup> The first session “Building health data ecosystems for integrated care: a new blue ocean?” was held on 22 June 2020, and had two keynote presenters: Saara MALKAMÄKI from Sitra (Finland) and Rachelle KAYE from Assuta Medical Centres (Israel).

Health data ecosystems can be considered **a blue ocean** where demand is created instead of fought over and competition is irrelevant because the rules are not set yet (Kim and Mauborgne, 2014). Enveloped by

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<sup>1</sup> More information: <https://www.ehtel.eu/imagining-2029/building-health-data-ecosystems-for-integrated-care.html>

the concept of “blue oceans”, the session defined **health data ecosystems**, brought together different **applications in the healthcare sector** and discussed **barriers and facilitators**.

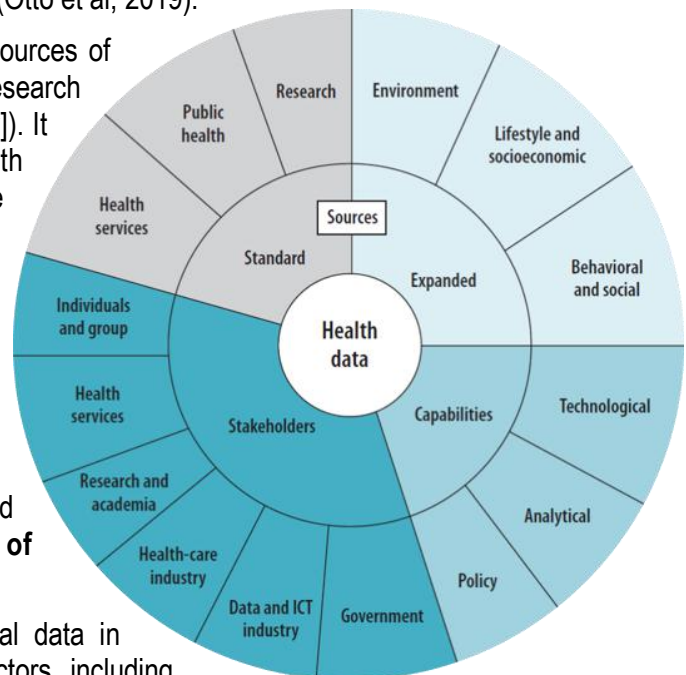
## What are health data ecosystems

There is no unified definition of health data ecosystems. An **ecosystem is a network of businesses** thought to resemble an ecological ecosystem because of its complex interconnected components. Hence, **a data ecosystem involves a group of entities that want to create new business** by engaging in data sharing, and they therefore contribute to pursuing common goals and value propositions. Data represents the **strategic resource** for the success of the ecosystem (Otto et al, 2019).

A **health data ecosystem** goes beyond traditional sources of data generated from health care, public health and research activities (see figure 1 – Standard [area coloured grey]). It incorporates data for health from individuals, the health IT industry, and government among others (see figure 1 – Stakeholders [area coloured turquoise]), through different data capture systems, including self-reported data, sensors, wearables and monitors of all kinds (Vayena et al, 2018).

From 2018 to 2021, the Finnish Innovation Fund, Sitra, is carrying out the IHAN project that builds the foundation for **a fair and functioning data economy**. IHAN creates a common concept for data sharing based on European-level rules and guidelines for the **fair use of data**.

IHAN is **piloting new concepts** based on personal data in collaboration with pioneering businesses from all sectors, including healthcare.



**Figure 1. Sources of a health data ecosystem**  
Adapted from Vayena et al, 2018

*“A successful ecosystem arises from a vision that all members want to achieve, but that no one can achieve alone,”* stated Sitra’s Saara MALKAMÄKI.

Significant **advances in integrated care** have been achieved through health data exchanges between primary, hospital and long-term care providers. With the advent of meaningful health data from different sources, the need to leapfrog from “egosystems” to ecosystems becomes evident.

The two systems stand in contrast to each other. **Egosystems** are a one-way street, because there is no feedback loop and no sharing of data between actors. **Ecosystems** are the opposite. In an ecosystem there are data cycles and **infomediaries** (intermediate consumers of data, such as builders of apps and “data wranglers”). Infomediaries are also **publishers** who share their cleaned-up, integrated, and packaged data in the ecosystem in a reusable way. These cleaned-up and integrated **datasets** are often more valuable than the original source (Pollock, 2011).

## Value and trust in health data ecosystems

Ecosystems are based on **new business models**. The potential for **value creation in the ecosystem business model** is greater than in traditional data environments. Value creation in an ecosystem can be formed in many ways, but at the heart of it is **participation and trust** in the data value network.

Participating organisations need to decide if they will take part in the ecosystem as direct or indirect consumers, and producers or providers of data and other related resources. A data ecosystem that follows fair rules creates **trust and value for all participants**.

In the **health and care domain**, participation may encompass patients, informal caregivers, health providers, information technology (IT) companies and research centres, among others. Understanding the value produced jointly and agreeing to act according to common rules are the **key success factors** of data ecosystems.

Data **ecosystems form strong links between actors** as they pursue common goals. In the context of integrated care, saving time and resources, streamlining operations, creating new health services, and getting access to expert knowledge are drivers for health data exchanges between partners.

Paradoxically, the data economy is evolving in two, partly contradictory, directions: **data protection and data sharing**. The first protects the inherent value of data, and the second supports the generation of new services and value. Given the special protection that must be given to health data, building trust in ecosystems becomes tantamount to overcoming fragmented data silos.

## Health data ecosystems in action: three examples from Israel

Israel hosts a **vibrant digital health ecosystem** that capitalises on over 25 years of data in EHRs collected by four major health maintenance organisations (HMOs). The country has a rich innovation environment, composed of companies, technology hubs, research and development centres, incubators, and multinational organisations (Figure 2).

**Assuta Medical Centers** is a private chain of healthcare facilities owned by Maccabi Healthcare Services, the largest HMO in Israel. It includes five hospitals and three medical centres with operating rooms and outpatient care located in three of Israel's major cities, Ashdod, Tel Aviv, and Raanana.

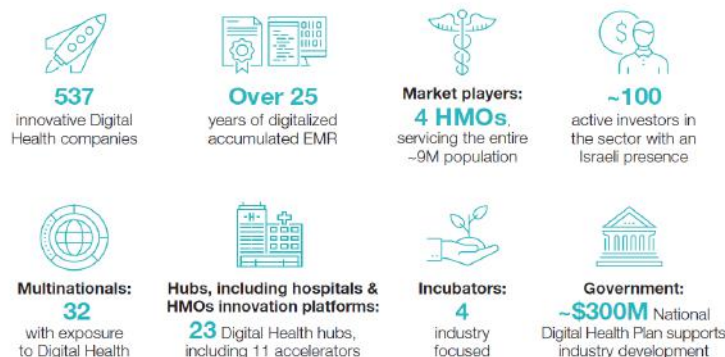


Figure 2. Israeli Digital Health Ecosystem in 2018

Source: Startup Nation Central<sup>2</sup>

<sup>2</sup> Startup Nation Central: <https://www.startupnationcentral.org/sector/digital-health/>

Three examples can illustrate health data ecosystems developments for integrated care in Israel: CONNECARE, COVID-19 dashboard, and K app.

## CONNECARE

Funded by Europe's Horizon 2020 programme, CONNECARE was a project on **digitally supported integrated care for chronic complex patients**.<sup>3</sup> It involved nine partners from six European countries (Germany, Israel, Italy, Spain, United Kingdom). CONNECARE deployed a person-centred integrated care model that connected patients and informal carers with a network of providers, including primary care doctors, specialists, hospital staff, and social workers. It had three major IT components: a self-management application for a mobile or tablet; a Fitbit (activity tracker) application for measuring steps, pulse and sleep quality; and a Smart Adaptive Case Management system for health providers to check data, coordinate with each other, and prescribe tasks for patients. Patients remain in control of their data and can provide consent to share data with care providers. In Israel, Maccabi and Assuta partnered to build the ecosystem and were able to see and share patients' data fetched by the activity tracker.

## Maccabi's COVID-19 dashboard

In response to the health crisis created by the 2020 COVID-19 outbreak, Maccabi Healthcare Services deployed **an integrated system that monitors and cares for COVID-19 patients at home**. Regional Telemedicine Centres, care managers, and family doctors participate in the system. Patients are equipped with a mobile application that captures data (such as saturation levels and fever) through biosensors and collects patient-reported outcomes measures. These data are automatically entered into the primary care EHR and monitored by care managers at telemedicine centres. Patients are contacted daily and can ask for a telephone appointment with their family doctor. Doctors can seamlessly turn these telephone appointments into video calls.

## K app

K is a **personalised virtual symptom checker** developed by Morris KAHN and the Maccabi Big Data Science Institute.<sup>4</sup> It is based on a sophisticated algorithm that cuts through a massive amount of data collected during hundreds of millions of medical visits that have taken place over the last 25 years.

The checker is learning and improving itself all the time. With each additional use, it perfects its knowledge and further refines the questions to be presented to the system's next user.

K can be integrated with Maccabi's EHR. It lets doctors see all the patients who have requested a chat in the K Portal. Doctors see the problems and symptoms that patients have chosen using K and can initiate a chat with the patient. All the information from the K portal is automatically transmitted to Maccabi's EHR, including doctors' decisions for the patients' treatment and follow-up.



Figure 3. K app

<sup>3</sup> CONNECARE project: <https://www.connecare.eu/>

<sup>4</sup> Morris KAHN and Maccabi Big Data Science Institute: <https://www.maccabitech.com>  
<https://www.maccabitech.com/big-data/k-app/>

The three efforts illustrate **health data ecosystems** well. From a health data ecosystem perspective, **all three initiatives represent efforts to provide added value** by combining data from different sources and actors. In CONNECARE and Maccabi’s COVID-19 dashboard, data exchanges between patients and health professionals shape the data ecosystem that combines patient-reported data, data collected by health professionals, and data captured by wearables. The combination of these three data sources generates an environment that boosts integrated care and improves patient involvement and empowerment.

Likewise, in a smart way, K combines patient-reported symptoms with the collective knowledge stored in EHRs and analysed through advanced artificial intelligence techniques so as to provide self-care guidance and prompt integrated professional care.

Despite the similarities from a data standpoint, each experience represents a different approach to building a health data ecosystem. Maccabi’s COVID-19 dashboard is an internal initiative where data is only shared within Maccabi’s information systems. CONNECARE goes a step further, and was built under the umbrella of a joint venture between Maccabi and Assuta. Finally, K represents an open health data ecosystem that is globally accessible, and involves potential integration with third parties.

## Outcomes from the expert discussion

The two formal presentations were followed by an open discussion. The virtual workshop discussion was guided by a **four-question live poll** that triggered debate among a front row of experts from several other European initiatives: Donna HENDERSON (SCIROCCO Exchange), Zoi KOLITSI (Digital Health Europe), and Ain AAVIKSOO (Guardtime Health). Twenty experts participated in the poll. They reflected the entire digital health ecosystem: international networks and associations (29%); health and care providers (24%); the technology industry (24%); health authorities and eHealth competence centres (18%); and universities and research centres (6%).

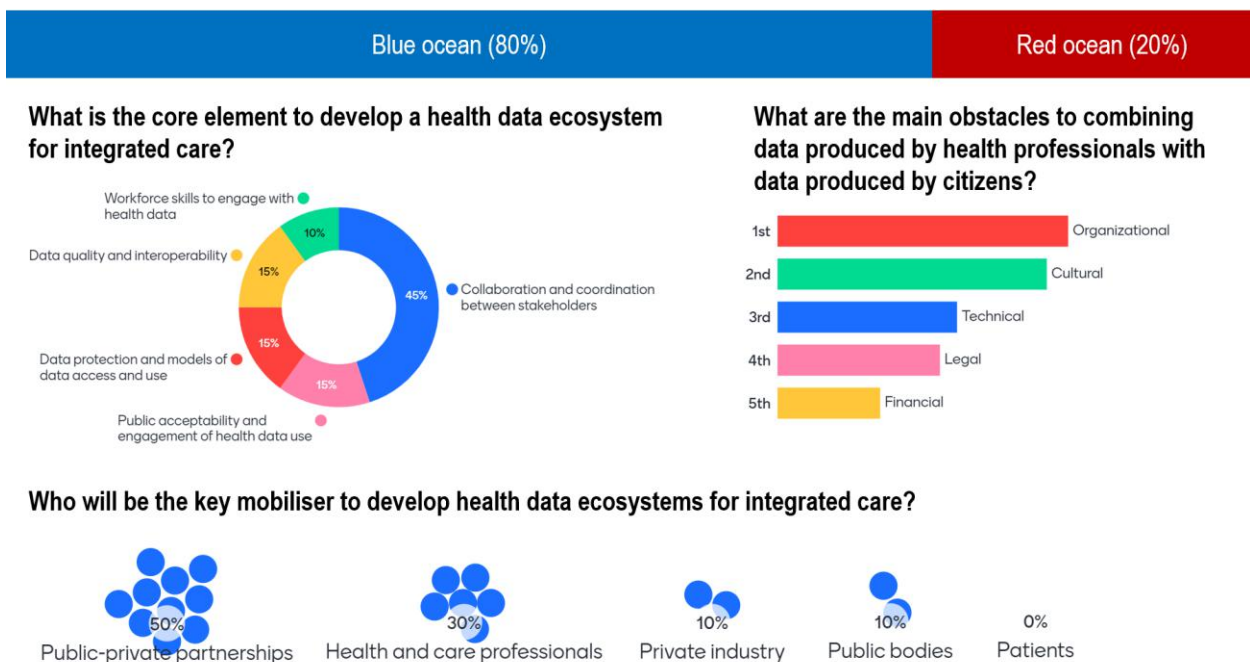


Figure 4. Live poll results on health data ecosystems for integrated care

The poll results were noteworthy. Predominantly, 80% of participants considered **health data ecosystems as a blue ocean for integrated care**. Experts also concurred in considering **collaboration and coordination between stakeholders** (45%) as the core element to developing health data exchanges supportive of new integrated care interventions. This percentage was well beyond the votes allotted to **other factors** like public acceptability and engagement (15%), data protection (15%), data quality and interoperability (15%), and workforce skills to engage with health data (10%). These were the **key enablers** of health data ecosystems for integrated care.

There is a synergy with the **perceived obstacles** to health data ecosystems for integrated care. The main obstacles identified by experts to exchange data produced by citizens and health professionals were of an organisational and cultural character.

In line with the previous results on core elements, **public-private partnerships** and **health and care professionals** were selected as key mobilisers to develop health data ecosystems for integrated care.

## Conclusions and next steps

Health service delivery produces **vasts amounts of data that can improve care integration**. Adding new data types from different sources enriches the data ecosystems' value, and helps to **increase its access, quality and responsiveness**, thus outlining the context for a blue ocean strategy to health and care delivery.

Health data ecosystems are, however, not easy to build and sustain without adequate **business and governance models**. **Trust** among health and care providers and between patients and caregivers is vital. Adherence to **fair data principles** and data sharing rules may help to accelerate the development of a health data ecosystem for integrated care, but might not be enough. Experts highlighted the organisational and cultural character of some obstacles to building health data ecosystems, pointing towards **business administration** and **stakeholder engagement** as enabling sources for transformation.

How to build **sustainable health data ecosystems** to boost integrated care remains uncharted territory. Deciphering their intricacies, based on **successful experiences**, will shape the agenda for upcoming sessions organised by the EHTEL Digital Integrated Care Taskforce. Future sessions will focus on the roles of **key stakeholders**, the contribution of **business and governance models** and **cross-sectoral collaboration**.

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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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