



G-SCIENCE ACADEMIES STATEMENT 2020

Digital Health and the Learning Health System

EXECUTIVE SUMMARY

With the enormous progress in digital technologies, it is possible to envision high functioning and continuously learning health systems that can improve resource allocation and lower costs while advancing research, healthcare, and patient experience and outcomes.

Health systems positioned for continuous learning and improvement are increasingly able to gather and apply evidence routinely and systematically in real-time; ensure that care delivery is optimized for the individual, including end of life; address barriers to health equity; manage the health of populations; identify and control emerging diseases; and assess outcomes to improve processes and training. Biomedical science will soon be able to draw upon vastly larger databases to generate new scientific knowledge and reduce impediments to healthcare for individuals and populations.

While digital health technology—e.g. bioinformatics and medical informatics—already makes these advances feasible, their realization will require extensive individual, organizational, national, and international collaboration. Action is required to ensure that actors across the world develop trustworthy technologies for deployment in applications to the benefits of people at all stages of their lives. Careful stewardship is required to ensure that the benefits of these technologies are shared across society.

Priorities requiring global cooperation include:

1) cybersecurity, safety, and privacy; 2) interoperability; 3) availability of reliable data and information; 4) secure virtual data repositories; 5) integrative analytics and predictive modeling; 6) mathematics of learning; 7) knowledge representation and management; and 8) IT literacy, public understanding, and ethics.

DEPENDENCE OF HEALTH ON RELIABLE INFORMATION FLOW: APPLICATIONS OF DIGITAL HEALTH

Health progress depends on the optimal generation and flow of reliable knowledge and information. Digital health is a broad term applied to a range of digital tools to record, organize, store, analyze, link, and share information—text, images, signals—for use in observing, assessing, learning, managing, and improving the healthcare of individuals and populations. (Figure 1).

With the development and rapid growth of these digital

the health effects of their interplay, as well as our abilities to share information across domains in operations and learning processes.

Health care. Movement of patient health records onto digital platforms offers enhanced prospects for more effective care for individuals, both within and among care sites, as well as for greater individual and family involvement and control in the care process. **Diagnostic tools** are increasingly developed on digital platforms, with imaging systems, lab on a chip (blood and serum chemistry

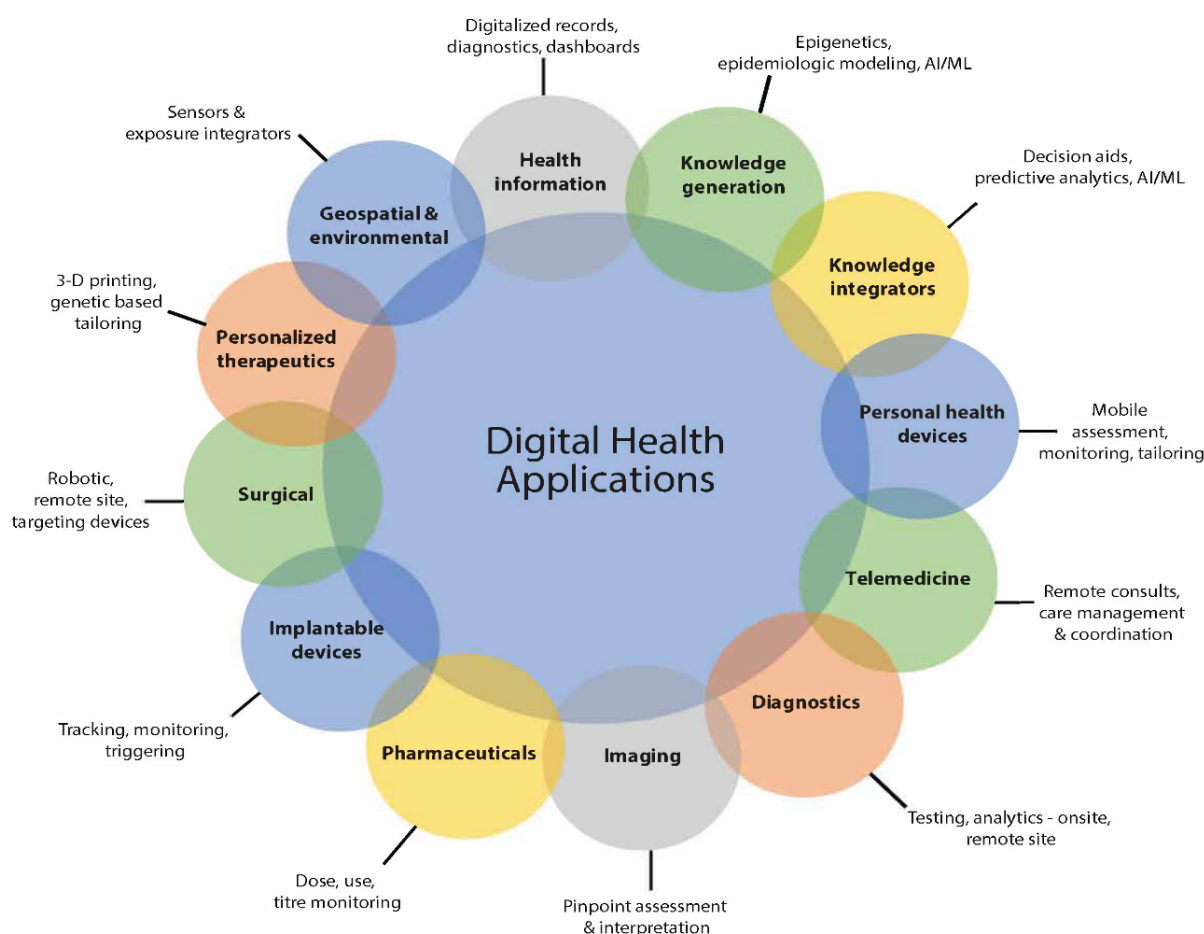


Figure 1. Evolving applications of digital technology in health

Source: National Academy of Medicine, Digital Health Action Collaborative, 2019.

tools, we now have profound opportunities to generate new health-related knowledge, monitor its application, predict results, and guide courses of action. The application of these tools has transformative implications for each of the domains that determine the health of individuals and populations: genetics, behaviors, social circumstances, physical environments, and health care. Improving health depends on our ability to understand the nature of those domains, their causal relationships, and

analyzers), monitors (e.g. cardio-pulmonary), and many others functioning through digital signals that generate data with the potential for more integrated insights, and for better and faster integration in individual care.

Application in *medical treatment* includes use of decision aids, predictive modeling, care coordination, dose regulators, and 3D printing of organic matrices treating conditions such as burns or joint damage. Genomic data

assume an increasing role for cancer prevention, diagnosis, and targeted treatment. Digital monitoring technologies allow real-time assessment in settings ranging from intensive-care units to daily activities through wearable devices. Cardiovascular diseases and medication adherence are examples in which monitoring can be improved. A basic application of digital technology is for *patient safety*. Harm to patients can result not only from human factors but also from system technical incompatibilities, disjointed communication, or breakdowns. All applications can benefit from digitally based safeguards. Digital health technology carries the potential to support *continuity of care* among providers as well as during care location transitions.

Remote site care access. Digital remote-site health monitors, including cell phones, smartwatches, implantable devices, and signal enabled clothing, are now used in the real-time assessment of a patient's condition. *Telemedicine* advances provide consultation outside customary healthcare-organization care sites. Rapidly evolving *remote-site treatment*, even for acute management, now includes wearable and implantable sensors and medical devices, e.g. cardioverter defibrillators. Remote robotic surgery, using wireless networking, allows surgeons the prospect of performing operative procedures at a distance. The hospital-in-the-home is an increasingly accepted practice.

Promotion and protection of health. Digital health has enabled enhanced *personal risk identification*, which can better pinpoint and predict individual vulnerabilities. Digital health has improved the ability of individuals to monitor their own exercise, diet, pulse, blood pressure, weight management, menstruation, sleep patterns, and stress management, meaning increased engagement and control over one's personal health.

On a population-wide scale, *disease and injury surveillance* draws directly on digital health capacity. Electronic case reporting automates the flow of data between providers and public health agencies about disease and preventable conditions (e.g. through immunizations). *Geospatial and environmental sensors* provide insights into factors such as environmental exposure, neighborhood risks related to social determinants of health, and impacts of the built environment, such as inaccessible sidewalks leading to sedentary habits. Geo-trackers embedded in inhalers, for example, can help pinpoint sites and conditions endangering asthma patients.

Discovery, innovation, and knowledge development. As very large data sets and exploration tools evolve, more structured and systematic generation of hypotheses and virtual testing will be enabled. This will accelerate developments in arenas such as genomics (understanding the nature and function of genomic factors that shape health, including gene mutations, differential gene expression, and epigenetics); *integrative analytics and predictive modeling*, through artificial intelligence, with expert systems natural language processing, and machine learning; and *protocols for data repositories*.

REQUIREMENTS FOR PROGRESS: SECURE AND RELIABLE DIGITAL HEALTH INFRASTRUCTURE

With potential applications of digital health technology of the breadth noted above, certain operational preconditions must be met, both to facilitate attainment of the potential and to safeguard against possible risks. Figure 2 offers a graphic representation of the facilitative and governing infrastructure required to steward the development and application processes.

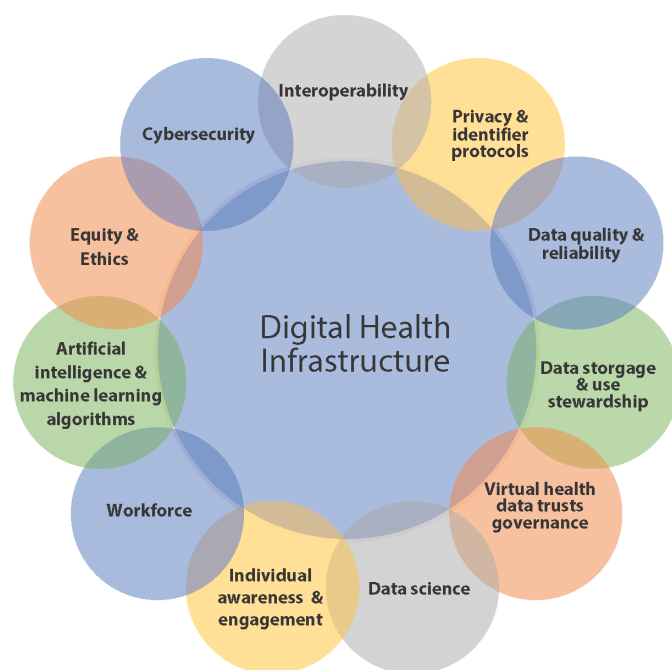


Figure 2. Infrastructure requirements for progress in digital health

Cybersecurity and privacy. There are many challenges, and risks to achieving the potential benefits from advances in digital health. Sustained multi-sector, multi-site, and multi-national collaborative efforts are required to develop and

apply creative solutions. A major priority for nations and health organizations is the collaborative development and implementation of *system security* protocols. Technical and process safeguards are essential to ensure that *individual privacy* is protected in accordance with individual wishes. Approaches are needed to share immutable records of transactions among network participants. Blockchain may offer one such approach.

Interoperability. Just as the flow of information among care sites is a basic requirement, the connectivity and communication among devices is an essential prerequisite for patient safety. Incompatible interfaces can and have had catastrophic consequences. Health Level Seven International (HL7), a non-profit standards organization for the exchange, integration, sharing and retrieval of electronic health information, has created a promising set of international interoperability standards (e.g. HL7 on Fast Healthcare Interoperability Resources). Such standards allow information to be shared and processed in a consistent manner. Full functionality will require action by all health care providers, as well as international collaboration.

Data reliability, storage, and access. The most basic determinant of the utility of digital health is *data availability, quality and reliability*. This requires standards and curation protocols for data and information (e.g. FAIR principles) to ensure their seamless utility across institutions, languages, and jurisdictions. Structure and maintenance guidelines as well as international cooperation is essential. Equally important are protocols for *data storage, access, control, sharing, and use*. In principle, authority over individual data lies with the individual from whom they derive, and access to and control of use belongs to the individual or their designee. Every step in the use of information, however, generally requires an element of ceding control, as well as the potential for value to be added. Economic, legal, philosophical and practical issues must be addressed. The differences that exist among nations concerning data access, control, and monetization clearly present limiting circumstances for the contributions of digital health. Thus, mechanisms for ongoing cooperative exchange are needed.

Data science and artificial intelligence. There is a clear need to invest in the capacity and cooperation necessary to foster advances in data science and artificial intelligence. This will require developing data-science tools as well as developing the pathways, agreements, and protocols for establishing curated virtual health-data

trusts. A basic, related need is development and cultivation of the *digital health workforce*, which is acute in most countries. This is especially critical for developing countries that have limited infrastructure, digitized records, weak data security systems, and often lose the few trained workers they have. The training challenge for leveraging digital health is vast—in health care, public health, and biomedical science.

Equity, ethics, and public engagement. Health data are intensely personal. Capturing the full potential from digital health will require a much deeper understanding and appreciation at the individual level. Responding to the public demand for progress and participation in building the digital health frontier is a compelling priority. The rapid development and application of digital health is also accompanied by the need for vigilance on ethical issues ranging from unauthorized access to misuse of personal information. Capacity building remains an essential component of global progress in health. In a data centric approach, developing countries may suffer from lack of digital data to make intelligent decisions. Careful stewardship is needed to ensure that the benefits of digital health are shared across society and the globe.

BROAD PRIORITIES

To realize the benefits that digital health offers to enhance the human condition, individually and collectively, systemic and dedicated collaboration is required across fields, sectors, and nations. The following are identified as key priorities in this respect.

- 1) **Cybersecurity, safety, and privacy:** technical, governance, and legal protocols and standards, as well as inter-governmental agreements for the safety, security, and privacy of the digital health infrastructure, ensuring proper ownership of personal data.
- 2) **Interoperability:** standards to ensure seamless device interfaces and reliable information exchanges.
- 3) **Availability of reliable data & information:** standards and curation protocols for data and information, including tools to track provenance, and improvements in the amounts and quality of open data.
- 4) **Secure virtual data repositories:** structure and maintenance guidelines, as well as storage, access, and release requirements to safeguard the operational integrity and security necessary for the virtual functionality of data repositories.

5) **Integrative analytics and predictive modeling:** artificial intelligence tools (including machine learning and deep learning) that are transparent to clinicians and patients, to mine large and heterogeneous databases for insights for individuals and populations as well as to serve in digital decision support systems.

6) **Mathematics of learning:** computational algorithms and mathematical models are foundational to the application of machine learning approaches to biologic processes that highly variable, introducing epistemic uncertainty and requiring novel adaptive mathematical concepts and appropriate context sensitivity.

7) **Knowledge representation & management:** information management software and tools for access, vetting, and delivery of information

8) **IT literacy, public understanding, and ethics:** public dialogue about digital health, bringing a range of stakeholders into the policy process as part of a governance system that builds trust and maintains vigilance and safeguards against abuses and unintended consequences, and in which the public can have confidence.



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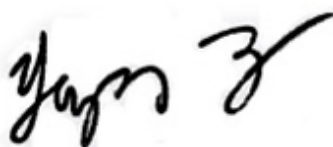
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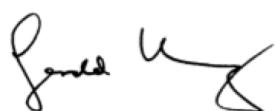
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