Basel, Switzerland
January 18, 2019

CONSULTATION REPORT

Digital Collaboration in Health and Life Sciences

For the attention of

digital COOPERATION
UN SECRETARY-GENERAL'S HIGH-LEVEL PANEL

fondation BOTNAR

IMPACT HUB Basel

Executive Summary

In response to the call for input and ideas from the High-Level Panel on Digital Cooperation, Impact Hub Basel, in collaboration with Fondation Botnar and the High-Level Panel on Digital Cooperation, hosted a consultation focused on digital collaboration in the area of health and life sciences in Basel, Switzerland on 15.01.2019.

The consultation was divided into two parts, starting with a two-hour consultation with 23 selected experts representing the private sector, the public sector, non-governmental organizations, and science and academia from across Switzerland. Facilitated by the Executive Director of the Secretariat of the High-Level Panel on Digital Cooperation, Amandeep Singh Gill, and Healthcare Executive and Impact Hub Basel advisory board member Susanne Brandl, this expert consultation aimed to identify:

• What is working and where the gaps are in collaboration between different stakeholder groups in the health and life sciences sector?
• What methods or mechanisms could enhance cooperation between these actors and bring greater benefits to public health?

Four experts (Dr. Flavia Bustreo, Prof. Ilona Kickbusch, Dr. Lukas Engelberger, and Prof. Balicer) presented use-cases throughout the expert consultation to illustrate some of the nuances and challenges, but also the benefits of cooperation across the health and life sciences sector on a global, local and operational level. Following the presentation of the various use cases, the participants broke into smaller group debates to identify common themes, and brainstorm how to resolve, improve, and modify collaboration methods and mechanisms for better health outcomes. Needs for improved collaboration were identified along five main themes of which an overview can be found on page 10-12.

After the group debates, the participants established in a plenary discussion the key recommendations for the High-Level Panel on Digital Cooperation:

1. Move from tools and solutions for single diseases and/or particular health conditions to solutions that help improve the whole healthcare system and to ensure benefits are equitable across the population.
2. Create a global framework and encourage national governments to map all pilots and programs in the country in a clearing house.
3. National governments should ensure digital is an integral part of the national health strategy, public policy and the healthcare system.
4. Lead the process to achieve global consensus and commitment on common ethical principles and norms.
5. Create a sense of urgency and incentives to foster cross-sectoral collaboration globally.
6. Generate global standards for the collection and exchange of health data
7. Comprehensive capability building to empower individuals, institutions, governments and communities; one better practice shared focused on empowerment of community health workers - enhancing their digital health literacy in order to effectively and efficiently help their communities.

Following the expert consultation, a panel discussion open to 120 attendees from the broader health and life sciences community was held to present the results of the expert consultation, and to engage and consult the public opinion.

Introduction

Patient-centric solutions, digital health technologies, value-based delivery models; over the past decade innovation across healthcare and life sciences has accelerated at an unprecedented pace. Traditionally, the health and life science industries have been slow in harnessing and integrating innovative approaches and risk-averse regulations have stifled the early adoption of digital technologies.

Digital technologies can improve efficiency and reduce complexity in health systems, making services more patient-centered, predictive and responsive, and the aggregation of data captured by such technologies can reveal trends and patterns among populations that could lead to lifesaving interventions. However, it is critical that emerging issues and risks related to the application and integration of digital technologies, such as governance, ethics, and security of data are acknowledged and addressed by policymakers, legislators and practitioners.

Therefore, we need increased and better digital cooperation in the health and life science sector to enhance the benefits of digital health technologies for population health and wellbeing. As keen supporters of digital innovation based at the epicenter of health and life sciences in Switzerland, Impact Hub Basel and Fondation Botnar have followed the establishment of the High-Level Panel on Digital Cooperation by the UN Secretary General with great interest.

In response to the call for input and ideas from the High-Level Panel, Impact Hub Basel, in collaboration with Fondation Botnar and the High-Level Panel on Digital Cooperation, hosted a consultation focused on digital collaboration in the area of health and life sciences in Basel, Switzerland on the 15 of January 2019.

Partners

The consultation was organized by Impact Hub Basel, in partnership with Fondation Botnar and the UN Secretary General's High-Level Panel on Digital Cooperation.

Impact Hub is a global network of over 16,000 members in over 100 hubs in more than 50 countries around the world, and is continuously growing. Its main purpose is to make a positive impact in our world by combining the skills of compassionate, committed and purpose-driven individuals focused on a common purpose. Each individual Impact Hub chapter is unique and relevant to the local community.

At Impact Hub Basel, our aspiration is to support social entrepreneurs and sustainable innovators. Through various offers ranging from events and co-working to different ideation, incubation and acceleration programs, we aim to promote the interaction between our members and the different stakeholders. In this way, we strive to create a highly collaborative ecosystem where innovation and change are encouraged, where access to expert resources, inspiration and knowledge is made easy and where communication and contacts between diverse, skilled people are facilitated.

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For inquiries, please send an email to basel@impacthub.net

Fondation Botnar is a Swiss foundation established in 2003 with the core purpose of improving the health and wellbeing of children and young people in growing urban environments around the world. To achieve this, Fondation Botnar acts as a catalyst, connecting diverse partners and investing in solutions that leverage artificial intelligence (AI) and digital innovation.

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General Consultation Structure and Objectives

The consultation was divided into two parts, starting with a two-hour consultation with 23 selected experts (an overview of the participants in the expert consultation can be found in appendix I). Facilitated by the Executive Director of the Secretariat of the High-Level Panel on Digital Cooperation, Amandeep Singh Gill, and Healthcare Executive and Impact Hub Basel advisory board member Susanne Brandl, this expert consultation aimed to identify:

• What is working and where the gaps are in collaboration between different stakeholder groups in the health and life sciences sector?
• What methods or mechanisms could enhance cooperation between these actors and bring greater benefits to public health?

As such, the participants of this consultation included a cross-section of representatives from the private sector, the public sector, non-governmental organisations, and science and academia from across Switzerland. Subsequently, an evening event open to the broader public was held, aimed at engaging and consulting the broader health and life sciences community. The event gained significant interest with seats limited to 120 in order to maintain a high-quality event, and registration at full-capacity multiple weeks in advance. The final attendee list again represented a variety of stakeholder groups from the health and life sciences sector, not only from the Basel region but from across Switzerland, including the cantons of Bern, Geneva and Zurich.

Expert Consultation Summary

Prior to the consultation, three expert participants were asked to prepare a short use-case to illustrate some of the nuances and challenges, but also the benefits of cooperation across the health and life sciences sector on a global, local and operational level. An additional use-case was provided remotely by Prof. Ran Balicer, Founding Director of the Clalit Research Institute and Director of Health Policy Planning at Clalit. These use-cases were presented throughout the expert consultation to spark discussion and learning. Through both smaller group discussions and plenary discussions, the participants distilled themes, commonalities and lessons learned that should be addressed in order to improve digital collaboration for better health outcomes.

Use Cases

The introductory use case was presented by Prof. Ilona Kickbusch, Director Global Health Centre at the Graduate Institute Geneva, who shared her views on health governance in the global arena from her roles as member of the World Health Organization (WHO) High-level Commission on Noncommunicable Diseases (NCDs) and co-chair of UHC 2030, the global movement to strengthen health systems for Universal Health Coverage (UHC). She highlighted how the health care system will change dramatically over the next decades and what challenges need to be taken into consideration when discussing potential solutions to overcome current barriers, particularly in low- and middle-income countries:

"In ten year's time, the health care system will be completely different through digital solutions and artificial intelligence (AI). Technology will not be an add-on, but an integral part of how the system works and how we govern it." - Prof. Ilona Kickbusch

She elaborated on the fact that, although some activities are in place, the current Sustainable Development Goals (SDGs) are lacking awareness of the barriers in access to health care in low- and middle-income countries, including hardware availability and access in resource-poor countries. She recently met with twelve organisations at WHO to accelerate SDG 3, Good Health and Wellbeing, with main questions revolving around how development agencies can work with the private sector, how solutions can be home-grown as opposed to be brought in from the outside, and how young people can be involved to push and demand improved and digital health services. And as solutions are being developed, what does the emerging data governance model look like - will this be the open Silicon Valley model, the private sector model, the bourgeois model or a state-driven model?

Dr. Lukas Engelberger, Member of the Government of Canton Basel-Stadt and Head of the Basel Public Health Department, shared a local use-case outlining Switzerland's current collaboration efforts and challenges in relation to electronic patient records.

He explained that federal legislation requires hospitals to offer certified electronic patient records (EPR, in German "Elektronisches Patientendossier" – "EPD") to their patients by April 2020. For patients and independent healthcare professionals (HCP), however, participation is voluntary. EPR are seen as a necessary and important step towards an integrated healthcare system and better cooperation among HCP. Hospitals and HCP are expected to establish professional communities (in German "Stammgemeinschaften") which require certification by the competent national authorities. While certification requirements and some financing will be provided on a federal level, no centralized structure is being established by the federal government. This leaves the cantons, hospitals and HCP with the difficult task of building up decentralized structures in the various regions of Switzerland. However, in Northwestern Switzerland (NWCH), cantons, hospitals and HCP associations have set up "E-Health NWCH", a common organization which is working on establishing e-health-systems such as the EPR in the region. E-Health NWCH is running a pilot scheme at University Hospital Basel, where EPRs can be opened for patients in some clinics, on a voluntary basis.

In Mr. Engelberger's opinion, controversial topics under discussion in E-Health NWCH include the future organizational structure of professional communities in the region and in Switzerland, the financing contributions by the various partners, and data protection matters. The public debate on the EPR is controversial as well, mainly focusing on risks and benefits from a patient's perspective.

"In politics, one of the main tasks is to establish trust and my biggest concern is whether enough trust can be built up in society in order to make the benefits of digital collaboration available to all of us." - Lukas Engelberger

Dr. Flavia Bustreo, leading public health professional and former Assistant Director-General for Family, Women's and Children's Health at the World Health Organization elaborated on a recent experience in Zanzibar, where she visited the Safer Deliveries program managed by the D-Tree. D-Tree is an organization leveraging technology to build digital solutions that strengthen health systems, improve program quality and achieve health impact, primarily across Africa and Asia. Safer Deliveries empowers, informs and encourages women, with the support of their families, to deliver in health facilities. It links pregnant women with community health workers (CHWs), community drivers, village savings groups and health facilities. These connections are supported by the use of digital technology to facilitate better decision making and the co-ordination of resources and support. Implementation of the program involves many different stakeholders, and has been very successful (women in the program are 50% more likely to deliver in a health facility and 4 times more likely to go for a postpartum visit). However, Flavia explained there are also a number of challenges associated with such projects, including scalability (not only geographically, but also whether the interface can be used for a broader scope) and having multiple projects targeting a similar problem run pilots simultaneously in geographically close areas with different digital tools and without being aware of each others' existence.

"Technology can be empowering, using digital tools has great potential. However, the unfolding of these high-potential projects suffer from 'pilotitis', where a pilot project is implemented in one place in one location in the country, and simultaneously in another location a similar project is happening, but with different (digital) tools." - Dr. Flavia Bustreo

Additionally, she stressed the importance of capability-building and knowledge sharing amongst all stakeholders involved to optimize collaboration; these projects are often led by people who are passionate about digital but lack public health knowledge, whereas government partners involved responsible for policy making understand the healthcare frameworks but lack the knowledge on technology and digital tools.

Prof. Ran Balicer, Founding Director of the Clalit Research Institute and Director of Health Policy Planning at Clalit, Israel's largest healthcare organization, shared an example of collaboration to develop a personalized decision support tool prototype for deciding on hypertension treatment intensity. He explained that in medicine, therapeutic treatment is often a balancing act – too little can cause harm and too much is dangerous. For hypertension treatment, too little can lead to stroke, but intensive treatment can cause damage, for example to the kidneys. The optimum middle point is unique to each individual due to the many variables that determine the threshold of where the damages exceed the benefits. To tackle this problem an interdisciplinary group was established, including data scientists, physicians, epidemiologists, people from frontline healthcare clinics and hospitals, and people from the Clalit Research Institute. Benefitting from a large and unique clinical dataset made available from the New England Journal of Medicine through their SPRINT Challenge the group was able to develop a tool leveraging AI and data science which allows for individualized treatment of hypertension, taking into account the patient's characteristics, needs and even preferences.

"The different schools of thoughts and mindsets of this interdisciplinary group allowed for this problem to be tackled in a unique way. They all had a very clear understanding of the clinical dilemmas physicians face, and through advanced capabilities in data science and by utilizing patient health records, they were able to create an innovative solution to the problem." - Prof. Ran Balicer

Discussion

Following the presentation of the various use-cases, the participants broke into smaller group debates to identify common themes, and brainstorm how to resolve, improve, and modify collaboration methods and mechanisms for better health outcomes. Needs where established along five themes of which an overview can be found below.

Theme	Needs

1. Inclusive technology and approaches	• Digital is much more than collection, processing and usage of data: digital is about cross-cutting, systemic solutions!
	  • It is often a means to get access to innovation/certain solutions; It needs to cater for all healthcare situations and systems and to ensure development of tailored care and service delivery, especially in developing and emerging countries;
	  • It can speed up the development process and related innovation;
	  • It needs to strengthen equity in health and ensure that the divide (North/South) does not get wider but rather be leapfrogged/bridged
	• Digital needs rigorous validation
	• Importance of public policy
	  • Systematic development / taxonomy of cases where policy is required
	  • Bridging the gap of analogue policy-making to digital public policy
	  • Need to convey a sense of urgency to all healthcare ecosystem stakeholders in view of immediacy of data and how it will influence and reshape the way we inform public policy
	  • Governments need to take the driver's seat and integrate digital in the healthcare system and care and service delivery
	• Need for "smart" regulation
	  • Speed outpaces capacity (skills, infrastructure, resources) of governments
	  • Global nature of oligopolies / big data needs
	  • UN has a unique role to play in creating trust in the digital space
	  • Cross-sectoral cooperation needed to define together WHAT needs to be regulated
	  • Balance between standardization and flexibility for innovation needs to be assessed carefully

Theme	Needs
	• Digital cooperation, standards for governance and application are needed to ensure interconnectivity and interoperability across sectors, beyond borders, diseases and particular health conditions; it is a shared responsibility! • Incentives to be defined per involved stakeholder group in order to broaden access (overcome silo thinking and behaviors) and acceptance to inclusive technology infrastructure • The individual needs to be a key driver and become aware of his/her ownership
2. Principles, mechanisms and approaches to digital cooperation	• (Re-)Build trust between various stakeholders as essential prerequisite for cooperation • Develop principles and modalities of cooperation – A shared responsibility! • Ensure better communications • Identify risks per stakeholder group and across • Consider social implications • Systemic view is key • Ethical frameworks; a global perspective would be supportive • Bridging of the divide; including ensuring south-south cooperation! • Hold stakeholders accountable, measure effectiveness and impact
3. Capacity-building and closing the digital gap	• (Re-)Build trust • Improve digital literacy & technology capacity at individual, institutional and governmental levels (esp. least developed countries) • Focus on individual level: children & youth – become life-long learners, adapt to continuous change; reskilling of workers; awareness creation for the general public • Focus at institutional level: lack of resources to respond, adapt & act; tech to be incorporated across the value chain and on a cross-sectoral level; • Knowledge and better practice sharing

Theme	Needs

4. Data as a transformative resource	• Types of data – complex relationships, multiple participants
	• Digital strategy/tools/systems serve to collect, process and use data as well as better understand, inform and offer more efficient and impactful care & service delivery
	• Data looked at as resource, right or public good depending on context – controversial discussions
	• Key issues - collection vs usage:
	  • Governance, ownership (personal information, raw data, processed data, sensitive vs anonymized data, IP), biases/quality, localization, cross-border flows, application
	  • Interconnectivity & sharing
	  • How to ensure protection & security (incl. cyber-security)?
	  • How to ensure transparency?

5. Human rights and human agency in the digital age	• Human is placed at the center of digital tech
	• Development and design of digital/tech require value- and ethical-based approach
	• Human rights represent a cross-cutting issue; international law (Universal Declaration of Human Rights) applicable in digital domain
	• Key issues:
	  • How to define added value? How to measure impact of tech on human well-being?
	  • How to balance private rights and public goods?

Key recommendations

After the group debates, the participants established in a plenary discussion the key recommendations the key recommendations for the High-Level Panel on Digital Cooperation:

1. Move from tools and solutions for single diseases and/or particular health conditions to solutions that help improve the whole healthcare system and to ensure benefits are equitable across the population.
2. Create a global framework and encourage national governments to map all pilots and programs in the country in a clearing house.
3. National governments should ensure digital is an integral part of the national health strategy, public policy and the healthcare system.
4. Lead the process to achieve global consensus and commitment on common ethical principles and norms.
5. Create a sense of urgency and incentives to foster cross-sectoral collaboration globally.
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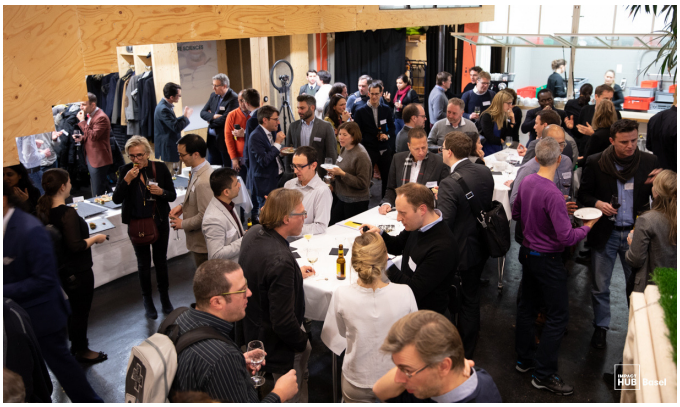
7. Comprehensive capability building to empower individuals, institutions, governments and communities; one better practice shared focused on empowerment of community health workers - enhancing their digital health literacy in order to effectively and efficiently help their communities.



Evening Consultation Summary

The evening consultation was open to the broader health and life sciences community and brought together 120 individuals representing various stakeholder groups in health and life sciences from across Switzerland, including the cantons of Basel, Bern, Geneva and Zurich.

After a short introduction by Hanna Byland, Co-Founder of Impact Hub Basel, Stefan Germann, CEO of Fondation Botnar and Amandeep Gill, Executive Director of the Secretariat of the High-Level Panel on Digital Cooperation, a moderated panel discussion took place to present the results of the afternoon consultation and to engage and consult the public opinion. The panel included:

• Susanne Brandl, Healthcare Executive and Advisory Board Member of Impact Hub Basel (moderator)
• Amandeep Gill, Executive Director of the Secretariat of the High-Level Panel on Digital Cooperation
• Prof. Ilona Kickbusch, Director Global Health Centre at the Graduate institute Geneva
• Dr. Flavia Bustreo, leading public health professional and former Assistant Director-General for Family, Women's and Children's Health at the World Health Organization
• Dr. Lukas Engelberger, Member of the Government of Canton Basel-Stadt and Head of the Basel Public Health Department.

Find below some quotes from the event highlighting key findings and outcomes of the consultation:

"We really need to think about data differently when it comes to health - every piece of data could determine a health insight and we need to ensure when the data is brought together the quality and patient rights are not exploited. Taking an inclusive approach is key in order to co-create solutions that cut across health challenges."
- Amandeep Gill

"We need to think about a global framework agreement to govern health data that motivates both governments and private entities, and also holds both to account— let's consider health data as a public good. Governments need to take the driver's seat and ensure that digital becomes an integral part of the national healthcare system."
- Prof. Ilona Kickbusch

"We need to foster environments suitable for AI and data governance frameworks across the world and to proactively engage governments, communities, individuals as well as public and private players in discussions at every level, to generate unbiased, accurate, and secure data as well as equally accessible care and service delivery models."
- Dr. Flavia Bustreo

"Nowadays we have great control over our finances through e-finance but who can say they have the same level of access to their medical data? We are determined to prove that it will work, but it is a clear example of technology not following the lead of politics but technology guiding its own way."
- Dr. Lukas Engelberger

Appendix I

Participant List Expert Consultation

First name	Last Name	Title/Function	Organization	Category
Felix	Addor	Deputy Director General, General Counsel and Director for Legal and International Affairs	Swiss Federal Institute of Intellectual Property	Public
Ann	Aerts	Head	Novartis Foundation	Private
Felix	Appiagyei	Medical Doctor	Formerly University Hospital Basel, Kantonsspital Winterthur	Public
Susanne	Brandl	Healthcare Executive (Facilitator)	Formerly Novo Nordisk Haemophilia Foundation	Private
Flavia	Bustreo	Public Health Professional	Formerly WHO, UNICEF, World Bank	NGO
Myriam	Cevallos	Scientific Advisor, Swiss Delegate for Health	State Secretariat for Education, Research and Innovation SERI	Public
Lukas	Engelberger	Regierungsrat Basel-Stadt (Gesundheitsdepartement)	Kanton Basel-Stadt	Public
Stefan	Germann	CEO	Fondation Botnar	NGO
Amandeep	Gill	Executive Director (Facilitator)	Secretariat of the High-level Panel on Digital Cooperation	NGO
Felix	Grisard	VRP	MTIP MedTech Innovation Partners AG	Private
Ernst	Hafen	Professor	ETH Zurich	Academia
Andrew	Jenner	Advisor to the Director General	IFPMA	NGO
Siddhartha	Jha	AI/Digital Program Manager	Fondation Botnar	NGO
Ilona	Kickbusch	Director Global Health Centre	Graduate Institute Geneva	Academia/NGO
Adrien	Lawrence	Managing Director	Swiss Personalized Health Network	Public
Martin	Leschhorn Strebel	Director	Medicus Mundi Switzerland	NGO
Thomas	Metcalfe	Strategic Innovation Leader, Pharma Development	Roche	Private
Stefano	Napolitano	Platform Business Developer	MIDATA.coop	NGO
Axel	Nemetz	Head of Life Sciences Germany, Austria, Switzerland	IBM	Private
Mattias	Reumann	Research Staff Member	IBM Research	Private
Karin	Schulze	Head Regulatory Affairs and Medical Devices	SFL-Solutions for Life Sciences	Private
Peter	Speyer	Head of Digital, Medical and RWE Solutions	Novartis	Private
Jörg	Utzinger	Director, Professor in Epidemiology,	Swiss TPH	Academia
Effy	Vayena	Professor	ETH Zurich	Academia