Accelerator Discussion Paper 6: Data and Digital Health

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INTRODUCTION

Digital technologies and improved data capacity are important catalysts for monitoring progress towards and accelerating the achievement of the 2030 SDG3 targets and tracking the 2023 milestones. Actionable and relevant data is the foundation to track progress toward SDG 2030, while harmonized digital systems optimize the health system to deliver in a coordinated manner quality, coverage, and equity of health services. Digital systems can catalyze a necessary transformation in the health system -- addressing ongoing data gaps and persistent health system challenges -- facilitating a more resilient, people-centred, and responsive health system. This paper provides key actions to strengthen country capacity to drive continuous health improvement and policy change and accelerate progress toward achieving SDGs.

Why is an accelerator on data and digital health needed?

Health equity is central to the achievement of the SDGs. The absence of timely, reliable and actionable health data means appropriate interventions can't be targeted and progress cannot be monitored. Not having data that is disaggregated by important equity stratifies means we do not know who are 'left behind' and who are the farthest who need to be reached first. Equity in access to digital technologies and in data leads to equity in health. However, digital systems and data collection tools developed by different partners, sectors or technology providers are frequently fragmented and unsustainable. Often, countries are not fully equipped to take advantage of digital tools and the resulting data to address health system challenges and optimize performance, set priorities, inform policies, plan resources or measure successes. Harnessing advances in digital technologies and predictive tools can improve accuracy, timeliness, efficiency, access to data; and drive precision medicine, responsive programmes and policy, and enhance service delivery and accountability in the health system. Although digital interventions can be applied to mitigate chronic problems in using data at all levels of the system and address persistent health system performance gaps; overly enthusiastic application of digital tools that neglect necessary foundational eHealth building blocks and consideration within the broader digital and health systems architecture will struggle to realize their potential at scale.

WHAT ARE THE CHALLENGES IN DATA AND DIGITAL HEALTH?

Limited coordination on and availability of data and information
Monitoring national and global development goals rely on reliable and timely data and information to inform public policy and health priority debates, guide efficient resource allocation in the health sector, identify regional and national health inequities, estimate and forecast national and subnational burden of disease in countries, identify emerging health issues and monitor and evaluate the effectiveness of health programs and policies. The World Health Statistics 2019 reports data gaps which will hinder countries' efforts to track and make progress on health SDGs. Sixty-three (63) of the 194 WHO Member States lack recent primary data for more than half of the health SDGs indicators. This problem is even more apparent for certain indicators and data characteristics. For 40% of indicators, less than half of the countries have recent primary data. For many indicators, there is no recent data on sex disaggregation. Less than half of all deaths around the world are reported with a cause of death (CoD), with 29.4 million deaths that are unreported each year, largely in low and middle-income countries. About 10% of health-related SDG indicators depend directly on reliable CoD data, underpinned by robust Civil Registration and Vital Statistics systems, and are critical for estimating national and subnational burden of disease in countries.

A lot of data collection is still paper-based in many countries. This situation presents challenges related to accessibility, productivity and security. In addition, most health professionals serving low resource settings struggle with inaccurate and incomplete information and digital systems that inadequately reflect their needs. Health information systems often focus exclusively on data for monitoring, ignoring other end user's needs for actionable information, such as point of care decision support, patient continuity of care, lab results and commodity management, and access to guidance and training support. Health managers with poor data struggle to understand systems performance and are obligated to make resource allocation decisions with limited insight. These neglected elements are critical for advancing access, quality and equity of essential health services, and accountability mechanisms.

Currently, there is insufficient coordination among partner agencies on digital and data systems. Competing priorities, burdensome documentation requirements, duplicative investments, and rarely used outputs result in low motivation to collect and use data related to and within digital systems. Digital investments aren't driven by end-user needs and are made in the absence of a clearly defined architecture or investment roadmap and resulting systems don't adhere to standards and are often incompatible. Additionally, there are multiple data sources, many of which are siloed leading to fragmented data systems. Data is often neither timely, nor policy-relevant, nor service delivery relevant, leading to the unnecessary burden on countries across all levels of the health system. There is a limited focus on building sustained country capacity for the development and implementation of digital systems, data generation, analysis and use, in line with principles and standards. However, sustainable and representative digital systems are ultimately required for effective service delivery and accountability, and management of the health system and to ensure the transition to national self-sufficiency.

Shifting disease burden and ageing population

The global burden of disease is shifting to chronic conditions as populations are ageing rapidly, requiring the increased engagement of health workers and patients. The predicted net shortage of 15 million health workers by 2030[1] increases the urgency of digital technologies for prevention, screening, diagnostics and management of risk factors and disease conditions (e.g. tobacco cessation, blood pressure, diabetes, hearing loss and, mental health conditions) to facilitate access, quality assurance, monitoring, and scale up.

Inconsistent data privacy, confidentiality, and security standards
Individual-level, digitized information is necessary for delivering the best-in-class health interventions (e.g., precision medicine and precision public health), addressing barriers to receiving quality health services, and monitoring progress towards the SDGs. However, millions of existing digital identities are vulnerable to fraud and public exposure of personal information because they are stored in unsecured systems. In addition, billions of people do not have a digital identity and are therefore not represented in the electronic data systems used to augment service delivery, monitor and collect data. Health workers, facilities, commodities, even health services themselves, need to be uniquely and securely identified, within a system that supports interoperability and effective data sharing and use, ensuring equitable access to best-in-class public health and medical interventions.

DIGITAL SYSTEMS AS CATALYST

Digital technology implemented in a sufficiently enabling environment goes beyond data improvements. Digital investments can help augment a limited health workforce through task shifting, mobile learning and decision support. Access challenges can be addressed through telehealth, AI triage applications and increased personalization of care for NCD's and chronic care. Supply chain information systems can help ensure that the right medicines and commodities get to the right facilities and individuals to avoid stock-outs and continue effective treatment. With the deliberate planning of digital systems with data needs in mind, many data gaps can be simultaneously addressed as a derivative benefit while digital systems are routinely and effectively used. Implementing digital systems well requires deliberate and systematic planning and coordinated investment to ensure countries are deriving maximum benefit.

JOINT ACTIONS TO BE TAKEN

What collective actions should partners take to unleash the potential of data and digital to accelerate <u>SDG3</u> and beyond?

1. **Commit to principles for data and digital health**
    ● Agree on core data principles for standardized reporting of country data.

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[1] Liu et al. (2017). "Global Health Workforce Labor Market Projections for 2030". *Human Resources for Health*. https://human-resources-health.biomedcentral.com/articles/10.1186/s12960-017-0187-2

- Apply the [principles of digital development](#) endorsed by many UN entities and others, to guide the approach of this accelerator. These include: design with the user; understand the existing ecosystem; design for scale; build for sustainability; be data-driven; use open standards, open data (except in the case of individual health data), open source, and open innovation; reuse and improve; address privacy and security; and be collaborative.
- Apply the Principles of Donor Alignment for Digital Health, which have been endorsed by UN entities such as UNICEF, UNFPA, and UNAIDS.
- Agree to strengthen sustained country capacity in a coordinated manner on the cycle of data generation (including disaggregated data by age, sex, geography, and socioeconomic status), analysis, reporting, application to inform policy-making, and dissemination to close data gaps for tracking and accelerate accountability for health SDGs.
- Protect personal health data from inappropriate use, disclosure, and abuse.
- Make open data the default with appropriate confidentiality safeguards: make de-identified health data, including population and facility survey data publicly available rapidly after collection (e.g., within no more than six months).
- Hold all entities, including countries and partner organizations, accountable for progress in advancing both the country capacity for and wisely investing in digital and data systems that accelerate and monitor progress toward the SDGs.

2. **Standardize core data and digital tools and compile, curate and leverage global public goods**
   - Compile, align, and curate and provide a central repository of global public goods, and registry of implementations of digital tools building on the Digital Health Atlas, while noting relevance to the other accelerators (primary health care, supply chain, financing, humanitarian etc.).
   - Provide a central repository to accelerate the uptake of innovation, building on the Health Data Collaborative assets/model.
   - Compile a dictionary and core set of tools, processes, norms/standards, and applications focusing on emerging technologies in data and digital health that hold great potential to advance integrated service delivery, client-level decision-making, and improved health systems (e.g. automation machine learning and artificial intelligence, cloud-based data capture and analytics, social media nudges, unique identifiers, and secure digital unique identifiers.)
   - Automate processes such that overburdened health workers can provide high-quality clinical care, reduce disease and disability, and empower communities and individuals to minimize their own health risks.
   - Use data science (i.e. big data and artificial intelligence (AI), including machine learning), to help reduce the need for services and the potential for human error, and increase health workforce productivity.
   - Establish initial, and then refine over time, core tools and best practices for accurate monitoring with data collection, analysis, and dissemination, including the SCORE [2]for

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[2] The SCORE for health data technical package of essential interventions, standards and tools that aims to support countries respond to the monitoring requirements of universal health coverage, the SDGs and other national and subnational priorities, WHO, 2019 (draft available).

health data technical package (or similar support tools) [3], the World Health Survey Plus Data Collection Platform- multimodal data collection for countries where data gaps are largest, and Civil Registration and Vital Statistics.

3. **Assess gaps in data and health information systems, and digital health maturity**
   To assess the data and digital health maturity within a country, it is important to draw from the "foundational building blocks" for a robust e-health system. These include: i) Common data standards/global goods; ii) Unified digital architecture and interoperability; iii) Governance leadership/strategy, and investments; iv) Legislation; v) Infrastructure and foundational services and applications; vi) Human workforce/capacity. Proposed actions will include:
   - Conduct a collective assessment of data and foundational digital health gaps where we lack trend information, health information systems, and digital health maturity, using the SCORE for health data technical package, Digital Health Index, and UNFPA's global Population Data Platform and programme and policy environments.
   - Advance standardization and interoperability among different data and digital systems wherever this will increase efficiency and/or comparability.
   - Meet certain maturity criteria in which the governance model of the technology aligns with the World Health Organization's National eHealth Strategy Toolkit.
   - Meet certain maturity criteria in which the measurement of digital health align with the World Health Organization's Measurement of digital health: methodological recommendations and case studies

4. **Strengthen country capacity for digital health in focused countries**
   - Strengthen country capacity in following focused countries: Ghana, Ethiopia, Rwanda, Sierra Leone, Sudan, Rwanda, Tanzania, Uganda, and additional countries identified through other accelerators.
   - Galvanize and accelerate specific progress in specific countries, and address leadership, legislation, resources, governance, enabling environments for digital innovations, which include data sources and management, infrastructure, and capacity to use evidence and digital interventions to inform policy-making.
   - Specifically, support country capacity for selecting, adapting, implementing, maintaining, and sustaining digital health interventions and health information systems in-country.
   - The process of designing and implementing strengthened HIS, in line with the Health Metrics Network assessment tool, consists of three phases:

     o **Phase 1 – leadership, coordination and assessment** – involves setting up national working groups and guidance committees and carrying out an assessment of current HIS.
     o **Phase 2 – priority-setting and planning** – use the results of the assessment to focus the working groups 'attention on performance gaps and problems that appear to deserve priority attention and then to generate the strategic ideas needed to strengthen priority HIS subsystems.

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[3] http://www.euro.who.int/en/publications/abstracts/support-tool-to-assess-health-information-systems-and-develop-and-strengthen-health-information-strategies

    o **Phase 3 – implementation of HIS strengthening activities** – involves time-phased implementation of agreed strategies, with monitoring and re-planning taking place at regular intervals.

5. **Support collective/aligned investment plans for data and digital health**
   - Align investment plan to support the enabling environment for digital health technologies including governance and coordination, through clear national plans. Ensure alignment to support capacity building across partners (health care workforce (e.g., providers); data management, analysis and use; technology development).
   - Identify and establish a network of regional centres of excellence.
   - Strategically plan for investments in foundational building blocks in digital health in order to move towards or strengthen existing systems for supporting key emerging technologies that will accelerate improvements in service delivery and public health planning at all levels of the health system. These emerging technologies include: cloud-based visual; automation; social media nudges; secure digital identities and unique identifiers

WHAT DIFFERENCE WILL THIS ACCELERATOR MAKE?

What gets measured gets done. The systematic use and sharing of information and data are critical to achieving SDG3 and health for all. Fortunately, technological innovations and advances today can help us by mitigating common data challenges (e.g., the fragmented ways data is collected, stored, processed, analyzed, etc.)

Digital health technologies and innovations can help improve health system performance, provide evidence and guidance to advise health care providers and policymakers, and enable individuals and communities to make healthy choices. Moreover, data and digital health technologies can enhance programme performance in real-time, enabling better decision-making and overcoming bottlenecks. This, in turn, contributes toward resilient communities and robust health systems. Finally, this accelerator on data and digital health will enable the success and performance of the other accelerators, in particular, the accelerators on primary health care and fragile and vulnerable contexts.