

Strengthening paper health register systems: strategies from case studies in Ethiopia, Ghana, South Africa and Uganda

Eva W Westley¹, Sharon A Greene², Gillian A M Tarr¹, Tove K Ryman^{2,3}, Sarah Skye Gilbert³, Stephen E Hawes^{1,2}

¹ University of Washington, Strategic Analysis, Research and Training (START) Center, Seattle, WA, USA

² University of Washington, Department of Epidemiology, Seattle, WA, USA

³ Bill and Melinda Gates Foundation, Vaccine Delivery Team, Seattle, WA, USA

Health information systems (HIS) include a spectrum of data collection tools that support clinical decision-making; facilitate tracking of patients, drug stock, and disease trends; and inform policymaking [1]. As intermediaries between individual patient records and population-level data, health registers occupy a unique space in HIS. Health registers are “a collection of records containing data about aspects of the health of individual persons” [2].

Paper health registers can be books, folders, or forms that include individual-level data for a population. Paper registers are primarily used at the facility level, though they can serve as inputs to higher level reporting. Because they serve health providers, program administrators, and health management decision-makers, registers can sometimes fail to meet all stakeholder identified needs. Studies of paper registers frequently document data quality challenges which compromise efforts to deliver effective care.

Despite the global shift toward digital data collection, there remain low-resource settings that are unable to support the infrastructure required for electronic register systems. For these settings, strengthening paper health register systems can bolster evidence-based decision-making in patient encounters, program planning and policy, and serve as a first step toward improving quality data in HIS as they shift toward electronic systems.

STRATEGIES FOR IMPROVING PAPER REGISTER SYSTEMS

We developed case studies on innovations in paper health register systems in low-resource settings in Sub-Saharan Africa. The resulting studies were informed by 14 expert interviews (2–4 per study) and 101 documents, including peer-reviewed and non-peer-reviewed literature. Case studies are described in **Table 1**.

This commentary synthesizes lessons learned from these case studies, illuminating four successful strategies for optimizing paper health register systems: support local solutions, align with global standards; collect only essential data elements; foster data use and data quality improvement; and invest in strengthening human resources. Within these strategies we identify specific, actionable recommendations that could be applied by policymakers, facility managers, health workers, or others who are interested in strengthening paper health register systems. While these recommendations may be obvious to those who work in HIS, they are not yet well-documented in the literature.

SUPPORT LOCAL SOLUTIONS, ALIGN WITH GLOBAL STANDARDS

Many of the challenges with registers occur when these systems are designed and implemented by outside stakeholders

Table 1. Summary of case studies*

	ETHIOPIA'S FAMILY FOLDER	GHANA'S SIMPLIFIED REGISTER	SOUTH AFRICA'S 3-TIERED STRATEGY	UGANDA'S TUBERCULOSIS REGISTERS
Health domain	Primary care	Primary care	HIV/AIDS	Tuberculosis
Innovation	Collects patient and household-level information in a folder system; services provided at the individual level are tracked by a tally system.	Condenses all primary health registers into five SRs.	Collects standard, reduced list of essential data elements from facilities using paper or electronic systems.	Records and reports data elements for 22 TB indicators using WHO standardized registers.
Data collection	Collected by health extension workers in the community and at health posts.	Collected by frontline health workers in the community and at health posts.	Collected from clinical stations by data clerks.	Collected by clinical staff, laboratory staff, and frontline health workers.
Data aggregation	Data aggregated at the primary health unit, which encompasses five to ten health posts.	Data aggregated at the district, regional, and national levels.	Data aggregated at the district, regional, and national levels.	Data aggregated at the district, regional, and national levels.
Integration into national systems	As of February 2014, 75% of health posts in the country use the FF.	MoTeCH implemented the SR in four regions.	Established as national standard for HIV programs in December 2010.	National standard since 1990; TB/HIV collaborative registers since 2005.
Decision-making	Data used to optimize decision-making at the local level and to prioritize doorstep care.	Data informs patient care decision-making and defaulter tracking.	Data used for regional and national decisions; district and facility-level decision-making is slowly growing.	Data used for national decision-making and international monitoring of TB indicators.
Plans for future sustainability (as of 2014)	Scale-up is continuing.	There is not yet a commitment for national adoption of the SR.	All facilities plan to move from paper toward the electronic tiers over the next few years.	TB/HIV collaborative activities will continue to be supported.

ART – Antiretroviral treatment, FF – Family Folder, MoTeCH – Mobile Technology for Community Health, SR – Simplified Register, TB – Tuberculosis, WHO – World Health Organization

*All case studies are publicly available at: <http://www.technet-21.org/en/discussions/tags/case-studies-on-paper-immunization-registers>.

not aware of the needs and constraints of frontline register users or the HIS that are already in place.

Externally-led efforts can take away a sense of ownership within the health system, result in duplicate data collection, and often increase system fatigue. Frontline health workers may not use registers they find unsatisfactory, and local health authorities may not endorse registers that fail to meet their needs. These case studies demonstrate that register systems inspired by grassroots solutions are often more accepted and more likely to be successfully scaled. Yet global and national standards are essential for consistent measurement and comparability of key health indicators [3,4]. While the data points included in registers should be aligned with global standards, standard registers designed by global organizations may not satisfy local needs. Recommendations include:

- Once a problem with the register is identified, connect with frontline register users who encounter that problem for insight
- Invest in buy-in meetings during planning and implementation to bring multiple stakeholders together
- As the register matures, hold periodic stakeholder workshops to sustain support at all levels

COLLECT ONLY ESSENTIAL DATA ELEMENTS

Data proliferation is a challenge in all HIS but is magnified in paper registers. Efforts to improve efficiency should

be undertaken with attention to the register's purpose and the broader HIS. An important first step in register design is to explicitly determine whether the register needs to inform clinical decision-making, reporting, or both. While stakeholders may generally accept that non-essential data elements should be trimmed, determining how to judge an element as non-essential requires compromise and can be a major challenge. For some health domains, international guidelines stipulate a minimum data set that can be used as a starting point. Integrating vertical health programs and their registers can consolidate the data points collected in a given register. Recommendations include:

- Consider using registers for either patient care or reporting needs (not both) if their dual purpose is detracting from data quality and use.
- Assess which data elements must be reported; define an essential data set.
- Look to internationally agreed upon case definitions and indicators to design a core set of data elements.
- Design official register systems or updates that complement each other for linked areas of care.
- Minimize indicator duplication across health domains.
- Optimize reporting mechanisms, not just content within reports.
- Use an alternative to traditional registers to link individual to aggregate data.

- Design staff positions that can easily task–shift as the register system matures
- Relieve the burden on health providers by allocating activities to data clerks
- Ensure that there is dedicated staff time to support the register system at the district or sub–district level
- Implement a supportive supervision model at the district– and facility–level to encourage decision–making with data from the registers

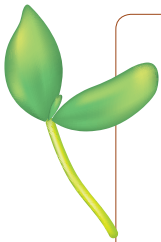
LIMITATIONS

Efforts were made to include experiences from different geographies, health domains, and stakeholders to best capture the common strengths and challenges faced by paper health registers. The recommendations revealed through these cases are influenced by the particular case studies that were selected and the sources that were most accessible to the researchers. Conclusions may not be generalizable to other contexts.

THE WAY FORWARD

Paper health registers are important tools in HIS and will continue to occupy a critical role in health service provision, administration, and reporting in many low–resource settings. However, implementing changes to these systems requires commitment of time and resources, and must be approached strategically to avoid system fatigue. Thus, it is important to consider adjustments and updates to multiple aspects of the system. Additional costing studies or operational research could identify efficiencies and reallocate resources toward the most promising solutions. Documenting and sharing lessons learned in other existing HIS can provide additional knowledge to continue to improve these systems.

These cases reveal that there are numerous factors outside of a register's physical attributes that can be addressed to strengthen register systems, including innovative human resource models, policymaking, and implementation strategies. Many stakeholders—including funders, policymakers, public health officials, and health providers—can be a part of strengthening paper register systems to support accurate reporting, evidence–based decision–making, and improved patient care.



Acknowledgements: The authors gratefully acknowledge the numerous individuals who generously shared their time and expertise to inform the case studies: Dr K O Antwi–Agyei and A Hodgson, Ghana Health Services; Edward Adimazoya and Francis Yeji, Mobile Technology for Community Health; Allison Stone, Columbia University; Dr Stephen Okoboi, The AIDS Support Organisation—Uganda; Dr Ezekiel Mupere, Makerere University; Eric Wobudeya, Makerere University—Johns Hopkins University Research Collaboration; Meg Osler, University of Cape Town; Catherine White, Clinton Health Access Initiative; Barbara Franken, Right to Care; Theunis Hurter, Anova Health Institute; Jenny Sequeira, John Snow, INC—Ethiopia; and Molly Abbruzzese and Tim Wood, Bill & Melinda Gates Foundation. This project would not have been possible without their insight. The authors also thank colleagues on the Vaccine Delivery Team at the Bill & Melinda Gates Foundation for their guidance and support throughout the project. The opinions, findings, conclusions, and recommendations expressed in this commentary are those of the authors and do not necessarily reflect the views of key informants, thought partners, or reviewers.

Funding: This work was funded by the Bill & Melinda Gates Foundation (BMGF) through a contract with the University of Washington Strategic Analysis, Research and Training (START) Center. SSG and TKR are employed by BMGF. EWW was previously an employee of Volt Workforce Solutions on assignment at the BMGF GAMT was supported in part by the National Institute of Environmental Health Sciences of the National Institutes of Health under award number T32ES015459.

Ethical approval: None required.

Disclaimer: The content is solely the responsibility of the authors and does not necessarily represent the official views of the Bill and Melinda Gates Foundation or the National Institutes of Health.

Authorship declaration: SKG and TKR developed the research questions and provided input regarding the specific case studies and approach. EWW, SAG and GAMT conducted key informant interviews, reviewed the literature, and with input from SEH, wrote the individual case studies. EWW took primary responsibility for the writing of the manuscript. All authors provided critical input to drafts and the final version of the manuscript.

Competing Interests: All authors have completed the Unified Competing Interest form at www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author). The authors declare no financial relationships with any organizations that might have an interest in the submitted work in the previous 36 months; and no other relationships or activities that could appear to have influenced the submitted work apart from that declared above in the Funding acknowledgement.

- 1 World Health Organization. Everybody's business: strengthening health systems to improve health outcomes: WHO's Framework for Action. Geneva: WHO Press, World Health Organization, 2007. p 1–56.
- 2 Australian Institute for Health and Welfare. Minimum guidelines for health registers for statistical and research purposes. National Health Information Management Group & Australian Institute for Health and Welfare (AIHW). Cat. no. AIHW 9792. Canberra: AIHW, 2001.
- 3 Alkraiji AI, Jackson TW, Murray I. The role of health data standards in developing countries. *J Health Inform Dev Ctries*. 2012;6:454-66.
- 4 Mutale W, Chintu N, Amoroso C, Awoonor-Williams K, Phillips J, Baynes C, et al. Improving health information systems for decision making across five sub-Saharan African countries: implementation strategies from the African Health Initiative. *BMC Health Serv Res*. 2013;13 Suppl 2:S9. [Medline:23819699](#) [doi:10.1186/1472-6963-13-S2-S9](#)
- 5 Mobile technology for community health in Ghana: what it is and what Grameen Foundation has learned so far. Grameen Foundation 2012 P1–155. Available at: <http://www.grameenfoundation.org/resource/motech-lessons-learned>. Accessed: 1 May 2014.

Correspondence to:

Stephen E Hawes PhD
Department of Epidemiology
University of Washington
Box 357236
1959 NE Pacific Street
Health Science Building F-261B
Seattle, WA 98195-7236
USA
hawes@uw.edu