### Norwegian Institute of Public Health, Division for Health Services: Impact Case 3

Institution: Norwegian Institute of Public Health

Administrative unit: Division for Health Services

Title of case study: eRegistries: Digital Health Interventions for Public Health Systems

Strengthening

Period when the underpinning research was undertaken: 2009 – 2022

Period when staff involved in the underpinning research were employed by the submitting

**institution:** 2009 – 2022

Period when the impact occurred: 2011 – 2022

## 1. Summary of the impact

This impact case features a multifaceted initiative that integrates science and policy, with strong local and global collaborations for comprehensive health impact. We strive to establish good quality health data and facilitate real-time utilization of data by health workers in low- and middle-income countries (LMIC), as well as for monitoring LMIC health systems over time. This is achieved through a streamlined approach, utilizing longitudinal data in digital registries (*eRegistries*) from a single source at the point of generation, that is, health facilities.

Our scientific endeavors span global scoping reviews, concept development, and intervention science, implementing global guidelines and a Lancet series. Policy contributions include WHO guidelines, taxonomy, and classification for digital health interventions. Locally, we have demonstrated significant impact on health systems and health information systems, healthcare delivery, and human resources, for example, in Palestine. We operate with a strong focus on research and capacity strengthening in LMIC, fostering infrastructure and personnel development from entry-level to senior scientists. The *eRegistries* initiative has contributed to global goods such as District Health Information Software 2 (DHIS2) used in 80 LMIC, user-friendly Apps for health workers, and global guidelines for digital health interventions.

# 2. Underpinning research

The *eRegistries* initiative emerged as the result of several NIPH-led global scholarly collaborations – including both academia, governmental and UN agencies – to address the <u>lack of quality data</u> and <u>unhelpful classification</u> <u>systems</u> for stillbirth prevention. This work became an integral part of our 2011 <u>Lancet Stillbirth Series</u>, acclaimed by the Editors for its global impact (box).

"Its powerful mix of advocacy and hard data attracted more media attention than perhaps any other [Lancet] Series, and made waves on numerous levels, from the individual to the intergovernmental."

Zoë Mullan, Editor

The NIPH and the World Health Organization (WHO) partnered in the *eRegistries* initiative as "<u>a</u> <u>direct response to The Lancet Stillbirth Series</u> to strengthen health information systems, specifically electronic health registries tracking women and children across the continuum of care". The *eRegistries* initiative developed concepts through three influential papers on data collection principles for health information systems (Frøen et al., 2016), technology and system needs, legal and ethical aspects, and clinical indicators for health systems. Notably, global scoping reviews revealed the absence of essential Health Information Systems (HIS) in LMIC and revealed the need to challenge the status quo.

Representing a new paradigm for public health surveillance in LMIC, implementing and studying the effectiveness of *eRegistries* in such settings was "high risk, high gain" and was awarded a European Research Council grant, <u>HEALTHMPOWR</u>, for cluster-randomized controlled trials in the West Bank of Palestine. With co-funding from the Research Council of Norway, WHO, Norad, and Centre for Intervention Science in Maternal and Child Health (CISMAC, National Center of Excellence) implementations and trials expanded to national scale including Gaza. Notably in our first hands-on implementation project in Palestine, we defied skeptics who claimed that radical transformations of health systems and health information systems in LMIC "cannot be done" or "will not work." Implementation science played a crucial role, where we employed co-design with users to drive necessary changes in the health system (Bogale et al., 2020).

The eRegistries projects in-country demonstrated immediate policy impact, which allowed us to contribute with conceptual as well as practical insights to our 2016 <u>Lancet Series on Ending Preventable Stillbirth</u>. Our research and implementations were also contributing steadily to global infrastructures like the District Health Information Software (DHIS2), specifically to guidance on individual-level data collection systems in LMIC.

Intervention science has been our focus across different country settings and projects, addressing the need for high-quality evidence of impactful digital health interventions highlighted by the WHO. A first-of-its-kind cluster-randomized controlled trial in Palestine demonstrated that a digital registry with clinical decision support is effective in improving quality of care for pregnant women (Venkateswaran, Ghanem, et al., 2022). A unique cluster-randomized controlled trial in Bangladesh showed that a digital registry is effective in improving health outcomes (Venkateswaran et al., 2024).

Policy-oriented research of changes in data showcased how enhanced data transforms indicators of healthcare quality, deepens understanding of population-scale health conditions, and influences priority setting in public health (Venkateswaran, 2019). Such approaches to policy-relevant research helped allay preconceived notions about the infeasibility of implementing relatively radical interventions in LMIC.

Our work has not only addressed data needs but also positioned LMIC as key players in driving impactful change. With strategic partnerships and a commitment to science, the project successfully navigated challenges, leveraging local expertise to influence global policies. By demonstrating the feasibility of improving data infrastructure in LMIC, the initiative not only debunked myths but also contributed valuable insights to the global health community. In summary, this comprehensive effort spans scholarly groundwork, project implementations and research evaluations in real world health systems, and policy impact research. As a result, we have been able to challenge conventional beliefs about feasibility, benefits, and limitations of data-driven interventions in LMIC.

### 3. References to the research

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## 4. Essential project researchers from our research unit

Alphabetically, project and work package leads in **bold**: Akuba Dolphyne, Binyam Bogale, Brian O'Donnell, **Eleni Papadopoulou**, Hollie Stone, **Ingrid K Friberg**, **J. Frederik Frøen**, Jagrati Jani Bolstad, Kim Frost, **Kjersti Mørkrid**, Linda Nyanchoka, **Mahima Venkateswaran**, Marie Hella Lindberg, Michael J Frost, Socheat Cheng, **Sonja Myhre**, **Victoria Nankabirwa**, Åse Pay.

## 5. Details of the impact

The intersection of science, policy, and local capacity building has given rise to this transformative eRegistries initiative. Our endeavour encompasses various facets, each contributing to a holistic approach to address critical health and health system challenges, as outlined below. Our projects and work represent a paradigm shift in health information systems in global health. By seamlessly integrating science, policy, local impact, capacity development, and the creation of global goods, our work exemplifies a model for comprehensive and sustainable data-driven digital health interventions and use of data.

#### **Scientific Advancements:**

At the core of this initiative lies a commitment to advancing scientific knowledge. We have employed a range of approaches – global scoping reviews of registries and data collection systems in LMIC, concept development to demonstrate the novelty of health system indicators (Flenady et al., 2016), implementation science and intervention science. Our research projects involve close collaborations and hands-on implementations with partners in LMIC, and end users of health information systems. This approach responds to top-priority research questions from authoritative bodies like the WHO while also responding to local needs. Our approach and methods have set a precedent for others to pursue similar challenging yet impactful research.

#### **Policy Influences:**

Our work extends its reach into the realm of policy, and we have contributed directly to the development of the WHO guidelines, taxonomy, and classification for digital health interventions, including leading the development of eleven systematic reviews for the WHO. We have contributed to the FIGO (The International Federation of Gynecologists and Obstetricians) position paper (Frøen et al., 2021) on data for the prevention of preterm birth and the WHO framework for mHealth Evidence Reporting and Assessment (mERA) (Agarwal et al., 2016). We have strived to ensure that the latest advancements in science are translated into tangible guidelines and frameworks that can guide global health efforts.

### **Local Impact in Country:**

The impact on the ground has been clear and pronounced, particularly in Palestine, where we implemented a digital registry for antenatal, postnatal, and newborn care in all public primary healthcare clinics. The accompanying research demonstrated positive impacts on the health information system, care delivery, quality of care, and the optimal use of human resources (Venkateswaran, Nazzal, et al., 2022). This large-scale implementation provides a good example of

localized impact of global guidelines and recommendations, underscoring the adaptability and relevance digital health interventions in diverse settings.

#### **LMIC Capacity Development:**

Recognizing the importance of strengthening sustainable capacity in LMIC, our projects align with the societal mandate of the NIPH, and its long history of involvement with capacity strengthening initiatives, the latest being the <u>Building Stronger [Public Health] Institutions and Systems</u>. We have leveraged such capacity strengthening initiatives and bridged them with research projects to maximize impact on infrastructure development and personnel training. Over the years our collaborations have fostered entry-level positions, and senior scientists and professors in LMIC institutions.

#### **Real-Time Data Infrastructure:**

A notable achievement of the initiative is the creation of a robust infrastructure for real-time, real-life data assessments. The ongoing <u>project</u> (Evidence-based policies and health systems interventions for antenatal care) in Uganda funded by the Research Council of Norway exemplifies this, allowing for the evaluation of the impact of policy or guideline changes in health systems. Specifically, we are examining what it takes for the health system to transition from 4 antenatal care (ANC4) visits to 8 antenatal care (ANC8) contacts. The emphasis on data and digital health in this project to support the delivery of the intervention is directly in response to WHO's priority research question on the implementation of ANC8. The approach of implementing longitudinal data collection systems, integrated into the existing health information system, provides an opportunity to study data in real-time and provide policy recommendations.

#### **Global Goods and Pandemic Response:**

All our software and implementation guidance are global public goods, free for all to use at DHIS.org. We have contributed to and curated "ready-made" meta-data packages that include implementation guidance, fostering communities of practice for shared learning and collaboration. Examples include the Reproductive, Maternal, Newborn, and Child Health (RMNCH) and childhood immunization, and the DHIS2 Tracker for Antenatal Care based on WHO's Digital Adaptation Kit (DAK). Our work with the DHIS2 developers over a decade to transition from their traditional aggregate data sources to individual-level registries has made such tools available for the 80+ LMIC using DHIS2. The snowballing impact of these contributions on a global scale is particularly evident in the realm of pandemic response and readiness; individual-level data health information systems played a crucial role in the COVID-19 response with over 40 countries repurposing "Tracker" systems of individual-level data from other programs towards COVID-19 response.

## 5. Sources to corroborate the impact

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