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Into practice

Developing and deploying a community healthcare worker-driven, digitally-enabled integrated care system for municipalities in rural Nepal

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ABSTRACT

Integrating care at the home and facility level is a critical yet neglected function of healthcare delivery systems. There are few examples in practice or in the academic literature of affordable, digitally-enabled integrated care approaches embedded within healthcare delivery systems in low- and middle-income countries. Simultaneous advances in affordable digital technologies and community healthcare workers offer an opportunity to address this challenge. We describe the development of an integrated care system involving community healthcare worker networks that utilize a home-to-facility electronic health record platform for rural municipalities in Nepal. Key aspects of our approach of relevance to a global audience include: community healthcare workers continuously engaging with populations through household visits every three months; community healthcare workers using digital tools during the routine course of clinical care; individual and population-level data

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generated routinely being utilized for program improvement; and being responsive to privacy, security, and human rights concerns. We discuss implementation, lessons learned, challenges, and opportunities for future directions in integrated care delivery systems.

1. Background: integrated care in a globalized world

Integrating the systematic measurement, monitoring, analysis, and application of key population health data to improve service delivery over time[1–6] is a critical yet neglected function of healthcare delivery systems. Effective integrated care approaches demand clear definitions and understandings of patient populations, combining population-level data across multiple sources, and integrating clinical workflows across facility and community sites. We choose the phrase integrated care here to highlight the bringing together of community-based care and counseling with facility-based services, and to provide clarity vis-à-vis related terms like surveillance, population health, or population health management. There are few examples in practice or the academic literature of affordable, digitally-enabled integrated care approaches embedded within healthcare systems in low- and middle-income countries (LMICs). Here, we describe the development of an integrated care delivery system involving community healthcare workers (CHWs) that utilize a home-to-facility electronic health record platform in rural Nepal. We discuss its design and implementation, lessons learned, and challenges and opportunities for future directions in population-based approaches to integrated care in LMICs.

As economies grow, populations age and expand, and new threats emerge, there is increasing recognition within LMICs for the need to advance principles of integrated care. Real-time data for healthcare systems integrated across time and space can help to better manage the healthcare of populations. Exclusively facility-based "passive" healthcare systems, while essential, may miss engaging with people suffering from or at risk for conditions that either never present or delay in presenting to a clinic or hospital. Demographic health surveys aimed at capturing regional or national prevalence are often of insufficient temporal or spatial resolution to offer real-time guidance to healthcare providers and planners.[7,8,9] The 2014 outbreak of Ebola that spread globally from West Africa stands as a glaring reminder of the need for a renewed effort around 'sensitive' health information systems that are predictive and responsive, and integrated into the routine course of delivering care for even the most remote populations.[10] Simultaneously, a growing burden of non-communicable diseases demands a population-based approach to enable an appropriate and affordable shift from systems organized around acute problems to those able to address longitudinal care needs.[11]

A key opportunity to address these challenges lies in two inter-related developments in global healthcare systems design: 1) the expanded scope of CHWs in healthcare delivery systems; and 2) digital systems for longitudinal care. Professionalized CHWs are increasingly recognized as essential to robust and adaptive healthcare delivery and population-level data systems.[7,12–16] They are on the frontlines, in communities and homes, of both communicable and non-communicable epidemics. Equipping them with digital tools can help provide near real-time information with greater temporal and spatial precision. Developing data systems and feedback loops that can effectively integrate the people-centered care work of CHWs, while safeguarding the privacy and dignity of communities, particularly vulnerable populations, presents both a challenge and an opportunity.

2. Organizational context: municipal public-private partnership in rural Nepal

Nepal is one of the world's newest democracies, having abolished a 240-year old monarchy in 2006 following the cessation of a decade-long Maoist "People's War" against the Nepali state. Eventually spreading throughout all 75 of Nepal's districts, a conservatively estimated 13,000 were killed in direct conflict.[17] Nepal's public healthcare sector—weak from decades of underinvestment, conditional aid, and neoliberal economic policies;[18,19] an emergent fee-for-service industry;[20] and internecine political perturbations[21,22]—was further decimated by the conflict.

In parallel, Nepal's healthcare sector is at a critical juncture. The 2015 earthquakes saw significant devastation to healthcare facilities throughout the country, and amidst the aftermath and reconstruction efforts, political parties signed a new Constitution, a full seven years after the monarchy had been abolished. This also initiated a process of devolution of centralized political and economic power in the form of the creation of seven new federal states and 744 village and town municipalities. The new Constitution includes healthcare as a fundamental right of its citizens[23]; though operationalizing this legislation into practice remains an enduring challenge. In November 2017, the Nepal Health Insurance Act was signed into law, formalizing a new mode of payment for the promotion of social protection and health financing; though, here too, there remains uncertainty about what this will look like in implementation.[24]

With these two political changes—decentralization on the one hand and a new federal financing structure on the other—new modes of healthcare delivery are being established. One such model involves public-private partnerships (PPPs) at the municipal level to strengthen care delivery alongside the government in these new localized structures. Here, we discuss one such PPP, between Nepal's Ministry of Health (MoH) and the non-profit healthcare organization *Possible*. Bayalpata Hospital in Achham District was the first facility established as part of the PPP, which operates as a regional training facility that treats over 100,000 patients a year, has full-spectrum inpatient, outpatient, laboratory, radiology, and surgical care, and is linked to a network of full-time employed CHWs. Achham, once a stronghold of the Maoists during the conflict, is one of Nepal's poorest districts.[25] A similar partnership was established upon invitation by the MoH at Charikot Primary Health Center in Dolakha District, not too far from the epicenter of the second major earthquake on May 12, 2015.

3. Problem: municipal integrated care in a LMIC context

There was a clear national and local opportunity for developing an integrated care delivery system, one that focused on the municipal level as the primary organizational unit in the healthcare sector going forward. The PPP's approach to CHW-centered, population-based healthcare delivery provided the opportunity and necessity for a digitally-enabled, integrated care system. There are three core technical functions that this platform needed to solve for: 1) serve as a reliable data collection source for monitoring community-based care and tracking patient outcomes at the municipality level, such as mortality rates; 2) integrate with a hospital-based EHR system; and 3) identify patients to facilitate longitudinal care using unique numerical IDs and biometrics. The goal is that this modular system could be deployed in other municipalities, within or outside of a PPP framework.

4. Solution: CHW-centered integrated care system

Nepal currently has a cadre of around 50,000 Female Community Health Volunteers, who, since the late 1980s, have been central to community-based reproductive, maternal, and child health throughout the country. This is a bedrock of the public healthcare system; the team comes from the orientation that, in building off the successes of the

Female Community Health Volunteers, CHWs should be employed and compensated for the work.[26] Thus, in addition to managing the municipal hospital, the PPP employs full-time CHWs who undertake three core functions: 1) active and passive identification of conditions in the community; 2) triage and referral care with facilities; and 3) community-based diagnosis, treatment, and counseling. The primary focus of the CHWs' work is around integrated care for reproductive-maternal-newborn-child health—particularly through age two years—and non-communicable diseases. The digital platform for community-based care needed to respond to these functions while being modular, affordable, easy to use, and able to integrate with the hospital-based EHR. Such features allow CHWs and their supervisors to both identify threats to population health and longitudinally track patient outcomes.

We provide an overview of the integrated platform's architecture in Fig. 1, and a more detailed description in Supplemental File 1. In brief, the system integrates facility and community care delivery – though the automated, digital integration of community-level and facility-based EHR data has not been fully achieved—has a biometric-enabled mhealth component, and provides a dashboard of ongoing population measures. As part of the system, we aimed to establish baselines for the following key metrics, for programmatic improvement[7]: 1) institutional delivery rate; 2) antenatal care coverage; 3) postpartum contraceptive prevalence rate; 4) infant mortality rate (per 1000 live births); 5) neonatal mortality rate (per 1000 live births); and 6) under-two mortality rate (per 1000 live births). Additionally, we have begun to track non-communicable disease goal measures across priority diseases, though we report on this elsewhere.

4.1. Deployment and initial results

Taking lessons learned from our initial experience with paper surveys, preliminary digital tools,[7,27] and from in-depth discussions with CHWs, we iterated on our initial deployment over the course of six months in Achham, in a catchment area population of 40,000 around Bayalpata Hospital, and subsequently replicated in a different catchment area population of 20,000 in Achham (Kamalbazar). The census instrument used for enrollment was adapted from the Demographic and Health Survey and Multiple Indicator Cluster Survey.

In the Bayalpata Hospital catchment area population, we enrolled households from February 15th to July 10th, 2016 and in the Kamalbazar Primary Health Center catchment area population, we enrolled households from June 5th to August 15th, 2016. We enrolled a total of 10,814 households, among which 9939 (92%) were "available", i.e. had household members present to provide responses. A total of 9909 (99.7%) of available households consented to be enrolled in the census. Among all households surveyed, 32% were *dalit* (so-called "untouchable" in Nepali) or *janajati* (indigenous), with the remaining households comprised of *brahmin* or *chhetri* families. We provide the outputs generated by the system in Supplemental File 2.

Following enrollment, we initiated pregnancy screening in both catchment area populations, while under-two child screening has not yet been initiated in the Kamalbazar Primary Health Center catchment area population owing to logistical phasing of the program. From February to June 2017, among a total enrolled population of 7707 married women of reproductive age in both catchment area populations, we screened a total of 5674 eligible women with a pregnancy screening questionnaire at least once, among whom 515 were further screened using urine pregnancy tests. Women whose urine pregnancy tests were positive (n = 293) were transitioned into antenatal care provision. Fig. 2 shows a workflow for pregnancy and child screening. CHWs also screened and provided counseling for a total of 1005 children under-two years for diarrhea, measles, malaria, and pneumonia in the Bayalpata Hospital catchment area population at least once between February to June 2017. Among those screened, 31 cases (28 children) were identified with symptoms such as indrawn chest, bulging fontanelle, wheezing, stridor, and/or nasal flaring, and were flagged for immediate referral to the hospital. In addition, 138 cases (123 unique children) showed symptoms of diarrhea and dehydration, such as long time for skin to return to original state upon pinching gently and/or passing stools three or more times in the preceding 24 h. These were all flagged for referral to the hospital. Fig. 3 represents a workflow for diarrhea screening, showing the decision-support functionality embedded within the digital platform.

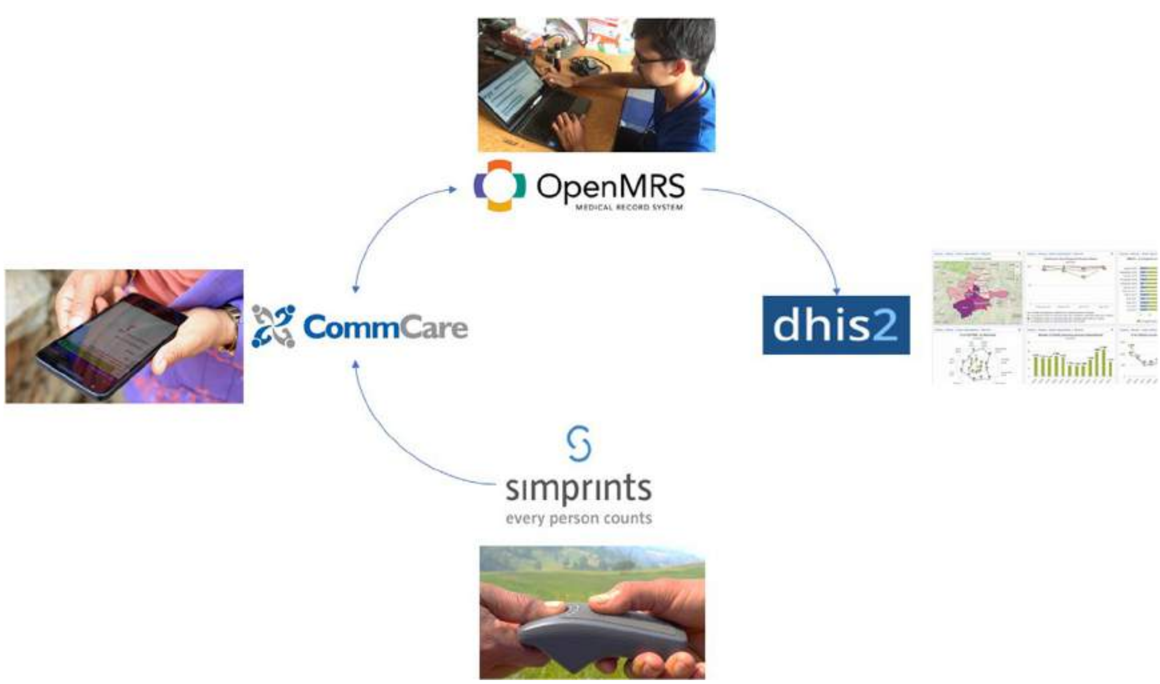

Fig. 1. Data architecture for a biometrics-enabled, integrated, home-to-facility electronic health record.

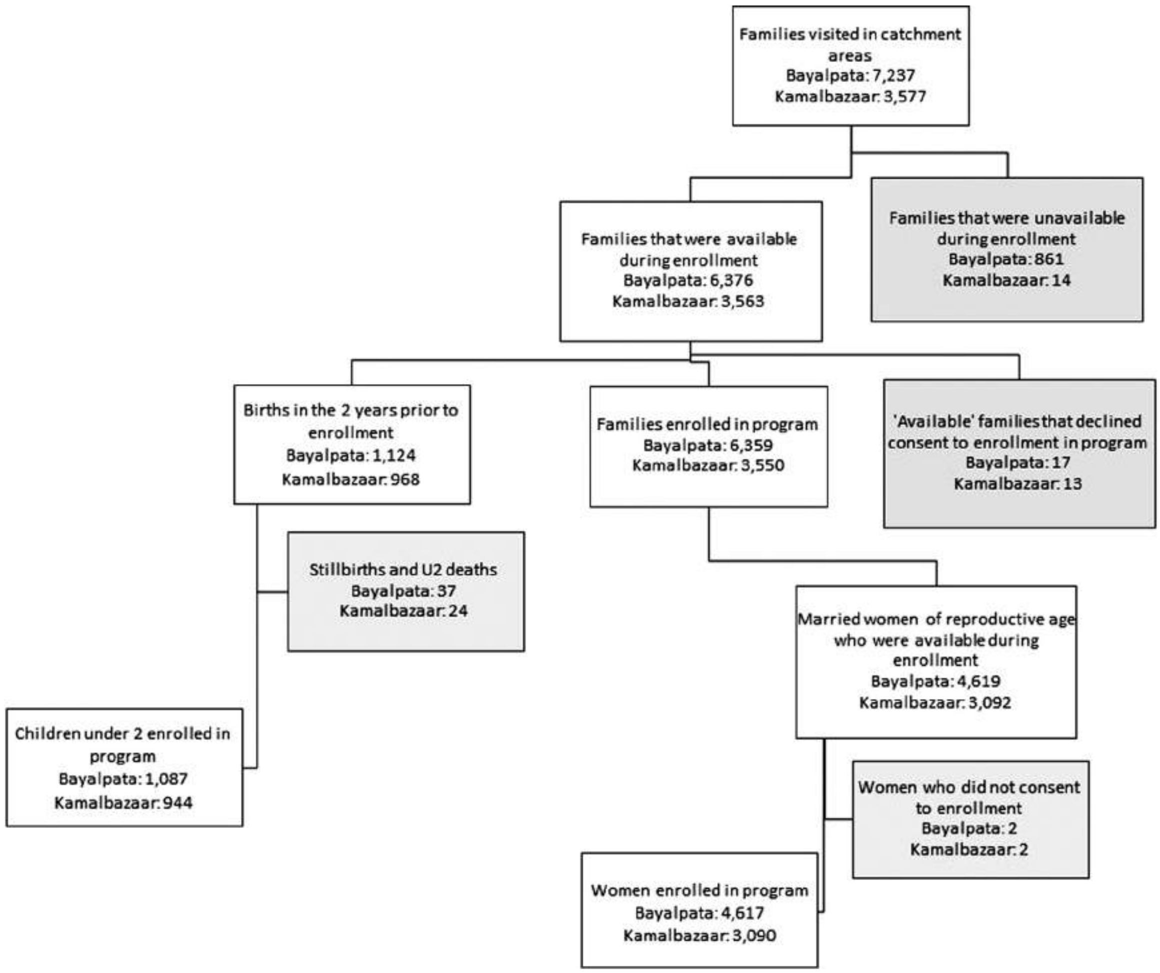

Fig. 2. Pregnancy and child screening workflow.

5. Unresolved questions and lessons for the field

5.1. *Incorporating other diseases and social determinants*

A comprehensive integrated care delivery system needs to respond to a broad range of diseases and risks relevant to population health. We have laid some groundwork for taking our present system beyond pregnancy and early childhood. In parallel, the team has initiated a non-communicable disease CHW follow-up program that supports patients detected at the hospital level, and we plan to initiate a surgical follow-up program in the coming year. As an entry point into the social determinants of health, we have also developed an approach to measure household expenditures on health, medical debt, and medical impoverishment, and are currently analyzing these data. Over time, we aim to incorporate these various streams of household-level health, socio-economics, and disease risk data into the comprehensive integrated care digital platform.

5.2. *User interface, data error, and data use*

In the spirit of 'building simple but no simpler than need be', we engaged Simprints to conduct intensive user-centered design for biometric fingerprint scanners, including the overall shape, feel, and features of the hardware, as well as the software workflow and feedback elements. Similarly, we worked collaboratively for several months with the Dimagi team to customize mobile applications and forms for CommCare. There have been significant challenges with our technology, particularly biometric scanners, including database syncing, data loss due to device breakages, inadvertent uninstallation of the main and supporting applications, and phone storage issues due to installation of entertainment applications. Some of these are intrinsic to implementing digital technology in rural areas, where fixes on the same day are typically not feasible. Regular feedback on system challenges are collected from CHWs through community healthcare nurses, who report all issues on an error tracking sheet, which are then resolved by the PPP's technical team every two weeks.

We have also created a monthly data system for direct use by CHWs. Data collected through the CommCare application are cleaned, summarized, and reviewed through regular data quality review sessions to track programmatic progress and challenges, identify patterns and deviations of care delivery, and monitor health outcomes among the catchment area population. Clean summary data are also visualized on topographical maps and provided to CHWs. An example map generated from GPS and pregnancy history data collected during enrollment showing the delivery locations (institutional versus non-institutional) of households with recent deliveries is displayed in Fig. 4. Moving forward, the team's goal is to further integrate these data with high quality laboratory data to connect syndromic and diagnostic information. We are continuing to develop analytics dashboards that are usable for providers in our instance of DHIS2, as shown in Fig. 5. The longer-term goal is to work with local municipalities to incorporate population monitoring within the government's DHIS2 platform.

5.3. *Community and government engagement*

In multi-level public healthcare systems such as Nepal, the ethical

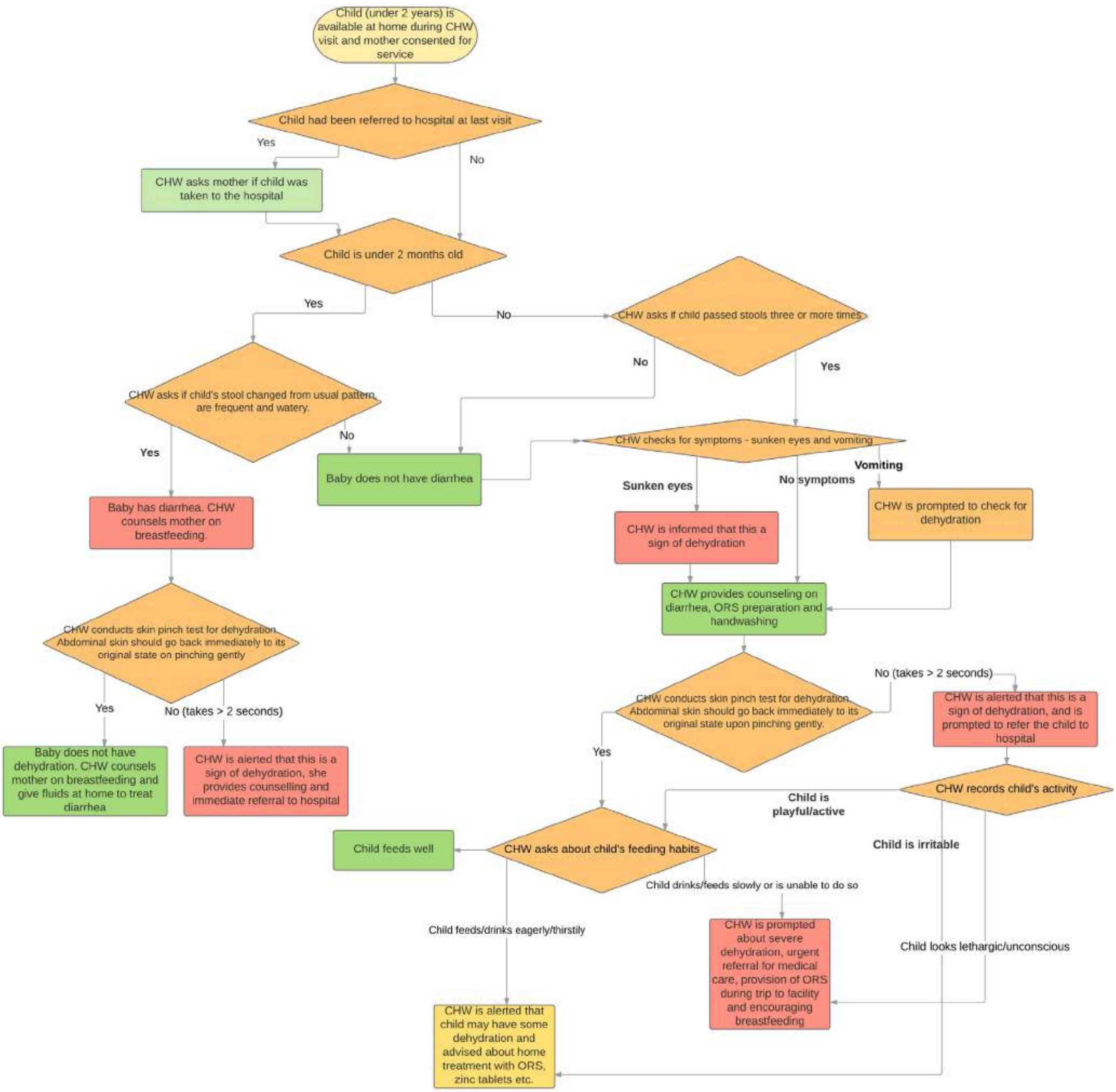

Fig. 3. Diarrhea screening workflow and decision support.

and effective deployment of any new program must engage multiple stakeholders, who often have different needs and perspectives. An asset in this process was *Possible*'s Community Advisory Board (CAB), comprised of local community members and public officials from the districts where we work, and which convened bi-annually to provide independent advice and critical feedback. Secondly, we engaged district level administrators and political leaders during the development and deployment of the system, which was essential to hearing and addressing their concerns along the way. Thirdly, CHWs have continued to serve as the drivers of new ideas and adaptive thinking, critically informing the PPP around what is working well, and what needs to be changed. As one example, they were the driving force behind defining eligible women to be enrolled as married women of reproductive age (15 – 49), as it was not appropriate to enroll and screen unmarried women for pregnancy. Additionally, CHWs made the ultimate decision to halt the use of biometric scanners when data errors and bugs made the technology more of a burden than a care-delivery support tool [see Supplemental File 1 for elaboration]. Fourthly, *Possible* has engaged with the central (federal) level government, including supporting the creation of both an eHealth Unit and an Implementation Research Unit within the MoH.

5.4. Emerging issues in security, privacy, and data ownership

The security and privacy of data collected through the system, both at the household and facility level, are of paramount concern for all stakeholders. At times, the use of the phrases "open source" or "cloud-based storage" generated concern among local and central government officials for the privacy and security of patient data. In the future, we aim to store all data on the MoH's central server database, as they are

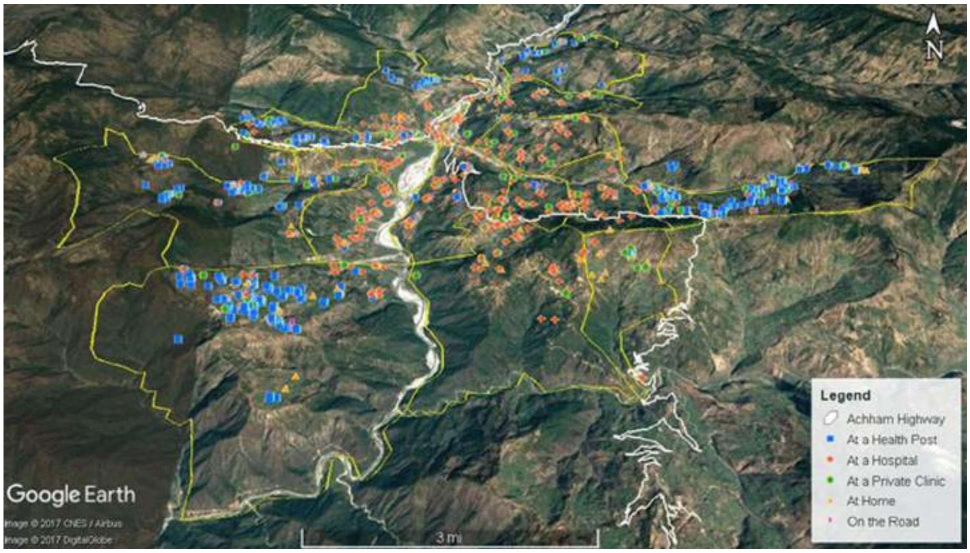

Fig. 4. Map of institutional births recorded after household enrollment and via population health management (February 2014 – June 2016).

entitled to be accountable owners of data collected. Yet, patients ultimately need to be in control of their own data and be protected from potential abuses by the State.[28] With terrorism and biosecurity high on the minds of many governments, and populations rightly suspect of the potentially sinister uses of "big data" programs, there is a broader, global challenge around the State's role in surveillance. It is essential that data protection not be viewed as a "box ticking" exercise, and that organizations iteratively engage with data protection compliance to understand how best to respect people's privacy and minimize the risk of inadvertent harm.

Fig. 5. Example of customizable DHIS2 dashboard integrated with the electronic health record.

5.5. Sensitivity in integrated care, and designing for both 'n = all' and 'n of 1'

To that end, it is useful to differentiate between two kinds of sensitivity: the ability of a system to accurately identify ("sense") and care for people longitudinally in remote communities with highly mobile populations; and the ethical sensitivity with which processes of enumeration and data collection are intervened *upon* people—what anthropologist Michael Fischer has termed the "peopling of technologies".[29]

This first kind of sensitivity refers to capturing data from entire populations—or achieving, statistically, "n = all." The concept of n = all is that of a complete, continuous census in which every person in a catchment area population is enrolled into a health information system that updates and integrates with high frequency facility level and household level data, such as condition prevalence, care-seeking behaviors, household economics, geo(topo)graphy, and socioeconomic factors.

The second kind of sensitivity reflects deeper ethical concerns about protecting dignity, civil liberties, and the social and cultural rights of communities. Social scientists have referred to this lens as paying attention to the scale of 'n of 1'[9,29] where each and every person counts, in both senses of that word. Regular face-to-face interactions by CHWs, listening and counseling, with individuals attuned to local context and need, constitute the kind of regular, frequent engagement that is so vital to systems of care and accompaniment that aim to put people at the center.[9,30,31]

5.6. Summary

We have described the deployment of a unique integrated care delivery system in rural municipalities in Nepal, and challenges encountered. With recognition of the limited generalizability of our case study, we have demonstrated that it is feasible to deploy such a system for pregnancy and early childhood healthcare in a resource-limited rural setting. This system has the following characteristics: 1) CHWs implement the system at the household level during the routine course of household clinical care; 2) community-level data are integrated with facility-level data through regular data reviews; 3) CHWs continuously engage with the population through household visits every three months; 4) data are utilized for program improvement as well as population health monitoring; 5) iterative design based on community/end-user engagement; and 6) the system aims to be responsive to privacy, security, and human rights concerns.

We will need to continue to iterate on the challenges we have faced, including community and stakeholder engagement, privacy, data ownership, and user interfaces. Over time, we aim to expand the system to include a broader range of conditions and risks. Larger questions of acceptability, affordability, and sensitivity will need to be addressed if this type of approach is going to be effectively scaled in Nepal and beyond.

Conflict of interest statement

DC, PT, IN, SPandey, LBK, JT, HR, AT, AR, SPoudel, DT, SKD, SH, NC, and SPK are employed by and Bibhav Acharya, SM, RS, Dschwarz, AK, WJW, and DM work in partnership with a nonprofit healthcare company (Possible) that delivers free healthcare in rural Nepal using funds from the Government of Nepal and other public, philanthropic, and private foundation sources. DC is a faculty member at a public university (University of Washington) and, DC and SH are employed part-time there. Bibhav Acharya is a faculty member at a public university (University of California, San Francisco). SM is employed at an academic medical center (Boston Medical Center) that receives public sector research funding, as well as revenue through private sector fee-for-service medical transactions and private foundation grants. SM is a faculty member at a private university (Boston University School of Medicine). SM and WJW are academic fellows at and RSchwarz, DSchwarz, and DM are employed at an academic medical center (Brigham and Women's Hospital) that receives public sector research funding, as well as revenue through private sector fee-for-service medical transactions and private foundation grants. MA, MNK, NPKC, Bhim Acharya, DRS, and PC are employed by the Government of Nepal. KBK is a faculty member at a public university (Tribhuvan University, Institute of Medicine). AHB is a medical resident at a public hospital (Contra Costa Regional Medical Center). JW is employed by a social enterprise and for-profit benefit corporation (Dimagi) that receives revenue from philanthropic, research, multilateral as well as contractual arrangements for developing and implementing information and communications technology for development projects. DStoristeanu is employed by a nonprofit technology company (Simprints) that develops and implements biometrics technology for development projects using funds from philanthropic and private foundation sources. RSchwarz is employed at an academic medical center (Massachusetts General Hospital) that receives public sector research funding, as well as revenue through private sector fee-for-service medical transactions and private foundation grants. RSchwarz, DSchwarz, and DM are faculty members at a private University (Harvard Medical School). DSchwarz is employed at an academic medical center (Beth Israel Deaconess Medical Center) that receives public sector research funding, as well as revenue through private sector fee-for-service medical transactions and private foundation grants. AK is a medical student at a private university (Icahn School of Medicine at Mount Sinai). SPK is a student at a private university (Eastern University). DM is employed at an academic medical center (Boston Children's Hospital) that receives public sector research funding, as well as revenue through private sector fee-for-service medical transactions and private foundation grants. DM is a non-voting member on *Possible*'s board of directors, but receives no compensation. All authors have read and understood Healthcare: Journal of Delivery Science and Innovation's policy on declaration of interests, and declare that we have no competing financial interests. The authors do, however, believe strongly that healthcare is a public good, not a private commodity.

Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at http://dx.doi.org/10.1016/j.hjdsi.2018.05.002.

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