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# Including the excluded: Achieving representation through Strengthening Health Information Systems in Lao PDR

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**Abstract:** Making it possible to identify and include marginalized population groups in routine health information systems is a means of digital inclusion. Our study examined the question of *How can health information systems be designed and implemented to enable the representation of marginalized population groups?* Through a series of iterative quality improvement assessments (2016-2019) of the health information system in Lao PDR a number of substantial changes were made to the routine health information systems. In our analysis we use Zuboff's notion of representation to illustrate how the development and implementation of a digital register in combination with the family information system enables digital representation of marginalized populations and communities. The impact of the changes implemented over the 4 years has addressed many challenges within the health information that enables representation. but we argue that addressing social exclusion requires more than representation.

**Keywords:** Lao PDR, DHIS2, Representation, Improvement Science, Zuboff.

## 1. Introduction

Exclusion is a complex and multifaceted condition and focuses attention on what Sen calls the 'relational roots of deprivation' [1]. The term exclusion is often used to identify various types of social disadvantage in employment, education, housing, health, and social networks: 'generally it describes the state of disadvantage faced by particular groups who are felt to be removed from mainstream society, and who cannot fully participate in normal life' [2, p.17]. Exclusion means many vulnerable people do not have access to health and social services. Health seeking and care-giving practices are generally poor [2]. Knowledge of their rights and entitlements is often limited and that exacerbates their inaccessibility of health services [3]. Often, vulnerable populations do not have the necessary documentation to access the services [4]. Additionally, vulnerability is not a state of being, but a continuum - a pathway that can be taken and exited from as the context changes [5, 6].

The rationale underpinning the implementation research presented in this paper is that to address exclusion from health care services there needs to be awareness and visibility of the situation. A Health Information System (HIS) can be used to identify the excluded. With HIS highlighting or making visible those not serviced by the health facilities the HIS can be used for advocating and influencing decisions and policies for the rights of inclusion of vulnerable populations. From this visibility stakeholders and services can then be mobilized to address the situation by acting effectively on the information being produced.

Making it possible to identify and include marginalized population groups are key aspects of the case of developing and assessing the HIS in Lao PDR. This paper explores the process and results of iterative assessment cycles for the quality improvement of Lao PDR HIS. In describing the process and outcomes of the assessments, we highlight key interventions and the approaches adopted by the Lao PDR Ministry of Health (MoH) to improve the HIS. These interventions included the development of digital registers for immunized children and a family folder project aimed at establishing a register of the entire population. In this way this article highlights the process and actions taken that address the question of: *How can HIS be designed and implemented to enable the representation of marginalized population groups?*

## 2. Exclusion, representation and HIS

Worldwide, nearly 230 million children under 5 years old do not have a birth certificate [4]. More than 24 million Indonesian children remaining undocumented [7]. As noted above this lack of documentation is linked with reduced access to health, social services, and education [4, 8]. For Lao PDR it is estimated that less than 90% of all children have been vaccinated for any childhood vaccine [9]. Various strategies have been developed to attempt to guide services to address this gap and improve coverage, such as Reaching Every Child (REC). This has led to a number of community based interventions such as door-to-door vaccination, delivering vaccines beyond infancy, focusing on marginalized populations [10]. Often the process of identifying the unreached is labor intensive. For example, in Kenya low performing facilities were mapped using DHIS2 and Quantum Geographical Information System (QGIS) and then a 3-day door-to-door defaulter tracing by community health volunteers was conducted with defaulters being immunized by a nurse [11]. Additionally, identifying the zero dose children can be difficult to calculate if the target population denominators are not accurate. Challenges related to denominator data often relate to disputes over official census data and changes in the geography of administrative and health subdivisions in countries. This can lead to alternative denominator data being used across programs and between levels of the health system [12]. The challenges for estimating denominators are also attributable to catchment area calculations and care-seeking behaviors [13]. Even when there is a reliable catchment area population estimate using the census people often seek care from health facilities outside their district of residence resulting in some districts having coverage of over 100% and others have very low coverage [13] - this is commonly referred to as the 'numerator/denominator mismatch'.

ICTs have also been argued as a useful means to include excluded or marginalized populations. Heeks discusses how the ‘bottom billion’ of the world’s population can be socially, politically, economically and psychologically excluded and that ICTs can assist in decreasing this exclusion [14]. However despite the proliferation of different community based information systems the majority of routine national HIS have data from the health facilities as the lowest level of data collected [15, 16]. Consequently, data is not captured on those not accessing formal health services. Even for HIS that partially include community sourced data the quality and coverage can mean that data is still missing [17] and the marginalized are still not represented in the formal HIS [18]. However, there are a number of examples where information systems have been historically used to address vulnerability, often with NGO’s acting as intermediaries [19]. Improved information infrastructure in these marginalised communities, can lead to better health services because of increased transparency and increased opportunity for political and social pressure. Through a parable (Annapurna wanting somebody to dig her garden, but finding it difficult to choose one of three laborers, as each would be chosen if different criteria, such as poverty, unhappiness and illness, was used to inform the making of the decision) Sen explains how decisions made are dependent on the informational base and indicators selected [1, p. 54]. So the process of IS development clearly determines the picture created and views expressed. Equally important to the information that is included is the information that is excluded.

In our analysis we use Zuboff’s [20] notion of representation as derived from her two terms automate and informate, which are used to capture the distinction between technology in general and digital technology specifically. While automating refers to computational power, informing refers to the ability of information technology to represent and textualise work being performed. In Zuboff’s analysis, all technologies, digital ones included, come with the potential to automate. What makes digital technologies distinct are their additional potential to also informate and that they do not consume their ‘input factors’ i.e. data and their outputs (information) may be used as input to open-ended purposes still without consuming the ‘input factor’. The ‘textualisation’ or datafication, is then, typically, an (unintended) bi-product of digital technology. With this, Zuboff recognized a potential for empowerment, user participation and processes of learning. Informate creates the potential for additional uses of digital technology supplementing the intended ones that cater for the immediate automation related efficiency concerns of the users.

### **3. Setting: Lao PDR HIS**

Under the framework of the health sector reform, the Lao PDR MoH approved the introduction of DHIS2 – a web-based, open source software for health information system (HIS) in early 2014 replacing the previous Excel based system [see 21 for more detail]. By the end of 2017, the HIS aggregated data from 9 health programmes and all the public health facilities nationally were collected within DHIS2. Lao PDR also gradually developed modules and sub systems in DHIS2 for a number of additional health program specific digital interventions, such as case based tracking of tuberculosis and HIV, and systems supporting the elimination of malaria. Mother and Child Health (MCH) and Immunization (EPI) are two of the priority programmes in the MoH.

Lao PDR had EPI coverages amongst the lowest in the region<sup>1</sup> with EPI data mainly being used for reporting purposes rather than for action or decision making [22]. EPI continued to use their Excel based reporting in parallel to DHIS2 for several years longer than the other programs (until 2018), despite a Ministerial Decree stating that all data should be integrated in DHIS2. An important reason for the parallel reporting was that the DHIS2 and the Excel systems generated different data and indicators. DHIS2 generated lower values for indicators than the values generated by the long standing Excel based systems for EPI which lead to managers and health workers

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<sup>1</sup> <https://www.gavi.org/programmes-impact/country-hub/west-pacific/lao-pdr>

unsure of which data source to use. Having duplicate data collection systems also increased the burden of data collection and reporting at health facilities.

Additional differences were that DHIS2 is designed to provide health facility service coverage data whereas EPI needs population coverage. The EPI programme also required data, such as vaccines stocks and campaign data, that was not included in DHIS2. There were also data quality problems stemming from the numerous data collection tools health workers needed to consult to generate indicators. For example, to track the vaccination for each child both the child's record at their residence and a chain of records needed to be checked requiring considerable back and forth checking in the facility hierarchy. This process of data collection and calculation of indicators compromised data quality.

#### **4. Methodology**

The overall design adopted in this project was *Improvement Science*. Improvement science focuses specifically on healthcare improvement with the goal to determine which improvement strategies work whilst simultaneously assuring effective and safe patient care. *Improvement Science* embraces many of the principles of other research designs such as implementation science, knowledge translation, and action research, but it is specifically designed to focus on what works best in complex situations, such as a healthcare setting. The overriding goal of improvement science is to ensure that quality improvement efforts are based on evidence (the theoretical gap mentioned above) as well as best practices [23]. Like implementation science and action research improvement science makes a specific contribution in the research setting itself. However, improvement science places a strong emphasis on the process of change and more involvement and buy-in from stakeholders is expected than in other research approaches. The rationale being that with increased involvement and capacity development results in more sustainable processes and outcomes. There have been a wide array of approaches that relate to improvement science, such as 'translational research targets, evidence-based care, accreditation and external accountability for quality and safety, risk management, error prevention, organizational development, leadership and frontline enhancement, and complex adaptive systems frameworks' [24]. Our approach was based on The Model for Improvement developed by Associates in Process Improvement [25].

Over four years, assessments of the routine health information systems resulted in recommended changes. The process of assessments undertaken was iterative - where results of initiated changes based on previous assessments were evaluated and further improvements made. Results from several assessment cycles are presented in this article. Assessments took place with a different focus annually from 2016 to 2019 (see Table 1), but also used a common assessment framework. Each assessment looked at:

- Legal and policy framework: data governance, coordination, legislation and support
- Human Capacity: training, supportive supervision, back up, guidance and aids
- Standardization: metadata standards, SOPs, analytic dashboard, data quality assurance
- Funding: planning, partners/donors harmonization, costing
- Infrastructure: computers, internet, electricity, mobile phones, 3G
- Data use: reports, feedback, review

The main focus of the assessments was on quality improvement where after each assessment the various stakeholders discussed and agreed on a number of actions to address the challenges or bottlenecks identified. The following year the assessment would identify whether the interventions or activities previously identified had addressed the challenges and if further improvements could be made. The process in general was to use the common assessment framework to review the routine reporting as well as having stakeholder's meetings throughout the assessment. For example, having meetings with stakeholders at Ministry of Health, WHO and the EPI program at central level and then also including some provincial, district and facility visits. For example, in 2018. Luang Prabang and Champasak provinces as well as 6 districts and 8 health facilities in these provinces

<b>Year</b>	<b>Focus of assessment</b>
2016	Data Quality and Governance
2017	MCH
2018	EPI and addressing the parallel data collection systems (DHIS2 and Excel),
2019	Reviewing the previous implementation and whether recommended actions had been taken.

**Table 1.** Specific focus of evaluation 2016-2019

were visited. In health facilities, and district and province offices the evaluation team studied all aspects of data registration, collection and reporting as well as routines for data validation and data use. Teams generally comprised representatives from the program under review, WHO, World Bank, MoH and University of Oslo (see Table 2 for details for all years).

In the provinces, the assessment started with a larger meeting where objectives and methods were presented and discussed and a similar meeting was conducted after the assessment to present and discuss findings. Generally, people from the provincial health information unit took part in the assessment at district and facility levels. In the districts, managers and staff from all program areas took part in a joint meeting to review all data collection and reporting routines and challenges before going into the details of the particular focus of the evaluation.

In the health facilities all the facility and village register books and reporting tools were reviewed and there was a discussion and demonstrations on how the registers, tools and data are used. Usually there was a large number of registers (see Figure 1). Observations and discussions took place on how data was validated and compiled from the various log books at field level and facility level and how this was reported and entered into electronic systems.

## **5. Findings & Interventions**

The main challenges identified and the actions taken each year are summarized in Figure 3. The actions listed were agreed upon with the MoH and concerned partners during the feedback sessions following the evaluations to address the priority issues raised. Often one action taken would necessitate another action or intervention, such as facility data collection in DHIS2 required addressing the connectivity challenges facility staff had. A number of changes made as a result of these evaluations had a major impact in identifying the excluded population groups from health services. These changes involved the development of a digital register and a family folder.

### **5.1. Digital register**

The Lao PDR MoH has divided villages into three zones where zone 2 and 3 represents areas that are hard to reach and which are a priority for health programs such as the EPI and MCH. A problem identified with DHIS2 was that reliable area or population based coverage indicators data on immunized children or ANC visits could not be calculated. This was because the data reported was based on the health facility where the child was immunized or ANC attended and not the village where the child or woman came from. In this way only service level coverages could be calculated. The provincial hospitals, for example, carry out a significant number of immunizations and many children immunized are from villages in districts outside the provincial capital.

To address this problem there was a move to case based rather than aggregate data reporting so that individual cases could be linked to areas – or more concretely to a village. This necessitated recording the village the individual was from/living in. This would enable then service provision coverages as well as population based/geographical based coverage for EPI and MCH. The event capture functionality in DHIS2 was used. Event means that there is one data entry for every time the child comes for immunization. Each case could then be registered

with date of birth, sex and vaccines given and linked to the village the child lived in rather than where the place where they received the service.

<b>Year</b>	<b>Meetings</b>	<b>Observational visits</b>
2016	<ul style="list-style-type: none"> <li>• Annual DHIS2 review meeting with health program managers, stakeholders, development partners and HISP Vietnam team.</li> <li>• Millennium Development Goals (MDGs) Lao PDR status dashboard demo and meeting with all the health departments and stakeholders towards publishing health data for public view.</li> <li>• Workshop and meetings on data administration, data collection and verification principle with Central and province health staff, DHIS2 core staff, WHO Lao team members, Development Partners and HISP Vietnam.</li> </ul>	<ul style="list-style-type: none"> <li>• 6 provinces</li> <li>• 12 districts</li> <li>• 15 health facilities</li> </ul>
2017	<ul style="list-style-type: none"> <li>• Annual DHIS2 review meeting with health program managers, stakeholders, development partners.</li> <li>• Meeting with WHO staff, MOH and development partner on Lao PDR status on UHC (Universal Health coverage) and SDGs (Sustainable Development Goals)</li> <li>• Data quality review workshop with central and province level health manager, WHO staff and HISP Vietnam.</li> </ul>	<ul style="list-style-type: none"> <li>• 4 provinces</li> <li>• 8 districts</li> <li>• 12 health facilities</li> </ul>
2018	<ul style="list-style-type: none"> <li>• Annual DHIS2 review meeting with health program managers, stakeholders, development partners.</li> <li>• Introduction meeting with EPI department on parallel system and advantage of online system.</li> <li>• Review meetings of EPI data collection registers and forms with MOH central level staff, WHO Lao team members, EPI managers and GAVI members.</li> <li>• Province and district level data quality meeting with Province and district health managers, WHO Lao team members, Central level MoH Staff</li> </ul>	<ul style="list-style-type: none"> <li>• 3 provinces</li> <li>• 6 districts</li> <li>• 8 health facilities.</li> </ul>
2019	<ul style="list-style-type: none"> <li>• Data uses and analysis meeting and workshop for central and province level health program managers.</li> <li>• Meeting with EPI, GAVI, WHO Lao team members, MOH staff on EPI data collection review and status.</li> <li>• Province and district level data quality meeting with Province and district health managers, WHO Lao team members, Central level MoH Staff</li> </ul>	<ul style="list-style-type: none"> <li>• 2 provinces</li> <li>• 9 districts</li> <li>• 10 health facilities</li> </ul>

**Table 2.** Meetings and visits conducted as part of annual assessments





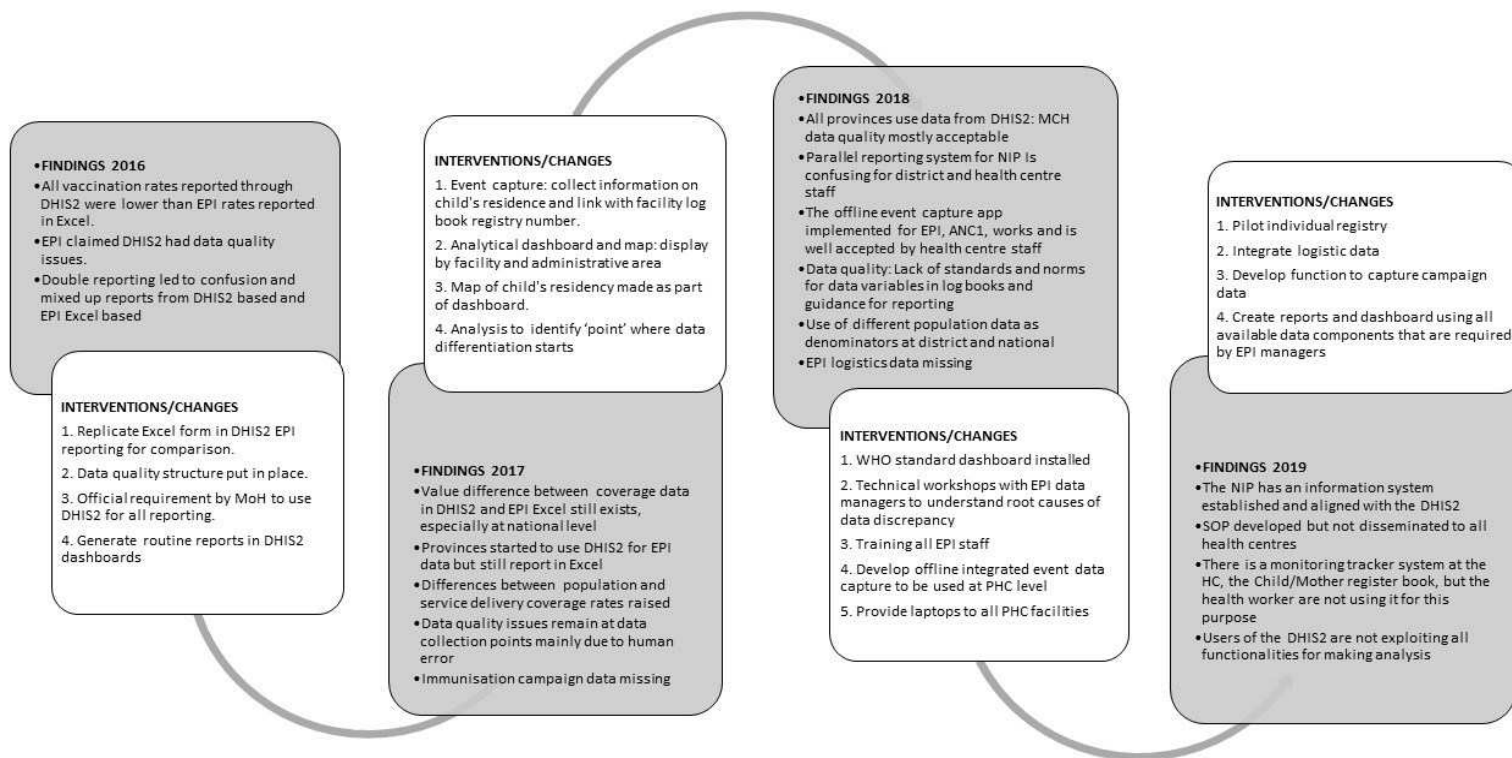
**Figure 1.** Collection of active log books and paper tools in one health center

A similar, but somewhat simpler solution was suggested for the MCH ANC program where only the ANC first visit cases, linked to the village, would be included. This would enable the key ANC related indicators to be calculated and, given that each case would be registered electronically, validated.

In order to achieve this shift in data collection, two challenges needed to be addressed:

1. *A current and up to date village list:* the current 9200 villages in Lao PDR that are included in DHIS2, were the official list and used as enumerator areas for the census, but a standardized list was not in place - different users used different names for the same villages and different programs have different lists. Standardizing the village list was needed.
2. *Connectivity issues and unique patient identifiers:* Internet is not available or is unreliable in most of Lao PDR, but internet would be required for case based reporting. Poor internet connectivity could mean that individuals with similar names could be entered without the system being able to detect the conflict, or the same person could be entered multiple times with slightly different spellings of the name. There is no unique person identifier in Lao PDR. This challenge was addressed by developing and implementing an *offline* case based *event* capture app – a data capture app that could push data to DHIS2 when the Internet was available. Off-line data entry meant that the data could be entered on a laptop and then synced when there was a connection. The offline app is programmed to locally generate unique identification (DHIS2 event UID) for each case, so that when user make any changes in offline mode can be synchronized to online DHIS2 instance and vice versa. If data is purely entered in online, health facility user can synchronize their data locally when they have internet connection. SOPs were created in coordination with MOH staff, EPI department and WHO Team members on duration of data synchronization.

The app was developed by the HISP Vietnam team and implemented in all health facilities in 2 provinces in 2018. The offline app includes the entire list of 9200 villages in Lao PDR with coordinates, so cases can be linked to the correct village. When the Internet is available, the online app can be used. Later evaluations showed that this online feature became the most important part of the app. The app was developed for initially for MCH and offered the potential of identifying for example # deliveries and ANC1 visits per facility/zone. The main purpose was to enable entering of data at the level of collection - previously data was entered at district level which required all the paper records, folders and registers to be transported to the district and



**Figure 2.** Timeline of the DHIS2/HIS integrated system in Lao PDR

often there were too many to carry. So data entry changed from district entry to systematic facility level DHIS2 data entry which is then validated at district level.

The 2018 evaluation explored the use of parallel systems (Excel and DHIS2) in EPI data collection. The reasons for this as noted above were issues with service versus population coverage, and confusion on which system to use as data from the two were not the same. During the evaluation it was discovered that in fact data was being exported from DHIS2 to an excel file and that this was being used for the excel calculations, so in fact there was confidence in DHIS2 as a system. By addressing the coverage problem, and ability to work offline, excel was no longer needed nor used as a parallel system.

### 5.2. Family folder project

Another change in the HIS was the use of tracker in DHIS2 to collect family and household data. The family and household data is obtained through an annual paper-based survey conducted by the community health worker for every village. In Lao PDR village boundaries are coterminous with facility catchment boundaries so using the data from the survey facilities generate a household profile for each household in their catchment area. However, in urban areas there are a number of villages that do not match facility level directly and these villages are entered into the system as separate organizational units at district level.

The data from the survey is compared with the census estimates which are calculated for the facilities by the district staff. As illustrated in Figure 3 most of the households are included in DHIS2.



**Figure 3.** Households registered versus census estimates

Additionally, there is a good match with the census estimates and village level survey data in relation to denominators (see Figure 4). However as can be seen in Figure 4 there are larger discrepancies in urban areas. This is largely due to the mobility of the urban population, but is also impacted by the migrant workforce.

The challenge of a standardized village list has also been addressed. This list is maintained by the Department of Home Affairs and the MoH is responsible for linking the villages to facilities.

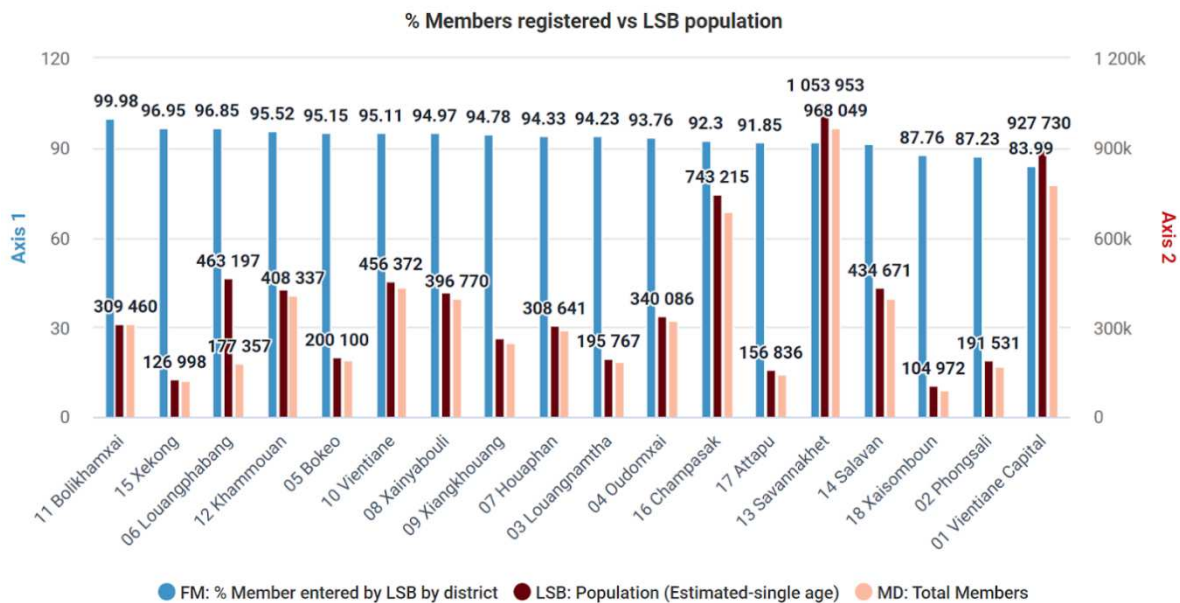


Figure 4. Comparison of population with registered members on the family information system

## 6. Discussion

Data about immunized children and pregnant women in each village is now available and these clients are now digitally represented and included in the registers online or offline. But what about the children that have not been immunized? As a director of the GAVI vaccine alliance said when being presented the case based register: “I am not interested in the children in the register”, as they have got their vaccines. “I am only interested in those children not in the registers - the zero dose children”. ‘Zero dose’ is defined as children missing one or more doses of vaccination.

Indirectly, by combining the data with the population linked to the villages, the representation of the immunized children could reveal information about those not having been immunized; by combining the number of immunized children with estimated number of children in the villages, areas of low immunization coverage may be identified, and consequently also “zero dose children”. The family folder project aiming at digitally representing the entire population is providing a more accurate population number including infants in the villages. As village boundaries are coterminous with catchment areas for facilities all children should then be included in the family survey. Combining the immunization register with the population register will then better enable the identification of the children that not being vaccinated. By combining number of doses given the first month of life with the number of doses being given at the 11th month of life, a drop-out rate of infants missing doses of vaccination, by village, can be calculated, as yet another informing aspect relating to the non-represented. Additionally, with the development of the ‘family folder project’, all families in all villages and towns in Laos are being registered in a DHIS2 application. The entire population will in this way be digitally represented and enrolled in the census. This development will help develop more accurate population figures for the villages. Linking the family folders to the immunization register will facilitate all newborns being enrolled for immunization and thereby further reducing the zero-dose problem.

However, for digital representation and inclusion for societal transformation to become a reality, there are cultural, social and health service barriers to be overcome. In visiting a health center in rural Laos as part of an evaluation of the information systems, the registers and reports were investigated. The data for ANC clients having had their first visit compared with the estimated number of pregnant women revealed that a significant number of pregnant women had not attended the services. Asking the health workers to what extent they had analyzed the data and notified the low service coverage, and if so, how they had acted upon the data to reach out, identify and enroll the women missing their ANC services. The response was that the women in the areas in question belonged to an ethnic minority group, which had a general low attendance and participation in the health services. Culture, ethnic differences and political issues alongside education and knowledge about health are among the factors creating barriers between marginalized groups and the health services. In this case also, the informing aspects of the representation of those women attending the ANC services, led the attention to those not attending the services. However, contrary to the immunization example, addressing the non-served is not as simple as just identifying them and then providing the services. Needed action would involve overcoming cultural barriers by active health promotion and education among the groups with low participation as well as engaging community leaders and the political levels. The transformative aspects of digital inclusion for social justice are therefore not only about digital representation, but need to be understood through the wider aspects of automating and informing dynamics addressing the societal level.

In relation to addressing the ‘zero-dose’ by combining the number of immunized children with estimated number of children in the villages, areas of low immunization coverage may be identified, and consequently also “zero dose children”. This digital representation was achieved through the combination of automating and informing, which reflected Zuboff’s third dilemma of technique, providing new combinations of information and new potentials for use. Providing proactive health services and a receptive population, we have illustrated here that digital representation may lead to the inclusion in terms of provision of health services both for those digitally represented and not represented.

In Zuboff’s conceptualizing of informing she highlights three sets of dilemmas: 1) of knowledge stemming from the representation of work performed which risks deskilling workers and meaning being lost or changed; 2) of authority; knowledge affords power and changes in knowledge may change the basis of power; 3) of technique; informing aspects are not fully controllable by management or health services who may initially focus only on those represented, open for unintended consequences of inclusion of those indirectly represented. The transformative aspects of digital inclusion for social justice is therefore not only about digital representation, but needs to be understood through the wider aspects of automating and informing dynamics addressing the societal level. The examples illustrate that digital representation may lead to inclusion of the marginalized at increasing levels of informing and social action; 1) digital representation leads to direct enrollments for health services when included in the immunization or ANC registers, 2) indirect inclusion through informing; data on those digitally represented shed light on those not represented and enable their representation, and 3) informing reveals social in-justice and may lead to collective action at the societal level for inclusion and social justice for the marginalized. Whether the knowledge, power and technique leads to collective action goes beyond digital representation, but without representation it is not possible. In our case, the representation of vaccinated children indirectly helps identify non-vaccinated children, which is further facilitated through the family folder project. Digital representation, in this way, may be seen as digital inclusion of marginalized populations.

The implications for practice are:

- Different denominators are needed for service and population coverage indicators
- Different population denominators can result in different indicators
- Comparisons of data using different denominators enables conversations for better understanding of what the indicators are measuring.

- Confidence in the data is needed for the data to be used.
- Using different sources of data facilitate representation of all families in HIS.

## 7. Conclusion

The development and implementation of a digital register that could be use offline and online in combination with the family information system has addressed many of the challenges exposed during the annual evaluation of Lao PDR’s HIS. Addressing service and population coverage indicators and enabling comparisons of data using census based denominators versus family survey denominator has meant the DHIS2 is now the only system used for EPI and ANC. This saves time for the facility staff but also builds confidence in the HIS. However more broadly it enables representation of all families in DHIS2.

Zuboff’s analytical approach may be of equal, if not greater, relevance today as “it may have an even stronger story to tell now than it did when first published” [20, p.7] as a result of the expanding scope and reach of digitalization. As illustrated in our examples, digital representation is of direct relevance to marginalized populations and communities, and may be important factors in their societal inclusion and development. The capacity to informate is an open-ended ability for repurposing, aggregation, and further manipulation stemming from the fact that digital representations are not consumed but “renders events, objects, and processes...visible, knowable, and shareable in a new way” [2, p9]. However, a two pronged strategy is needed - first is through the creation of awareness and visibility of the situation - representation in the system - and the second through mobilizing the stakeholders and services to address this situation by acting effectively on the information being produced. Overall these strategies can be supported by designing an IS for action - an IS that can be used for advocating and influencing decisions and policies for the rights of inclusion of vulnerable populations.

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