

# Accepted Manuscript

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PII: S0277-9536(18)30282-X

DOI: [10.1016/j.socscimed.2018.05.039](https://doi.org/10.1016/j.socscimed.2018.05.039)

Reference: SSM 11775

To appear in: *Social Science & Medicine*

Received Date: 30 December 2017

Revised Date: 20 May 2018

Accepted Date: 22 May 2018

Please cite this article as: Hutchinson, E., Nayiga, S., Nabirye, C., Taaka, L., Staedke, S.G., Data value and care value in the practice of health systems: A case study in Uganda, *Social Science & Medicine* (2018), doi: 10.1016/j.socscimed.2018.05.039.

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SSM-D-18-00006R1

**Data value and care value in the practice of health systems:  
a case study in Uganda.**

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**Abstract**

*In anthropology, interest in how values are created, maintained and changed has been reinvigorated. In this case study, we draw on this literature to interrogate concerns about the relationship between data collection and the delivery of patient care within global health. We followed a pilot study conducted in Kayunga, Uganda that aimed to improve the collection of health systems data in five public health centres. We undertook ethnographic research from July 2015 to September 2016 in health centres, at project workshops, meetings and training sessions. This included three months of observations by three fieldworkers; in-depth interviews with health workers (n=15) and stakeholders (n=5); and six focus group discussions with health workers. We observed that measurement, calculation and narrative practices could be assigned care-value or data-value and that the attempt to improve data collection within health facilities transferred 'data-value' into health centres with little consideration among project staff for its impact on care. We document acts of acquiescence and resistance to data-value by health workers. We also describe the rare moments when senior health workers reconciled these two forms of value, and care-value and data-value were enacted simultaneously. In contrast to many anthropological accounts, our analysis suggests that data-value and care-value are not necessarily conflicting. Actors seeking to make changes in health systems must, however, take into account local forms of value and devise health systems interventions that reinforce and enrich existing ethically driven practice.*

**Keywords**

*Uganda, Value; ethics; data collection; care giving; health systems*

## Introduction

Anthropologists, like others working in global public health have become increasingly interested in numbers; tracing the political-economy through which particular indicators have emerged in the last twenty years (Adams, 2016; Biehl, 2016; Storeng & Béhague, 2014) and their social lives that have unfolded as they assembled in different settings (Crane, 2013; Rottenburg et al., 2015). Many argue that the collection of increasing amounts of data brings great technical promise to global endeavours by bypassing ideology, enabling objective evaluation and allowing money to be traced and better spent. Anthropological interpretations have been characteristically questioning and critical. Anthropologists have been involved in analysing discourses around the promise of numbers. They have attended to the ways in which practices of epidemiology and the requirements of philanthro-capitalists intertwine (Reubi, 2015), showing how increasing collection and use of data forms a fundamental characteristic of the endeavour of global public health (Adams, 2016; Biehl, 2016). They have asked how the collection of data is implicated in the technocratic narrowing of the goals of global public health (Storeng & Béhague, 2014) and how political decisions are in fact hidden through the insistence on the political neutrality of numbers (Adams, 2016). Anthropologists have challenged the shaky foundations upon which some politically powerful indicators are based (Gerrets, 2015), and the ways in which the collection and use of data ultimately changes and challenges the world in which people provide and seek health services (Crane, 2013).

Where anthropologists have asked a range of questions about the ways in which the reliance upon indicators shapes global health, at the heart of much of the work on low-income settings is a concern with the relationship between data collection and care-

giving. Gerrets (2015) for example, asks how care practices shape data and what the relationship is between the ontology of disease objects as they are imagined biomedically and the objects that sit at the heart of the global health data. Others have analysed what happens to caregiving when a deep concern with data collection is pushed out of the core of global public health and incorporated into everyday practice in its peripheries. Case studies show how when political ambition mingles with the need to show the positive impact of a programme, the collection of the right sort of data can take precedence over the care of patients with profound and worrying effect (Oni-Orisan, 2016). These findings appear part of a broader change in the hierarchy of activity in many low income settings, in which the collection of data has taken primacy over the provision of health services (Adams, 2016; Biehl, 2016).

These accounts provide a thick description of data collection practices but have mostly focused on social relations within vertical programmes and during experiments. The analysis of routinely collected health system data has been of less interest. While the two are not discretely divided in practice, they are rooted in different political economies, with different desires and interests embedded within them. Data gathered for vertical programmes follow direct links to colonial interests in disease burden and provides information for central government, donor agencies and multilateral organisations. In post-colonial states, health information systems (HIS) began with the 1978 Alma Ata declaration and its commitment to ensuring that primary care was shaped and delivered according to local need (World Health Organization, 1978). The establishment of HIS and their successor health management information systems (HMIS) brought with it an imperative that data should be of value to those working

within the different social fields (from the Ministry of Health to peripheral health facilities) that make up the health system (Sandiford et al., 1992).

This paper is concerned with the ways in which value is created around HMIS in the different arenas that make up the Ugandan Health System. The analytical frame begins with an understanding that the health system is made up of sites that contain distinct constellations of social relations within which different forms of what is good, useful or ethical are enacted. Our interest lies with the ways in which numbers (numerical values) and the practices through which they are created get caught up with those socially constituted, expressions of what is right or important (ethical or moral values) (Graeber, 2013; Marsland & Prince, 2012; Miller, 2008; Otto & Willerslev, 2013) and how, as these values intertwine, they become implicated in the construction of hierarchies and social orders (Iteanu, 2013).

Interrogations of the interconnections between these different forms of value are found across anthropological sub-disciplines (Graeber, 2013; Haynes & Hickel, 2016; Marsland & Prince, 2012; Otto & Willerslev, 2013) but have been less in evidence in medical anthropology. Fassin's analysis of the lives of 'others' is a notable exception showing how global health constructs those living at the peripheries of the socio-economic system as being worth less in both economic and moral terms. There is, however, a rich body of work on bioethics in medical anthropology that examines the intertwining of research data (numerical values) with locally constituted moral and ethical positions (values) (Geissler et al., 2008; Molyneux & Geissler, 2008). This work challenges the abstract principles of bioethics that obscure the idiosyncrasies of everyday life within biomedical research projects in low income settings (Geissler et al., 2008; Hoeyer &

Hogle, 2014; Kingori, 2013; Kingori & Orfali, 2013). It shows how highly unequal socio-economic relations shape everyday ethics creating novel forms of exchange value (Fairhead et al., 2006; Geissler et al., 2008). Of particular interest for this study is the way that decisions made about whether to ask research questions or fabricate answers are connected to local moralities about the vulnerabilities of research participants (Kingori & Gerrets, 2016).

Drawing on anthropological work on value and ethical practice, this paper explores the relationship between HMIS data collection and care giving within the Ugandan health system. We make the analysis by examining the ways in which global health actors, health workers and volunteers constructed the value of measurement, calculation and narrative practices. The paper follows a pilot project established with the intention of improving health systems data collection in peripheral health centres that began as a new Out Patient Department (OPD) register was introduced by the Ministry of Health. We explore the project as an extended case study during which concerns about the role, position and meaning of care and data were (re)formulated, moving between project meetings, training sessions and everyday activities and attend to moments when different assemblages of value(s) (the 'data-value' or 'care-value') were used as the basis upon which these practices were evaluated. At each juncture we ask whose authoritative judgement on the form and meaning of measurement, calculation and narrative practice prevailed, and with what consequences.

## **Background and methods**

In Uganda, plans for the first national health information system (HIS) were drawn up in the mid-1980s (Gladwin et al., 2003). It was not, however, until 1997, following

considerable public sector reform that the collection of health data was transformed away from a model concerned with constructing rates of disease to one that was created to support districts and health centres as they took responsibility for their services (Kintu et al., 2005). Since then, the Ugandan HIS has been through multiple iterations. Responding to concerns about the management of health systems, it was reformulated as a health management and information system (HMIS) through which facilities report to the district and districts report to central government. Within the health facilities, despite a marked increase in data collection, the means of collecting HMIS data has changed little since the 1980s. It continues to be collected by hand in registers (up to 13 per facility) and in specially formulated government tools so that it can be aggregated into weekly, monthly, quarterly and yearly reports. Following the decentralised structure of the health system, these reports are given to the health district and are fed into the national data management system. According to the HMIS manual, the data provided within these registers is expected to be of equal use for all levels of the health system.

[The HMIS] has been designed for use at the health unit, health sub-district, district and national levels for planning, managing and evaluating the health care delivery system. These critically important tasks are necessary in order to continually improve the quality of health care in Uganda. The HMIS is the Ministry of Health's official routine reporting system replacing all pre-existing routine reporting instructions for health units and districts. Health Facilities are the major contributors to this routine information.

(Ministry of Health, 2010, iii)

At national level, HMIS is described as fitting into the reporting structures around the national planning for health. At the health facilities, it is expected to help the health worker who is in-charge of the facility (the 'in-charge') make evidence-based decisions around management, problem-solving, and the quality of care. The manual details

practices that overlap: accurate history taking and proper examination, use of instruments, recording of the patient history, the organization of the clinic (including waiting times) and the continuity of treatment (Ministry of Health, 2010).

The 2010 HMIS manual is silent, however, about how its data is shaped by global health research and service delivery. This is despite the fact that Uganda has been the site of significant interest by overseas organisations concerned with improving health (Tappan, 2017) and, since the 1990s, has witnessed considerable economic and intellectual investment by global health actors (Crane, 2013; Meinert & Whyte, 2014; Taylor & Harper, 2014) that has transformed poorly resourced health centres into sophisticated research sites (Crane, 2013). As patients move between projects, programmes and research centres located within and parallel to the public system (Meinert & Whyte, 2014), the collection of their data has become a critical site of activity, shaping and challenging the way in which care is provided (Crane, 2013). In 2015, the Ugandan Ministry of Health responded to increasing data demands by making a policy commitment that only government registers and forms could be used to gather data in public sector OPDs. At the same time, the Ministry published a new version of the OPD register. Into this document, the data requirements of global health actors had been inscribed; as a result the data points had more than doubled, increasing from 14 to 31 (see Figure 1 and Figure 2).

Insert figure 1 here

Insert figure 2 here

A comparison between Figure 1 and Figure 2 reflects new interest in non-communicable diseases (hypertension, diabetes, and risk factors), and more detailed data collection points for nutrition, malaria and tuberculosis (TB). The new register demands the following additional measurements and readings: middle upper arm circumference (MUAC) and height blood pressure and blood sugar. There are also additional calculations: body mass index (BMI), weight for age z-scores and height for length z-scores and additional information from the patient on tobacco and alcohol use. Details of the processes through which a diagnosis for malaria and tuberculosis are made are also required. For the first time, it has a separate column for patients with a disability and distinguishes those in need of palliative care. In all, two new measurements, two new tests, 3 new forms of calculations 3 additional columns of details about tests done have to be recorded. These requires a measuring tape, a MUAC tape, a blood pressure monitor and blood sugar testing kit. It also demands that health workers are comfortable asking sensitive questions about alcohol and tobacco use, are able to identify disabilities and determine the need for palliative care.

### **The project and methods**

In Kayunga district, the distribution of the new OPD register in 2015 was quickly followed by a pilot intervention to improve the completeness and accuracy of routinely collected data in 5 health centres. The intervention was sponsored by the US government and, characteristic of much of the health research in Uganda, was evaluated by a US and Ugandan University research collaboration (Brown, 2015; Crane, 2013;

Meinert & Whyte, 2014). The intervention itself was conducted by a US based private company developed initially by civil rights activists which since the 1980s provided technical assistance to the United Nations and governments (both donors and donor recipients) for health.

This project was one of a number that the company was working on in Uganda and in other countries in the region. The project responded to evaluations of HMIS in Uganda that suggest that data collected by health centre staff was often inaccurate, incomplete and rarely delivered on time (Mpimbaza et al., 2015). It created a new layering of data practices; health workers were expected to analyse their health facility data, reflect on whether it was falling below standard in terms of completeness, accuracy and timeliness and to consider reasons why this might be the case. Health workers were invited to a training session held in their facilities on how to complete the OPD register (1); workshops held in Kampala (3) and in the local town (1) to teach the health workers about the project's aims and methods; and mentoring sessions (up to 8) held at the health facilities to facilitate reflection and change. The health workers received (per diem) payments ranging from \$1.10 USD per mentoring session to \$40 USDs for training meetings in Kampala. Observing these practices and assessing whether they were effective or not in precipitating change, a team of quantitative researchers gathered data from the OPD, laboratory and pharmacy registers - using different methods of assessment. The intervention was implemented in peripheral health facilities, including level II and III health centres (HC II and HC III), and in one health facility that provided more complex services (HC IV).

Ethnographic research was carried out over a 14-month period across different fieldwork sites by three Ugandan field workers and a British anthropologist. Participant observation began at an informal dinner for the key project partners and subsequent project workshop at a hotel in Kampala (see below). Four months later, as the intervention in health centres began, the Ugandan fieldworkers fluent in Luganda began to conduct fieldwork in the outpatient departments of five health centres located in one district. One fieldworker was attached to the largest health centre (HC IV) and the other two were attached to one health centre III and one health centre II. The first weeks of observations were unstructured but following these, the fieldworkers had a joint supervisory meeting at the end of each week to decide on the focus for the subsequent week. These included following patients journeys through the health facility (Mogensen, 2005), shadowing particular health workers to observe their practice over the course of a day or a week, staying with the OPD register for the day, moving around if it moved and observing who was involved in filling it in over the course of a day. They were encouraged to describe overall context, social relations, the use of different technologies and instruments in practice and to be attentive to moments of crisis or conflict. Alongside observations of everyday practice, the researchers observed meetings between project staff and health workers when data collection practices were discussed and a training at which they were taught how to complete the new OPD register. As part of the decision to "follow the thing", (Marcus, 1995) field workers travelled to workshops and training meetings in the local district and Kampala. Fifteen semi-structured interviews with health workers involved in the intervention and five interviews with district and national level health officials in the Ugandan health system were conducted. Three focus group discussions (FGDs) with 36 health workers from participating health centres were held at the beginning of the project and a further 3 at

the end of the project. Influenced by Mosse's thesis that the social construction of success is critical in managing effective projects in international development, the FGDs were used to explore the changes in discourse around data collection that occurred during the course of the project (Mosse, 2004). All of the FGDs were conducted in English except for two that were conducted in Luganda. The FGDs were transcribed and translated directly into English using a meaning-based translation (Larson, 1998). The paper draws primarily on the ethnographic observations in health centres, at the training meetings and from the original stakeholders' workshop when senior members of donor agencies and the Ugandan government met to discuss the scope and aims of the project and interviews with staff.

The study was approved by the Ugandan National Council for Science and Technology (UNCST Ref HS 1882), the Makerere University School of Biomedical Sciences Research & Ethics Committee (SBS-REC Ref 276), the London School of Hygiene and Tropical Medicine (number 9717) and the Centers for Disease Control and Prevention Institutional Review Board (CDC Ref 6741). Written informed consent was obtained from all study participants.

### **Two regimes of value**

*Constructing the value of data and positioning the value of care among national and global health actors*

In Uganda, as is common practice in development and global health, the project began with a stakeholders' workshop that brought together multiple actors to set out responsibilities and interpretive frameworks (Park, 2014). Despite the fact that this was a relatively small scale pilot project, present at the workshop were senior staff from the

Ministry of Health and Malaria Control Programme; the US based director of “the company” and local staff; the donor agency funding the intervention and its evaluation; and representatives from an American and UK based University conducting the quantitative and qualitative evaluation.

It opened with introductions followed by presentations from the most senior representatives of the Ministry of Health, the donor agency and the company. These echoed the literature on routine data collection in peripheral health facilities across East and Southern Africa. The depiction of health workers failing to collect accurate and complete data was uncontested, as was the interpretation that this had a negative impact for those working in health in general and in malaria targeted programmes in particular. Recent improvements in the movement of data between district and national level and the use of computers had made the scale of the problem apparent. It rendered visible "its flaws, inconsistencies, inaccuracies" and lack of completeness.

A senior representative from the Ministry of Health underscored the problem that this poor quality data presented to the government. He described a recent resurgence of malaria in the north of Uganda that occurred following the end of a programme of indoor residual spraying. The case illustrated the problem at hand. It linked poor data to the spike in numbers of malaria cases that had only been brought to the attention of the government around 5 weeks after it began. It also highlighted the credibility of the company, they had been instrumental in alerting the government to the outbreak and had worked with them to scale up treatment.

But, incomplete and incorrect data was not the only issue considered by this group to render routine data problematic. Focusing on the OPD register, they argued that prior to the introduction of the new register the tool had had little value for those working in malaria surveillance programmes. The old OPD had focused on the diagnosis assigned to each patient, and only allowed the number of cases classified as malaria to be reported (the numerator) with no space for the health worker to record the number of cases that had presented with fever or history of fever that were suspected to be malaria (the denominator). In this setting, in which the value of data lay in its ability to depict changes over distance and periods of time to track trends in malaria cases, evaluate the impact of interventions and policy change, the limitations of the old OPD register had been profound. Moreover, the old OPD register did not allow for accurate information on the use of diagnostic testing, by then a key component of global and national policy on malaria. With no detail on whether the diagnosis of malaria had been confirmed by a laboratory test, the success or scale-up of rapid diagnostic tests for malaria was uncertain. For one US based researcher, the lack of denominator meant that the old register was without practical purpose. In contrast, the excitement around the new register lay with its ability to allow researchers and policy makers to track trends in malaria cases over time, to detect malaria epidemics and enable the Ministry of Health to take credit for their successes and to determine if particular interventions (for example, the introduction of bed nets) were working. Its value to these actors would, however, only be realised if it were to be filled in accurately and if these data were then effectively filtered through the HMIS system.

In addition to the concern about how these new variables would and could be used at national and global level, a second major theme emerged about how the relationship

between data collection and care-giving should be configured, how one activity was likely to impact or shape the other. The company staff were concerned that improvements in care-giving feature in order to pique the interest and sustain the enthusiasm of the health workers for the project. Care work was considered to have such affective power that it would drive forward health worker desire to change their health facilities. For the staff at the donor agency, two competing views of the relationship between data and care emerged, neither of which posited care as having utility for the project and both of which implied the project design did not have to be overly concerned with its provision. First, was the idea that care could be divided from data collection work in the facilities and improvements in care could be managed by another intervention. Second, was the position that care and data collection involved essentially the same activities. Here, focusing on malaria and configuring care as case management, the necessity of recording whether a patient came with febrile illness, whether they were tested, what the outcome of that testing was and whether they received medication meant that the new OPD register would encourage good quality care and simultaneously render care practices more visible.

*Descriptions and demonstrations of the care-value of measurement, calculation and narrative practice in the facilities*

As the project moved its main activity into the health facilities, all clinical staff, nurses, records assistants and volunteers were offered a series of half-day trainings (at the health centres) on how to complete the registers. At the health centre IV, the staff training began in the early afternoon in November in a large room at the HIV clinic, next to the OPD. Here, two trainers worked with ten members of staff (2 clinicians, 1 clinical officer, 2 records assistants, 1 lab assistant and 2 health workers).

Following introductions, the trainers handed out copies of the new OPD registers, keeping a recently completed register in front of them. Looking at this register, they noted the gaps in data on village and parish and then asked the group how they recorded the age of patients. It was straightforward to get, one junior health worker said, except for elderly people and the children who come alone, who often do not know their age. Raising concerns about the impact of the missing data on patients, one junior health worker asked whether it could lead to overdosing. The records assistant responded. He was unconcerned about the gap in data in the OPD, when he compiled his monthly reports missing age was not a problem he could fill it in basing it on the treatment prescribed.

The discussion moved on. The staff agreed that the MUAC field was rarely completed. While this was attributed to the lack of MUAC tapes by more junior health workers, one of the clinicians argued that the problem was not lack of equipment but the focus of the decision-making about when to make the measurement, what value to put on it. For him, the importance of measurement did not rest with its value for data collection in the OPD but instead rested with his clinical evaluation of the patient. He agreed that routine MUAC measurements were important for nutrition programmes, but at the OPD a MUAC measurement should only be taken if he suspected a child was malnourished. There was no resolution for this tension between care and data value and the conversation moved on to weight and height.

The acting in charge stated that patients' weight was mostly taken at triage, but that the scales in the health centre were unreliable. Height on the other hand was rarely taken

and, according to one clinician, BMI was never calculated. The acting in charge responded that BMI was difficult to calculate but his main concern was with the value of these measurements for the care of patients, their care-value. He knew how to manage underweight cases but what should he do with those who were overweight? Again, there was no resolution and the records assistant wrapped up the conversation by turning it back to concerns about data. He agreed that the field for weight and height was often left blank but that it must be taken for every patient. Unlike the data point for age, there was no proxy.

Prompted by the trainer, the discussion moved on to blood pressure and blood sugar measurements. The laboratory assistant stated that the clinicians were responsible for taking these but that machines and testing kits were rarely available. Echoing the discussion of the MUAC tape, the clinicians declared that blood pressure and blood sugar must only be taken for patients with indications. They did not describe what these were.

The trainer then moved the conversation on to the data point for the next of kin and palliative care, expressing concern about the inconsistency in the recording of data. She prompted participants to describe how they gathered data for tobacco and alcohol use. The records assistant described how patients fail to tell the truth if they are asked directly whether they drink or smoke so she assesses them through smell. A clinician and the in-charge agreed but then followed up by asking why they were collecting this information and how they should record use of alcohol and tobacco substitutes which were equally important. Again this concern with the intersection between the measurements for the register and measurements or questions related to care found no resolution. The participants turned to consider malaria.

The malaria data points raised little discussion. In contrast, the in-charge declared that he never completed the data points for TB. Instead, he put it into the TB register. Then, rather than the OPD register being understood as a document that demanded excessive tests, calculations, measurements and the duplication of data, the interpretation switched and it became a document that limited health workers' ability to describe important elements of diagnostic decision making and the prescription of medication. The in-charge and clinicians complained about the lack of provision for remarks about why a patient was tested for TB and lack of space to record several diagnoses and full details of the medication prescribed.

This led the in charge to criticised health workers whose interest lay in accounting for medicines. He was countered by the lab assistant who proposed that all the information on drugs be captured in the register for exactly this reason. The records assistant, broadening the debate, argued that all information gathered in the OPD must be to support the management of patients. The trainer prompted them to find a resolution between patient management and data collection, but again none was found. The training drew to an end with a brief discussion about how to record disability.

The conversations that unfolded in the training demonstrate the difficulties of standardising questions for data collection and how the complexities of life, the problems of asking sensitive questions shape the data that is recorded. In this health centre, it seems likely that the category for age reflected either age provided by the patient or the amount or the type of medicines prescribed. Tobacco and alcohol consumption recorded, likely reflected whether individuals came to the OPD with a

particular smell on their body or clothes or with a cough. There were overlaps in the data collected (TB registers as well as TB fields in the OPD register) but the OPD register failed in some instances to allow for the detail that clinicians and more senior members of staff thought it necessary to record.

In comparing these meetings, we encounter actors who evaluations of the appropriate position and content of the register were dominated by considerations of its use-value (the multiple pragmatic material uses of an object (here practices) that enable people to know or act on in society) (Marx, 1990). But, as they considered the use of the register they connected it to different ideas of what is right or important which connect into different temporalities and scales. Within the first project workshop what was at stake were large-scale, future assessments. Action connected the Ugandan Ministry of Health to foreign Universities and donor agencies concerned with identifying outbreaks and analysing the success of large interventions. At the OPD, the use-value of these practices were linked to the practicalities of immediate action, to part of a process that also involved responding to clinical judgement as the health workers sat with their patients and seeking to make improvements in the patient's health (Mol, 2008).

While use value dominated, there were other forms of value in process. As the meeting consolidated hierarchies (Park, 2014) and structured responsibilities (Brown & Green, 2017), the power of data-value was identified as its ability create legitimacy, enabling individuals and organisations to lay claim to their success. At the health facility, discussions of the care-value of practice also contained symbolic value, working to situate actors within the hierarchies of the health system. Connecting personhood and clinical knowledge, the ability to describe the relations between measurements,

calculation and history taking distinguished senior health workers from more junior staff members (Hutchinson et al., 2015).

### **Incorporating data value at the health facilities**

According to the representative of the company, the failure to give the project care value, to link to practices of diagnosing, managing and treating patients would likely mean that the health workers would not engage with the project. As the project began, health workers contested the central premise of the project that poor quality data was a result of poor health worker practice arguing instead that it came from an unmanageable increase in data collection tools across the health facilities and an ongoing human resources shortage. As it developed, the desired shift in attitude towards data, described by the district level officials as "ownership" of data by the health workers in the facilities, did not come into being. The tools used to improve data collection were consistently identified by health workers as belonging to members of the company staff and the new data collection practices being enacted for research purposes or for the sake of the company representatives.

Yet, as is common in global health, as the project progressed the work associated with it took on a transactional nature (Geissler et al., 2008), with involvement in trainings and meetings, and knowledge and adherence to its goals understood as being exchanged for payments at the trainings (4) and at the meetings in the health facilities (up to 8 per facility). While health workers described how they appreciated the training that they had been given, during fieldwork there were regular interjections by health workers about the need for projects to provide financial incentives for staff. This was also described in the FGDs at the end of the project.

“Firstly...I would like to thank you for the way you have treating us, [other] projects have failed due to the supervisors. Secondly, the money that they give when [they] are going to health centres, let that thing remain.”

(Low-level health workers, FGD).

While it was good socio-economic relations not payments alone that were critical, through these transactions data collection was connected to economic exchange, it was given exchange-value. This in turn worked to transfer data-value into the health centres and junior and senior health workers who were involved in the project and caught up with its goals had to manage the imperative of collecting data and the new hierarchy of practice that it implied.

*Positioning the new OPD register and data value in the health centre IIIs and IV*

In this new setting, the first noticeable change was the movement of the new OPD register within the health facility. Prior to the intervention, the OPD register moved around during the course of the day. It could be with health workers who triaged patients or with the health worker who was taking patient histories and making diagnoses. Following the arrival of the project, in the HC II, it sat with health workers in the single room where all services were provided. In the HC IIIs and HC IV, a table was set up in a patient waiting area (in the HC IIIs) or in a separate room and the register was filled in from there. Around the register, patients, patient books (personal records that patients carry with them and into which a preliminary diagnosis would be written) and health workers circulated. Patients made between 2 and 3 extra stops returning to the OPD register as they moved between the space in which they were registered, the consulting room, the laboratory and the dispensing room.

In the HC IV and HC III, the data value of measurements that were carried out by more junior members of staff on arrival took precedence. Alongside name, residence, age, next of kin, height, weight and MUAC measurements; BMI calculations and z-scores were done for the majority of patients. Others that were carried out by senior staff and clinicians did not become routine. Few blood pressure measurements were observed by researchers and no blood sugar tests were witnessed. It was not always clear, however, whether this was due to lack of equipment, lack of desire or that senior health workers and clinicians felt overwhelmed by the information and calculations that were now required to collect. One upon seeing a woman with four children argued, for example

“Imagine, I am expected to measure the MUAC, BP, weight, height and BMI for all these patients, the saliva that I will use up to do this is enough to fill up your project vehicle. This is what I was trying to explain at the first [project training]”. (Senior health worker, HC IV)

In the HC IV, the increase in work could sometimes be absorbed by health volunteers completing records; and by patients who helped by taking height and weight measurements. But one morning in November, when the records assistant was busy compiling the monthly data report one health worker was left with the register, extending waiting times. With the initial interaction between health worker and patient dominated by data-value, the caring processes that were meant to be enacted on arrival (triage) had broken down. Patients who had arrived at the facility since 6am had still not been seen by mid-morning and an adolescent girl collapsed in the waiting room and was carried in to see the clinical officer.

Despite these long waiting times, many of those attending as patients or caring for those who were sick, waited at the health centres without complaint. Halfway through the fieldwork, however, rumours began to circulate about a woman who had died while waiting to be seen in the district hospital (independent of the project). That week, at a HC III a quarrel erupted between a carer and the records assistant who was completing the OPD. The waiting room was full, patients sat on the floor. A man with two children who had arrived as the health facility opened demanded to know why they were not being attended to. The women sitting next to him asked him to stay quiet but he replied that he had 'a right' to express himself as there had been a delay in treatment. He turned to the records assistant at the OPD register. "Do you want my children to die?" he asked. As the records assistant replied the value of completing the register for its own ends was paramount and there was no commitment to providing care nor description of how it could be of use in the health centre, its use-value seemed to have disappeared. "We have to complete the recording of details in the OPD register but if you want, you can be given your book and you can go away!" he replied.

These difficulties of providing care in the health centres that were part of the project were exacerbated when the commitment to data-value coincided with mistakes in data collection. In December, a nursing assistant in a health centre III concerned about "data completeness" removed the register from the OPD to look for incomplete patient records. Finding ten, he spent an hour with 2 other registers to find the missing data, refusing to return the register before he was finished.

He returned to the OPD waiting area packed with patients. The clinician had arrived in the meantime. He ignored the primacy of data collection in the health centre and started

seeing patients, sending those who needed tests to the laboratory. According to the new data focused rules of the health facility, however, those without their patient numbers could not receive their laboratory results, and so they were all sent them back to the waiting room to be clerked. Once the register had been returned, the patients surged towards the table and a junior health worker began allocating patient numbers. But she made a mistake, giving numbers associated with the previous month that if used would confuse data reporting processes. Realising this, she called over the nursing assistant who left to get the records officer and then she left the OPD.

The records officer arrived and was left to manage the situation alone. She began completing the register and patient flow improved. But here, processes of triage (with care-value) and clerking (with data-value) began to overlap. Although she was a records officer, she called over two children shivering violently. Bypassing their consultation with the clinician, she took their medical history and sent them directly to the lab for a malaria test.

Despite these difficulties with patient flow and the provision of care for those visiting the health centre, the project maintained its commitment to data collection making ongoing adaptations to patient flow to ensure that data collection was completed. In the health centres III and IV, most patients were sent to the laboratory for a blood test. Once the patients returned to the consulting room with the results they received a diagnosis and prescription. They would then take their books to the dispensing room so that the final data points could be entered. But, when there were stock outs of medicines (as there were for three weeks during the project) and the care that could be enacted was limited, patients would collect their books once their test results had been written into it

and leave the health facility. This left their entry into the OPD register incomplete. Project staff encouraged the health workers to find ways to discipline patients into staying at the facilities. At the project meetings the health workers from the health centres III and IV agreed to institute a process whereby health workers took patient books to and from the dispensing lab instead of the patients.

Initially the patients were saying there are a lot of things, [that they had to] move here and there. They are complaining that the system had changed. That is why you find that some [patients] would take back their [patient] books and leave without getting treatment. But, very few do this now because now at least the tracking system is being hardened. The clinician will take those books to the lab and the lab people will bring them back. So, there is no way you can get your book and go without [supplying] our data.

(Nurse, Health Centre IV)

In this description, the care-value of practice is entirely lost and patients appear as suppliers of data. Inevitably, this attention to data with no consideration of care meant that the provision of care and treatment was delayed. This was particularly troubling when there were stock outs at the facility and patients had to travel to find medicines and the money to pay for them. The researchers witnessed one case of a patient with malaria asking for his patient book to be returned to him so that he could go and get medicine elsewhere being convinced by a health volunteer to stay so that the OPD register could be completed.

**Resisting and combining data value**

These descriptions echo what is often found in anthropological studies on data collection in Global Health, but in the health facilities that we studied there were also moments when the imperative to collect data was resisted and became secondary to other activities. When very sick or very distressed patients arrived at the health facility or in its vicinity, measurement and calculation practice appeared to have no place at all. Over the course of the research several of these events were witnessed including a case of a man who lived next to a HC II and had been poisoned, and a situation in which a distressed woman arrived at the HC IV. In both cases, the OPD register was abandoned by the health workers, the calculations and measurements left to one side and the patient attended to by taking the history (from carers rather than the patient) and, in the first case, by making a referral to a local herbalist and in the second case by providing medication.

Aside from these moments of crisis, among different cadres of health workers there was an ongoing concern about the ways in which asking questions around alcohol and tobacco use could undermine relations between health workers and their patients. In practice, questioning patients about alcohol and tobacco was difficult and not simply because the health workers were worried that patients would not tell them the truth. They were difficult to disconnect from judgements about the patients' moral personhood. This was especially the case among women ("If they ask women, "do you smoke cigarettes?" this makes them uncomfortable and they respond "I am a lady, why do you ask me if I smoke?" Junior health worker, HC II) but also among patients who were identifiable as devoutly religious. As they had described was the case during the

OPD register training, health workers at all facilities were seen bypassing these questions and filling the answers according to their own observations.

Among more senior staff, however, the relationship between undertaking tasks to complete the register and enacting care remained in tension. As they worked with the new register, they continued to seek care-value within the document. Thus, the concern with questions about alcohol and tobacco was not only about its potential to undermine good relationships with patients but also how it could support clinical judgement and improve diagnosis and treatment. During an interview, one clinical officer explained "Tobacco can bring drug interaction, [and] they put [this question] with the belief that the patient who drinks may fail to adhere with the drugs given. That is why they tried to squeeze this column in instead of putting temperature for children." The same interviewee remained critical of the space for final diagnosis and treatment. His interpretation stood in direct contrast to the global and national level actors looking for the data value in the OPD register in the workshop. Where they looked for rates of disease and found the broad category 'diagnosis' unhelpful, he recommended that the register be adapted so that the diagnosis column could be expanded and multiple diagnoses to be better recorded.

Beyond these struggles, however, were the rare moments when senior health workers brought data-value and care-value together, as they interpreted and translated activities associated with the collection of data for the OPD register with the desire to make an improvement in care-giving. At these times, the relationship between the register and care was no longer one in which data value dominated and the register was a tool that simply extended waiting times, was a barrier between the patient and clinician,

demanded difficult questions. Instead the document also held care-value for its ability to facilitate a deeper understanding of patient and their needs.

We spend more time [filling in the register] but I think it is required; it is necessary because it gives you a chance to understand your patient better. There are so many opportunities [for diagnosis that] we used to miss but with this register, people have picked up and [that has] helped. An adult may come with just a fever, but when you take his BP you find that he is hypertensive, which you may have missed. For the patients, some of them appreciate that with this kind of register, they are being attended to better. They are given more attention than before. But I think that it is consuming their time that they are spending a lot of time at the health unit. Because the time taken to fill the register, the patient has to visit at least twice. In the previous time, we would have put the OPD register at the dispensing end [of the visit]. So the patient would have passed through everything and at the end of the day they would have been registered in the dispensing [log], registered in the OPD and given their drugs. But this time, she has to first reach register then go to the other services, then come back to the register the services that were done before she goes to another step. That visiting the register twice makes them feel like they take more time but others appreciate it because they are given ample time to talk about their problems.

(In-charge, HC III)

While rare, it is likely that these moments when data-value and care-value were not pitted against one another and data collection did not have to take precedence over the provision of health services that constituted the most important of the project. At these

times, measurement, calculation and narrative practices could be enriched by holding both forms of value simultaneously and improvements in one (taking blood pressure to fill in the OPD register) was able to create an improvement in the other (diagnosing patients with hypertension). These moments raise questions about the potential for objects such as the OPD register to facilitate practices that bridge data value and care value by attending to both simultaneously.

### **Conclusion and application**

HMIS comes with a commitment that its data will be of value across the health system (Sandiford et al., 1992). The realization of this is complicated by the fact that health systems do not have a single set of values. Instead, they contain multiple arenas in which different constellations of social relations prevail, in which different goals and problems are managed at different scales and with different temporalities in mind. While some, numerical values (data) and the importance of pragmatism (use-value), cross between these different sites, there are also be multiple and competing ways in which what is ethical, good or right is evaluated.

Our research suggests that separating data collection and care-giving in health centres is impossible as measurement, calculation and narrative practices form part of both. This means that transferring data-value into health facilities can shift the hierarchy of activities, diminishing care-value, making practice poorly related to patients' needs. Yet, where other anthropologists have criticised the emphasis on data-value in global health our analysis ends with a recognition of the potential for a more positive resolution. Practices can contain both data-value and care-value and when well-trained health

workers seek to combine these values as they work then activities are enriched and strengthened.

Having attended to the different values in evidence in this case study, our interpretation ends with two questions, what are values and what makes them good to think with? Certainly data-value and care-value can be conceptualised as assemblages or regimes, dynamic collections of practices, objectives, objects and ethics that are brought together as people act on the world within different temporalities and at different scales. But, values also emerge as relations with different qualities (Miller, 2008). Use-value, exchange-value or symbolic value connect elements together in different ways. By attending to value as assemblages and relations, a powerful means of illuminating what is at stake in global health emerges, providing us with analytical tools to interrogate whose judgement on the form and meaning of practice prevails and with what consequences for the people that global health promises to support.

## References

- Adams, V. (2016). *Metrics: what counts in Global Health*: Duke University Press.
- Biehl, J. (2016). Theorizing global health. *Medicine Anthropology Theory*, 3, 127-142.
- Brown, H. (2015). Global health partnerships, governance, and sovereign responsibility in western Kenya. *American Ethnologist*, 42, 340-355.
- Brown, H., & Green, M. (2017). Demonstrating development: meetings as management in Kenya's health sector. *Journal of the Royal Anthropological Institute*, 23, 45-62.
- Crane, J. (2013). *Scrambling for Africa: AIDS, Expertise, and the Rise of American Global Health Science*. New York: Cornell University Press.
- Fairhead, J., Leach, M., & Small, M. (2006). Where techno-science meets poverty: Medical research and the economy of blood in The Gambia, West Africa. *Social Science & Medicine*, 63, 1109-1120.
- Geissler, P.W., Kelly, A., Imoukhuede, B., & Pool, R. (2008). 'He is now like a brother, I can even give him some blood'—Relational ethics and material exchanges in a malaria vaccine 'trial community' in The Gambia. *Social Science & Medicine*, 67, 696-707.
- Gerrets, R. (2015). Charting the road to eradication: Health facility data and malaria indicator generation in rural Tanzania. *The World of Indicators: The Making of Governmental Knowledge through Quantification (Cambridge Studies in Law and Society)*, 151-187.
- Gladwin, J., Dixon, R., & Wilson, T. (2003). Implementing a new health management information system in Uganda. *Health Policy Plan*, 18, 214-224.
- Graeber, D. (2013). It is value that brings universes into being. *HAU: Journal of ethnographic Theory*, 3, 219-243.
- Haynes, N., & Hickel, J. (2016). Hierarchy, Value, and the Value of Hierarchy. 60, 1-20.
- Hoeyer, K., & Hogle, L.F. (2014). Informed consent: The politics of intent and practice in medical research ethics. *Annual Review of Anthropology*, 43, 347-362.
- Hutchinson, E., Chandler, C., Clarke, S., Lal, S., Magnussen, P., Kayendeke, M., et al. (2015). 'It puts life in us and we feel big': shifts in the local health care system during the introduction of rapid diagnostic tests for malaria into drug shops in Uganda. *Critical Public Health*, 25, 48-62.
- Iteanu, A. (2013). The two conceptions of value. *HAU: Journal of ethnographic Theory*, 3, 155-171.
- Kingori, P. (2013). Experiencing everyday ethics in context: Frontline data collectors perspectives and practices of bioethics. *Social Science & Medicine*, 98, 361-370.
- Kingori, P., & Gerrets, R. (2016). Morals, morale and motivations in data fabrication: Medical research fieldworkers views and practices in two Sub-Saharan African contexts. *Social Science & Medicine*, 166, 150-159.
- Kingori, P., & Orfali, K. (2013). Special issue introduction: Bioethics in the field. *Soc Sci Med*, 98, 260-263.
- Kintu, P., Nanyunja, M., Nzabanita, A., & Magoola, R. (2005). Development of HMIS in poor countries: Uganda as a case study.
- Larson, M.L. (1998). *Meaning-Based Translation: A Guide to Cross-Language Equivalence*. Lanham, MD: University Press of America and Summer Institute of Linguistics.

- Marcus, G.E. (1995). Ethnography in/of the World System: The Emergence of Multi-Sited Ethnography. *Annual Review of Anthropology*, 24.
- Marsland, R., & Prince, R. (2012). What Is Life Worth? Exploring Biomedical Interventions, Survival, and the Politics of Life. *Medical Anthropology Quarterly*, 26, 453-469.
- Marx, K. (1990). *Capital: A Critique of Political Economy. Volume 1*: Penguin.
- Meinert, L., & Whyte, S.R. (2014). Epidemic projectification: AIDS responses in Uganda as event and process. *The Cambridge Journal of Anthropology*, 32, 77-94.
- Miller, D. (2008). The uses of value. *Geoforum*, 39, 1122-1132.
- Ministry of Health. (2010). The Health Management Information System, Volume 1: Health Unit Procedure Manual. Uganda: Ministry of Health Resource Centre.
- Ministry of Health. (2015). Out Patient Department Register. Uganda: Ministry of Health Resource Centre.
- Mogensen, H.O. (2005). Finding a path through the health unit: practical experience of Ugandan patients. *Med Anthropol*, 24, 209-236.
- Mol, A. (2008). *The Logic of Care: Health and the Problem of Patient Choice*: Routledge.
- Molyneux, S., & Geissler, P.W. (2008). Ethics and the ethnography of medical research in Africa. *Soc. Sci. Med.*, 67, 685.
- Mosse, D. (2004). *Cultivating Development: An Ethnography of Aid Policy and Practice*. London: Pluto Press.
- Mpimbaza, A., Miles, M., Sserwanga, A., Kigozi, R., Wanzira, H., Rubahika, D., et al. (2015). Comparison of routine health management information system versus enhanced inpatient malaria surveillance for estimating the burden of malaria among children admitted to four hospitals in Uganda. *Am J Trop Med Hyg*, 92, 18-21.
- Oni-Orisan, A. (2016). The Obligation of Count: The politics of monitoring maternal mortality in Nigeria. *Metrics: What counts in global health*, 82-104.
- Otto, T., & Willerslev, R. (2013). Prologue. Value as theory: Value, action, and critique. *HAU: Journal of ethnographic Theory*, 3, 1-10.
- Park, S.-J. (2014). Global public health workshops, technologies of participation and the authorization of knowledge in antiretroviral therapy in Uganda. Working Paper 6 of the Priority Programme 1448 Leipzig and Halle: The German Research Foundation.
- Reubi, D. (2015). Epidemiological reason: epidemiologists, philanthropists and global health. *Anthropology and Global Health: interrogating theory, policy and practice* University of Sussex, UK.
- Rottenburg, R., Merry, S.E., Park, S.-J., & Mugler, J. (2015). *The world of indicators: The making of governmental knowledge through quantification*: Cambridge University Press.
- Sandiford, P., Annett, H., & Cibulskis, R. (1992). What can information systems do for primary health care? An international perspective. *Social Science & Medicine*, 34, 1077-1087.
- Storeng, K.T., & Béhague, D.P. (2014). "Playing the Numbers Game" : Evidence - based Advocacy and the Technocratic Narrowing of the Safe Motherhood Initiative. *Medical Anthropology Quarterly*, 28, 260-279.
- Tappan, J. (2017). *The riddle of malnutrition: the long arc of biomedical and public health interventions in Uganda*: Ohio University Press.
- Taylor, E.M., & Harper, I. (2014). The politics and anti-politics of the global fund experiment: understanding partnership and bureaucratic expansion in Uganda. *Med Anthropol*, 33, 206-222.

World Health Organization (1978). Alma Ata Declaration. *Geneva: World Health Organization.*

ACCEPTED MANUSCRIPT

**Acknowledgements**

The study was funded by the US President's Malaria Initiative through UCSF grant No. 5UGH000076-04 and USAID contract AID-617-O-00016.

ACCEPTED MANUSCRIPT

Figure 1

## Headings in the pre-2015 Out Patient Department register (Health Management and Information System Form 031)

1	2	3	4	5	6	7	8	9	10	11	12
Serial number	Name of patient	Residence	Age	Sex	Weight	Next of kin	Tick classification	New diagnosis	Drugs and treatment	Reference In Number	Reference out Number
		village	parish				new attendance case	re-attendance case			

(Ministry of Health, 2010)

Figure 2

## Headings in the new Out Patient Department register (Health Management and Information System Form 031)

1	2	3	4				5	6	7	8	9	
Serial number	Name of patient	Residence	Age				Sex	MUAC	1. BMI	Blood Pressure	Next of Kin	Need for Palliative care (yes or no answer)
		(include village, parish, sub-county, district)	0-28 days	29 days – 4 years	5-59 years	60 years and above		Weight	2. Weight for age Z-score	Blood sugar		
		Height	3. Height/length for age Z-score									

10		11	12			13				14	15	16	17	18
Tick Classification			Malaria test			TB								
New attendance	Re-attendance	Tobacco use (Yes/ No) Alcohol use (Yes/ No)	Fever (Yes/ No)	Test done (B/S, RDT, No)	Result (POS/NEG/NA)	New presumed TB case	patient sent to the lab	lab TB result,	linked to TB clinic	New diagnosis	Drugs/treatment	Disability (Yes / No)	Ref. in Num	Ref. out Num

## Research Highlights

- Considers data collection practices in health systems rather than vertical programmes
- Examines how measurement, calculation and narrative practice can have data or care-value
- Demonstrates pushing data-value into health centres undermines care
- Shows how well trained health workers can combine data and care-value
- Calls for further analysis of use of value for medical anthropology