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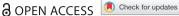
# Kristin Bergtora Sandvik

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# Wearables for something good: aid, dataveillance and the production of children's digital bodies

Kristin Bergtora Sandvik (10 a,b)

<sup>a</sup>Department of Criminology and Sociology of Law, University of Oslo, Oslo, Norway; <sup>b</sup>Humanitarian Studies, PRIO, Oslo, Norway

#### **ABSTRACT**

The article contributes to the emergent critical literature on the creation of data in aid by exploring how the use of digital technologies creates corresponding 'digital bodies'. The article argues that dataveillance is becoming a central practice of aid. To explore this proposition, the article interrogates the making of children's digital bodies as objects of intervention through an examination of the development of 'Khushi baby', a wearable digital necklace for tracking infants immunization records in India.

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#### Introduction

The ongoing digitization and datafication of international aid increasingly shape our understanding of and response to questions of poverty, health emergencies and humanitarian crisis. The uptake of technology and the proliferation of innovation initiatives and start-ups are part of a broader turn to innovation as a central vehicle for improvement in the development, global health and humanitarian sectors. These actors contribute to a profound transformation in international aid away from material assistance towards data collection about intended beneficiaries as the central vehicle for interventions. The point of departure for this article is how the use of digital technologies creates corresponding 'digital bodies' (Lupton, 2016) - images, information, biometrics, and other data stored in digital space – that represent the physical bodies of populations affected by conflict and natural hazards, but over which these populations have little say or control (Jacobsen, 2015). The technology explored is wearables, smart devices that can be placed on or inside the bodies of aid beneficiaries for many purposes, including tracking and protecting health, safety and nutrition. I argue that dataveillance - the systematic monitoring of people or groups, by means of personal data systems in order to regulate or govern their behavior (Degli, 2014) – is becoming a central practice of aid. Yet almost no attention has been given to wearable devices as a vehicle for data extraction in the Global South (Ruckenstein & Schüll, 2017). To explore this proposition, I interrogate the making of children's digital bodies as objects of intervention through a case study of the development of 'Khushi baby'. Khushi baby is a wearable digital necklace for infants initially aimed at reducing child mortality and originally trialed in India but recently proposed to include a host of other capabilities and to be deployed in more countries, including Myanmar, Nepal, Malawi and Kenya. The case study unpacks the processes through which dataveil-lance is produced and marketed as an effective protection tool.

The Khushi baby device was originally developed as part of the course 'Appropriate Technology in the Developing World' designed to tackle ongoing global issues, at the Center for Engineering Innovation & Design at Yale University. Khushi Baby was launched in 2014 in the rural district of Udaipur, Rajasthan. The entity behind Khushi is often described as a company or a start-up but is registered as a tax-exempt charity (in the US) and as a non-profit (in India). Starting out with five part-time volunteer members, by 2017 Khushi baby had grown to comprise of nine full-time staff, five part-time staff, nine summer interns and a field team of more than 30 surveyors (SEASYale, 2017). Speaking to the savvy, talent and networking-skills of its founders, Khushi baby has been enormously successful in attracting funding and prizes: they have won several prestigious innovation competitions, including the UNICEF 'Wearables for Good Challenge' (2015) and the Johnson and Johnson GenH Challenge (2017). Khushi has also been the finalist for a host of other awards in India and the US, and several team-members have received prestigious innovation honors. Khushi has raised funding through crowdsourcing platforms, and has received grants from GAVI, the International Initiative for Impact Evaluation (3ie) and several other donors. With an emphasis on evidence-based decisionmaking, they have systematically and thoughtfully sought to present documentation of their activities at their own platforms (web site, wordpress blog, facebook, twitter) and also publicized and promoted their work through a host of social media platforms and channels (Castillo & Vosloo, 2017; UNICEF, 2015). In 2017, Khushi published a study of their work in the journal Vaccine (Nagar et al., 2018). As part of its evolving narrative, based on two randomized trials, Khushi has made broad claims about the number of people reached and the impact of the product: the success measures are here the number of necklaces deployed ('among 10 000 patients'), the number of vaccinations 'tracked' (50,000), and the number of villages (350, 600 +) and mothers (3000) 'monitored' for immunizations and maternal health outcomes (Khushi 2016, 2018; Nagar, 2016). This self-presentation exists in close symbiosis with highly sympathetic coverage by social innovation platforms, international organizations, the international media and philanthropic foundations.

The article contributes to this special issue through its analysis of how the values, ideas and concepts embedded in data analysis are also productive of new forms of aid, while being entrenched in contexts of structural inequality and transnational market relations and innovation ideologies. The article draws on Roth and Luczak-Roeschs proposition (2020) that to unpack the rise of data in aid – here labeled 'humanitarian data' – focus must be given to the socio-technical work that is necessary to acquire, process, store and use data, as well as to study the power relations that are ingrained in these processes. Roth and Luczak-Roesch posit that the context of humanitarianism, ICT and Big Data are a particularly intriguing to study due to their ambivalent position of seeking to address inequalities while at the same time perpetuating them. The topical focus for this article is the creation of data through the miniaturization and personalization of ICT technology in aid, producing intimate digital objects to be used by individual beneficiaries on or inside

their bodies, as illustrated through the example of 'wearables for good'. Wearables are promoted as being capable of delivering or monitoring reproductive health; producing security and accountability through more efficient registration or by monitoring or delivering nutrition. This type of digital goods is developed at the interface of the affordances of emergency response contexts - broadly defined - and the accelerating digitization of beneficiary bodies.

My proposition is that dataveillance is not a byproduct of how wearables co-constitute digital bodies in aid, but in fact, the main product. Dataveillance characterizes the networked, continuous tracking of digital information processing and algorithmic analysis (Van Dijk, 2014). In the specific case of tracking devices, dataveillance is typically distributed across multiple interested parties - in the case of health, including caregivers, insurance payers, pharmacies, data aggregator and analytics companies, and individuals who wittingly or unwittingly provide information (Ruckenstein & Schüll, 2017). This requires a rethink not only with respect to the nature of aid, but also with respect to the relations of aid and questions of data labor and data gifts. Moreover, vulnerable infants, which are Khushi baby's primary intended beneficiaries, belong to the category of victims that incur the greatest deal of sympathy, where urgency most powerfully operates as a legitimating device for intervention. They are also group with the least power to resist interventions. Despite the massive technologization of aid targeting children, so far, no critical thinking has gone into considering the production of children's digital bodies in aid. To begin to bridge this knowledge gap, and drawing on Deborah Lupton's work on digital bodies (Lupton, 2016) the article contributes a set of critical insights about children's digital bodies in aid and the specific nature of risk and harm these bodies might incur.

The article is part of a larger study on ethical humanitarian innovation and digital bodies. The topic for the article emerged from research on the making of humanitarian goods through innovation challenges, focusing on UNICEFs, 2015 'Wearables for Good Challenge', where Khushi was one of two winners. The article draws on longstanding participant observation and engagement with the humanitarian technology and innovation field (where the author has been the ethics advisor for several entities), a close reading of Khushi baby's own online documentation of its development process - including scholarly papers - as well as reports made available by Khushi, and a review of the literature. An earlier version of this article has been circulated to the Khushi team for comments. As a desk study of the journey of Khushi baby, my analysis is necessarily both incomplete and kept on a general level. However, methodologically, while drawing on a desk study has clear limitations, I believe this can be an adequate starting point for formulating a set of critical questions and sketching out pointers for a research agenda on wearables, dataveillance and children's digital bodies in aid. The themes explored in the article have been identified partly by way of using critical perspectives from the literature as analytical prisms, and partly through the construction of a chronological narrative, focusing on the trajectory of Khushi's shifting self-representation and expanding horizon. I also hope that this article, as an act of 'critical friending', can provide a useful point of reflection for Khushi baby.

The article proceeds as follows: In the first part, I locate the contribution in the context of the literature. I then explore the trajectory and the shifting affordances of the Khushi baby wearable through discussions of problem framing, function creeps, the intrusiveness of digital humanitarian goods and finally the landscape of inequality in which dataveillance lands. A brief conclusion follows.

## **Background**

The article contributes to the literatures on innovation and humanitarian goods (Redfield, 2012; Scott-Smith, 2016) and socio-technical devices in STS (Tapia & Maitland, 2009) as well as critical humanitarian and data studies (Burns, 2015; Read et al., 2016; Taylor, 2017), ethics and technology (Sandvik et al., 2014) and critical security studies (Salter et al., 2019). Through its focus on wearable devices as a vehicle for data extraction in the Global South, the article also contributes to the field of mHealth (Al Dahdah, 2019), children's rights in a digital age (Livingstone & Bulger, 2014) and political geography (Donovan, 2015; Taylor & Broeders, 2015).

The article understands wearables as a form of 'techno-science' that contributes to the production of legible, quantifiable and consumable bodies, and a form of ordering practices that are materially productive of aid, but which may also engender new protection needs for the digital/physical beneficiary body (Jacobsen & Sandvik, 2018). We must interrogate what wearables can do (including the intensification of surveillance of everyday practices), how its capabilities are framed (including through problem re-framing) and who does the framing. To that end, we must also consider the nonhuman elements that mediate the dynamics and experiences of wearables: device parameters and affordances, analytical algorithms, data infrastructure, and data itself, as well as the processes and practices around them (Carter et al., 2018). Wearables can be passive applications (apps) that can be downloaded to smartphones, tablets, and smartwatches that aid travel and mobility; dedicated wearables that record activity; and more sophisticated multifunction wearables that also record multiple data streams including biomarkers (such as heart rate). Wearables provide measuring, selection, screening, legibility, calculability and visibility. Increasingly they are also becoming vehicles for physical delivery of medicine or reproductive control. For the purposes of this article, the central capability of these technologies is that they generate massive amounts of data in a field traditionally afflicted by a lack of timely and accurate information (Sandvik & Raymond, 2017). Regardless of purpose, wearables all share a key premise: the gadget is not the main product - the ability to harness and manipulate a data flow is, 'as physical and virtual units of human value to be bought and sold in the digital data economy' (Lupton, 2016, p. 117).

The rapidly growing academic literature on wearables examine how citizens are turned into 'datafied subjects' and practices of datafied self-care (Wissinger, 2018). The literature is characterized by a near-total geographic bias, focusing on the everyday life and perceptions of citizenship in the Global North: development and humanitarian contexts have not been analyzed (but Sandvik, 2019). As pertinently noted by Ruckenstein and Schüll (2017), the health wearables literature is concerned with elite citizens in technologically sophisticated contexts characterized by 'a cultural model of the ideal citizen as digitally literate and self-advocating; and a robust public debate around the ethical, legal, and social implications of big data'. Most scholarship on sensor technologies and self-tracking devices focus on voluntarily collected data by individuals, for their own purposes. In contrast, and similar to the mhealth-examples in Al Dahdah (2019), the context for this article is resource poor settings where users do not have

a high level of digital literacy and are not empowered or in a position to make informed decisions about self-tracking and where structural conditions of depravation are built into the physical design and functions of the product.

A key critical issue in the wearable technology literature, is how such technology can augment the human body, how it affects human relationships to self and other, and whether wearable technology can promote human autonomy, when it is locked into commercial and power relationships that don't necessarily have the users' best interests at heart (Wissinger, 2017). These questions are highly pertinent also for the international aid field - where the risks are greater and the power of users much smaller (Sandvik et al., 2017). Wearables are part of a process of miniaturization of the communicative architecture of aid. As observed by Collier et al. (2017) with respect to humanitarian goods - a literature that has so far not been linked up with critical data studies - the grand aid schemes of yesterday are today found as gadgets. Small technologies of government now permeate the field of international aid. The smallness of these devices stand in contrast to the massive modernist projects of the period of technological imperialism (Headrick, 1981). Wearables are part of a general trend in aid, whereby 'tremendous intellectual and moral energy, as well as the financial and organizational resources, are being devoted to inventing and disseminating ... micro-endeavors' (Collier et al., 2017). While not designed to provide paradigm shifts, the devices are surrounded by what the authors describe as 'salvational talk'. The underlying motif here is 'a dream of scaling up microtechnologies to have macro effects.' Discourses surrounding these goods are free of talk of social justice, focusing on devices that can achieve benefits without 'the messy complications and entanglements of collective action' (Collier et al., 2017).

Finally, in popular culture, in the 1980s and 90s, 'digital bodies' arose as a concept referring to those avatars and images that represented and simulated the humans' off-screen (Haraway, 1985; O'Riordan, 2011). Haggerty and Ericson (2000) described data doubles as 'surveillant assemblages', which abstracted human bodies from their territorial settings and separated them into a series of discrete flows to be reassembled in different locations as discrete and virtual 'data doubles', which could be scrutinized and targeted for interventions. I suggest that the accelerated digitization of everyday life means that it is now meaningful to speak about 'digital bodies' co-constituting our personalities, relationships, legal and social personas - and as producing and circumscribing our rights and privileges as individuals and citizens (Sandvik, 2019). In this context, what is different about children's digital bodies? Like the push for digitization of adult bodies, the digitization of children's bodies is animated by promises of popular culture. However, these promises are of almost unlimited care and control: directly by parents but indirectly by marketing agencies and tech companies building consumer profiles. Whereas a fundamental critique of the data double rationale has been that biometrics give the body unprecedented relevance over the mind, that only the coded body can 'talk', and that the 'talking individual becomes suspect and even unnecessary' (Aas, 2006), in contrast, in most cultural contexts, children have never been endowed with the agency to 'talk' like adults, thus the digital body does not represent a parallel kind of 'loss'. As explained by Lupton (2016) in the political economy of the Global North (and the Global East), children are becoming the objects of a multitude of monitoring devices that generate detailed data about them. Critical data researchers and privacy advocates are only beginning to direct attention to these practices, in particular the array of specific harms they may encounter, including the erosion of privacy. Lupton and

Williamson (2017) describe how, as commercial actors capitalize on and profit from children's personal information, children have become increasingly datafied. The data generated by these technologies are often used for dataveillance, or the monitoring and evaluation of children by themselves or others. This may include recording and assessing details of their appearance, growth, development, health, social relationships, moods, behavior, educational achievements and other features (Lupton & Williamson, 2017).

## **Problem framing and moral economy**

Classifications of emergencies are inherently sociological. As noted by Calhoun (2010), as cultural constructs, 'humanitarian' and 'emergency' and the focus on 'urgency' shape understandings of what happens in the world, who is supposed to act and what is supposed to be done. In the context of the ongoing digitization of aid, attention must be given to how the framing of structural problems shifts to problematizations being amenable to technological innovation and intervention and the interests of technology stakeholders.

Khushi's problem framing relies on a set of very specific mobilizing frames that serve as calls to action – an aspiration that something can and must be done – and offer moral rationales. The first moral frame revolves around human suffering among the most vulnerable, more specifically, infant deaths globally, nationally and locally. According to Khushi, '1.5 million children worldwide continue to die from vaccine-preventable diseases each year ..., and about 500,000 of these children are in India alone' (Venkat, 2016). On a national level, '800,000 children under the age of five die every year in India from vaccine preventable diseases' (Women's Forum, 2019). In Khushi's initial area of operation, the District of Udaipur, in Rajasthan, India, '40 out of 1000 infants do not see their first birth-day' (Nagar, 2019).

The initial pitch for the Khushi necklace focused on reducing infant mortality by increasing vaccination rates (Uchegbu, 2014) through giving health care workers in remote areas access to real-time data to make sure children are up to date on their vaccinations. The creation of a digital health record that does not require connectivity contributes to remove a key practical barrier to patient identification in rural India. Two types of rationalities are offered: that areas are underserved because they are difficult to access ('hard to reach') and that the existing governmental health care provision is sub-optimal. The Khushi-team portrays their product as a game changer and as operable and able to collect and store data in 'even the most isolated communities' in rural India (SEASYale, 2015), also described as being among 'the remotest regions in the world' (Nagar, 2014). However, the device is more than a 'last mile data collection platform for immunization tracking', it is also having the 'potential to generate attention, awareness, and hopefully demand' for immunizations (Nagar, 2016). To that end, the device is described as 'ideal for use in rural communities, relying on low-power wireless technology for operation instead of batteries' (NFC forum, 2017). A central aspect of the problematization is the manner in which the key problem is construed as one of lack of data: 'Too many, especially at the last mile, are falling through the cracks due to health systems that unreliable and accountable data' (Globalinnovationexchange, 2019).

An important part of the pitch focuses on effectiveness, efficiency and accuracy. It sets up a dichotomy between tech and paper-based bureaucratic procedures vulnerable to

human manipulation and mis-handling. It is explained that '[u]nlike paper immunization brecords that are difficult to maintain and access and can be lost or destroyed' health care personnel can use the Khushi baby mobile app to read the necklace, identify which vaccinations are needed, upload the vaccine data into the cloud, and monitor the infant in real time (NFC forum, 2017). Digitization also saves time, as the traditional paperbased tracking process is complicated, requiring data entry and processing at multiple stages. Additionally, according to Khushi, the paper-based system suffers from threats to its validity, including data manipulation and entry error at each stage of processing, lack of data validation, and slow processing time for data analysis and decision-making. Basic infrastructure issues are prevalent. Mothers who move fall out of the system. Overcrowding prevent health workers from performing adequate check-ups, and pregnancy cards may be inconsistent or incomplete (Castillo & Vosloo, 2017).

It is important to note that these problems did not disappear with the introduction of the necklace. Khushi's monitoring and evaluation strategy initially focused on tracking the direct effect of the platform for improving adherence to the immunization schedule and data-processing time (Castillo & Vosloo, 2017). The strategy shifted after Khushi realized that comparison data suffered various threats to validity: health workers would underreport, manipulate and make up data, or information would be of poor quality or missing (Castillo & Vosloo, 2017; Khushi, 2018). As will be discussed later in the article, in response Khushi embraced more sophisticated and invasive technology to obtain more comprehensive 'better quality' data.

## The production of solutions and function creep

Closely corresponding to this type of problem framing is a form of technology-oriented solutionism premised on notions of technological optimism and even utopianism: a belief in technological progress as inevitable, apolitical, and problem-free. The burgeoning 'ICT for good' literature espouses optimistic and frequently utopian claims about the capacity of technology to mitigate political, economic, social, and cultural forms of human suffering; to solve structural problems in the various 'do good' sectors that focus on conflict; and even effectively contribute to end crisis and 'make peace' (Sandvik, 2017). Here I look at how the Khushi baby necklace was constructed as a solution with global and local reach, able to remedy structural as well as individual health challenges.

Khushi's initial aspirations for social change presents the device as a concept potentially representing 'a new, worthwhile paradigm for the interface between patient and provider', imaginably one day acting as a 'digital key' to a gamut of health and social security services and serving as a 'medical passport'. Khushi's vision of society is one of 'a more connected, healthier India, and a more vigilant, accessible world' (Nagar, 2016). In parallel, the product is systematically described as 'culturally relevant' (Weforum, 2015) and promoted as a carefully circumscribed cultural artifact produced through behavioral science and human design thinking incorporating user participation:

"The necklace is not only used as a data storage device, but is also a culturally tailored piece" of jewelry, as the black thread on which the pendant is strung is commonly believed to ward off evil spirits in the Udaipur community and in many tribal regions of India" (Venkat, 2016)

To develop the necklace, mothers were presented with six form factors and asked whether they would prefer to wear the wearable or to have their child wear the wearable. Community consensus pointed towards the child wearing the black threaded pendant, with the black thread culturally familiar and symbolic of protecting the child from evil (buri nazar). Khushi gives a vivid description of how, after a community meeting at the field site in Udaipur with village elders, community health workers, traditional birth attendants, local informers, health officials and about 100 mothers, the Khushi team succeeds in designating the form factor for the chip. They end up selecting a pendant wearable with black thread and chip in an amulet. All the options were battery free and affordable, and included stickers, chips stickers, chips on bangles for mothers, and chips embedded in silicon wristbands for children, anklets, and wristlets (Nagar, 2016). In this initial phase, Khushi anticipated that the necklace could also serve as a social symbol and a potential talking point for caregivers (mothers), and also be usable as a 'campaign tool' for increasing immunization camp attendance rates and vaccination completion rates in the future (Venkat, 2016).

While Khushi is explicit that gadgets *cannot* fix structural problems (Nagar, 2017), within the Khushi narrative, the systemic conditions that compromise service provision can be fixed by data. Referring to the need for extensive training of nurses at the village level to enable them to fill in forms properly, and the fact that health workers are overstretched and 'stressed for time and resources' Khushi suggests that these problems can be overcome: the nurses are 'working hard, but not with good data – we want to give them good timely accurate data. With better quality data, we can deliver better quality care' (SEASYale, 2017). This belief in the agentic power of digitization and datafication goes hand in hand with self-responsabilization. The device is described as 'decentralized and patient-centric'. Here, 'a patient can travel to any health provider ... and present their most updated health history', regardless of which tablet the healthworker is using and when data was last synced (Geneva healthf forum, n.d.g).

As is common for innovators traveling the path to scale, Khushi's overall objectives, as well as the objectives for the wearable changed over time, from being focused on process and the device's capability of streamlining vaccination data to a business model emphasizing its technical capacity to do many things. At the outset, Khushi was promoted as a digital solution for tracking maternal and child health records, targeting women frontline health workers. This included a necklace with a computer chip inside promising to store up to two years of vaccination records for young children. The most important technical feature was that of enabling functionality without connectivity. The system used near field communication (NFC) technology to send and receive information through a smartphone, permitting health workers to scan chips, access health information and update data (Khushi, 2016-17). Iterations and new beginnings are necessary elements in any innovation process. In their 2016 report, Khushi described how they 'wireframed, paper-prototyped, defined schemas, and started building from scratch'. However, in the product development phase, the co-producing of problem-framings happening through the introduction of more advanced technology and new partners fundamentally changed the nature of the Khushi wearable. This engendered both a significant expansion in surveillance capabilities and a radical scope creep. By 2019, the updated Khushi baby platform 2.0 has drastically expanded the scope of Khushi's mission. At Khushibaby.org, the platform is now presented as suitable for 'tracking maternal and child health, chronic disease, tb and HIV medication adherence, conditional cash transfers, ration cards, emergency medical response and hospital readmissions'. My proposition is that through this process of incremental material and discursive changes, the product is transformed from a single-objective artifact into a comprehensive process of dataveillance.

# **Technologization and intrusiveness**

Over time, the Khushi necklace has been packed with more and more technology. The 2017-2018 annual report indicates that an expansion of purpose, technologies and partners is envisioned. This includes text to speech integration, infant facial biometrics with the larger international partner IDEMIA; 'Full Immunization Predictive Modeling' and 'Stillbirth and Early Infant Death Machine Learning'; as well as 'Voice Call Machine Learning' and a Blockchain application as a 'health wallet' (Khushi, 2018) - as well as GIS (Nagar, 2019). While this represents a very significant scaling up of Khushi's data-hoarding abilities, and several of these innovations call for scrutiny of the ethics of data collection (stillbirth and early infant death in particular) and the digital literacy (health wallet) of users, I am here interested in the introduction of biometrics to Khushi baby in 2017.

By 2016, Khushi had determined that they wanted to do child face biometrics as well as biometric authentication on NFC tags, with direct upload to government registries (Khushi, 2016-2017). The circle of individuals required to give biometric print tracked by the device increases gradually to include babies, mothers and health workers, in response to technological opportunity as well as perceived resistance by users (Legoullon, 2017). Biometrics here become part of a protection narrative where the deployment of biometrics serves as the justification for more data collection: biometric security has been added to its platform to 'further protect the personal information of patients'. In this narrative, data security emerges as an important value. To maintain data security, user data on the KB dashboard is encrypted, password-restricted and SSL-secured when being transferred. Moreover, data stored on the necklace can only be accessed by a 'live' (has to be present) thumbprint from the mother or care giver. Correspondingly, a thumbprint is required from the health worker to access the data (Castillo & Vosloo, 2017). In parallel, the proposed range of biometric data expands from fingerprints to footprints to 'infant facial recognition' (Castillo & Vosloo, 2017). Biometrics is also intended to authenticate ownership of health records and ensure verification that the right persons are giving and receiving care (SEASYale, 2017). Whereas the necklace is initially promoted as easy-to-use and requiring low skills, the implicit requirements for digital literacy and patient agency expand significantly with the introduction of increasingly intrusive technology involving frequent updates.

Through the 'combination of NFC technology, biometric authentication, GPS, time-tracking, and data-driven models' capable of preventing 'false record creation or manipulation' Khushi is also explicitly becoming a health worker surveillance tool. According to Khushi, the technology allows for the detection of fraudulent data, compared with other similar platforms which 'cannot detect whether the health worker actually saw a patient, or is just reporting so to "reach her target" (Globalinnovation exchange, 2019). The platform allows Khushi support staff to see daily active users and monitor crash-free sessions. The Khushi dashboard records how many health workers checked in to camps, how long they spent per patient, and what equipment they are short of during these patient encounters. This serves as an 'auditable proof that health care reached the beneficiary', enabling health officials to 'respond in real-time to health worker attendance, performance and data quality' (Planetbiometrics, 2017).

Importantly, the incorporation of biometrics technology also entails the acquisition of new partners that also come with their own separate controversies. In this case, a key partner has recently been prohibited from operating in Kenya, one of the countries where Khushi wants to expand into. In 2019, the Kenyan national assembly banned the controversial industry giant Idemia from the country for ten years, after it was accused of procurement malpractices in connection with elections (Muhindi, 2019). Bringing in more partners performing surveillance also gives more actors access to – and possibly ownership of – user data. Given the differences in power, expertise and resources between a start-up and a multinational actor, maintaining the integrity of contracting practices across multiple jurisdictions (adhering to differing personal data, data security and intellectual property rights regimes) is exceptionally difficult for actors like Khushi. Expansions of the supply chain also multiply cyber vulnerabilities and increases digital risk. When Khushi discusses problems related to technology, they are never related to tech solutionism. Cyber security risks, technological malfunction and the ethics of using biometrics on an ever-widening range of individuals are not considered. Furthermore, the rapidly shifting landscape of the global biometrics industry makes transparency with respect to the supply chain hard. In the case of Khushi, the provider of the biometric tablet Safran Identity & Security became MorphoTablet, and then OT-Morpho which subsequently became part of the abovementioned industry leader Idemia (Idemia, 2017).

### Dataveillance, inequality and children's digital bodies

This part draws out a set of more general critical issues from the case study. At the heart of the analysis of Khushi is the notion of 'data colonialism': the processes of exploitation and subjectification of social life as a resource for data extraction in the Global South as part of global data capitalism (Thatcher et al., 2016; Van Dijck, 2014). Segura and Waisbord (2019) argue that we must avoid totalizing claims about the nature of global data capitalism (which risks underplaying the actual physical violence of colonialism) and pay appropriate attention to resistance, re-appropriation and the wiggle room for data-activism in the Global South. Wearable devices can be abandoned, tinkered with or destroyed. Yet, in the case of basic health services, the nature of children's and infants digital bodies and the location of poor rural families in the capitalist economy are such that there is not much room for resistance that will not also at the same time further reduce access to care. Here, I want to point to three key implications of dataveillance becoming a central practice of aid. This concerns scope, participation and knowledge production, and children's digital bodies.

The expanding scope of Khushi baby raises several important questions. Collier et al. (2017) observe that as products move through design and use, and through spaces of poverty and humanitarian emergency, we are reminded about the difficulty of imagining ways of expressing care and concern without fostering markets. This tension is aptly captured by Katina Michael's comments, as she was acting as a judge in an innovation challenge involving Khushi:



Of course, Khushi Baby has the best interests of children at heart, their care and hope for a better life, supporting health workers in their aims, but it is amazing how scope creep can easily pervade emerging technologies. Placing chips in bracelets or just about any other common fashion item can be a temptation for product developers who see potential for even greater functional applications (Michael, 2017).

# Michael continues by pointing to a set of key ethical and legal challenges:

"It is easy to see how this mobile app might well be implemented for MedicAlert-style bracelets of various types in different kinds of markets. But underlying care applications are always the dominant factor of control. Stringent guidelines must ensure that the data gathered by the wearable device are not used retrospectively in nonmedical contexts. There also need to be regulatory guidelines introduced on how long the device is worn by infants and how the gathered data will be archived and who has access to the information and for how long (Michael, 2017).

Michal's comment raises several important questions: what is a 'non-medical context'? Does that for example include ration cards? Michael also points to the need for regulating the physical use of the device. An early Khushi report describes how 'One child who had been given the pendant in July 2014 was still wearing the pendant upon receipt of his measles shot in April 2015'. In the initial phase, Khushi framed their primary objective as 'tracking child immunizations in the first two years after birth, so the infants wear the necklace'. Does this imply that the child will continuously wear the tracking device? What are the digital and physical child safety considerations that arise? The functionality of the device increasingly rests on relational data-circuits. Khushi explains that 'as we transition to storing data for maternal and child health, this pendant will be first worn by the pregnant mother and then passed on to the child to link their data' (UNICEF, 2015). This challenges us to think about the mechanics through which continuous tracking is co-constituted, and what it means that dataveillance is becoming both the product as well as the precondition for the product.

Another important aspect of the expanding scope of Khushi baby concerns the area of uptake as Khushi moves from being a local to a global product. At the time of writing, the scope of possible uses for the Khushi wearable was expanding quickly beyond the domain of infant immunization as the ambitions of Khushi were becoming global. This in turn creates tensions with the moral economy built around the necklace being culturally appropriate locally and regionally. This reorientation rests on the assumption that Khushi can fundamentally change the content and function of the product and scope for dataveillance, without changing the design that has been 'accepted'. Hence, there is a need to reflect on the possible tension between the necklace as a culturally sensitive value and the possible application of the product 'anywhere in the world' (Khushi, 2016).

Roth and Luczak-Roesch (2020) emphasize the importance of paying attention to knowledge production and participation in the different stages of the data life-cycle, as the emergent critical literature on innovation initiatives in aid note significant challenges with respect to the participation of poor people on digital platforms (Schwittay & Braund, 2018). In the present case study, problems and solutions are co-constituted around the absence of data and the making of dataveillance. Other studies of mHealth applications in India suggest that in practice, it is hard for patients to identify and access clinical partners and that there are cultural challenges with respect to the promotion of patient 'selfmanagement' (Papreen et al., 2017; Nahar et al., 2017). This type of critical insight also applies to Khushi. To add to this, I want to foreground the tension between accessibility and consent. How does language around consent intended to legitimate the introduction of new surveillance components to Khushi square with the early focus on the device being accessible and intelligible for users with very low digital literacy? A key concept underpinning the design of the necklace was that it had to work among communities with limited reading and technical and digital literacy skills. In a later iteration of the device, the importance of enabling user consent for updates is emphasized. For example it is specified that by combining the NFC, biometric and security features of the MorphoTablet, the Khushi Baby platform can authenticate individual ownership of health records and take patient consent before making any updates (Idemia, 2017). However, given that these updates will need to be frequent, and ensuring meaningful consent requires significant digital literacy among users, the lack of attention to meaningful user participation points to a different and uncomfortable possibility: that low user digital literacy operates as a prerequisite for dataveillance.

A final issue concerns the possible negative ramifications of the datafication and dataveillance of children in low resources contexts and fragile settings. In the wearables literature focused on the Global North, data doubles operate as triggers for intervention, and as shared artifacts for co-constructing and negotiating meaning (Ruckenstein, 2014). In contrast, in the Khushi setting, the wearable device speaks for digital bodies that are mute (infants), poorly resourced (mothers) and perceived to be undependable (frontline healthcare workers). At the same time, in the Khushi narrative, the potential for digital risk and harm for children is invisible. Risk is phrased as an issue of data security and malfunction and human manipulation of data. A growing field of political commentators, data activists and academics are concerned with how people's life chances and access to opportunities are shaped by the types of social sorting afforded by dataveillance. Children - and in particular in low-resource settings – have few or no opportunities to challenge the knowledge produced through algorithms. They also have scant techno-legal consciousness with respect to how their personal data is being exploited, commodified and used for decisions about their future access to resources, such as healthcare, education, insurance, welfare, or employment.

#### Conclusion

The Children's Rights Convention of 1989 represented a watershed moment in thinking about children's right to integrity, to be heard and to protection of their physical bodies. Time has now come to articulate and integrate an understanding of children's digital bodies in international aid within this normative framework (Livingstone & Bulger, 2014). The mainstreaming of dataveillance of children as a form aid, ranging from educational technology to infant biometrics means that critical discussions of the ethical and legal implications of children's digital bodies in the ongoing digitization of aid are becoming urgent. This article has attempted to situate the Khushi baby wearable necklace in an analytically ambiguous space of complex and sometimes contradictory impulses to do no harm, to care and to control. The case example explores how dataveillance is co-produced in digital aid. It brings out how the expansion of Khushi's technological capacity also engenders an expansion in the circle of people tracked by the device as well as the

type of data it collects. With the technological transformation of the device, there is a shift in the moral economy rationale and the problem framing towards legitimating and enabling increased dataveillance.

While Khushi baby represents the prototypical case of successful and adaptive transnational entrepreneurship to produce social change for the most vulnerable - merging the resources of U.S elite educational and philanthropic institutions with India's go-getting tech innovation culture, and consciously and publicly mapping and documenting the innovation process – it also represents an instructive case of the type of technical, normative and practical scope creep common to the innovation field. In this case study, I have been concerned with the exceptionally intrusive nature of wearables when used in the aid context, and the fact that the deeply unequal relationship between innovators, humanitarian/development actors and recipient communities is the prerequisite for the data flow and the dataveillance practices Khushi baby enables. Over time, the wearable itself gets packed with more technology, including biometrics, enabling new capabilities, routinizing practices tracking a larger number of direct and indirect users and embracing an increasingly broad set of objectives.

The category of startup initiatives to which Khushi baby belongs is bringing much needed innovation to international aid. The dodged refusal to accept that some populations are abandoned by their governments is commendable and important. At the same time, we need more scrutiny of how the type of datafication these entities enable and the dataveillance practices they bring about, contribute to the global data economy. As data becomes the backbone of global governance, private sector actors become key providers of experimental dataveillance practices. We know little about how they think about the difference between aid and experimentation or their vision of data justice. On a conceptual level, we need a better grasp of children's digital bodies in aid, how they are produced and what harms might arise. Furthermore, in the specific case of wearables, it is unclear what the underlying political economy of exchange is. If wearables have almost no cost and the wearer is not compensated for carrying it, but the data circulating back to the private sector actor has significant commercial value, we could think of this as unpaid labor (potentially giving rise to difficult questions about forced labor and child labor) – or as gifts.

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#### **Notes on contributor**

Kristin Bergtora Sandvik (S. J. D Harvard Law School 2008) is a professor of legal sociology at the Faculty of Law, University of Oslo and a Research Professor in Humanitarian Studies at PRIO. Her work focuses on refugee resettlement, legal mobilization, humanitarian technology, innovation and accountability. [email: bergtora@prio.org]



#### **ORCID**

Kristin Bergtora Sandvik http://orcid.org/0000-0003-4671-6410

#### References

- Aas, K. F. (2006). 'The body does not lie': Identity, risk and trust in technoculture. Crime, Media, Culture: An International Journal, 2(2), 143-158. https://doi.org/10.1177/1741659006065401
- Al Dahdah, M. (2019). Between philanthropy and big business: The rise of mHealth in the global health market. Development and Change, https://doi.org/10.1111/dech.12497
- Burns, R. (2015). Rethinking big data in digital humanitarianism: Practices, epistemologies, and social relations. GeoJournal, 80(4), 477-490. https://doi.org/10.1007/s10708-014-9599-x
- Calhoun, C. (2010). The idea of emergency: Humanitarian action and global (dis) order. Zone
- Carter, S., Green, I., & Speed, E. (2018). Digital technologies and the biomedicalisation of everyday activities: The case of walking and cycling. Sociology Compass, 12(4), e12572. https://doi.org/10. 1111/soc4.12572
- Castillo, N. M., & Vosloo, S. (2017). Khushi Baby: Case study by UNESCO-Pearson Initiative for Literacy, https://unesdoc.unesco.org/ark:/48223/pf0000260596
- Collier, S., Cross, J., Redfield, P., & Street, A. (2017). Issue 9: Little development devices / humanitarian goods, https://limn.it/articles/precis-little-development-devices-humanitarian-goods/
- Degli, S. E. (2014). When big data meets dataveillance: The hidden side of analytics. Surveillance & Society, 12(2), 209–225. https://doi.org/10.24908/ss.v12i2.5113
- Donovan, K. P. (2015). Infrastructuring aid: Materializing humanitarianism in northern Kenya. Environment and Planning D: Society and Space, 33(4), 732-748. https://doi.org/10.1177/ 0263775815598107
- Geneva Health forum. (n.d.g). Wearable mHealth solution for maternal and child health at the last mile. http://ghf2020.g2 hp.net/wpcproduct/khushi-baby/
- Globalinnovationexchange. (2019).https://www.globalinnovationexchange.org/innovation/ khushi-baby-e14644e1-93b3-4f51-a9ed-d779d00012c4
- Haggerty, K. D., & Ericson, R. V. (2000). The surveillant assemblage. British Journal of Sociology, 51 (4), 605–622. https://doi.org/10.1080/00071310020015280
- Haraway, D. (1985). Manifesto for cyborgs: Science, technology, and socialist feminism in the 1980s. Socialist Review, 15(2), 65-108.
- Headrick, D. R. (1981). The tools of empire: Technology and European imperialism in the nineteenth century. Oxford University Press.
- Idemia. (2017). OT-Morpho partners with Khushi Baby to deliver advanced health monitoring of mothers and children in India https://www.idemia.com/press-release/ot-morpho-partnerskhushi-baby-deliver-advanced-health-monitoring-mothers-and-children-india-2017-07-12
- Jacobsen, K. L. (2015). Experimentation in humanitarian locations: UNHCR and biometric registration of Afghan refugees. Security Dialogue, 46(2), 144-164. https://doi.org/10.1177/ 0967010614552545
- Jacobsen, K. L., & Sandvik, K. B. (2018). UNHCR and the pursuit of international protection: Accountability through technology? Third World Quarterly, 39(8), 1508-1524. https://doi.org/ 10.1080/01436597.2018.1432346
- Khushi annual report 2016. (2016). https://www.khushibaby.org/KhushiBabyAnnualReport 2016.
- Khushi annual report 2017-18. (2018). https://www.khushibaby.org/KhushiBabyAnnualReport 2017-18.pdf
- Legoullon, P. (2017). Khushi Baby, for better vaccination of children and better monitoring of pregnancies in Indian rural areas. Fondation Pierre Fabre https://www.odess.io/files/documents/ enquetes/CR ODESS2017-KhushiBaby English.pdf
- Livingstone, S., & Bulger, M. (2014). A global research agenda for children's rights in the digital age. Journal of Children and Media, 8(4), 317-335. https://doi.org/10.1080/17482798.2014.961496



- Lupton, D. (2016). The quantified self: A sociology of self-tracking. Polity Press.
- Lupton, D., & Williamson, B. (2017). The datafied child: The dataveillance of children and implications for their rights. New Media & Society, 19(5), 780-794. https://doi.org/10.1177/ 1461444816686328
- Michael, K. (2017). June 14, 2017 Novel NFC Applications to Enrich Our Connections. http://www. katinamichael.com/opinion/tag/innovation
- Muhindi, S. (2019). IDEMIA loses bid to block 10-year ban https://www.the-star.co.ke/news/2019-05-13-idemia-loses-bid-to-block-10-year-ban/
- Nagar, R. B. (2014). https://www.changemakers.com/sustliving2014/entries/khushi-baby-inc
- Nagar, R. B. (2016). Tying community engagement with appropriate technology at the last mile: A cluster randomized trial to determine the effectiveness of a novel, digital pendant and voice reminder platform on increasing infant immunization adherence among mothers in rural Udaipudr, India. http://elischolar.library.yale.edu/ysphtdl/1203
- Nagar, R. B. (2017). https://khushibaby.wordpress.com/2017/02/26/field-notes-5/
- Nagar, R. B. (2019). https://challenges.openideo.com/challenge/briefsgates-vaccine-innovation/ ideas/khushi-baby
- Nagar, R. B., Venkat, P., Stone, L. D., Engel, K. A., Sadda, P., & Shahnawaz, M. (2018). A cluster randomized trial to determine the effectiveness of a novel, digital pendant and voice reminder platform on increasing infant immunization adherence in rural Udaipur, India. Vaccine, 36 (44), 6567–6577. https://doi.org/10.1016/j.vaccine.2017.11.023.
- Nahar, P., Kannuri, N. K., Mikkilineni, S., Murthy, G. V. S., & Phillimore, P. (2017). mHealth and the management of chronic conditions in rural areas: A note of caution from southern India. Anthropology & Medicine, 24(1), 1−16.
- NFC forum. (2017). https://nfc-forum.org/resources/khushi-baby-engaging-community-wearablehealth/
- O'Riordan, K. (2011). Revisiting digital technologies: Envisioning biodigital bodies. Communications, 36(3), 291–312. https://doi.org/10.1515/comm.2011.015
- Papreen, N., Kannuri, N. K., Mikkilineni, S., Murthy, G. V. S., & Phillimore, P. (2017). Mhealth and the management of chronic conditions in rural areas: A note of caution from southern India. Anthropology & Medicine, 24(1), 1-16. https://doi.org/10.1080/13648470.2016.1263824.
- (2017).Planetbiometrics. https://www.planetbiometrics.com/article-details/i/6081/desc/otmorpho-partners-with-khushi-baby-on-infant-biometric-project/
- Read, R., Taithe, B., & Mac Ginty, R. (2016). Data hubris? Humanitarian information systems and the mirage of technology. Third World Quarterly, 37(8), 1314-1331. https://doi.org/10.1080/ 01436597.2015.1136208
- Redfield, P. (2012). Bioexpectations: Life technologies as humanitarian goods. Public Culture, 24 (1)(66), 157–184. https://doi.org/10.1215/08992363-1443592
- Roth, S., & Luczak-Roesch, M. (2020). Deconstructing the data life-cycle in digital humanitarianism. Information, Communication & Society, 23(4), 555-571. https://doi.org/10.1080/1369118X. 2018.1521457
- Ruckenstein, M. (2014). Visualized and interacted life: Personal analytics and engagements with data doubles. Societies, 4(1), 68–84. https://doi.org/10.3390/soc4010068
- Ruckenstein, M., & Schüll, N. D. (2017). The datafication of health. *Annual Review of Anthropology*, 46(1), 261–278. https://doi.org/10.1146/annurev-anthro-102116-041244
- Salter, M. B., Cohn, C., Neal, A. W., Wibben, A. T., Burgess, J. P., Elbe, S., & Williams, M. C. (2019). Horizon scan: Critical security studies for the next 50 years. Security Dialogue, 50(4), 9-37. https://doi.org/10.1177/0967010619862912.
- Sandvik, K. B. (2017). Now is the time to deliver: Looking for humanitarian innovation's theory of change. Journal of International Humanitarian Action, 2(1), 1-11. https://doi.org/10.1186/ s41018-017-0023-2.
- Sandvik, K. B. (2019). Making wearables in aid: Digital bodies, data and gifts. Journal of Humanitarian Affairs, 1(3), 33-41. https://doi.org/10.7227/JHA.023

- Sandvik, K. B., Jacobsen, K. L., & McDonald, S. M. (2017). Do no harm: A taxonomy of the challenges of humanitarian experimentation. International Review of the Red Cross, 99(904), 319-344. https://doi.org/10.1017/S181638311700042X
- Sandvik, K. B., Jumbert, M. G., Karlsrud, J., & Kaufmann, M. (2014). Humanitarian technology: A critical research agenda. International Review of the Red Cross, 96(893), 219-242.
- Sandvik, K. B., & Raymond, N. A. (2017). Beyond the protective effect: Towards a theory of harm for information communication technologies in mass atrocity response. Genocide Studies and Prevention: An International Journal, 11(1), 9-24. https://doi.org/10.5038/1911-9933.11.1.1454
- Schwittay, A., & Braund, P. (2018). Participation 2.0? Crowdsourcing participatory development@ DFID. Information Technologies & International Development, 15, 1–15.
- Scott-Smith, T. (2016). Humanitarian neophilia: The 'innovation turn' and its implications. Third World Quarterly, 37(12), 2229-2251. https://doi.org/10.1080/01436597.2016.1176856
- SEASYale. (2015). https://seas.yale.edu/news-events/news/khushi-baby-started-ceid-wins-unicef-
- SEASYale. (2017). CEID-made Khushi Baby advances its mission with expanded trials, March 15 https://seas.yale.edu/news-events/news/ceid-made-khushi-baby-advances-its-missionexpanded-trials
- Segura, M. S., & Waisbord, S. (2019). Between data capitalism and data citizenship. Television & New Media, 20(4), 412–419. https://doi.org/10.1177/1527476419834519
- Tapia, A., & Maitland, C. (2009). Wireless devices for humanitarian data collection: The socio-technical implications for multi-level organizational change. *Information, Communication & Society*, 12(4), 584-604. https://doi.org/10.1080/13691180902857637
- Taylor, L. (2017). What is data justice? The case for connecting digital rights and freedoms globally. Big Data & Society, 4(2), 2053951717736335. https://doi.org/10.1177/2053951717736335
- Taylor, L., & Broeders, D. (2015). In the name of development: Power, profit and the datafication of the global South. Geoforum; Journal of Physical, Human, and Regional Geosciences, 64, 229-237. https://doi.org/10.1016/j.geoforum.2015.07.002
- Thatcher, J., O'Sullivan, D., & Mahmoudi, D. (2016). Data colonialism through accumulation by dispossession: New metaphors for daily data. Environment and Planning D: Society and Space, 34(6), 990–1006. https://doi.org/10.1177/0263775816633195
- Uchegbu, A. (2014). From class project to health startup, https://yaledailynews.com/blog/2014/11/ 13/from-class-project-to-health-start-up/
- UNICEF. (2015). https://wearablesforgood.com/finalist-khushi-baby/
- Van Dijck, J. (2014). Datafication, dataism and dataveillance: Big data between scientific paradigm and ideology. Surveillance & Society, 12(2), 197-208. https://doi.org/10.24908/ss.v12i2.4776
- Van Dijck, J. (2014). Datafication, dataism and dataveillance: Big Data between scientific paradigm and ideology. Surveillance & Society, 12(2), 197-208.
- Venkat, P. G. (2016). Intermediate assessment of the Khushi Baby Crct: Implementation of a novel Mhealth solution for vaccination record keeping in rural Udaipur, Rajasthan, India. http:// elischolar.library.yale.edu/ysphtdl/1300
- Weforum. (2015). 6 ways tech can transform humanitarian response https://www.weforum.org/ agenda/2015/12/6-ways-technology-can-transform-humanitarian-response/
- Wissinger, E. (2017). Wearable tech, bodies, and gender. Sociology Compass, 11(11), e12514. https:// doi.org/10.1111/soc4.12514
- Wissinger, E. (2018). Blood, sweat, and tears: Navigating creepy versus cool in wearable biotech. Information, Communication & Society, 21(5), 779-785. https://doi.org/10.1080/1369118X. 2018.1428657
- Women's Forum. (2019). Meet the top 10 of the women & access to health call for initiatives! Women's forum for the economy & society. http://www.womens-forum.com/news/Finalists-Women-Access-Health-Call-for-Initiatives.