Ethics of AI in global health research

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Case study
Ethical issues associated with the development of an ear biometric tool for patient identification in Zambia

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Brief description of the research project

In 2017, with funding from the Fogarty International Center at NIH, we launched Project SEARCH (Scanning EARs for Child Health). Our team has focused on uniquely solving the challenge of identifying patients – through biometric analysis of ears. Ears have significant advantages over other biometric targets: facial scans raise privacy concerns; iris scanners are expensive and can frighten small children, and fingerprint scans perform poorly in children <5 years. We created a powerful mHealth identification App (the SEARCH App) that runs on the ubiquitous Android operating system[1,2]. In field studies, the SEARCH App achieved near-perfect subject identification among Zambian infants as young as six months old, a significant advance over fingerprint technology[3,4]. Building on this foundation, the project intends to show the value of integrating SEARCH's biometric ID system with the SmartCare EMR (the electronic medical records system used in public health institutions in Zambia).

Background

In 2005, the President's Emergency Plan for AIDS Relief (PEPFAR) funded a collaboration between Zambia's Ministry of Health (MOH) and the CDC to deploy an electronic management system to coordinate the delivery of HIV care. Since its initiation SmartCare has been scaled up and expanded to track outpatient care, maternal/child health, tuberculosis treatments, and monitor the status of orphans and vulnerable children. SmartCare relies on a 'CareCard' as the primary identifier. Physically, the CareCard resembles an ATM bank card with a magnetic strip. In pediatric HIV care, these cards are issued to the child's guardians.

Relying on the CareCard for identification has proven a critical limitation of SmartCare. As with paper Under-Five Carecards (UFCs), the cards are easily lost, damaged, or used inadvertently by another individual (the cards do not display a name or photograph, just the assigned ART number). Additionally, they suffer from a high rate of technical error when damaged cards cannot be scanned, when the internet goes down, or when the software is incompatible between card and reader – all of which occur frequently. If the patient has lost or forgotten their CareCard or is using someone else's card, or when there is a technical failure, demographic information (such as names and dates of birth) is used in an often-fruitless attempt to find the patient in the SmartCare database. Each failure requires that a new identity be created for that individual and a new CareCard issued. With a 30-40% combined failure rate, patients quickly accumulate handfuls of these cards, spreading their medical history across multiple unlinked aliases in SmartCare's database. Given these limitations, some clinics have reverted to using paper registries to duplicate the electronic, undermining the motivating rationale for an EMR. The work of disambiguating double documentation for paper and electronic forms creates backlogs going back months. Even when eventually entered electronically, the data are so late and incomplete as to be practically useless for programmatic monitoring. And the problem is not unique to Zambia: in South Africa, our team encountered similar challenges when trying to track ART retention due to the proliferation of aliases in the national EMR[5].

Ethical Issues

Issue #1: Fairness and equity

Bias in data is a challenge that presented itself early on in the project. The team was initially limited to using datasets collected at the Museum of Science in Boston to finetune the biometric tool. Publicly accessible datasets of darker-coloured ears captured in controlled conditions could not be found at the time. Initial tests conducted with the tool on a dataset in Lusaka (Zambia) showed a drop-off in performance. It was clear at this time that a major limitation to future work would come from the fact that the training datasets in use at the time were not representative of the intended use-case population. This necessitated a data collection exercise primarily focused on creating a dataset of darker-coloured ears captured from young Zambian infants. Data from 224 infants were captured while attending vaccination visits at Chawama First Level Hospital in Lusaka from November 2019 to April 2020. Images were taken by one data collector, who was thoroughly trained in the use of the data collection tool. Two images were taken of both the left and right ear were taken at each visit.

Written consent forms (approved by both the Boston University IRB and the University of Zambia Biomedical Research Ethics Committee) translated into two local languages, were provided to all the study participants. The intended use of the data was laid out in the consent form. Participants who provided consent and intended to attend well-child visits at the facility in the future were included in the study.

The various tests conducted on the datasets early on in the project allowed us to identify data bias and the resulting algorithmic harm early in the development process. The main issue identified was that we would have ended up developing a tool that would perform poorly in its targeted setting. Our images were captured with the assistance of a 3D-printed opaque plastic cylinder we call the ‘Donut’. The Donut is mounted to a phone and allows for the standardisation of conditions during image capture - angle, distance to ear and lighting. The contrast between the darker ears and the light-coloured material of the Donut would lead to the camera’s auto-exposure feature underexposing (darkening) the ear to avoid having too bright of a background. This was not a problem with the earlier datasets that had a majority of light-coloured ears. At that time, our tool could not extract enough detail from the images as some of the ear features could not be identified in the overexposed images. We went on to employ a few post-image capture techniques that would assist our tool in feature extraction in later versions of the tool. It is indeed possible that while relying on datasets collected in Boston, we could have stumbled on some version of this problem. The performance loss we saw on initial tests with the locally collected dataset meant that we tackled this problem earlier in the project.

Issue #2: Transparency and engagement

A series of focus group discussions and interviews were conducted with mothers and health officials in Zambia's rural and urban settings. The University of Zambia Biomedical Research Ethics Committee granted ethical approval for this activity. The key focus of this activity was to engage the stated stakeholders and gain an understanding of how receptive the community would be to the app being developed.

Participants were recruited from three health facilities in Lusaka and Southern provinces. Focus group participants were recruited using a set of inclusion criteria: 1) they were mothers younger than 45 years of age, 2) had one or more children, and 3) had experience using the UFC (paper-based under-five card). Participants were approached during their clinic visits, had the study described to them, and underwent a consent discussion. In total, focus group discussions were conducted with 59 mothers across the three health facilities. Participants were recruited until budgetary and timing constraints didn’t allow for further recruitment. Participants received information on the study in their preferred language.

In-depth interviews were conducted with the nurses in charge and clinicians at each of the three facilities as well as the District Health Director (DHD) or Information Officers (IO) at the district level. We felt that this group would help us answer these questions:

- What are their perceptions on the use of biometrics as a tool for child identification in place of a child health card?
- Would a biometric identification system generate value for healthcare workers?
- What concerns could they anticipate about the community's acceptance of a biometric system?
- In what way would end-users (clinicians, parents and children) react to a biometric system?

Potential clinic staff participants had the purpose of the study described to them and underwent a consent discussion.

Partner acceptance was an issue that some mothers expressed concern over. Mothers highlighted their partner's aversion to western world technologies, fear of malicious intent, and general unwillingness to support change.

Being aware that we were inserting ourselves into an environment with a tool that the key stakeholders were encountering for the first time meant that community engagement activities had to be conducted. With that in mind, these activities were included in the grant application that was submitted to the funding agency. It might have seemed a bit premature to be conducting this level of engagement since we were not yet at the implementation stage, but we thought it was important to get the views of the likely end users and the mothers earlier in the process. An EHR system has been used in public health facilities across the country for at least the past decade, but we felt that there would be a distrust of our tool which was more people-facing than an EHR system running in the background that patients never have to interact with. The main takeaway from these activities was that further engagement was needed to get over the various sociocultural barriers that stood in the way of an eventual rollout[6].

Conclusions

Adequate community sensitisation will be key in tackling the sociocultural issues that cause hesitance toward proposed digital solutions. The invasive nature of capturing biometric data goes further to heighten fears around technology. We generally feel that the task of community engagement must be shared by both researchers and the Ministry of Health. The Ministry has an important role in dispelling any fears that the populace might have towards AI tools and new technologies as a whole. If this is communicated to clinicians and the patient populace, an eventual rollout would occur with minimal issues. Researchers still have a very important role to play in clearly laying out how the tool will benefit the end users.

References

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