

Data Pipeline for Digitizing Perioperative Flowsheets from Low Middle Income Countries

**Assessing the Effectiveness of Patient-Engagement Tools in Enhancing Representation in
Healthcare Systems**

A Thesis Prospectus

In STS 4500

Presented to

The Faculty of the

School of Engineering and Applied Science

University of Virginia

In Partial Fulfillment of the Requirements for the Degree

Bachelor of Science in Systems Engineering

By

Christos Chen

November 1, 2021

Technical Team Members:

Christos Chen, Darren Klein, Mariam Guirguis

On my honor as a University student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments.

ADVISORS

Sean Ferguson, Department of Engineering and Society

Donald Brown, Department of Systems and Information Engineering

Introduction

In the majority of high-income countries, medical data is digitally recorded pervasively in both operative and nonoperative settings. The collection of such data in a healthcare setting enables the potential for the improvement of medical practices, healthcare policies, and ultimately - patient outcomes. Today's increasingly data-rich society brings a multitude of opportunities and challenges for the building of a better tomorrow. The ability of most low- and middle-income (LMIC) countries to support digital medical data collection for research and quality improvement is limited due to numerous barriers, including limited resources, poor IT infrastructure, and insufficient data collection tools (Tuti et al, 2015). In an effort to reduce these barriers, my capstone team is working to develop and improve a data pipeline that would enable real-time feedback in the operating room as well as enable historical data digitization to improve patient outcomes at the University Teaching Hospital of Kigali in Rwanda (CHUK). The implications of the implementation of such data infrastructure could be wide-ranging, as the digitization of historical medical data will provide researchers and healthcare providers the ability to improve quality of care and evaluate macro-metrics for health outcomes in Rwanda. However, as with all data-driven technologies, implementation brings the potential for the exacerbation of existing inequalities due to a lack of representation of communities who may need care the most (Ibrahim et al, 2021).

In recent years, healthcare systems have aimed to utilize patient engagement strategies to improve equitable care delivery with technologies such as patient reported outcome measures (PROMs) and mobile-health (M-Health) technologies, such as wearable sensors. These tools have been found to provide invaluable insights into driving patient-centered care, increasing point of contact, and improving overall patient representation in healthcare systems. However, there are a number of barriers that limit where patient engagement strategies may be effectively implemented and the benefits reaped have been found to be differential among different communities.

This paper will explore the development and improvement of medical data infrastructure in Rwanda and assess the effectiveness of existing patient engagement approaches in improving equitable representation in healthcare systems.

Technical Topic

Surgical mortality is ten times greater in developing countries than developed countries (Weiser et al, 2008). Notably, many of the surgical operations performed on patients in LMIC are deemed low-risk by hospitals from HIC, yet have a high perioperative mortality rate (POMR) in LMIC. Specifically, cesarean sections are an example of low-risk operations that have a high POMR in LMIC, where 94% of all maternal deaths occur (World Health Organization, 2019). Literature has championed POMR as a useful indicator of institutional and national surgical safety (Ng-Kamstra JS et al, 2018). To actively track health indicators such as POMR, there must be robust, accurate collection of data in a standardized and centralized fashion. However, current practices in most LMIC are paper-based, inhibiting the storage of copious amounts of historical data and the ability to understand macro health trends. In Africa, within which Rwanda sits, the POMR is twice greater than the global average (Biccard et al, 2018). Employment of simple preoperative risk calculators has been found to be inadequate for improving outcomes, demonstrating the need for advanced risk assessment inclusive of intra-operative and continuous, longitudinal post-operative data (ASOS-2 Investigators, 2021). Aiming to combat high POMR in LMIC, my capstone team is working with Rwandan healthcare practitioners to improve the existing data infrastructure system at CHUK.

The technical advisor for the capstone project is Professor Donald Brown of the Department of Systems and Information Engineering. Dr. Marcel Durieux of the Department of Anesthesiology in the School of Medicine is providing continual guidance and support for the capstone team. The capstone team is continuing work done by previous Systems Engineering capstone teams (2019-2020 and 2021-2021).

The current process enlists the user to utilize a mobile application to scan the paper flowsheet inside of a wooden apparatus named SARA, which was created to ensure consistent quality of scans. The user will then approve or retake the scan and send it to the University of Virginia, who will receive encrypted scans via email, and receive confirmation of successful flowsheet data delivery. The data will then be decrypted and fed into image processing analytics systems. In this phase, images will be cropped into three sections (checkbox, graphical, and handwritten), from which data is extracted. The improvement of the analytical image processing will be the focus of the graduate members from the School of Data Science. In the last stage, the extracted, processed data will be cleaned, stored in a PostgreSQL database, and delivered back to CHUK. There currently does not exist a process for the storage and return of data to CHUK.

Our objective is to improve the existing system to enhance surgical outcomes and optimize care-providers' engagements with existing data infrastructure and processes. Through conversations with stakeholders, several key opportunities for improvement have been identified. The app currently has no method for returning processed data to CHUK, preventing collected data from informing surgical decisions and outcomes. To bridge this gap, the team has proposed the development of health-metrics-risk calculation, informing doctors of a patient's risk rapidly after surgical operations via ingested flowsheet data. It was also found that the mobile application lacks thorough testing, and may hold usability barriers particularly with older audiences. To improve user experience with the app, stakeholders and users will be engaged to identify opportunities for optimizing usability and experience. Some scans performed with the mobile application may be ineffectual candidates for image processing due to factors such as light ink, even with devices such as SARA working to improve consistency. To improve the quality of data ingestion, the capstone team proposes the development of an interpretability score to inform the user of scan quality in real-time, with a rejection threshold rejecting scans scoring poorly in analytical interpretability, which have the potential to harm data integrity.

With the proposed changes, the existing system's data veracity, volume, value, and efficiency will be improved. The value-add generated by improvements will maintain the streamlined nature of the user-experience, while providing real-time interactive, actionable insights to medical practitioners and management.

STS Topic

In recent years, great effort has been applied to assessing the quality of patient care. These efforts have been driven by desires to decrease inequalities within healthcare systems (Chow, A. et al, 2009). Patient engagement can improve governance and delivery of services, and shape patient and provider policies and education (Bombard, Y. et al, 2018). Patient Reported Outcome Measures (PROMs) have become an increasingly popular method of engaging with patients with a health condition by assessing their feel and function. Data collected from PROMs can then be utilized to shape organizational structures, outcomes, and processes to improve healthcare systems (Chow et al, 2009). Another form of patient engagement that has become increasingly prevalent is M-Health. The World Health Organization(2011) defines M-Health as "medical and health practice supported by mobile health devices", and M-Health has had increasing adoption in recent years, supporting the prevalence of patient-centered data. This data has the potential to

improve health accessibility, support greater care delivery, and enhance diagnosis and treatment accuracy (Cunningham et al, 2016). I will examine the effectiveness of patient-engaging innovations in the healthcare delivery-space such as PROMs and M-Health in improving patient representation and involvement in health systems.

The growing availability of healthcare data has driven the desire for increased personal care. Efforts have been made in recent years to better engage patients in healthcare systems in efforts to reduce inequity and improve patient-centered care. The use of PROMs has been found to enhance communication between individuals and care providers, ensuring that healthcare decisions are sourced from collaboratively-identified patient needs while also increasing discussions about patient experience, and uncovering undiagnosed patient health states and preferences (Rutherford, C. et al, 2021).

Both PROMs and m-Health strategies aim to utilize individual health data with the intention of centering care around the patient. Many frameworks have been developed in efforts to evaluate equitable practices in data-driven systems. To investigate the strengths and limitations of various patient-engagement strategies in increasing equity in healthcare systems, the data feminism framework described by Klein and D' Ignazio will be applied in the following evaluation. The Data Feminism framework ascertains that those who work with data should: (1) Examine power (2) Challenge power (3) Elevate emotion and embodiment (4) Rethink binaries and hierarchies (5) Embrace pluralism (6) Consider context (7) Make labor visible (D'Ignazio and Klein, 2020).

The true representativeness of the PROMs process is examined upon an interrogation of patient-engagement data that may be left out of the PROM process. A high level of support is required to help patients complete PROMs, support implementation, and enter data for paper-based PROMs. As a result, the data collected from PROMs is likely to exclude invaluable data of communities that lack adequate resources for PROM collection and potentially improperly prescribe unrepresentative treatments in effect. While PROMs were found to increase the effectiveness of triaging patient care, the patient-responsibility of providing subjective-experience based health state descriptions has the potential to worsen existing cultural, racial, or gender-based disparities as stigmas may inhibit marginalized groups to inaccurately or under-report health states or outcomes. It was found that even after accounting for socioeconomic factors, perceptions of discrimination incrementally contribute to racial disparities in self-reported health (Williams and Collins, 2001).

The collection of data from PROMs should be tied to actionable, equitable treatments that fight the existing biases that have led minority individuals to receive unequal medical treatment, despite reporting similar health states as their counterparts. Studies have shown that even seemingly equitable healthcare decisions, such as identical treatments for identical reported symptoms, may result in differential efficacy amongst different ethnic populations (Campbell and Edwards, 2012). Thus, data collection afforded by PROMs must seek to integrate cultural context, with an understanding of the systemic power structures affecting patient care and outcome differentials. Without robust understanding of such context behind the data, the potential benefits for increasing equitable, representative treatment are limited at best, and may even worsen existing disparities through the ignorance of the power dynamics situating collected data.

In addition, the method of the implementation of PROMs will affect the manners in which the data is situated, and the underlying power structures that shape the stories that are able to be shared. Digital implementation of PROMs, while popular in many HIC with advanced, robust digital infrastructure, has the potential to exclude marginalized voices who may be in most need of improved, context-driven care but find themselves excluded due to the digital divide. Equipped with invaluable, patient-reported data - healthcare practitioners must consider the ways in which the provided data is situated in a cultural, political, and social context and the various power differentials that shape data collected. An interrogation of underlying power structures proves necessary in this context for adequately addressing inequities that result from patient-centered data collection processes like PROMs.

Meanwhile, the emergence and rapid growth of mHealth strategies have created a unique opportunity to engage communities. Racial and ethnic minorities are more likely to use their mobile apps to access health information (Ray et al, 2017). Thus, M-health affords the potential for empowering the voices of the underrepresented, and could equip researchers and practitioners with the ability to create more inclusive, equitable healthcare systems. However, many existing socioculturally tailored mHealth solutions have not embraced a pluralism of diverse perspectives beyond usability studies (Huh et al, 2018). Thus, many M-Health solutions have been developed with a dearth of context, depriving their potential to empower marginalized communities and fight power differentials. Consequently, these have the ability to exacerbate disparities in some communities, while providing incremental benefits to other communities.

Next Steps

Future work in the coming months entails performing the following tasks, with literature review being performed throughout as needed.

Technical Project Schedule

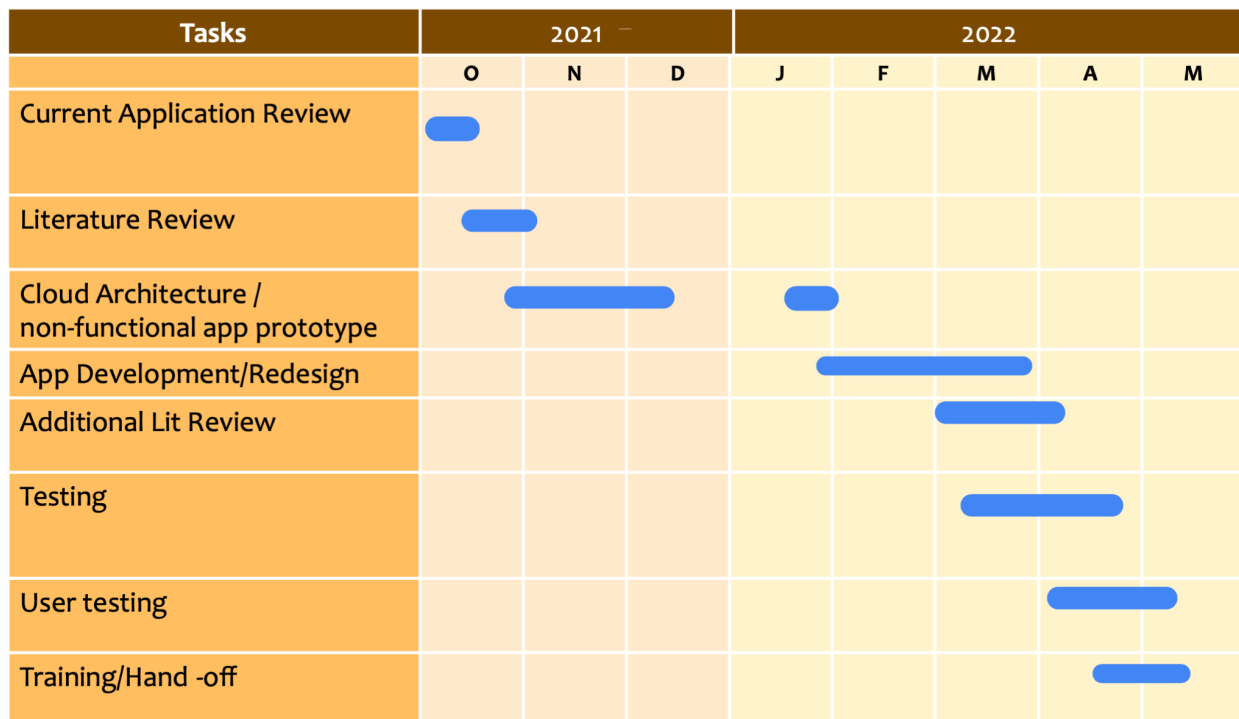


Figure 1. Proposed Schedule for Technical Project.

Looking towards the future, the STS project will aim to potentially include some diverse perspectives from healthcare practitioners on how the PROMS, mHealth technologies, and others affect and inform the work that they do - aiming to collect their experiences with such technologies affording more equitable care. The STS project will aim to further explore the differentials between HIC and LMIC in the benefits and risks that are afforded by the employment of patient health engagement strategies such as mHealth and PROMS. In particular, questions such as scalability should be brought into question. Should health systems be scalable and deliver more generalized benefits, or does each health system require engagement strategies tailored to socio-economic and cultural factors within LMIC? In the same way that IT solutions may not be cut and dropped into LMIC areas with undifferentiated benefits, I will consider examining frameworks for individuals and

organizations to evaluate patient engagement strategies so that they may optimize patient representation in healthcare systems and thus the benefits delivered.

STS Research Project Timeline

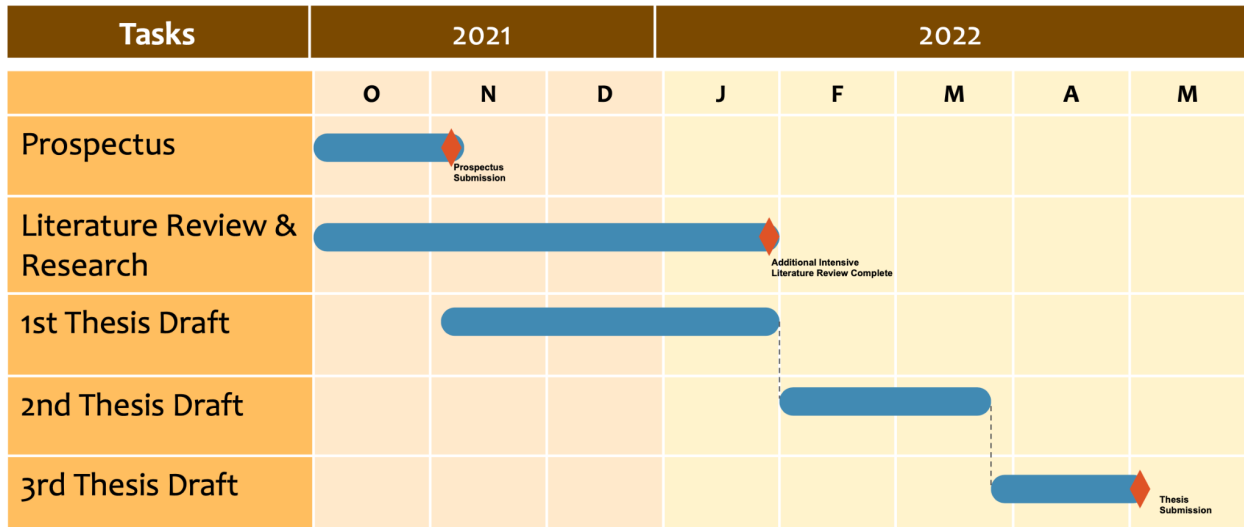


Figure 2. Proposed Schedule for STS Project

References

- Koumpouros, Y. (2014). Big Data in Healthcare. In A. Moumtzoglou, & A. Kastania (Eds.), *Cloud Computing Applications for Quality Health Care Delivery*(pp. 35-58). IGI Global. <http://doi:10.4018/978-1-4666-6118-9.ch003>
- D'Ignazio, C., & Klein, L. (2020). Seven intersectional feminist principles for equitable and actionable COVID-19 data. *Big data & society*, 7(2), 2053951720942544. <https://doi.org/10.1177/2053951720942544>
- Ibrahim, H., Liu, X., Zariffa, N., Morris, A. D., & Denniston, A. K. (2021). Health data poverty: an assailable barrier to equitable digital health care. *The Lancet. Digital health*, 3(4), e260–e265. [https://doi.org/10.1016/S2589-7500\(20\)30317-4](https://doi.org/10.1016/S2589-7500(20)30317-4)
- Tuti, T., Bitok, M., Paton, C., Makone, B., Malla, L., Muinga, N., Gathara, D., & English, M. (2016). Innovating to enhance clinical data management using non-commercial and open source solutions across a multi-center network supporting inpatient pediatric care and research in Kenya. *Journal of the American Medical Informatics Association : JAMIA*, 23(1), 184–192. <https://doi.org/10.1093/jamia/ocv028>
- Weiser, T. G., Regenbogen, S. E., Thompson, K. D., Haynes, A. B., Lipsitz, S. R., Berry, W. R., & Gawande, A. A. (2008). An estimation of the global volume of surgery: a modelling strategy based on available data. *Lancet (London, England)*, 372(9633), 139–144. [https://doi.org/10.1016/S0140-6736\(08\)60878-8](https://doi.org/10.1016/S0140-6736(08)60878-8)
- Ng-Kamstra JS, Arya S, Greenberg SLM, et al (2018). Perioperative mortality rates in low-income and middle-income countries: a systematic review and meta-analysis. *BMJ Global Health* 2018;3:e000810.
- World Health Organization. (2019). Trends in maternal mortality 2000 to 2017: estimates by WHO, UNICEF, UNFPA, World Bank Group and the United Nations Population Division. World Health Organization. <https://apps.who.int/iris/handle/10665/327595>. License: CC BY-NC-SA 3.0 IGO
- Biccard, B. M., Madiba, T. E., Kluyts, H. L., Munlemvo, D. M., Madzimbamuto, F. D., Basenero, A., Gordon, C. S., Youssouf, C., Rakotoarison, S. R., Gobin, V., Samateh, A.

- L., Sani, C. M., Omigbodun, A. O., Amanor-Boadu, S. D., Tumukunde, J. T., Esterhuizen, T. M., Manach, Y. L., Forget, P., Elkhogia, A. M., Mehyaoui, R. M., ... African Surgical Outcomes Study (ASOS) investigators (2018). Perioperative patient outcomes in the African Surgical Outcomes Study: a 7-day prospective observational cohort study. *Lancet (London, England)*, 391(10130), 1589–1598. [https://doi.org/10.1016/S0140-6736\(18\)30001-1](https://doi.org/10.1016/S0140-6736(18)30001-1)
- ASOS-2 Investigators (2021). Enhanced postoperative surveillance versus standard of care to reduce mortality among adult surgical patients in Africa (ASOS-2): a cluster-randomised controlled trial. *The Lancet. Global health*, 9(10), e1391–e1401. [https://doi.org/10.1016/S2214-109X\(21\)00291-6](https://doi.org/10.1016/S2214-109X(21)00291-6)
- Chow, A., Mayer, E. K., Darzi, A. W., & Athanasiou, T. (2009). Patient-reported outcome measures: the importance of patient satisfaction in surgery. *Surgery*, 146(3), 435–443. <https://doi.org/10.1016/j.surg.2009.03.019>
- Bombard, Y., Baker, G. R., Orlando, E., Fancott, C., Bhatia, P., Casalino, S., Onate, K., Denis, J. L., & Pomey, M. P. (2018). Engaging patients to improve quality of care: a systematic review. *Implementation science : IS*, 13(1), 98. <https://doi.org/10.1186/s13012-018-0784-z>
- Rutherford, C., Campbell, R., Tinsley, M. et al. Implementing Patient-Reported Outcome Measures into Clinical Practice Across NSW: Mixed Methods Evaluation of the First Year. *Applied Research Quality Life* 16, 1265–1284 (2021). <https://doi.org/10.1007/s11482-020-09817-2>
- Williams, D. R., & Collins, C. (2001). Racial residential segregation: a fundamental cause of racial disparities in health. *Public health reports (Washington, D.C. : 1974)*, 116(5), 404–416. <https://doi.org/10.1093/phr/116.5.404>
- Campbell, Claudia M, and Robert R Edwards. "Ethnic differences in pain and pain management." *Pain management* vol. 2,3 (2012): 219-230. doi:10.2217/pmt.12.7
- Brewer LC, Fortuna KL, Jones C, Walker R, Hayes SN, Patten CA, Cooper LA(2020). Back to the Future: Achieving Health Equity Through Health Informatics and Digital Health. *JMIR Mhealth Uhealth* 2020;8(1):e14512
- Stover, A.M., Haverman, L., van Oers, H.A. et al. Using an implementation science approach to implement and evaluate patient-reported outcome measures (PROM) initiatives

in routine care settings. *Qual Life Res* (2020).
<https://doi.org/10.1007/s11136-020-02564-9>

P. M. Cunningham et al., "Implications of baseline study findings from rural and deep rural clinics in Ethiopia, Kenya, Malawi and South Africa for the co-design of mHealth4Afrika," 2016 IEEE Global Humanitarian Technology Conference (GHTC), 2016, pp. 666-674, doi: 10.1109/GHTC.2016.7857350.

Huh, J., Koola, J., Contreras, A., Castillo, A. K., Ruiz, M., Tedone, K. G., Yakuta, M., & Schiaffino, M. K. (2018). Consumer Health Informatics Adoption among Underserved Populations: Thinking beyond the Digital Divide. *Yearbook of medical informatics*, 27(1), 146–155. <https://doi.org/10.1055/s-0038-1641217>

Ray, R., Sewell, A. A., Gilbert, K. L., & Roberts, J. D. (2017). Missed Opportunity? Leveraging Mobile Technology to Reduce Racial Health Disparities. *Journal of health politics, policy and law*, 42(5), 901–924. <https://doi.org/10.1215/03616878-3940477>