Case Report

Using cloud-based, open-source technology to evaluate, improve, and rapidly disseminate community-based intervention data

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ABSTRACT

Building Uplifted Families (BUF) is a cross-sector community initiative to improve health and economic disparities in Charlotte, North Carolina. A formative evaluation strategy was used to support iterative process improvement and collaborative engagement of cross-sector partners. To address challenges with electronic data collection through REDCap Cloud, we developed the BUF Rapid Dissemination (BUF-RD) model, a multistage data governance system supplemented by open-source technologies, such as: Stage 1) data collection; Stage 2) data integration and analysis; and Stage 3) dissemination. In Stage 3, results were disseminated through an interactive dashboard developed in RStudio using RShiny and Shiny Server solutions. The BUF-RD model was successfully deployed in a 6-month beta test to reduce the time lapse between data collection and dissemination from 3 months to 2 weeks. Having up-to-date preliminary results led to improved BUF implementation, enhanced stakeholder engagement, and greater responsiveness and alignment of program resources to specific participant needs.

Key words: social determinants of health, data collection, software, cloud computing, technology

INTRODUCTION

Health and economic disparities are a function of social determinants of health (SDoH), the conditions in which people are born, grow, live, work, and age that are shaped by the distribution of money, power, and resources.¹ These disparities have alarming consequences; over one-third of the annual total deaths in the US are attributable to social and economic factors including income inequality and low educational attainment.² The Charlotte-Mecklenburg county of North Carolina (NC) is a community with

persistent health and economic disparities. A recent national study ranked Charlotte-Mecklenburg county 50th out of 50 major metropolitan cities for economic mobility (ie, moving from low to high income).³ This community is the focus of an innovative collaborative effort to address SDoH, in part through improving access to community resources.⁴

The Building Uplifted Families (BUF) initiative is a local community transformation effort in the Renaissance West Community Initiative (RWCI), a residential nonprofit organization. BUF involves

Table 1. System requirements for user-centered design of REDCap Cloud and open-source technology applications

System Requirement	Description
Flexibility and customization	Ongoing community intervention efforts with evolving methods and partnerships
Free and open-source supported	Community-supported program with limited budget; workforce supplemented by students and volunteers
Interoperable with REDCap Cloud and other technology solutions	Existing technology and data collection infrastructure using REDCap Cloud
Web-based access to results with easy user access through multiple technology platforms	User base consists of stakeholders and project leadership with limited time and attention
Scalable to future optimized processes	Expand to future project goals, funding support, and availability of additional data sources (ie, electronic medical record data)

an unprecedented cross-sector community partnership among local healthcare systems, nonprofit health and human service organizations, a local academic institution, and the county's public health department. The initiative was funded as part of the national BUILD Health Challenge which focuses on strengthening cross-sector community partnerships to advance equity.⁵ The BUF intervention is delivered through a team of Life Navigators who work one-on-one with RWCI residents to address SDoH factors of healthcare access, employment, and education through the development of individualized goals and the targeted referral of residents to community resources. Key project stakeholders from each sector are engaged through a Partnership Advisory Board (PAB) that aligns resources, brainstorms solutions for barriers, and makes programmatic decisions.

Communication, shared vision, and informed decision-making are critical barriers to success in complex community improvement efforts such as BUF.^{6,7} Formative evaluation strategies can overcome these barriers by using preliminary results to support iterative process improvement and collaborative engagement among a diverse team of cross-sector partners.^{8–10} The implementation of REDCap Cloud,¹¹ a health information technology solution to collect electronic participant data, created integration challenges with other data sources leading to delays in the synthesis of information for decision support. BUF was a dynamic, pilot program with a broad number of stakeholders and concurrent implementation across multiple sectors (community, education, and healthcare system). Thus, the absence of up-to-date preliminary results created barriers for timely decision-making and program adaptation. To address these challenges, we created the BUF Rapid Dissemination (BUF-RD) model, a structured, multistage data governance system for data collection, analysis, and dissemination of results, supplemented by open-source technologies. This article describes the model development and beta test results.

MATERIALS AND METHODS

Design and technology

Overview

Prior to this work, preliminary results were shared with program staff and the PAB using hard copy reports, developed through manual integration and analysis at 3-month intervals. Our user-centered design process was anchored in the project goal of optimizing the application of current REDCap Cloud technology to reduce the 3-month time lapse. We conducted a detailed assessment of system requirements and current infrastructure limitations using key informant interviews and regular meetings with the Life Navigators and

BUF program manager (Table 1). The following methods to achieve our project goal were identified: i) automating data cleaning and integration to reduce manual labor; ii) standardizing data access and exchange with the BUF program manager; and iii) creating a flexible and adaptable system to incorporate new data sources and allow for rapid iteration. The BUF-RD model was developed to provide governance for data and technology use in 3 distinct stages: 1) data collection, 2) data integration & analysis, and 3) dissemination of results to program staff and project stakeholders. Design and technology considerations for each stage are described below.

Stage 1: data collection

Identified, individual-level participant data were collected by Life Navigators and entered into REDCap Cloud,¹¹ a third-party cloud-based data collection system built on an open-source database created by Vanderbilt University and supported by the National Institutes of Health. Demographic data were collected at enrollment, while other data used to evaluate trends over time (work-force, education, and health) were collected at 3-month intervals. Referrals to resources were recorded as delivered, with a frequency unique to the needs of each participant. Additional program data were collected by the BUF project manager that described the type and availability of referral resources within the RWCI community. Data measuring the cross-sector partnership of BUF were collected by the university data and evaluation team as the frequency and attendance at PAB meetings (program level) and self-report measures of the partnership effectiveness (individual level). Data collection methods are summarized in Table 2.

The REDCap Cloud application programming interface is compatible with open-source programming language and integration with other technology solutions. Our design process identified the need for structured program-level data collection and data exchange with the BUF program manager. Data collection methods were expanded to include Google Sheets, a shared cloud-based spreadsheet available through Google Drive. This method allowed for aggregate counts to be recorded and shared in real time between the data and evaluation team and the BUF program manager. The data and evaluation team monitored data collection quality and completion electronically, and sent regular reports to the BUF program manager.

Stage 2: data integration and analysis

The variety of data sources and types, along with varying frequency of data collection, necessitated an extensive amount of data manipulation. Thus, we prioritized an integrated software solution with combined functionality for data management, analysis, and dissemination. We selected RStudio,¹² a free open-source statistical

Table 2. Summary of data collection methodologies and attributes

Source (Partner)	Population	Level	Type & Method	Measures
Life Navigators (RWCI)	BUF Participants	Individual	Identified, Self-Report	<ul style="list-style-type: none"> • <i>Demographics</i>: gender, age, race, ethnicity, # children in household • <i>Workforce</i>: employment, income • <i>Education</i>: highest level of education, enrollment in education and training programs • <i>Health</i>: self-rated physical and mental health, insurance coverage, access to primary care, utilization of the emergency department
		Individual	Identified, Objective	<ul style="list-style-type: none"> • Referrals to RWCI and Community resources and events
Project Manager (RWCI) Evaluators (University)	RWCI Community BUF Partnership	Program	Aggregate Counts, Objective	• Total number of RWCI resources and events
		Program	Aggregate Counts, Objective	• Frequency and attendance at PAB meetings
		Individual	Deidentified, Self-Report	• Partnership effectiveness

Note: Methodologies described as the data collector (source), subject of evaluation (population), unit of measurement (level), type of data and collection method (type and method), and measures of social determinants of health and process factors in alignment with the evaluation strategy (measures).

Abbreviations: BUF, Building Uplifted Families; PAB, Partnership Advisory Board; RWCI, Renaissance West Community Initiative.

software solution to develop semiautomated code scripts for each process. For the beta test, data were manually downloaded from REDCap and Google Sheets and imported into RStudio. This design will scale to a fully automated system through application programming interface connections between Google Sheets,¹³ REDCap Cloud,¹⁴ and RStudio.

The analytic strategy for the BUF-RD model was descriptive and presented data as aggregated counts, proportions, and changes in proportions over time. These metrics were considered “actionable,” in that they provided an understanding of the participant population (ie, demographic and baseline social and economic factors) to inform targeted intervention adjustments; monitor the alignment between resource needs, availability, and allocation (ie referrals); and track changes in population proportions of social and economic factors over time. Since participant data are identified and collected at 3-month intervals, the data collection and integration protocols are easily adapted into a separate comprehensive effectiveness analysis incorporating multivariate, longitudinal regression models.

Stage 3: dissemination

Results from the analysis were disseminated through the BUF Community Dashboard. The user interface was designed to create an interactive version of the program’s logic model, an organizational method used to plan program activities tied to project goals with measurable outcomes.^{15,16} Logic models are supported as part of a strategic and responsive visual planning process for successful community development measurement systems.¹⁷ The dashboard was created using the RStudio package, RShiny,¹⁸ and web-hosted in the Shiny Server.¹⁹ This space is available for free at the base level, with additional space and services available by subscription. Descriptive results were primarily visualized in the dashboard using the “plotly” package.²⁰ Total participant counts were presented by RWCI community subgroupings (Residence of Renaissance and Little Rock) along with the proportions of demographic factors among overall RWCI and community subgroupings (Figure 1a). The aggregated counts of referral types were presented by main and subcategories using an interactive sunburst chart (“sunburstR” package²¹) that displays proportions using layered rings based on a hierarchical

structure (Figure 1b). Total counts of main referral categories were also presented monthly over time. Data collected at multiple time points (workforce, education, & health) were presented as changes in population proportions over time and visualized using either bar graphs (Figure 1c) or Likert-scale graphs (“Likert” package;²² Figure 1d).

The BUF Community Dashboard visualizing simulated data, along with source code to replicate the 3-stage BUF-RD model is available using the following link: https://carlene-mayfield.shinyapps.io/BUF_Dashboard/. An illustration of the BUF-RD model system design is displayed in Figure 2.

Security and compliance

The BUF-RD model was developed and supported by the data and evaluation team of University of North Carolina at Charlotte (UNCC) and executed through a service contract between UNCC and RWCI that included the university’s REDCap Cloud system and data sharing between the data and evaluation team and RWCI staff. The project was approved by the UNCC Institutional Review Board as nonhuman subjects research, since data were collected by program staff (eg, Life Navigators) as part of program operations and were analyzed for quality improvement purposes. Participant consent for data collection was not required.

A few additional security considerations were required. Data collected through REDCap contained identified, Protected Health Information and were stored on the REDCap Cloud server in compliance with current federal regulations (HIPAA 1996 and HITECH 2009). Third party, cloud-based data systems are endorsed by data security experts.^{23–25} In the Shiny Server environment, applications run in individually protected environments with secure sockets layer encryption, with additional security options for log-in and password protected access. Since a barrier-free access to the dissemination stage was prioritized in our system requirement conversations, protected access to the dashboard was not included in the beta test model. Therefore, data were deidentified for analysis and individual-level information was not included in the dashboard. This strategy met the initial beta test goal of rapidly disseminating preliminary results from actionable metrics to support decision-making among

Figure 1. Screenshot of the Building Uplifted Families (BUF) Community Dashboard showing: (a) the user interface and demographics page as well as data visualizations; (b) sunburst chart of hierarchical main and sub-categories; (c) 6-month trends by counts using a standard bar graph; and (d) 6-month trends by proportions using a Likert-scale graph.

program leadership. Life Navigators were able to access the REDCap database directly to reference identified information for their assigned participants.

RESULTS

Beta results

The BUF-RD Model was deployed for a 6-month beta test to support BUF operations. During this period, the time lapse between data collection and dissemination was reduced from 3 months to 2 weeks (minimal time required for manual processes). The dashboard was used at 5 PAB meetings and 4 operational working team meetings to review progress and stimulate project implementation discussions. For example, at baseline, a large portion of participants reported not having insurance coverage. Through focused strategy, the proportion of uninsured program participants was reduced by over 50% by the end of the beta test period. In another example, aggregate dashboard numbers showed that BUF program participants were consistently reporting access to a regular primary care provider, which was in contrast to Life Navigators' perceptions of resident use of healthcare services. This inconsistency prompted a series of conversations that led to an understanding that participants were misattributing their emergency department and urgent care as primary care. In response, nurses from the healthcare system partners developed a tailored healthcare utilization education program for participants. Viewing this information through interactive visualizations improved BUF implementation and enhanced stakeholder engagement. Also, having up-to-date information led to greater

responsiveness and alignment of program resources to specific participant needs.

DISCUSSION

The BUF RD Model is a 3-stage governance system to optimize the use of a health information technology solution (REDCap Cloud) with open-source technology and software solutions. Our effort was challenged by: i) major changes in the evaluation and overall partnership structures; ii) frequent staff turnover; iii) the co-occurrence of program implementation and data collection system development; and iv) limited experience in electronic data capture among team members that impacted trust in technology solutions. To overcome these challenges, we applied a user-centered design process through regular collaborative meetings and user observations.²⁶ In similar evolving community-based efforts, we recommend a regular internal evaluation of personnel and resources as described in [Supplementary Table S3](#).

Similar to other studies, our project used technology and electronic data collection to enhance formative evaluation methods.^{27,28} Dashboards have been used in healthcare settings to improve patient care and safety by giving providers access to tailored information to support decision-making^{29–32} and in community settings to monitor intervention activities and shape adaptive interventions.^{33,34} Our model demonstrated the benefits of incorporating dashboards as part of a larger governance system for standardizing and enhancing formative evaluation and created a replicable and adaptable process that can be applied to similar community-based initiatives. Future

Figure 2. System design diagram outlining the progression of data through stages of the Building Uplifted Families Rapid Dissemination Model (BUF RD-Model) by source, type, and technology solution.

Abbreviations: RWCI, Renaissance West Community Initiative; PAB, Partnership Advisory Board.

applications of this work should prioritize interoperable data environments and identified data sharing strategies^{35,36} through interdisciplinary teams that include technology and evaluation experts as project stakeholders.³⁷

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AUTHOR CONTRIBUTIONS

The BUF-RD design, dashboard user interface, and all associated data integration, cleaning, analysis processes were designed and led by the lead author, CAM. The REDCap Cloud system design and development was led by JJ, LS, and MEG. VCS and MD were co-PIs of the BUF data and evaluation effort, and, along with JT, they provided organizational leadership, content expertise, and feedback. All authors reviewed manuscript drafts, provided critical feedback, and approved the final submission draft.

SUPPLEMENTARY MATERIAL

[Supplementary material](#) is available at *Journal of the American Medical Informatics Association* online.

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CONFLICT OF INTEREST STATEMENT

None declared.

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