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Title

From Crisis to Opportunity in a Big Data Study: Barriers and Facilitators in a National Web-Based COVID-19 Surveillance Study

Priority 1 (Research Category)

Big Data

Presenters

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Abstract

Context: In March 2020 a COVID-19 Community Research Partnership (CRP) surveillance study was launched. We describe the barriers and facilitators to recruitment and retention during enrollment of >12,000 participants. Objective: To describe the barriers and facilitators to recruitment and retention while collecting daily syndromic and serologic data in a virtual setting. Methods: Key communication strategies designed to proactively enhance participation and retention were: Set up of a study call center; FAQs were emailed to participants and placed on the study webpage; preemptive messaging for getting started after enrollment, updating addresses, and in-home testing were designed; Later setup of a central call center for National team; design and implementation of national messaging for large scale in-home serological testing. Setting and Participants: Healthcare System linked to Six other National study sites. Healthcare system employees and patients, North Carolina residents and bordering counties. Atrium enrolled >12,000 participants, with over 65,000 participants enrolled nationally. Results: Key barriers: missing email communications, incorrectly entered participant information, participant fatigue due to longevity of study, use and return of serology kits. Facilitators: developing appropriate tailored messaging, preemptive communication for pending and failed validations, and development of “Unsubscribe” or “Paused” statuses. Proactive strategies kept the “Pending” enrollment below 10% and “Failed Validation” below 1% of total enrollees. The “Unsubscribe” option allowed withdraw rates to stay below 1% while the unsubscribe rate stayed below 10%. Tailored messaging supported the return of ~79% of test kits with ~43% of missing kits recovered. Conclusions: Large participant enrollment and data accrual resulted in the need for creative approaches to trouble shooting “big data” challenges associated with the rapid start-up of a high enrolling COVID -19 surveillance study. Preemptive messaging and anticipating participants’ needs enhanced enrollment, participation and retention.