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“Closing the Loop” Developing State-Level Data Sharing Interventions to Promote Optimum Outcomes Along the HIV Continuum of Care

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Abstract

This manuscript describes the experiences of three state departments of health (SDoH) that successfully launched data sharing interventions involving surveillance and/or patient data collected in clinics to improve care outcomes among people living with HIV. We examined 58 key informant interviews, gathered at two time points, to describe the development and implementation of data sharing interventions. We identified three common themes across states' experiences: creating standard practices, fostering interoperability, and negotiating the policy environment. Projects were successful when state teams adapted to changing circumstances and were committed to a consistent communication process. Once implemented, the interventions streamlined processes to promote linkage and retention in care among low-income populations living with HIV. Despite using routinely collected data, key informants emphasized the labor-intensive process to develop and sustain the interventions. Lessons learned from these three state experiences can help inform best practices for other SDoH that are considering launching similar interventions.

Keywords HIV care continuum · Data sharing interventions · Surveillance data · Implementation science · State surveillance

Resumen

Este manuscrito describe las experiencias de tres departamentos estatales de salud (SDoH, por su sigla en inglés) que implementaron con éxito intervenciones de intercambio de datos que incluían datos de vigilancia y/o de pacientes recogidos en clínicas para mejorar los resultados médicos para personas que viven con el VIH. Analizamos 58 entrevistas con informantes claves, conducidas en dos etapas, para describir el desarrollo y la implementación de intervenciones de intercambio de datos. Identificamos tres temas comunes en las experiencias de los estados: la creación de prácticas estándar, el fomento de la interoperabilidad y la negociación del entorno de políticas. Los proyectos tuvieron éxito cuando los equipos estatales se adaptaron a circunstancias cambiantes y se comprometieron en un proceso de comunicación constante. Una vez implementadas, las intervenciones racionalizaron los procesos para promover el vínculo y la retención en la atención médica en poblaciones de bajos ingresos que viven con el VIH. A pesar de utilizar datos recopilados rutinariamente, los informantes clave enfatizaron el proceso de trabajo intensivo para desarrollar y sostener las intervenciones. Las lecciones aprendidas de estas tres experiencias estatales pueden ayudar a informar mejores prácticas para otros SDoH que estén considerando iniciar intervenciones similares.

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Background

Consistent retention in HIV care as a pathway to suppressed viral load plays a critical role in ending the epidemic. In addition to reducing onward transmission, early diagnoses combined with linkage and retention in care can help people living with HIV maintain optimum health [1, 2]. Despite the availability of free or reduced cost treatment and care services for low-income people living in the US through the Ryan White HIV/AIDS Program (RWP) [3], many who could benefit from HIV treatment are sporadically engaged in care or have never linked to care following diagnosis [4]. Structural barriers, such as housing and food instability, reduce access to treatment [5, 6]. Social barriers, such as HIV stigma and shame, can isolate patients and reduce health care seeking behaviors [5–8]. The RWP covers a number of support services that mitigate barriers to consistent engagement in care; however, identifying people who are not currently engaged in care in a timely, consistent fashion remains a challenge.

Surveillance data, such as HIV test results and laboratory results for CD4 and HIV-viral load, can help identify patients that are not currently or fully engaged in care. For example, surveillance data can identify patients who tested positive for HIV but never initiated care, as evidenced by an absence of laboratory testing; patients with HIV who linked to care but have not had a lab test in six-months or longer; and patients with HIV who are in care but have a high viral load, indicating a potential need for an update to their treatment plan. A number of HIV clinics across the country have created internal monitoring protocols that query lists of patients from electronic medical records (EMRs) who have missed appointments, have no recent lab results on file, or are not virally suppressed [9, 10]. At the local level, several city and county departments of health have successfully developed similar, larger-scale approaches that rely on surveillance data to track people who are out of care or who never linked to care [10–12]. At the state level, the promise of data-informed interventions to maximize linkage and retention in care remains largely unrealized. Louisiana is a notable exception, having successfully developed a program called LaPHIE (Louisiana Public Health Information Exchange) that provided medical chart alerts for providers to encourage re-engagement in HIV care in a portion of care facilities run through the Louisiana State University Health Care Services Division (LSU HCSD). Over the course of 2 years, LaPHIE identified 345 out-of-care patients with HIV, 85% of who received a CD4 or viral load test over the study period indicating a return to care post intervention [13].

To support innovative state-level interventions to improve linkage and retention along the HIV continuum

of care, the Health Resources and Services Administration (HRSA) Special Projects of National Significance (SPNS) developed the Systems Linkage and Access to Care for Populations at High Risk of HIV Infection Initiative [14]. The Systems Linkage Initiative (hereafter SLI) funded six state departments of health (SDoH) to design and implement information exchange approaches to increase access to HIV treatment: Louisiana, Massachusetts, New York, North Carolina, Virginia, and Wisconsin. Three of the participating states—Louisiana, Massachusetts and North Carolina—launched data sharing interventions that relied on either surveillance and/or EMR data to identify people who could benefit from intensive support services [9, 12, 13]. Data sources involved in these efforts will be described in this paper and include: clinic-specific EMR, AIDS Drug Assistance Program (ADAP) databases, enhanced HIV/AIDS Reporting System (eHARS), Ryan White CAREWare, state sexually transmitted disease (STD) surveillance databases, and electronic disease surveillance systems (eDSS).

As compared to county- or clinic-level interventions, state-level data sharing may offer a more complete picture of who is out of care and who never linked than is possible with local surveillance alone [15–18]. In this paper, we draw on the experiences of Louisiana, Massachusetts and North Carolina in developing and implementing data sharing interventions as part of SLI. We explain the development processes, challenges and benefits in order to prepare other decision makers for similar state-level interventions. Our conclusions inform best practices for future attempts to ‘close the loop’ in data sharing and use of routinely collected patient information to strengthen patient linkage and retention efforts.

Methods

This paper draws on key informant interviews collected as part of a larger mixed methods evaluation of SLI [19]. We designed a purposeful sampling approach to identify interview participants who were able to provide a variety of perspectives on intervention development and implementation. Our sample included three categories of informants: (1) *leadership*: including Principal Investigators, Project Directors, and other key project staff at the SDoH; (2) *collaborators*, including staff at clinics/agencies that served as demonstration pilot sites, as well as external project consultants; and (3) *interventionists*, those who delivered the intervention directly to clients, e.g., patient navigators, linkage to care specialists and data managers. Eligibility requirements further included being age 18 or older, being fluent in English, and willing and able to give informed consent. To recruit informants, we first approached them via e-mail or

telephone to ask if they would be interested in participating in an in-depth interview.

We interviewed key informants at two time points: [1] the formative phase about a year into the study as interventions were being piloted and refined, and [2] the summative phase about 4 years into the project when SLI were being implemented widely within a state. From the three states profiled in this manuscript, we interviewed a total of 43 key informants during the formative phase (Louisiana (LA) $n = 13$; Massachusetts (MA) $n = 17$; North Carolina (NC) $n = 13$) and 15 during the summative phase (LA $n = 4$; MA $n = 6$; NC $n = 5$). There was minimal overlap between the two key informant samples ($n = 5$ participants), due in part to changes in staffing and a desire to capture a variety of perspectives. We conducted a majority of interviews over the phone or in a private office during a site visit to a participating state, with one or two interviewers. Before beginning the interviews, we reviewed an information sheet on the study and obtained verbal consent. The Institutional Review Board at the [University of California, San Francisco] reviewed and approved all study procedures and materials.

We designed semi-structured interview guides for each phase of data collection. The guides were tailored as appropriate to the participant and state project. The interviews took between 40 and 60 min. Each interview was audio-recorded and transcribed verbatim. To organize and sort data, we entered all interview transcripts into Dedoose (Version 5.0.11, 2014).

We employed analytic methods consistent with the Framework Analysis approach, incorporating a multi-step process for team coding [20]. The analytic process included: reading and re-reading interview transcripts; applying inductive and a priori codes; code interpretation; theme identification via comparative analysis of tabled summaries and coded experts from the two phases and across states, and returning to re-read a subset of interviews in full to refine the themes further and to ensure analytic validity. To validate our findings, we shared individual state summary tables depicting key themes from the formative and summative phases with each state evaluator for her or his review and input.

Results

The three state initiatives utilized different data sharing strategies and intervention designs to increase linkage, retention and viral suppression among patients who were newly diagnosed with HIV, lost to care, or poorly engaged in care (Table 1). All three aimed to “close the loop,” by bringing routinely reported patient information back to care providers to improve tracking and follow-up of patients with HIV who had either never linked to care (newly diagnosed”), had no recent lab tests (out of care), or whose lab results suggested

a need for a change to their treatment plan (at risk of falling out of care). An overview of state interventions and data sources is provided in Table 1.

Drawing on examples of state-level data sharing interventions, we organized findings around three themes or critical areas for consideration: *creating standard practice*, *fostering interoperability*, and *negotiating the policy environment*. We close each example with a description of the added value of the intervention for states that were able to implement during the evaluation study period. The first area, *creating standard practice* refers to the processes that SDoH and collaborators undertook to develop standard definitions for patient eligibility for inclusion in the interventions and to create standard protocols for patient identification, referral and follow-up. Because these interventions bridged multiple agencies and providers, the process to create and monitor adherence to standard protocols and definitions required significant effort. The second area, *fostering interoperability* broadly describes lessons learned around the technical processes to share data across information systems containing different types of data. The third area, *negotiating the policy environment* summarizes state efforts to ensure that data sharing interventions complied with existing state and federal regulations protecting patient health information and privacy. This area also describes how SDoH responded to shifts in the larger HIV treatment policy environment—such as changes to health care coverage as part of the Affordable Care Act (ACA) [21]—that affected the context in which data sharing interventions were developed and implemented.

Louisiana

As described in the background section, LaPHIE links the statewide public health surveillance system with a hospital’s local EMR data to identify patients living with HIV who have not received care for at least 12 months [13]. Real-time alerts are sent to providers, along with a sample script to read to the patient and encourage them to reconnect to HIV care services. LaPHIE expanded the use of surveillance data historically collected for solely public health purposes, leveraging this routinely collected information to improve individual patient care. The intervention proved successful in linking patients to needed services, thus Louisiana decided to adapt and scale up the intervention into a wider network of health facilities (Table 1).

Creating Standard Practice

Developing common definitions for newly diagnosed, out of care, and at risk of falling out of care- proved a hurdle to expand LaPHIE in Our Lady of the Lake Regional Medical Center (LOL) hospital settings. Leadership from SDoH, collaborators from LSU, and providers from LOL

Table 1 Overview of interventions

State	Intervention description	Data sources	Types of data shared	Intended impact
Louisiana	LaPHIE expansion: EMR in emergency departments cross-checked patients with SDoH data to identify newly diagnosed HIV+ individuals with no lab results in past 6 months or previous HIV+ individuals with no HIV care in past 9 months. It provided pop-up alerts with script for providers to read to patients and encourage engagement in-care	State Department of Health Lab Database Proprietary EMR	CD4 tests HIV viral load tests	Direct clinician outreach to out of care patients who present for emergency services, a strategic entry point for people who otherwise may not interact with medical facilities
Massachusetts	SDoH produced line lists for each participating health facility. One list contained patients who were in care but had detectable viral load while the other contained patients who had not had a lab in 6 months or longer	State Department of Health Lab Database State vital statistics database Proprietary EMRs	CD4 tests HIV viral load tests	Complete and streamlined line lists of patients out of care or at risk of dropping out of care for intensive patient navigation services
North Carolina	SDoH expanded access to the NC Ryan White CAREWare database for retention staff in Ryan White Part B, C and D funded organizations and state bridge counselors (SBC) to improve identification of persons who were out of care and expedite referrals. The CAREWare referral function was developed to allow inter-agency and extra agency referrals for retention in care interventions. This included referrals to and among SBCs	CareWare eHARS NCeDSS ADAP	CD4 tests HIV viral load tests	To directly give access to statewide patient information to retention staff for determining if patients were actually in care and accessing services at another location SBC could check if a patient completed referrals back to care and remained in care following services. If the patient did not keep the appointment as intended, the SBC could then follow-up with patient, eliminating provider referral steps

worked together to answer some key implementation concerns. OLOL leadership negotiated a shift in defining an “out of care” patient and “newly diagnosed and never linked to care.” Rather than using the 12-months without lab tests as the definition of “never linked to care” as in the original LaPHIE design, the expanded LaPHIE system provided alerts for newly diagnosed patients with no CD4 or HIV viral load tests in *6 months or longer*. For patients with an earlier HIV diagnosis, LaPHIE would provide an alert if they had missed 9 months or more of lab work, an expanded definition of “out of care” from the standard 6 months to maximize the chance that clients were in fact out of care, rather than delayed in taking labs at 6 months. Next, OLOL and LSU worked to *create standard practice* for confirmatory HIV testing and case management. Collaborators initially expressed concern regarding potential “strain on resources and staff time to implement” and reluctance to “have talks with clients about their HIV diagnosis from 2 years ago.” Targeted provider trainings, aimed at overcoming skepticism through education around anticipated benefits to patients and instruction on patient flow protocol, assuaged concerns about the intervention. An in-house monitoring system allowed OLOL and SDoH leadership to track alerts and referrals, with the intention of providing ongoing support to providers who might feel uncomfortable using the LaPHIE system.

Fostering Interoperability

After building support for the intervention with the new provider, OLOL, the project tackled infrastructure investments. *Fostering interoperability* between OLOL and SDoH posed several roadblocks to LaPHIE scale-up. The EMR at OLOL used a different programming language than the existing LaPHIE system embedded in the EMR at LSU HCSD, posing barriers to interoperability. Information technology experts from each of the participating institutions worked closely together to identify a solution to interface and share patient data between the two servers.

Negotiating the Policy Environment

A shifting policy and health care delivery environment in Louisiana presented obstacles to LaPHIE expansion. The LaPHIE expansion coincided with a major restructuring of the public hospital HIV care network. As the state transitioned to a public/private hospital partnership model and a Medicaid managed care model supported by the ACA, *negotiating the policy environment* became a central part of scale-up efforts for key players at SDoH, LSU HCSD and the new private hospital partner, OLOL, in Baton Rouge, Louisiana. From 2011 to 2012, more than one thousand patients transitioned from the LSU HCSD public HIV clinic to OLOL.

With the change in provider, the LaPHIE expansion lost priority to other more pressing concerns for OLOL and SDoH. Logistics such as notifying all patients of the change, connecting them to new providers, and migrating patient files to a different EMR took precedence over the LaPHIE intervention expansion during the initial transition. More importantly, as a private entity, OLOL expressed concerns about sharing patient information with SDoH. While LSU and SDoH had a long “history of collaboration and data sharing,” this proved a new arrangement for OLOL and state government. Particularly in the context of ACA, leadership from SDoH described an “inordinate amount of confusion” around the legality of the exchange. Evidence of how effective LaPHIE had been in re-engaging patients in care, combined with data from patient focus groups showing acceptability, helped overcome OLOL leadership’s privacy concerns. Leadership’s willingness to adapt to shifting circumstances was essential to LaPHIE scale-up.

Almost every day is like a PDSA [Plan, Do, Study, Act] cycle for us, because it’s like ‘Oh this is our plan. This is what we started doing.’ And then it’s like, ‘Oh. The landscape changed.’ And so you study what was changing and then modify often.

-Leader at SDoH

Of note, the challenges described in this example prevented the LaPHIE expansion during the evaluation period, although the state successfully scaled-up the intervention after our research had concluded.

Massachusetts

In Massachusetts, the SDoH developed an intervention that used HIV surveillance laboratory data to improve engagement in HIV care. This intervention involved identifying patients who were potentially out of care, defined as having a detectable viral load, and communicating with those patients’ HIV medical providers regarding their care status and engagement efforts. The state used its robust surveillance system as a foundation for developing and launching the intervention. Since 2012, Massachusetts had required that all HIV-related laboratory test results, including CD4 and viral load test results, be reported directly to the SDoH. The state used the laboratory data for routine HIV surveillance, producing surveillance reports and generating important information about trends in the HIV epidemic. With resources from SLI, Massachusetts advanced toward its goal of maximizing use of laboratory data to facilitate linkage to, and retention in, HIV medical care.

To “*close the loop*,” the Massachusetts SDoH developed an intervention that routinized the generation of two lists for each participating HIV care facility: an out of care list and a detectable viral load list. The SDoH produced these lists

on a monthly basis using routinely reported data from the state's eHARS (see Table 1) database and SDoH database of providers matched with health facilities. The out of care list identified patients at each facility who had no laboratory test results reported for at least six months, indicating a potential disengagement from care. The viral load list identified patients whose laboratory test results showed a detectable level of HIV, suggesting a possible need for provider follow-up. Staff at the participating facilities reviewed the lists, accessed internal patient data, and consulted with colleagues to assess status of those patients, then provided pertinent feedback on the patients to the SDoH.

Creating Standard Practice

With direction and support from health department leadership, Massachusetts HIV/AIDS Surveillance Program staff developed a system to generate and share patient lists with participating facilities. SDoH provided various types of resources (e.g., contract funding, technical assistance, etc.) to help participating clinics build the data management capacity essential to implementing the intervention. SDoH supported facilities in expanding the role of data management staff from data entry and report generation to data interpretation and follow-up. Data management staff was required to consult internal data sources—primarily, but not exclusively, EMRs—to verify patient information and collect data regarding patient care status and/or treatment. The facilities then submitted follow-up reports to the SDoH, which updated its records accordingly. The facilities were also required to share the information on the patient lists with the patients' medical providers to promote necessary service and/or care adjustments.

Negotiating the Policy Environment

In Massachusetts, state regulations protect the privacy of patient health information that is collected through routine HIV surveillance thus the SDoH implements protocols restricting access. With guidance from its legal team, the SDoH identified a method to share information regarding patient care status between medical care providers and the surveillance program. Leadership determined that SDoH would only share information about patients who met the out of care definition and whose test results indicated a detectable viral load. In line with the goal of protecting patient privacy, SDoH also determined that it would not share information about where patients were accessing care if they were attending a different care facility. SDoH provided a list of patient names who had at one time received services at the participating clinic or hospital but had dropped out of care, so that patient navigators or outreach workers at that facility could contact patients and support them to re-engage in care.

Massachusetts successfully negotiated its state policy environment and maximized the use of available data to improve care outcomes, while abiding by regulations that protect patient privacy. The process of negotiating and establishing parameters for the intervention had the added benefit of increasing information exchange among programs at SDoH, as summarized in the quote below.

This project has brought together several big programs in the bureau and developed really strong partnerships and relationships across programs. So now, we have staff from our surveillance office that come on a regular basis to the office of HIV/AIDS full staff meeting, and they give us updates on what the client profile is looking like. They gave an update recently on our new care continuum. So it's benefited both this project and I think it's going to have a long-lasting impact on how we work across the whole bureau.

– Leader at SDoH

Added Value of State Data Sharing Intervention

SDoH leaders, HIV care providers, and interventionists developed a system that used surveillance data to identify patients potentially in need of additional support services or care/treatment plan adjustments. Once SDoH and providers established a standard practice, the patient lists became shorter and manageable, and monthly communication between the SDoH and the facilities became more efficient. Participating facilities articulated positive attributes of the data-to-care intervention. This was particularly true among clinics with high patient volume and without the internal capacity to produce similar types of patient reports. As described by one of the collaborators, the lists proved to be “earthshattering” in the way they streamlined and simplified patient follow-up efforts.

North Carolina

North Carolina's project, NC LINK, included implementing a data sharing intervention that combined increased access to patient information with several innovative approaches to retain persons in HIV care (Table 1). Clinics used out of care lists and developed retention protocols for staff to locate patients and facilitate a return to care. In addition, NC LINK developed a cadre of publically funded State Bridge Counselors (SBC), who delivered a “low-touch” intervention to increase both linkage and re-engagement in care for people living with HIV [19, 22]. “Low-touch” refers to interventions that were brief in duration and intensity, as compared to longer-term, more comprehensive interventions. SBC received training in Antiretroviral Treatment and Access Study (ARTAS), a strengths-based, time limited intervention

to link newly diagnosed individuals to medical care, substance abuse and mental health, and to address barriers to care [4].

NC LINK provided support for data sharing in the NC CAREWare database among all funded agencies and the SBC team. Access to statewide Ryan White service data through NC CAREWare allowed immediate and accurate elimination of persons who were initially considered out of care, but were determined to be receiving care in another location within the state. Data tables in CAREWare were created for documenting retention activities. As a result, the statewide Ryan White service data became available to each organization's retention staff and the SBC team. CAREWare data sharing was activated only within and between providers who were serving the same client. This became an important distinction for more widespread data sharing acceptance, as this helped decrease privacy concerns.

NC LINK supported several electronic referral mechanisms. The referral function within CAREWare was utilized for communication within organizations (including the SBC team) to allow assignment of retention interventions to a particular SBC. Clinic retention staff used this function to make referrals to the SBC for assistance with locating and contacting patients who were unable to be reached by the clinic retention staff and considered "lost to care." Development of a referral mechanism within the North Carolina Electronic Disease Surveillance System (NC eDSS) expedited the process to refer newly diagnosed clients to SBC for linkage verification or follow-up efforts.

Creating Standard Practice

Developing standard definitions for eligibility and referral tracking led to greater efficiencies in patient follow-up, yet developing these proved a major undertaking. Differences among providers on how to define eligibility and track referrals quickly arose. Protocol development required significant investment from the research team collaborators. One collaborator noted that defining "who's at risk for out of care, who's out of care, how to refer them to care, and the process by which the SBC will look for them" took about 2 years to complete. Once protocols were developed, retention staff, SBC, and NC LINK support staff met monthly via conference calls to address any questions that arose during implementation. Monthly calls harmonized referral and tracking practices across providers, bringing efficiencies to patient follow-up. Frequent stakeholder meetings and strong leadership from SDoH eventually led to overcoming logistical hurdles. The data sharing intervention opened up communication and collaboration across state agencies and providers, contributing to a greater sense of cohesion among and between retention staff and SBC, with resulting de-duplication of work efforts.

I think there's more collaboration, exchange of information. Before, because of HIPPA, everybody was kind of like doing their own thing, duplicating efforts. Now, it's a little bit more open. It's like, 'I do this. How do you do it?' Or somebody says, 'Well this is how we've been taking care of this problem.' And I think it's a process where all of us are learning from each other. And there's less duplication of effort.

– Collaborator

Added Value of Data Sharing Intervention

NC LINK State Bridge Counselors leveraged the increase in access to patient information to create a more efficient and comprehensive program to support retention in treatment. Rather than referring patients to care and waiting for those who dropped out of care or never linked to be flagged via providers, SBC could look up patients electronically. Using the shared NC CAREWare, SBC could access information (e.g., service documentation) to confirm a patient's re-engagement in care. This reduced the number of back-and-forth calls to clinics and prevented duplication of services. Before NC LINK, multiple interventionists might have reached out to the same client. One interventionist summarized that access to CAREWare "just made it [patient follow-up] easier, made it faster." This sentiment was echoed across key informant interviews, which emphasized that this data sharing intervention expedited patient follow-up by introducing efficiencies and increasing coordination of efforts.

Conclusion

Findings from this qualitative evaluation of three state-level data sharing interventions suggest that it is feasible and beneficial to leverage routinely collected patient health information to improve linkage and retention in HIV primary care by closing loops between SDoH and providers. Drawing on state surveillance and EMR datasets, the interventions in Massachusetts, Louisiana and North Carolina identified patients in need of intensive follow-up and support services to engage in treatment [9, 13, 19]. The idea of using routinely collected patient information to hone linkage and retention efforts seems straightforward, yet in practice, data sharing interventions were complex to get off the ground. Once they were implemented, leaders, collaborators and interventionists all described the interventions as dramatically improving systems to support optimum care for patients with HIV who were newly diagnosed, out of care, or at risk of falling out of care.

The three state examples that we profiled suggest that developing standard practice and protocols required substantial lead-time and communication across participating

agencies. Regular monitoring helped ensure that agencies continued to use the same guidelines and eligibility definitions over time. For interoperability, dedicated technical staff that collaborated and problem solved across institutions proved essential for data sharing across systems. Finally, SDoH worked closely with legal advisors and collaborators to ensure that data sharing interventions protected patient privacy and complied with all state regulations in this area. Our findings build on previous research showing that data sharing interventions are acceptable to patients and other stakeholders, as potential improvements in care outcomes outweigh concerns around privacy [23, 24]. We hope that these lessons learned can help future states to “close the loop” between SDoH and providers.

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Compliance with Ethical Standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical Approval All procedures involving human participants were in accordance with the ethical standards for the institutional review board and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent Informed consent was obtained from all individual participants included in the study. No personal identifying information is included in the manuscript.

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