Introduction to the Lifia.me

Lifia.Me

Online Peer Support Community Portal

Lifia.me is an online peer support platform with the intent to develop healthy and sustainable online communities that have proven clinical benefits and improve quality of life for people living with chronic conditions. The service encompasses a hosted technical platform as well as a strategy for creating a local network of stakeholder groups to sustain the community. Primary stakeholder groups may include clinics, medical providers, and researchers.

The platform is being launched to serve people living with HIV (PLWH), in conjunction with Ryan White grantees offering supportive services to help with insurance premiums, housing, and utility assistance, transportation, nutritional supplements and groceries, medication assistance, and mental health, dental and vision services.

Many of these clinics offer expanded medical care coordination services with Peer Support Navigators who help PLWH handle the vagaries of the financial, medical, and administrative systems they must navigate.

Lifia.me is an additional way to support PLWH with an online community that fosters peer relationships. The service will work with clinical staff trained in support techniques like motivational interviewing to foster a social support network for PLWH where they can privately share concerns and receive advice and answers from others living with HIV.

The implementation plan for clinics includes the following:

- Planning for the Online Community
- System Configuration, including limiting access of Moderators
- Configuring the token and text-messaging interface (SMS) service
- Security, pen testing, access control verification, and HIPAA compliance testing
- Hosting and monitoring services

Our team will work closely with Ryan White clinical staff to build the community and ensure smooth introduction and operation of Lifia.me within a community. Lifia has plans for expanded features for the forums. After the first year, we plan to include a text messaging interface service. We also plan to add a matching algorithm in year two, depending upon grant funding with Professor Introne (currently at Syracuse University). Local clinical staff are responsible for advertising and inviting PLWH into Lifia.me.

THE NEED

A critical aim of Ryan White programs is to link more patients into care sooner and to keep them in care. The moment of diagnosis is critical for people living with HIV (PLWH), especially for low-income individuals who have difficulty connecting to clinical care. We hope that the Lifia.me online community will encourage PLWH to get others tested so more undiagnosed people can be notified and linked into care.

THE SOLUTION

Online services can provide newly diagnosed patients with a rich support network that links them to clinical services. Online support is underutilized by PLWH because of concerns about privacy and, in the case of low-income patients, lack of Internet access. Lifia and Dr. Introne's team developed a support platform that provides newly diagnosed individuals with easy access to a trusted, private online space. After the first year, a mobile text-based channel (SMS) is planned which will present like a text-based hotline at hospitals and clinics where HIV diagnoses are rendered. The platform will provide a place for PLWH to support their peers (including Peer Navigators) to maintain effective self-care strategies. Dr. Introne will continue to study the peer-support platform to understand the communication dynamics and help us improve the dynamics and better reach clients who are hard to retain in care. So as PLWH join the community, they will have the option to opt-in to the Lifia Research Network where their quality of life and other outcomes can be connected to your Lifia.me account and studied to improve the effectiveness of the Lifia.me forums.

THE BENEFITS

- Improve clients' sense of a journey with Ryan White clinics, through safely connecting to a helpful community offering a social support network.

- Educate clients with anonymous ways to ask questions and avoid embarrassment while learning from other PLWH.

- Foster clients' sense of belonging and wellbeing, hope, respect, love of self and inner peace.

- Increase clients' retention rates, their self-care capabilities and adherence to care plans.

- Provides outreach to spread the word in the community about Ryan White clinics.

- Gather ideas for new initiatives and improve services (e.g. connecting with community supports for employment, domestic violence, strengthen relationships with local authorities, improved coordination of services, etc…)

THE BACKGROUND

Online health support communities are a distinct and ubiquitous type of online social support network and have proliferated on the Internet since its inception. Whereas numerous studies have examined these communities and documented their efficacy [2], [12]–[15], several pressing issues remain if they are to support low-income PLWH. First, based on early focus group interviews conducted by the PI, PLWH are highly concerned about the trustworthiness of individuals encountered online. Second, low-income individuals often lack personal access to Internet services, and public kiosks (e.g., library workstations) raise privacy concerns. However, they frequently use text-based mobile services, which do not rely on Internet access.

Social determinants of health—which include factors such as socioeconomic status, education, social support networks, and other structural determinants—are usually central factors in successfully managing chronic conditions, and this is especially the case for PLWH. Even when services are available, such social determinants may dictate whether or not PLWH can take advantage of them.

Increasingly, researchers have identified perceived social support, which is correlated with other social determinants such as education and socio-economic status, as an important factor in self-care and medication adherence for PLWH [1]–[5]. Social support may be defined as the belief that one is cared for, loved, and valued by others, and belongs to a network of communication and mutual obligation [6]. Social support can be particularly beneficial for linking PLWH to care [7]. However, because PLWH often suffer from a high degree of social stigma, their access to face-to-face social support can be limited [8], [9]. For this reason, it is thought that online support communities could potentially play an especially important role in improving access to social support [10]. In addition to providing social support, online networks can be explicitly deployed as an outreach intervention to draw PLWH into care services [11].

Dr. Introne, the Principal Investigator (PI), has demonstrated that online support communities exhibit systematic patterns of interaction that can lead to robust support provision for newcomers [17], [18]. A key finding is that an active group of core members who have strong relationships with one another are critical for sustaining large populations and responding quickly to incoming users. These core members function as "expert patients" who offer peer support to a much larger group of more peripheral members. Core members often coach newcomers on effective self-care strategies, and guide them to medical providers who can provide clinical support.

Based on this work, and focus group interviews with PLWH, the PI designed and implemented a prototype support platform for PLWH. The platform will eventually have three novel features:

1. To address concerns about privacy and trust, the community is based on a web-of-trust model, wherein an initial community of PLWH are invited to the platform by care providers. These individuals are in turn able to extend invitations to others. This model preserves linkages to the care networks where clinical services can be obtained. (Available on day one.)

2. To address issues with Internet access, the system will have both a web-based interface as well as an interface that can be accessed entirely via SMS-based messaging. The SMS-based interface is designed to be easy to use for less technically adept individuals but offers a richer set of features for those that desire them. (Available after year one.)

3. To reach individuals who are not already connected to care, the system will be promoted via an anonymous hotline number, allowing individuals who are not yet part of the community to text in at any point. The hotline will be "staffed" by the existing community of PLWH. (Available after year one.)

We will be seeking research partners to pursue funding from NIH. The research will evaluate clinical measures to confirm if the portal improves medication adherence. It will also add sophisticated "matching algorithms" to better connect online community members with compatible "buddies" and others who can help support them with challenges related to social, health systems, stigma, health literacy, providers, medications, and symptom supports.

ABOUT US

Lifia Services are managed by A.J. Boggs & Company, a Michigan Corporation with more than 25 years of experience. A.J. Boggs has worked with 16 U.S. states and territories to improve patients conditions through better systems to support clinical care, case management, provider education, testing, and prevention interventions. We provide clients with hosting support for CAREWare, including secure hosting with effective climate control, back-up power, managed services, assured cybersecurity and compliance with HIPAA and other federal regulations. We also provide assured effective business continuity and disaster recovery services.

Our team also develops systems to support grant monitoring of public health programs with data analysis reporting, electronic health records (EHR) interfaces, Enhanced HIV/AIDS Reporting System (eHARS) and AIDS Drug Assistance Program (ADAP) data integration with CAREWare. A.J. Boggs also offers a web-based ADAP application and eligibility management system.

The firm's client portfolio includes organizations in healthcare, defense, manufacturing, state and federal government agencies. For more information, visit www.ajboggs.com.

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