

University of South Carolina School of Information Science

1

Using Action Research to Create a National LGBTQIA+ Digital Health Information Resource
University of South Carolina National Leadership Grant Proposal

The University of South Carolina (USC) School of Information Science requests \$293,134 for a three-year National Leadership Grant that applies action research to understand what health information sources LGBTQIA+ communities use to address their health questions and concerns and implements findings to create a national health information resource for them. It meets a national need to address LGBTQIA+ health disparities ([Healthy People, 2030](#)) and strengthens community engagement and collaboration between public library workers, health sciences librarians, and LGBTQIA+ communities (Goal 2, Objective 2.2). The PI will leverage strategic partnerships established in prior IMLS-funded projects to meet these needs and goals, including the USC Arnold School of Public Health Center for Community Health Alignment (CCHA), the South Carolina State Library, and the Network of the National Library of Medicine (NNLM) Region 2. The project addresses the following research questions: 1) What health information sources do LGBTQIA+ communities use to address their health questions and concerns? 2) How do community, social, and cultural contexts, including barriers and facilitators, shape source selection? 3) What are regional differences and similarities among health information sources used? Answers to these questions will inform the development of an LGBTQIA+ health information resource comprised of national and regional resources co-created by public library workers, health sciences librarians, and LGBTQIA+ communities.

Project Justification: LGBTQIA+ populations face health disparities compared to heterosexual, cisgender peers due to social stigma and structural discrimination, leading to stress-related health problems and a lack of social safety ([Diamond & Alley, 2022](#); [Zeeman et al., 2019](#)). Informational challenges contribute as LGBTQIA+ individuals struggle to access healthcare information, navigate the healthcare system, and overcome barriers to care ([Romanelli & Hudson, 2017](#)). By designing interventions to address these challenges, public and health sciences libraries can extend their historical roles of serving as community anchors to meet the health-related information needs and practices of LGBTQIA+ communities ([Horriagan, 2015](#); [Hawkins et al., 2017](#)). In an [Early Career Grant \(RE-07-18-0066-18\)](#), the PI investigated how SC LGBTQIA+ communities navigate these barriers through an information practices approach. This approach envisions communities' information-related activities and skills (i.e., practices) as shaped by community, social, and cultural factors. A key finding from this project was that communities engaged in collective practices that defended members from barriers immediately experienced and protected them from potential risks. Practices like word-of-mouth sharing of which healthcare professionals to visit and avoid illustrated how LGBTQIA+ people served as critical health information intermediaries for their communities, providing relevant contextualization of outside sources and information for their members ([Kitzie, Wagner, & Vera, 2020](#)). Based on these findings, an [IMLS National Leadership Grant \(LG-246360-OLS-20\)](#) identified SC LGBTQIA+ community leaders serving as critical health information intermediaries for their communities as community health workers (CHWs). A CHW serves as "a frontline public health worker who is a trusted member of and/or has an unusually close understanding of the community served" ([American Public Health Association, 2019](#)). Their localized knowledge results in effective health promotion among underrepresented communities ([Scott et al., 2018](#)). Certifying these leaders contributed to the growth of the CHW workforce in SC, as several project participants are now employed as CHWs full-time. Both projects also examined how to establish effective partnerships between LGBTQIA+ communities and information professionals. The Early Career Grant used the World Cafe methodology ([Brown & Isaacs, 2005](#)) to facilitate community forums between public library workers and LGBTQIA+ community leaders in four nationally representative locations (i.e., KS, CO, SC, and PA) with over 100 participants across the four forums. These forums initiated collaborations between library workers and community members, including health information resource sharing and collective organizing ([Kitzie et al., 2021](#), in progress). The PI created a toolkit with plans for widespread dissemination in Winter 2023 for public libraries and other organizations looking to replicate these forums. So far, community forum participants are adapting the toolkit draft to further these community conversations at sites like the PA State Library and the KS GLSEN chapter. The National Leadership Grant established partnerships between SC CHWs and health sciences librarians across North America to co-create health information resources for CHWs' LGBTQIA+ communities. Examples of resources created include a video web series explaining health topics important to trans and non-binary people, an app for pansexual people who have come out later in life to connect with the community, and an LGBTQIA+ inclusive health intake form ([Kitzie, Vera, & Wagner, 2022](#); [Vera et al., 2023](#)). This project seeks to extend findings from these prior works by fostering librarian-community partnerships through the participatory methods used in prior works to design an effective health information intervention for LGBTQIA+ communities. It responds to a gap identified by both projects between how formal sources like healthcare and information professionals *think* LGBTQIA+ communities engage with health information sources (e.g., always trusting information from doctors) and how these communities *actually* interact with them (e.g., collectively verifying information from doctors). The end product will be a digital resource containing national and region-specific resources. This resource

directly addresses challenges identified by LGBTQIA+ communities across both projects related to a lack of relevant, centralized health information resources (e.g., [Kitzie, Vera, & Wagner, 2022](#)). Further, it fosters community engagement between LGBTQIA+ communities and librarians nationally.

Project Work Plan. This project has three stages, which correspond to each work year. In **Stage 1 (2024-2025)**, the PI will identify one health sciences librarian from each of the seven NNLM regions to collaboratively identify, collect, and organize national resources on LGBTQIA+ health topics. These resources can include but are not limited to open-access grey literature, reports, and articles. Five LGBTQIA+ CHWs will review and add to these resources since they have resources the librarians may not be privy to. The PI will source librarians and CHWs from the network she created as part of the National Leadership Grant. In Stage 1, the PI will also leverage pre-established public and state library contacts, including the SC State Library, from the Early Career Project to identify 12 public library sites, three per US region (Northeast, Midwest, South, West), that will agree to host forums between LGBTQIA+ community leaders and public library workers in Stage 2. Each site will have a public library worker and LGBTQIA+ community leader responsible for planning and executing the forum. These site representatives will receive virtual training from the PI on the forum toolkit from the Early Career Grant and LGBTQIA+ cultural humility training from CCHA developed by the PI and SC LGBTQIA+ CHWs in the National Leadership Grant. In **Stage 2 (2025-2026)**, the PI will work with the web developer to create a digital resource that hosts the national resources identified by the NNLM librarians and amended by the LGBTQIA+ CHWs. The PI will solicit feedback from both groups regarding plans for national outreach and dissemination of this resource to LGBTQIA+ communities. The PI will work with site representatives to schedule and coordinate half-day community forums between public library workers and LGBTQIA+ community leaders, who have a macro-level view of their communities' health information practices ([Kitzie et al., 2021](#), in progress). These forums will elicit information about the health information resources LGBTQIA+ communities use at regional levels. The PI will use this information to identify, collect, and organize these regional resources, including, but not limited to, lists of LGBTQIA+ affirming healthcare professionals and health information resources created by communities. In **Stage 3 (2026-2027)**, the PI will work with the web developer to add these resources to the digital resource created in Stage 2. The PI will produce a report overviewing the research findings from this project and, with the digital resources, engage in national dissemination utilizing the network of librarians, CHWs, and community leaders created in Stages 1 and 2. Data collection and analysis occur across the three stages. In Stage 1, the PI will interview the CHWs using a semi-structured protocol organized by the project's key research questions. The PI will draw from interviewing elicitation techniques that were successful in prior works, such as health information world mapping (Kitzie, Wagner, & Vera, 2021; Kitzie et al., 2022b). In Stage 2, community forum sites serve as critical points of data collection, as the participatory techniques of the World Cafe method facilitate collaborative note-taking ([Brown & Isaacs, 2005](#); [Kitzie et al., 2021](#), in progress). Site representatives will take photos of these notes and upload them to a password-protected cloud server shared with the PI. Data collected, therefore, includes CHW interview transcripts and health information world maps, collaborative notes from each of the 12 forums, and observational notes taken by the researcher throughout the project.

Diversity Plan. "Community" is a fraught concept since no collective authority exists on what it means to identify as LGBTQIA+. However, the concept proves helpful to envision how LGBTQIA+ people engage in shared health information practices based on everyday experiences of stigma and discrimination ([Morris & Hawkins, 2016](#)). This project respects the diversity of experiences within LGBTQIA+ communities by recruiting LGBTQIA+ CHWs and leaders with various social identities, locations, and experiences. The team will select librarians based on their history and outreach to LGBTQIA+ communities and give preference to those with minoritized identities, social locations, and/or experiences. Through the two prior IMLS projects, the PI has established recruitment networks and techniques for maximal variety sampling that she will employ to meet these goals.

Project Results. The PI will publish and/or present research findings in at least LIS two venues per year (e.g., ASIS&T, iConference, ALA, ALISE). An open-access version of the research findings, data collection, analysis materials, and a report summarizing research findings will be available on a public website hosted by USC. The digital health information resource will be hosted on USC's web server, although the PI would be open to other hosting options, such as vis-a-vis NNLM or Open Science Framework.

Budget Summary. The funds requested from IMLS are \$293,134 (direct = \$212,322, indirect = \$80,812). The budget includes: 1) Summer comp for PI at \$44,356; 2) Fringe benefits at \$16,012; 3) PI Travel - conference at \$7,500; 4) Consultants/Contractual at \$50,500; 5) Student support, including tuition, pay, and travel at \$69,954; 6) Participant support - \$24,000. Indirect costs at the University's federally negotiated indirect rate of 49%, applied to the MTD of \$164,922, are assessed at a rate of 49% for a total of \$80,812.