

Now more than ever, people are leveraging data and information systems to support the health of others. While many global health environments are in the process of scaling up their digital health infrastructure, people often find themselves working in silos trying to address similar challenges related to data and data use.

In 2023, the Data Use Community (DUC) worked collaboratively to bridge those silos for implementers, data scientists, health informatics practitioners, and agencies. The community came together to share what's working, not working, and harvest from our experiences some better practices that we can take with us into 2024. With hundreds of members from over 45 countries attending the monthly community meetings, a lot of scar tissue was generously shared amongst each other to learn from.

Formed with support from the OpenHIE Community and aid organizations, including PEPFAR and others, the Data Use Community was established to:

- **Provide a space for practitioners to share and learn from each other's experiences.**
- **Understand in-country challenges from in-country colleagues.**
- **Support countries as they strengthen capacity and ownership of data use strategies.**
- **Build out a repository of best practices.**

The community started conversations with a focus on approaches for enhancing continuity of treatment and reducing interruption in HIV treatment, as we had to start somewhere!

As many countries approach epidemic control, it is clear that some of the remaining "last-mile" obstacles can only be addressed using longitudinal patient-level data. Teams shared how they are using information systems to generate, process, and analyze data to support patient care and improve HIV treatment continuity. It was during our monthly meetings that the community identified patient identity management as a priority to have deeper dive discussions on.

The DUC met multiple times throughout 2023 to discuss:

- **How are we using data from technology interventions to help patients stay in treatment?**
- **How are we approaching patient identity management so that the correct data can be used for patient care?**



Data-Driven Solutions

If you did not have the opportunity to join the community meetings in 2023, here are some examples of how members of our community are using digital data-driven solutions to improve treatment continuity:

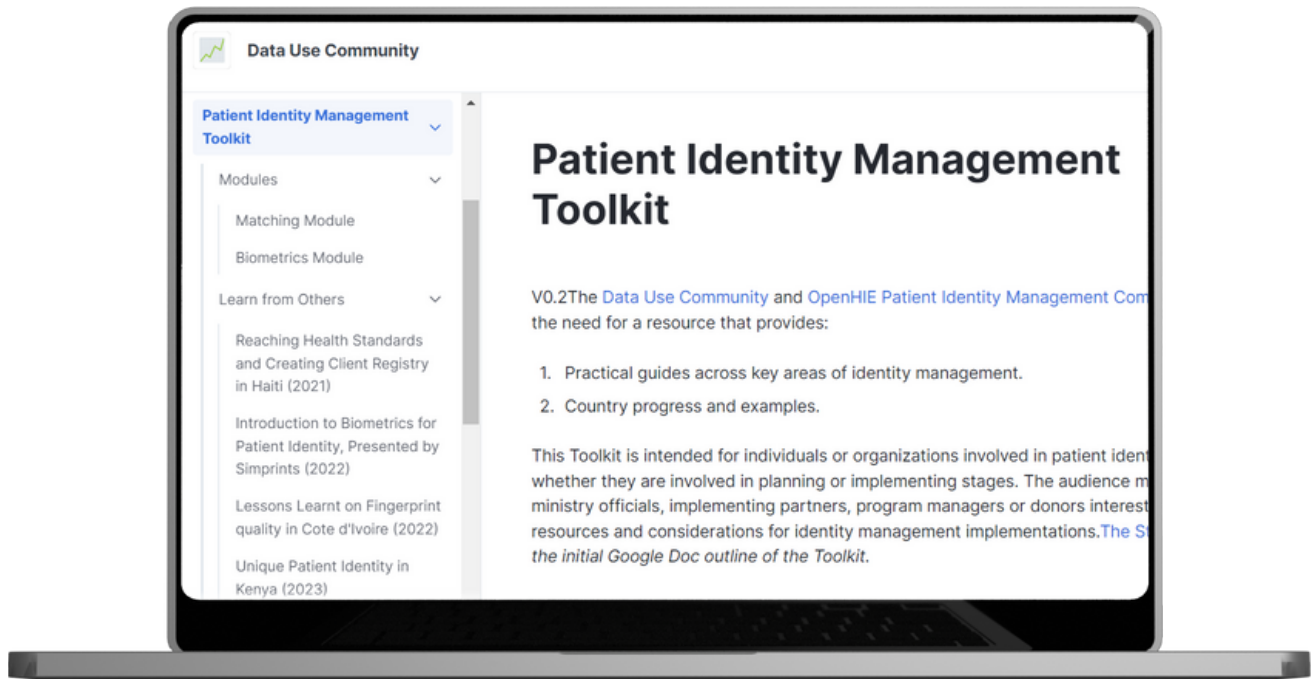
- Community members from IntraHealth shared the Rapid, Efficient, and Data-Driven Implementation (READI) approach to monitor program performance, accelerate project start-up, and conduct precision analyses.
- Community members from Lighthouse Trust in Malawi, alongside ITECH and Medic, shared their experience with the Community-based ART Retention Suppression (CARES) App to provide high-quality point-of-care EMRs app in a nurse-led community-based ART program setting, enabling improved patient care and program-level M&E.
- Community members from Uganda shared their experience functionalizing guidelines for Differentiated Service Delivery Models in UgandaEMR for decongesting facilities.
- Community members from Nigeria shared their experience implementing the NigeriaMRS Patient Treatment Response dashboard that is used to predict IIT/LTFU in HIV-treated Nigerians. The machine learning prediction model will help HIV program stakeholders identify high-risk IIT clients for proactive intervention.
- Community members from Palladium Kenya shared how they are using data/technology to support individuals currently within an HIV treatment continuity gap to return to services, including activities such as targeted counseling and/or training on prevention and wellness to address patient missed appointments.



Patient Identity Management

If you did not have the opportunity to join the Data Use Community and OpenHIE Patient Identity Management collaborative meetings, here are some examples of the approaches shared to integrate a person's electronic records within and across service delivery sites and supporting activities:

- Community members from Kenya shared the strategy and the steps that the Kenyan government took to help ensure the implementation and acceptability of a UPI system to uniquely identify patients and deliver optimum health care.
- Community members from Haiti and Nigeria shared experiences with biometrics to provide high-quality care to patients to move between services, facilities, and networks.
- Community members from Malawi shared the Demographic Data Exchange (DDE), the Master Patient Index (MPI) for Malawi, currently being developed by EGPAF in Malawi.
- Community members from Zimbabwe shared insights into the progress made with unique patient identification management.
- Community members from Ethiopia shared their work with biometrics using Simprints. This has greatly improved the speed of their registration process but still has challenges ensuring all records contain complete & accurate information and are not duplicates.
- Community members from Rwanda shared how they are using national ID numbers to identify patients within the system, and they can query this system to search for a matching record and pull the information for patients.



Building on the patient identity management discussions, the community started to bring together our collective learnings into a [Patient Identity Management Toolkit](#). This was created from an expressed need for a resource containing examples of work-in-progress and practical guides across key areas of patient identity management.

Dr. Toan Ong and Dr. Shaun Grannis kicked off the development of a [module on patient matching](#) in the Toolkit. **It outlines key steps for designing and implementing an effective approach for matching person-level records within and across health-related datasets.** Additionally, Bernadette Eichman and Erin Kim contributed to the start of a [module on biometrics](#). The Toolkit modules are intended to be communally developed and governed. If you would like to contribute and share your perspective, comment in the module documents or connect directly with the module moderators.

The community also continued to use and contribute to the [Technology Intervention Framework](#) (TIF). The TIF was created as a way to organize our conversations and describe the technology interventions for HIV retention in care at different points of a visit cycle - outside the visit, during a visit, and when a visit is missed.

The Data Use Community in 2024

2023 was an engaging year for the Data Use Community. The community expressed a desire to continue conversations in 2024 around topics such as:

- **Patient Identity and Data Linkage.** The need for good patient identification mechanisms, the development of patient-level data linked with national systems, and the deduplication of data.
- **Data Security and Privacy.** How personal and sensitive data, particularly health data, is secured across platforms.
- **Data Ownership and Quality.** Ownership of data and improving data quality, with a focus on involving individuals who generate the data and ensuring data cleaning and quality control.
- **System Integration & Interoperability.** How do different health information systems, EMRs, and applications communicate and share data with each other?
- **Artificial Intelligence.** The use of AI data analysis, data utilization, and process management. The community expressed a desire to explore how AI can enhance these aspects.

Please share your requests and community feedback in the [Data Use Community survey](#).

We plan to continue hosting the monthly community meeting and the deeper dive collaborative sessions on patient identity management throughout 2024.

Cheers to all for a great year of working together towards viral suppression and improved data use. Let's keep it going in 2024!

Join this community of over 500 individuals who have attended meetings from 45 countries, and over 1,000 members on the mailing list.

- Sign up for the [mailing list](#) to receive updates and calendar invitations to community events.
- Join the [virtual forum](#) and post your data use successes, announcements and questions.
- Join us and engage at the [monthly meetings](#).
- Take a look at all of the previous meeting notes and recordings on [the Wiki](#).

