



# Utilizing Health Information Technology in the Ryan White HIV/AIDS Program to End the HIV Epidemic in the United States

## Technical Expert Panel Executive Summary

The Health Resources and Services Administration (HRSA) Ryan White HIV/AIDS Program (RWHAP) Part F Special Projects of National Significance (SPNS) Program supports the development of innovative models of HIV care and treatment to respond quickly to the emerging needs of clients served by RWHAP recipients. Health information technology (HIT) has transformed how health care is delivered by focusing on how hardware and software store, retrieve, and share data and how health care information is utilized. It has become integral to program planning and communication with stakeholders. The application of HIT can enhance data collection and reporting to achieve process and outcome improvements in RWHAP. HIT continues to evolve, presenting opportunities and challenges to health care providers. The RWHAP SPNS Program has funded HIT projects to inform its approach for evaluating and providing information technology (IT) assistance to RWHAP-funded sites. RWHAP recipients and subrecipients use HIT in various ways—to improve health outcomes and engagement in care, to improve the patient experience, and for quality improvement activities. For example, by sharing data across providers, HIT creates an opportunity to find clients who may have fallen out of care and not reached viral suppression. If the client accesses any provider in the data sharing system, steps can be taken to support their adherence to care or re-engage them in care. Similarly, patient portals and apps can support adherence and engagement by enhancing the patient experience.

When RWHAP was reauthorized in 2009, the purpose of the RWHAP Part F SPNS Program was expanded to include funding special projects to develop a standard electronic client information data system to improve the ability of recipients to report client-level data. However, the RWHAP SPNS Program was already funding HIT initiatives prior to 2009. The first initiative, which focused on evaluating the impact of IT on improving the delivery and quality of HIV care, was conducted from 2002 to 2006. In all, the RWHAP SPNS Program has funded 13 HIT initiatives. These RWHAP SPNS initiatives have had important outcomes that reach beyond the participating recipients, including the following:

- Encouraging broader uptake (i.e., serving as a catalyst)
- Identifying lessons learned that can facilitate HIT implementation by other recipients
- Encouraging innovation in the use of HIT to improve the quality of care and health outcomes for people with HIV through efficiencies in data collection, sharing, and reporting
- Identifying cost-effective HIT-related interventions

### Benefits of HIT in RWHAP Settings

The TEP participants discussed the usefulness of HIT in RWHAP settings and provided the following input regarding the benefits for patients, clinicians, and systems.

#### *Patients*

- Provide greater access to data through portals and apps so that patients can track their health outcomes (e.g., viral load), identify areas for improvement, and celebrate successes.
- Provide the ability to initiate data-informed, health-related conversations with clinicians. These can often serve to increase the patient's health literacy.
- Provide the opportunity to interact with peers through various apps, creating an additional support network.
- Streamline processes (e.g., patients enroll once, eligibility data are shared across multiple providers).



### Background: Health Information Technology Virtual Technical Expert Panel

The Health Resources and Services Administration (HRSA) HIV/AIDS Bureau (HAB), which administers the Ryan White HIV/AIDS Program (RWHAP), convened a Technical Expert Panel (TEP) in July 2022. The Health Information Technology (HIT) TEP explored the following topics:

- How the RWHAP Part F Special Projects of National Significance (SPNS) Program supports the effective use of HIT by RWHAP recipients and subrecipients
- Gaps and areas of opportunity for applying HIT across RWHAP HIV care and treatment programs
- Concepts for facilitating new HIT and HIV care projects

Twenty-two experts representing RWHAP Part F recipient staff, consultants, and academics responsible for HIT participated in the panel. Information from the TEP will be used to inform the future work of HRSA HAB, RWHAP recipients, and partners by identifying potential technical assistance and training needs, strategic partnerships, and program priorities to address the HIT needs of this community. TEPs are nonadvisory and consultative in nature only.

- Facilitate re-engagement in care. Patients out of care can be flagged in the system. If they access a service, such as oral health services, they can be encouraged to re-engage in medical care.
- Track referrals to support services to ensure that patients follow up or receive help accessing these services if more support is needed.

### **Clinicians**

- Add key factors that impact health data to allow clinicians to address the needs of the whole person, not just a specific condition.
- Build patients' health literacy and foster partnerships with them.
- Enable easier access to data and reduce data entry burden to allow clinicians to spend more time with patients.
- Collect and share data on key factors that impact health so clinicians have a greater understanding of the challenges facing patients.

### **Systems (such as RWHAP Parts A and B recipients and large health systems)**

- Facilitate re-engaging patients who are out of care. Any time patients access services within the system, it presents an opportunity to re-engage them in care.
- Allow systems to identify patients who are thought to be lost to care but are now receiving care from another provider, thereby reducing efforts related to locating and re-engaging patients.
- Reduce staff time related to data entry, which can lead to reduced costs.
- Share data across recipients, subrecipients, and support service providers to allow the RWHAP recipient organizations to compile more comprehensive data for planning purposes.
- Make data available for public health purposes, such as identifying trends in specific communities impacted by HIV.
- Allow recipients to see how their outcomes compare with other providers, and foster discussion related to improving care.
- Support systemwide quality improvement projects.

### **Various Roles in HIT**

The TEP participants provided additional insights on how the design and implementation of successful HIT projects involves a wide range of partners and stakeholders throughout all phases. Partners are directly involved in the project (e.g., providers participating in the data sharing network), while stakeholders are other parties that stand to benefit from the project (e.g., patients, clinicians, public health partners, support service providers). This creates a shared vision and ensures that the capacities and needs of all partners and stakeholders are taken into consideration.

Given the focus on improving patient outcomes, patients should be involved in planning and implementing activities. Other key participants that should be involved in all phases of HIT projects include the following:

- **Leadership.** Leaders can provide resources and push projects forward, ensuring that staff are on board.

- **Champions.** Individuals within a system or organization who effectively advocate for HIT can get everyone on board. They then work to keep everyone engaged in the process and committed to achieving the desired result.
- **Clinicians.** Frontline staff will be the ones collecting and managing the data. HIT needs to make their work easier and not add an additional burden.
- **IT Staff.** This individual within the RWHAP provider organization is responsible for IT for HIV data. In large organizations, this may be an IT staff member who has time to address the needs of the HIV program. In small organizations, this may be a consultant or someone on staff with limited IT experience. Regardless of IT capacity within an organization, it is important to involve IT staff in the design of HIT projects.
- **Stakeholders.** Stakeholders can vary widely depending on the project—consider both how they can benefit and what they can contribute.

### **Key Steps for Launching an HIT Project**

- Include patients in a meaningful way from the beginning.
- Get buy-in from leadership and identify champions.
- Listen to providers and clinicians.
- Engage vendors from the beginning.
- Build relationships with partners.
- Get buy-in from stakeholders.
- Establish policies for data governance.
- Acknowledge and support change at various levels (e.g., RWHAP Parts A and B recipients and subrecipients).
- Integrate quality improvement methods.
- Expect the unexpected (e.g., challenges).

### **Facilitating an HIT Project**

During the TEP, expert panelists identified strategies for best facilitating an HIT project. These included identifying common characteristics and challenges to HIT implementation and highlighting the opportunities for progress. While every HIT project will have different goals and partners, the following are some facilitators to help ensure success:

- Recognize different levels of HIT expertise and capacities. Provide training when possible (e.g., data literacy).
- Optimize an existing data system instead of adopting a new one. An existing system can be optimized with work-arounds.
- Acknowledge that organizations are often very protective of their data.
- Develop a common language related to HIT across partners and stakeholders.
- Use an incremental approach and expect changes (e.g., a partner implements a new system during the project).
- Involve IT staff to the extent possible.

- Ensure that partners have the necessary technology (i.e., hardware, software, and other equipment) to participate.
- Meet with the IT vendor on a regular basis.
- Standardize data elements (i.e., coding). Discuss with partners why each data element should be included in the project.
- Acknowledge that implementing HIT can take time, sometimes years.
- Ensure institutional memory (i.e., people with knowledge of the system's development remain involved in the project, and the process is documented).

## How HRSA HAB Can Support Implementation of HIT by RWHAP Recipients and Subrecipients

Panelists suggested various ways HRSA HAB can support RWHAP recipients and subrecipients as they implement HIT projects.

### Coordination and Collaboration Across Federal Agencies

- Promote better coordination at the federal level (e.g., data harmonization across federal programs, standard schedule for reporting, standard periods for recertification).
- Encourage more collaboration with federal partners that are leaders in HIT (e.g., Office of the National Coordinator for Health Information Technology, Center for Medicare & Medicaid Innovation).

### Data Sharing

- Encourage recipients to participate in health information exchanges and common data models to facilitate data sharing. Given the barriers to getting partner buy-in, support from HRSA HAB could reduce reluctance.

### Reporting

- Standardize reporting across RWHAP Parts and streamline the reporting requirements.
- Make CAREWare more user friendly, and expand the scope beyond the RWHAP Services Report (RSR) so that users can review performance measures and health outcome data and use these data for quality improvement activities.

## Implementing an HIT Project: Challenges

- Obtaining funding/resources (e.g., for hardware/software, to support data entry and analysis)
- Finding sufficient staff time to oversee the project
- Lacking an understanding of IT and how to share data
- Sharing data across different systems
- Making changes to electronic health records, especially in large organizations
- Overcoming potential partners' resistance to sharing data
- Effectively using HIT to support quality improvements

## Resources

- Identify resources for HIT projects, keeping in mind that the RWHAP statute limits administrative costs, including for HIT, to 10 percent of the grant.
- Provide funding to support integration of surveillance and HIV care data with real-time access.
- Increase funding to support HIT for RWHAP Part C Capacity Development recipients.

## Technical Assistance (TA)

- Based on recipients' available data sources and resources, provide individualized TA on how to assess HIT capacity, identify challenges, and initiate planning for an HIT project (e.g., readiness assessment, structured TA plan).
- Offer to jurisdictions TA that is related to data sharing (e.g., how to address legal issues related to data sharing, how to use data to improve health outcomes).
- Provide TA on how to capture, analyze, and use data.
- Support peer-to-peer site visits so that recipients can learn from others in real-world settings.
- Provide strategies to recipients on how to negotiate with HIT vendors.
- Provide guidance to recipients on how to measure HIT's return on investment.
- Use the National Ryan White Conference as a venue to promote HIT (e.g., workshops on HIT, CAREWare, RSR).
- Conduct regional trainings on HIT, which could focus on specific local barriers and promote collaboration.
- Encourage recipients to publish their HIT-related findings (e.g., journal articles).
- Develop HIT manuals and other tools (e.g., readiness assessments, FAQs), including a TA webpage with links to HIT resources.

## Conclusion

The TEP participants' vast experience and insight provided key takeaways on the benefits of HIT in RWHAP settings for improving the delivery and quality of HIV care for patients, as well as the benefits for clinicians and systems. Some of the key takeaways also touched on the importance of involving a wide range of partners and stakeholders, including patients, when designing and implementing successful HIT projects. TEP participants discussed challenges and facilitators that could assist RWHAP providers when implementing their projects and help inform recommendations for various ways HRSA HAB could support HIT projects. The discussion topics have the potential to support RWHAP providers in the design and implementation of effective HIT intervention strategies to improve engagement, retention in care, and health outcomes for RWHAP clients.