Improving Health Outcomes

Moving Patients Along the HIV Care Continuum and Beyond

JUNE 2017

INTERVENTION OVERVIEW & REPLICATION TIPS

Active Referral Intervention

Virginia Department of Health

This intervention document is part of a training manual, **"Improving Health Outcomes: Moving Patients Along the HIV Care Continuum and Beyond"** and is published by the Special Projects of National Significance (SPNS), under the HIV/AIDS Bureau (HAB) of the Health and Human Service's (HHS), Health Resources and Services Administration (HRSA).

The full manual highlights 10 interventions along the HIV Care Continuum. Individual intervention chapters as well as the full manual are available.

- Diagnosing HIV
- ▶ Linkage to Care
- Retention in Care
- Prescription of ART & Medication Access
- Beyond the Care Continuum: Addressing HCV Comorbidity and Coinfection

U.S. Department of Health and Human Services
Health Resources and Services Administration
HIV/AIDS Bureau

Linkage to Care

Linkage to care, as it relates to the Care Continuum, refers to linking individuals who are HIV-positive to HIV primary care. This may include newly diagnosed individuals, persons previously diagnosed who have never been linked to care, or persons who have fallen out of care and are being re-linked. The standard of care for linkage is that persons who are diagnosed with HIV be linked to HIV medical care as soon as possible and no later than 30 days following diagnosis.[34]

Underserved populations, including many racial, ethnic, and sexual minorities, face numerous structural, financial, and cultural barriers that impede their linkage to and engagement in care.[35] Of those newly diagnosed, 74.5% of persons age 13 and older are linked to care within one month of diagnosis though just 56.5% are retained in HIV care.[36] Delaying HIV care and treatment can lead to poorer health outcomes and earlier death, instead of better health.[37] Delaying initiation of HIV care and treatment also creates the opportunity for HIV transmission to occur.[38]

Addressing several key areas has been found to improve linkage and re-engagement in care, including

- removal of structural barriers;
- increased social support services;
- use of peers, client navigation, and care coordination;
- a culturally responsive approach;
- appointment scheduling and follow up;
- timely and active referrals post-diagnosis;
- integrated one-stop-shop care delivery (e.g., co-located substance use, mental health, and other service offerings);

[34] CDC. Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 dependent areas, 2014. *HIV Surveillance Supplemental Report* 2016;21(No.4). **www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-supplemental-report-vol-21-4.pdf** Accessed September 16, 2016.

[35] CDC. Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 dependent areas, 2014. *HIV Surveillance Supplemental Report* 2016;21(No.4), Table 5a. **www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-supplemental-report-vol-21-4.pdf** Accessed September 16, 2016.

[36] CDC. Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 dependent areas, 2014. *HIV Surveillance Supplemental Report* 2016;21(No.4). **www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-supplemental-report-vol-21-4.pdf** Accessed September 16, 2016.

[37] Horstmann E, Brown J, Islam F, et al. Retaining HIV-infected Clients in Care: Where are We? Where Do We Go From Here? *Clin Infect Dis.* 2010;50:752–61.

[38] AIDSInfo. *Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents.* Clinical Guidelines Portal. Available at: **https://aidsinfo.nih.gov/guidelines**

- active approaches to reach and re-engage individuals who are out of care—for instance, using the Internet and mobile devices (e.g., for social networking, texting); and
- assistance with entitlements/benefits paperwork to secure additional financial, insurance, identification, and social support services.

A warm transition is also critical. This is the act of "applying social work tenets to public health activities for those with chronic health conditions, including HIV-infection."[39] Often the HIV tester is linking a client to another provider and possibly even to another facility. What this linkage looks like, how active it is, how comfortable the client is made to feel in establishing yet another new relationship shortly after receipt of their diagnosis can either help increase the likelihood of linkage to care or add to challenges that complicate it. Without a caring, supportive, and warm transition approach, pre-existing barriers to care and other stressors will continue to take priority.[40]

SPNS has tested and identified interventions that have proven effective in linking, re-engaging, and retaining clients in care, even for some of the hardest-to-reach and most vulnerable populations.

[39] Jordan AO, Cohen LR, Harriman G, et al. Transitional Care Coordination in New York City Jails: Facilitating Linkages to Care for People with HIV Returning Home from Rikers Island. JAIDS (Suppl). 2013;(2); S212–219.

[40] Jordan AO, Cohen LR, Harriman G, et al. Transitional Care Coordination in New York City Jails: Facilitating Linkages to Care for People with HIV Returning Home from Rikers Island. JAIDS (Suppl). 2013;(2); S212–219.

Improving Health Outcomes

Moving Patients Along the HIV Care Continuum and Beyond

Diagnosing HIV

INTERVENTION OVERVIEW & REPLICATION TIPS

Social Networks Testing
Wisconsin Department of Health Services

Linkage to Care

INTERVENTION OVERVIEW & REPLICATION TIPS

Assess, Test, Link: Achieve Success (ATLAS) Program
Care Alliance Health Center (OH)

Enhancing Linkages to Care for Women Leaving Jail
University of Illinois at Chicago

Video Conferencing Intervention
Louisiana Department of Health and Hospitals

▶ Active Referral Intervention
Virginia Department of Health

Louisiana Public Health Information Exchange (LaPHIE)
Louisiana State University, Health Science Center and Louisiana Department of Health Hospitals, Office of Public Health

Retention in Care

INTERVENTION OVERVIEW & REPLICATION TIPS

My Health Profile
New York-Presbyterian Hospital

Prescription of ART & Medication Access

INTERVENTION OVERVIEW & REPLICATION TIPS

Care Coordination Intervention
Virginia Department of Health

Beyond the Care Continuum: Addressing HCV Comorbidity and Coinfection

INTERVENTION OVERVIEW & REPLICATION TIPS

Hepatitis Treatment Expansion Initiative
University of California, San Francisco, San Francisco General Hospital HIV Clinic

Hepatitis Treatment Expansion Initiative
Washington University School of Medicine (MO)

INTERVENTION OVERVIEW & REPLICATION TIPS

Active Referral Intervention

Virginia Department of Health

The table below provides a general overview of the Active Referral intervention so readers can assess the necessary steps required for replication. This intervention uses Disease Intervention Specialists (DIS) to more actively and immediately link clients to HIV care services.

Intervention at-a-Glance	
Step 1	**Clients Receive HIV Test** Clients test positive for HIV at a local health department or are referred from another HIV-testing agency, such as a clinic or community-based organization (CBO).
Step 2	**Receives Morbidity Reports** Reports are sent from physicians, hospitals, and laboratories for persons diagnosed with HIV or other reportable STD cases.
Step 3	**Identify HIV-positive Clients** The DIS immediately engages new HIV-positive clients. These are individuals who a) test HIV positive at the health department, b) are referred to the health department after they test positive elsewhere, c) are referred to the Active Referral intervention, or d) are identified by the DIS as priority cases from the morbidity report. (Priority cases include new HIV cases as well as primary and secondary syphilis cases, and associated sexual partners.)
Step 4	**Conduct Counseling and Outreach to Priority Clients** The DIS follows interview procedures with newly identified HIV-positive clients, discusses their diagnosis, and provides education and risk reduction counseling using motivational interviewing. The DIS also discusses linkage to HIV medical care and available support services that meet client needs.
Step 5	**Secures Consent** DIS prepares referrals and uses a Coordination of Care and Services Agreement (CCSA) form to discuss linkage to medical care or patient navigator and gain informed consent to coordinate services. Upon consent, DIS assists clients in filling out and indicating type of health information to be shared with referral party.

Step 6

Conduct Follow-up

DIS confirms client linkage to medical care or patient navigation by receiving a faxed completed CCSA form back from the referral point, or through a follow-up phone call to complete the CCSA form. As client attends medical visit(s), this is documented on the CCSA form.

Source: Virginia Department of Health. *Active Referral: Implementation Manual. Virginia Department of Health, Special Projects of National Significance, System Linkages and Access to Care Initiative.* Final Report. October 2015.

Resource Assessment Checklist

Organizations should walk through a Resource Assessment (or Readiness) Checklist to assess their ability to conduct this work. If organizations do not have these components in place, they are encouraged to develop this capacity so that they can successfully conduct the Active Referral intervention. Questions to consider include:

- ☐ Does your organization have access to reportable new HIV cases in your jurisdiction?
- ☐ Does your organization offer or do you have a partner agency/agencies that offer patient navigation, HIV primary care, and social support services? If not, is your organization able to create relationships with entities that do?
- ☐ Are there Coordination of Care and Services Agreement (CCSA) forms in place at your agency and, if not, are you able to create and formalize such forms?

Note: Most states have DIS staff but each state is different, so understanding your state structure is important to getting this work off the ground.

Source: Virginia Department of Health. *Active Referral: Implementation Manual. Virginia Department of Health, Special Projects of National Significance, System Linkages and Access to Care Initiative.* Final Report. October 2015.

Setting the Stage: Grantee Intervention Background

The Virginia Department of Health (VDH) sought to establish an Active Referral intervention so clients are linked to HIV primary care immediately upon diagnosis. Active Referral was incorporated into routine Disease Intervention Specialist (DIS) activity, which has been primarily supported through existing CDC funding. With support from the SPNS Systems Linkages and Access to Care for Populations at High Risk of HIV Infection (System Linkages) Initiative, VDH was able to provide necessary training and additional staff time needed for administrative and evaluative operations, particularly Active Referral protocol development.

By creating a formalized written protocol, the SPNS project helped refine the methodology for ensuring clients reach the services they are referred to. Standardization of the DIS Active Referral process has helped minimize organizational and systematic challenges from the previous infrastructure.

A project planning-group was created to guide overall project design and implementation, including representatives from other interventions taking place across the state. VDH did this to ensure optimization of linkage and retention strategies and to avoid duplication. Additionally, consumers were recruited to weigh in on the process and provide feedback during the Plan, Do, Study, Act (PDSA) cycles.[82]

According to the VDH,

> *"Prior to SPNS, there was no standardized procedure for DIS staff to link a newly diagnosed PLWH into medical care or get confirmation of their attendance at an appointment. While many DIS staff were actively engaged in the process of linking patients to care, methods used by individual DIS staff varied, as did the extent of follow-up. With the introduction of the Active Referral protocol, DIS staff now have a uniform method for getting patients linked to care and documenting that link."*[83]

VDH's Active Referral intervention uses DIS staff and testing referral agencies across the state of Virginia to rapidly link clients to care upon diagnosis, as well as HIV-positive clients who are not fully linked to care. More specifically, the intervention target populations include

1. newly diagnosed;
2. sporadically in care or at risk for falling out of care;
3. lost to care; and
4. previously diagnosed/never engaged in care.[84]

DIS staff work directly with referral sources and coordinate with patient navigators and medical providers. This includes a feedback loop so DIS knows if clients have entered into care.

The intervention was piloted in the Central and Southwest regions and then expanded across the state.

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[82] Virginia Department of Health. *Active Referral: Implementation Manual. Virginia Department of Health, Special Projects of National Significance, System Linkages and Access to Care Initiative.* Final Report. October 2015.
[83] Virginia Department of Health. *Active Referral: Implementation Manual. Virginia Department of Health, Special Projects of National Significance, System Linkages and Access to Care Initiative.* Final Report. October 2015.
[84] Virginia Department of Health. *Active Referral: Implementation Manual. Virginia Department of Health, Special Projects of National Significance, System Linkages and Access to Care Initiative.* Final Report. October 2015.

Description of Intervention Model

CHALLENGE ACCEPTED

THE CHALLENGE: linking newly diagnosed individuals during that critical "capture" moment immediately following diagnosis, as well as ensuring linkage is truly active and engaged so clients follow through.

Intervention Model: **Active Referral Model**

The Institute of Healthcare Improvement (IHI) Collaborative Learning Model is a process where systems, organizations, and providers implement and measure small-scale interventions and then share their experiences in an effort to accelerate learning and widespread implementation.[85] IHI informed the development and piloting of the Active Referral intervention.

The Active Referral intervention involves DIS staff and testing and referral agencies across the state working together to ensure clients are rapidly linked to care upon HIV diagnosis, using a standardized active referral protocol. DIS accomplish this by working directly with referral sources and with assistance from medical providers and patient navigators (where available). This allows DIS staff to more efficiently and consistently receive confirmation of linkage to HIV medical care.

The Active Referral intervention sought to increase the percentage of newly diagnosed individuals who are linked to care and to link them within 30 days of their diagnosis or initial referral to a patient navigator.[86] DIS staff are located in 35 health districts across Virginia and supervised by local health department STD nurses, nurse managers, or DIS frontline supervisors. DIS across the state take some direction from Virginia's STD Surveillance, Operations & Data Administration (SODA) field operations and approximately five DIS staff members are directly supervised by regional SODA field operations.

Each region has at least one "champion" who serves as the go-to person for Active Referral and linkage-to-care issues. These individuals help provide technical assistance where needed. They also help to identify any overlap of processes and procedures between DIS' Active Referral intervention and the work being done by patient navigators.

[85] Institute for Healthcare Improvement. *The Breakthrough Series: IHI's Collaborative Model for Achieving Breakthrough Improvement.* White Paper. 2003.
[86] Rhodes A. Virginia Department of Health. Personal Correspondence. February 2, 2017.

Staffing Requirements & Considerations for Replication

Staffing Capacity

Based on the VDH work, here are the types of staff necessary to replicate this intervention.

Disease intervention specialists (DIS): DIS are responsible for the Active Referral intervention. Primary tasks include

- following up on priority clients (Note: by law, DIS have authority to locate persons diagnosed with an infectious disease that impacts public health and provide test results on behalf of the testing facility);
- providing STD prevention education;
- reducing ongoing disease transmission;
- conducting appropriate testing and counseling;
- providing referrals to connect clients to care;
- offering partner services;
- reporting required health conditions; and
- following up on active linkage to care.

DIS supervisor: This individual supervises the DIS and ensures their compliance with the Active Referral protocol. Depending on where DIS are working out of in the state, this supervisor could be a health department STD nurse, nurse manager, DIS frontline supervisor, or STD Surveillance, Operations & Data Administration (SODA) field operations manager.

Regional "champion:" Each region also has at least one "champion" who serves as the go-to person for Active Referral and linkage-to-care issues. These individuals help identify any processes and procedures overlap between DIS' Active Referral intervention and the work being done by other synergistic interventions in the state. Where necessary, these individuals may offer TA.

Staff Characteristics

Core competencies include

- familiarity with, and course completion of client-focused HIV risk-reduction counseling models;
- skill in the counseling process;
- active listening skills;
- ability to use and be comfortable with interactive negotiating styles rather than persuasive; approaches to communicate and engage clients;
- using open-ended question to solicit further information from clients;
- interest in learning new counseling and skills-building techniques;
- ability to build client trust and create a supportive environment;
- "people" skills;
- non-judgmental attitude; and
- skilled at eliciting behavioral information and providing referral resources.

Source: Virginia Department of Health. Active Referral: Implementation Manual. Virginia Department of Health, Special Projects of National Significance, System Linkages and Access to Care Initiative. Final Report. October 2015.

The Care Continuum Team Roster

While several programs and interventions across the state of Virginia—and operating through the state health department—have clear synergies, it is important to know the key "players" and how their work all fits together to support client advancement along the HIV Care Continuum.

Disease intervention specialists (DIS): DIS workers are part of an "Active Referral" intervention focused on rapidly linking newly diagnosed HIV-positive individuals into care. The DIS receive a list of new diagnoses, identify priority cases, reach out to them, discuss the diagnosis and provide some HIV education and active linkage to a patient navigator. The patient navigator will help this client manage their way through the health care system. DIS also assist those who have fallen out of care and bring them back.

Patient Navigation: Patient navigators work across all five health regions of Virginia to carry out linkage and retention activities by providing healthcare systems navigation and support.

CHARLI: This is a pre- and post-release correctional program for inmates operating through state funds, focused on HIV testing and the establishment of a release plan to community-based organizations, with a particular emphasis on linkage to support services.

Care Coordination: An intervention first funded through a grant from the Health Resources and Services Administration's HIV/AIDS Bureau, Special Projects of National Significance and sustained through Ryan White funds. Care coordination's primary focus is on ensuring access to medication and HIV medical care for recently released inmates, including facilitation of coverage and support for and tracking of medication pickup and medical appointments. This includes referral for expedited ADAP coverage and a 30-day supply of ART immediately after release.

Sources: Virginia Department of Health. *Care Coordination Implementation Manual: Virginia Department of Health, Special Projects of National Significance, System Linkages and Access to Care Initiative.* Final Report. October 2015.

Virginia Department of Health. *Active Referral Implementation Manual: Virginia Department of Health, Special Projects of National Significance, System Linkages and Access to Care Initiative.* Final Report. October 2015.

Replication Tips for Intervention Procedures and Client Engagement

This section provides tips for readers interested in replicating the intervention and, where applicable, includes grantee examples for further context.

DIS Processes

The Active Referral intervention establishes a new, formalized role for DIS staff to readily engage and offer newly identified HIV clients a direct referral to a medical provider or patient navigator.

Documented client follow-up is an essential part of this intervention and in ensuring they link to care.

When a client is newly diagnosed or newly identified with HIV at a local health department, they are immediately engaged in the Active Referral Process, where DIS assist with coordination of linkage to HIV medical care and other services. Additionally, DIS receive morbidity reports from physicians, hospitals, and laboratories for persons in their district who are diagnosed with HIV and other reportable STDs. DIS are then responsible for following up with priority STD diagnoses (i.e., HIV, primary and secondary syphilis, and associated partners) and engaging them in care and services through the Active Referral process.

By using motivational interviewing and creating rapport, DIS provide education and prevention messaging to clients, and also discuss referrals to available services. Referrals to support services are often critical for keeping clients engaged, because when basic survival needs are unmet, HIV becomes less and less of a priority.[87]

DIS should be sure to clarify for clients what the Active Referral DIS Intervention is. Interested clients sign a Coordination of Care and Services Agreement (CCSA) form (valid for 24 months) and provide DIS staff and patient navigators with authorization to contact and reengage clients if they become lost to care. If clients are interested in the patient navigation program, then a "warm transition" from DIS to the patient navigator should occur.

The Active Referral intervention calls for DIS staff to directly contact the provider or patient navigator (either via phone or fax) to make and/or confirm an HIV medical care appointment on behalf of or with the client. The CCSA form is provided (usually faxed) to the referral point. Two-way communication between DIS and patient navigators, as well as clearly defined roles and responsibilities between the two, is key.

An important part of the CCSA form is the section where navigators and providers fill out and fax back confirmation that the referral was received and that the client was seen. Documented client follow-up is an essential part of this intervention and in ensuring they link to care.

[87] Virginia Department of Health. *Active Referral Implementation Manual: Virginia Department of Health, Special Projects of National Significance, Systems Linkages and Access to Care Initiative.* October 2015.

Securing Buy-in

It is important to educate medical providers, social support staff, DIS, and patient navigators about how Active Referral is both similar to and different from existing DIS job responsibilities and how Active Referral is aligned with patient navigation and community health workers. As VDH explains,

> *"This helped all parties understand that no one role stood alone in serving as advocates for their patients, which in turn helped patients trust each role as well."* [88]

Trainings should be provided to help DIS staff better explain to clients what services are being offered, and how these services are beneficial to clients' health. These trainings are continuously refined over time. Additionally, patient navigators were invited to portions of the trainings to encourage networking between them and the DIS. This creates an improved Care Continuum model and improved DIS offerings. It also keeps stakeholders engaged in the system and invested in the work.

Based on staff recommendations, trainings on data collection and data quality were added. Trainings typically last approximately 3 hours and cover topics such as public health goals, health department versus field perspectives, how to move from passive to active referrals, motivational interviewing, use of the Active Referral protocol, communication best practices, and others.

VDH explains that, "Training experienced DIS staff on conducting Active Referral requires addressing a common misconception: that DIS staff were already doing Active Referral work."[89] Although DIS staff facilitated referrals, they were not doing Active Referral as defined in the SPNS project. Some were not following up to ensure clients arrived at their first appointments; some were doing these activities but not documenting the work. This is where a formal, standardized protocol and required documentation are useful in routinizing the process and clarifying tasks and expectations for staff.

Some tips for collaborating with partners and clarifying roles include the following:

- **Knowing the key entities with whom to outreach.** For Virginia, this included reaching out to multiple state programs (HIV care, HIV prevention, STD operations, HIV Surveillance), local health department staff, Ryan White grantees, community-based organizations, and related intervention programs (e.g., CDC's Care and Prevention in the United States [CAPUS] demonstration project operating in the state).
- **Holding inclusive meetings with stakeholders to involve them early on in planning.** For the Active Referral intervention, VDH held statewide meetings with stakeholders, including conference calls, and technical working sessions to strategize about key areas of the project during the initial developmental phases of the intervention.
- **Ensuring clarity about why changes in job procedure were being made.** This involved explaining the importance of changes in the current DIS process and how they help better link clients to care to reduce the risk of onward transmission.
- **Show you're listening and that feedback is valued.** VDH asked DIS to review draft protocols and forms and wove DIS recommendations directly into updated documents and trainings.

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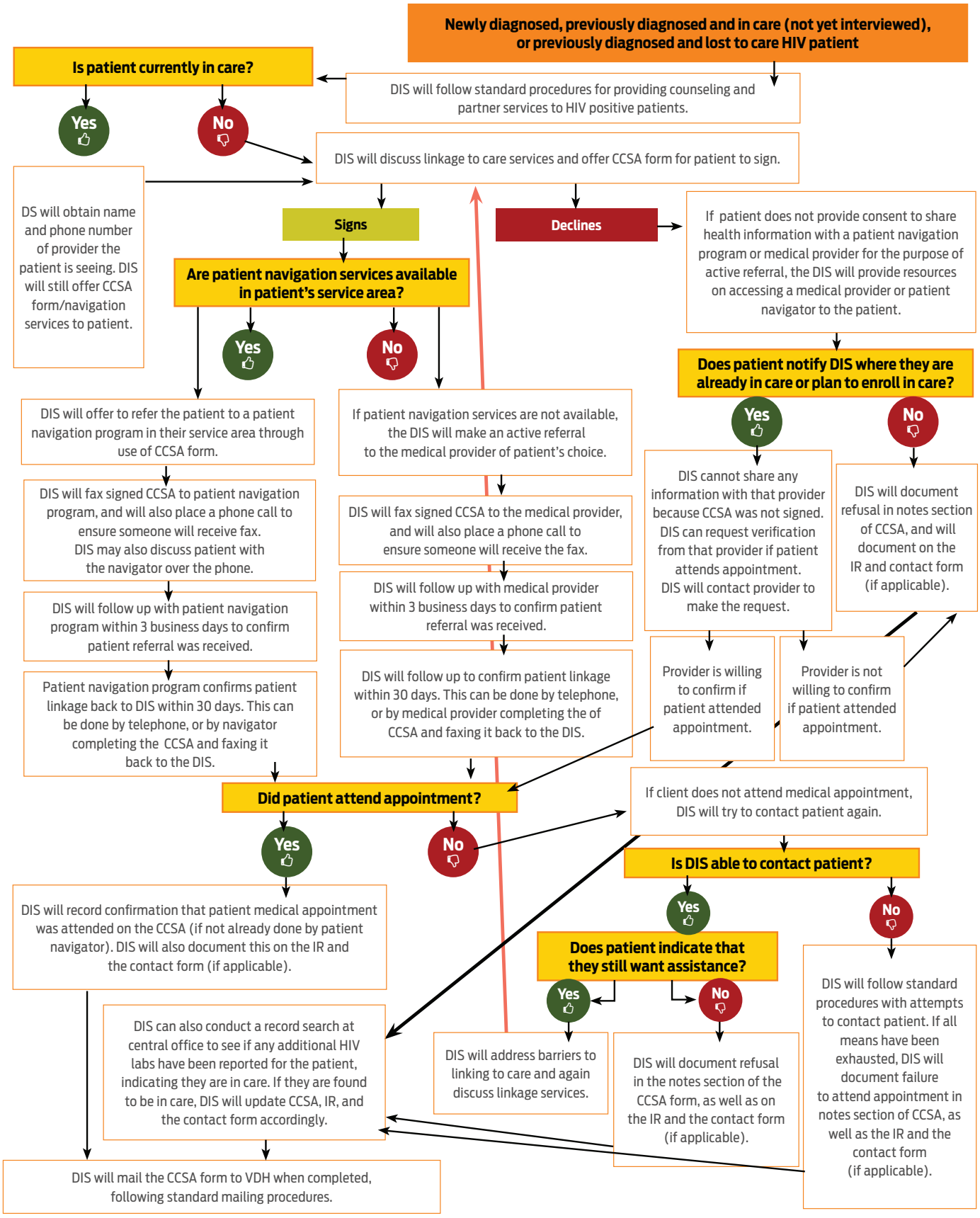
[88] Virginia Department of Health. *Active Referral Implementation Manual: Virginia Department of Health, Special Projects of National Significance, Systems Linkages and Access to Care Initiative.* October 2015.

[89] Virginia Department of Health. *Active Referral Implementation Manual: Virginia Department of Health, Special Projects of National Significance, Systems Linkages and Access to Care Initiative.* October 2015.

Active Referral Process Map



- **Increase communication.** This includes increasing communication between DIS and patient navigators to help them feel more connected and less confused about their respective roles. DIS also provides updates in monthly statewide STD prevention meetings and stays in touch with contacts at referral sites.

Overcoming Implementation Challenges

Because of the evolving nature of this work as well as staff turnover, trainings are ongoing. This creates the opportunity to address questions that arise during implementation of Active Referral.

Because both DIS and patient navigators work toward the common goal of handling referrals and creating a relationship with clients to better link and retain them in care, staffing challenges or perceptions of overlap have to be clarified and addressed.

Collecting accurate data on newly diagnosed cases can be a challenge, because of either incomplete laboratory reporting or reluctance by some providers to allow surveillance staff to review data. Continued enforcement of protocols and communication outreach may help address these challenges.

Promoting Sustainability

The development of the Active Referral intervention protocol and associated forms took VDH longer than expected. This time could possibly have been reduced by spending more structured time with DIS up front to understand how the intervention could be incorporated into their process, and by dedicating a higher proportion of staff time toward the protocol and form development.

That said, now that a protocol has been established, it is formally woven into DIS regular job assignments, incorporated into goal-setting under ongoing CDC grant funding that supports DIS activity, and is now considered a standard statewide process. As such, there is no real additional cost required to sustain the activities.

Although Active Referral was completed by DIS staff for the SPNS grant, VDH is now working to expand the intervention to anyone who engages with clients in linkage and re-engagement work.

Conclusion

The key components of an Active Referral intervention are a protocol to ensure consistency among DIS workers, engagement of community partners, linkage to patient navigators, and ultimately, client linkage and retention in HIV medical care.

Given the critical time period immediately following HIV diagnosis and the importance of receiving medical care, the value of linkage interventions, such as Active Referral, cannot be underscored enough.

Other Available Resources

- **Systems Linkages and Access to Care for Populations at High Risk of HIV Infection (System Linkages) Initiative**