

# PEER NAVIGATION FOR KEY POPULATIONS



## **ACKNOWLEDGMENTS**

The guide was adapted from the HIV Prevention Trials Network (HPTN) O61 Peer Health Navigators Operations Manual, Version 2.0, 15 July 2009, the Key Populations Implementation Science Study – South Africa (2016),\* and *Building Blocks to Peer Success: A toolkit for training HIV-positive peers* (2009), developed by the Center for Advancing Health Policy and Practice at Boston University's School of Public Health.

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## LIST OF ACRONYMS

|              |                                |
|--------------|--------------------------------|
| <b>ART</b>   | Antiretroviral therapy         |
| <b>CBO</b>   | Community-based organization   |
| <b>CD4</b>   | Cluster of differentiation 4   |
| <b>DIC</b>   | Drop-in center                 |
| <b>FHI</b>   | Family Health International    |
| <b>GBV</b>   | Gender-based violence          |
| <b>HIV</b>   | Human immunodeficiency virus   |
| <b>HTS</b>   | HIV testing services           |
| <b>KP</b>    | Key population                 |
| <b>MOU</b>   | Memorandum of understanding    |
| <b>MSM</b>   | Men who have sex with men      |
| <b>OST</b>   | Opioid substitution therapy    |
| <b>PEP</b>   | Post-exposure prophylaxis      |
| <b>PLHIV</b> | People living with HIV         |
| <b>PN</b>    | Peer navigation                |
| <b>PrEP</b>  | Pre-exposure prophylaxis       |
| <b>SOP</b>   | Standard operating procedure   |
| <b>STI</b>   | Sexually transmitted infection |
| <b>UIC</b>   | Unique identifier code         |
| <b>WHO</b>   | World Health Organization      |

# 1

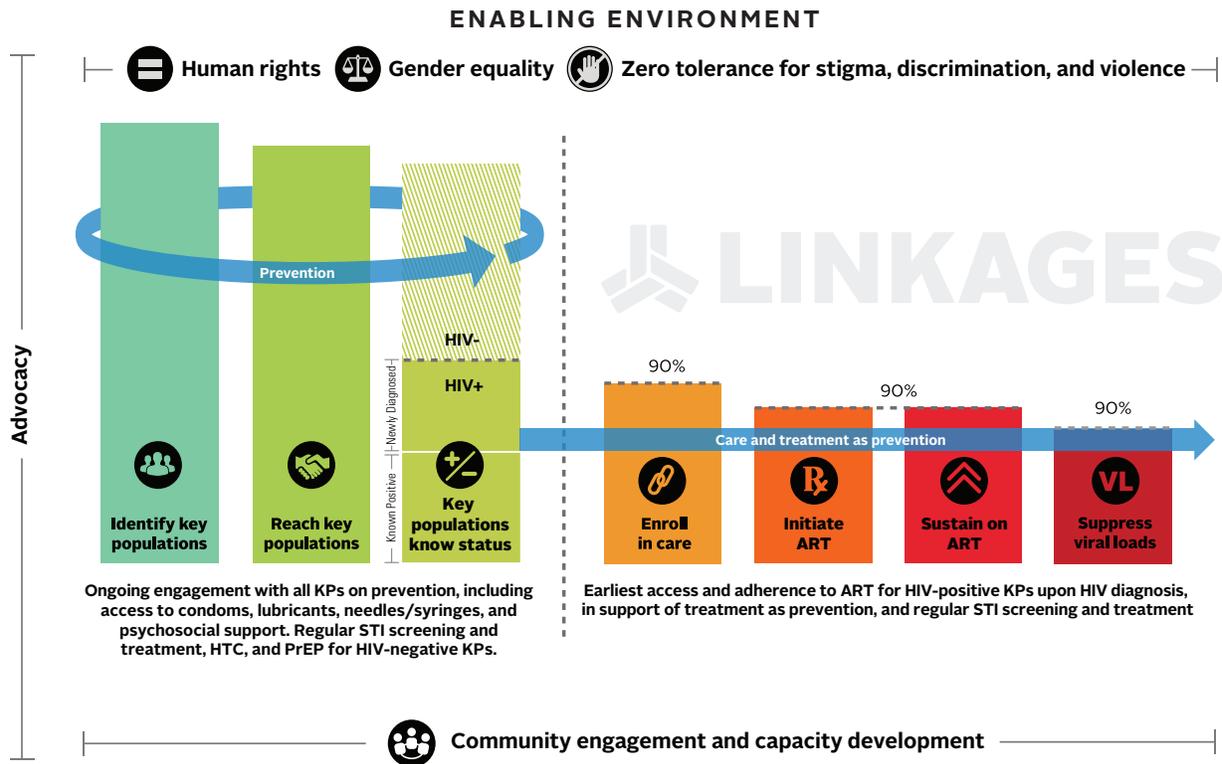
## INTRODUCTION

*Linkages Across the Continuum of HIV Services for Key Populations Affected by HIV (LINKAGES)*, funded by PEPFAR and the United States Agency for International Development (USAID), focuses on key populations (KPs) — men who have sex with men, sex workers, people who inject drugs, and transgender people. In the context of increasing HIV prevalence among key populations and decreasing resources for HIV programming, it is essential that epidemic responses utilize sustainable, effective approaches for reaching, testing, linking, and retaining service beneficiaries in the continuum of HIV services. The use of such approaches is particularly important considering the UNAIDS 90–90–90 goals—that by 2020, 90 percent of all people living with HIV know their HIV status, 90 percent of people diagnosed with HIV infection receive sustained antiretroviral therapy (ART), and 90 percent of people receiving ART are virally suppressed.

The HIV cascade is an organizing framework for illustrating how LINKAGES and other programs can improve services from the point at which a beneficiary is reached in the community through viral suppression for those living with HIV. The figure on the following page presents this framework and shows where peer-led interventions can support services along the cascade (Figure 1). Programs are increasingly focusing on the role peers can play in supporting HIV-positive service beneficiaries throughout the cascade, including linking them to care and helping them attend diagnostic and clinical appointments and adhere to their treatment regimens.

Peers are people who share similar attributes, such as gender, sexual orientation, age, health condition, or socioeconomic status. Peer-led interventions have become a standard approach in many programs working with key populations. With training and support, KP members can reach their peers effectively with prevention commodities, such as condoms, lubricants, and sterile drug-injecting equipment, as well as information and support for behavior change to reduce vulnerability to HIV. Peers can also help link service beneficiaries to other HIV, health, and social services and to interventions that support positive health outcomes and build social cohesion.

The purpose of this document is to provide guidance for programs implementing peer navigation as part of a core package of HIV-related interventions for key populations. It is part of the **LINKAGES Peer Navigation Toolkit**, which also includes a facilitator's guide, PowerPoint presentations, and additional resources designed to be used in a variety of contexts, according to local needs. Each program is advised to use the information and tools provided to inform the development of country/program-specific standard operating procedures (SOPs) to ensure that all providers within the service network clearly understand their roles and responsibilities. Peer navigation (PN) SOPs should be based on the unique needs of each country/program, the composition of the teams providing services, and the existing structures providing community- and facility-based HIV services.



LINKAGES also recommends that the training manuals and accompanying tools included in the toolkit be adapted to the capacity-building and implementation needs of a program and its participants. As much as possible, key population members should be involved in the design, implementation, evaluation, and improvement of LINKAGES programs.

## 2

## OVERVIEW OF PEER NAVIGATION FOR HIV PROGRAMS

Comprehensive HIV programming for key populations includes service provision along the entire cascade. In the first third of the cascade, programs can use a variety of approaches for identifying, reaching, and recruiting individuals to access HIV testing and counseling services. These approaches might include enhanced peer outreach to improve the quality of behavior change communication and increase reach via social networks. The role of peer outreach workers generally ends when a beneficiary accesses counseling and testing services or, for those already living with HIV, when he or she enrolls or re-enrolls in care and treatment.\* The goal for peer navigation is that newly diagnosed individuals are supported to enroll in treatment and remain within the service network to achieve viral suppression.

Peer navigation picks up from where peer outreach traditionally leaves off. Peer navigators work full time as part of a case management team to assist HIV-positive service beneficiaries in enrolling in and accessing care and treatment services, while supporting them to identify and overcome barriers that interfere with achieving personal health-related goals. Peer navigators can be drawn from the pool of peer outreach workers but should receive additional training to ensure they have expert knowledge of all the relevant facility- and community-based services available for their beneficiaries. Ideally, navigators are peers whose experiences have been similar to those of the beneficiaries. For example, the LINKAGES project typically trains peer navigators who are living with HIV and within a specific KP community, so that they have an intimate understanding of the lived experience of the peers they support.

It should be noted that the specifics on who peer navigators are, how they are introduced to HIV-positive KP peers, where they work, how much they get paid, and other implementation issues should be decided by the in-country team, in consultation with the KP community and implementation partners. The KP HIV program may decide that someone other than a KP peer would be best suited to be a peer navigator. For example, where KP networks are limited in size, service beneficiaries may be concerned about disclosure of their HIV status when working with a member of their own key population. For this reason, LINKAGES does not require that navigators be members of the key populations they serve. Before adapting navigator terms of reference for each country context, programs should consult with representatives of KP beneficiaries to ensure that the navigator options reflect their preferences. Criteria for navigator selection should be determined in conjunction with KP members, community stakeholders, facility staff, and other key players. Resources permitting, beneficiaries should be able to choose from a variety of navigators. These options might include community health workers trained in the provision of navigation services.

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\* The term “peer outreach worker” refers to a KP individual who is trained to conduct outreach to other members of the same key population. Peer outreach workers may also be known as peer educators, peer leaders, or by other terms.

## 2.1 | Special considerations in working with key populations

Key population members face different challenges in accessing HIV and related services compared to other potential beneficiaries. It is important to keep the following issues in mind when working with key populations.

### 2.1.1 | Legal barriers and enablers

Laws, regulations, and policies can be barriers to effective service access and uptake. In providing support for key populations, it is important to be aware of potential legal barriers and local policies, such as anti-sodomy laws, laws against sex work, and penalties for carrying drugs for personal consumption or drug injection equipment (i.e., needles and syringes). Conversely, many people, including KP members, may not be aware of their individual rights under local law.

*Programs should train navigators on basic human rights and ensure that they have simple job aids to guide discussions with their beneficiaries. Where possible, programs should also ensure there are links to free or no-cost legal assistance for beneficiaries.*

### 2.1.2 | Codes of conduct

To serve as a navigator to HIV-positive peers, navigators must sign a code of conduct. Peer navigators and their service beneficiaries may be members of the same community, and therefore may encounter each other in social settings. To ensure that these navigator-peer relationships are strictly professional and confidential, appropriate codes of conduct in social settings must be articulated, understood, and agreed upon. Codes of conduct should include a clause prohibiting dating and sexual activity between navigators and beneficiaries, as well as a strict no-coercion or bribery clause, given the often criminalized and stigmatized nature of KP experience.

## 2.2 | The case management team

In an ideal setting, peer navigators work as part of a team that addresses a variety of needs. An individual living with HIV may have clinical, psychosocial, diagnostic, mental health, substance use/dependence, gender-based violence (GBV)-related, legal, and other needs. Through the case management approach, a team of individuals works collaboratively to discuss and prioritize beneficiary needs, sharing the responsibility of ensuring that they are met.

**TEAM COMPOSITION** will vary in each country and program based on available resources and capacities. The team might consist of a trained case manager, a clinician (nurse/doctor), and a social worker and a psychosocial counselor, in addition to a peer navigator. In settings where resources are limited, the team may include only a peer navigator, a clinician, and a navigation team supervisor. Recommended practice is that the case management team meets weekly to discuss individual cases, consider problems, and develop solutions to ensure optimal outcomes for each beneficiary.

**CASE MANAGERS** generally have received professional training and have substantial experience supporting beneficiaries' use of services within a network. Case management is a multi-step process to ensure timely access to, and coordination of, medical and psychosocial services for a person living with HIV and (in some models) his or her family/close support system. This process may involve all or some of the following activities: service planning, service plan implementation, coordination, clinical guidance, monitoring and follow-up, case conferencing, crisis intervention, advocacy for services, consultation with providers, psychosocial support, supportive counseling, and beneficiary education.<sup>1</sup>

**CLINICALLY TRAINED PROVIDERS**, including doctors, nurses, and other specialists, provide clinical care. These services are essential for ensuring that beneficiaries receive relevant diagnostic tests, are prescribed appropriate medication, and are effectively monitored in terms of clinical outcomes and overall physical health.

**SOCIAL WORKERS HELP INDIVIDUALS**, families, and groups of people cope with the social problems they face. They are usually proficient in teaching their beneficiaries the skills and mechanisms needed to improve their lives. In addition to providing professional counseling, social workers often serve as liaisons between institutions and collaborate with other health professionals to ensure beneficiary wellness. They may also address legal issues, such as assisting with hearings and providing testimony relating to their beneficiaries. Some social workers engage in research, policy development, and advocacy. They maintain case history records and prepare reports as needed for individuals and institutions.

**PEER NAVIGATORS** have in-depth understanding of specific issues related to key populations. They collaborate with providers in the care network to support beneficiaries to enroll in care and to access and navigate the services they need to maintain healthy lives and achieve their health-related goals. Peer navigators' duties might include referral to clinical, psychosocial, and other care and support services, accompaniment to appointments (including support with transportation), adherence support, routine appointment reminders, follow-up for missed appointments, and tracking of those lost to follow-up. They generally handle a caseload of 20 to 40 individuals living with HIV, depending on the stage of the epidemic in the area, the quality of health services, and the number of high-need individuals to whom they are providing support. More detailed information on their roles and responsibilities is provided below.

*This implementation guidance acknowledges that in numerous settings, peer navigators may take on many, if not most, of the roles traditionally assigned to case managers. Programs can determine independently how best navigators can complement existing services, taking into consideration local policies and regulations, navigator capacity, and resources for supportive supervision.*

### 2.2.1 | Complementarity and task shifting

In addition to the team members described above, others may be involved in case management, including HIV testing counselors, psychosocial counselors, contact investigators, and care coordinators. Their roles may overlap to varying degrees. Task shifting is an approach to reducing the burden of responsibilities on facility or other staff to improve service access and quality. It involves shifting some duties, such as intake assessment, counseling and testing, or referral, to lay workers, such as navigators. Task shifting ultimately can lead to shorter wait times, greater capacity to manage high client load, cost savings, more efficient use of resources, and improved quality of care. It is particularly helpful for KP service beneficiaries in resource-limited settings who do not have access to a case manager or a social worker.

In some cases, navigators may take on some of the duties of facility-based staff as part of a task-shifting agreement developed between a community-based or nongovernmental organization and a public-sector service site. Each program will need to consider all the human resources available within the service network and decide with the various providers where navigation can enhance service access, uptake, and retention. Clearly defining the roles and responsibilities of each team member will be critical to the success of case management and peer navigation.

For more information on the differences among peer outreach, case management, and navigation, please consult the table in **Appendix H**.

## 2.3 | Roles and responsibilities of the navigator

While specific services may vary based on the needs of a given program, it is essential that navigators build the trust of their beneficiaries without judgment or prejudice. To do so, navigators and facility-based staff must work together to present themselves to beneficiaries as part of one team. A navigator can be a friend, sounding board, health educator, health care facilitator, guide, coach, advocate, and community resource. Navigators are *not* medical experts, substance use counselors, mental health specialists, or social workers. A comprehensive list of possible navigator roles and responsibilities is provided below. Many responsibilities may be shared with other providers within the support team. The roles correspond to the latter half of the HIV services cascade.

### Enroll in care and initiate treatment

- **Refer and link service beneficiaries to clinical, psychosocial, and other support services.** Navigators may be matched with HIV-positive beneficiaries shortly after each beneficiary's positive diagnosis (for more information, refer to **3.2.1, Matching beneficiaries with navigators**). Through an initial assessment and planning process, navigators support beneficiaries to access diagnostic and clinical services and initiate treatment. As part of their role, they may walk beneficiaries through the initial registration at a service site. They should have extensive knowledge of the health, psychosocial, and other support services available in their area and beyond. Navigators ensure that service beneficiaries are aware of nutrition, peer support, legal aid, psychological, GBV, and case management services and receive the necessary support to access these services.
- **Liaise with health and other social service providers as needed.\*** One of the first steps of a PN program is establishing how peer navigators will work with the staff at project-supported and/or referral health facilities where HIV-positive peers seek services. Overall, navigators support beneficiaries to build an open, trusting relationship with their healthcare providers and other service providers, helping them overcome communication, transportation, and other barriers. They can organize weekly or biweekly support groups for service beneficiaries, assist group facilitators, and introduce discussion topics. A navigator may liaise directly with a service beneficiary's clinician, social worker, health educator, legal support provider, and other providers to help ensure effective access to all relevant services, if such support is consistent with the SOPs of the KP program and is agreed upon by both the beneficiary (via informed consent) and the service facility. Navigators also maintain strong relationships with clinical and other support staff and help ensure, to the best of their ability, that the services to which they refer beneficiaries are non-stigmatizing, client-friendly, and confidential.

### Sustain on treatment

Support service beneficiaries to adhere to their treatment regimens. Working in tandem with case managers, navigators support their beneficiaries to adhere to treatment independently. They provide training on treatment literacy to help beneficiaries understand the importance of treatment and viral suppression. They also help each beneficiary identify challenges to adherence and develop a plan for adhering to his or her treatment regimen (using the **Life Steps** approach).<sup>+</sup> Support may involve a combination of counseling, goal-setting, tips, suggestions, and personal strategies.

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\* Each program should develop a memorandum of understanding (MOU) between community-based partner organizations and treatment facilities to outline the roles and responsibilities of navigators and other providers collaborating on navigation. This MOU should include a client flow algorithm (see Section 3.1).

<sup>+</sup>LINKAGES recommends the use of the Life Steps adherence counseling approach, described in Section 3.3.2, to support service beneficiaries to adhere to their treatment plans and achieve other important goals.

Navigators provide practical advice about medication-taking cues, medication refills, clinical visits, options for obtaining medical care and treatment, side effect management, reminders, and organizational tools that have worked for them. Support may include regular calls and messages, accompaniment to appointments, evaluation and adjustment of adherence plans, and delivery of medication, as needed. Navigators may also periodically visit service beneficiaries at home, conduct pill counts, and help them interpret CD4 count and/or viral load test results.

- **Provide counseling and emotional support.** Navigators work in conjunction with other members of the case management team to provide basic counseling and support to enable their beneficiaries to navigate the continuum of HIV services, adhere to treatment, and live positively. Using a hierarchy of needs approach, which suggests that the most basic level of needs must be met before an individual will strongly desire (or be motivated to address) their secondary or higher-level needs, navigators help beneficiaries prioritize needs and provide them with appropriate support. (See **3.2.2, The first meeting**, for more information on this approach.) Navigators are skilled in recognizing complex cases and understand when to refer beneficiaries for professional counseling and support. They may also host regular peer support groups to build social cohesion and participation and may help beneficiaries advocate for policy changes, services, and their individual rights
- Give feedback and support to team members. Navigators are positioned to receive first-hand information from beneficiaries about challenges in accessing services, breaches of confidentiality, and feedback on the services provided within the network. They participate in and report on each case at weekly consultation meetings the case management team holds to identify challenges and solutions. They also participate in weekly or biweekly supportive supervision and check-in meetings that supervisors hold to determine how things are going and to address navigators' psychosocial and other related needs so they can optimize performance and job satisfaction. Navigators may provide technical support for the design or redesign of community- and facility-based interventions to ensure that they are culturally relevant, appropriately tailored to the needs of their service beneficiaries, strategic, and accessible.

## 2.4 | Optional roles

Some programs may have the capacity and permission from the government to train and certify their navigators to serve as qualified HIV counselors and testers. Navigators who are both from the KP community and living with HIV intimately understand the service network and are strategically poised to provide counseling and testing to service beneficiaries. Navigators may take on the following additional roles and responsibilities if doing so is considered beneficial to a program.

### Reach/Recruit

- **Conduct community-based outreach.** Some programs may choose to have peer navigators who also function as community outreach workers. Their responsibilities might include conducting individual- and group-level behavior change communication sessions in hot spots and other locales, providing commodities such as condoms and lubricants, and referring beneficiaries in the community to HIV counseling and testing.

### Test

- **Provide counseling and testing services.** Navigators may refer partners of beneficiaries or other individuals to mobile or fixed testing sites at public or community-based facilities, or provide community-based testing directly (using oral or finger-prick testing, with referral for confirmation at a facility). Navigators may also accompany individuals to attend testing services. If not providing testing services directly, they may provide a directory of available testing services and/or guidance on where beneficiaries can access more information by phone, Internet, or in person at drop-in centers (DICs) or other client-friendly sites.

- **Provide tailored post-test counseling and support to service beneficiaries.** Navigators who conduct counseling and testing can provide strategic behavioral communication, motivational counseling, and commodities, including condoms, lubricants, and safe injection equipment. They can emphasize routine testing and consistent use of condoms and lubricants with sexual partners. They can also support service beneficiaries to engage partners and children at risk in accessing HIV testing services.
- **Assist in partner notification.** Navigators may assist in partner notification services, which is also known as disclosure or contact tracing. Partner notification is defined as a voluntary process whereby a trained provider asks people diagnosed with HIV about their sexual and/or drug injecting partners and then, if the HIV-positive client agrees, offers these partner(s) HIV testing services (HTS). Partner notification is provided using passive or assisted approaches.

Whether or not navigators are involved in testing, they should understand the different testing modalities in their local context and be prepared to provide basic information about window periods and where individuals can be tested.

## 2.5 | Linking service beneficiaries with navigators

A beneficiary may be linked to a navigator in different ways, depending on the client flow algorithm for a given program and the configuration of its program/case management team. Service beneficiaries may be informed about the role of navigators during HIV post-test counseling or may learn about it later from a program officer or another team member. It is important to provide service beneficiaries with options for their care, including the option not to be linked to a navigator. For those who wish to be linked, beneficiaries should be able to choose from a variety of treatment facilities, including those based in DICs and the public or private sectors. One option is for a case manager or another person to discuss navigator assignment with the beneficiary and, based on an initial assessment, determine together which navigator may be best suited to the beneficiary's needs. This approach can help ensure that peer navigators' caseloads are balanced.

Confidentiality is critical at this stage. Beneficiaries should be informed that their health and other information will be kept strictly confidential and that navigators will have access to their information on a need-to-know basis. Beneficiaries should have the option to determine what information they are willing to share with a navigator throughout the process. Voluntary, assisted partner notification could also be offered to the newly diagnosed peer to ensure that partners receive HTS as well.

## 2.6 | The beneficiary-navigator relationship

In the early stages of support, navigators work with each beneficiary to identify goals, develop action plans to meet those goals, and build the necessary skills so that service beneficiaries can address their own needs over time. Navigators must have in-depth knowledge of local services and must know how to link their beneficiaries to those services based on individual needs. In the absence of a case manager, navigators may need to establish and maintain contact with service providers, organizations, and facilities and to keep their beneficiaries informed about changes in personnel and services. Scheduled follow-up visits will provide opportunities to reassess needs and modify action plans accordingly.

In the early stages of support, navigators work with each beneficiary to identify goals, develop action plans to meet those goals, and build the necessary skills so that service beneficiaries can address their own needs over time. Navigators must have in-depth knowledge of local services and must know how to link their beneficiaries to those services based on individual needs. In the absence of a case manager, navigators may need to establish

## Flexibility is key

Needs, barriers, goals, and priorities will vary by individual and may be dynamic.

and maintain contact with service providers, organizations, and facilities and to keep their beneficiaries informed about changes in personnel and services. Scheduled follow-up visits will provide opportunities to reassess needs and modify action plans accordingly.

In some cases, service beneficiaries may not have many challenges to address, and regular support may be required for only a few weeks. Beneficiaries who have few or no needs may transition from PN support until they need it again in the future (see **Section 4** on transition for more information). Other individuals may need intensive support in the early stages and may eventually develop the skills and capacity to manage their care independently.

Some individuals may achieve self-sufficiency within the first few weeks, but may later experience challenges that require intensive support. Individuals with complex situations may require long-term support. For example, an individual may be dealing with multiple challenges that make it difficult to adhere to his or her medical appointments and/or treatment, such as homelessness, violence, substance use or dependence, or difficulty attending appointments during normal business hours. Support for complex cases may be needed for a navigator's entire period of employment. Programs should have a standard operating procedure that determines how often and by whom a stable beneficiary should be contacted to ensure his or her needs are being met. Sample SOPs for contact frequency are provided in **Section 3.3.3, Differentiated models of service delivery.**

## 2.7 | Building trust

Building rapport and trust with beneficiaries is vital to motivating change. If beneficiaries do not trust their navigators, they will be less likely to share important details, express any discomfort, and adhere to guidance. Depending on a beneficiary's background, personality, and other factors, it may take time to build the trust required to discuss more personal and sensitive issues. Navigators should pay attention to the content of what a beneficiary is sharing (some will share only surface-level details at first) and his or her body language, which will be important indicators of how much the beneficiary is ready to share. Navigators can consider the following tips for strengthening trust with their beneficiaries.<sup>3</sup>

Start small. Before delving into a beneficiary's biggest problem, navigators should offer useful information, positive feedback, or encouragement. It may help to try an intervention on a smaller issue early in the process. Navigators should attempt to address only problems they are reasonably confident they can handle, and they should be forthright about how much experience they have on a specific issue. If necessary, navigators can suggest that they will follow up on an issue to obtain further guidance or can refer the beneficiary to someone with substantial knowledge/experience. These steps will help build confidence in the relationship.

**Treat the beneficiary with respect.** From the very first contact, it is critical that navigators treat their beneficiaries with respect. Navigators should review beneficiary files before meeting, meet at appointed times and locations, start sessions on time, return calls promptly, present themselves professionally, and have the necessary resources to be properly prepared for each meeting.

The **LINKAGES Peer Navigation Training Toolkit** provides modules on **active listening** and **counseling skills**. Active listening is a way of engaging an individual that focuses entirely on what he or she is saying. It confirms understanding of both the content of the message and the emotions and feelings underlying the message to ensure that understanding is accurate.

The characteristics of an active listening strategy include the following:

- Being collaborative and nonjudgmental
- Avoiding overstating or understating
- Using the language of the beneficiary or similar language

The following graphic depicts the flow of an active/reflective listening strategy, to be used when discussing behavioral change with beneficiaries.

There are three levels of listening (and responding), which include:<sup>4</sup>

- **Simple** – Repeating, rephrasing; staying close to what the beneficiary has said
- **Amplified** – Paraphrasing; testing the meaning/what is going on below the surface
- **Reflection of feelings** – Emphasizing the emotional aspect of communication



When reflective listening is used correctly, beneficiaries are more likely to feel acknowledged and valued. Effective use of reflective listening will contribute to a relationship in which the beneficiary is more willing to deepen the conversation, build trust, and move toward making long-term change.

#### **A note on self-disclosure**

*Disclosing personal information may be a helpful way to build rapport. Some beneficiaries will appreciate learning from navigators' personal experiences and how they cope with challenges. However, navigators should be cautious not to dominate conversations with their personal stories. Too much disclosure, done too early, can inhibit beneficiaries from feeling comfortable sharing.*

### **2.7.1 | Stigma, discrimination, violence, and security**

Stigma and discrimination against key populations are commonplace. Substantial evidence also shows that stigma in health facilities and by law enforcement services is particularly common and that it creates significant barriers to service access and redress for abuse. Global evidence suggests that key populations have an elevated risk of violence and abuse and that these experiences are common.<sup>5,6</sup> Abuse can take various forms, including physical, sexual, psychological, and economic. Key populations may experience violence, harassment, and/or blackmail from sexual or domestic partners, sex work clients, law enforcement officials, community members, and even family members.

## 2.7.2 | Language and terms

Many terms commonly used to describe key populations are derogatory or outdated. Key population members may also prefer certain terms.

## 2.7.3 | Mobility and hidden populations

Some key populations, particularly sex workers, are highly mobile. Others, due to high levels of perceived and/or actual stigma, remain hidden and are averse to being associated with a KP-focused program or DIC.

*Programs need to be adaptive and responsive and consider ways that service beneficiaries who change locations can be followed up effectively. Options include assigning unique identifier codes, mobile phone-based support (i.e., reminders, notifications), and coordination with other programs in the region/country where applicable. These aspects should be considered in advance of program implementation and included in the program design.*

## 2.7.4 | Community empowerment and social cohesion

As part of a comprehensive program, navigators can play an important role in empowering key population members and groups. Community empowerment is “a collective process that enables key populations to address the structural constraints to health, human rights, and well-being; to make social, economic, and behavioral changes; and to improve access to health services.” Community empowerment is critical to improving the health and well-being of key populations and important to supporting services and facilities led by organizations of people from key populations.

*Navigators should understand the meaning of social cohesion and social participation, and why they can be important components of an effective HIV prevention, care, and treatment response. Where possible, navigators should be aware of opportunities for KP service beneficiaries to form groups, join groups, and participate in local events that build community resilience, increase service uptake, and reduce stigma and violence, among other positive outcomes.*

## 2.8 | Confidentiality

Navigators will need to be aware of the various ways that beneficiary confidentiality can be compromised, including in person, on the phone, through email and text messaging, and in the handling of hard copy documents. Depending on the design of the program and the agreements established with network facilities and providers, navigators may at times work offsite and interact on service beneficiaries' behalf with a range of individuals, which can increase the risk of breach of confidentiality of beneficiary information.

### 2.8.1 | Measures for protection

Programs should ensure that navigators receive sufficient training and follow strict procedures to safeguard beneficiary information in person and through digital/mobile media. Beneficiaries should be given the option of choosing to receive text messages, voicemails, and/or emails. Programs should also develop procedures for ensuring that navigators do not remove materials with beneficiary identifying information from program sites. Navigators who meet service beneficiaries offsite should not carry anything that has a service beneficiary's contact information, including names, numbers, addresses, or other means of contact (e.g., Facebook, WhatsApp). If a beneficiary provides change of contact information while meeting with a navigator in the field, the navigator should ask the beneficiary to come to a service site (or call the navigator later at the site) to update the site's official contact register.

In addition, because navigators may often interact with facility staff, programs may need to develop agreements with service sites on the sharing of beneficiary information. Beneficiaries will need to be asked for consent for each level of sharing between providers and service sites.

Navigators may be members of the same community as their service beneficiaries, and therefore may encounter service beneficiaries in social settings. They should take care in approaching service beneficiaries during these situations and should be careful not to reveal a beneficiary's participation in the program to anyone without the express consent of the beneficiary. Service beneficiaries and navigators may have a preexisting relationship or share acquaintances. Every effort should be made to ensure that the navigator and beneficiary are comfortable in their working relationship. Where necessary, it may make sense to reassign navigators if relationship boundaries are unclear or stressed.

Each program should have a system in place to address any breaches in confidentiality. **Navigators who breach confidentiality should be dismissed, and programs may want to consider supporting legal action or another recourse based on local policies or laws.** Programs also need to have measures in place to protect beneficiaries if a confidentiality breach has implications for their safety and well-being.

**NOTE:** A sample **confidentiality statement** is provided in **Appendix D**. Programs can adapt this statement to their context (inserting local laws, procedures, and/or penalties as appropriate). Programs should ensure that navigators sign two copies — one for the program files, and one for the navigator to maintain for his or her own records.

# 3

## IMPLEMENTING NAVIGATION

Programs may want to develop a visual schematic of this client flow and identify which individuals and/or agencies will require clarification of their roles and responsibilities as part of the case management process. Some examples of client flow models are provided in **Appendix K, Sample Client Flow Models**. It may also be necessary to develop formal agreements with referral sites providing clinical, psychosocial, and other services, to ensure that peer navigator roles within the process are clearly understood and to determine to what degree navigators will have access to beneficiary information. Confidentiality is critical along the entire continuum, from messaging, to record keeping, to discussing cases in case management meetings. This guide provides recommendations on maintaining confidentiality in **Section 2.8, Confidentiality**.

### Navigation prerequisites

*Before implementing peer navigation, programs should consider the following:*

- The feasibility of implementing peer navigation with government and community partners (assess factors such as government buy-in and referral/counter-referral)
- The number of peer navigators required to meet program needs
- Budgeting for full-time navigators, recurring costs (such as transport and communications), and supervision
- Ensuring there are sufficient and competent staff to supervise the navigators
- The location(s) where peer navigators will be based
- Which facilities/providers will need to be part of the service network
- The kinds of agreements (e.g., memoranda of understanding) required to ensure smooth operation and client flow

Refer to **Appendix J, Activities Checklist for Navigation Planning and Implementation**, for a complete overview of the steps required to plan and implement a peer navigation program.

### 3.1 | Country/program-specific SOPs

Programs should develop standard operating procedures for navigation and support to ensure that each member of the case management team (including the navigator) understands his or her roles in the context of counseling, referral, linkage, enrollment, retention in care, and provision of professional services (such as mental health and drug rehabilitation services). The SOPs should explain clearly the process for determining how and when service beneficiaries are assigned to a navigator, rules of engagement, expectations in terms of privacy and confidentiality, focal point collaboration at referral sites, and standards for meeting, referral, support, follow-up actions, and timing.

In some cases, navigators may be based at DICs or community-based organization offices. Others may be based at public-sector facilities. LINKAGES recommends the development of visual client-flow algorithms that include all major service providers to ensure navigators and service sites understand how beneficiaries should

navigate within the network. Navigators should be trained in following these SOPs, and the SOPs should be periodically reviewed and updated as needed, with refresher training provided to the navigators after updates. (Refer to the **Jamaica Peer Navigation Protocol**, included with this toolkit, as an example of an overarching set of SOPs for navigation.)

## 3.2 | Navigation planning

### 3.2.1 | Matching beneficiaries with navigators

Programs can determine how best to match beneficiaries with navigators based on beneficiary preferences, team composition, local regulations, and available resources. Some beneficiaries may need time after a positive diagnosis to adjust to their health status before meeting with a navigator. Others may wish to have prompt support so that they can ask questions and gain a better understanding of what a positive diagnosis entails. Ideally, programs should have a case manager or coordinator who can work with beneficiaries shortly after diagnosis to assess their needs, discuss available options, and jointly determine who might be an appropriate navigator (taking into consideration skills, strengths, and caseloads). Before matching a beneficiary with a navigator, it is important to obtain informed consent, ensuring that the beneficiary is aware that his or her positive diagnosis and some personal details will be shared as part of the process.

#### Where possible/applicable, service beneficiaries should be able to choose:

- the gender of their navigator
- whether the navigator comes from their key population
- to receive support from another person, such as a counselor or social worker
- to opt out of support entirely

If the beneficiary opts out or does not have a need for navigation, the case manager, counselor, or other assigned team member should ensure that the beneficiary is provided with all relevant information and resources based on local case management SOPs. Because some beneficiaries may develop challenges in the future, a coordinator for the program should check in periodically with those who opt out of navigation to determine

potential or emerging needs and whether or not navigation may be needed or desired. Specific guidance on this process is provided in **3.3.3, Differentiated models of service delivery**.

For those who opt in, the case manager, post-test counselor, or other assigned individual can provide the beneficiary with a navigator's contact information and can link the beneficiary to the navigator via phone to arrange a day, time, and place to meet. With the beneficiary's consent, the navigator may also be provided with the beneficiary's contact information for follow-up at a time determined by the beneficiary. Where navigators are based at DICs or the same facilities that provide testing, individuals may be connected directly to a navigator on the same day, or on a later day, depending on their preference.

### 3.2.2 | The first meeting

The **first navigation meeting** should be focused on building a relationship with the beneficiary. Navigators should be cautious about moving too fast or trying to cover everything. Beneficiaries will often indicate either through verbal or nonverbal communication how comfortable they are and how much they would like to discuss in the first session. It is critical to keep in mind the guidance provided in **Section 2.6** on building trust, including starting small, treating the beneficiary with respect, and utilizing active listening skills. Navigators may need to plan a day and time for a second meeting to begin discussing beneficiary needs, priorities, and support.

At a minimum, navigators may wish to accomplish the following in the first meeting:

1. Introduce themselves
2. Explain their role
3. Provide emotional support and encouragement as needed
4. Discuss treatment initiation and reiterate treatment literacy messages addressed in the post-test counseling session
5. Provide contact information
6. Agree on a day, time, and place for the next meeting

### 3.2.3 | The second meeting

By the **second meeting**, navigators may begin to explore a beneficiary's specific situation and needs. In programs where a trained case manager is part of the case management team, he or she may conduct an **intake assessment** for newly diagnosed beneficiaries. **The Intake Assessment Tool (Appendix A)** is designed to collect information about the beneficiary that will help identify and prioritize an action plan based on a hierarchy of needs (see Figure 1). For example, immediate physical and medical needs, such as co-morbidity, housing, and safety, usually take precedence over emotional needs. The case manager may then meet with the navigator to discuss the beneficiary's needs, including areas where the beneficiary may require support.



Figure 1. Maslow's Hierarchy of Needs

In programs where a case manager or nurse is not available to conduct an intake assessment, the navigator may take on this role. The sample **intake assessment** provided in **Appendix A** is intended to guide a conversation, rather than to serve as a data collection tool. There are many examples of intake assessments online, and this tool can be modified based on the available services in the community, the capacity of the navigators employed by the program, and the typical needs presented by beneficiaries. The intake assessment should include information about:

- Basic health needs
- Transportation
- Housing
- Employment
- Nutrition
- Current health status
- Access and utilization of health care (including HIV treatment and care)
- HIV risk behaviors and current partners
- Current or recent psychosocial challenges
- Current and recent substance abuse issues

Each service beneficiary comes with unique knowledge, strengths, resources, needs, and challenges. When prompted with probing questions, beneficiaries are often capable of identifying what may prevent them from accessing HIV and related services. Some beneficiaries may underestimate the structures and individuals already in place to support them throughout their care. In the second meeting, navigators can work with their beneficiaries to identify key barriers to access for clinical and nonclinical services and facilitators that may help them overcome those barriers. Navigators should keep the following questions in mind:

- What does the beneficiary already know?
- What are the beneficiary's attitudes and beliefs?
- How ready is the beneficiary to address his or her challenges and needs?

It may take several visits before a beneficiary is prepared to go through part or all of the intake assessment. Navigators should be patient and allow their beneficiaries to set a pace that is comfortable for them.

When the beneficiary is ready for a more in-depth discussion, navigators can use the following suggestions to guide the conversation:

1. Ask open-ended questions about the beneficiary's perspective on his or her infection and treatment, and what needs he or she may have.
2. Gauge the amount of information the beneficiary can/wants to receive. (Beneficiaries who are newly diagnosed have just received a potentially life-altering diagnosis and are likely to be processing a substantial amount of new information; they may be overwhelmed by too much information.)
3. Provide information in response to goals, concerns, and problems discussed.

4. Ensure that the beneficiary understands the meaning of the information provided.
5. Conduct the intake assessment (if not already conducted).
6. Work with the beneficiary to establish HIV treatment and care priorities and to schedule medical and diagnostic appointments as needed.
7. Assess whether the beneficiary has adequate social support.
8. Discuss other referral needs and options.
9. Agree on a plan of action for the immediate future (if not already determined with the case manager). See below for more guidance on action planning.
10. Deal with the beneficiary's emotional reactions (and your own).\*

### 3.2.4 | Action plan development

Assessing service beneficiary needs may take time, and some beneficiaries may feel more comfortable discussing them after the first couple of sessions. By the second or third meeting, navigators can work with their beneficiaries to develop strategies to ensure they can effectively access the services they need. Information gathered during the assessment can feed directly into the development of an action plan (**Appendix B**). The Action Plan Tool provides a structure for identifying all the possible needs a beneficiary may have. Together, the navigator and beneficiary can prioritize which needs must be addressed immediately and which can be addressed later. If the action plan was not developed during the first visit, navigators should begin by reviewing the intake assessment with their service beneficiaries. Culturally and KP-specific tools for social behavior change communication may assist navigators with action planning at this stage.

In developing the action plan, navigators should support their service beneficiaries to identify their own needs. Navigators can make suggestions, but prioritization and goals must be based on what the beneficiary identifies and decides. In some cases, beneficiary needs and barriers may have little to do with their HIV diagnosis; navigators should respect service beneficiaries' choices and do their best to support them. They should assist each beneficiary to develop realistic short- and long-term goals and objectives and to determine appropriate steps and timelines for achieving them. Together, the navigator and beneficiary can brainstorm potential obstacles to achieving these goals and objectives and strategize ways to overcome them.

### 3.2.5 | Linkage to care and treatment

One of the principal roles of the navigator is to help ensure that beneficiaries are effectively linked to care and treatment services. This process will vary by program and should follow locally adapted SOPs. At a minimum, navigators will need to ensure that beneficiaries:

- have scheduled necessary diagnostic and medical appointments
- are aware of the location of their appointments, whom they will meet, and what will be done

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\*Modified from Quality assurance measures for voluntary counseling and testing services. Washington: IMPACT/AIDS MARK; 2001.

- have the means to attend to their appointments on time, including transportation, time off work if needed, daycare, etc.
- are reminded of their appointments 24 hours before they take place
- have attended their appointments at the appropriate times
- are contacted in the event they did not show for an appointment (within 24 hours)

The action plan that navigators develop with their beneficiaries can address potential obstacles for these initial appointments. Adherence counseling and addressing complex issues, including GBV and mental health, are discussed below.

### 3.3 | Follow-up sessions

In the first session, service beneficiaries and navigators decide together when their next session will be and the frequency and times of the sessions thereafter. Initially, meetings with service beneficiaries are likely to be more frequent (i.e., once a week) to help them adjust to an HIV diagnosis, attend appointments, obtain prescriptions, and address immediate needs and challenges. The first few visits also tend to be the most intensive, particularly for service beneficiaries with multiple or complex needs. During these sessions, navigators should encourage, support, and help build the skills of their beneficiaries to address those needs, provide referral and linkage to available services (see below), and follow up to ensure beneficiaries access the services. Navigators and beneficiaries can review and update beneficiaries' action plans as appropriate.

Over time, meetings may become less frequent (i.e., once a month). In subsequent meetings, navigators and service beneficiaries may review action plans, address any adherence issues, and ensure that medical and related appointments are maintained. After service beneficiaries begin ART, navigators can also check whether their service beneficiaries have adjusted well to taking routine medication and are adhering to their regimens. Navigators should meet with the case management team weekly to review current cases and discuss recommendations. (Case management meetings are discussed in further detail in **Section 5.6.2.**)

It is important to note that the goal of navigation is more than just providing direct assistance. It includes helping service beneficiaries to develop skills, identify their own needs, and access services on their own. Navigators should continue to follow up with service beneficiaries who identify few or no goals at the initial assessment, to assist with emerging needs.

#### 3.3.1 | The minimum package of services

The minimum package of services that may occur during a navigation session is as follows:

- **RELATIONSHIP BUILDING:** Spend extra time building rapport with the beneficiary. Rapport building is critical for the success of the navigator-beneficiary relationship, particularly during the first few visits.
- **GENERAL HEALTH EDUCATION:** Help improve the beneficiary's knowledge of the factors associated with his or her own health. For example, if a beneficiary identifies that he or she has a chronic ailment, such as diabetes or asthma, the navigator can share information about that condition. Navigators should use their knowledge of local resources to link service beneficiaries to the appropriate services for their health needs.
- **FOCUSED HIV EDUCATION AND COUNSELING:** Provide education about HIV, such as how the virus is transmitted, medication management, and dealing with the psychosocial implications of living with HIV.
- **COACHING ON COMMUNICATION WITH MEDICAL OR SERVICE PROVIDERS:** Provide information on how and where to seek an appointment. Assist individuals to become self-reliant, empowered, and proactive in seeking care and meeting their needs and to communicate clearly and assertively with their service providers.

- **SUPPORT FOR SERVICE BENEFICIARIES TO ADHERE TO THEIR TREATMENT REGIMENS:** Support the beneficiary to obtain treatment adherence self-efficacy using the *Life Steps* (see **Section 3.3.2**) approach. The navigator can employ a combination of counseling, goal setting, tips, suggestions, and strategies, including review and revision of the treatment adherence plan and/or delivery of medication. He or she may assist the beneficiary to link to a peer support group. Navigators can provide practical advice about medication-taking cues, reminders, and organizational tools that they or others have found effective.
- **APPOINTMENT REMINDER:** Contact service beneficiaries to remind them of an upcoming scheduled meeting or an upcoming appointment for other services. Use the beneficiary's preferred method of contact.
- **ACCOMPANYING BENEFICIARIES TO APPOINTMENTS:** Beneficiaries may want navigators to accompany them to, for example, appointments for HIV care, substance abuse treatment, mental health care, medical check-ups, diagnostics, or social support services addressing GBV, legal, or other issues.
- **SUPPORT FOR POSITIVE HEALTH, DIGNITY, AND PREVENTION:** Help increase the self-esteem, confidence, and ability of beneficiaries to care for themselves and to avoid passing HIV to others. (Refer to **Section 3.3.4, Positive health, dignity and prevention**, in this guide for more information.)
- **COMMODITY PROVISION:** Provide condoms and lubricants, and sterile injecting equipment, as needed. Where possible, navigators should link with donor-supported interventions to forecast condom, lubricant, needle, and syringe needs and ensure a regular supply is available through free distribution, social marketing, or other means in common outlets, service provision sites, and venues.
- **ASSISTANCE WITH SOCIAL GRANTS:** Assist beneficiaries in understanding and applying for applicable social grants, welfare opportunities, and other potential support.
- **ASSISTANCE WITH LEGAL SERVICES:** Assist beneficiaries in identifying and contacting appropriate legal service agencies and individuals as needed.
- **CRISIS RESPONSE:** Help beneficiaries obtain immediate services (medical, housing, or mental health). Note: navigators are not intended or trained to be crisis managers or “hotlines” and should discourage service beneficiaries from seeing them in this way. (Boundaries should be clarified early on). However, there may be situations in which a beneficiary contacts a navigator for emergency assistance and the navigator can assist in connecting him or her to appropriate help. Sites and navigators should establish procedures for dealing with these situations in advance, and navigators should practice setting clear boundaries and following standard procedures when responding to beneficiaries in crisis.

### 3.3.2 | Adherence counseling and the Life Steps for ART Adherence tool

For service beneficiaries who have begun or are about to begin treatment, it is critical to develop plans for ensuring they can manage their treatment effectively and remain adherent to their drug regimens. This guide includes an **Adherence Counseling Checklist (Appendix C)** for the first adherence counseling meeting and a different checklist for subsequent meetings. The checklists provide a simple guide for navigators to use with their beneficiaries to ensure they have addressed all possible adherence-related needs.

#### The Life Steps Approach

*Life Steps* can be done as one long counseling session (taking about an hour), or it can be broken up and done over the course of a few counseling sessions. Service beneficiaries are supported to identify adherence goals for each step, possible barriers that could prevent them from achieving their goal(s), and a plan and a backup plan for overcoming potential barriers.

## LIFE STEPS: 13 STEPS

|    |   |
|----|---|
| 1  | Educate about adherence.  |
| 2  | Plan for transportation to the clinic.                                      |
| 3  | Plan for keeping appointment dates and obtaining medication.                |
| 4  | Formulate a daily medication schedule.                                      |
| 5  | Plan for storing medications.   |
| 6  | Plan for obtaining medications when away from home.                         |
| 7  | Identify social supports.   |
| 8  | Identify motivation for adherence and create association with reminders.    |
| 9  | Plan for coping with medication side-effects.                               |
| 10 | Plan for communicating with treatment team.                                 |
| 11 | Prepare for taking medication when using substances (e.g., drugs, alcohol). |
| 12 | Prepare to cope with slips in adherence.                                    |
| 13 | Review all plans.   |

As a supplement to the checklists, this guide also includes the **Life Steps for ART Adherence tool**. This tool provides a systematic way to support service beneficiaries to identify barriers to adherence and problem-solve ways to address those barriers should they arise. The idea is to help service beneficiaries develop a plan and consider a backup plan should the first plan fail. The steps are integrated in the Adherence Counseling Checklist, but are expanded upon in the tool. Please refer to the **Life Steps manual** included as part of the **Peer Navigation Training Toolkit** for full instructions on the development and maintenance of plans for each beneficiary. Navigators should be familiar with the steps and should ensure that they address each step with their service beneficiaries.

The approach has the following features:

- 13 steps
- Each **step** focuses on addressing common barriers to adherence
- One long counseling session (~ 1 hour) or a few shorter counseling sessions

Each **Life Step** follows a typical format, referred to as A-B-C:

- A. Identify the adherence goal.
- B. Identify the barriers to reaching the goal.
- C. Make a plan and a backup plan for overcoming the barrier.

*Ideally, the beneficiary (or navigator) writes down the agreed-upon plans for each step during the session. At the end of the session, the beneficiary can take a copy of the plans home for review and follow-up. In some cases, due to concerns about unwanted disclosure or potential violence, some service beneficiaries may prefer not to carry anything home with them. Navigators should be sensitive to this choice and should discuss alternative ways of reminding beneficiaries of their plans and backup plans.*

Based on the discussions that arise from the use of the Life Steps tool, beneficiaries may wish to alter their action plans. Combined, **the action plan, Adherence Counseling Checklist, and Life Steps adherence plan** ensure that all needs across clinical, psychosocial, and other areas have been discussed, solutions have been developed, and timelines to achieve goals have been established.

### 3.3.3 | Differentiated models of service delivery

As previously noted, each beneficiary will have different needs that may change over time. If a program provided the same services the same way on every encounter, it would be difficult to meet individual needs effectively and efficiently. Differentiated service delivery is a client-centered approach that simplifies and adapts services to reflect the preferences and expectations of each beneficiary, while reducing unnecessary burdens on the health system. By providing differentiated services, programs can focus resources on beneficiaries most in need and provide all beneficiaries with individualized care.

The World Health Organization's (WHO's) guidance is that everyone who is diagnosed with HIV should immediately start treatment. However, even some countries with such test-and-start policies have been slower to operationalize them. Peer navigators may find that some of their HIV-positive beneficiaries are not on ART. Regardless of their treatment status, beneficiaries will also vary in terms of the level of support they require to remain within the continuum of services. Some will require minimal support, if any, and can be classified as *low-need* at a given time. Others may require more intense and/or frequent support and could be classified as high-need. Determination of low-versus high-need classification may be made during the intake assessment, based on the development of individual action plans. Note that need levels may increase or decrease over time, depending on emerging issues or changes in circumstances.

#### Pre-ART beneficiaries

Beneficiaries who are not yet on ART may have several issues that need to be addressed to help them manage their HIV diagnosis, health, and related circumstances. For example, a pre-ART beneficiary may be classified as high-need if he or she is dependent on a substance, homeless, experiencing GBV, highly malnourished, not earning income, or struggling to make appointments. High-need beneficiaries may need to meet with navigators more often and may require multiple referrals and accompaniment and/or more frequent checking in.

#### Beneficiaries on ART

Similarly, beneficiaries on ART may have diverse needs depending on their circumstances. The WHO has developed a classification system for individuals on treatment that determines whether their treatment is stable (low-need) or unstable (high-need).

The WHO defines individuals on ART as stable if they have ALL the following characteristics:<sup>8</sup>

- On ART for at least one year, AND
- No adverse drug reactions requiring regular monitoring, AND
- No current illnesses or pregnancy, AND
- Good understanding of lifelong adherence, AND
- Evidence of treatment success: Two consecutive undetectable viral load measures (OR, in the absence of viral load monitoring, rising CD4 counts or CD4 counts above 200 cells/mm<sup>3</sup> and objective measures of adherence)

WHO defines individuals starting on ART as *unstable* if they have the following characteristics:<sup>9</sup>

- CD4 count < 200 CD4 cells/mm<sup>3</sup> OR WHO Stage 3 & 4 defining illness (see box below)
- OR comorbidities that require more, or more frequent, clinical care

Given that some programs will implement return-to-care initiatives, whereby navigators contact beneficiaries either lost to follow-up or designated eligible for treatment, navigators may have a mix of new beneficiaries and those already engaged in the service network. Among these individuals, some will not be on treatment for various reasons, and some will have initiated treatment. The tables below provide recommended guidance on the frequency and kinds of support new and existing beneficiaries may require, based on high- versus low-need and stable versus unstable treatment outcomes. Programs should refer to national guidelines while adapting these SOPs to the local context.

#### WHO clinical staging of HIV and case definition

The clinical staging and the case definition of HIV for resource-constrained settings were developed by the WHO in 1990 and revised in 2007. Staging is based on clinical findings that guide the diagnosis, evaluation, and management of HIV, and it does not require a CD4 cell count or viral load. Clinical stages are categorized as 1 through 4, progressing from primary HIV infection to advanced AIDS. These stages are defined by specific clinical conditions or symptoms. For a complete list of Stage 3 and 4 conditions and symptoms, refer to the following website: <https://aidsetc.org/guide/hiv-classification-cdc-and-who-staging-systems>.

**Table 1: Differentiated care approach for service beneficiaries**

| Differentiated care approach for those living with HIV-positive but not yet on ART |   |   |
|--|---|---|
|  | Low-need  | High-need   |
| <b>New and existing service beneficiaries</b>                                      | Until initiation of ART: Follow up by phone or in person at least 1x per month after initial meetings and client classification as low-need | Until initiation of ART: Follow up as often as necessary to ensure that basic needs are met and the beneficiary is not lost to follow-up (i.e., weekly) |
|  | Call beneficiary 1 day before each appointment; call within 24 hours of a missed appointment to reschedule/provide support                  | Call beneficiary 1 day before each appointment (accompany if necessary); call within 24 hours of a missed appointment to reschedule/provide support     |

**Table 2: Differentiated care approach for new and existing service beneficiaries on ART**

| <b>Differentiated care approach for those living with HIV-positive but not yet on ART</b> |   |  |   |
|---|---|--|---|
|   | <b>Stable ART/Low-need</b>  | <b>Unstable ART/High-need</b>  |   |
| <b>New service beneficiaries</b>  | Months 1-3: Follow up by phone or in person 1x per month after initial meetings                         | Months 1-3: Follow up by phone or in person every 1-2 weeks; provide accompaniment to appointments as needed                                 |   |
|   | After Month 3: Follow up by phone or in person 1x every 3 months  | Refer service beneficiaries with side effects to clinical provider; reassess health status shortly after referral                            |   |
|   | Call the beneficiary the day before each appointment date; call within 24 hours of a missed appointment |  | After month 3: Follow up by phone or in person 1x every 2-3 months                                      |
|   |   |  | Call the beneficiary the day before each appointment date; call within 24 hours of a missed appointment |
|   | Follow up on viral load/CD4 diagnostics<br>Goal: 2 consecutive undetectable viral measures              | Follow up on viral load/CD4 diagnostics<br>Goal: 2 consecutive undetectable viral measures   |   |
| <b>Existing service beneficiaries</b>   | <b>Stable ART/Low-need</b>  | <b>Unstable ART/High-need</b>  |   |
|   | Every 6 months: Follow up by phone or in person   | Months 1-2 (or 3 if needed): Follow up by phone or in person every 1–2 weeks   |   |
|   | Call the beneficiary the day before each appointment date   | After month 2 or 3: Follow up by phone or in person 1x every 2-3 months until beneficiary has 2 consecutive undetectable viral load measures |   |
|   | Follow up on viral load/CD4 diagnostics   | Refer service beneficiaries with side effects to clinical provider; reassess health status shortly after referral                            |   |

### 3.3.4 | Positive health, dignity, and prevention

People living with HIV have the right to choose whether they want to have sex, their preferred methods for enjoying sexual pleasure, and how they wish to ensure safety for themselves and their sexual partners. People living with HIV also can choose to use alcohol or other drugs. In some cases, PLHIVs' perceptions of risk may change when their health situation improves. The term for meeting the health and prevention needs of people living with HIV is "Positive health, dignity, and prevention." This approach aims to increase the self-esteem, confidence, and ability of HIV-positive people to care for themselves and to avoid passing HIV to others. Reinforcement of prevention messages will be critical throughout navigation support. Service beneficiaries should be provided information on:

- Risk of transmission through sexual intercourse or sharing of nonsterile injecting equipment
- Appropriate methods of sexual protection, as well as safe injecting practices
- Available services

Serodiscordant couples need to know about their risk-reduction options, and navigators can serve an important role in helping couples avoid onward infection. Navigators should be aware that some individuals may be reluctant to attend counseling with a partner, and it may take time and additional support to engage partners. They should also be aware that many couples face challenges in maintaining consistent condom use during periods when viral load is still detectable in the person living with HIV. For more information on HIV prevention for serodiscordant couples, see **HIV prevention within serodiscordant couples: a new paradigm**.<sup>10</sup>

For partnerships with people who inject drugs, it is important to develop a plan for safe injection (including injection equipment for diabetics and for transgender women who are injecting hormones). People who inject drugs also need to develop risk-reduction plans for sexual transmission with their partners. For more information on HIV prevention for drug users and their partners, see the **Toolkit for implementing a comprehensive HIV prevention program for people who use drugs**.<sup>11</sup>

#### The importance of an undetectable viral load

It is important for navigators to promote the individual and community-level benefits of achieving and maintaining an undetectable viral load. Navigators might want to consider the following messages of encouragement and caution:

- **You can live a healthier and longer life.** Using ART to reach an undetectable viral load means that there is less HIV in your body. Less HIV means less damage to your immune system, allowing you to stay healthier and live longer.
- **You can reduce HIV transmission risk.** Studies have shown that people living with HIV who use ART can reduce the likelihood of transmitting the virus to their HIV-negative partners by as much as 92 percent to 96 percent. More people on effective treatment and with their virus in check means more HIV infections are prevented.
- **"Undetectable" does not mean "cured."** An undetectable viral load means that so few copies of the virus are present in the blood that today's monitoring tests are unable to detect them. Even with an undetectable

viral load, however, an HIV-positive person still has the virus.

- **It is still possible to transmit HIV.** Your viral load can fluctuate between monitoring tests. This can happen for no known reason, when you have a sexually transmitted infection (STI) such as chlamydia or gonorrhea, or when ART doses are missed. During these viral load “blips,” the chance of transmitting the virus may be higher. Also, viral load tests monitor only the amount of HIV in the blood, not the amount in semen or vaginal fluid. It is not yet known how much virus needs to be present in body fluids for transmission to be possible.

#### **Additional services**

In addition to clinical care, ART, and psychosocial support, navigators should help service beneficiaries access other relevant services in the community, including prevention and support for domestic and gender-based violence, treatment for drug and alcohol dependence, STI diagnosis and treatment, legal aid, and support for orphans and vulnerable children.

#### **PrEP and PEP**

Navigators should be familiar with both PrEP (pre-exposure prophylaxis) and PEP (post-exposure prophylaxis). Both are methods of preventing HIV that involve taking antiretroviral medications before one is diagnosed with HIV. These treatments may not be available in all areas.

PrEP is increasingly recommended for anyone who is at high risk of HIV acquisition. It involves a daily pill containing two antiretroviral drugs that will prevent the person taking it from contracting HIV.

PEP is used for people who have experienced a high-risk exposure. It involves taking a combination of three drugs as soon as possible after exposure (preferably within two hours and before 72 hours). Regimens and guidance may vary by country, state or province, or facility. It is important that navigators understand what the guidance is for the area/facility where they are working.

### **3.3.5 | Identifying and responding to gender-based violence and abuse**

KP service beneficiaries may be at elevated risk for violence and abuse, which are often categorized into five types: physical, sexual, emotional, economic, and other human rights violations. The **PEPFAR FY 2014 Updated Gender Strategy**<sup>13</sup> defines GBV as:

*Any form of violence that is directed at an individual based on biological sex, gender identity (e.g., transgender), or behaviors that are [perceived as] not in line with social expectations of what it means to be a man or woman, boy or girl (e.g., men who have sex with men, female sex workers).*

Anyone can be a perpetrator of GBV, particularly when there are power differences. Navigators and program staff can refer to the **LINKAGES Program Implementation Guide**<sup>14</sup> (Program Area 3, Element 3.1) for more

detailed information on techniques for preventing and addressing GBV.

### **GBV identification**

GBV identification refers to asking a beneficiary a series of questions to determine if she or he has experienced or is experiencing GBV. LINKAGES recommends asking all members of key populations about experiences of GBV when they engage with the program, provided the person is asked in private and there are available resources to make referrals. However, getting beneficiaries to disclose GBV is not the end goal. Some service beneficiaries may not want to share their experiences, and that decision should be respected. What is most important is creating an environment where beneficiaries feel comfortable and safe, so that if they choose to share their experiences, they will feel supported.

Depending on the country program, the role of a navigator may include:

- Raising awareness about GBV
- Asking service beneficiaries about their experiences with GBV and explaining why it is important to ask about violence and abuse
- Delivering important information about post-GBV services to consider after an assault (such as PEP and emergency contraception)
- Providing first-line response, including active listening; delivering core messages; checking in with service beneficiaries about safety and exploring safety strategies; providing information about health, psychosocial support, and legal services; and making appropriate referrals
- Accompanying victims of violence to seek additional services

### **GBV response services**

There are five GBV response services that should be available to all victims of violence and abuse either via referral or in LINKAGES-supported facilities:

- **Health services:** treatment of injuries, HIV testing, PEP, emergency contraception (within five days), STI testing and treatment, rape kit/forensic exam, hepatitis B testing and vaccination (if available in country), and tetanus booster or vaccination (if available in country)
- **Psychosocial support:** support groups, mental health assessment, and other psychosocial support (short- and long-term)
- **Legal services:** documentation of an incident of violence and support to interact with the justice system (i.e., access to a lawyer or paralegal)
- **First-line response:** Active listening, the provision of key messages and information on rights, safety planning, and referrals to other services
- **Accompaniment** to services

### **3.3.6 | Mental health emergencies**

When a navigator perceives that a beneficiary has a serious mental health problem (or is informed of this by the beneficiary), the navigator should contact the program manager, case manager, nurse, or a lead identified by the program SOPs who can provide consultation and guidance on what to do. If mental health services are not available, navigators should be provided with (and should help update/maintain) a list of emergency contacts and a protocol for handling likely scenarios. Supervisors should ensure the availability of appropriate support for beneficiary emergencies, as well as the safety of navigators, throughout program implementation. Supervisors should also maintain up-to-date calendars of scheduled meetings between navigators and service beneficiaries.

Some navigators may find themselves coordinating among multiple providers in an emergency. For example, if a beneficiary ends up in the emergency room, an attending staff member may contact the navigator to obtain background information on the individual's medical history, either from program records or from his or her regular health care provider. If such a situation occurs, the navigator will need to have signed permission from the beneficiary before releasing any health information to a provider. The specific rules and procedures should follow the local laws on disclosure and international best practice standards.

### 3.3.7 | Disclosure

#### Benefits

Disclosing one's HIV status can be beneficial for several reasons. Family and friends can provide essential support if they are adequately informed. Providers who know a beneficiary is living with HIV can offer more appropriate care and treatment. A romantic partner can provide emotional support and help practice safer sex. Disclosure may lead to greater likelihood of adherence to treatment. Disclosing to a sexual partner, or having someone such as a peer navigator provide voluntary partner notification, also allows the partner — who may have been exposed to HIV — to seek HTS. If the partner tests positive, she or he can seek treatment and care immediately to ensure more positive health outcomes.

#### Risks

People who disclose their positive status may also face the potential of stigma, violence, and abandonment, often at the hands of the people closest to them. Stigma can include self-stigma and stigma perpetuated by families, communities, and other people. After disclosure, people living with HIV may also face rejection, discrimination, and loss of privacy and confidentiality. For members of key populations, confidentiality of medical information, including HIV status, is essential to the protection of their human rights, because they often face elevated risks if their domestic partners, families, or communities discover that they are HIV-positive. People living with HIV may also feel significant guilt if they believe they may have infected their sexual partners.

#### Supporting beneficiaries to disclose

Trust is an important part of disclosure. KP individuals who are living with HIV will likely have the following questions: Who can I trust? If I tell someone, will he or she reject me? Will they abuse or hurt me? Will they tell someone else that I am living with HIV or have AIDS? Service beneficiaries may need support in determining whom they can trust, deciding with whom they want to share their status, and practicing how to disclose. Navigators can help service beneficiaries weigh the risks and benefits of disclosing their status.

Below are some general disclosure tips:<sup>17</sup>

- Be selective. Choosing whom to tell or not tell is your personal decision. It is your choice and your right.
- Consider the five “W’s” when thinking about disclosure: who, what, when, where, and why. Who do you need to tell? What do you want to tell them and what are you expecting from each person to whom you are disclosing your HIV status? When should you tell them? Where is the best place to have this conversation? Why are you telling them?
- Take your time. In most situations, you can take your time to consider whom to tell and how to tell them.

- Consider whether there is a real purpose for you to tell this person or if you are simply feeling anxious and want to “unload” your feelings.
- Telling people indiscriminately may affect your life in ways you have not considered.
- Feeling uncertain about disclosure is a very common reaction.
- You have a virus. You don't have anything to apologize for simply because you are HIV positive.
- Keep it simple. You don't have to tell the story of your life.
- Avoid isolating yourself. If you are unable to tell close friends, family members, or other loved ones about your HIV status, allow yourself to draw upon the support and experience of others in the HIV community. Consider joining a support group or an online forum, such as the POZ forums.
- There is no perfect roadmap for how to disclose. Trust your instinct, not your fears.
- Even if the response you receive in a specific situation does not go the way you had hoped, you are going to survive it and your life will go on.
- Millions of others have dealt with this experience and have found their way through it. You will get through it too.

Navigators will need to be trained on counseling techniques to support their beneficiaries both to disclose and to manage potential shame and negative feelings associated with infecting one's partner. For more information and exercises on how to support service beneficiaries to disclose, refer to the **Peer Navigation Training Toolkit (Facilitator and Participant Training manuals)**. Please also refer to **Appendix I, Disclosing your status**, which provides a guide that navigators can use to support their service beneficiaries to disclose safely. There are also numerous online resources on safe disclosure.

### 3.4 | Documentation

It is important for navigators to keep careful records of all contacts with beneficiaries. **Tool 11A, the Case manager/peer navigator – individual form** in the *LINKAGES Program Monitoring Guide*,\* should be filled in and maintained regularly to keep track of all contacts with service beneficiaries and should be monitored by the site coordinator/supervisor for accuracy and completion. To ensure confidentiality and safety for service beneficiaries, the logs should be kept in a locked cabinet at the coordinating office at each site and should not be taken outside the site. Navigators should complete information upon returning to the site, taking special care to protect their service beneficiaries' confidentiality and privacy (refer to section **2.8, Confidentiality**, for more information). Navigator forms should be stored until the program ends, and then destroyed.

### 3.5 | Data entry for electronic client information systems

Some programs may have incorporated an electronic client information system to track service beneficiaries as they navigate through the service network and/or to ensure that beneficiaries receive information, appointment/treatment reminders, and updates on their mobile devices. Each of these programs will need to develop specific procedures for data entry into program devices and SOPs on beneficiary messaging. It is advised that these systems collect only the minimum information required to find and send messages to beneficiaries effectively, and that a clear understanding of client flow be established as part of the orientation and training on the use of

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\*The FHI360 LINKAGES Program Monitoring Guide can be retrieved at the following: <https://www.fhi360.org/sites/default/files/media/documents/resource-linkages-monitoring-tools.pdf>

the electronic system. It is important to note that beneficiaries who are on government-supported ART may also have electronic medical records independent of the program.

## 3.6 | Additional considerations

### 3.6.1 | Setting boundaries

Service beneficiaries can be vulnerable and form emotional, financial, and other dependencies. They may also express sexual attraction toward their navigators, and/or navigators may discover they have emotional or sexual interest in one or more beneficiaries. Program staff, including navigators, should be prepared for this, and should understand that sexual relationships with beneficiaries are strictly prohibited. These norms and regulations should be repeated regularly in training and refresher training sessions.

### 3.6.2 | Office hours

Each navigator should designate clear office hours with his or her service beneficiaries. Sites should develop a system for tracking navigator-beneficiary meetings, such as an electronic calendar or central billboard. Supervisors may also request that navigators check in with them on a regular basis when they are meeting with beneficiaries offsite. Some supervisors may also wish to phone offsite locations (such as partner organizations) on a regular basis to ensure that navigators are indeed meeting with beneficiaries as scheduled.

Some navigators may wish to be available to service beneficiaries by phone at any time, day or night. The navigator and supervisor(s) should discuss and decide upon their approach together, considering issues such as office hours, acceptable meeting locations, burnout, availability of clinical supervision, and personal safety. Some navigators may find that limiting their availability to established office hours at a fixed site during specific days of the week is easier to manage than being available at all times or every day. They should minimize travel time and costs as much as possible.

# 4

## TRANSITION

The purpose of this section is to provide guidance for programs that must phase out navigation services for an individual or a program. Sites should use the information provided in this guide to inform the development of SOPs for the phase-out of services. There will likely be different procedures and approaches for different types of service beneficiaries.

### 4.1 | Preparation for transition

#### 4.1.1 | Begin early

It is important to inform beneficiaries early on that there will be an end to the navigation services provided by the site staff, or a transition of services to another service site or agency. This message should be re-emphasized approximately six months prior to the end/transition of services, when the navigator and beneficiary should start planning for the conclusion of their work together. The earlier the navigator begins preparing the beneficiary for transition, the smoother the process is likely to be. Near the end of phase-out (perhaps four to six weeks before the end of programming), the navigators should reconnect with the beneficiaries to remind them of the end of the program, discuss possible resources that beneficiaries can access after the program ends, and set up appointments for formal closure of the navigator–beneficiary relationship.

#### 4.1.2 | Have a plan

As the transition period approaches, the navigator and beneficiary should discuss how remaining goals, if any, will be met, or plan together how the beneficiary will meet these goals in the future. This planning can be done using the action plan or a site-adapted version of the **Tool for Transition of Navigation (Appendix G)**. The navigator should think in advance about what the beneficiary has accomplished and what goals are outstanding, and should have a plan in mind for how the last visit will go. Service beneficiaries should lead the goal-setting process, and navigators should provide guidance as needed to support the beneficiary to prepare for achieving those goals after navigation has ended.

### 4.2 | Conducting the last visit

#### 4.2.1 | Applaud accomplishments

Navigators should applaud and praise their beneficiaries' successes and help them recognize what they have achieved. Successes can be as simple as showing up for and participating in navigation sessions, as well as reduction of risky behaviors or maintaining adherence. Documenting progress in the action plan provides a tangible reference, illustrating the beneficiary's success and advances. Navigators can also plan a special event with their service beneficiaries (individually or in a group session) to congratulate those who have successfully managed their own care. Programs may wish to provide official certificates of positive living or other forms of recognition for positive health choices.

#### 4.2.2 | Address unresolved needs

Some service beneficiaries may have unresolved needs, such as goals that were not met, and others may have only just begun navigation services toward the end of the program. At the last official encounter, it is important to identify these needs and collaboratively plan steps the beneficiary can take to meet them. By writing these

not-yet-achieved goals on paper for beneficiaries to take away, navigators may help them maintain focus once they are on their own and perceive their outstanding needs/goals as manageable.

### 4.2.3 | Provide referrals

Referral service type, quality, and accessibility will vary by program/country. There also may be regional variations in service availability within each country. While it is important to note that some critical services may be unavailable or inadequate, navigators should still provide service beneficiaries with as much information as possible on what is available to meet their (present and potential) needs. Programs may wish to update and provide a directory of services, a small card with phone, email, or web-based contact information, and/or brochures from service providers as part of the final referral process.

### 4.2.4 | Tool for Transition of Navigation

The **Tool for Transition of Navigation (Appendix G)** serves as a template for supporting service beneficiaries to summarize accomplishments and plan for when navigation services come to an end. Programs can adapt the tool according to their local context. Whether this tool is used, or another developed, programs should ensure that navigators work with their service beneficiaries to:

- Review and celebrate accomplishments.
- Identify remaining challenges and how those might be met after the program ends.
- Discuss the range of services available to service beneficiaries.
- Document closure of the relationship.

### 4.2.5 | Non-navigator point person

Where possible, it may help to identify a point person located near the beneficiary who can provide referral information and guidance once navigation services come to an end. This person can be a nurse, social worker, psychosocial counselor, clinic administrative assistant, or other individual who has agreed in advance to receive questions, either in person or by phone. Some individuals may agree to become navigators beyond the life of the program. It will be important to establish clear rules and boundaries in advance, to ensure that these individuals are not overwhelmed with requests that are above and beyond their capacity to respond.

# 5

## MANAGING NAVIGATION

### 5.1 | Hire the right navigators

By hiring motivated, experienced, and reliable navigators, programs can help ensure service beneficiaries receive optimal support throughout the continuum of services. Applicants should meet specific criteria, based on program needs. They should be chosen based on their ability to communicate in an appropriate language. Navigators need to be trained in the core competencies of navigation, relevant SOPs, reporting, and use of data. A navigator should also be knowledgeable about the services available in his or her catchment area and should be perceived as a trusted, respected resource by both service beneficiaries and facility staff. Consult the **Navigation Training Toolkit** included with this guide for a comprehensive set of tools for building the capacity of newly hired individuals.

For more information on how to identify and choose optimal candidates, refer to **Appendix F** in this guide for a **Sample Job Description/Terms of Reference** and a list of core competencies and associated duties. Competencies and duties will vary based on the context and the roles designated for navigators.

### 5.2 | Training

All navigators should successfully complete the LINKAGES peer navigation training course and should demonstrate a robust understanding of the design, rationale, and implementation of the continuum of HIV care based on each country/program context. Programs can determine the additional skills necessary for navigation and should identify the means of building capacity for effective provision of services and support. Programs should support the participation of navigator teams in regularly scheduled meetings to share best practices, brainstorm challenges, and support one another. The frequency of these meetings should be determined in consultation with navigators and their supervisors.

### 5.3 | Navigator–beneficiary pairing

Each program should establish SOPs on matching service beneficiaries with navigators. Ideally pairs will remain together for the entirety of the program (i.e., for as long as the beneficiary needs or requests navigation, the navigator is employed, and the program remains functional). Programs should develop a system for monitoring the functionality of the navigator-beneficiary pairs and for soliciting confidential feedback from service beneficiaries. For example, programs may wish to develop a beneficiary satisfaction survey administered monthly or quarterly by program leadership (online options may help increase response rates and ensure confidentiality). Programs might also consider providing beneficiaries with small incentives for filling out the surveys.

Please refer to section **2.4, Linking beneficiaries with a navigator**, for recommendations on the kinds of options beneficiaries should have in selecting a navigator.

In advance of pairing, it may be necessary to determine whether navigators and service beneficiaries know each other socially. If possible, programs should present the name of the navigator to the beneficiary before pairing them, to reduce the need for re-pairing. Each site should also assess whether a navigator will be able to provide unbiased care to someone who is a social acquaintance and should describe the procedures for handling such a situation in their site-specific SOPs. Sites may also wish to establish rules regarding intimate relationships with service beneficiaries (i.e., in the event a navigator and a beneficiary decide to be involved in a relationship, navigation for that beneficiary could be reassigned to a different navigator). Each program will need to

incorporate local laws and regulations pertaining to this work in their guidance. Ongoing assessment and support regarding personal boundary issues should be provided regularly as part of clinical supervision. Both clinical and operational supervisors should provide a structure, feedback, and support that strongly encourage navigators to maintain appropriate boundaries.

## 5.4 | Pairing with a new navigator

In some cases, it may be necessary to provide a beneficiary with a different navigator than the one originally assigned. This may occur for a variety of reasons, including but not limited to situations where the beneficiary feels uncomfortable with the navigator, the navigator feels uncomfortable with the beneficiary, beneficiary confidentiality has been broken or is in question, a procedural or ethical rule or policy has been broken, the navigator moves or leaves the program or experiences debilitating secondary trauma (see **Section 5.7**), or the beneficiary moves. It is critical for program leadership to be flexible and to address concerns raised either by service beneficiaries or navigators immediately, efficiently, and effectively. Under no circumstances should a beneficiary be required to remain with a navigator or vice versa if either expresses concern.

**NOTE:** *When beneficiary confidentiality or a procedural rule has been broken, navigators should be released from the program.*

If a beneficiary is transitioning to a new navigator, it is important to ensure a smooth transfer of the beneficiary file and records and, where possible, for the outgoing navigator to brief the incoming navigator on any outstanding issues or circumstances. This briefing should be done with the consent of the beneficiary. The incoming navigator should be fully aware of the individual plans developed by the beneficiary in conjunction with the previous navigator, and with any challenges the beneficiary has faced in achieving his or her plans.

## 5.5 | Caseload

Beneficiary needs will vary, with some attaining self-sufficiency quickly and others requiring substantial, long-term support. The caseload is the total number of HIV-positive service beneficiaries for whom a navigator is responsible for providing ongoing support. Current literature recommends a caseload of 20 to 40 beneficiaries. However, caseloads should be determined based on several factors, including: a) the total number of individuals currently in the care network; b) high- versus low-need classification; c) the total number of navigators; and d) individual navigator capacity.

For example, a navigator may have only 10 active cases, but if all of them are high-need, those 10 may consume all the navigator's time for the first few months. Other navigators may be able to handle 40 or more beneficiaries, if most of them require only occasional support. Supervisors should help ensure that caseloads are balanced according to navigator capacity. High-performing navigators may be able to handle a larger or more complex caseload. Programs should periodically review the factors listed in the paragraph above and, based on these and other relevant factors, adjust caseloads, hire additional navigators, or find alternative means of efficiently and effectively supporting beneficiaries in need.

## 5.6 | Supportive supervision

The navigator is a member of the case management team, often linked with a community-based organization or facility. However, navigators work somewhat independently compared to clinical and nonclinical facility staff. They may meet or talk with service beneficiaries on their own schedules, outside the operating hours of the facilities that the program is collaborating with or supporting. Programs should establish a system for supervision of navigators that includes both clinical and operational oversight. Performance should be monitored using established quality assurance standards and procedures based on the minimum package of services outlined above and should be reviewed regularly.

It is up to individual programs to determine scheduling for regular case management, supervisory, and check-in meetings. (General recommendations are provided below.) Programs should also determine a plan for emergency clinical supervision in the case of a crisis (see **Section 3.3.1**). SOPs should outline appropriate locations for meetings, how navigators can manage their hours, and how schedules will be tracked. Ideally, clinical supervision will be available during weekdays and normal hours when navigators meet with their service beneficiaries, though this will depend on each local context. The priority for meeting locations and times should be the safety and security of both navigators and their service beneficiaries.

### 5.6.1 | Operational supervision

Navigators will likely benefit from having a home base where they can meet with service beneficiaries, other navigators, or supervisors, pick up supplies, register information, and coordinate events. This base can be the office of a community-based organization, a drop-in center, or a government treatment facility. Each site or group of sites should have a designated coordinator who supervises the overall implementation of navigation. The coordinator can be responsible for the following (if a case manager is not assigned these duties):

- Matching navigators with eligible service beneficiaries
- Ensuring that all services are provided in accordance with SOPs
- Supporting navigators to liaise with referral service providers
- Ensuring that program data are collected, recorded, and reported appropriately
- Establishing regular supervision meetings

The navigator should be very familiar with all services available in the community, focal points from each site, and the SOPs on navigation. She or he should be ready to help navigators address issues related to the operational details of their work, such as scheduling, reimbursement for travel to meetings, management of referral information, and liaison with focal points. Coordinators should develop a system for tracking all navigator-beneficiary meetings (e.g., a daily calendar), whether they are on or off site.

### 5.6.2 | Case management and clinical supervision

Each program will need to establish its own case management/clinical supervision procedures and structure, as well as agreements with public health facilities based on available human resources and services. Nurses or other designated providers can serve as immediate clinical supervisors for navigators. They should help navigators set boundaries with their service beneficiaries and develop methods for dealing with crises. They can also help ensure that clinical support is available for navigators in situations when a licensed mental health worker's assistance is needed.

The case manager or another assigned individual (such as a supervisor or peer navigator lead) can be responsible for organizing **weekly case management meetings** to review cases, discuss challenges, and brainstorm solutions. Weekly case management meetings can be conducted in groups. During the meetings, navigators can provide rapid overviews of each case they are managing, with the goal of reviewing all cases. Programs may choose to conduct more in-depth discussions of challenging or successful cases once a month, or more often if desired.

Programs may also wish to conduct **weekly or biweekly one-on-one sessions** between supervisors and navigators. These sessions can be an opportunity for supervisors to check in with their navigators, provide encouragement and support, and help them deal with personal issues, including stress, burnout, and any concerns that arise from the job.

## 5.7 | Caring for navigators

Working with HIV-positive service beneficiaries, especially those with complex problems, requires considerable energy and commitment. Navigators may experience stress and burnout due to a substantial workload, lack of recognition, stigma from their communities, and other factors that can influence morale. Stress and burnout should be monitored, and outlets should be provided for navigators (and other staff) to share their experiences and discuss solutions.

Programs may wish to bring teams of navigators together each month to share their experiences in working with service beneficiaries and to recognize their contributions. The meeting should be a safe space, with the understanding that what is disclosed must not be shared outside the group, and staff should feel comfortable speaking candidly about sources of stress and issues of concern. Navigators should also feel comfortable and should be encouraged to share their experiences with fellow navigators on their own time (while respecting beneficiary confidentiality) or to raise issues with their supervisors. Supervisors need to make time and space to listen to navigators as well. This can happen during regular evaluation sessions or one-on-one sessions when supervisors review progress and problem-solve with navigators. Resources and time permitting, supervisors may wish to schedule these check-ins once a week.

It may also be helpful to establish supportive services for navigators, given the emotional and psychological demands they are likely to face as part of their work. Some navigators will appreciate having the opportunity to process the events of the week and receive emotional support from colleagues to manage stress. Services could include a peer support group made up of navigators and/or regular access to professional counseling.

### Secondary trauma

Emotional duress that results when an individual hears about the first-hand trauma experiences of another is called **secondary trauma**. Its symptoms mimic those of post-traumatic stress disorder. Individuals affected by secondary stress may find themselves re-experiencing personal trauma. They may also experience changes in memory and perception, alterations in their sense of self-efficacy, and disruption in their perceptions of safety, trust, and independence. If serious, secondary trauma may make it challenging for a navigator to provide supportive services. Peer navigation programs should have SOPs in place to manage instances of secondary trauma, including procedures for providing a beneficiary with a new navigator if necessary (**see Section 5.4**).

## 5.8 | Reimbursement for travel and time

Programs should examine ways to ensure navigators are reimbursed for travel expenses for beneficiary encounters and assisting beneficiaries to make appointments. To ensure sustainability in the long-term, programs may wish to address transportation barriers by increasing access to community-based or mobile services and/or supporting beneficiaries to obtain gainful employment or social welfare to cover the costs on their own.

## 5.9 | Directory of services

Prior to implementation, each program should develop a **directory of services** (a sample is provided in **Appendix E**). Programs should perform a formal review of the directory at minimum every six months, and it should be updated whenever navigators or other team members have new information. Navigators should visit each facility and provider in the directory to develop personal relationships and to be sure they can accurately describe the services and providers to their service beneficiaries. Programs may opt to send navigators to visit certain sites as “mystery clients” to evaluate their services or may ask beneficiaries to rate service quality, accessibility, and the competence of the providers.

## 5.10 | Program monitoring and evaluation

LINKAGES has developed guidance on micro-planning for community-based interventions designed to reach KP beneficiaries with tailored messaging and commodities, and a **Program Monitoring Guide** for KP programming across the service cascade.\* Each program should ensure that planning and monitoring of navigation programs is integrated with the overall LINKAGES approach across the cascade and is aligned with the monitoring and evaluation framework described in the guide.

It is important to track and review progress regularly. While each program can develop its own quality assurance standards and tools for assessing the quality of navigation, there are some standard tools that can be used to gauge program progress and outcomes. At minimum, programs should regularly analyze data collected via **Tool 11A** of the **LINKAGES Program Monitoring Guide** and should determine in what ways peer navigation is contributing to positive outcomes, including return-to-care initiatives (ART enrollment) and PEPFAR’s TX-RET indicator (which tracks progress on retention in care). The TX-RET indicator for PEPFAR is the “Percentage of adults and children known to be alive and on treatment 12 months after initiation of lifelong antiretroviral therapy.” Programs can set targets for client retention rates for each navigator based on their caseloads. They can also solicit qualitative feedback from beneficiaries, clinical providers, and other service providers on the quality of support provided via navigation.

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\*The Program Monitoring Guide can be found at the following link: <https://www.fhi360.org/sites/default/files/media/documents/resource-linkages-monitoring-tools.pdf>

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# A APPENDIX A. INTAKE ASSESSMENT

This tool can be used to guide a conversation between you and your beneficiary. It should be completed by the second or third session. The goal is to identify areas where your beneficiary may need assistance in prioritizing and accessing services and in reducing HIV and other STI-related risk behaviors. Remind your beneficiary that all information is confidential.

Each area is prefaced with a **goal (in bold)** and includes prompts to assist you in obtaining the information you may need to understand your beneficiary's profile and the issues that may affect his/her ability to maintain his/her health. While it is recommended that you cover all the sections below, it is not necessary to go through all the prompts; your discussion with your beneficiary should not feel like an interrogation. Feel free to use your own appropriate language to ask questions and probe for answers. There is a space for you to write notes, and after the discussion you can determine low- or high-need classifications for each area based on your notes. LINKAGES recommends that you review this form periodically with your beneficiary to identify areas that may have changed.

Begin by explaining the purpose of the discussion, the topics that will be covered, and about how long it should take.

| GOAL/PROMPTS  | NOTES | LOW NEED | HIGH NEED |
|---|-------|----------|-----------|
| <p><b>Goal: Understand how the beneficiary identifies him/herself</b></p> <ul style="list-style-type: none"> <li>Gay, bisexual, straight, trans, other</li> </ul>   |       |          |           |
| <p><b>Goal: Understand the beneficiary's living situation</b></p> <ul style="list-style-type: none"> <li>Can you tell me a little bit about your current living situation?           <ul style="list-style-type: none"> <li>Rent, own, live at workplace (brothel), homeless currently or in last six months, live alone, live with someone</li> <li>If with someone, how is that relationship?               <ul style="list-style-type: none"> <li>Stable/unstable, how long in current situation?</li> </ul> </li> </ul> </li> </ul> |       |          |           |
| <p><b>Goal: Understand sexual relations/partnerships over the last 6 months</b></p> <ul style="list-style-type: none"> <li>Tell me about your current partner(s)/client load           <ul style="list-style-type: none"> <li>Male, female, transgender person</li> <li>HIV status of regular sexual partner</li> <li>Number of partners/clients in the last 6 months</li> <li>Condom use with regular partner (sometimes, always, never)</li> <li>Condom use with clients (sometimes, always, never)</li> </ul> </li> </ul>            |       |          |           |

| GOAL/PROMPTS  | NOTES | LOW NEED | HIGH NEED |
|---|-------|----------|-----------|
| <p><b>Goal: Understand employment/financial situation and effect on health/risk</b></p> <ul style="list-style-type: none"> <li>• Employment/earning status and stability of employment/earning</li> <li>• Other means of support/income</li> <li>• Effect of financial situation on lifestyle and health <ul style="list-style-type: none"> <li>▶ Ability to obtain/maintain medical care</li> <li>▶ Survival sex/exchange of sex for drugs, money, place to stay</li> </ul> </li> </ul>  |       |          |           |
| <p><b>Goal: Understand beneficiary's general health status and needs</b></p> <ul style="list-style-type: none"> <li>• Rating of own health <ul style="list-style-type: none"> <li>▶ Excellent, good, fair, poor</li> </ul> </li> <li>• Any chronic medical conditions? <ul style="list-style-type: none"> <li>▶ Diabetes, asthma, heart disease, others</li> <li>▶ Substance use disorder or dependence</li> <li>▶ Mental health</li> </ul> </li> <li>• Current use of health care <ul style="list-style-type: none"> <li>▶ Regular doctor/health care provider</li> <li>▶ Where does he/she usually go when ill?</li> <li>▶ Private insurance, out-of-pocket, or rely on national health system?</li> </ul> </li> <li>• Additional health care needs <ul style="list-style-type: none"> <li>▶ Dental care</li> <li>▶ Vision care</li> <li>▶ Food/nutrition</li> <li>▶ Fitness</li> </ul> </li> </ul> |       |          |           |

| GOAL/PROMPTS  | NOTES | LOW NEED | HIGH NEED |
|---|-------|----------|-----------|
| <p><b>Goal: Understand if beneficiary may benefit from help with substance use issues</b></p> <p><i>[Note: Begin by talking with the beneficiary about whether s/he uses alcohol or drugs. If in that conversation, s/he denies ever using either, skip to the mental health section. If drug or alcohol use comes up later, you can return to these questions.]</i></p> <ol style="list-style-type: none"> <li>1. Have you ever felt you ought to cut down on your drinking or use of drugs?</li> <li>2. Have you ever tried to cut down on your drinking or use of drugs, but couldn't?</li> <li>3. Have people annoyed you by criticizing your drinking or use of drugs?</li> <li>4. Have you ever felt bad or guilty about your drinking or use of drugs?</li> <li>5. Have you ever had a drinking or drug use problem? <ul style="list-style-type: none"> <li>• Are you currently being provided medication-assisted treatment for your substance abuse treatment?</li> <li>• Have you ever used a needle to inject drugs? <ul style="list-style-type: none"> <li>▶ If yes: Last 6 months?</li> </ul> </li> <li>• Have you ever shared needles? <ul style="list-style-type: none"> <li>▶ If yes: Last 6 months?</li> </ul> </li> </ul> </li> </ol> |       |          |           |

| GOAL/PROMPTS   | NOTES | LOW NEED | HIGH NEED |
|--|-------|----------|-----------|
| <p><b>Goal: Understand if the beneficiary may benefit from a referral for mental health</b></p> <ol style="list-style-type: none"> <li>1. Have you ever been diagnosed with a serious mental illness?</li> <li>2. Have you received mental health treatment in the last 6 months?</li> <li>3. Have you taken prescribed medications to help improve your mental health in the last 6 months?</li> <li>4. During the last 4 weeks, how much of the time has your physical health or emotional problems (being down or anxious) interfered with social activities, like visiting with friends, relatives, etc.?</li> </ol> |       |          |           |
| <p><b>Goal: Understand additional needs</b></p> <p><i>The beneficiary may have needs that don't fit into the categories above or that may reveal themselves as the encounter progresses. These might include the need to address:</i></p> <ul style="list-style-type: none"> <li>• Gender-based violence and/or abuse</li> <li>• Food/nutrition deficiency</li> <li>• Transportation</li> <li>• Family issues (e.g., stigma)</li> <li>• Legal support</li> <li>• Disclosure</li> <li>• Other</li> </ul>  |       |          |           |

# B

## APPENDIX B. ACTION PLAN\*

What issues has the beneficiary identified that may need to be addressed to ensure he/she can effectively adhere to his/her treatment regimen and maintain positive living?

- Health care and/or medical aid (including general health, dental, vision) \_\_\_\_\_
- Food/nutrition
- Violence prevention and/or response
- Mental health counseling
- Adherence (taking HIV medications properly) and/or CD4/viral load monitoring
- HIV care and treatment
- Transportation
- Alcohol and substance abuse/dependence treatment services and type (e.g., OST)
- Financial assistance
- Housing
- Employment/income
- Fitness
- Education
- Clothing
- Legal services
- Complementary health options (including traditional healing, acupuncture, massage, and herbal therapy)
- Other services \_\_\_\_\_

Immediate referrals:

Priority Goals/Needs:

---

\*Should be completed in conjunction with the Life Steps for ART Adherence tool

## Next Appointment

Things that could make it difficult to achieve my goals include:

My plan for overcoming these difficulties includes:

My confidence that I can achieve my goal:

1

2

3

4

5

Not confident

Neutral

Very confident

# C

## APPENDIX C. NAVIGATOR ADHERENCE COUNSELING CHECKLISTS

### Navigator Adherence Counseling Checklist: Initial session

Date: \_\_\_\_\_ Beneficiary UIC: \_\_\_\_\_ DOB: \_\_\_\_\_

Name of Navigator: \_\_\_\_\_

**PURPOSE:** *The purpose of this checklist is to provide guidance for peer navigators working with service beneficiaries to support adherence to their treatment regimens and clinical and diagnostic appointments. After going through the initial steps on this page, navigators should use the Life Steps Adherence Counseling tool (provided with the Peer Navigation Implementation Guide) with their beneficiaries to develop step-by-step action plans for addressing potential barriers to adherence. When/where navigators/beneficiaries do not have sufficient time to conduct the full process of developing a Life Steps action plan, the guidance on the second page can be used.*

\_\_\_\_\_ **Build rapport.**

- Check in on the beneficiary's well-being.
- Discuss living with HIV and health maintenance; provide counseling as needed.
- Emphasize that the beneficiary can ask any questions at any time.

\_\_\_\_\_ **Define and discuss medication adherence.**

- Explain that adherence is the degree to which a person sticks to the prescribed regimen.
- Emphasize the collaborative process and taking an active role in one's treatment.
- Review the potential for nonadherence to lead to medication resistance.

\_\_\_\_\_ **Discuss the beneficiary's ART regimen.**

- Review the prescription and guidance from the clinician.

\_\_\_\_\_ **Discuss potential side effects.**

- Review expectations about side effects; emphasize that they generally diminish over time.

\_\_\_\_\_ **Discuss the importance of clear communication with the beneficiary's clinician.**

- Emphasize the importance of continued communication about side effects.
- Review the importance of asking questions so that the best decisions can be made about medicines.

\_\_\_\_\_ **Implement the Life Steps Adherence Counseling tool.\***

*\*If there is not enough time to go through the Life Steps Adherence Counseling tool, proceed to the next page and use the checklist as a guide.*

\_\_\_ **Create a daily medication schedule (beneficiary's adherence plan).**

- Develop a concrete, simple adherence plan using appropriate tools (e.g., pillboxes).
- Discuss when the doses will be taken in different circumstances (e.g., at home, at work, when using substances, if applicable).
- Review food restrictions and ensure that the plan accommodates specific medications.

\_\_\_ **Develop reminder strategies.**

- Specifically address the involvement of the partner and/or other support people.
- Suggest and discuss reminder strategies (e.g., watch, timer, notes, ribbons placed in the home).

\_\_\_ **Discuss family, community, social support, and privacy.**

- Discuss who knows the beneficiary's HIV status and how they can help with adherence.
- If necessary, strategize how the beneficiary can keep his/her HIV status private and still maintain adherence.

\_\_\_ **Address potential barriers to adherence.**

- Brainstorm potential barriers to adherence and ways to overcome such obstacles.

\_\_\_ **Address what to do when the beneficiary misses a dose.**

- Emphasize that although the goal is optimal adherence, no one is perfect.
- Discuss ways to get back on track as soon as possible after a missed dose.

\_\_\_ **Discuss appointment attendance and contact information.**

- Discuss how the beneficiary will get to future appointments; if necessary, strategize about potential barriers to attendance (e.g., transportation).
- Make sure that the service beneficiary has contact information for potential questions or emergencies.

\_\_\_ **Review what has been covered and answer the beneficiary's questions.**

- What questions do you have about your regimen?

## Navigator Adherence Counseling Checklist: Follow-up session

Date: \_\_\_\_\_ Beneficiary UIC: \_\_\_\_\_ DOB: \_\_\_\_\_

Name of Navigator: \_\_\_\_\_

**PURPOSE:** *The purpose of this checklist is to provide guidance for peer navigators working with service beneficiaries to support ongoing adherence to their treatment regimens and clinical and diagnostic appointments. Navigators can review progress/challenges based on the Life Steps Adherence Counseling plans developed in a previous session and/or use the checklist below.*

\_\_\_\_\_ **Continue to build rapport.**

- Encourage the beneficiary to start the session with any concerns or questions.
- Emphasize that the beneficiary can ask a question at any time.

\_\_\_\_\_ **Ask about the beneficiary's experience with adherence.**

- Confirm that the beneficiary understands the importance of medication adherence.
- Confirm that the service beneficiary understands the relationship between adherence and resistance.
- Answer any questions and correct any misunderstandings; consult a clinician if necessary.
- Emphasize that ART should not be shared with others.

\_\_\_\_\_ **Discuss side effects.**

- Ask the service beneficiary if he/she is experiencing any side effects and/or if he/she has any questions.
- Assist the beneficiary in eliminating or reducing side effects; consult a clinician if necessary.

\_\_\_\_\_ **Review the status of the beneficiary's doctor-patient communication.**

- Ensure that the beneficiary is comfortable talking to his/her clinician about treatment issues.
- If problems exist, assist the beneficiary to improve communication.

\_\_\_\_\_ **Review the beneficiary's ART regimen.**

- If the beneficiary is still unfamiliar with the regimen or the regimen has changed, review the particulars of each drug — what it looks like, its name, what it does, and how it is taken.
- Answer any questions related to the ART regimen; consult a clinician if necessary.

\_\_\_\_\_ **Review the beneficiary's daily medication schedule.**

- Adjust the adherence plan as necessary.

\_\_\_\_\_ **Review reminder strategies.**

- Ask about the effectiveness of the reminder strategies being used, including partner support.
- Suggest alternatives and new approaches as appropriate.

\_\_\_\_\_ **Review the role of family, community, and social support and assess privacy.**

- Discuss how the service beneficiary's family and friends are helping or hindering adherence.
- Determine if privacy issues are negatively influencing adherence.
- Suggest alternatives and new approaches as appropriate.

\_\_\_\_\_ **Discuss new/emerging barriers to adherence.**

- Determine if any new barriers to adherence have arisen; help address these issues.

\_\_\_\_\_ **Address missed doses.**

- Ask the service beneficiary how he/she has handled missed doses.
- Discuss ways to handle similar situations in the future; consult a clinician if necessary.

\_\_\_\_\_ **Discuss appointment attendance.**

- If the beneficiary is having trouble making appointments, discuss alternative strategies.
- Make sure that the beneficiary has contact information for questions or emergencies.

# D

## APPENDIX D. SAMPLE CONFIDENTIALITY STATEMENT\*

### **Agreement by Employee/Contractor to Comply with Confidentiality Requirements**

#### ***Summary of statutes pertaining to confidential health records and penalties for disclosure***

Any information collected or maintained in the course of navigation-related activities that may directly or indirectly identify an individual is considered confidential health record(s) and must be handled with the utmost privacy and confidentiality. LINKAGES and its collaborating agencies prohibit the disclosure of HIV/AIDS-related health records that contain any personally identifying information to any third party, unless authorized by law, or by the written consent of the individual identified in the record or his/her guardian/conservator. Except as permitted by law, any person who negligently discloses information contained in a confidential health record to a third party may be subject to a civil penalty plus court costs. Any person who willfully or maliciously discloses an individual's HIV status or the contents of a health record, except as authorized by law, may be subject to a civil penalty plus court costs. Any willful, malicious, or negligent disclosure of information contained in a health record in violation of local law that results in economic, bodily, or psychological harm to the person named in the record may be punishable by imprisonment and/or a fine, plus court costs.

Any person who is guilty of a confidentiality infringement of the foregoing type may be sued by the injured party and shall be personally liable for all actual damages incurred for economic, bodily, or psychological harm as a result of the breach.

Because an assurance of case confidentiality is the foremost concern of this program and its collaborating agencies, any actual or potential breach of confidentiality shall be immediately reported. In the event of any suspected breach, staff should immediately notify the director or supervisor of the navigator, who in turn should notify the program manager/country director. LINKAGES senior management, in conjunction with the local health and/or other relevant departments/ministries shall promptly investigate the suspected breach. Any evidence of an actual breach shall be reported to the law enforcement agency that has jurisdiction, with the consent of the person whose confidentiality was breached.

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\*Adapted from the California Department of Public Health, Office of HIV/AIDS Form 868 9 (Revised 10/12). Retrieved from [www.cdph.ca.gov/pubsforms/CtrlDForms/cdph8689.pdf](http://www.cdph.ca.gov/pubsforms/CtrlDForms/cdph8689.pdf).

**Employee confidentiality pledge**

I recognize that in carrying out my assigned duties, I may obtain access to private information about persons diagnosed with HIV that was provided under an assurance of confidentiality. I understand that I am prohibited from disclosing or otherwise releasing any personally identifying information, either directly or indirectly, about any individual named in any HIV/AIDS confidential health record. Should I be responsible for any breach of confidentiality, I understand that civil and/or criminal penalties may be brought against me. I acknowledge that my responsibility to ensure the privacy of protected health information contained in any electronic records, paper documents, or verbal communications to which I may gain access shall not expire, even after my employment or affiliation with the program has terminated.

By my signature, I acknowledge that I have read, understand, and agree to comply with the terms and conditions above.

\_\_\_\_\_

Employee name (print)

\_\_\_\_\_

Employee Signature

\_\_\_\_\_

Date

\_\_\_\_\_

Supervisor name (print)

\_\_\_\_\_

Supervisor Signature

\_\_\_\_\_

Date

## E APPENDIX E. SAMPLE DIRECTORY OF SERVICES

| ORGANIZATION   | SERVICES PROVIDED (USE CODES)  | FEES FOR SERVICES           | ADDRESS                  | PHONE NUMBER                                  | HOURS OF SERVICE   | CONTACT PERSON | NOTES |
|--|--------------------------------|-----------------------------|--------------------------|---|--|----------------|-------|
| Name of Organization A                               |                                |                             |                          |   |  |                |       |
| Name of Organization B                               |                                |                             |                          |   |  |                |       |
| Name of Organization C                               |                                |                             |                          |   |  |                |       |
| Name of Organization D                               |                                |                             |                          |   |  |                |       |
| Etc.   |                                |                             |                          |   |  |                |       |
| <b>For services use the following numeric codes:</b> |                                |                             |                          |   |  |                |       |
| 1. Adherence counseling                              | 9. Food support                | 15. Microfinance            | 23. PMTCT services       | 30. Alcohol and/or substance abuse management | Other services might include LGBT, MSM, crisis management, etc |                |       |
| 2. Antiretroviral therapy                            | 10. HIV counseling and testing | 16. Needle/syringe programs | 24. Post-test clubs      | 31. Support for domestic violence victims     |  |                |       |
| 3. Child care  | 11. HIV+ care services         | 17. Nutrition counseling    | 25. PrEP services        | 32. Treatment support                         |  |                |       |
| 4. Clinical care                                     | 12. Legal support              | 18. OB/GYN services         | 26. Psychosocial support | 33. TB services                               |  |                |       |
| 5. Condoms & lubricants                              | 13. Material support           | 19. Peer counseling         | 27. Social services      | 34. Youth support groups                      |  |                |       |
| 6. Education/schooling                               | 14. Mental health services     | 20. PEP services            | 28. Spiritual support    | 35. Other_____                                |  |                |       |
| 7. Family planning                                   |                                | 21. Pharmacy                | 29. STI services         |   |  |                |       |
| 8. Financial support                                 |                                | 22. PLHIV support           |                          |   |  |                |       |

**NOTE:** Programs and individuals within agencies may differ in their ability to provide services to people living with HIV (PLHIV), those who are lesbian, gay, bisexual or transgender (LGBT), or other men who have sex with men (MSM). The "Notes" column may be used to identify personnel who are client-friendly and those to avoid. Sites are encouraged to consider such notes carefully when referring service beneficiaries to services and for researching the cultural competency of agencies at all levels.

# F

## APPENDIX F. SAMPLE NAVIGATOR JOB DESCRIPTION/TERMS OF REFERENCE

### Summary

A navigator assists service beneficiaries living with HIV to identify and overcome barriers that interfere with achieving health-related personal goals and to help ensure that they effectively navigate and remain within the continuum of HIV services. Ideally, navigators are peers living with HIV who serve as medication-adherent role models. In collaboration with a facility-based case manager and other service providers within the network, each navigator typically assists 20 to 40 beneficiaries.

### Specific roles and responsibilities:

- Provide tailored post-test counseling and support to service beneficiaries.
- Refer and help beneficiaries access and enroll in clinical, diagnostic, psychosocial, and other support services.
- Liaise with health and other social service providers as needed.
- Support service beneficiaries to adhere to their treatment regimens.
- Provide counseling and emotional support.
- Give feedback and support to team members.

### Educational background and core competencies

- Excellent communication skills (written and verbal) and demonstrated ability to work independently, adhere to deadlines, and work as part of a team
- Ability to develop, plan, and implement short- and long-term goals
- Ability to coordinate and implement multiple projects, tasks, and events
- Ability to handle a large workload in a professional, timely manner
- Skill in establishing priorities and organizing resources

### Specific experience/other requirements

- Proficiency in another language that is relevant to the country context
- Demonstrated ability to meet program guidelines with respect to required reporting
- Experience working with communities of men who have sex with men and/or transgender individuals, and sex workers (male and/or female) preferred

Those living with HIV are strongly encouraged to apply. Program-specific training will be provided and required

| COMPETENCIES  | POTENTIAL DUTIES  |
|---|---|
| <b>Solid communication and counseling skills</b>  | <ul style="list-style-type: none"> <li>• Conduct motivational interviewing.</li> <li>• Provide active listening and counseling.</li> <li>• Present information in a professional, efficient, and effective manner.</li> <li>• Present beneficiary information and challenges when communicating with providers and supervisors.</li> <li>• Support service beneficiaries to ask providers productive questions and obtain the information they need.</li> </ul> |
| <b>Understanding of the care network (including the availability of clinical, psychosocial, violence and abuse prevention and response, and legal services)</b> | <ul style="list-style-type: none"> <li>• Provide ongoing follow-up to ensure service beneficiaries attend appointments.</li> <li>• Liaise with the case management team.</li> <li>• Liaise with social support services to address housing, substance use, and mental health needs.</li> <li>• Develop/revise action and monitoring plans.</li> </ul>   |
| <b>Ability to promote positive health, dignity, and prevention</b>  | <ul style="list-style-type: none"> <li>• Provide adherence counseling and planning.</li> <li>• Address self-stigma and other kinds of stigma.</li> <li>• Assess and provide support for people who experience violence and abuse.</li> </ul>  |
| <b>Maintenance of confidentiality</b>   | <ul style="list-style-type: none"> <li>• Uphold local policies on confidentiality and privacy.</li> <li>• Support service beneficiaries in instances of breach of confidentiality.</li> <li>• Record/maintain information in a safe/secure location.</li> </ul>   |
| <b>Sound documentation skills</b>   | <ul style="list-style-type: none"> <li>• Adhere to existing SOPs in recording and reporting.</li> <li>• Document relevant beneficiary information and share with the HIV case management team.</li> </ul>   |

\* Adapted from the LINKAGES Jamaica Peer Navigation Protocol (2016).

# G

## APPENDIX G. TOOL FOR TRANSITION FROM NAVIGATION SERVICES

of all navigators.

### Core competencies and potential duties for navigators\*

UIC: \_\_\_\_\_ Navigator: \_\_\_\_\_

Enrollment Date: \_\_\_\_\_ First visit: \_\_\_\_\_

Last visit: \_\_\_\_\_ Total number of Encounters: \_\_\_\_\_

---

### Navigation Action Plan

#### Needs:

- |   |   |   |
|---|---|---|
| <input type="checkbox"/> Health Care              | <input type="checkbox"/> Education                            | <input type="checkbox"/> Health Insurance |
| <input type="checkbox"/> Transportation           | <input type="checkbox"/> Dental Health Care                   | <input type="checkbox"/> Clothing         |
| <input type="checkbox"/> Optical Health Care      | <input type="checkbox"/> Legal Services                       | <input type="checkbox"/> Housing          |
| <input type="checkbox"/> Mental Health Counseling | <input type="checkbox"/> Alcohol and Substance Use/Dependence |   |
| <input type="checkbox"/> Financial Assistance     | <input type="checkbox"/> Food/Nutrition                       | <input type="checkbox"/> Fitness          |
| <input type="checkbox"/> Employment/Income        | <input type="checkbox"/> GBV Services                         | <input type="checkbox"/> Other Services   |

#### HIV+--Specific Services:

- |  |   |
|--|---|
| <input type="checkbox"/> Adherence (take medications properly) | <input type="checkbox"/> HIV Care and Treatment and/or CD-4/Viral Load Monitoring |
|--|---|



# H

## APPENDIX H. ROLES AND RESPONSIBILITIES OF PEER OUTREACH WORKERS, NAVIGATORS, AND CASE MANAGERS

**NOTE:** In the absence of a trained case manager, peer navigators may take on some or most of the case manager's roles

|  | FUNCTION   | PEER OUTREACH WORKER | NAVIGATOR             | CASE MANAGER |
|--|--|----------------------|-----------------------|--------------|
| COMMUNITY-BASED  | Represents one or more key population(s)   | ✓                    | Optional              |              |
|  | Conducts community outreach  | ✓                    |                       |              |
|  | Provides commodities, including condoms, lubricants, and/or safe injection equipment   | ✓                    | ✓                     |              |
|  | Serves as HIV-positive, treatment-adherent role model  | Optional             | Preferred             |              |
|  | Conducts motivational interviewing   | ✓                    | ✓                     | ✓            |
|  | Identifies and assesses health and social support needs of service beneficiaries   | ✓                    |                       |              |
|  | Links service beneficiaries to HIV testing services  | ✓                    | For partners/families |              |
|  | Links service beneficiaries to other clinical and social support services, including for TB, alcohol and substance dependence, hepatitis | ✓                    | ✓                     | ✓            |
|  | Monitors progress service beneficiaries are making toward goals  |                      | ✓                     | ✓            |
|  | Provides post-test guidance on available diagnostic and clinical services  | Optional             | ✓                     | ✓            |
| FACILITY-BASED   | Conducts detailed client intake assessment   |                      | Optional              | ✓            |
|  | Supports HIV-positive service beneficiaries to complete referrals to clinical services   |                      | ✓                     | ✓            |
|  | Provides routine follow-up for service beneficiaries   |                      | ✓                     | ✓            |
|  | Supports service beneficiaries to maintain treatment adherence   |                      | ✓                     | ✓            |
|  | Supports service beneficiaries to make medical appointments  |                      | ✓                     | ✓            |
|  | Provides guidance and experience on positive living and prevention for sexual partners   |                      | ✓                     | ✓            |
|  | Reviews caseload to identify and find service beneficiaries lost to follow-up, in coordination with clinical staff                       |                      | ✓                     | ✓            |
|  | Provides psychosocial support, supportive counseling, and beneficiary education  |                      | ✓                     | ✓            |
|  | Provides clinical guidance, monitoring, and follow-up  |                      |                       | ✓            |
|  | Conducts case conferencing and crisis intervention   |                      |                       | ✓            |
| Advocates for services and conducts consultations with providers |  |                      | ✓                     |              |

## I APPENDIX I. DISCLOSING YOUR STATUS\*

**GET A SENSE OF PEOPLE'S POSSIBLE REACTIONS.** Test how your friends, family members, or partner(s) might react to your HIV status by asking them questions such as “What do you think about HIV?” and “Have you met anyone with HIV?” or by talking about a news story related to HIV. This will help you get a sense of what people think about HIV and how they might react.

**PRACTICE.** Practice disclosing to people you trust, or who already know your status. They could include family members or friends and people in your support group. Remember, though, that all people will not react in the same way.

**LEARN FROM OTHERS.** Speak to other people living with HIV or members of your support group to learn from their experiences different ways to disclose.

**CONSIDER TIMING.** Consider things like the best time to tell the person. When dating, some people tell a partner when they first meet, while others wait until later. If you decide to wait, remember that you must do everything you can to keep your partner safe by abstaining from sex or using a condom every time. If you are in a long-term relationship, try to find a time when your partner is calm and has time for a long conversation.

**CHOOSE A SAFE PLACE.** Think of disclosing in a location in which you feel comfortable and safe — whether it is a private place (such as in your house or a friend's house) or in a public place where other people are around. If you think the person you are disclosing to might get violent or angry, try to tell him or her in a safe environment and have a plan for your safety. For support, you might bring along a trusted friend or family member who already knows your status. Work with your navigator to ensure you have the support you need to prevent and address potential instances of violence and abuse.

**BE READY FOR A CONVERSATION ABOUT HIV AFTER YOU DISCLOSE.** Your partner(s) might have questions about living with HIV, such as the risk of transmission and how to practice safer sex. They might also have questions about the source of your infection and about your relationship. Try to have some printed materials about HIV facts that you can provide. A counselor can also help with this.

**REMEMBER THAT DISCLOSURE IS A PROCESS RATHER THAN A ONE-TIME EVENT.** Expect to have several conversations. Your partner(s) might need time to deal with various emotions. They might have new questions about HIV.

**PLAN TO BE WITH PEOPLE YOU TRUST AFTER YOU DISCLOSE.** You can celebrate a positive outcome or get support for dealing with a negative outcome.

**CONSIDER PARTNER NOTIFICATION.** Navigators can assist in partner notification services, which is also known as disclosure or contact tracing. Partner notification is defined as a voluntary process whereby a trained provider asks people diagnosed with HIV about their sexual partners and/or drug injecting partners, and then, if the HIV-positive client agrees, offers these partner(s) HIV testing services. Partner notification is provided using passive or assisted approaches.

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\* Adapted from: International Planned Parenthood Foundation (IPPF). Healthy, happy and hot: a young person's guide to their rights [Internet]. London: IPPF; 2010 [cited 2012 Oct 22]. Available from: <http://ippf.org/resources/publications/healthy-happy-hot>.

# J APPENDIX J. ACTIVITIES CHECKLIST FOR NAVIGATION

| NO.  | MAIN ACTIVITY   | NOTES/SUB-ACTIVITIES/<br>CONSIDERATIONS | PERSON<br>RESPONSIBLE | DUE DATE | DONE?<br>(Y/N) |
|--|---|---|-----------------------|----------|----------------|
| <b>1. Initial program planning and budgeting</b> |   |   |                       |          |                |
| <b>1.1</b>                                       | <p>Consider:</p> <ul style="list-style-type: none"> <li>• Current number of cases and estimated cases based on epidemiology and program targets</li> <li>• Staffing needed to provide supportive supervision</li> </ul>   |   |                       |          |                |
| <b>1.2</b>                                       | <p>Consider:</p> <ul style="list-style-type: none"> <li>• Cost for full-time salaries of peer navigators</li> <li>• Cost for additional supervisory staff/staff time</li> <li>• Potential costs to contract with government or other facilities</li> <li>• Initial and recurring costs, including mobile phones, SIM cards/credit, and transportation.</li> </ul> |   |                       |          |                |
| <b>1.3</b>                                       | <ul style="list-style-type: none"> <li>• Consult with key partners to ensure that timeline is feasible.</li> </ul>  |   |                       |          |                |
| <b>1.4</b>                                       | <ul style="list-style-type: none"> <li>• Paper-based or electronic?</li> <li>• Integration with existing systems, including unique identifier codes (UICs)</li> </ul>   |   |                       |          |                |
| <b>1.5</b>                                       | <ul style="list-style-type: none"> <li>• Ensure there is agreement on roles and client flow (see Section 2 below).</li> <li>• Determine where navigators will be based.</li> <li>• Determine which facilities will be included as part of the network of services.</li> </ul>   |   |                       |          |                |

| NO.   | MAIN ACTIVITY   | NOTES/SUB-ACTIVITIES/CONSIDERATIONS   | PERSON RESPONSIBLE | DUE DATE | DONE? (Y/N) |
|---|---|---|--------------------|----------|-------------|
| <b>2. SOP development and establishment/clarification of referral network</b> |   |   |                    |          |             |
| <b>2.1</b>  | <ul style="list-style-type: none"> <li>Develop KP client flow algorithm in a visual format.</li> </ul>  | <ul style="list-style-type: none"> <li>Algorithm should map the interactions of all key individuals, organizations, and client tracking forms along the continuum of services.</li> <li>Ideally developed in conjunction with the Ministry of Health, facility, and CBO partners</li> </ul>   |                    |          |             |
| <b>2.2</b>  | <ul style="list-style-type: none"> <li>Meet with referral sites (care and treatment, STI diagnosis and treatment, GBV services, legal aid, etc.)</li> </ul> | <ul style="list-style-type: none"> <li>Conduct initial high-level meetings to introduce/discuss program and begin formalizing two-way referral mechanisms.</li> <li>Introduce draft client flow algorithms and revise as needed.</li> <li>Discuss adopting UICs and/or client tracking.</li> <li>Develop agreements with referral sites as needed to formalize KP client flow and referral/counter-referral.</li> </ul>   |                    |          |             |
| <b>2.3</b>  | <ul style="list-style-type: none"> <li>Develop/adapt standard operating procedures (SOPs) for client flow</li> </ul>  | <ul style="list-style-type: none"> <li>Programs should collaborate with key partners within the network on the development, review, and approval of SOPs.</li> <li>SOPs should describe each step as KP beneficiaries are assigned to a navigator, enrolled in care, referred and supported to access services, counter-referred, and followed up (including those lost to follow-up).</li> <li>Issues to consider include: <ul style="list-style-type: none"> <li>Confidentiality and safety</li> <li>Crisis situations</li> <li>Data security</li> <li>Coordination with other programs/services</li> </ul> </li> </ul> |                    |          |             |

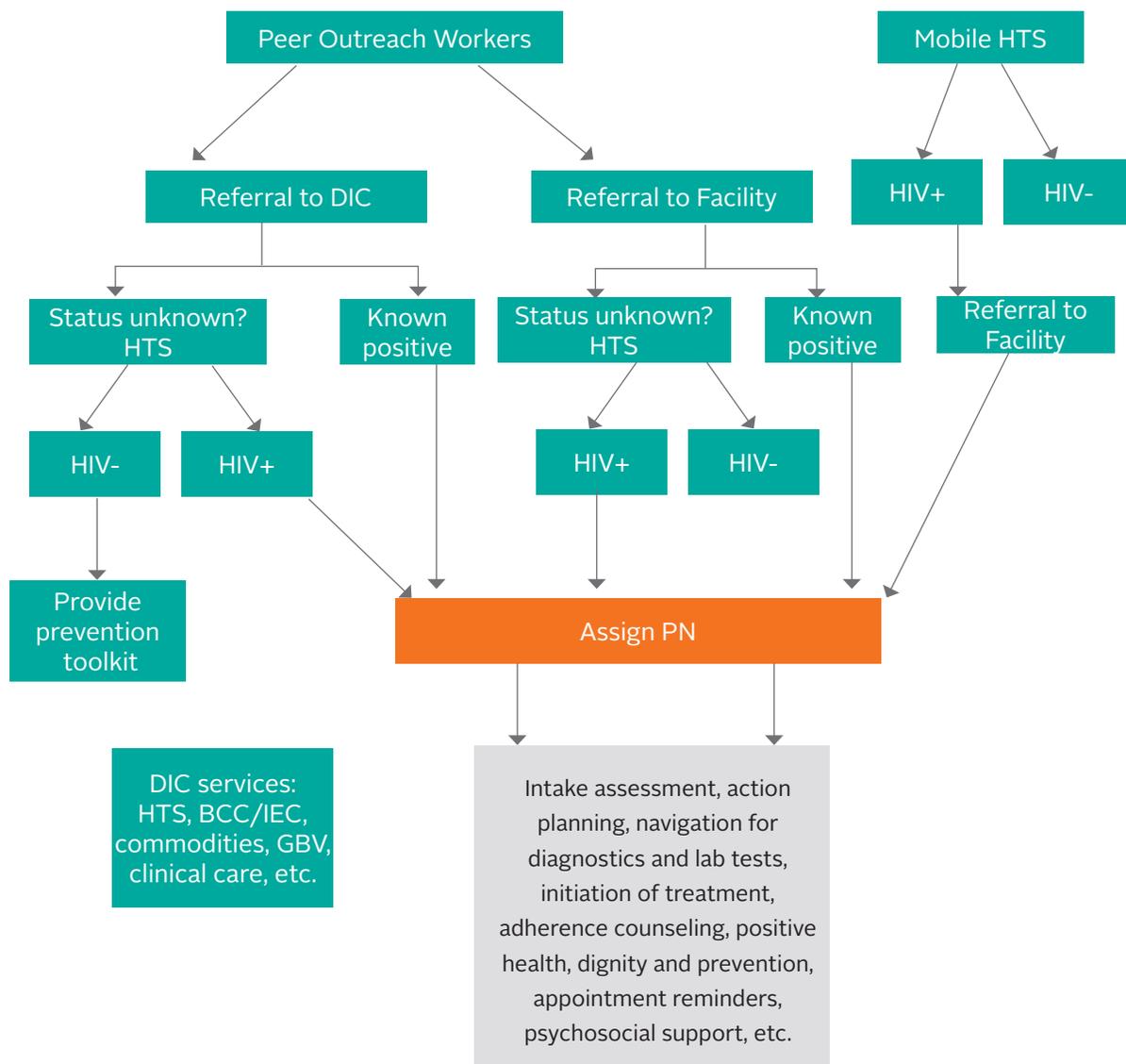
| NO.   | MAIN ACTIVITY   | NOTES/SUB-ACTIVITIES/CONSIDERATIONS  | PERSON RESPONSIBLE | DUE DATE | DONE? (Y/N) |
|---|---|--|--------------------|----------|-------------|
| <b>2. SOP development and establishment/clarification of referral network</b> |   |  |                    |          |             |
| <b>2.3</b>  | Develop SOPs for supervisors (or revise existing ones). | <ul style="list-style-type: none"> <li>Should include regular program monitoring meetings and check-ins, as described in the LINKAGES guide</li> </ul>   |                    |          |             |
| <b>2.4</b>  | Adapt peer navigation forms/documents.                  | <ul style="list-style-type: none"> <li>Adapt materials/tools from LINKAGES Peer Navigation Guide, or develop as needed: <ul style="list-style-type: none"> <li>Job description</li> <li>Confidentiality statement</li> <li>Client intake</li> <li>Action plan</li> </ul> </li> <li>Navigation monitoring form (Tool 11A of the LINKAGES Program Monitoring Toolkit)</li> <li>Adherence counseling checklists/Life Steps tool</li> <li>Transition from navigation tool</li> </ul> |                    |          |             |
| <b>2.5</b>  | Develop a directory of services.                        | <ul style="list-style-type: none"> <li>Directory should be both paper- and web-based if possible, and IEC materials should refer beneficiaries to a URL with the most updated information.</li> <li>Programs should establish a systematic means to review the directory and update its information on a regular basis.</li> </ul>   |                    |          |             |
| <b>3. Training</b>  |   |  |                    |          |             |
| <b>3.1</b>  | Adapt training for peer navigators.                     | <ul style="list-style-type: none"> <li>Review LINKAGES curriculum and adapt modules as needed.</li> </ul>  |                    |          |             |
| <b>3.2</b>  | Train peer navigators and their supervisors.            | <ul style="list-style-type: none"> <li>Agree on timing for refresher training as appropriate.</li> </ul>   |                    |          |             |

| NO.   | MAIN ACTIVITY  | NOTES/SUB-ACTIVITIES/CONSIDERATIONS   | PERSON RESPONSIBLE | DUE DATE | DONE? (Y/N) |
|---|--|---|--------------------|----------|-------------|
| <b>4. Tracking, program monitoring, and supervision</b> |  |   |                    |          |             |
| <b>4.1</b>  | Develop KP client flow algorithm in a visual format.               | <ul style="list-style-type: none"> <li>Adapt tracking tools/logs for KP beneficiaries as they move through the service network.</li> </ul>  |                    |          |             |
| <b>4.2</b>  | Develop SOPs for program monitoring and supervision.               | <ul style="list-style-type: none"> <li>Conduct initial high-level meetings to introduce/discuss program and begin formalizing two-way referral mechanisms.</li> <li>Introduce draft client flow algorithms and revise as needed.</li> <li>Discuss adopting UICs and/or client tracking.</li> <li>Develop agreements with referral sites as needed to formalize KP client flow and referral/counter-referral.</li> </ul> |                    |          |             |
| <b>4.3</b>  | Develop data visualization tools (dashboards).                     | <ul style="list-style-type: none"> <li>Dashboards should be designed to assist supervisors and navigators to understand progress, identify gaps, and develop solutions.</li> <li>Could include cascade analyses and/or additional visual representations.</li> </ul>  |                    |          |             |
| <b>4.4</b>  | Conduct regular data feedback sessions to inform program revision. | <ul style="list-style-type: none"> <li>Sessions should include facility and CBO leadership (where possible), supervisors, providers, and navigators.</li> </ul>   |                    |          |             |

| NO.                          | MAIN ACTIVITY  | NOTES/SUB-ACTIVITIES/CONSIDERATIONS  | PERSON RESPONSIBLE | DUE DATE | DONE? (Y/N) |
|------------------------------|--|--|--------------------|----------|-------------|
| <b>5. Financial tracking</b> |  |  |                    |          |             |
| 5.1                          | Develop/adapt recurring costs and reimbursement tracking SOPs and forms. | <ul style="list-style-type: none"> <li>SOPs should include how navigators are advanced/reimbursed for travel, mobile charges, and other related expenses, and should delineate roles and responsibilities in financial tracking for all relevant staff.</li> </ul> |                    |          |             |
| <b>6. Implementation</b>     |  |  |                    |          |             |
| 6.1                          | Begin implementation.  | <ul style="list-style-type: none"> <li>Programs may wish to phase in peer navigation, beginning on a small scale or with high-performing partners or districts/regions, or other scaled means of rolling out navigation.</li> </ul>                                |                    |          |             |

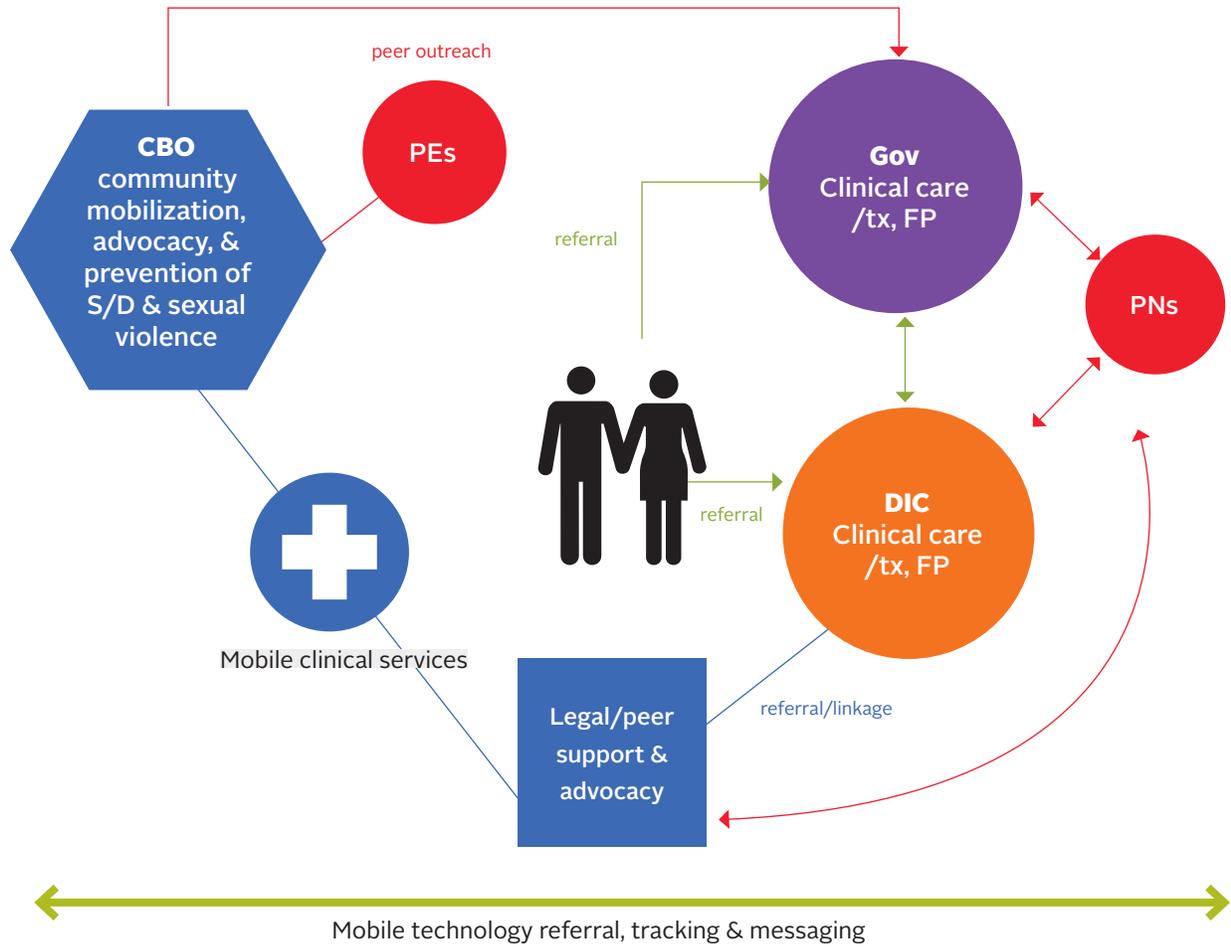
# K

## APPENDIX K. SAMPLE CLIENT FLOW MODELS\*



\*NOTE: The client flow algorithms provided here are simplified for the purpose of illustrating examples. Programs will benefit from providing greater detail, identifying specific service sites and client tracking/data entry procedures along the algorithm, and including other program elements, such as enhanced peer outreach, community-based testing, etc.

USAID-funded **Continuum of prevention, care and treatment of HIV/AIDS with Most-at-risk Populations**  
(CHAMP) – Cameroon (2014-2019)

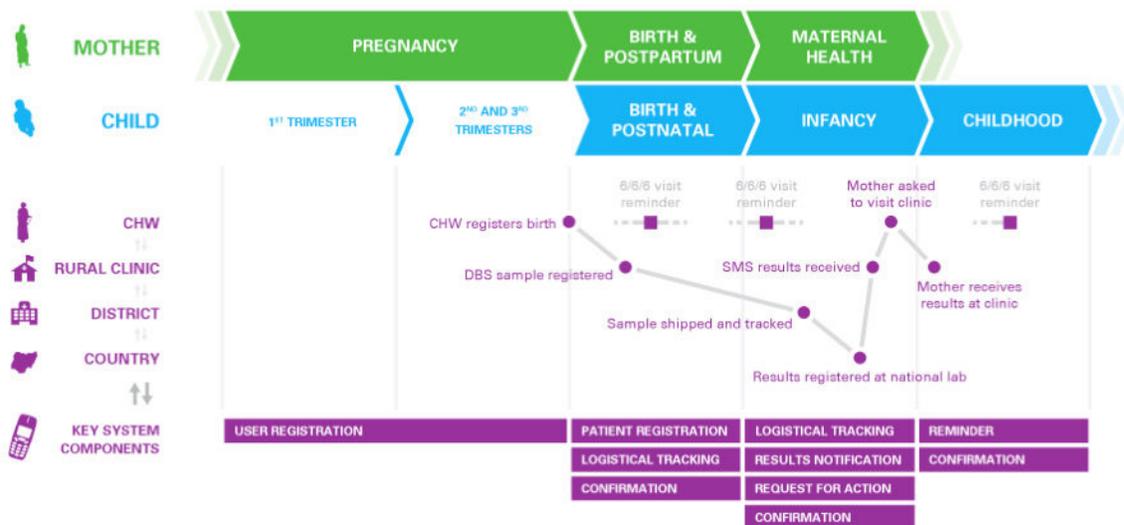


## UNICEF-supported mHealth initiatives in Zambia, Malawi, and Rwanda

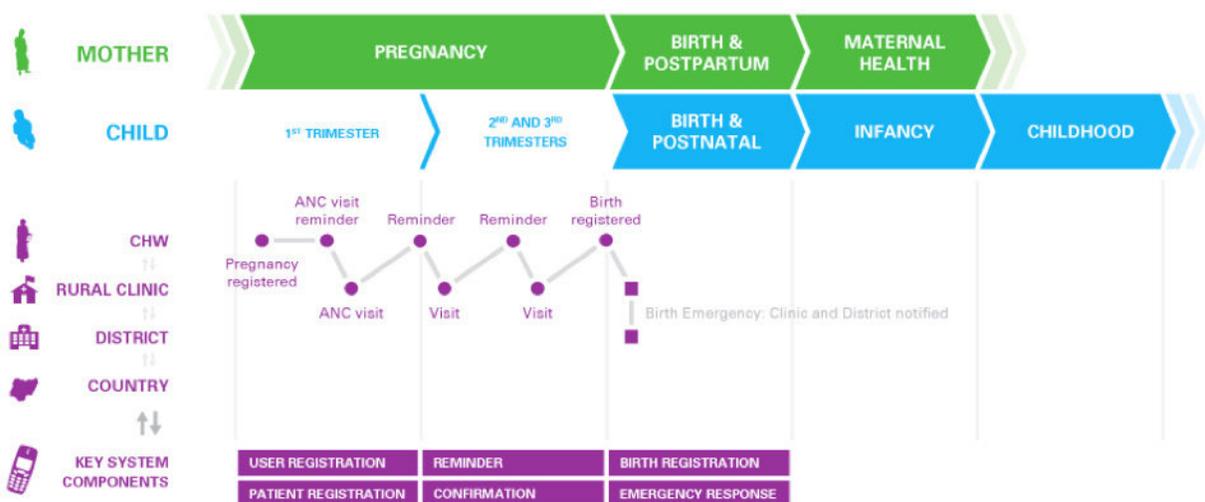
From *Visualizing the Future of mHealth* (June 22, 2012)

Retrieved from <http://unicefstories.org/2012/06/22/visualizing-the-future-of-mhealth/> on May 9, 2017

### MWANA INITIATIVE, ZAMBIA & MALAWI



### MOBILE ANC, RWANDA



## L

## APPENDIX L. ADDITIONAL REFERENCES

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