Understanding Retention and Engagement: *How can we improve?*

Authors: Tamaryn Nicholson & Kate Rees
Prepared by Melanie Bisnauth

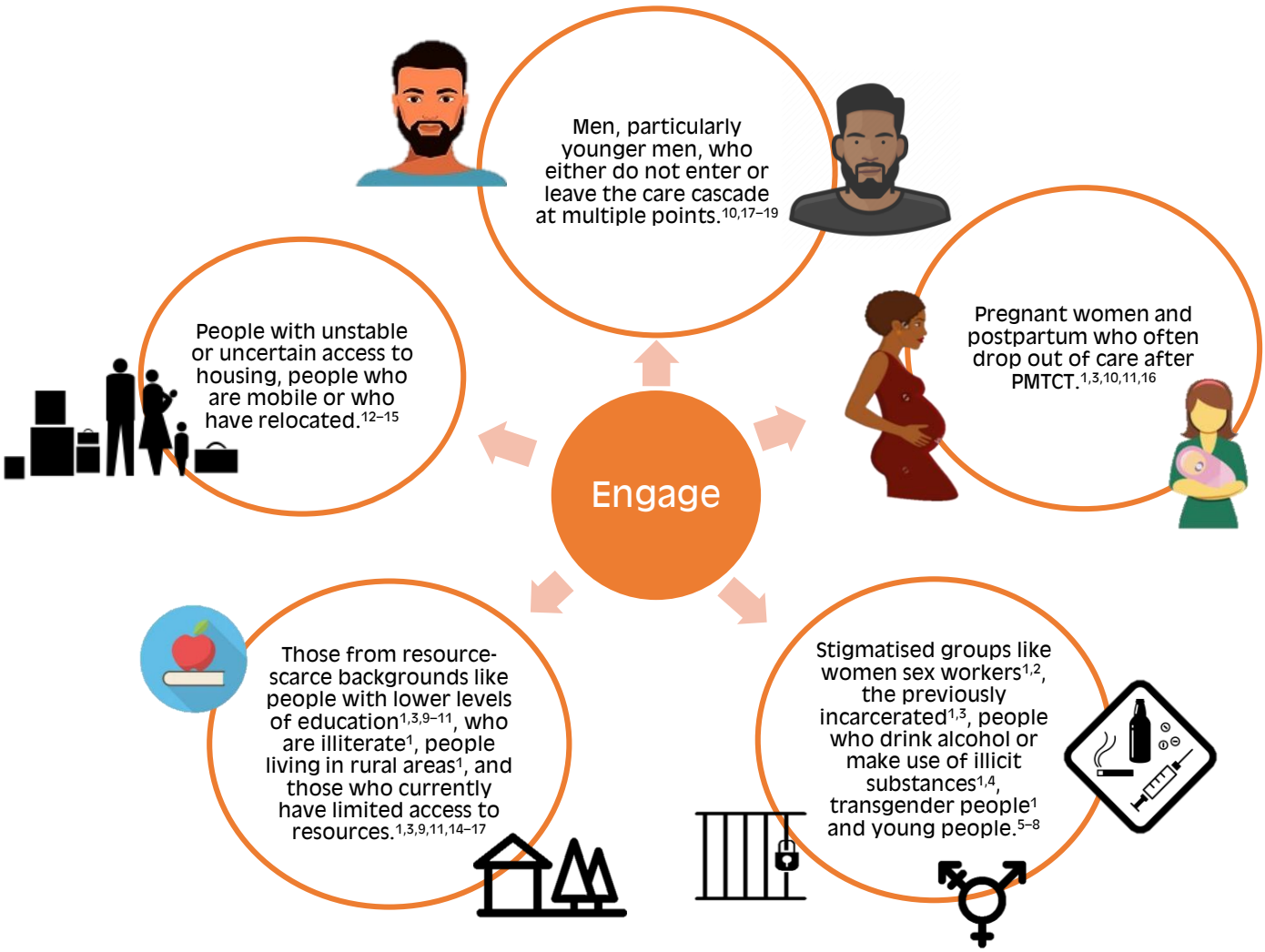
We must understand retention

Our HIV programme will not be able to reach the 2nd or 3rd 90-90-90 targets (ART coverage and viral suppression) without improving retention. In this summary, we outline a) who we're losing from care, b) why we're losing them, and c) how we can change these patterns.

Who are we losing?

We know that not all groups of people respond to care in the same ways and health providers respond to people differently. This means that some groups are more or less likely to be initiated on ART and remain in care.

Currently, research indicates that we must pay attention to engaging with the following target populations:



There is usually not one factor that causes disengagement but multiple factors ***act together*** to keep people out of care.

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So why are we losing people?

There are opportunities for disengagement across the care cascade, each of which presents an opportunity for someone to be lost from care. Not only this, but many of these factors have the potential to act together to produce breaks in care - *and keep people out of care* - once interrupted.

While any one factor can have a negative impact, the cumulative impact of several factors causes longer term disengagement (Figure 1). For example: A person might have an initial general dislike for, or distrust of Western medicine but still attend a clinic for ART. Their remaining distrust, however, can be compounded by factors like concerns or worries about the effects of ART, difficulty getting to the clinic and/or the features of the clinic and staff itself. A disruptive event like not being able to secure childcare during an appointment might cause this person - already disinclined to attend the clinic - to miss the appointment resulting in a short-duration disengagement. Missing this appointment might, in turn, result in a negative reaction from clinic staff reinforcing a lack of trust in the healthcare system, longer-term disengagement and unwillingness to return.

Figure 1. Factors for Longer Term Disengagement

Because of this, we should think of retention and disengagement as long-term processes rather than as results of a particular short-term cause and effect dynamic. Throughout engagement with the health care system, patients face multiple opportunities in which engagement can either be reinforced or undermined; this can originate from their personal and professional lives in addition to direct engagements with the health care system itself.

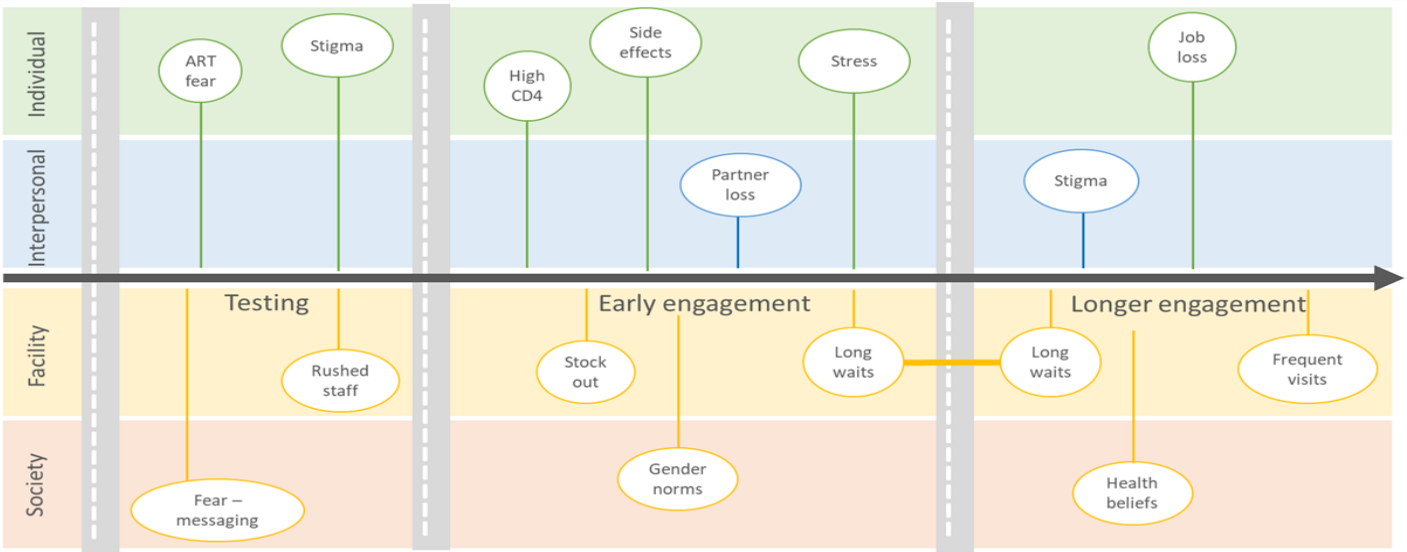

Figure 2. Factors affecting disengagement from care over the course of time

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To maintain and promote engagement, we need to be mindful of the way that interactions and issues, even at initial points of contact like testing, can continue to affect care engagement along the entire care cascade. In this way, we can prevent the 'tipping point' from being reached and keep more patients in care.

Facility Barriers

There are a great number of factors that impact on whether or not people remain engaged in care at the facility level. This includes those related to treatment options and effects, relationships with clinic staff, the amount of support staff receive, the facilities themselves and the services they offer.

As can be seen above, barriers to health facility level factors, like staff-patient relationships and dynamics, are undercut by systemic problems fueled by a lack of resources. Because of this, actions taken to address these barriers must also speak to underlying causes like high workloads and low levels of training.

Barriers to engagement can operate within and across multiple levels including the intrapersonal, interpersonal, health facility and social level. These are often connected. However – while not absolute – we do have more control over what happens in health facilities and as part of healthcare programs.

What can health services do?

One of the most frequently cited ways to help people to remain engaged in care is through social support; this can come from families, friends, or romantic partners but it can also come from health facility staff and services.

At the health system level, peer support in the form of peer education[3], peer mentors[3], peer support groups[8] and the provision of emotional and psychological support from peer counsellors. [22,1,27,28,30] Counselling can also help with reducing internalized or felt stigma.[22] Similarly, support groups and support in the form of adherence, ART education or other networks and/or clubs help to prevent disengagement.[1,2,22]

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What can health services do? cont'd...

In addition to this type of support, some facility services are associated with increased engagement including:

- integrated care
- offering service packages tailored to particular groups
- providing food support
- using mobile technology interventions to provide appointment reminders and between-visit clinic contact
- providing transportation assistance
- providing point of care tests and speedy test results
- instituting patient education and empowerment initiatives
- implementing intensive case management strategies

Fortunately, while we might not be able to address personal challenges faced by individual patients in their daily lives, we may still be able to reduce the cumulative burden of continued care-engagement by providing support services via health facilities (Figure 3) and enabling close interpersonal relationships between staff and patients. In doing so, we can prevent disengagement from care.

Figure 3 highlights the interventions being implemented in Johannesburg Health District with the support of Anova to address the different factors in which impact retention along the care continuum.

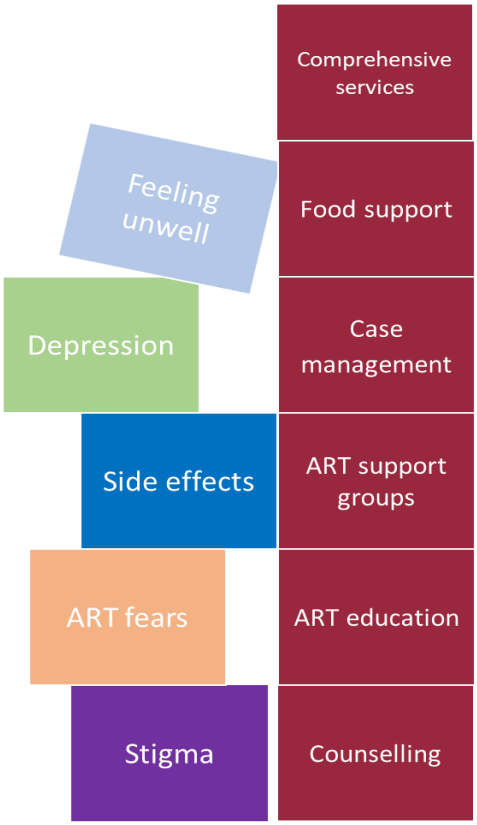
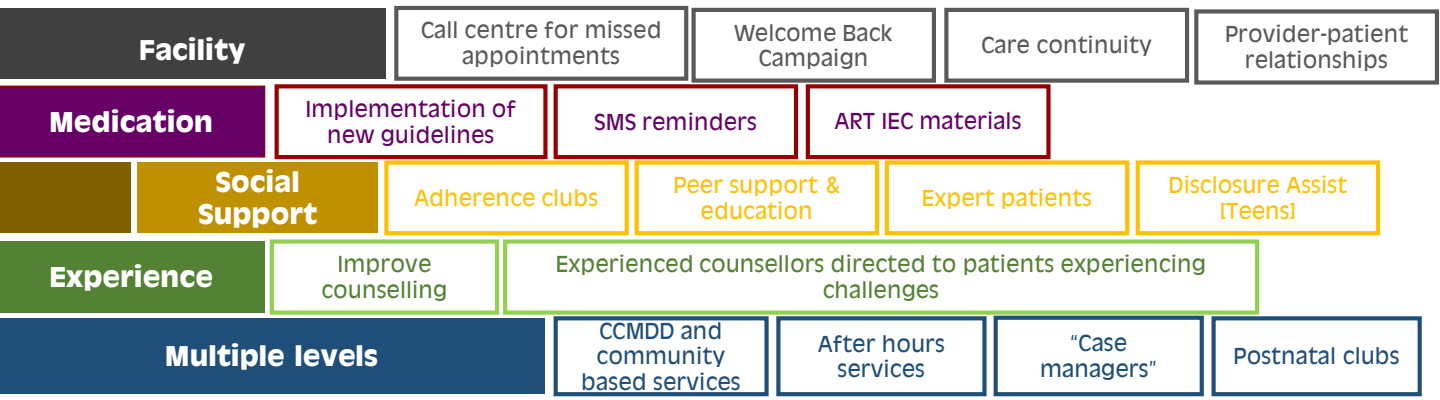


Figure 3. Interventions being implemented in Johannesburg Health District with support from Anova



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