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The Challenge of and Opportunities for Transitioning and Maintaining a Continuum of Care Among Adolescents and Young Adults Living with HIV in Resource Limited Settings

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Abstract

An unprecedented number of youth living with HIV (YLHIV) are aging into adolescence and young adulthood, increasing concerns about the possibility of these youth being lost in the transition from supported care (sometimes in pediatric settings) to more independent healthcare settings and perhaps furthering the emerging disparities in outcomes (e.g., higher nonadherence to treatment, increased morbidity and mortality). In resource-rich settings where there is likely greater recognition of adolescent cognitive and developmental challenges, transitioning YLHIV to adult healthcare has emerged as a major challenge. In resource limited settings (RLS), where the burden of HIV is significant and healthcare resources often stretched, the challenge to move toward healthcare independence and maintain a fluid continuum of care for YLHIV may be the greatest. We review key issues in transitioning YLHIV in RLS, highlighting steps in the transition process, examining evidence where available, and discussing challenges and opportunities to understanding and optimizing outcomes.

Keywords

youth living with HIV; adolescents; transition; pediatric; adult care; outcomes; resource-limited settings

Introduction

With the successes to date in management of HIV in infants and children, including earlier diagnosis, early antiretroviral treatment (ART) initiation and opportunistic infection (OI) prevention and treatment, rising numbers of children are surviving into adolescence and

adulthood. There are also significant numbers of youth with perinatal HIV infection who are newly diagnosed later in childhood and youth, particularly females, at high risk of acquiring HIV during the second decade of life. [1,2] The clinical and psychosocial complexities of managing youth living with HIV (YLHIV) are increasingly being recognized and disparities in their treatment and outcomes becoming more apparent as youth demonstrate greater nonadherence, attrition from care, morbidity, and mortality than their adult counterparts. [3,4] With an unprecedented number of YLHIV aging into adolescence and young adulthood worldwide, there is mounting concern about the possibility of these youth being lost in transition from pediatric to adult care settings and perhaps furthering the emerging disparities in outcomes. In resource-rich settings there is high recognition of adolescent cognitive and developmental stages. Hence, adolescent medicine exists as a specialty with enhanced infrastructure targeted towards the care of youth. Despite this, transitioning YLHIV from pediatric to adult care remains one of the major challenges for YLHIV.[5,6] In resource-limited settings (RLS) issues regarding a physical transfer from pediatric to adult care setting may not always be the primary concern since many areas may share the same general HIV providers and even clinic space for pediatric, youth, and adult HIV populations. Furthermore, separate pediatric and adolescent clinics may not exist in many settings. In these cases, transition would entail more movement towards independent adult care (navigating the healthcare system with less support) rather than a different clinical environment. Indeed, the identification of innovative ways to continue and maintain the delivery of quality HIV healthcare to all ages – from infancy through youth and into adulthood – remains more at the core of healthcare needs in low-middle income countries. The dialogue surrounding how best to shift healthcare delivery to meet the needs of an individual living with HIV throughout a highly dynamic stage of life that comprises adolescence and young adulthood may take precedence over simply discovering ways to simply transfer or move YLHIV from one healthcare setting to another.

Worldwide, there is a steady pipeline of YLHIV who, over the next several years, may need to transition to an adult clinical setting, a reality that underscores the need to establish, define, understand, and solidify best practices for maintaining the continuum of HIV care well into the adult stage. Toward this aim, our goal is to review key issues in transitioning and maintaining YLHIV in HIV care, highlight steps in the transition process, examining evidence when available, and discuss particular challenges and potential opportunities to understanding and optimizing outcomes for YLHIV.

Epidemiology of YLHIV

Worldwide there are 1.8 billion adolescents and young adults between the ages of 10 and 24, with 90% living in RLS, primarily in South America, sub-Saharan Africa, and Asia).[1] Of those, there are approximately 5 million YLHIV between the ages of 10–24 (3.9 million 15–24; 1.1 million 10–14 years old) and there are another estimated 2.1 million children under age 10 living with HIV infection[7,8], with about 200,000 newly diagnosed each year. [1,9,10] Not a monolithic group, YLHIV globally include those who have acquired infection perinatally and non-perinatally, the latter through primarily unprotected sexual intercourse and injection drug use, with a minority infected through blood transfusion and other modalities. The great strides made through prevention of mother to child transmission

(PMTCT) programs, as well as earlier diagnosis and ART initiation has reduced childhood infections and improved the survival of children living with HIV infection. However, despite efforts to provide access to all who need it, worldwide, 54% of pregnant women in low and middle income countries received an HIV test, two-thirds of pregnant women known to have HIV receive PMTCT, and 48% of children of women diagnosed with HIV undergo appropriate diagnostic testing to assess infection status.[7,11] Significant numbers of these children are being diagnosed in late childhood and often in adolescence when they present with OIs, growth failure, or other co-morbidities after progressive immune deterioration or when identified by testing algorithms developed to capture those that may have eluded diagnosis at a younger age.[12] Further, individuals between the ages of 15 and 24 account for an estimated 34% [9] of incident HIV infections, with risk factors varying by region (young girls in Sub-Saharan Africa, men who have sex with men in North and South America, commercial sex workers in Asia and people who inject drugs in Eastern Europe). [13] As an escalating number of children who likely acquired HIV perinatally are surviving into adolescence and adulthood, increasingly challenges in their care and management are being recognized.[4]

Psychosocial and Medical Challenges of YLHIV

Psychosocial challenges

Cognitive, developmental, psychosocial, health infrastructure-related, and environmental challenges impact YLHIV's capacity to engage and remain in care (Table 1). Complexities inherent during the cognitive and development phase of adolescence may trigger age-appropriate defiance of oversight and autonomy seeking, but may also lead to opposition against authority, experimentation, a limited capacity to perceive risk, and a sense of invincibility. Youth are also traversing significant evolutionary stages of multi-level physical, psychosocial, and environmental change and development.[4] In addition, the interplay between culture as well as psychological and mental development may add a layer of complexity for the YLHIV and their healthcare providers.

Medical challenges: adherence, morbidity, and disparate outcomes

Several of the developmental issues encountered by YLHIV, while often normal and age-appropriate, can result in nonadherence to medical care, management, and medications, with resultant virologic failure (up to 72% [14,15] of YLHIV) and ART resistance which can be of significant consequence, particularly in settings where access to 2nd and 3rd line ART regimens is limited.[4] Co-morbidities (infectious and non-infectious/HIV and non-HIV related) increase the complexity of medication adherence and how YLHIV need to engage in the medical system. These challenges are being associated with the potential for increased mortality risk. For example, between period 2005–2012, AIDS-related deaths among adolescents increased by about 50% (from 71,000 in 2005 to 110,000 in 2012), in contrast with a 32% decrease among all other age groups during the same period.[16] AIDS-related conditions are now the leading cause of death among adolescents (10–19) in Africa and the second leading cause of death among adolescents globally.[10] This increase may be attributed to decreased access to life-saving treatment, as well as nonadherence, limited treatment options, and other challenges of care and management of YLHIV.[4,11]

Aggregated YLHIV data included with older adults (i.e., 15–29 or 18–40) diminishes the capacity to truly assess outcomes for YLHIV. However, when disaggregated data in the U.S. is evaluated, it is increasingly recognized that YLHIV have the highest rates of attrition and nonadherence to medical care.[3,17–20] Lessons from resource-rich settings that have a large proportion of their YLHIV approaching adulthood reveal significant challenges with attrition in this population. In the U.S.–based HIV Research Network (HIVRN) cohort, only 44% of non-perinatally acquired YLHIV were still engaged in care 1 year after entry with a staggering 22% remaining retained in care after 3 years.[3] In examining both perinatal and non-perinatal YLHIV between the ages of 12 and 24, the HIVRN also showed increased likelihood of youth being lost to follow up (LTFU) with increasing age.[21] Notably, in the latter study, the authors were unable to comment on transition as robust mechanisms to follow youth beyond the age of transition, which was 25 in most of the included clinics, was limited. There are little outcomes data from RLS. Nglazi et al[22] show that adolescents had substantially lower rates of virologic suppression (<400 copies/mL) at 48 weeks on cART compared to young adults (20–28); 27.3% vs 63.1% respectively ($p<0.001$) and Evans et al. showed that at 12 months post ART initiation, 17–30% of adolescents had experienced virologic failure. [14,15] In the Evans study, older adolescents and young adults had a higher likelihood of being lost to follow-up LTFU after initiating ART (HR 1.78 95% CI 1.34–2.36; HR 1.63 95% CI 1.41–1.89) with young adolescents less likely LTFU (HR 0.43 95% CI 0.26–0.69) compared to adults.[15]

Clinical Structures of care for YLHIV

The structures of health care particularly in RLS are highly variable. Specifically, YLHIV between the ages 10–24 may be seen in general care with patients of all ages, less likely environments focused only on pediatric care, adolescent care, or youth-friendly clinical spaces defined by the World Health Organization (WHO) as provision of services that are Accessible, Acceptable, Equitable, Appropriate (including sexual and reproductive health services), Effective, and delivered in a non-judgmental and confidential manner.[23] While standards for provision of youth friendly services exist, there is significant variability in its delivery. There is variability in the clinical space (environment and attitude and perceptions of the staff), issues of disclosure, clinic size (provider and patient ratio); the care delivery model may also be different (primary and multidisciplinary care in the same space, integration of primary and HIV care, ability to co-locate services (sexual reproductive services, alcohol, tobacco, and other substance abuse), and availability of support services. Lastly there are differences in provider training, the provider-patient relationship, and involvement of family and guardians in the youth's care and family structure where many YLHIV may be orphaned and living with extended family and their healthcare managed by caregivers who are not their biological parents. The increasing understanding and appreciation of the unique characteristics of the adolescent stage has led to the establishment of adolescent medicine as a subspecialty and the development of the concept of youth-friendly approaches and clinics to facilitate the engagement of adolescents in multi-faceted care. However, there are limited providers with adolescent-specific training, particularly in RLS. Specifically, while 90% of adolescent medicine providers reside in North America, 90% of youth live in RLS.[24] The capacity to provide age and developmentally appropriate

comprehensive care to youth in general, and YLHIV, in particular, may be severely limited to non-existent in many RLS. There are real-world challenges to providing youth friendly primary care in RLS and the capacity to provide that care to YLHIV may be even more restricted, creating potential gaps in the care and management of HIV within the context of the emerging adolescent/young adult and as a result potentially enhance the disparities outlined above. As a result, depending on the setting, there may be several transition models (e.g., transition from pediatric to youth-friendly care, transition from pediatric directly to adult care, or care is provided in combined programs where adults and pediatric patients are seen by the same providers without any real distinction of adolescence and no transition occurs). In fact, the last model, where the transition is not a physical change, but one of a change in approach to assumption of more independence may actually be the most relevant to RLS and the necessary interventions may be specific to such programs.

Transition defined

Transition is the “purposeful and planned movement of children with special health care needs from child-to-adult-centered health care.”[25] It is considered to be a multi-faceted and active process that takes the entire youth into context, addressing the medical, psychosocial, as well as the academic and vocational needs of youth as they traverse from supported healthcare to independent healthcare. If done well, this transition of medical care may simultaneously facilitate transition in other areas of life. The need to transition to independent healthcare is not unique to YLHIV as there are many conditions (e.g., sickle cell disease, cystic fibrosis,[26] type I/II diabetes mellitus,[27–29] rheumatologic conditions, [30] neurodegenerative disorders) where ultimately youth outgrow the infrastructure of pediatric clinics and must transition to adult care. In fact, many models have been tried to optimize transition with variable successes.[31] A recent Cochrane review highlighted the challenges with transition across several chronic disease conditions and underscored the lack of data supporting any interventions to improve transition outcomes.[32] However, the medical, psychosocial milieu and the impact of HIV on families and communities that is specific to HIV, particularly in RLS, make issues related to transition unique and likely more challenging than in most other chronic conditions. Given the limitations described, children and YLHIV may transition to adult care anywhere between the ages of 8 and 15. In fact, in many RLS, transfer may occur even earlier when the child is stable due to resource constraints in more specialized environments. This transition can set the stage for gaps in care resulting from limited provider experience or knowledge of the unique developmental, psychosocial, as well as the physical attributes of this age range. Given the realities of transition in RLS, YLHIV may actually remain in general HIV care or actually transfer from pediatric to adult clinics, both settings where there may be limited experience in the care and management of YLHIV and their unique needs, therefore, mechanisms to bolster their maintenance in care as they transition are desperately needed. Care providers in RLS also need to enable YLHIV to develop independence regarding maintenance of their HIV care. Closely aligned is the necessity to build capacity to effectively care for YLHIV on both sides of the divide, define successful transition, establish mechanisms to monitor and track, and to assess outcomes including factors associated with good outcomes.

What is SUCCESSFUL transition?

As there has been significant attention paid to the continuum of care examining the steps from diagnosis to virologic suppression for persons living with HIV, there is a critical need to examine the continuum of care post-transition for YLHIV. To visualize this a transition continuum with the starting point being the number of YLHIV eligible for transition to adult services, followed by those who effectively transfer care (seen at least once by an adult provider in the adult clinic), then the proportion who become engaged in care, retained (utilizing regionally appropriate established measures for care and retention like the HRSA measure for the U.S.), and then maintenance or improvement in the level of ART use and adherence and virologic suppression is shown in Figure 1. Further, maintenance of immunologic integrity and disease free survival would also be important. The outcomes of the transition continuum would need to be assessed longitudinally and maintained (i.e., continued retention and adherence to therapy with virologic suppression), as short term outcomes are insufficient to truly determine sustainable success. In this particular age group secondary outcomes including anthropometry (weight, height), WHO HIV clinical staging and CD4 count, sexual and reproductive health outcomes including sexual partnerships, unsafe sex, unplanned pregnancies, contraception uptake and adherence, and episodes of STIs and mental health issues may be important in evaluation comprehensive outcomes.

Challenges of transition

The medical and psychosocial challenges that impact YLHIV often result in multiple patient, provider and systemic barriers to transition (Table 2). Frequently there is little transition preparation and planning for YLHIV. Linkage between referring and receiving clinics is frequently lacking. The barriers, including poor communication, have consistently emerged as themes in qualitative studies examining challenges/barriers to transition from the perspectives of both YLHIV and their providers.[6,25,29,33] Barriers can align, generating circumstances where YLHIV fail to transition effectively. There is limited data about transition outcomes in RLS and, again, it is important to highlight that the health infrastructure is often significantly different than that of resource-rich settings, making issues of transition unique. Data collection systems are frequently not set up to track transition and outcomes from one clinical environment to another, confounding this problem. Most of the limited available data from the United States, United Kingdom, and Thailand is highlighted in Table 3. The YLHIV in the studies, given the regions they are from tend to be older than the likely age of transition in RLS. Reported rates of transition from pediatric to adult care vary from 47–92%.[34–38] Ryscavage et al reported on their transition program utilizing medical and psychosocial support, case management and peer providers for 50 youth ages 21–25, with 19 PHIV and reported only 50% retained in care (defined as 2 visit in 12 months with 1 in each 6 month period) 12 months following transition.[35] One of the only published studies examining transition outcomes in RLS, a unique cohort-based transition approach of 67 PHIV over the age of 15 in Thailand, report 73% remaining in active follow up one to greater than six years after transition.[34] Others, including our own respective transition clinics, the Accessing Care Early (ACE) clinic at Johns Hopkins (Agwu, Griffith) and Jackson Fund Martin Clinics at Mt. Sinai (Jao), report transition rates of 72 and 77% respectively, 12 months after transfer from the pediatric/

adolescent clinics. The compiled data in Table 3 reflect the significant variability in definitions of successful transition across the studies to date, which makes comparison of interventions and assessment of outcomes across studies challenging.

Current limitations in studying transitions for YLHIV

With recognition of the potential challenges, there is mounting interest in quantifying the problem of transitions, assessing factors associated with transition outcomes, such as readiness, and determining interventions that may improve those outcomes.[39,40] There are currently many limitations to examining transitions (Table 2).[41] First and foremost, inconsistent definitions of critical terms such as successful transition, adolescent, and youth for example, along with incomplete and inconsistent data collection limit the ability to examine utilization data to determine transition. These challenges exist worldwide, but are particularly highlighted in RLS. With increasing utilization of electronic medical records across clinics, institutions, and regionally, some of the challenges may be overcome. Additionally, various initiatives (e.g., PHACS, CIPHER and funding agencies) are attempting to coordinate and harmonize data between and across cohorts to begin to tackle the questions about transition in various settings, including RLS. It is hopeful that over the ensuing years we will begin to see published quality reports of baseline transition outcomes as well as potentially results of emerging interventions. [41]

Potential interventions that can improve transitions and impact longitudinal outcomes for YLHIV

Adherence interventions which have been designed include: alternate models of care such as adherence and youth clubs, service integration, targeted focused structures/specialty clinics, support groups, peer navigators, and others.[42] A recent review by Judd et al examined interventions to improve adherence outcomes for youth living with perinatally acquired HIV infection (PHIV) transitioning to adult care and found no studies specifically examining interventions for YLHIV from pediatric to adult clinical services, with most studies examining adherence among YLHIV prior to the transition in middle and high-income countries, with none in RLS.[43] Looking to lessons from outside the HIV experience, in a Cochrane review of interventions to improve transitions in chronic non-HIV conditions, the authors examined a variety of interventions (e.g., workshops, SMS-based education interventions, structured transition programs) with a variety of outcomes (e.g., readiness to transition, use of health services, disease outcomes) and found that there were few randomized control studies, a variety of outcomes, and short longitudinal follow-up. While these were reported to show some promising evidence for improvements in patient knowledge, no clear and consistent impact on outcomes of transition (e.g., higher rates of follow-up, treatment adherence, and quality disease management) was demonstrated.[32,44] Given the current landscape of challenges and negative outcomes being seen for YLHIV, focusing on transitions may be critical to turning the tide and optimizing outcomes. Handbooks and toolkits, as well as training programs focused on the delivery of youth friendly services may improve care for YLHIV in RLS.[45] To underscore the importance of certain aspects of HIV care, increasingly standard quality of care indicators are being

utilized to evaluate HIV care outcomes and to improve standards by providing a score card for programs. Specifically, benchmarks along the cascade from ART initiation to VL suppression are being used. In RLS, standardization may be more challenging, given varying funders and varying capacity to obtain laboratory data, inconsistent implementation of medical data collection systems etc. However, attempts are being made to improve this at country-level. No such standards exist for transition and therefore if this is not part of quality improvement standards, programs likely have little incentive for improving transition and its outcomes. Adding transition to quality improvement standards may be one mechanism to highlight its importance and therefore compel programs to strengthen this process.

While evolving research is attempting to determine best practices for transitions, YLHIV continue to approach the age of transition and guidelines have been developed to assist providers and programs with transitioning YLHIV.[25] While mostly consensus opinion and not evidence-based, they do provide practical recommendations for programs to address YLHIV through the period of transition. Given the potential identified differences between the clinical settings and infrastructure between resource rich and RLS, the recommendations do need to be adapted to the specific context of the RLS. However, certain issues, such as the need for documentation, communication, clarity, education, tracking, and involving the YLHIV and preferably the caregivers in the transition process, to name a few, likely transcend clinical setting.[46] Programs should evaluate and publish their experiences, both positive and negative, to inform the greater community on how to enhance the continuum of care, particularly during the period of transition, for YLHIV.

Questions remaining surrounding successful transition

In order to specifically examine and ultimately optimize transitions, several questions must be asked, including: What is the best definition of successful transition and how generalizable is the definition? What providers, services, and interventions are essential to successful transition? What is the best age for transition? Should we use an age cutoff or disease measure such as VL suppression? What is/are the best model(s) and practice(s)? Can there be one best model? Are different models needed in different settings? How is the issue of transition tackled in clinical structures relevant to RLS? Where should interventions be targeted? Pediatric or Adult Clinics, Providers? Do transition plans make a difference in outcomes? How should we evaluate success and for how long? What will it cost? Who should pay? How should policies be shaped to ensure that programs prioritize transition outcomes as key quality indicators for YLHIV? With such questions, there is ample opportunity and need for research, including implementation science approaches to providing answers. Recognition that YLHIV are not a homogenous group is important as there are likely a multitude of approaches that may be successful and may vary depending on the individual and context.

Conclusion

Worldwide an unprecedented number of YLHIV, a majority residing in RLS, are approaching adolescence and young adulthood and needing to transition to healthcare independence as an adult. With variability in healthcare delivery and infrastructure, the

transition is often not a physical one in RLS. However, in addition to the medical and psychosocial challenges, increasingly evident poorer outcomes with nonadherence and attrition raise concern that a poor transition will exacerbate the emerging disparities in outcomes. Lessons being learned from resource-rich settings regarding transition may provide some insights to how transition can be assessed and potentially managed in RLS. Nonetheless, contextual differences likely demand that RLS will need to determine what practices and interventions may be most effective in their individual settings. Given the magnitude of the HIV epidemic, it is likely that how we approach the transition of YLHIV and the systems that are developed to support them as they navigate from more heavily supported healthcare environments to healthcare independence as an adult will impact long-term healthcare outcomes of YLHIV as well as youth with other chronic conditions.

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Figure 1.

Table 1

Medical and psychosocial challenges for YLHIV

Medical Challenges	Perinatal	Non-perinatal
<u>Disease</u>		
Advanced disease/immunosuppression	X	*
Co-morbidities	X	*
Neurocognitive delay and dysfunction	X	*
Mental health (anxiety, depression, PTSD), substance use	X	X
Delayed puberty and short stature	X	
Suboptimal responses to vaccines	X	*
<u>Treatment</u>		
Treatment experienced	X	*
More complicated cART	X	*
Treatment fatigue	X	X
Drug-resistant virus	X	*
<u>Psychosocial challenges</u>		
Stigma	X	X
Disclosure (HIV, sexuality)	X	X
Limited support systems	X	X
Clinical staff may be only reliable support	X	X
Poor adjustment to illness/status, self efficacy, outcome expectancy	X	X
Denial/guilt	X	X
Limited health literacy, limited self-management	X	X
Logistic barriers: insurance, childcare, transportation	X	X
Attempting to be normal and live life with HIV	X	X

* some youth living with non-perinatal HIV infection

Table 2

YLHIV, provider, and system barriers to transition

Youth
Adolescent and/or family resistance to change
Lack of knowledge about health care transition
Longstanding relationships; transitioning—>feelings of abandonment; concern about staff on the other side
Limited social support (non-disclosure, dysfunctional/deceased family relations, orphans)
Mental health including cognitive limitations
Limited health literacy
Need for greater patient self-management
Sexual and gender health needs
Stigma (multi-level) HIV+, sexual orientation, identity, substance use (concerns about assumptions of others)
Disclosure of HIV status at adult HIV-specific clinics
Socioeconomic concerns
Physical aversion of the clinic (patient behaviors, sicker patients, memories)
Competing needs (education, childcare, employment)
Provider and System
Care-based barriers to simultaneous transition of medical, mental health, substance abuse and case management providers
Provider resistance from both sides of the “bridge”
Lack of providers with expertise and/or desire to treat YLHIV
Communication difficulties between pediatric/adolescent and adult providers
“Cultural” differences in settings and/or approach
Differences in medical treatment practices of pediatric/adolescent vs. adult providers and clinics
Less comprehensive care on adult side
Decreased flexibility
Larger patient volume and patient-to-provider ratio

Table 3

Transition outcomes

Study	Region Population	Program details	Outcome
Ryscavage et al (AIDS Care 2016)	50 (19 PHIV) (21–25y); USA	Transition team, with medical, psychosocial, case management, peer navigators.	50% retained at 12 months ¹
Hansudewechakul R et al (JIAS 2015)	67 PHIV (>15–18’y) Thailand	Cohort-based transition, group meetings, provider trainings, transition camp	73% remain in active follow-up
Maturo et al J Ped Nurs 2015	38 NPHIV (18–24y); USA	Movin Out ² 5-phase transition protocol	47% successfully completed 5 phases (utilization unclear)
Righetti A et al J Assoc Nurses AIDS Care 2015	45 PHIV (0–18y) Italy	Transition of entire peds program→adult program	84% retained in care
Agwu (JHU ACE) Jao (JFMC) (Unpublished)	46 (25 PHIV) 44 (16 PHIV) (25y); USA	Comprehensive transition program (med-peds providers, transition navigators, case managers); embedded in adult clinic	72% ² 77% ²
Hope et al CROI 2016 #835	211 PHIV; 17y median; UK	F/u within past 12 months at adult clinic within vs. outside hospital	92% (within) 72% (outside)

¹ Retention (2 visits in 12 months; 1 per 6 month period);

² Transferred & attending >2 adult visits at least 90 days apart 1y post transfer