

## Health-care transition from adolescent to adult services for young people with HIV

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### Abstract:

HIV-related care and treatment engagement are crucial steps to improve individual and population-level health; yet, many young people (18–25 years old) with HIV are not maintained in, or disengage from, care. Health-care transition and the transfer to adult care are particularly vulnerable points in the care and treatment of young people with HIV. In this Review, we explore barriers and facilitators to health-care transition, evaluate existing health-care transition programmes, and identify best practices for the improvement of health-care transition outcomes and health. Although we examine health-care transition across a range of geographical regions, most examples are from the settings in which the most research has been done—the USA and western Europe.

**Keywords:** HIV | healthcare transition | youth | adolescent health

### Article:

#### Key messages

- Issues at the level of the individual contribute to failure to successfully transition to adult HIV care, including poor health literacy, few life and health-care management skills, stigma, drug use, mental health issues, attachment to paediatric staff, and fear of adult clinics
- Clinic-level barriers to health-care transition include insufficient training in adolescent development, support services in adult care settings, and communication between paediatric and adult care systems
- Facilitators to health-care transition include: development of formal, written transition policies (with input from and for both paediatric and adult teams) that use a multidisciplinary approach, with designated staff focused on health-care transition; staff training in adolescent development; strategies to facilitate physical connection of youth with adult care clinic; support services in both paediatric and adult clinic settings, including health-related self-care and life skills training, patient navigators and social workers, support for mental health and substance abuse problems, support for adherence to medication, and open communication between paediatric and adult teams

- Individualised care plans that use a developmental approach to target young people with HIV (especially those most at risk for failing health-care transition) would be helpful to tailor programmes and target resources to improve individual and population-level health outcomes
- An evaluation of health-care transition would benefit from the development of patient registries, with input from paediatric and adult providers; formalised interclinic data-sharing agreements; medical records abstraction, including behavioural and biological markers, and psychological outcomes; and in-depth process assessments for health-care transition failures

## Introduction

Globally, 1.8 million adolescents are estimated to have HIV, with approximately 250 000 new infections reported annually.<sup>1,2</sup> As a result of treatment innovations (eg, treatment as prevention and achieving an undetectable viral load), HIV is now a chronic, rather than an acute, condition; young people with perinatally and behaviourally acquired HIV can live extended lives. To fully realise the public health benefits of these treatment innovations, people with HIV must remain engaged in care.<sup>3</sup> Yet, there are many stages across the HIV care continuum at which individuals might disengage, and young people with HIV are particularly at risk of this behaviour when transitioning from adolescent to adult HIV health-care and treatment services.<sup>4</sup> In the USA, for example, fewer than half of young people with HIV know their status, only a quarter are engaged in care, and approximately 6% achieve viral suppression; by contrast, 51% of adults with HIV are engaged in care and 28% are virally suppressed.<sup>4,5</sup> Successful progress through the HIV care continuum is challenged by clinical and structural factors across diagnostic and care systems.<sup>6</sup> The transition of young people with HIV from adolescent to adult services has become the focus of many studies and resultant reviews over the past 6 years.<sup>7–12</sup>

Health-care transition is the purposeful movement of young people (18–25 years old) from child-centred to adult-centred care,<sup>13</sup> and successful transition is defined as young people having a non-paediatric provider, insurance, a recent health-care visit, and no treatment delay.<sup>14</sup> Transition to adult care is especially crucial for young people with HIV to remain healthy, maintain an undetectable viral load, and reduce secondary transmission.<sup>15</sup> As an infectious disease, HIV requires intensive, coordinated medical and behavioural management (eg, treatment of substance use and mental health care) to reduce the risk of transmission and its disproportionate effect on marginalised communities, such as sexual and ethnic minorities.<sup>16</sup> In the USA, approximately 25000 young people with HIV are scheduled for health-care transition in the next decade,<sup>16</sup> and a nascent body of research suggests that only 50% will remain in adult care 1 year after they transition.<sup>17</sup> Little health-care transition data are available from other (often less resourced) settings (eg, African and Asian countries), and these countries might have even lower rates of successful health-care transition than high-income settings.<sup>8,11</sup>

The low percentage of successful health-care transitions in resource-rich countries highlights the need for effective approaches to support the seamless process of transition, care engagement, and continued treatment in adult HIV care settings.<sup>18</sup> As such, organisations like WHO,<sup>19</sup> the American Academy of Pediatrics (AAP),<sup>20</sup> and the New York State Department of Health<sup>21</sup> have established HIV-related health-care transition guidelines. These guidelines recommend that: adolescent clinics develop formal written protocols, timelines, and evaluation plans; adolescents are introduced to transition early and provided with individualised pre-transition preparation; health-care transition is initiated between the ages of 18 and 25 years, and includes visits to adult

clinics and data sharing (eg, medical and health records) between adolescent and adult clinics; and health-care transition outcomes are evaluated for young people (eg, engagement in adult care and viral loads).<sup>19,20</sup>

This Review examines the existing HIV-related health-care transition literature to highlight what is known from the perspectives of young people, caregivers, and providers; reports, from multiple clinics, of strategies to support young people during their health-care transition; and gaps in the existing research to provide recommendations to advance HIV-related health-care transition science and practice. We explore barriers and facilitators to health-care transition, evaluate existing health-care transition programmes, and identify best practices for the improvement of health-care transition outcomes and health for young people with HIV. Although this Review will examine health-care transition across a range of geographical regions, most research has occurred in the USA and western Europe, and thus most examples are from those settings (appendix).

We identified some inconsistency in the use of transition-related terms.<sup>13</sup> Here, we use the term transition (or health-care transition), as defined above,<sup>22</sup> to refer to the process as a whole, and transfer to represent the actual movement of care from paediatric and adolescent care systems to adult care systems.

### **Barriers to health-care transition and transfer**

HIV infection poses many barriers to the challenging process of health-care transition for young people with HIV. This marginalised population is at risk of multiple psychosocial complications, such as substance abuse and mental health, which substantially affect the success of health-care transition.<sup>13,23</sup> Neglect, abandonment, or HIV status and chaotic social environments are also suggested to contribute to psychosocial problems, and the health-care transition is even more challenging for young people without basic life skills (eg, time management, financial competency, and meal preparation).<sup>24,25</sup> Elderly caregivers often struggle to deal with adolescent behaviour in general; thus, they might find it difficult to support a young person through their health-care transition.<sup>24,25</sup> The period of adolescent development is also a challenge for health-care providers, because many paediatric providers do not have the training or capacity to teach adolescents about sex, relationships, and responsibilities, which have important implications for disease transmission and mirror other developmental milestones of achieving adulthood.<sup>24</sup> These themes reflect reports of young people feeling ill-prepared for their health-care transition, fear and anxiety related to a change of provider and the navigation of a new health-care system in adult care settings, and the need for more personal responsibility that comes with getting older.<sup>25,26</sup> Additional training related to adolescent development might also be indicated for paediatric and adult providers and team members.<sup>27</sup>

Such psychosocial issues might contribute to the consistent theme of poor health literacy, poor adherence to care within health-care transition of young people with HIV, and the resultant medical consequences of high rates of viral resistance and medically complex patients. For example, Vijayan and colleagues<sup>25</sup> reported that only a third of a cohort of patients who were perinatally infected achieved their expected reading level, contributing to poor health literacy and adherence to medication. Several studies of mostly young people who were perinatally

infected showed detectable viraemia, low CD4 cell counts, and double and even triple class drug resistance with complex medical histories at the time of transfer.<sup>13,28–30</sup> Many of these young people were born in the pre-highly active anti-retroviral therapy era and experienced medication fatigue,<sup>13,30</sup> which will probably be a less important factor as biomedical treatments continue to advance.

Young people who are infected with HIV perinatally often develop strong relationships with paediatric providers, resulting in a sense of loss at transfer of care. This dissolving of paediatric relationships and fear of anticipated cultural shifts represented by adult systems is a consistent theme expressed by patients, caregivers, and paediatric providers.<sup>13,23,25,26,31–33</sup> Furthermore, the strategies used by paediatric and adolescent providers to keep young people engaged in care (eg, youth-friendly spaces and allowing patients to come late for appointments) might exacerbate these perceptions of clinical cultural change, and challenge young people's ability to be independent and autonomous after transfer of care.<sup>23</sup>

Barriers to successful transition after transfer of care reflect similar themes to those before transfer of care. Difficulties in the forming of connections between adult providers and young people reflect the sense of culture clash felt by young people in the adult setting.<sup>34</sup> This might be exacerbated by adult providers'—perhaps unrealistic—high expectations of patient readiness, developmental capacity, and responsibility and behaviour.<sup>27,34,35</sup> Structural barriers arise because of the short supply of support services in the adult setting when compared with the paediatric setting (eg, insurance eligibility and transportation).<sup>35</sup> Mental health also presents challenges for young people with HIV after transfer, with reports of high rates of prescriptions of psychotropic medications and admissions to psychiatric hospitals, and few emotional support services and a limited understanding of patient psychosocial needs by adult providers.<sup>35,36</sup> Absence of communication between paediatric and adolescent and adult care systems is also consistently cited as a substantial barrier to successful transfer of care.<sup>27,32,35,36</sup>

Despite the challenges of health-care transition, a shift in the paradigm has been suggested; specifically, to focus on the benefits of transfer to adult care, including opportunities for young people to develop skills for increased independence, control and responsibility (and satisfaction in response to being treated like an adult), and access to high-quality adult care.<sup>32,33,37,38</sup> Persson and Newman<sup>39</sup> had a more positive take: this population of young people should not be exclusively considered as vulnerable; they should also be seen as having specific strengths (eg, resilience, foresight, coping strategies, expertise, or life skills as a result of their illness) that can be positively exploited to increase the likelihood of successful health-care transition.

### **Health-care transition facilitators and strategies**

Little research has specifically addressed the development and implementation of formal health-care transition protocols and policies, and most adolescent clinics do not have such protocols.<sup>13,23</sup> In the absence of substantial research, expert opinion recommends the development of a formal, written policy for the transition of young people to adult care by the paediatric and adolescent HIV care team, with input from adult HIV care providers, which should include goals and timelines, be shared with all members of the health-care team, and be implemented with

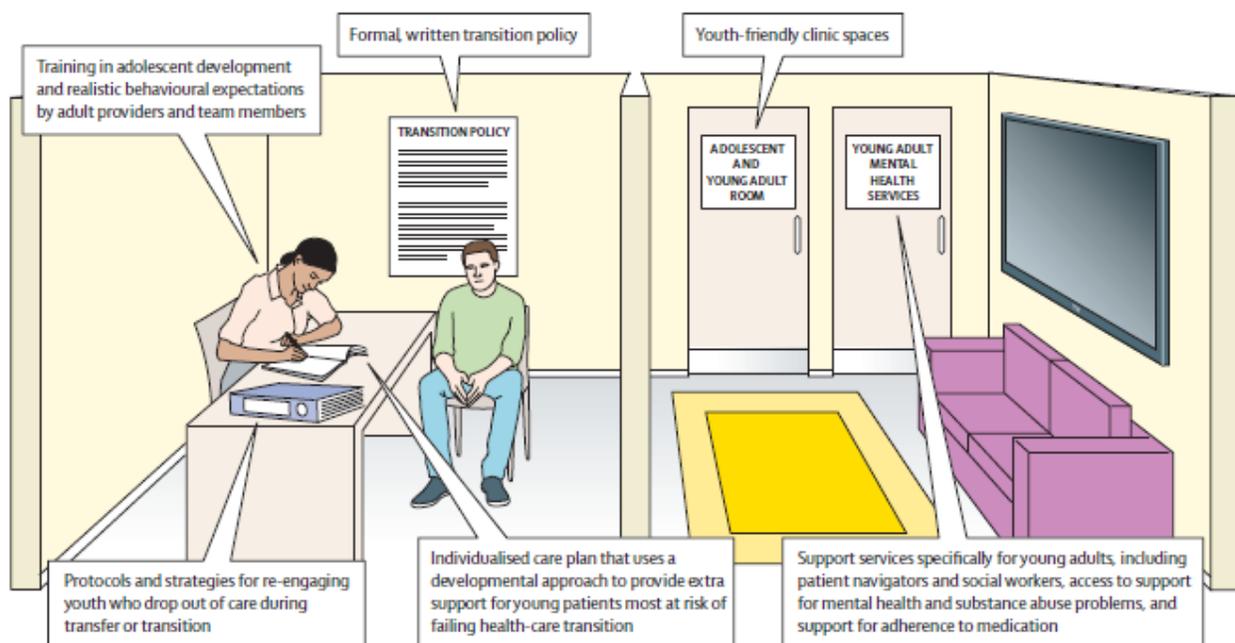
appropriate staff training.<sup>20</sup> Multiple studies suggest the need for clinic staff to take a multidisciplinary team approach and identify a staff member to specifically focus on the transition process,<sup>13,23</sup> with social workers often fulfilling this role.<sup>40</sup> Panel 1 presents a summary of the strategies for the preparation of health-care transition for youth to adult care.

<p><b>Panel 1.</b> Strategies for the preparation of transfer and connection of young people with HIV with adult care</p> <ul style="list-style-type: none"><li>• Written transition policy that includes designated clinic staff support, protocols for formal communication between paediatric and adult providers, and timelines and goals for the entire transition process, including post transfer</li><li>• Development of an individualised, written transition plan for each patient that addresses behavioural, emotional, and mental health problems, provides assistance with logistics (eg, navigation of health insurance and other social services), and includes a portable medical summary and emergency plan</li><li>• Training in adolescent development for paediatric providers and team members</li><li>• Training in health literacy, health-related self-care, and life skills for young people in paediatric clinic settings before transfer</li><li>• Strategies to facilitate physical connection of young people with the adult care clinic, including:<ul style="list-style-type: none"><li>○ Adolescent clinic staff attend the young person's first adult medical appointment</li><li>○ Adult provider does first visit at adolescent clinic</li><li>○ Adult clinic site visits to meet the new adult provider before transfer</li><li>○ Young person is consulted when adult clinic appointments are scheduled</li><li>○ Specific adolescent and young adult HIV clinic</li><li>○ Having a peer volunteer or staff member straddle both paediatric and adult clinics</li><li>○ Ongoing communication and support from the paediatric team during and after transfer, but discontinuation of provision of care by the paediatric team after transfer (to reinforce the primary role of the adult providers)</li></ul></li></ul>
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The preparation process for the health-care transition should begin in early adolescence (after full disclosure and explanation of infection status, in the case of young people who were perinatally infected with HIV), or at an appropriate time after the initial diagnosis.<sup>20,26,38</sup> Early initiation of these discussions allows for substantial preparation time before transfer of care<sup>39</sup> and patient training in independent living skills, including health-related self-care.<sup>26</sup> Multiple studies identify the need for consideration of developmental level, with formal readiness assessment tools to reveal areas of strength and weakness, which might help focus patient education target areas and individualised management and care plans throughout the health-care transition process.<sup>20,36,41</sup> Given the multiple psychosocial barriers to health-care transition identified in this population, particular attention should be paid to the identification and addressing of behavioural, emotional, and mental health problems.<sup>20</sup> The transition should occur with the involvement of the young person and caregiver, and should have realistic goals.<sup>20,32</sup> The AAP guidelines<sup>20</sup> recommend an individualised, written transition plan that includes a portable medical summary and an emergency care plan, and that should be discussed at least annually with all parties and modified as appropriate. The plan should also provide assistance with logistics throughout the transition process<sup>36</sup> and address system-level concerns, such as the navigation of health insurance and other social services.<sup>41</sup>

The transfer to adult care should ideally be initiated at an older, rather than younger, age (ie,  $\geq 18$  years old, but older than this is thought to be better);<sup>26</sup> however, contextual and system-level factors affect the process. Clinical protocol and infrastructure effect timing of care transfer, which probably varies by setting (eg, region and resources).<sup>8,11,12</sup> Multiple studies cite

communication<sup>23,36,40,41</sup> between paediatric and adult providers as being a factor crucial to health-care transition success, although little research provides detailed descriptions of how this might be implemented, and it is reported as frequently limited in practice.<sup>23</sup> Connecting young people to adult care is also seemingly crucial to health-care transition success, with multiple examples reported. Strategies include the adolescent clinic staff attending the young person's first adult medical appointment, the adult provider making the first visit to the adolescent clinic, the young person visiting the adult clinic site to meet the new adult provider before transfer, the adult provider working with the young person to schedule their adult clinic appointments, and the establishment of a specific adolescent HIV clinic and peer support system.<sup>20,33,41</sup> Ongoing communication and support from the paediatric team during and after transfer, perhaps by a nurse, social worker, or peer, might further improve the success of health-care transition.<sup>20,24,40</sup> One particularly innovative approach was proposed by Tulloch and colleagues,<sup>24</sup> who used peer volunteers as co-providers who straddled paediatric and adult clinics to assist in the transition process. This strategy is consistent with WHO recommendations<sup>19</sup> to shift tasks to less specialised workers to improve communication and young people's connection to adult clinics. Other strategies to improve the transition process seek to shift more of the responsibility for successful health-care transition to adult care systems, including the use of clinical policies and environments that make adult clinics more youth friendly, create more similar expectations between adolescent and adult clinics, and provide more personal and consistent care (figure 1).<sup>27,36</sup> Finally, although the paediatric and adolescent health-care team should encourage and support young people and be a resource for the adult health-care provider after transfer, the paediatric and adolescent team should withdraw from the provision of care to prevent confusion and reinforce the new and primary role of the adult provider.<sup>20</sup>



**Figure 1.** Key components of a post-transfer youth-friendly adult clinic

### Specific transition-related programmes

Several transition-related programmes specifically addressed the aforementioned barriers, demonstrated innovation, and aligned with overall health-care transition recommendations. The first group of programmes addressed transition preparation. White and colleagues<sup>42</sup> implemented a small intervention consisting of training an outreach coordinator in health literacy and health-care transition using the American Medical Association's tools on the Teach Back method,<sup>43</sup> which is designed to improve patient understanding of health-related topics. Subsequently, the outreach coordinator implemented a programme focusing on health literacy and medication management for young people preparing to transfer to adult care, which resulted in improved understanding of health literacy and significant increases in youth knowledge of medication and health-care navigation management before and after intervention ( $p \leq 0.001$ ), which are skills likely to be important for successful health-care transition. A small UK-based study<sup>44</sup> examined the effect of participation of young people who were perinatally infected with HIV in the Looking Forward Project, which was designed to provide a comprehensive approach to health-care transition preparation, including adherence to medication and healthy sexual relationships (eg, communication and condom use). The young people who participated reported that the events were helpful in developing improved attitudes toward adherence to medication and the future; however, there were no reports of changes in attitudes toward transition. Wiener and colleagues<sup>36</sup> also implemented a small formal health-care transition readiness programme, which included a structured readiness assessment tool; through a pre–post evaluation design, they found that participating caregivers and infected young adults showed increased health-care transition readiness and decreased anxiety. In this study, participants' primary concern was the low social support after-care transfer.

Other programmes had unique approaches to connecting paediatric and adolescent clinic sites to adult clinic sites. Hansudewchakul and colleagues<sup>45</sup> described post-transition retention in care for 67 young Thai people who transitioned to adult HIV care from a single clinic between 2008 and 2014. This clinic prepared the adolescents as a cohort (instead of individuals) through an offsite health-care transition programme that allowed young people to interact with adult providers before transfer of care. Following this, the young people had their initial adult clinic appointment on the same day, and paediatric and adolescent clinic staff and adult clinic staff conducted case conferences to support health-care transition efficiency and acceptability. The authors stated that young people who transition as a group have increased peer support, which might facilitate health outcomes (eg, adherence to medication and viral suppression). Additionally, they proposed that retention in care post transfer is supported by a programme that includes the paediatric and adolescent clinic and the adult clinic, and recognises individual young people's readiness. Nyabigambo and colleagues<sup>46</sup> evaluated a free HIV transition clinic in Uganda, by conducting interview questionnaires and medical record reviews of 15–24-year-old patients. Only 32% of patients were regular users (attended every monthly appointment in the preceding 6-month period), with the main determinants of regular use including a CD4 count of less than 250 cells per  $\mu\text{L}$ , being on antiretroviral therapy, receiving counselling services, female sex, and having a regular caregiver at home. Services most used were clinical examination, laboratory services, and counselling (all in clinic). The least-used services were home visits and peer support (both community based). The authors postulated that young people with improved health did not feel the need to use services regularly, and that stigma might lead men to use clinic services less frequently. The seemingly beneficial localisation of health services might be offset by the requirement for young people to have to transfer between multiple clinics (eg, transfer

from paediatric clinic, to transition clinic, and then to adult clinic), so further research might help to determine the efficacy of this innovative approach. Maturo and colleagues<sup>47</sup> described the development of a formal health-care transition policy and programme, called Movin' Out, which occurred after the clinic experienced high numbers of health-care transition failure. This programme moved the transfer of care from 21 to 25 years old, and included: the initiation of the formal transfer process when the patient was aged 23 years (discussions with patient at all clinical visits, and including education, support, and review of realistic expectations); the introduction of the patient to the adult provider at 24 years old, at which time he or she also received clinical care from the adult provider in the paediatric setting for a number of visits; and the accompaniment of the patient by the paediatric social worker or peer mentor to the adult clinic appointment with the same adult provider.

### **Evaluation of health-care transition**

The evaluation of health-care transition is hampered by the absence of a universal, clinically relevant definition of success.<sup>13</sup> Hussen and colleagues<sup>10</sup> suggested that patient attendance at a first visit, or even a second visit, does not necessarily suggest long-term engagement, because only 50–89% of young people with HIV who successfully transition were retained in adult care after 1 year, and even fewer (56%) after 2 years.<sup>17,48</sup> This poor retention suggests transfer is an important but insufficient piece of health-care transition—akin to care linkage after a positive HIV test result being crucial to, yet unique from, care engagement.<sup>49</sup> The development of a system such as a patient registry, like the one available in some European countries,<sup>28,29,50,51</sup> would allow young people with HIV to be clinically followed up, and the completion and outcome of the health-care transition process documented. Qualitative and quantitative methods have been proposed and used in several studies to assess health-care transition, including behavioural (eg, adult clinic attendance and medication adherence) and biological (eg, viral load and CD4 cell count) markers.<sup>52</sup> However, there are few data from which health-care transition success can be evaluated.<sup>23</sup> The Movin' Out programme<sup>53</sup> used medical record assessment after health-care transition (minimum of 1 year after transfer to the adult clinic) for 18 young people with HIV who transitioned successfully (72%).

Biological outcome measures have been assessed in only a few studies. One Dutch study<sup>51</sup> used an existing comprehensive national data registry and medical records abstraction to assess biological and social and treatment data at baseline, at transfer, and after health-care transition. Participants had a significantly increased risk of virological failure around and shortly after transfer of care ( $p = 0.03$ ), with presence or absence of virological failure during the paediatric period strongly predicting virological failure as an adult. Hussen and colleagues<sup>48</sup> did a retrospective study of patients who were predominantly behaviourally infected with HIV, who transitioned from paediatric to adult care within the same centre (all of whom were housed within the same building and shared the same electronic medical record system, but with no uniform transition protocol in place). Shorter linkage time and pre-transfer viral suppression predicted better outcomes post transfer, and retention fell significantly during the 2-year follow-up, prompting recommendations for intensive and longer duration of transition support (both before and after transfer) for high-risk patients. In a study<sup>54</sup> of mostly young Spanish people who were perinatally infected with HIV, immunological and virological control was poorer among young people transferred to adult care compared with those not yet transferred. However, young

people who were transferred were much more likely to have been diagnosed before the era of combination antiretroviral therapy, thus potentially biasing the results. Similarly, in the USA, a downward trend in CD4 cell counts in patients post transfer of care has been reported.<sup>36</sup>

Mortality can be an indicator of poor health-care transition. Studies in high-income countries have highlighted increased mortality rates after transition to adult care in young people who were perinatally infected with HIV,<sup>50,55</sup> with causes of death including AIDS complications and suicide. Common problems after health-care transition, such as disengagement from care (attributed to the different care cultures between paediatric and adult clinics) and inadequate adherence to medication have been documented in this population. Poor adherence in paediatric clinic, resistance of the infection to antiretroviral therapy, advanced disease status, and mental health diagnosis has also been noted in this group. These issues highlight the complex factors associated with HIV more broadly for young people. These issues are not unique to health-care transition but must be considered in attempts to provide care continuity through the transition process.

Following up young people after their health-care transition, especially those who move to a new medical system without shared medical records, contributes to evaluation challenges. To address some of these challenges, Tassiopoulos and colleagues<sup>56</sup> did a feasibility survey of Pediatric HIV/AIDS Cohort Study (PHACS) Adolescent Master Protocol participants. Based on these preliminary data, the ongoing PHACS is making accommodations for study participation entirely off-site, through chart abstraction, online data collection, and mailed-in specimen collection. Outcomes will include transfer to and retention in adult care, adherence to medication, and a comprehensive assessment of medical and psychosocial outcomes, including laboratory testing. Panel 2 presents recommendations for the evaluation of health-care transition.

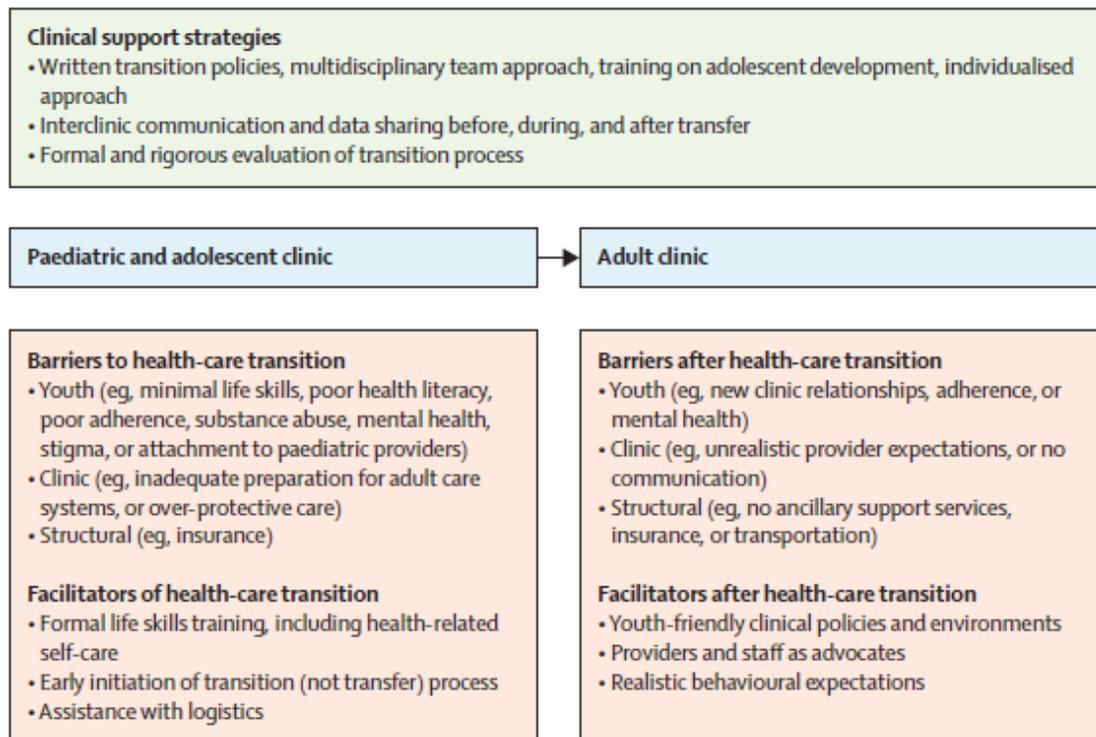
**Panel 2.** Recommendations for evaluation of health-care transition

- Development of a community (or national) patient registry, with input from both paediatric and adult providers
- Formalised interclinic data sharing agreements and protocols
- Medical records abstraction to assess behavioural markers (eg, adult clinic attendance, adherence to medication), biological markers (eg, viral load, CD4 cell count), and psychosocial outcomes, at baseline, during transfer, and at a distal post-transfer time point
- In-depth assessment of process for patients who disengage from care or have poor health outcomes (including mortality), or both, during transition

## Recommendations and next steps

Many individual and clinic-level barriers to health-care transition exist including poor health literacy, few life skills (including issues related to sexuality), insufficient health-care self-management skills (including adherence), stigma, drug use and mental health issues, attachment to paediatric providers and fear of transitioning to adult clinics.<sup>7,12,13,23,25,26,31–33,35</sup> For young people infected with HIV perinatally, the spectre of multidrug resistance complicates the already difficult health-care transition process.<sup>28–30</sup> However, addressing these barriers is possible through strategies including initiation of the health-care transition preparation process at an early age, with frequent reinforcement; addressing behavioural, emotional, and mental health problems in an ongoing fashion; providing education for all stakeholders; and anticipation of and proactive handling of challenges (figure 2). A multidisciplinary approach and designated staff to focus on

health-care transition preparation could aid the transition process.<sup>13,23,27</sup> Although development of formal health-care transition protocols and policies is part of existing health-care transition recommendations, more evidence is needed to support its actual implementation pre-transfer<sup>13,23</sup> and post transfer.



**Figure 2.** HIV-related health-care transition strategies

The connection of young people to adult providers, to bridge these separate worlds, is recommended,<sup>23,32,33,41,57</sup> although system-level barriers present significant obstacles to its implementation. Notable and innovative examples of successful connection strategies exist in both high-income and low-income settings.<sup>27,32–38,41,48</sup>

Post transfer there is a need to shift some responsibility for health-care transition success to adult clinics, to ensure that adult clinics support young adults in the same ways paediatric and adolescent settings do before transfer, and to develop individualised care plans that use a developmental approach. Health-care transition can have benefits including patients' opportunities for increased control, responsibility, and independence. Young people with HIV can be viewed as having specific strengths (eg, commitment to their health and well-being, and perseverance in the face of adversity) that can be positively exploited to increase the likelihood of successful health-care transition.<sup>39</sup> Understanding each individual's vulnerabilities and strengths can inform the implementation of individualised care plans, and can emphasise the need for extra support for young people with HIV most at risk of failing health-care transition.

Despite the absence of a universal definition of health-care transition success,<sup>13</sup> our Review suggests a combination of behavioural and biological indicators is ideal. The few studies that have evaluated health-care transition showed care disengagement, inadequate adherence to

medication and virological failure, and some mortality.<sup>36,50,51,53–55</sup> With current system-level barriers, the inability to access young adults who fail to transition is a challenge to the identification of the reasons for failure; however, the research (and common sense) suggests that the factors are the same as the individual and clinical barriers to pre-health-care transition.

Moving forward, a population-level database, such as that which is used in the UK and Ireland<sup>50</sup> and the Netherlands,<sup>51</sup> would probably help to address health-care transition barriers. With the shift to electronic medical records, this type of data should become easier to access and collate. Although the research might be somewhat stymied until these system-level barriers are overcome, communication and data sharing between the paediatric and adolescent clinics and adult clinics, despite these clinical-level and system-level barriers, will help to facilitate clinical collaboration, continuous care engagement, and research initiatives. Recognition of the important role of the adolescent and adult clinics in health-care transition is a key component to ensure active engagement, communication, and data sharing. Research should strive to include a registry of transferred patients, including those deemed to have been unsuccessful transfers; use qualitative and quantitative (including biological) markers; define a universal definition of success; and provide evidence-based assessments of health-care transition programmes.

To maximise the benefits of the recent biomedical innovations across the globe, we need to create systems that will facilitate the ability of young people with HIV to live full and healthy lives before, during, and after health-care transition.

#### **Search strategy and selection criteria**

We searched PubMed, PsycINFO, and Google Scholar databases using (“HIV” AND “transition” OR “health-care transition” OR “transfer of care” AND “adolescent” OR “youth”) for publications from the past 15 years (2002–17). We also searched the reference lists of articles identified by this strategy; publications that appeared relevant based on their titles were reviewed via the same method as those found through database searches. This process also allowed us to include studies published in 2017, but not yet indexed (eg, two health-care transition-specific journal issues were published in May, 2017). Inclusion criteria included articles in English, publication in a peer-reviewed journal, and original, empirical research. Literature reviews and policy statements were used to supplement the Review, and to add expert opinion in areas with little supporting research.

#### **Contributors**

DMS and AET equally contributed to manuscript development (eg, inclusion criteria decision, article review, synthesis, and writing).

#### **Declaration of interests**

We declare no competing interests.

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