



## Transition experiences of young adults with perinatal HIV in the Netherlands

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### ABSTRACT

**Introduction:** The process of transition from paediatric to adult care is a crucial step towards self-management of healthcare for young adults with chronic health conditions. In the Netherlands, the On Your Own Feet program offers an extensive framework for supporting optimal transition. In this national study, we aimed to evaluate the transition experiences of young adults with perinatal HIV who transferred from a paediatric to an adult HIV treatment centre.

**Methods:** Participants who transferred to adult care less than six years ago received questionnaires on transition experiences, the validated On Your Own Feet – Transition Experiences Scale (OYOF-TES), and demographics. Demographic and healthcare-related variables were collected from patients' medical files. We explored correlations between OYOF-TES scores and other variables.

**Results:** Of 44 participants, 29 responded (65.1 %). Their median age was 20 (IQR 19–23). Overall, high scores were found on the subscales 'Reception in adult care' (median 4.8, IQR 4.0–5.0), 'Alliance paediatric and adult care' (median 4.0, IQR 3.4–4.4), and 'Transfer readiness' (median 4.2, IQR 3.8–4.8). The lowest scores were found in the subscales 'Preparation for transfer' (median 3.3, IQR 2.7–4.0) and 'Youth involvement' (median 3.5, IQR 2.5–4.5). Higher scores on transition experiences were correlated with younger age and female sex, while lower scores were correlated with those of whom one or both biological parents died during childhood.

**Conclusion:** Transition experiences in our population were positive. Younger participants felt better prepared for the transfer, which indicates that transition is increasingly becoming a joint effort between young adults and healthcare professionals and that pathways accustomed to individual needs improve the transition experience for young adults with perinatal HIV.

### 1. Introduction

Around the age of 18 years, in the Netherlands, adolescents with perinatal HIV (PHIV) transfer from paediatric to adult care. This is seen as an imported step towards managing their own healthcare. Consequently, healthcare professionals (HCP) have become aware of the importance of paying dedicated attention to the transition process, defined as "the purposeful, planned process that addresses the medical, psychosocial, educational and vocational needs of adolescents and

young adults as they grow up learning to live with their lifelong health condition".<sup>1</sup> This transition can be challenging for chronically ill adolescents and young adults (AYA) due to social and developmental issues.<sup>2</sup> Zhou and colleagues described ineffective communication between HCP, lack of a planned transition and a negative attitude towards the transition identified as major barriers to transition in chronically ill AYA.<sup>3</sup>

Comparable results were found in a review on transition experiences of young adults living with perinatal HIV (PHIV-YA) that described

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feelings of loss after leaving the paediatric team.<sup>4</sup> International studies reported on problems regarding autonomy, risk of non-adherence, loss to follow-up and mortality after transition.<sup>5–8</sup> For PHIV-YA, positive results were observed in structured transition programs that focus on education, competence and autonomy as well as in programs that facilitate contact between adult HCP and young adults in the pre-transfer period.<sup>4</sup> Further, successful transition programs for PHIV-YA share specific characteristics, including a joint program with room for their individual needs and involvement of adult HCP at an early stage.<sup>7–9</sup> For example, in the Netherlands, the On Your Own Feet program offers an extensive framework for both HCP as well as chronically ill adolescents in supporting optimal transition.<sup>10</sup> Recently, a national quality standard guideline containing essential characteristics necessary for successful transition was developed. Essential conditions to guide a smooth transition process according to this guideline are: a transition coordinator, an individualized transition plan focusing on fostering independence and autonomy, collaboration with adult HCP during paediatric care, the possibility to meet future HCP before the actual transfer and the possibility of an extended consultation with new HCP.<sup>11</sup>

In 2016, we performed a study in the Netherlands on virological outcomes of AYA with perinatal HIV before and after transfer to adult care. They were vulnerable to develop an unsuppressed HIV viral load (HIV-VL) during the transition period. An increased risk of detectable HIV VL was observed in those with a lower educational level, those who lacked autonomy regarding medication adherence at transition and those with insufficient knowledge regarding HIV. A high rate of 13.8 % lost to follow-up after transition was reported.<sup>12</sup> An evaluation of HIV-VL suppression in those diagnosed with HIV before the age of 18 years, showed low suppression rates of only 83 % in those aged 18–24.<sup>13</sup> This is in sharp contrast to the average HIV-VL suppression rate of 98 % and 96 % in children and older adults living with HIV in the Netherlands respectively.<sup>14</sup> Although several international studies assessed post-transfer outcomes of PHIV-YA, few included the evaluation of their own transition process despite the acknowledgment that transition and other healthcare programs should be developed with the input of youth themselves.<sup>15,16</sup>

This study aims to evaluate transition experiences of young adults with perinatal HIV who had transferred from Dutch paediatric HIV treatment centres to an adult HIV treatment centre to identify gaps in transitional care. Additionally, we explored associations between transition experiences and demographic variables.

## 2. Methods

This study is part of a larger multicentre cross-sectional study on Health-Related Quality of Life (HRQOL), transition experiences and adherence of PHIV-YA in the Netherlands.

### 2.1. Participants, sampling and procedures

For the evaluation of transition experiences, all patients with PHIV who transferred from paediatric to adult care < 6 years ago and had at least one visit in adult care were eligible for inclusion. We choose only to include patients who transferred < 6 years ago for reasons of recall bias. An exclusion criterion was not being sufficiently proficient to read or write in the Dutch language. People with a learning disability who were not able to read or write were also excluded.

Transition programs of all four paediatric HIV treatment centres which participants transferred from, meet at least the afore mentioned essential conditions as formulated by the national quality standard guideline.<sup>11</sup>

Eligible individuals were informed about the study and asked to participate by their HIV specialist nurse during their visit at the outpatient clinic. Those who consented to participate received an email invitation with a link to an electronic informed consent form (ICF). After signing the ICF, the questionnaires became available. Participants gave

permission for collection of additional health and demographic characteristics from their patient file. The questionnaires were available through CASTOR.<sup>17</sup>

### 2.2. Outcome measures

For this study, we used the validated On Your Own Feet – Transition Experiences Scale (OYOF-TES) that includes subscales on different transition experiences.<sup>18</sup> The questionnaire includes 20 items in 5 subscales. Subscale 1: Reception in adult care (4 items,  $\alpha=.861$ ), Subscale 2: Alliance between pediatric and adult care (5 items,  $\alpha=.832$ ), Subscale 3: Preparation for the transfer (3 items,  $\alpha=.637$ ), Subscale 4: Readiness to transfer (6 items,  $\alpha=.796$ ), Subscale 5: Youth involvement (2 items,  $\alpha=.671$ ). Items are rated on a 5-point Likert scale (range 1 (strongly disagree)–5 (strongly agree)). The total OYOF-TES score was calculated by summing the scores of the individual items (theoretical range 20–100). Additionally, participants were asked to rate their overall satisfaction with the transition process and their trust in paediatric and adult HCP on a visual analogue scale (VAS) ranging from 1 to 10, where 1 represents the lowest and 10 the highest satisfaction (questionnaire available as [supplemental material](#)). Finally, the participants had the possibility to leave recommendations for improvement of the transition process.

### 2.3. Demographic variables

The following health and demographic variables were collected: country and year of birth, sex, current educational level, transfer within same or to different treatment centre, age at transfer, time of transfer (< 2, 2–4, or 4–6 years ago), history of contact with youth social services, death of one or both biological parents, period of lost to follow-up > 12 months, last HIV-VL in paediatric care and last HIV-VL in adult care. HIV-VL suppression was defined by an HIV-RNA measurement < 50 copies/ml.

Limited data was collected for non-participants; sex, HIV-VL suppression at last visit, time of transfer, period of lost to follow-up > 12 months.

The study was assessed by the committee for medical ethics of the Amsterdam UMC and was not subject to the Medical Research Involving Human Subjects Act (WMO).

### 2.4. Statistical analyses

Sample characteristics were described by median (IQR) and number and percentages where appropriate. To compare characteristics between responders, non-responders and non-participants we used the Mann-Whitney *U* test for non-normally distributed continuous variables and the Chi-Square or Fisher exact test for proportions. As our results from multiple subscales of the OYOF-TES questionnaire were non-normally distributed, we reported the median (IQR) of the sub-scores. Mean (min-max) scores were reported for the VAS scores on satisfaction and trust.

Our data did not meet the assumptions of a linear regression. Correlations between OYOF-TES sub-scores with a normal distribution and variance and binary variables were explored using Point Biserial tests (*r*). Correlations between OYOF-TES scores with a non-normal distribution and/or variance and binary variables were explored using Mann-Whitney *U* tests. The correlation coefficient for the Mann-Whitney *U* test was calculated using the following equation:  $r = Z / \text{Sqrt } N$ .<sup>19</sup>

Spearman Rho tests ( $\rho$ ) were used to assess correlations between OYOF-TES scores (with a non-normal distribution and/or variance) and continuous or ordinal variables.

Variables of potential influence on transition experiences were sex, age, education level, parental loss, youth social services, transfer within same or different treatment centre, being lost to follow up > 12 months, and country of birth. We considered correlations with a P-value < 0.05

and a correlation coefficient > 0.4 (moderate to high) clinically relevant.<sup>20</sup>

Statistics were performed using IBM SPSS Statistics for Windows, Version 28.0. Armonk, NY: IBM Corp.

### 3. Results

Between November 2020 and April 2022, Seventy-one persons were identified and eligible for inclusion in the study. Of those, 26 were not included as they refused to participate (N = 19), could not be reached (N = 6), or died (N = 1). Forty-five agreed to participate in the study. One person accidentally did not receive the OYOF-TES questionnaire. Of the remaining 44 persons, 29 responded (66 %) (Fig. 1).

#### 3.1. Participant characteristics

Apart from sex, known characteristics of responders, non-responders and non-participants did not differ significantly (supplemental table 1 and 2). Women were less likely to participate or to respond than men. Twenty-one (72.4 %) of the responders were male (Table 1). The median age at transfer was 18.0 years and for 12 (41.4 %) the transfer occurred less than two years ago. At the time of transfer to adult care, six (20.7 %), had one or both parents deceased. Apart from one respondent, all participants had an undetectable HIV-VL at transfer as well as at the last visit prior to the study date (Table 1). For the majority (69.0 %), the highest completed level of education was medium.<sup>21</sup>

#### 3.2. Transition experiences

The total median score on the OYOF-TES was 82.0. Overall high scores were found on the subscales 'reception in adult care,' 'alliance paediatric and adult care,' and 'transfer readiness'. The lowest scores were found in the subscales 'preparation for transfer' and 'youth involvement' (Table 2). Two topics contributed the most to the low scores on preparation; thirteen participants (45 %) stated that they had not met their future HCP in advance (score 1 or 2), of whom six had transferred within the same center. Further, six participants felt they were not involved in the preparation of a transition plan (score 1 or 2) (results not shown). The level of youth involvement was assessed by having a say in the timing of the transfer and where to transfer to.

Overall satisfaction with the transition process was 8.0. Mean trust in paediatric care was 9.1, and the trust in adult care was 8.6 (Table 2 and Fig. 2).

Recalculation of median (IQR) and exploration of the data distribution excluding one outlying participant did not affect the results noteworthy (supplemental table 3).

**Table 1**  
Demographic and clinical data of research population.

Demographic and clinical characteristics		N	(%)
Sex	Male	21	(72)
	Female	8	(27.6)
Country of birth*	The Netherlands	13	(44.8)
	Other	16	(55.2)
Age at transfer in years (IQR)		18	(18–18)
Age at study date in years (IQR)		20	(19–23)
Educational level*	Lower	8	(27.6)
	Medium	20	(69.0)
	High	1	(3.4)
Time transfer	< 2 years	12	(41.4)
	2–4 years	7	(24.1)
	4–6 years	10	(34.5)
Transfer within same treatment centre	Yes	23	(79.3)
	No	6	(20.7)
HIV-VL undetectable at transfer	Yes	28	(96.6)
	No	1	(3.4)
HIV-VL undetectable at last visit	Yes	28	(96.6)
	No	1	(3.4)
Loss to follow up > 12 months	Yes	3	(10.3)
	No	26	(89.7)
One or both parents deceased pre-transfer	Yes	6	(20.7)
	No	23	(79.3)
Involvement of youth social services pre-transfer	Yes	12	(41.4)
	No	17	(58.6)

Abbreviation: VL= Viral Load.

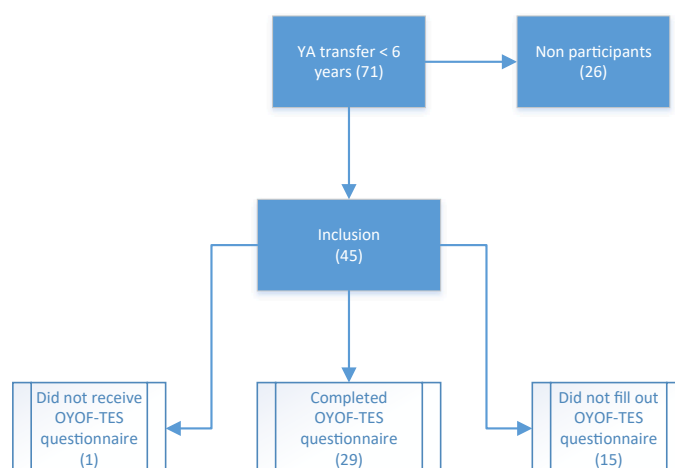
Data are reported as number (%) or median (IQR).

\* Self-reported by participants.

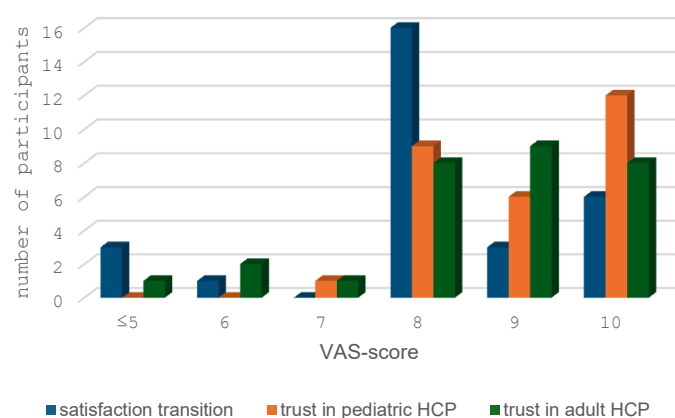
**Table 2**  
Transition experiences of young adults with perinatal HIV (N = 29).

OYOF-TES scores (20–100)	Median	IQR
Total	82.0	(71.5–90.0)
<i>Likert scores (1–5)</i>		
Reception in adult care	4.8	(4.0–5.0)
Alliance paediatric and adult care	4.0	(3.4–4.4)
Preparation for transfer	3.3	(2.7–4.0)
Transfer readiness	4.2	(3.8–4.8)
Youth involvement	3.5	(2.5–4.5)
<i>VAS scores (1–10)</i>		
Satisfaction process	8.0	(3–10)
Trust in paediatric care	9.1	(7–10)
Trust in adult care	8.6	(5–10)

Abbreviation: VAS= Visual Analogue Scale



**Fig. 1.** Flowchart inclusion.



**Fig. 2.** Satisfaction with the transition process, Trust in paediatric care and Trust in adult care on a visual analogue scale (1–10), N = 29.

### 3.3. Correlations with transition experiences

Higher scores on the total OYOF-TES subscale and the subscale 'preparation for transfer' were correlated with younger age ( $\rho = -0.42$ ,  $P = .024$ ,  $\rho = -0.53$ ,  $P = .003$  respectively). Further, higher scores on 'involvement' were correlated with female participants ( $r = 0.55$ ,  $P = .002$ ).

Lower scores on the total OYOF-TES subscale ( $r = -0.59$ ,  $P < .001$ ), 'reception in adult care' ( $r = -0.64$ ,  $P < .001$ ,  $z = -3.433$ ), 'alliance between paediatric and adult care' ( $r = -0.45$ ,  $P = .014$ ,  $z = -2.406$ ) and 'readiness for transfer' ( $r = -0.55$ ,  $P = .002$ ,  $z = -2.978$ ) were correlated with those who lost one or both biological parent(s) during paediatric care.

Higher scores on trust in paediatric care were correlated with higher scores on trust in current HCP ( $\rho = 0.55$ ,  $P = .002$ ). Higher scores on trust in current HCP were correlated with higher scores on reception in care and satisfaction with the total process ( $\rho = 0.56$ ,  $P = .002$  and  $\rho = 0.79$ ,  $P < .001$  respectively). Higher scores on satisfaction with the total process were correlated with the total OYOF-TES score ( $\rho = .64$ ,  $P < .001$ ) and subscales 'reception in adult care', 'alliance paediatric and adult care' and 'transfer readiness' ( $\rho = .55$ ,  $P = .002$ ,  $\rho = .62$ ,  $P < .001$ , and  $\rho = .65$ ,  $P < .001$  respectively).

No correlations were found between OYOF-TES outcomes and education level, youth social services, transfer within same or different treatment centre, being loss to follow up > 12 months, or country of birth.

### 3.4. Recommendations from participants

We asked the participants for recommendations to improve the transition process. Twenty (69 %), stated they were happy with the way things went. Four would have liked more (age-appropriate/ written) information about HIV or transition, and two needed more time for the transition process. One mentioned difficulty in contacting the adult department by telephone, and one would have liked to meet different HCP in advance. One participant expressed the wish for a specialised youth clinic that could function as an intermediate step and facilitate peer contact.

## 4. Discussion

We reported on the transition experiences of PHIV-YA in the Netherlands who transferred to adult care in six years prior to this study. An unexpected outcome was the almost similar high score on trust for both paediatric and adult health care providers. Indeed, multiple studies describe the lack of trust in new adult HCP and feelings of loss experienced when leaving their paediatric HCPs, who were present during

defining moments in their childhood life. This phenomenon is considered an important barrier for a successful transfer.<sup>4,22,23</sup>

There are several explanations for the high scores on trust in our population. First, the fact that HIV is still a condition surrounded by stigma and secrecy.<sup>24,25</sup> A recent report from the UK National Aids Trust reveals expression of negative attitudes and stigmatizing perceptions towards people with HIV, and low public knowledge about what it means to live with HIV.<sup>26</sup> It is not exceptional that HCP are the only persons that people with HIV disclose to, and relations between patient and HCP are often strongly developed.<sup>27</sup> It is therefore likely that patients quickly develop a bond of trust with their new HCP once in adult care. A survey on patients' perspectives of outpatient HIV care in the Netherlands, showed that highly preferred and received aspects of HIV care were, among other things, demonstrating empathy and active engagement while respecting the confidentiality of the individual's HIV status, and dedicating ample time for meaningful conversations with the patient.<sup>28</sup> Further, HCP describe the large responsibility and commitment towards vulnerable patients who experience isolation and fear of disclosure. Trust, related to the social implications of HIV, was named as an important factor contributing to a close relationship.<sup>27</sup> This suggests that trust may be an essential aspect of treatment compared to other diagnoses.

We did not find a correlation between age and trust scores, and high trust scores were found amongst the whole age range. However, a high trust score in the older aged, may be related to the fact that they have known their current HCP for a longer period of time, while in those younger aged, feelings of being better prepared in the transition process could play a role in the experienced trust post-transfer.

In addition, HIV care in the Netherlands is well organised, and assigned to 24 designated HIV treatment centres, of which four have a co-located paediatric treatment centre. The vast majority of our study population therefore transferred within the same centre, making them already familiar with a number of organisational aspects of care within the organisation.

Despite the high scores on satisfaction, relatively low scores were found in the subscales preparation and involvement. Meeting your future health care providers in advance is one of the key recommendations for a successful transition,<sup>9,11</sup> but was not experienced by all participants even for those transferring within the same centre. In case of transfer to an adult HIV treatment centre on a different location, it could be possible to arrange a(n) (online) meeting. Different strategies to facilitate the connection with adult HCP are described (e.g. attendance of medical appointment at adult clinic with paediatric staff or vice versa, lateralisation of clinical visits or the use of peer volunteers).<sup>9</sup> In the last decade, the number of Dutch guidelines and quality standards in healthcare addressing transition from paediatric to adult has increased.<sup>29</sup> The correlation between younger age and feeling better prepared for transition in our population could reflect an increased attention for individualised transition programs in paediatric HIV treatment centres.

An explanation for low scores on involvement is that, in the Dutch healthcare system, patients must transfer to adult care at the age of 18. Therefore, their influence on the timing of transfer is limited. This issue could be resolved by establishing a youth (friendly) post-transfer clinic where care is provided by a dedicated team.<sup>30,31</sup> Or, if feasible, by coordinating the transfer time in collaboration with the young adult, as recommended by some participants and the Dutch quality standard.<sup>11</sup> We also found a correlation between female participants and higher scores on involvement in the transition process. Previous research on transition of youth with chronic illnesses, including HIV, found higher scores on self-advocacy in females.<sup>32</sup> Further, in a large U.S. study in youth with special health care needs, females were more likely to be well prepared for transfer.<sup>33</sup> On the contrary, Varty and colleagues found multiple studies that did not demonstrate the relation between sex and transition readiness.<sup>34</sup>

Finally, lower scores on the total OYOF-TES and on subscales



'reception in care' and 'readiness for transfer' correlated with having lost one or both parents. Although they were not lost to follow-up care, their transition process was probably more complex. Childhood trauma such as the loss of one or both parents is frequently present in this population,<sup>4,7</sup> and could be challenging during the process of transition due to the effect on mental health and subsequently on adolescent development.<sup>7</sup>

Although three participants were temporary lost to care, our study participants represent a specific sample of the Dutch PHIV-YA population, namely those who transferred in the last six years, remained in care after transition, and had a suppressed HIV-VL. Post-transitional retention in care, HIV viral suppression and strong bonds with new HCP based on trust were previously reported as indicators for successful transition.<sup>35,36</sup> We have to keep in mind that some PHIV-YA become lost to follow up after transfer to adult care. Youth-centred care preferably developed in cooperation with PHIV-YA adults themselves may contribute to better retention in care.<sup>31,37–39</sup> The last report of the national HIV registry (SHM) reports on 169 PHIV-YA who transferred to adult care of whom 11 were lost to follow-up. Seven died at a median age of 26.8 (IQR 24–30), of whom four died from AIDS. HIV-VL suppression rates in those who transferred to adult care and who were still in care, were 84 %<sup>40</sup> Therefore, we cannot extrapolate our outcomes to the whole population of PHIV-YA in the Netherlands.

#### 4.1. Strengths and limitations

Our results represent the transition experiences of a substantial part of the total population of people with HIV that went through the transition process in the past six years in the Netherlands. Responders, non-responders and non-participants did not differ significantly on key characteristics. Generalizability outside the Netherlands is probably limited.

The sample size of the study population was relatively small. Further, our data was analysed using correlation and therefore our outcomes does not give information on causation.

#### 4.2. Recommendations

Using the essential conditions as described by the national guidelines is essential in designing a centre specific transition protocol. Recommendations from the guidelines are: a transition coordinator, an individualized transition plan focusing on fostering independence and autonomy, collaboration with adult HCP during paediatric care, the possibility to meet future HCP before the actual transfer and the possibility of an extended consultation with new HCP. Pathways accustomed to individual needs can further improve the transition experience. Increased and meaningful involvement of PHIV-YA in developing youth-centred care pre-and post-transfer should be encouraged, as this may contribute to keeping PHIV-YA in care after the transfer. Finally, it would be beneficial to gain a deeper understanding of the experiences and perspectives of PHIV-YA following their transition to adult care. We suggest that this should be investigated through qualitative research methods, such as in-depth interviews. This approach may yield valuable insights into their motivations and experiences.

#### 4.3. Conclusion

Transition experiences in our population were positive. Younger participants felt better prepared for the transfer, which indicates that transition is increasingly becoming a joint effort between young adults and healthcare professionals and that pathways accustomed to individual needs improve the transition experience for young adults with perinatal HIV.

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## CRediT authorship contribution statement

**Sattoe Jane:** Writing – review & editing, Validation, Methodology, Conceptualization. **van der Knaap Linda:** Writing – review & editing, Visualization, Validation, Project administration, Methodology, Data curation, Conceptualization. **Weijsenfeld Annouschka:** Writing – original draft, Visualization, Project administration, Methodology, Formal analysis, Data curation, Conceptualization. **Pajkrt Dasja:** Writing – review & editing, Validation, Supervision, Methodology, Conceptualization. **Nellen Jeannine:** Writing – review & editing, Methodology, Conceptualization. **Vermont Clementien:** Writing – review & editing, Methodology, Conceptualization. **van Staa AnneLoes:** Writing – review & editing, Methodology, Conceptualization.

## Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Annouschka Weijsenfeld, Linda van der Knaap, Jane Sattoe, AnneLoes van Staa, Clementien Vermont, Jeannine F.J.B. Nellen, Dasja Pajkrt. J.N. has received fees, paid to the institution, for educational activities from BMS, Gilead, ViiV Healthcare and GSK. All other authors report no conflicts of interest.

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## Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at [doi:10.1016/j.hctj.2025.100098](https://doi.org/10.1016/j.hctj.2025.100098).

## Data availability

Data will be made available on request.

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