

Scaling up peer-led community-based differentiated support for adolescents living with HIV: keeping the needs of youth peer supporters in mind to sustain success

Sarah Bernays^{1,2§}, Maureen Tshuma³, Nicola Willis⁴, Kudzanayi Mvududu³, Adrian Chikeya³, Juliet Mufuka³, Frances Cowan^{3,5} and Webster Mavhu^{3,5}

1 Global Health and Development, London School of Hygiene and Tropical Medicine, United Kingdom

2 School of Public Health, University of Sydney, Australia

3 Centre for Sexual Health and HIV/AIDS Research (CeSHHAR), Harare, Zimbabwe

4 Africaid, Harare, Zimbabwe

5 Department of International Public Health, Liverpool School of Tropical Medicine, United Kingdom

§ Corresponding author: Sarah Bernays

Edward Ford Building,
Fisher Rd,
Camperdown,
2006,
Australia

Phone number

Phone: +61 02 9036 7137

Email: sarah.bernays@sydney.edu.au and sarah.bernays@lshtm.ac.uk

E-mail addresses of authors:

SB: sarah.bernays@sydney.edu.au

MT: maureen.tshuma@gmail.com

NW: nicola@zvandiri.org

KM: smvududu@gmail.com

AC: adrianchikeya@gmail.com

JM: jmufuka10@gmail.com

FC: Frances.Cowan@lstmed.ac.uk

WM: w mavhu@gmail.com

Keywords : HIV, Adolescents, differentiated service delivery, peer support, community based, health systems

1 **Abstract**

2 Introduction: Low rates of viral suppression among adolescents living with HIV (ALHIV) indicate
3 that more effective support is urgently required at scale. The provision of peer support has
4 generated considerable enthusiasm because it has the potential to ameliorate the complex social
5 and relational challenges which underpin suboptimal adherence. Little is known about the impact
6 on young peer supporters themselves, which is the focus of this paper.

7 Methods: We present qualitative findings from the Zvandiri trial investigating the impact of a peer
8 support intervention on the viral load for beneficiaries (ALHIV, aged 13-19 years) in Zimbabwe.
9 The Zvandiri peer supporters aged 18-24 years, known as community adolescent treatment
10 supporters (CATS), are themselves living with HIV. Individual in-depth interviews were
11 conducted in late 2018 with 17 CATS exploring their experiences of delivering peer support and
12 their own support needs. Interviews were analysed iteratively using thematic analysis.

13
14 Results: The CATS reported that being peer supporters improved their own adherence behaviour
15 and contributed to an improved sense of self-worth. The social connections between the CATS
16 were a source of comfort and enabled them to develop skills to manage the challenging aspects of
17 their work.

18 Two substantial challenges were identified. Firstly, their work may reveal their HIV status.
19 Secondly, managing the emotional labour of this caring work; given how commonly the
20 complexity of the beneficiaries' needs mirrored the circumstances of their own difficult lives. Both
21 challenges were ameliorated by the support the CATS provided to each other and ongoing
22 supervision from the adult mentor.

23 There was variation in whether they felt their roles were appropriately valued through the
24 remuneration they received and within the health system. There was a consensus that their
25 experience meant that they would graduate from being a CATS with transferable skills that could
26 enhance their employability.

27 Conclusions: Their experiences illustrate the advantages and opportunities of being a CATS. To
28 minimise potential harms it is vital to ensure that they feel valued in their role, which can be

29 demonstrated by the provision of appropriate remuneration, recognition and respect, and that there
30 is continued investment in ongoing support through ongoing training and mentoring.

31 Word count: 350 words

32

33

DRAFT

34 **Introduction**

35 A tenacious driver of the higher rates of morbidity and mortality amongst adolescents living with
36 HIV (ALHIV) is suboptimal adherence to HIV treatment (1-4) Although the global target is to get
37 95% of those on treatment to be virally suppressed, combined data from East and Southern African
38 countries show that only 45% of adolescent girls living with HIV are virologically suppressed
39 (versus the goal of 86% under UNAIDS 95-95-95 targets for 2030) (5). This makes them more
40 vulnerable to treatment failure.

41
42 The provision of one-to-one peer support at scale has generated considerable enthusiasm because
43 it has the potential to ameliorate the complex social and relational challenges that are known to
44 affect adolescents' capability to engage in sustained adherence to HIV treatment (6-9). Peer
45 support is predicated on the basis that sharing knowledge and experience can provide emotional,
46 social and practical support (10-12). The similarity in experiences between the adolescent
47 beneficiaries and young peer supporters provide the opportunity for effective support. However,
48 being responsible for helping others experiencing the same problems may also exacerbate the
49 vulnerability of peer supporters.

50
51 Community-based peer support models have not proven to be consistently effective for children,
52 adolescents, and young people living with HIV(13). However, the Zvandiri trial, a cluster-
53 randomised trial which evaluated a theoretically-informed peer-led differentiated service delivery
54 intervention on HIV in Zimbabwe (14, 15), found 42% lower prevalence of virological failure or
55 death at 96 weeks among participants receiving the Zvandiri intervention than among those solely
56 receiving standard HIV care at rural clinics (16, 17). A detailed explanation of the intervention and
57 trial is outlined in related publications (18, 19). The findings from this trial add to the growing
58 body of evidence to support the scale-up of differentiated service delivery incorporating peer-
59 supporters to support adolescents' ART (anti-retroviral treatment) adherence and retention in care.
60 With an emerging investment in peer support programmes (20), there is a clear need to address the
61 knowledge gap that exists about the impact, value and risks of such interventions for the young
62 peer supporters themselves. In this paper we draw on qualitative research conducted with the peer-
63 supporters, known as Community Adolescent Treatment Supporters (CATS), in the Zvandiri trial
64 to explore their experiences of delivering peer support and to identify their own support needs.

65

66

67 **Methods**

68 **Study setting**

69 The current HIV prevalence among those aged 15-49 years old in Zimbabwe is 12.7% (24). The
70 trial was conducted with public clinics in two rural districts (Bindura and Shamva) in Mashonaland
71 Central province, Zimbabwe. The trial communities are characterised by high youth
72 unemployment, a struggling economy, persistent stigma around HIV, faith healing and a stretched
73 healthcare system with weak mental health provision.

74

75 **Data collection**

76 We conducted individual in-depth interviews between November- December 2018 with 17 of the
77 18 CATS, aged 19-24 years, who were actively working in the intervention sites (n=6 female,
78 n=11 male). The one active CATS not interviewed was temporarily away from the district during
79 the fieldwork period. There were 29 CATS who had been trained but were no longer active in the
80 trial by the time of data collection. After the initial recruitment, a large proportion left in the early
81 stages of the trial as they found the work did not suit them. We outline, using the information
82 available, the reasons that the 29 CATS were no longer working in Table 1.

83

Reason for Attrition	Number of CATS
Relocated	5
Employment	2
Married	3
Pregnancy	1
Lack of engagement (competing priorities, limited time to commit to CATS' duties, inadequate commitment)	18
Total	29

84

85 Table 1: Reasons CATS had left the trial intervention

86

87 We explored how the CATS' considered that the intervention affected their lives, their experiences
88 of being involved and their support needs. Individual interviews were conducted by one male and
89 two female Zimbabwean researchers (AC, MT and KM) in private spaces in the public clinics and
90 lasted approximately an hour. All the interviews were conducted in Shona, the participants'
91 language.

92

93 With the participants' permission, the interviews were audio recorded. The interviewers listening
94 back to the recordings wrote up the interviews into detailed interview scripts (25, 26). Iterative
95 data collection and analysis was conducted, in which the team discussed each interview in weekly
96 analytical meetings. This informed the refinement of the topic guides. Our theoretical approach
97 was informed by social constructionism with particular attention paid to relational agency, which
98 is attentive to the restricted agency young people may have and how this is framed by their
99 relationships, but is also fluid and so may be dynamic and transformative (27).

100

101 A thematic analytical approach was adopted, which involved SB, MT, AC and KM coding the
102 scripts to develop a coding framework. Excel was used to organise the coding. Themes were
103 developed through data-led analytical memos. Selected extracts were transcribed verbatim and
104 translated for equivalent meaning in English. SB and WM provided analytical training to MT, AC
105 and KM throughout 2018-2019.

106

107 Ethical approval was granted by the Medical Research Council of Zimbabwe (#2032) and the
108 ethics committees of the London School of Hygiene & Tropical Medicine (London, UK; #11042)
109 and University College London (London, UK; #2358/004). Written informed consent was
110 collected prior to participation. Pseudonyms are used for all participants.

111

112 **Results**

113 **Feeling valuable: helping them, helps me**

114 Changes in adherence behaviour

115 In general, the CATS reported that working as a CATS had brought them considerable opportunity
116 and advantage, including improving their capacity to manage their HIV status. Although the remit
117 of the CATS was to support other ALHIV, many of them themselves had been struggling with
118 adhering to treatment: *“Prior to being a CATS, I would take them anytime (ARVs). If I wasn’t*
119 *reminded at times I would skip.”* (Progress, female, aged 20). Many reported that the training and
120 education which they received through the programme had improved their treatment literacy and
121 galvanised their commitment to compliance: *“I only got to know about all of this when I became*
122 *a CATS.”* (Rudo, female, aged 24).

123 All of the CATS who had previously struggled with adherence described how the reminder
124 structures they put in place for beneficiaries helped them too: *“I send adolescents reminders, so*
125 *there is no way that I won’t also take my medication at seven o’clock.”* (Geoffrey, male, aged 20);
126 *“when you see the impact of those that are not taking their medication on time and think about*
127 *yourself who is taking on time you realise there is a difference.”* (Taurai, male, aged 21). These
128 insights encouraged them to comply.

129 *“When I became a CATS and seeing others this gave me strength that even if I wanted to*
130 *default I should know it’s my own life being affected. From then, it has helped me to know*
131 *that medication should be taken correctly and on time.”* (Rudo, female, aged 24)

132 Overall the CATS considered their work fulfilling and were proud that the support they offered
133 had a positive impact. The majority considered that their proximity of their own experiences to
134 those of the beneficiaries’ enabled them to make a unique contribution, which underpinned why
135 they were so effective:

136 *“This is work that I enjoy as I work with my age-mates. I am able to relate to them well...*
137 *it may be difficult for the adult to understand them.”* (Lisa, female, aged 20).

138 Many of them reported that they had developed an increased sense of self-worth, which motivated
139 their investment in their own health. Farai explained the mutual benefit of the peer support that he
140 offered:

141 *“I find myself really happy because of the interaction with the adolescents, giving them support*
142 *and sharing with them what I have gone through. I am able to motivate them. It is really helping*

143 *me too because we share problems with the adolescent on what they are going through and*
144 *what I am going through. We help each other.” (Male, aged 22)*

145 Gaining comfort and strength from the CATS’ community

146 For most CATS their experience of living with HIV prior to engaging with the Zvandiri
147 programme had been defined by solitude. They described having been burdened by anxiety about
148 the anticipated loneliness and limited prospects that would characterise their futures. The CATS
149 had regular and various opportunities to interact with each other through the coordination meetings
150 and reported deriving significant benefits from engaging in a community of young people affected
151 by HIV. Feeling accepted and connected transformed their expectations of what it meant to live
152 with HIV: *“I realised that I was letting myself down. This programme gave me confidence to love*
153 *myself.” (Lazarus, male, aged 20).*

154 Sharing their experiences was also instrumental in developing their capacity to deliver their duties
155 as CATS. They consistently emphasized the value of being able to collectively develop support
156 strategies and resolve problems in the regular discussions they had with the other CATS and
157 mentors. *“We help each other and sharpen each other intellectually with ideas” (Tapiwa, male,*
158 *aged 20). Progress reflected a widely held opinion: “I have learnt a lot including that if you face*
159 *any challenge don’t make it your own but share it with others so that you can help each other solve*
160 *it.” (Female, aged 20).*

161

162 **Dilemmas in being ‘seen’ as a CATS**

163 The Zvandiri intervention was new to the districts in the trial. So the CATS were a new cohort and
164 had no prior experience of the intervention. The youngest CATS to be recruited at the start of the
165 trial were 18 years old. Many were still in the process of accepting their HIV status. Despite the
166 internal progress made around self-acceptance, they were mindful of prevailing stigmatising
167 attitudes that persisted within their local communities. Consequently, the majority of CATS
168 concealed the nature of their work from others in the community. As Lazarus explains:

169 *“I don’t show them what the job entails, but they try to find out what I do. I am an open*
170 *person but ... I am not able to do that (to talk about his status in public).” (Male, aged 20).*

171 Public disclosure of one’s HIV status is not a requirement of being a CATS. For a significant
172 minority the risk of their role, and consequently their HIV status, being discovered was a source
173 of worry and stress. They described finding this difficult to manage, particularly in the first months
174 of working as a CATS. Although the risk persisted, with support and guidance from other CATS
175 and their mentors, their anxiety tended to ease over time as they became more robust in managing
176 other people’s questions. Geoffrey described a common pattern in his reaction to uncomfortable
177 questions from those within the wider community:

178 *“This mainly happened in the first days... At first it pained me and you would really have*
179 *so many different thoughts ...(Fellow) CATS will then say to me ‘my friend, I came across*
180 *this numerous times. They are not people to listen to, what you need to do is just ride your*
181 *bicycle and go’. I ended up doing that. Now I have a good relationship with them and no*
182 *one asks me what I am doing.” (Male, aged 20).*

183 There were two exceptional cases when individuals had less control over who knew about their
184 status within the community. For one CATS his HIV positive status had been widely presumed
185 because as a child he had been known as a ‘sickling’. In the second case a healthcare worker had
186 disclosed a CATS’ HIV positive status to other patients at the clinic. Although this has been “a
187 painful experience”, it was attributed to a rare act of thoughtlessness by the healthcare worker. In
188 general, the risk of deductive disclosure in which their HIV positive was revealed by virtue of
189 being eligible to work as a CATS appeared to be low and to be well managed by both the young
190 people, their mentors and others involved.

191

192 **Critical support needs to offset risks of being a CATS**

193 Events such as falling sick, struggling with their mental health or problems within their own
194 households were rare, but did at times influence their capacity to fulfil the obligations of the role.
195 In addition, hearing about the shared challenges they faced as young people growing up with HIV,
196 contributed to the CATS’ precarious vulnerability. The substantial support offered by the CATS’
197 mentors was a critical factor mediating the emotional burden which accompanied their work. On
198 some occasions this involved the mentors needing to be flexible about an individual’s CATS
199 workload.

200 The Zvandiri mentors, adults with professional experience caring for adolescents living with HIV,
201 provided training, as well as ongoing supervision to the CATS and took on the management of
202 mental health referrals and support in complex cases. The counselling and personal support
203 provided by the mentors played a pivotal role in enabling the CATS to continue to provide support,
204 without being overwhelmed or risk 'burn-out'. Sarudzai recalled how her mentor "*follows up every*
205 *week to check on me*" (female, aged 20), which acted as a safety net to manage the daily stresses
206 that could otherwise disrupt the CATS' adherence and wellbeing. Practically, the mentors also
207 focused on keeping the number of cases that a CATS was responsible to fewer than ten and
208 equipping them with bicycles so that they could cover the relatively long distances to complete the
209 required number of home visits. These were pivotal management strategies to support the CATS
210 in their work.

211 In the first few months of their role as CATS, young people had to absorb a lot of information,
212 implement new skills and develop relationships with beneficiaries and caregivers. Concomitantly,
213 having just finished school and entering the employment market, they were by definition very
214 early on in their careers as caring professionals. In common with anyone embarking on a career in
215 a caring profession, the CATS were still learning how to manage the burden of responsibility
216 involved in their role. They praised the mentors and other CATS in supporting them through this
217 early period. For example, the mentors commonly facilitated introductions of CATS to households
218 where caregivers were initially reticent for their child to be engaged in the programme. Over time
219 it became easier, but ongoing support remained critical:

220 *"I say its easy (CATS work) because you are not left to work with the adolescents by*
221 *yourself. In most cases I work with others and you are helped if you have any questions...*
222 *It's the mentor that supports me."* (Lisa, female, aged 20)

223 Without exception the CATS reported feeling a keen sense of responsibility for the health and
224 wellbeing of their beneficiaries. When beneficiaries received high viral load results it was not
225 uncommon for the CATS to feel 'hurt', 'disappointed' and 'worried'. Chipo (female, aged 21)
226 explains how in such instances, "*I may blame myself and wonder if I am failing to do my work or*
227 *is it the adolescent who is just not understanding."* The impact was even more acute when a
228 beneficiary died.

229 In general, the opportunity to engage the mentor when they were struggling and stressed was
230 pivotal to CATS being able to manage the related stresses of complex cases. Part of this involved
231 acknowledging that some of the problems' beneficiaries encountered were likely to be beyond the
232 remit of what the CATS could be expected to influence. Managing their expectations was key: not
233 all of the problems could be resolved, but with the intervention's support they might be
234 ameliorated. *"She was able to help with advice... well she was able to help to a certain level which*
235 *made the situation lighter though this didn't completely solve the problem."* (Chipo, female, aged
236 21)

237 Despite the pressures, the CATS were generally very positive about the consistency of the support
238 that they received. In only a few instances was this support considered to have been late or
239 insufficient. The negative reactions of CATS when support was considered inadequate, although
240 rare, further reinforces the importance of timely, responsive and proactive support to mitigate the
241 risks of being a CATS.

242

243 **Being valued: the role of remuneration and recognition**

244 Competing commitments: working in my household and working visiting homes

245 The CATS considered themselves to be both valuable and valued in their roles. The stipend they
246 received for their work was welcomed by most of the CATS. Those who could generally spend it
247 on their own needs consistently described it as helpful: *"I have been able to do certain things like*
248 *I managed to take my class four (driver's licence) as well as to make a part payment for a course*
249 *(operating earth moving equipment)."* (Tanatswa, male, aged 20). However, many CATS had
250 additional responsibilities and needed income to support their dependents and they were more
251 likely to describe the remuneration as insufficient. Some had contemplated quitting to take up work
252 with better pay.

253 The relatively "low" remuneration (US\$20 a month) paid to the CATS created challenges in how
254 their role was perceived within their own households, as well as within the clinics. For a minority
255 their limited earning was a source of household tension. The remuneration was considered
256 inadequate to justify the time spent away from household chores.

257 *“At home I was not being treated well ...they were giving me giving me a hard time. They*
258 *would always say ‘you are running away from doing chores, the money you are getting is*
259 *peanuts. How can you work for only twenty dollars (US\$)”* (Tinashe, male, aged 23).

260 The competing demands of contributing to their household and fulfilling their duties as a CATS
261 was most apparent during farming seasons when the CATS often had to stay at home to work in
262 the gardens: *“I will be preoccupied with other household chores... as I will be at home some of*
263 *the times because on the other side I am the head of the house.”* (James, male, aged 22).

264 Recognition of skills to support transitioning on

265 In the first few months of the intervention healthcare workers reportedly expressed some
266 ambivalence about the contribution that the CATS could make. However, over time most of the
267 CATS described feeling recognised and valued within the clinics where they worked. *“They*
268 *(healthcare workers) say ‘you are clever, you are doing your work well’ ... I start to feel elated*
269 *and I know that it is really working well.”* (Chipo, female, aged 20). The vast majority of the CATS
270 articulated their hopes that the CATS’ role would be formally recognised within the health system.

271 Being a CATS is a time limited role, with young people unable to continue once they are 25 years
272 old. Many were hoping that they would go onto be employed by the Zvandiri programme but
273 recognised that this was a narrow option only available to a few. In general, the transferable skills
274 they gained through their training and professional experience increased their employability. There
275 were some challenges in describing their work experience because without a generic qualification,
276 having to describe the precise nature of their role risked deductive disclosure. In some cases, CATS
277 transitioned to taking on other roles in the clinics or benefitting directly from sponsorship
278 opportunities:

279 *“I collected my school results (ordinary level) recently. There are subjects I am supposed*
280 *to rewrite. The nurse from this clinic has offered to pay my examination fee to supplement*
281 *these subjects that I want to write. So for me, there are many opportunities.”* (Farai, male,
282 aged 22)

283

284 **Discussion**

285 Increasing attention is now being paid to community-based peer-support programmes as a
286 mechanism to improve clinical outcomes and wellbeing (20-22). While the predominate focus of
287 research on peer support for ALHIV has focused on the potential benefits to those receiving peer
288 support (29), this study demonstrates that peer supporters themselves also benefit through
289 improved adherence behaviours and self-confidence. But it was characterised as emotionally and
290 at times physically gruelling work, resonating with existing research on other peer support
291 programmes (20, 30). These findings illuminate the specific challenges and needs that might arise
292 for young peer supporters providing HIV support in resource-stretched settings. Despite the
293 celebration of the effects of peer support, the discursive emphasis on the ‘adolescent’ and/or
294 ‘youth’ characteristic of the CATS may act as a glass ceiling, inadvertently justifying not
295 adequately valuing the contribution that they make in their title or in their pay.

296 There needs to be a formalised recognition of their contribution within the health system. There is
297 currently some tension in how they are seen. This could be overcome if they were described as
298 paid lay counsellors, rather than volunteers who receive a stipend. The CATS are not acting in a
299 peer educator or navigator role but operating as skilled peer counsellors. Equivalent adult cadres,
300 ordinarily working in the role of primary counsellors, are remunerated more than they are; CATS
301 currently receive marginally more than village health workers (31). While the CATS entry
302 qualifications may be less and their initial training shorter than the standard six-month duration for
303 primary counsellors, the CATS as young adults receive training and supervision through the work
304 that they are doing. To accelerate their integration more emphasis needs to be placed on the initial
305 preparatory work with healthcare workers in the clinic and caregivers within the households to
306 assuage initial resistance . Given that many CATS described the resistance they encountered as
307 dispiriting, this may be an opportunity to mitigate early attrition.

308 If there were more formal recognition of CATS as primary lay counsellors, for example where
309 they graduated with a certified accreditation, this would also support their ability to demonstrate
310 their impressive skillset once they transition on from being a CATS. This would avoid the current
311 deductive disclosure risks that accompany explaining their prior role as a CATS. Instead it would
312 equip them with neutral language to articulate the skillset and experience that they have gained,
313 enabling them to leverage the employment opportunities that their experience warrants; a need
314 recognised but rarely actioned in HIV youth activities more generally (32).

315 Although many of the CATS' support needs relate to their age and shared HIV experiences, they
316 also reflect those that would be required by anyone, regardless of age or HIV status, on their
317 initiation into a professional caring role. To support the implementation of the intervention at scale,
318 continuing to budget for intensive mentor support for new cohorts of CATS and investing it as an
319 integral principle of youth peer support is vital (29). This would ensure that there is adequate
320 support to ameliorate the cluster of challenges relating to stakeholder resistance, concerns around
321 the occupational risks of deductive disclosure and related stigma (34, 35) and under-appreciating
322 the value of peer-supporters, which can occur upon initial roll out of the intervention within
323 communities. The findings demonstrate the supportive value that the CATS gain from each other,
324 in common with various manifestations of peer support (36), but also illustrate that this can be
325 further reinforced by the opportunities to mentor and be mentored through the provision of ongoing
326 training and coordination meetings with peers (17).

327 A strength of this study was attending to the experiences of those providing peer support, making
328 a valuable contribution to the emerging evidence-base that has generally focused narrowly on the
329 recipients. However, by not interviewing those who had already left the programme, the results
330 may be biased towards those with more positive experiences as peer supporters. Further research
331 with those who work only briefly as peer supporters is required to understand the factors shaping
332 attrition. However, a pertinent distinction should be drawn between peer supporters affected by
333 *attrition*, who stop due to the effects of inadequate pay, support or poor health and *transition*, when
334 individuals move onto other opportunities reflecting their successful growth in navigating
335 considered decisions about becoming parents or seeking more sustainable employment
336 opportunities. From the available information among the 29 inactive CATS, the latter was more
337 common. Without further research there is a risk that attrition rates may be over-estimated. Peer
338 supporters who move on before they exceed the age threshold may not represent an intervention
339 failing, but instead indicate successful 'graduation'.

340

341 **Conclusions**

342 The experiences of the CATS demonstrate the considerable personal value that they gain from
343 their work. To be able to maximise the benefits and minimise potential occupation harms over

344 time, ongoing intensive and age-appropriate training and mentoring, as well as the establishment
345 and maintenance of systems and remuneration which values the peer support role that CATS play,
346 are integral to the success of peer support.

347 **Competing interests**

348

349 Authors declare no competing interests.

350

351 **Author's contributions**

352 SB was the lead social scientist, designing the process evaluation study with WM and FC which
353 forms the basis of the data presented in this manuscript. MT, KM and AC collected the data with
354 the support of SB, WM, NW and JM. All authors contributed to the overview of data collection
355 and preliminary analysis for this paper through focused team discussions. SB, MT, KM, AC and
356 WM conducted the data analysis. SB developed the manuscript with support from WM, MT, KM
357 and AC. All authors read, reviewed and approved the final manuscript.

358

359 **Acknowledgements**

360 The research reported in this publication was funded by ViiV Healthcare's Positive Action for
361 Adolescents Programme. The content is solely the responsibility of the authors and does not
362 necessarily represent the official views of ViiV Healthcare. We thank study respondents, without
363 whom this study would not have been possible.

364

365

366 **References**

367

368 1. Ferrand RA, Simms V, Dauya E, Bandason T, McHugh G, Mujuru H, et al. The effect of
369 community-based support for caregivers on the risk of virological failure in children and
370 adolescents with HIV in Harare, Zimbabwe (ZENITH): an open-label, randomised controlled trial.
371 Lancet Child Adolesc Health. 2017;1(3):175-83.

- 372 2. WHO. Health for the World's Adolescents: A second chance in the second decade. Geneva:
373 WHO; 2014.
- 374 3. Boerma RS, Boender TS, Bussink AP, Calis JC, Bertagnolio S, Rinke de Wit TF, et al.
375 Suboptimal Viral Suppression Rates Among HIV-Infected Children in Low- and Middle-Income
376 Countries: A Meta-analysis. *Clin Infect Dis*. 2016;63(12):1645-54.
- 377 4. Enane LA, Vreeman RC, Foster C. Retention and adherence: global challenges for the
378 long-term care of adolescents and young adults living with HIV. *Curr Opin HIV AIDS*.
379 2018;13(3):212-9.
- 380 5. Brown K, Williams DB, Kinchen S, Saito S, Radin E, Patel H, et al. Status of HIV
381 Epidemic Control Among Adolescent Girls and Young Women Aged 15-24 Years - Seven African
382 Countries, 2015-2017. *MMWR Morb Mortal Wkly Rep*. 2018;67(1):29-32.
- 383 6. Bernays S, Paparini S, Gibb D, Seeley J. When information does not suffice: young people
384 living with HIV and communication about ART adherence in the clinic. *Vulnerable children and*
385 *youth studies*. 2015:1-9.
- 386 7. Bernays S, Paparini S, Seeley J, Rhodes T. "Not Taking it Will Just be Like a Sin": Young
387 People Living with HIV and the Stigmatization of Less-Than-Perfect Adherence to Antiretroviral
388 Therapy. *Med Anthropol*. 2017;36(5):485-99.
- 389 8. Ammon N, Mason S, Corkery JM. Factors impacting antiretroviral therapy adherence
390 among human immunodeficiency virus-positive adolescents in Sub-Saharan Africa: a systematic
391 review. *Public Health*. 2018;157:20-31.
- 392 9. Arnold EM, Swendeman D, Harris D, Fournier J, Kozina L, Abdalian S, et al. The Stepped
393 Care Intervention to Suppress Viral Load in Youth Living With HIV: Protocol for a Randomized
394 Controlled Trial. *JMIR research protocols*. 2019;8(2).
- 395 10. Boothroyd R, Fisher E. Peers for Progress: promoting peer support for health around the
396 world. *Family Practice*. 2009;27:i62-i8.
- 397 11. Fisher EB, Boothroyd RI, Elstad EA, Hays, L., Henes, A., Maslow, G.R. and Velicer, C.
398 Peer support of complex health behaviors in prevention and disease management with special
399 reference to diabetes: systematic reviews. *Clinical Diabetes and Endocrinology*. 2017;3.
- 400 12. Solomon P. Peer support/peer provided services: underlying processes, benefits, and
401 critical ingredients. *Psychiatric Rehabilitation Journal*. 2004;27:392-401.

- 402 13. Mark D, Armstrong A, Andrade C, Penazzato M, Hatane L, Taing L, et al. HIV treatment
403 and care services for adolescents: a situational analysis of 218 facilities in 23 sub-Saharan African
404 countries. . Journal of International AIDS Society. 2017;20:21591.
- 405 14. WHO. HIV and adolescents: guidance for HIV testing and counselling and care for
406 adolescents living with HIV: recommendations for a public health approach and considerations for
407 policy-makers and managers. Geneva: WHO; 2013.
- 408 15. Willis N, Napei T, Armstrong A, Jackson H, Apollo T, Mushavi A, et al. Zvandiri-Bringing
409 a Differentiated Service Delivery Program to Scale for Children, Adolescents, and Young People
410 in Zimbabwe. J Acquir Immune Defic Syndr. 2018;78 Suppl 2:S115-S23.
- 411 16. Mavhu W, Willis N, Mufuka J, Bernays S, Tshuma M, Mangenah C, et al. Effect of a
412 differentiated service delivery model on virological failure in adolescents with HIV in Zimbabwe
413 (Zvandiri): a cluster-randomised controlled trial. Lancet Global Health 2020;8(2):e264-e75.
- 414 17. Grimsrud AT, Pike C, Bekker LG. The power of peers and community in the continuum
415 of HIV care. . The Lancet Global Health. 2020.
- 416 18. Mavhu W, Willis N, Mufuka J, Mangenah C, Mvududu K, Bernays S, et al. Evaluating a
417 multi-component, community-based program to improve adherence and retention in care among
418 adolescents living with HIV in Zimbabwe: study protocol for a cluster randomized controlled trial.
419 Trials. 2017;18(1):478.
- 420 19. Willis N, Napei T, Armstrong A, Jackson H, Apollo T, Mushavi A, et al. Zvandiri-Bringing
421 a Differentiated Service Delivery Program to Scale for Children, Adolescents, and Young People
422 in Zimbabwe. JAIDS Journal of Acquired Immune Deficiency Syndromes. 2018;78:S115-S23.
- 423 20. WHO. Adolescent friendly health services for adolescents living with HIV: from theory to
424 practice. Geneva, Switzerland: World Health Organization; 2019.
- 425 21. Mark D, Bloch K, Cluver L, Toska E, Ronan A, Gittings L, et al. The power of peers:
426 multi-country analysis of adolescent viral suppression in sub-Saharan Africa. International AIDS
427 Conference; Amsterdam2018.
- 428 22. PEPFAR. PEPFAR Solutions Database. Operation Triple Zero: empowering adolescents
429 and young people living with HIV to take control of their health in Kenya.; 2018.
- 430 23. Mavhu W, Willis N, Mufuka J, Bernays S, Tshuma M, Mangenah C, et al. Differentiated
431 service delivery model to reduce virological failure in adolescents with HIV in Zimbabwe
432 (Zvandiri): a cluster-randomised controlled trial. Lancet Global Health 2020:
433 .

- 434 24. Zimbabwe country factsheet [Internet]. UNAIDS. 2018.
- 435 25. LeCompte MD, Schensul JJ. *Designing & Conducting Ethnographic Research*. Lanham,
436 MD and Oxford: Rowman Altamira Press; 1999.
- 437 26. Schensul SL, Schensul JJ, LeCompte MD. *Essential Ethnographic Methods: Observations,*
438 *Interviews, and Questionnaires*. Lanham, MD and Oxford: Rowman Altamira Press; 1999.
- 439 27. Bernays S, Bukenya D, Thompson C, Ssembajja F, Seeley J. Being an 'adolescent': The
440 consequences of gendered risks for young people in rural Uganda. *Childhood* (Copenhagen,
441 Denmark). 2018;25(1):19-33.
- 442 28. Rutakumwa R, Mugisha JO, Bernays S, Kabunga E, Tumwekwase G, Mbonye M, et al.
443 *Conducting in-depth interviews with and without voice recorders: a comparative analysis.*
444 *Qualitative Research*. 2019;p.1468794119884806.
- 445 29. Mark D, Hrapcak S, Ameyan W, Lovich R, Ronan A, Schmitz K, et al. Peer Support for
446 Adolescents and Young People Living with HIV in sub-Saharan Africa: Emerging Insights and a
447 Methodological Agenda. . *Current HIV/AIDS Reports*. 2019:1-8.
- 448 30. Burke EM, Pyle M, Machin K, Morrison AP. Providing mental health peer support 2:
449 Relationships with empowerment, hope, recovery, quality of life and internalised stigma.
450 *International Journal of Social Psychiatry*. 2018;64(8):745-55.
- 451 31. Perry H, Crigler L, S. H. Case Studies of Large-Scale Community Health Worker Programs
452 was derived from the Developing and Strengthening Community Health Worker Programs at
453 Scale: A Reference Guide and Case Studies for Program Managers and Policymakers 2017.
454 Available from: [https://www.chwcentral.org/blog/zimbabwe%E2%80%99s-village-health-
455 worker-program](https://www.chwcentral.org/blog/zimbabwe%E2%80%99s-village-health-worker-program).
- 456 32. Oliveras C, Cluver L, Bernays S, Armstrong A. Nothing about us without RIGHTS—
457 meaningful engagement of children and youth: from research prioritization to clinical trials,
458 implementation science, and policy. . *Journal of acquired immune deficiency syndromes.*
459 2018;78:S27-31.
- 460 33. Skirbekk H, Korsvold L, Finset A. To support and to be supported. A qualitative study of
461 peer support centres in cancer care in Norway. *Patient education and counseling*. 2018;101:711-6.
- 462 34. Busza J, Simms V, Dziva Chikwari C, Dauya E, Bandason T, Makamba M, et al. “It is not
463 possible to go inside and have a discussion”: how fear of stigma affects delivery of community-
464 based support for children’s HIV care. . *AIDS care*. 2018;30(7):903-9.

465 35. Mburu G, Ram M, Oxenham D, Haamujompa C, Iorpenda KF, L. Responding to
466 adolescents living with HIV in Zambia: a social–ecological approach. *Children and Youth Services*
467 *Review*. 2014;45:9-17.

468 36. Reif LK, Rivera VR, Bertrand R, Belizaire ME, Joseph JMB, Louis B, et al. “FANMI”: a
469 promising differentiated model of HIV Care for Adolescents in Haiti. . *Journal of acquired*
470 *immune deficiency syndromes*. 2019;82(1):e11.

471

DRAFT