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3 **Manuscript Title: What can volunteer co-providers contribute to health systems? The role**  
4 **of people living with HIV in the Thai paediatric HIV programme.**

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29

30 **Keywords**

31 PLHIV volunteer; co-provider; task-shifting; paediatric HIV; Thailand; Asia; health system  
32 strengthening

33

34 **Abstract**

35 In Thailand people living with HIV (PLHIV) have played a major role in shaping policy and  
36 practice. They have acted as volunteer co-providers, although their potential in terms of  
37 paediatric service provision has seldom been explored from a health systems perspective.  
38 We describe the Thai paediatric HIV care system and use both demand- and supply-side  
39 perspectives to explore the impact, opportunities and challenges of PLHIV acting as  
40 volunteer co-providers.

41

42 We employed qualitative methods to assess experiences and perceptions and triangulate  
43 stakeholder perspectives. Data were collected in Khon Kaen province, in the poorest  
44 Northeastern region of Thailand: three focus group discussions and two workshops (total  
45 participants n=31) with co-providers and hospital staff; interviews with ART service-users  
46 (n=35). Nationally, key informant interviews were conducted with policy actors (n=20).

47

48 Volunteer co-providers were found to be ideally placed to broker the link between clinic and  
49 communities for HIV infected children and played an important part in the vital psychosocial  
50 support component of HIV care. As co-providers they were recognized as having multiple  
51 roles linking and delivering services in clinics and communities. Clear emerging needs  
52 include strengthened coordination and training as well as strategies to support funding.

53

54 Using motivated volunteers with a shared HIV status as co-providers for specific clinical  
55 services can contribute to strengthening health systems in Asia; they are critical players in  
56 delivering care (supply side) and being responsive to service-users needs (demand side). Co-  
57 providers blur the boundaries between these two spheres. Sustaining and optimising co-  
58 providers' contribution to health systems strengthening requires a health systems approach.  
59 Our findings help to guide policy makers and service providers on how to balance clinical

60 priorities with psycho-social responsiveness and on how best to integrate the views and  
61 experience of volunteers into a holistic model of care.

62

63 **Research highlights**

64

65 1. As co-providers, volunteers constitute the interface between families, communities  
66 and clinics

67 2. Volunteer co-providers have multiple roles in HIV services and strengthen health  
68 systems in Asia

69 3. A shared identity and strong sense of purpose can foster commitment

70 4. A health systems approach can optimize volunteer contributions

71

72 **Keywords**

73 PLHIV volunteer; co-provider; task-shifting; paediatric HIV; Thailand; Asia; health system  
74 strengthening

75

76

77 **INTRODUCTION**

78 Task-shifting is a widely used mechanism for dealing with constraints in human resources for  
79 health. It is the delegation of tasks to cadres of less qualified health-workers, intended to  
80 reduce costs yet ensure deployment of capable personnel [1,2]. The impact of task-shifting  
81 on health outcomes is well-documented, and its potential for strengthening the broader  
82 health system is now gaining attention [3,4]. Volunteers working as peer supporters are one  
83 such cadre whose contribution to task-shifting is expanding. Peer support volunteers share  
84 key personal characteristics, circumstances, or experiences with patients, this is thought to  
85 add value to how they provide services; peer volunteers do not generally complete short-  
86 term, competency-based training [5].

87

88 HIV services, like those for other chronic diseases, require provision by a multidisciplinary  
89 team. Antiretroviral treatment is highly effective, but is complex to manage [6]. Providers  
90 of HIV services need a broad range of skills covering clinical HIV management, monitoring  
91 procedures, supporting adherence, and ability to link to community social and economic  
92 support [7-10]. Paediatric HIV care has further complications and providers should be  
93 equipped with additional capacity in paediatric medicine, caregiver assessment, providing a  
94 service guided by children’s cognitive development, offering age appropriate emotional and  
95 psychosocial support and adolescent targeted services [8,11-13]. People living with HIV  
96 (PLHIV) are well integrated into task-shifting initiatives as peer-supporters in many settings  
97 but the relating evidence is skewed towards Africa [3].

98

99 The familiarity of PLHIV with a given social setting and personal experiences of HIV infection  
100 and treatment make them ‘expert patients’ who can move between the public-health  
101 system and communities [14]. People with similar demographic characteristics can be  
102 effective communicators within their communities and are able to build trusting

103 relationships to improve knowledge and influence behaviour [15,16]. The contribution of  
104 peer volunteers has been shown to be invaluable in supporting paediatric HIV care in many  
105 contexts [17,18]. They may be active in antiretroviral treatment (ART) clinics and in the  
106 community. Evidence exists that they can be important in supporting monitoring, HIV status  
107 disclosure, adherence, quality of life indicators, greater equity in access to services,  
108 increased paediatric testing, shortened waiting times, reduced stigma and better overall ART  
109 outcomes including association with lower patient mortality [6,19-22]. Task shifting to  
110 volunteer PLHIV may have an important potential contribution to the comprehensive  
111 provision not only of psychosocial support but also clinical support services to ensure that  
112 children affected by HIV receive the same standards of social acceptance, personal  
113 development and quality of life as others [23]. There is however scant evidence of the  
114 potential of PLHIV volunteers to be integrated as formal co-providers for paediatric HIV  
115 services, despite the additional needs of this population.

116

#### 117 ***PLHIV as co-providers of HIV care in Thailand***

118 HIV policy and agenda setting in Thailand has historically unfolded through multi-  
119 stakeholder consultation with clinicians, academics, civil society representatives, non-  
120 government organizations (NGOs) and providers [24-26]. Thai PLHIVs have been recognized  
121 as a valuable resource since the 1990s and are trained to support patients and delivery  
122 processes in clinics and communities [27]. In the limited literature regarding the  
123 contribution of these 'co-providers' they are highly praised and considered a vital element of  
124 service provision [28,29].

125

126 Since the early 2000s the Ministry of Public Health has encouraged the provision of ART  
127 through a multidisciplinary team, which includes PLHIV volunteer workers organized through  
128 a national network. The model requires that the PLHIV volunteer group must have at least

129 two trained core members, be able to work regularly, have transparent financial  
130 management and a clear work-plan [30]. The volunteers are coordinated in groups at  
131 provincial and district level through the national network who develop curricula and train  
132 the volunteers, developing their capacity to work with hospital ART teams [28,30,31]. The  
133 PLHIV role is to provide administrative and general support in ART clinics and psychosocial  
134 support to patients in clinics and communities; PLHIV are able to support and care for  
135 patients and in such a way that hospital staff often have limited time or capacity to do  
136 [24,28,32]. This is particularly important with children's services; HIV infection impacts on a  
137 wide range of aspects of their health and well-being and their support needs are more  
138 prominent.

139

#### 140 ***Thai paediatric ART services***

141 Children's HIV services in Thailand are provided free of charge through a holistic model,  
142 incorporating clinical and psychosocial aspects with volunteer PLHIV an integral part of  
143 service delivery. Services are increasingly provided as a 'one-stop' clinic aiming to maximize  
144 convenience while offering a range of services. This includes consultations with a nurse,  
145 paediatrician, pharmacist and social worker; clinical monitoring and volunteer-group  
146 activities. Clinics are sometimes linked to off-site services provided by volunteers (and  
147 occasionally hospital staff). In 2006 the 'Children's ART Network' was introduced and has  
148 been gradually scaled-up; this decentralized system aims to reduce the burden on provincial  
149 hospitals and improve adherence [33,34]. Through this network, children diagnosed with  
150 HIV-infection initiate ART at tertiary hospitals and are referred back to a district hospital  
151 when their health becomes stable [35-37]. At district level the programme again assumes  
152 the integration of the volunteers and aims to mobilise the PLHIV and communities to give  
153 psychosocial and adherence support, and strengthen capacity for long-term clinic follow-up

154 and home-visits [37,38]. The findings in this paper relate to services provided through the  
155 decentralized model described.

156

157 The objective of this paper is to analyse the impact, opportunities and challenges of PLHIV  
158 acting as volunteer co-providers of paediatric HIV care in Thailand. We describe the role of  
159 PLHIV volunteers in reference to the Thai paediatric HIV programme and report findings  
160 from a qualitative study in order to assess the potential contribution of volunteers to  
161 strengthening health systems in an Asian context. We draw on a framework developed by  
162 Yaya-Bocoum et al. that conceptualises the wider range of effects of task shifting through a  
163 'systems-thinking' lens [4].

164

165 The framework presents 20 possible effects of task shifting on the system as a whole, many  
166 of which are not only positive, but are unintentional. The negative effects in their study were  
167 found to be unrelated to task-shifting *per se*, but reflections of weaknesses in the underlying  
168 health-system. They are broadly divided into supply and demand side effects and health  
169 outcomes effects; the supply side incorporating human resources issues such as workload,  
170 motivation, staff retention and confidence, while the demand side incorporates the social  
171 impact, patient satisfaction, access and equity issues. We use this framework as a basis for  
172 analysing and describing the contributions of the co-providers.

173

## 174 **METHODS**

175 Qualitative methods in HIV research are valued for bringing in-depth understanding to the  
176 patient experience and recognition of the important influence of contextual factors that  
177 occur at intra- and interpersonal, community, social, cultural, and economic levels [39]. We  
178 used multiple qualitative methods to assess and triangulate a range of perspectives on the  
179 role PLHIV volunteers in paediatric HIV services. We conducted three focus group

180 discussions with service providers and volunteer co-providers (total participants n=31),  
 181 individual interviews with ART service-users (n=35), and policy actors (n=20); and (Table 1).  
 182 Service-provider and service-user participants were recruited from a university, a provincial  
 183 and a district hospital in Khon Kaen Province, in Thailand's poorest Northeast region (to  
 184 represent all levels of service provision). Data were collected May to December 2009. The  
 185 university hospital is a tertiary provider, whence most paediatric patients initiated treatment  
 186 before being referred back to the district hospital and provincial hospitals; it has close links  
 187 and an advisory role to HIV service providers across the region.

188 **Table 1 Type and source of data collected**

Site	Service provider FGD	Service-user interviews	Policy actor interviews
Type	1 District hospital (8 participants) 1 Provincial hospital (11 participants) 1 University hospital (12 participants)	29 caregivers 6 adolescents	4 - NGOs 2 – International agencies 5 – Academic / Expert 9 - Government
Total	<b>3 (31)</b>	<b>35</b>	<b>20</b>

189

190 ***FGDs with PLHIV co-providers and hospital service-providers***

191 The three FGDs, held with 8-12 participants, took place at each hospital included in the  
 192 study and were chosen in order to observe and understand the team dynamic. All members  
 193 of the paediatric HIV team were invited, including the PLHIV volunteers, paediatricians,  
 194 nurses, pharmacists and social workers. In this paper 'provider' refers to formal hospital  
 195 employed health staff and 'co-provider' refers to PLHIV volunteers. Areas explored in the  
 196 FGDs included: (co-) provider and patient challenges in paediatric services, co-provider roles  
 197 in clinic and community, NGOs and support groups. FGDs were used so as to understand  
 198 how group norms and dynamics shaped experiences amongst the multidisciplinary HIV care  
 199 teams [40,41]. FGD groups were mixed as they reflected the structure of the HIV care team:  
 200 men and women, HIV positive and negative, varying professional status. Use of mixed FGDs  
 201 with a range of participants was considered carefully, but after observation of team  
 202 dynamics and consultation with staff this was considered acceptable and an enabling way



203 for the voices of all providers and co-providers to be heard. All but one of the PLHIV  
204 volunteers (n= 8) were female). They were conducted in Thai by experienced Thai  
205 facilitators and the lead author.

206

### 207 ***Service-user interviews***

208 Thirty-five paediatric ART clinic service-users (caregivers: grandparents, parents, other  
209 relatives; and older children) participated in qualitative interviews using a semi-structured  
210 guide designed to elicit detail. Information was asked about family and socio-economic  
211 needs, HIV support structures, PLHIV volunteers, HIV education, perceptions about services,  
212 challenges related to HIV. The interviews were carried out in Thai or local Northeastern  
213 dialect by a female PLHIV researcher and lead author. Participants were selected  
214 purposively by the HIV care teams on clinic days to represent a range of different  
215 experiences including: adolescence; orphanhood; a range of income levels; adherence  
216 issues; experienced social exclusion, stigma or abuse; psychosocial difficulties or isolation;  
217 HIV disclosure issues. Registered patients who had not experienced any of these HIV related  
218 difficulties were rare; effort was made to ensure positive and negative experiences were  
219 elicited. Child participants were required to be 12 years or older.

220

### 221 ***Interviews with policy actors***

222 Policy actors (n=20) were purposively sampled following discussion with Ministry of Public  
223 Health and academic advisors; additional respondents were recruited through snowball  
224 sampling (Table 1). Inclusion criteria were based on current or recent contribution and  
225 experience of HIV policy processes. Interviewees were sought from all sectors contributing  
226 to paediatric HIV policy. NGO staff were considered as policy actors given the long-standing  
227 and important contribution they have made to HIV policy. Interviews were conducted by

228 the lead author in English and/or Thai and covered issues relating to paediatric policy  
229 development, priorities and the role of peer supporters.

230 ***Analysis***

231 All qualitative data were recorded, transcribed and translated to English then analysed using  
232 a thematic framework in QSR Nvivo (v8) software. Emerging themes were grouped and  
233 coded by the lead author, the entirety of transcripts were coded to minimize risk of  
234 selectivity of data. Codes were refined, shared and discussed in the light of the Yaya-  
235 Bocoum framework [4] with two members of the research team. In addition, preliminary  
236 themes and analyses were presented to co-/providers in the two one-day workshops. These  
237 workshops were run by two facilitators and the lead author. Most participants had been  
238 present at the initial FGDs, the aim was to check for validity, minimize possible bias in the  
239 analytic process, and obtain feedback which was used to structure the final coding frame  
240 from which final queries were run in the software. The workshops served as a data  
241 collection method and a means of analytic triangulation and so were also recorded, coded  
242 and analysed. Provider participants were this time divided according to cadre: provider and  
243 co-provider because the focus was on problem-solving and generating ideas, for which this  
244 group dynamic was appropriate.

245

246 Trustworthiness and validity of the data were strengthened through methodological  
247 triangulation of the results between FGDs, interviews and workshops and between types of  
248 respondents. These triangulation techniques were used to enhance reliability through a  
249 reflective, multi-dimensional interpretation of the data and resolution of contradictions [42].

250 Results obtained from the different methods were intuitively related to each other and  
251 checked for convergence and divergence [43].

252

253 The research protocol received ethical approval by the Liverpool School of Tropical Medicine  
254 (Protocol No.07.57), the Thai MOPH (Protocol No.150/2551), Khon Kaen University (for  
255 Srinagarind Hospital) and Khon Kaen Provincial Hospital (also covering the district level  
256 hospital). Written consent was obtained directly from participants, including young  
257 participants. Young participants who attended clinic unaccompanied did not require  
258 additional consent from a caregiver, written consent was obtained from a caregiver for  
259 those who were accompanied.

260

261 The findings in this paper present combined triangulated results from all participants,  
262 organized using both adapted demand and supply side effects extracted from the Yaya-  
263 Bocoum et al framework [4]. Where appropriate, feedback and suggestions from the  
264 workshops are also included in the findings section. Illustrative quotations are used and  
265 annotated with the type of method, participant information and the following abbreviations:  
266 SU=Service-user; CP=Co-provider; P=Provider; Pol=Policy actor; Gov=Government employee;  
267 NGO=non-Government organization staff.

268

## 269 **FINDINGS**

270 We present the findings according to the demand and supply side effects of co-providers.  
271 They are then ordered as the major themes that emerged in the data. Each theme  
272 incorporates data from various respondent types to show where views differ or confer.

273

### 274 ***DEMAND SIDE EFFECTS***

#### 275 ***Contribution of co-providers to service quality***

276 The co-providers were recognized by service-users, providers and to some extent policy  
277 actors (particularly NGOs) for conducting multiple tasks both in and out of clinic setting.  
278 Table 2 summarizes the range of contributions cited by respondents. Not all co-provider

279 volunteers performed all roles but their contributions were considered an important part of  
 280 enabling a more holistic care package in which co-provider volunteers created a link  
 281 between service-users and hospital providers, one NGO activist explained that:

282 *“It is important to have PLHIV support in every hospital, they can help, though they*  
 283 *don’t always have sufficient experience. Without this help the hospitals can’t cope.”*  
 284 *(Female Pol interview, NGO)*

285 **Table 2 – PLHIV contribution to ART services (demand-side)**

286

Co-provider role	Community	Hospital
Health advice and information	✓	✓
Moral support and preparing for disclosure of status	✓	✓
Advice on financial matters	✓	✓
Adolescent specific advice	✓	✓
Telephone advice	✓	
Home visits	✓	
Community education events	✓	✓
Life skills and youth camps	✓	
Tackling stigma	✓	✓
Attending pre-clinic case conferences		✓
Admin support and measuring/recording weight and blood pressure		✓
Linking with provincial health office/ local administrative organizations	✓	
Pill counting		✓
Adherence checking	✓	✓

287

288 In addition to the interaction service-users had with co-provider volunteers in clinic and at  
 289 home, many children and their caregivers regularly attended several different support  
 290 groups; attendance was reported at the following types of activities: 1) group activities on  
 291 HIV-clinic days: organized by hospital staff and supported by co-provider volunteers; 2)  
 292 community peer-support groups: organised at district or sub-district level by the PLHIV  
 293 network (often with a financial or meal incentive); 3) child and adolescent camps: organised  
 294 by volunteer groups or hospitals.

295

296 The PLHIV support which existed in each of the three hospitals in this study were perceived  
297 by most co-/providers to have an essential role in improving the quality of the service that  
298 patients received. As HIV-positive individuals, co-providers knew that they were well-placed  
299 to understand the circumstances of the service-users:

300 *“Our job doesn’t stop in the hospital, we wouldn’t be able to analyse people properly;*  
301 *we need to be able to visit them at home, see the condition of the child at home, how*  
302 *they fit in to the community, observe their environment, it isn’t enough just to ask at*  
303 *clinic.” (Female District Co-P, workshop).*

304 *“The volunteers are very important, usually children are living with elderly caregivers*  
305 *and some of them are excluded from school and there is just no one that they can talk*  
306 *to...the regular hospital staff don’t have much time beyond the clinical side of*  
307 *treatment.” (Female Pol NGO, interview)*

308

309 **Patient satisfaction: Sharing identities, developing rapport**

310 Appreciation of the central role played by co-providers was a strong theme; both HIV  
311 positive adolescents and the caregivers of younger children expressed the importance of  
312 this:

313 *“[We get] Knowledge and interaction with people who know about things that I don’t*  
314 *know... Things like taking medication, or every day life skills... The volunteers are good,*  
315 *they don’t interfere too much but if I have a problem I know I can talk to them and*  
316 *they won’t tell anyone, else they help.” (Female adolescent SU, age 17)*

317

318 *“The volunteers help explain the medicines, but [at the group activities] I like the*  
319 *games we do with friends, and drawing pictures... [they say] that we don’t need to*  
320 *worry about living with others, sharing with others, eating together, it is fine, there is*

321 *no need to think about it, HIV isn't that easy to catch." (Female adolescent SU, age*  
322 *14.)*

323

324 The co-providers were viewed as integral to services but also as outsiders from the hospital  
325 team, giving them an in-between or link status. A unique attribute that was recognised was  
326 their ability to communicate with service-users, partly due to their shared language (Isaan  
327 dialect) and experiences:

328 *"We help on many levels in the hospital...one role is, when patients come for*  
329 *treatment, they come to the volunteers first; what I mean is that they trust us... and*  
330 *talk about things in a way they couldn't say to the doctor." (Female University Co-P,*  
331 *workshop).*

332 *They (volunteers) can help improve relations, and there is plenty of potential for*  
333 *building their capacity too." (Female University P, FGD)*

334

335 Service-users and co-providers developed trusting relationships that sometimes functioned  
336 on an emotional and practical level and covered a range of issues:

337 *"I trust the volunteers the most because they give good advice, we are close."*  
338 *Grandmother SU, interview)*

339 *"There is one volunteer I have known since the start, she has given me helpful*  
340 *information, she said she is also infected and [explained] that I didn't need to*  
341 *be disgusted by my nephew, she helped me to understand... It is such a shame*  
342 *that when my sister was alive they didn't have these support groups, people*  
343 *you can talk to." (Aunt SU, interview).*

344

345 Not all interviewees had attended PLHIV group activities, but those who had attended found  
346 they were generally helpful, and only a minority did not wish to attend. Groups had multiple

347 and over-lapping functions as sources of HIV-related knowledge (on treatment, disclosure,  
348 care and transmission), a forum for advice for discussing financial-support solutions and  
349 sharing experiences with other HIV-infected and affected people:

350 *“I like it [at the groups], the children can have fun drawing, but for me it is nice*  
351 *to have people massage me, they do exercises with us too, as well as giving us*  
352 *information about health and treatment. I can now also help other people...*  
353 *They [volunteers] help, like suggesting ways to make an income and they say*  
354 *that if I need help then I should ask them.” (Grandmother SU, interview).*

355 Doctors encouraged group attendance and service-users at the university hospital were  
356 unable to avoid the hospital-based group as they were obliged to collect their prescriptions  
357 from the group-activities room. For some people the groups were a rare opportunity to talk  
358 openly about HIV:

359 *“The doctor suggested I go to the group; they give us advice about the*  
360 *medicines. It is good to be a member; you meet and talk to other people about*  
361 *this, it is comforting. I know the volunteers are infected too; there is no*  
362 *discrimination between people.” (Grandmother SU, interview).*

363 Recognition that co-provider contribution to improved patient satisfaction was not universal  
364 however, for example, occasionally service-users did not want the extra support or to  
365 discuss HIV related issues, fear of disclosure and inability to talk openly about HIV acted as a  
366 deterrent for some to talk to co-providers or attend group activities in the community:

367 *“I don’t want to talk to anyone about it. I don’t know what the result [of going*  
368 *to the volunteer activities] would be; what do they do? I’m already busy looking*  
369 *after the children.” (Father SU, interview).*

370

371 **Better access to services close to home and promoting equity**

372 The current paediatric HIV service delivery model expects volunteers to provide a degree of  
373 follow-up in the community even though some service-users chose to attend clinic at distant  
374 hospitals. This had demand side benefits that were noted by some respondents. Home  
375 visits by co-providers were seen as useful, to give health advice, informal support to the  
376 family (such as encouraging other at-risk family members to have HIV testing), and so that  
377 they could get a sense of underlying problems such as poor HIV knowledge or discrimination  
378 in the community or at school. The visits also sometimes provided an opportunity to be  
379 advised on health problems at home between clinic visits:

380 *“If there is any problem they’ll come and visit us at home, they’re good, they*  
381 *have plenty of time for us.” (Grandmother SU, interview).*

382 *“Volunteers from here visited home, they gave [HIV related] information to the*  
383 *neighbours. We lived in a rented compound, so people had complained.”*  
384 *(Father SU, interview).*

385 *“We organized training in a school which improved (HIV) understanding.” (Female*  
386 *District Co-P, FGD)*

387 In the community, support extended beyond medical help to general advice such as co-  
388 ordinating financial support:

389 *“We can help families make the application for money from the local administration...*  
390 *they can apply for funds for raising cows, farming fish, or growing vegetables.”*  
391 *(Female District Co-P, workshop).*

392 It was noted by some policy makers and (co-)providers that the distribution of support from  
393 volunteers was not even across the province or the country as a whole, and that access to  
394 support at home or in the community was irregular. For example families living in areas of  
395 low prevalence were less likely to have a strong volunteer presence, while other districts  
396 simply lacking enthusiastic or skilled PLHIV and so were neglected:



397 *“It varies, some areas have many PLHIV groups and some have very few.” (Female Pol*  
398 *Gov, interview)*

399 *“There are some places where children are not accessed by volunteers, they are very*  
400 *important as often otherwise they have no support at all. It is only a very small*  
401 *number of children we come across who are close enough to their caregiver or to their*  
402 *teacher and can get the advice they need from them.” (Female Pol NGO, interview)*

403 It was suggested that simple mapping of child residence and regular review of all cases in  
404 clinic would indicate oversights in community support mechanisms.

405

#### 406 **SUPPLY-SIDE EFFECTS**

##### 407 ***Tackling team challenges: Staff turnover and confidence***

408 Co-providers were seen to have an impact on issues where hospital teams had difficulties.  
409 Two of the three hospitals had staffing problems, either shortages or high turnover, many of  
410 the members of the hospital paediatric HIV teams at the provincial and district levels were  
411 relatively new to their posts and staff confidence was quite low in these sites:

412 *“The hospital administration knows there is a shortage of staff for every*  
413 *position.” (Male District P, FGD).*

414 Some respondents therefore felt that volunteers were an important aspect of long-term  
415 continuity in service provision in an environment of high staff turnover and it was noted that  
416 some volunteers had long-standing relationships with service-users:

417 *“...the group can help a lot because there are not enough staff here,*  
418 *particularly in things like contact with patients, because sometimes we are*  
419 *already acquainted.” (Female Provincial Co-P, FGD).*

420

421 Staff confidence in their ability to do their work well and deal with complex issues like  
422 disclosure counselling were also seen as hindrances to delivering good quality services:

423

424 *“We feel we aren’t that good, we need to improve ourselves. Well, we need to*  
425 *receive more training and have a clearer system; we need to build a system,*  
426 *and to improve our confidence for things like counselling.” (Male Provincial P,*  
427 *FGD).*

428

429 Co-providers had potential to mitigate some of these problems, but despite expressing pride  
430 in their skills and potential, some also experienced problems with low confidence. They  
431 made suggestions about how their knowledge could be improved:

432 *“It would be good to be trained in communication with children, but also for*  
433 *child development and appropriate activities. Sometimes I lack confidence in*  
434 *talking to children on these issues.” (Female District co-P, FGD)*

435

#### 436 **Cost and sustainability**

437 Co-provider attendance at clinic depended on the commitment of the local PLHIV networks  
438 to provide training and financial support. Activities were often reliant on short-term funds  
439 from local institutions, although some funding was also available from central government.  
440 The FGDs revealed that PLHIV groups found it increasingly difficult to secure government  
441 funds and future funding for training was uncertain:

442 *“The provincial health office provides training for the [PLHIV] group leader of*  
443 *each district, that is 26 districts. The regional Disease Control Office used to*  
444 *give us money to organize activities and home visits, but their budget is small*  
445 *now.” (Female District P, FGD)*

446 Co-/provider and policy respondents talked about the changes to PLHIV groups’ subsidy. In  
447 2009 financing of the ARV programme was taken over by the National Health Security Office.  
448 When the new Office was set up there was no longer a comprehensive volunteer funding

449 mechanism and volunteer expenses could not be guaranteed, even though the policy-level  
450 interviewees concurred that PLHIV groups have long been accepted as a valuable resource.  
451 The official stance is that groups could receive funding (allocated from central to local  
452 government) but that they would now need to actively demonstrate their value. Co-  
453 providers explained that they lacked the skills (for example, grant and proposal writing) to  
454 do so.

455 *“Groups are not guaranteed funding and must undergo formal registration to compete*  
456 *for shrinking funds.” (Male Pol Gov, Interview).*

457 Sustainability of co-providers and insufficient budgets to cover costs were a recurrent  
458 concern across all sites voiced by co-/providers. For example, despite the integral role the  
459 seven co-providers at the district hospital were playing at the time of this study, they  
460 received no financial support at all because the hospital did not have a budget for such  
461 activities, local sources of funding had been exhausted and central government funding had  
462 not been allocated to them.

463

#### 464 ***Coordination and training needs***

465 Some co-providers felt that their informal position meant that good leadership in the PLHIV  
466 network was crucial and poor provincial leadership would have an impact on the functioning  
467 of all the groups within that province. The national network for PLHIV was recognized as  
468 having strength in co-ordination needs and facilitated good quality peer support by  
469 providing training and tools, distributing new information, co-ordinating funds and activities  
470 and liaising with the formal health sector:

471 *“It continues to operate a hierarchically structured network ranging from policy-*  
472 *advocates at national level to offices in every region and province, to support-*  
473 *volunteers in villages, who work to educate communities, tackle discrimination and*  
474 *provide peer-support.” (Male Pol Gov, Interview).*

475 Government level action would however have been welcomed by several respondents:

476 *“The national PLHIV network is good, but there should be greater central*  
477 *government cooperation and support of the network groups... if you have a*  
478 *problem with a child in the community ... you can go to local authority but they*  
479 *have limitations, the network representatives can go in and encourage them to act,*  
480 *but they don’t have power without central government support.” (Female*  
481 *Provincial P, Workshop).*

482

483 Co-providers’ clinic activities were shaped by the current needs of the staff and patients in  
484 each setting. Co-providers explained they received a basic qualification about ART from  
485 their local PLHIV network and in addition received a variety of further *ad hoc* trainings in  
486 opportunistic infections, drug resistance, self-care, leadership, counselling and disclosure.  
487 These were offered by the provincial health office, hospitals and other organizations. The  
488 successful running of the HIV clinic days was largely deemed to depend on cohesion in the  
489 team, efficiency and communication between team members, both providers and co-  
490 providers:

491 *“The clinic co-ordination is mostly good, people help each other, but I think it*  
492 *could develop more.” (Male District P, FGD).*

493 *“We are on the HIV committee which is active in each department.” (Female*  
494 *District Co-P, FGD)*

495 Some co-providers felt the need for greater recognition of their contribution, one approach  
496 suggested for this would be to give those who had acquired a certain level of accredited  
497 training a formally certified role in the ART clinic:

498 *“We have the ability, but don’t have the confidence to speak out.” (Female Provincial*  
499 *Co-P, Workshop)*

500

501 **Performance Gaps**

502 ART guidelines – where they had been issued to HIV clinics– were thought to be effective  
503 and were used frequently in order to check dosing, side effects and all medical issues likely  
504 to be encountered in the HIV clinic. However providers felt there were deficiencies in  
505 psychosocial guidance, adolescent issues, communications and disclosure,

506 *“We have hardly any tools for this [communication with patients] at all, really*  
507 *very few... We don’t see anything new like for example, how to deal with*  
508 *teenagers” (Female District P, FGD)*

509 In contrast, some co-providers, noted they had received valuable additional guidelines from  
510 other sources, this district hospital respondent felt this contributed to the performance of  
511 the team overall:

512 *“We receive them [guidelines] from the network; we have guidance in*  
513 *communication with HIV-infected children, how we should talk to them, care*  
514 *for them, what we should ask them, stigma, problems at school and so on”*  
515 *(Female District Co-P, FGD).*

516 Co-providers suggested (and demonstrated) that, as a result of the involvement of national  
517 PLHIV network members in HIV-policy formulation, they received up-to-date guidelines and  
518 information about HIV policies. Their knowledge sometimes preceded and/or exceeded that  
519 of the hospital staff; for example, they were aware of the right to annual-viral load testing  
520 before some hospital employees. They regarded this knowledge as potentially helpful  
521 particularly in hospitals where staff turnover was high and clinical staff might struggle to  
522 keep up with developments across the health sector. Such contributions were generally  
523 well-accepted by hospital staff at all sites.

524

525 Paediatric-specific issues were an area where performance of providers and co-providers  
526 was uneven and some policy makers felt that paediatric HIV support lagged behind adult  
527 support services.

528 *“Work with children has not yet reached the results that we want to see. For*  
529 *example, working on attitudes... Frequently people [providers and charities] simply*  
530 *don’t know what to do with such children, so they just ‘release’ them” (Female Pol*  
531 *NGO, interview)*

532 One reason suggested for this was that co-providers were initially based in adult ART clinics  
533 and support for children only emerged gradually as the need was recognized. Some co-  
534 providers, and indeed hospital staff, expressed limited experiences with paediatric-HIV  
535 issues; co-providers themselves did not necessarily have HIV-positive children of their own  
536 or any direct experience of them beyond their volunteer duties. They suggested their  
537 existing skills could be usefully developed and productivity improved by expanding  
538 knowledge on specific areas relating to nutrition, children’s rights, clinical management of  
539 paediatric ART, sex education, communicating with adolescents and special psychosocial  
540 support for individual vulnerable children such as orphans and those with elderly caregivers.  
541 It was suggested that acquisition of these and other paediatric skills would counter the  
542 sense that they (sometimes) feel exploited or under-used due to the perceived tendency of  
543 clinic staff to allocate menial tasks to them.

544

#### 545 **DISCUSSION**

546 Within the context of northeastern Thailand our study shows that as paediatric HIV service  
547 co-providers, volunteers constitute a critical interface between community, family and clinic.  
548 Using the framework developed by Yaya-Bocoum *et al* [4] as a basis for this analysis we  
549 observed both the effects and the potential that co-providers have for health systems within  
550 the supply and demand spheres: although the distinction between these two spheres was

551 sometimes blurred due to overlapping contributions. Co-providers were seen to have an  
552 important linking role: clinics and communities; patients and hospital staff. Their work  
553 frequently made the difference between merely *adequate* provision of care and a *holistic*  
554 provision of care.

555

556 On the demand side there was a high level of appreciation of the added value co-providers  
557 bring by taking services to the community; it created accessible and equitable provision of  
558 services on a range of health and support issues. On the supply side co-providers were seen  
559 as a valuable human resource that helped mitigate staff retention and turn-over problems,  
560 improved team performance and efficiency and filled gaps in service provision and through  
561 bringing additional skills to the team. Services were threatened due to the reduction of  
562 government and other funding sources.

563

564 Our data did not map exactly on to Yaya-Bocoum's framework of twenty health-systems  
565 effects. The effects that we identified were broader and more interlinking and lacked many  
566 of the potentially negative effects on the health system shown in their framework. For  
567 example, tension about roles, responsibilities and hierarchies; professional protectionism;  
568 frustration due to increased demand in services; and low motivation were not pronounced  
569 in our study. Documented challenges and limitations to task-shifting include investment for  
570 training, support and remuneration for staff and volunteers, integration of new members  
571 into health-care teams and the supervisory time load [44]. The issue of investment was  
572 indeed a problem in the Thai scenario; co-providers do have some costs and a long term  
573 funding commitment is essential to ensure both sustainable and effective services. There is a  
574 clear need to improve the funding mechanism. Financing PLHIV hospital activities was  
575 believed to be a sustainable and cost-effective measure by a World Bank review (in 2004)  
576 given the perceived benefits [29].

577

578 The findings reported here broadly corroborate limited existing evidence from Thailand  
579 relating to PLHIV interventions which cite their benefits such as sharing experiences,  
580 meeting people, a sense of solidarity, receiving information, learning about coping  
581 mechanisms, emotional support and feeling less isolated and more positive [45,46] and their  
582 impact on reducing the workload of hospital staff [47]. There is no published evidence from  
583 Thailand reporting the negative impact of PLHIV co-providers and contrary to the health-  
584 systems effects framework, in our study the effect of volunteer co-providers was largely  
585 positive. One reason for this may be that task-shifting in the context of Thai HIV services is  
586 long-established, the PLHIV network has been involved in HIV policy and service provision  
587 since the earliest days of the epidemic and has always had government backing as co-  
588 providers of HIV care.

589

590 There is an increasing focus on care and support for HIV at community level in line with task  
591 shifting approaches and initiatives to foster community peer support. There is little  
592 knowledge about what types of peer intervention work best, and why, except that success  
593 seems usually to be dependent on building upon existing relationships between peers and  
594 the target group [48]. The shared identity and experience of peer supporters is likely to  
595 support the motivation and commitment of co-providers some of whom are long-standing  
596 activists for HIV patients' rights and all of whom are part of a strong national network. They  
597 are able contribute as co-providers by drawing on their own personal experiences and  
598 unique position to support service-users as 'expert patients' who can move between the  
599 public-health system and individuals [14]. The needs of children are broader and more  
600 complex than those of adult patients [8,11-13]; our data show that the contribution of co-  
601 providers is valued in supporting these additional needs. Paediatric care involves a complex  
602 triangle of children, adults and caregivers; it also involves giving information and advice



603 appropriate to developmental stage and supporting the transition of childhood into  
604 adolescence. The potential to respond to these needs give co-providers in the Thai context  
605 a multi-dimensional role across policy, service provision and communities and an ideal task-  
606 shifting position for strengthening the health system across those spheres. Our data  
607 demonstrate the strong potential of a formal role of volunteers integrated as co-providers in  
608 paediatric HIV service provision that link and support HIV positive children, communities and  
609 clinics.

610

611 There are limitations to the capacity of the co-providers in this study and it is likely that  
612 intervention will be needed to maintain the motivation, skills and retention of this vital  
613 cadre. Our study highlighted the need for recognition and more formal integration of PLHIV  
614 volunteers (such as certification and accreditation of training). Capacity would inevitably be  
615 strengthened by their participation in formal HIV team training and meetings that are  
616 organized through the Ministry of Public Health.

617

618 Our findings suggest a systems-thinking approach is a logical one which, at policy level,  
619 involves standing back from individual components and keeping the strengthening of the  
620 whole system in mind when designing and evaluating innovations [49]. It is likely that the  
621 contributions of co-providers in the Thai HIV programme are not actually perceived by most  
622 policy actors as task-shifting *per se*, nor as having a role in health systems strengthening and  
623 this oversight may ultimately limit their potential. While the conditions described in this  
624 paper may appear unique to the Thai context, there is evidence of scope for transferability.  
625 The PLHIV model and training curriculum has been adapted and exported to other countries  
626 in the region: Vietnam, Cambodia, Laos, Nepal, Burma and Yunnan in Southern China [28].  
627 This demonstrates willingness from other Asian nations to learn from the Thai experience  
628 and to enhance HIV service provision through task-shifting to this cadre. Distribution of

629 some child and adolescent specific tools enhanced the quality of services but it was felt  
630 more focus on paediatric skills for co-providers was needed.

631

632 Our study has several limitations. Service-user respondents were selected by health care  
633 workers, interviewed at health facilities and were recruited from a cultural group previously  
634 documented as averse to expressing criticism [50,51]. There was indeed a general reluctance  
635 from service-users to criticize providers, and adolescents in particular were reticent to  
636 express themselves fully although efforts were made to mitigate this by use of a trained and  
637 experienced PLHIV social worker interviewer. It was possible to recruit few adolescents for  
638 interview, therefore the service-user perspective is largely one of adults used as proxy  
639 respondents. There was unease among policy actors to discuss financing issues possibly as a  
640 result of the restructuring of the recent financing of the health sector. Data on health  
641 outcomes effects (part of the evaluation framework) were beyond the scope of this study,  
642 our findings suggest a further larger study with focus on health-systems strengthening  
643 would be beneficial. Existing evaluations of task-shifting have not tended to focus on their  
644 impact on health-systems [4]. Qualitative techniques have enabled recognition of the value  
645 of PLHIVs as co-providers, but future evaluation would benefit from the development of  
646 additional measurable indicators.

647

#### 648 **CONCLUSION**

649 Motivated PLHIV volunteers constitute a critical interface between families and health  
650 services in paediatric HIV care in Thailand. Using volunteers as co-providers for specific  
651 clinical services, can contribute to strengthening health systems in Asia both from the  
652 demand side (patient and the caregiver) perspectives and from the supply-side (human  
653 resources). Our findings can help to inform policy makers and service providers on how to  
654 balance clinical priorities with psycho-socio responsiveness and on how best to integrate the

655 views and experience of volunteers into a holistic and equitable model of care. In order to  
656 optimise and sustain the vital contribution of volunteer co-providers an approach that  
657 embeds them within the health systems is required. They, as any other human resource  
658 require support, training, coordination and motivation from the health system alongside the  
659 recognition and appreciation from service-users, communities and individual health care  
660 workers.

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