Author’s response to reviews

Title: The patient voice: A survey of worries and anxieties during health system transition in HIV services in Vietnam

Authors:

Shoko Matsumoto (smatsumo@acc.ncgm.go.jp)
Hoai Dung Nguyen (dnguyenh2024@gmail.com)
Dung Nguyen (dung.niitd@gmail.com)
Giang Tran (giangminh08@gmail.com)
Junko Tanuma (jtanuma@acc.ncgm.go.jp)
Daisuke Mizushima (dmizushi@acc.ncgm.go.jp)
Kinh Van Nguyen (kinhvn@nhtd.vn)
Shinichi Oka (oka@acc.ncgm.go.jp)

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Author’s response to reviews:

Technical Comments:
Authors email addresses
- Please include a title page at the front of your manuscript file. It contain, at minimum, the names, institutions, countries and email addresses of all authors, and the full postal address of the submitting author.

In accordance with your suggestion, we have added email addresses for all authors to the title page.

Editor Comments:
1. Please do not capitalize "Patient" in the title.
Thank you for pointing this out. We have changed the word to “patient.”

In Title (page 1, line 1):
The patient voice: A survey of worries and anxieties during health system transition in HIV services in Vietnam

2. The "Background" page line 31: perhaps it could be noted what kind of facilities the SHI-registered facilities are if they are not urban hospitals.
Thank you for your valuable comment. To be eligible for SHI coverage for HIV services, PLHIV must obtain a SHI card that can be used only in a SHI-registered health facility near their registered
residence or in same-level facilities of SHI-registered hospitals/clinics in the same province. We have revised the manuscript to explain this, as follows:

In the Background section (page 3, lines 91–96):
“As ART has been provided free of charge mainly owing to the support of international donors, many HIV patients are currently served by central urban hospitals and receive better quality of care. However, to be eligible for SHI coverage for HIV services, PLHIV must obtain a SHI card that can be used only in a SHI-registered health facility near their registered residence or in same-level facilities in a SHI-registered hospital/clinic in the same province.”

3. Same page, line 41: Can it be said briefly why the patients didn't have copays at the hospitals where they have been served?
Thank you for your comment. As ART and most of the HIV services have been provided by international donor programs, HIV patients did not need to pay any treatment fee in their copayments. We have revised the manuscript accordingly:

In the Background section (page 3, lines 91–93):
“As ART has been provided free of charge mainly owing to the support of international donors, many HIV patients are currently served by central urban hospitals and receive better quality of care.”

4. Same page, first sentence of last paragraph: The sentence states what looks like a strong opinion about how the transition has been progressing. Is there a reference for this statement?
Thank you for your comment. Although previous reports and our experience in day-to-day clinical practice in NHTD have identified several barriers to achieving universal SHI coverage in HIV patients, we think that these have not yet been fully addressed. The donor- and government-led transitions have been progressing rapidly, and we strongly feel that patients have been left behind during the transition. However, we accept that the tone of this sentence was too strong and we revised it accordingly and added a reference:

In the Background section (page 4, lines 105–106):
The above-mentioned transition seems to be progressing rapidly owing to strong political commitments rather than patient-centered approaches [10].

5. Same page, line 49: Please rewrite using passive voice without the "we" since the reader doesn't know who "we" is.
In accordance with your advice, we revised the manuscript as follows:

In the Background section (page 4, lines 106–109):
“To achieve universal health coverage and to ensure a decentralized service delivery system that meets the needs of PLHIV, it is important to listen carefully to patients’ voices to safeguard the continuation of effective, local HIV treatment, and to prevent patients from worrying about the new health system.”

6. "Materials and methods" page: Why the quotation marks around "Hanoi cohort"?
Thank you for your comment. The quotation marks were used as this is the specific name given to the cohort established in NHTD. We changed the sentence as follows:
In “Study design and study subjects” in the Materials and methods section (page 4, lines 117–119):
“This cohort, the so-called “Hanoi cohort,” was established in 2007 at the HIV outpatient clinic at the National Hospital for Tropical Diseases (NHTD), one of the largest central-level HIV clinics in Hanoi, Vietnam.”

7. For all the multiple choice questions, were respondents asked to specify an answer when they chose “Other”?
We provided a space for comments next to the “Other” option. The respondents could provide explanations in this space, although this was not mandatory. We have clarified this as follows:

In “SHI coverage” in the Materials and methods section (pages 5, lines 136):
“If they selected “Other,” they were able to provide reasons (although this was optional).”

In “Concerns about receiving HIV services in SHI-registered hospitals/clinics” in the Materials and methods section (page 5, lines 145–146):
“If they selected “Other,” they were able to provide reasons (although this was optional).”

In “Willingness to regularly visit the current hospital” in the Materials and methods section (page 5, lines 154–155):
“If they selected “Other,” they were able to provide reasons (although this was optional).”

8. The explanation in the discussion section under “Strengths and limitations” of how the multiple choices were developed for the questionnaire should be in the methods section.
Thank you for your comment. We have added an explanation of how we developed the questionnaire to the Methods section.

In “Study design and study subjects” in the Materials and methods section (page 4, lines 124–127):
“To develop the questionnaire used in this survey, an expert panel was formed by HIV/AIDS specialists, including HIV clinicians, social workers, and a social epidemiologist. The panel developed the questionnaire and response options using information from previous relevant reports [10, 11] and experiences in day-to-day clinical practice.”

9. The first sentence under "Toward universal SHI coverage" should be rewritten as "...is not an issue only in Vietnam". ("only" is misplaced)
Thank you for pointing this out. We have rephrased to ensure that “only” is in the correct place.

In “Toward universal SHI coverage” in the Discussion section (page 8, line 271):
“The transition of HIV finance is not an issue only in Vietnam.”

Reviewer reports:
Introduction:
1. More details on SHI schemes are needed for readers to understand the broader context of health insurance in Vietnam. What does "social health insurance" mean? Does it include both "compulsory" and "voluntary" health insurance? What is covered in this paper?
Thank you very much for your valuable comment. We have added an explanation of the SHI scheme in Vietnam to the Background section as follows:
In the Background section (page 3, lines 77–83):
“After 3 years of piloting voluntary health insurance schemes in some provinces, Vietnam introduced social health insurance to all provinces in 1992 to cover formal-sector workers and pensioners. With the goal of universal coverage, the Vietnamese government issued the first SHI law (Decree No. 63) in 2008, which expanded coverage to people experiencing poverty by fully subsidizing premiums for this group and informal-sector workers. To increase universal health coverage, the SHI law was revised in 2014 and SHI became mandatory for all citizens [3].”

Methods:
2. Study participants: It is not clear if the study participants (received HIV services and recruited at NHTD) had already been "decentralised" to receive HIV service at their SHI registered health facilities? Or they are still attending OPC at NHTD at the time of the survey. The question "Do you have any concerns about receiving HIV services in your SHI-registered health facilities" provided database on participant's perception or experience?

Thank you for your important comment. This survey was conducted at NHTD before the start of the decentralization. All respondents were receiving ART and other HIV services at NHTD at the time of the survey. Participants responded to the question “Do you have any concerns about receiving HIV services in your SHI-registered health facilities” based on their perception. We have clarified this in the manuscript as follows:

In “Study design and study subjects” in the Materials and methods section (page 4, lines 119–121):
“At the time of the survey, the Hanoi cohort participants were still regularly receiving ART and other HIV services in NHTD, and they were invited to complete the survey during their regular consultations.”

In “Methods” in Abstract (page 2, lines 36–38):
“Insurance coverage, reasons for not having a SHI card, perceived concerns about receiving HIV services in SHI-registered local health facilities, and willingness to continue regularly visiting the current hospital were self-reported.”

In “Concerns about receiving HIV services in SHI-registered hospitals/clinics” in the Materials and methods section (page 5, lines 139–144):
“The presence of perceived concerns about receiving HIV services in SHI-registered hospitals/clinics was evaluated with the question “Do you have any concerns about receiving HIV services in your SHI-registered health facilities?”; possible responses were “yes” or “no.” Participants with perceived concerns were then asked about the nature of their concerns; possible responses were “Disclosure of HIV status to neighbors,” “Low quality of HIV services,” “Fear of not getting along with unfamiliar medical staffs,” and “Other.””

Justifications for categorisation of variables are needed e.g. duration of receiving services at NHTD (<5 year (why?), 5-9, >10 years?), residence (Hanoi/around Hanoi (? which ones how far?)/others Thank you for your comment. To categorize duration of receiving HIV services at NHTD, we used the 25% percentile (66 months) and the 75% percentile (112 months) for the cutoff value. For residence, we used three categories to differentiate between provinces around Hanoi and other provinces. “Provinces around Hanoi” included eight provinces bordered by Hanoi, which are regarded as neighbor provinces. “Other provinces” referred to provinces that are a substantial traveling distance from Hanoi. Individual income was categorized according to monthly income per capita in 2012, as reported by the General Statistics Office of Vietnam. Educational attainment was divided into three groups: low (never went to school, primary school, or junior high school), middle (high school), and high (vocational
school/college or university), based on the fact that Vietnam is a relatively highly educated country: the primary school enrollment rate reached over 90% and the tertiary education enrollment rate reached 25% to 30% in 2018.

We have added an explanation of these categories to the manuscript accordingly:

In “Demographics and HIV-related factors” in the Materials and methods section (pages 5 & 6, lines 163–177):
“Duration of receiving HIV services at NHTD was divided into the following categories using 25% and 75% percentile values: <5 years, 5–9 years, and ≥10 years. Marital status was divided into two categories: married and not married (including divorced or widowed). Residence was divided into three categories: Hanoi, provinces around Hanoi, and other provinces. Provinces around Hanoi included eight provinces bordered by Hanoi and regarded as neighbor provinces. “Other provinces” referred to provinces that are a substantial traveling distance from Hanoi. Employment was categorized as not employed, employed, or retired. Individual income was divided into the following categories according to monthly income per capita in 2012, as reported by the General Statistics Office of Vietnam [12]: low (<1,500,000 Vietnamese dong [VND]), middle (1,500,000–4,999,999 VND), and high (≥5,000,000 VND) (1 VND = 0.000043 USD). Disclosure of HIV status was evaluated dichotomously. Educational attainment was divided into three groups based on the fact that the primary school enrollment rate reached over 90% and the tertiary education enrollment rate reached 25% to 30% in 2018 [13]: low (never went to school, primary school, or junior high school), middle (high school), and high (vocational school/college or university).”

3. Variable selection for regression should be theoretically, not statistically driven as previous researches have examined and identified factors associated with outcome of interest (health insurance coverage)
Thank you for your important comment. We developed the questionnaire on the basis of information from previous research and experiences of the expert panel in their day-to-day clinical practice. However, in the multivariate model we used variables that had p-values <0.05 in the univariate analysis for adjustment, solely to identify the factors that were strongly related to the outcome variables. We have added an explanation of how the questionnaire was developed to the Methods section as follows:

In “Study design and study subjects” the Materials and methods section (page 4, lines 124–127):
“To develop the questionnaire used in this survey, an expert panel was formed by HIV/AIDS specialists, including HIV clinicians, social workers, and a social epidemiologist. The panel developed the questionnaire and response options using information from previous relevant reports [10, 11] and experiences in day-to-day clinical practice.”

Results:
4. 22.9% participants had history of IDU & 20.9% those who don't have SHI card "don't know how to get it" indicates that a significant portion of study subjects may not/cannot be covered under "compulsory" health insurance. This needs to be explained in more details in the discussion
Regarding the route of HIV transmission in Vietnam, the HIV epidemic is concentrated in key populations, including people who inject drugs. Therefore, it was not unexpected that we found that 22.9% of patients had an IDU history. We have added information about the mode of HIV transmission to the Background section.

In the Background (page 3, lines 66–68):
“The HIV epidemic is concentrated in key populations, including people who inject drugs; 45% of new infections in 2013 occurred among men who shared needles when injecting drugs [2].”

We also added a discussion about the lack of information as a major reason for not having a SHI card to the discussion section, as follows:

In “Toward universal SHI coverage” in the Discussion section (page 9, lines 291–307):
“Feeling that it was burdensome to obtain a SHI card and lacking information on how to obtain a SHI card were the most frequently reported reasons for not having one, and younger age (&lt;40 years old) and being unmarried were identified as possible risk factors. A burdensome feeling could arise for various reasons, including complicated administrative procedures for SHI registration, long waiting times, or feeling that a card is not necessary [11]. As SHI cards are issued based on residential information, disclosure of HIV status to others at the time of obtaining a card may be an additional reason for not having one. Alternatively, the reported lack of information about obtaining SHI cards may reflect patient lack of interest in SHI, as well as problems related to availability and accessibility of information. In particular, it may be difficult for younger people to understand the benefits of SHI, and unmarried persons might be less motivated to enroll into SHI. As previously suggested, providing adequate information about SHI could encourage the enrollment of PLHIV in SHI [7, 11, 19]. In a previous study, we found that family is often the only and the strongest supporter of PLHIV [20]. Raising awareness of the necessity and benefits of SHI, especially among younger and unmarried individuals, and providing support tailored to individual needs (e.g., the most convenient way to register for SHI) for both patients and family could enhance the understanding of SHI enrollment and patients’ willingness to join SHI and help to achieve universal SHI coverage.”

22% "do not have SHI card" and 86% "had concerns about receiving…” are large outcomes. Odds ratio overestimates the association. Appropriate method to estimate risk ratio is preferred and should be used (e.g. Poisson regression with robust standard error)

Thank you for your suggestion. We used logistic regression in this study as it is the most widely used statistical method for cross-sectional studies with binary outcomes. Although, as you point out, the odds ratios estimated in logistic regression may overestimate the prevalence ratio, and the interpretation of odds rations are somewhat unintuitive, the odds ratios produced by logistic regression were not inherently incorrect. In the manuscript, we discussed the factors significantly associated with “not having a SHI card” and “having concerns about receiving HIV services in SHI-registered hospitals/clinics,” but did not discuss the estimated effect sizes, as we believe that the former message is more important than the latter for our study purpose. For these reasons, we think that logistic regression is still applicable for this study.

Discussion:
5. The first paragraph is repeated and should be placed in the result
   The first paragraph is the introductory paragraph summarizing the study aims and the basic findings. An introductory paragraph in the Discussion is often recommended to assist readers in understanding the subsequent discussion.

6. As commented above procedures for individual obtaining health insurance card should be described and discussed
   Thank you for your comment. We have added some general information about the use of the SHI in Vietnam to the Background section in response to your previous comment (please see Introduction 1.), and have added a related discussion of this issue to the Discussion section as follows:
In the Background (page 3, lines 77–83):
“After 3 years of piloting voluntary health insurance schemes in some provinces, Vietnam introduced social health insurance to all provinces in 1992 to cover formal-sector workers and pensioners. With the goal of universal coverage, the Vietnamese government issued the first SHI law (Decree No. 63) in 2008, which expanded coverage to people experiencing poverty by fully subsidizing premiums for this group and informal-sector workers. To increase universal health coverage, the SHI law was revised in 2014 and SHI became mandatory for all citizens [3].”

In the Background (page 3, lines 91–96):
“As ART has been provided free of charge mainly owing to the support of international donors, many HIV patients are currently served by central urban hospitals and receive better quality of care. However, to be eligible for SHI coverage for HIV services, PLHIV must obtain a SHI card that can be used only in a SHI-registered health facility near their registered residence or in same-level facilities in a SHI-registered hospital/clinics in the same province.”

In “Toward universal SHI coverage” in the Discussion section (page 9, lines 295–297):
“As SHI cards are issued based on residential information, disclosure of HIV status to others at the time of obtaining a card may be an additional reason for not having one.”

7. The study sample may not be "representative" for the whole PLHIV population in Vietnam & should be taken into account in the discussion

Thank you very much for your important comment. We agree that our results may not be applicable to the whole HIV population in Vietnam, as various factors related to HIV services, including financial support for SHI and ART, differ between provinces. Therefore, we have mentioned this limitation in the discussion of SHI coverage.

In “Toward universal SHI coverage” in the Discussion section (pages 8 & 9, lines 277–290):
“At NHTD, one of the largest HIV clinics in Hanoi, the SHI coverage was 78%, indicating that SHI enrollment has been rapidly progressing (40% in 2014 [5]), but that universal SHI coverage has not been reached. Although previous reports have highlighted financial burden as the main barrier to SHI access [11, 18], in this study, the most frequently reported reasons for not having a SHI card were that obtaining one was burdensome and there was a lack of information about accessing SHI, rather than financial problems. In addition, two finance-related variables (individual income and employment) were not associated with lack of a SHI card in the logistic regression analyses. Various recent policies and schemes introduced by central and local government (e.g., subsidies for premiums for people living in poverty and near-poverty, allocation of local budgets for purchasing SHI cards) might have successfully contributed to the expansion of SHI. This interpretation should be tested in other settings, as our study participants at NHTD may be receiving better financial support from local government and other authorities; such support may vary between provinces depending on their financial resources and commitment to HIV prevention and control.”

8. What is the definition of "universal SHI coverage"? 100% coverage? The 78% SHI coverage in this sample is high? What is the national coverage? In the general population and in PLHIV? The authors should provide these statistics to give more broader context for the discussion

Thank you for your valuable comment. We defined “universal SHI coverage” as 100% SHI coverage. We have clarified this in the Background section.
“As part of the transition from donor-based to SHI-based HIV service delivery, a Prime Minister’s Decision (No. 2188/QD-TTg) was issued in 2016 that introduced a new goal of 100% SHI coverage (hereafter referred to “universal SHI coverage”) for PLHIV by 2020.”

We also added information about SHI coverage in the general population to the Background and Discussion sections.

In the Background (page 3, lines 83–85):
“According to a report from the Vietnam Social Security (VSS), Vietnam has achieved a remarkable increase in SHI coverage; the number of health insurance card holders reached 83.5 million (88.5% of the total population) in 2019 [4].”

In “Toward universal SHI coverage” in the Discussion section (page 8 & 9, lines 277–279):
“At NHTD, one of the largest HIV clinics in Hanoi, the SHI coverage was 78%, indicating that SHI enrollment has been rapidly progressing (40% in 2014 [5]), but that universal SHI coverage has not been reached.”

9. The discussion related to "quality of health services...." needs clarification/context: perceived quality... or actual experienced receiving HIV services at decentralised care?
   As mentioned above (please see Methods 2.), this survey was conducted at NHTD before the start of decentralization. All respondents were receiving ART and other HIV services at NHTD at the time of the survey. Participants were asked about their perceived concerns. Therefore, concerns about the quality of health services at SHI-registered hospitals/clinics reflect their perception, not their actual experience. We have clarified this in the manuscript as follows:

In “Study design and study subjects” in the Materials and methods section (page 4, lines 119–121):
“At the time of the survey, the Hanoi cohort participants were still regularly receiving ART and other HIV services in NHTD, and they were invited to complete the survey during their regular consultations.”

In “Concerns about receiving HIV services in SHI-registered hospitals/clinics” in the Materials and methods section (page 5, lines 139–144):
“The presence of perceived concerns about receiving HIV services in SHI-registered hospitals/clinics was evaluated with the question “Do you have any concerns about receiving HIV services in your SHI-registered health facilities?”; possible responses were “yes” or “no.” Participants with perceived concerns were then asked about the nature of their concerns; possible responses were “Disclosure of HIV status to neighbors,” “Low quality of HIV services,” “Fear of not getting along with unfamiliar medical staffs,” and “Other.””

10. Selective sample” attending HIV services at national hospital for a long period, leaving outside of Hanoi (must have economic means to visit clinic regularly) … should be considered a limitation
   Although we have already noted this limitation under “Strengths and limitations” in the Discussion section, we have added some text to clarity this.

In the “Strengths and limitations” in the Discussion section: (page 11, lines 373–375):
“However, a few limitations should be acknowledged. First, as this was a single-center study, the participants who were receiving HIV services at a central urban hospital may not be representative of Vietnam’s entire HIV population.”
Conclusion
11. No data supporting "SHI coverage progress rapidly"

We have added data in response to a previous question (please see Discussion 8.).

In “Toward universal SHI coverage” in the Discussion section (page 8 &amp; 9, lines 277–279):
“At NHTD, one of the largest HIV clinics in Hanoi, the SHI coverage was 78%, indicating that SHI enrollment has been rapidly progressing (40% in 2014 [5]), but that universal SHI coverage has not been reached.”