

# APN PLUS POSITIVE CHANGE

## LIVING LONGER WITH HIV IN THE ASIA PACIFIC

A PEER-LED STUDY BY APN+

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## INTRODUCTION

HIV has become a manageable chronic illness with the advent of combination antiretroviral therapy (NIH 1998). Since then, while HIV positive persons may entail phases of acute illness, the effectiveness of the medication means HIV infection is no longer the death sentence it once was (Reiter, 2000). Indeed, with current projections indicating that positive persons in therapy are likely to live a normal lifespan (The Mills et al. 2011; Antiretroviral Therapy Cohort Collaboration 2008), scientific research has shifted its focus towards HIV and aging. However, a quick look at the literature shows that this light of inquiry has often been narrowly focussed on the perspectives of biomedicine and in Western contexts, with the predominance of studies concentrating on the acceleration of diseases associated with aging (eg. Effros et al. 2008; Stoff et al. 2004) and the toxicity of long-term effects of ARV (eg. Gilks et al. 2006; Casau 2005). In addition, with current HIV and aging biomedical research determined by the biological age of cohorts rather than the length of time cohorts have been living with HIV, these studies inevitably disregard younger cohorts who have been living longer with HIV. We feel that these narrow foci have created knowledge gaps that need to be redressed, and forward an alternative view of HIV and aging. We propose three points of departure: first, we centre on positive persons' portrayals of living with HIV in contrast with the objective focus on disease and toxicity; second, our criterion of living longer is based upon having lived 10 years or more with HIV rather than focusing on age specifics; and third, we specifically focus on the experiences of positive persons living in the Asia Pacific region.

## Research Objectives

This study has the following objectives:

1. To raise awareness and encourage discussion among positive people in the Asia Pacific region about living longer (10+ years) with HIV;
2. To create a body of knowledge about living longer with HIV that is culturally and/or norms specific to the Asia Pacific region;
3. To inform advocacy on appropriate, effective and sustainable responses to living longer with HIV;
4. To lead a positive community-centred response of living longer with HIV in the Asia Pacific region.

## Review of Literature

This review does not intend to offer an exhaustive survey of available literature. Guided by a study group composed of individuals who have lived with HIV for 10 years or more organized by the Asia Pacific Network of People Living with HIV (APN+), the purpose of this review is to determine the important areas of lived experience that should be included in any study of living longer with HIV, be it in the Asia Pacific or elsewhere. In doing so, we take heed that "living with HIV in the era of effective treatments is not solely about living longer through treatment use but it is

also about living well, and living well is an existential experience that is subjectively defined, assessed and performed.” (Wong and Ussher 2008: 128). Within the subjective domains of lived experience, consultations with the study group and a survey of literature have established the common themes of psychosocial wellbeing, treatment access and adherence, career prospects and economic wellbeing, role of the family, and sexual and romantic relationships. Each of these domains is explored below.

### *Psychosocial wellbeing*

It was the late Jonathan Mann who had identified stigma, discrimination and denial as the third phase of the epidemic after the first two phases of HIV and AIDS. In their seminal work, Parker and Aggleton (2002) conceptualized how HIV compounded pre-existing stigma in society, such that not only was HIV being associated to marginalized behaviours, but positive persons were presumed to come from marginalized groups; sparking thus a vicious cycle of discrimination against them. The evidence of linkages between stigma and discrimination and psychosocial wellbeing were clear: an Indian study comparing levels of stigma in positive persons with people infected with leprosy found that positive persons had higher levels of internalized and perceived stigma, which had curtailed their social participation (Stevenson et al 2011). It was therefore unsurprising that a recent review of psychosocial problems of positive persons found that people living with HIV faced three key decisions in their lives: status disclosure, adherence to treatments, and decisions on sexual activity and parenthood. However, notwithstanding the universality of stigma faced by positive persons, and the centrality of psychosocial aspects in their lives, a review had revealed few studies that looked at the psychosocial needs positive persons (Bravo et al. 2010). With new evidence showing that happy people lived longer (Diener and Chan 2011), it is thus crucial that the psychosocial needs of positive people, and barriers to fulfilling those needs, are both identified and met. In this respect, it is pertinent to note that a study on quality of life constructs among positive persons in Hong Kong have found that psychosocial aspects were more important in characterizing their quality of life than either their physical functioning or the presentation of HIV-related symptoms (Ho et al. 2010).

### *Treatment access and adherence*

Psychosocial wellbeing and treatment access and adherence are intricately related. A systematic review of treatment adherence in developing Asian countries found that mental health disturbance, fear of disclosure, and stigma and discrimination were key individual and social factors impeding treatment access and adherence. On the other hand, the availability of family and social support positively impacted treatment outcomes (Wasti et al. 2012). An APN+ peer-led study to document HIV-related discrimination in Asia found that discrimination predominantly occurred in the healthcare setting and included breaches of confidentiality (Paxton et al. 2005). Among marginalized populations such as injection drug users, evidence showed that systemic and institutionalized discrimination compounded barriers to treatment access (Wolfe et al. 2010); with the situation made worse among those with substance use and mental health co-morbidities (Gonzalez et al. 2011).

### *Career prospects and economic wellbeing*

The advent of highly active antiretroviral therapy (HAART) saw improving and sustained health outcomes for positive persons to keep working and enabled many who previously had to leave employment due to ill health to return to work (Hunt 2003). However, positive persons in Asia still face real possibilities of discrimination at work. These ranged from duties being changed, to loss of promotion, and their eventual dismissal if ever their HIV status had become known (Paxton et al 2005). A small survey on diversity management among Asian multinational and national

companies had found that most companies had no formal or informal policies to help positive workers disclose their HIV status and to manage existing and future positive employees (Yap and Ineson 2012). This finding was supported by a comparative survey of Thai public-listed companies conducted between 1998 and 2007, which concurred that the lack of proactive HIV workplace policies had persisted throughout the decade (Busaya and McLean 2010). Of concern, there were few recent studies investigating employment and career prospects for positive persons in the Asia Pacific region. Furthermore, sustaining a level of economic wellbeing in the face of HIV remains a challenge. Households where the primary breadwinner is positive, or where there are multiple persons are infected with HIV, can easily be overwhelmed. Studies have shown that the economic burden of HIV and AIDS can be catastrophic, reaching more than the annual household income in developing countries (Russell 2004). HIV is, in short, an economic burden for many positive individuals and their families.

### *Role of the family*

The role of the family in Asia Pacific HIV-affected households is complex. In many cases, families have often taken on the informal burden of care giving (Vithayachockitikhun 2006) and have been found to exert a positive influence in treatment adherence (Wasti et al. 2012; Knodel et al. 2011). Among gay Asian Pacific islanders, an in-depth study has shown that families influenced sex behaviours through the perception of familial obligation and a sense of shame (Han et al. 2009); elements not unlike the filial piety characteristics that been observed among Chinese migrant gay men (Chapman et al. 2009). However, the roles families played in the lives of positive persons can also be negative, such as when families stigmatize and discriminate against positive persons. Negative relationships were unfortunately also more common among women than men (Paxton et al. 2005). For example, a Vietnamese study found that women married to positive male partners had been pressured by their in-laws to have children in order to produce a male heir to carry on the family lineage, often by having their husband's HIV status concealed from them (Oosterhoff et al. 2008). However, despite the centrality filial piety and its possible impacts on behaviour in the Asia Pacific, as well as the importance of familial systems as social support structures, it was surprising to find few studies that explored these relationships between HIV-affected individuals and their families.

### *Sexual and romantic relationships*

There was a serious lack of studies exploring sexual and romantic relationships among positive persons (Schiltz and Sandfort 2000). Sexual relationships reported in the literature tended to be singularly framed by public health discourses that centred on HIV prevention, risk behaviour from sex without condoms and substance abuse, and which focused mainly on most-at-risk populations (eg. Chaiyamahapurk et al. 2010; Elford 2006; Rhodes and Cusick 2000). Crucially, there was hardly any literature on the normalcy of sexual relationships among positive persons. Given the importance of sexual health in contributing to overall individual wellbeing, this omission was unexpected. Justifiably, HIV positive persons would benefit from research that went beyond the limiting constructs of public health. Some of the areas of possible interest are: exploring how to initiate and develop more stable sexual or romantic relationships; addressing issues on the disclosure of HIV status and sexual preferences between partners; and the fostering of sexual empowerment.

Taken together, each of these areas can have profound effects and compounding impacts on positive persons as they live longer with HIV. In contextualizing these domains in the cultural norms of this region, the primary research question we seek to answer is what it means to be living longer with HIV in the Asia Pacific.

## Research Questions

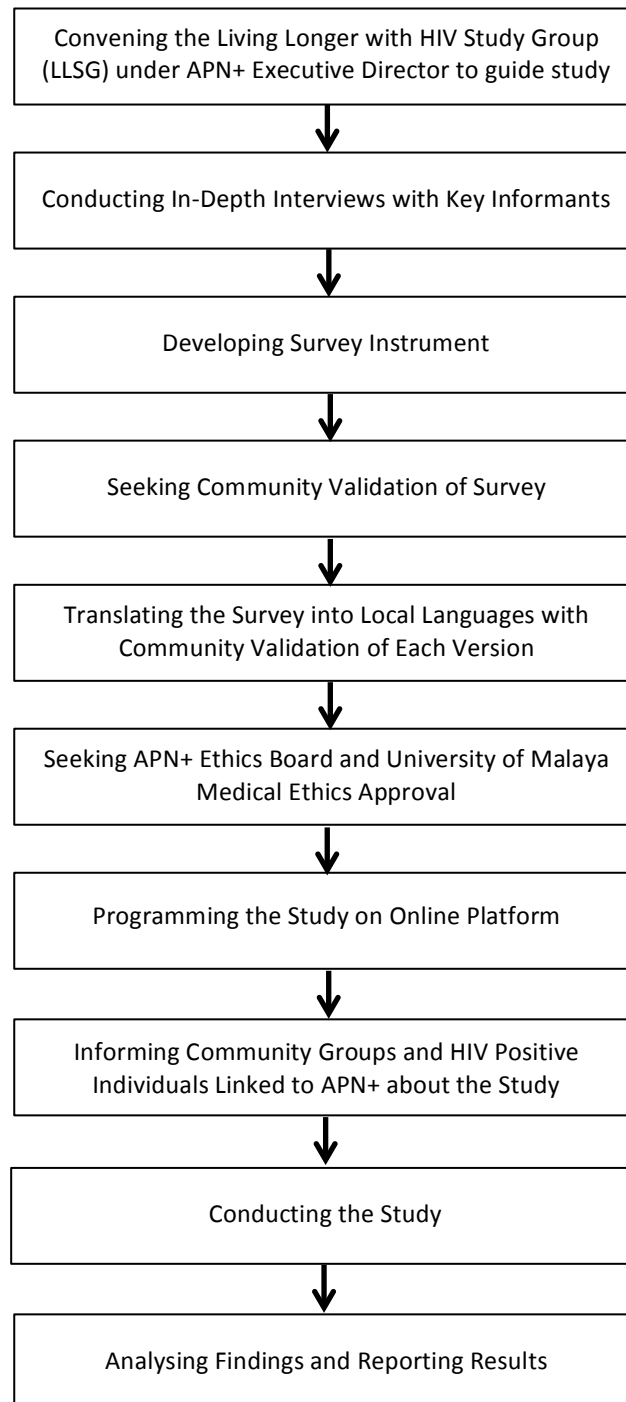
From the review of literature, this study was conceptualized to answer the following research questions about people living longer (10 or more years) with HIV in the Asia Pacific:

1. How is their psychosocial wellbeing (economic, social, general health, comorbidities)?
2. How is their access to HIV treatment and health outcomes (viral load, CD4)?
3. What is their level of stigma?
4. What are the differences in characteristics and outcomes as the person lives longer (20 or more years vs. 10 – 19 years) with HIV?

## METHODS

The following flowchart provides a brief overview of the research process.

**Chart 1: Flowchart of Living Longer with HIV in the Asia Pacific Research Process**



### *Living Longer with HIV Study Group (LLSG)*

A Study Group comprising 2 men and 2 women living 10 or more years with HIV in the Asia Pacific and linked to APN+ convened under the direction of the APN+ Executive Director to guide the development of the study. To ensure variation of opinions, one of group has been living with HIV since her teens, another has been one of the longest surviving person with HIV in the region, and another was an ex-injection drug user. The group discussed the study regularly with the consultant researcher and provided the necessary context to design a study that would have been useful as an advocacy tool as much as it was to generate research knowledge.

### *Key informant interviews*

Members of the LLSG were also interviewed as key informants as people who have been successfully living with HIV. The LLSG also suggested individuals who might provide additional perspectives on the topic, and arranged for these interviews to take place in person or online. Key additional interviews included people living with HIV in the Pacific region, and people who were not involved with HIV work or connected to the network. In this manner, 5 other individuals were interviewed besides the members of the LLSG.

### *Survey instrument development*

The survey was developed in an iterative process with drafts of the instrument commented upon by the LLSG. This was to ensure the data generated by the survey might be useful from community advocacy and knowledge perspectives. The final instrument had 5 sections that were divided by themes. These were demographic characteristics, socio-economic issues including work, career, finances, status disclosure and social support, HIV treatment issues, HIV risk behaviour assessment, and stigma assessment with the Berger Stigma Scale.

### *Community validation*

The draft survey was validated by in-country community organisations and individuals linked to APN+ for appropriateness of language and contextual accuracy. Getting contextual information correct was key to the success of the survey given that the Asia Pacific region is the most diverse region in the world in terms of peoples, languages and cultures.

### *Translation of survey*

In-country community organisations helped to translate the English version of the survey into 7 other commonly used Asia Pacific languages. These were Chinese, Hindi, Indonesian, Khmer (Cambodian), Malay, Thai, and Vietnamese. The translated versions of the survey were also community validated prior to implementation.

### *Research ethics*

As part of the research process, the study founded the APN+ Ethics Committee to provide community ethical oversight. Living Longer with HIV in the Asia Pacific was the first study to be considered by the committee. The study has also been approved by the University of Malaya Medical Ethics Committee.

### *Survey Monkey*

The survey, and its language versions, was only made available online on the Survey Monkey platform. The survey was not password protected. Only completed surveys were included in the analysis.

### *Community mobilisation*

A call-out was made to in-country and regional community groups, individuals and affiliates of APN+ through its Yahoo listserve, to circulate information about the survey widely, and to encourage participation. Subsequent reminders were also sent out periodically, with the last one 2 weeks before the end of data collection.

### *Data collection*

Data collection began on 18<sup>th</sup> November 2013 at the launch of the survey at the 11<sup>th</sup> International Congress on AIDS in Asia and the Pacific (ICAAP) in Bangkok. To be eligible, participants had to be HIV positive for 10 or more years, were born and currently live in the Asia Pacific region, and aged 18 years or older. Data collection ended on 28<sup>th</sup> February 2014 with a total of 360 completed surveys.

### *Data analysis*

Descriptive statistics were performed to provide proportion of demographic and socio-economic variables of interest. These were differentiated between people living 10 – 19 years with HIV and those living 20 or more years with HIV. Measures of association were conducted to test the statistical difference in the distribution between these two groups. The Berger Stigma scale score was computed between 1 and 10, where 1 is the lowest level of stigma and 10 is the highest. Distinction was also made between the four components of stigma embedded within the scale to provide a better understanding of stigma in the population. Finally, logistic regression was performed on key proxy outcome indicators of economic, social, physical and mental wellbeing to predict factors that contributed to them. These proxy indicators were not having enough money for food in the past 3 months, currently on HIV treatment, ever been diagnosed with depression, and the occurrence of a high level of stigma (a score of 7 or more out of 10 on the Berger Stigma Scale).



## RESULTS

### Participant Characteristics

#### *Personal characteristics*

A total of 360 participants from the following 21 countries and territories completed the survey: Viet Nam, Thailand, Sri Lanka, South Korea, Singapore, Philippines, Papua New Guinea, New Zealand, Nepal, Mongolia, Malaysia, Laos, Japan, Indonesia, India, Hong Kong, Guam, Fiji, China, Cambodia, Australia. Participants were between 18 and 75 years with an average age of 40.95 years (and standard deviation of 8.76 years). Sixty-eight participants (19%) have been living with HIV for 20 or more years. The majority of participants was 35 years or older, male, heterosexual, and married. 34.5% (n = 120) were women and 2 individuals were transgender. 27.5% (n = 96) reported being homosexual, bisexual, transsexual, or queer. More than 3 in five (64%) participants have children. Age and sexuality were significantly associated with living 20 or more years with HIV. See Table 1 below.

**Table 1: Personal characteristics of people living with HIV in the Asia Pacific and associations with living 20 or more years with HIV (N = 360)**

Participant Characteristics	Total N (%)	Living with HIV		P-value
		10-19 years n (%)	20+ years n (%)	
<b>Age</b>				
35 or older	262 (73.6)	202 (69.9)	60 (89.6)	< .001
Younger than 35	94 (26.4)	87 (30.1)	7 (10.4)	
<b>Gender</b>				
Male	228 (65.5)	178 (63.3)	48 (71.6)	ns <sup>a</sup>
Female	120 (34.5)	103 (36.7)	17 (25.4)	
Transgender	2 (.6)	0 (-)	2 (3.0)	
<b>Sexuality</b>				
Heterosexual	253 (72.5)	217 (77.0)	36 (53.7)	< .001 <sup>b</sup>
Homosexual	52 (14.9)	35 (12.4)	17 (25.4)	
Bisexual	30 (8.6)	22 (7.8)	8 (11.9)	
Transsexual	3 (.9)	2 (.7)	1 (1.5)	
Queer	11 (3.2)	6 (2.1)	5 (7.5)	

**Table 1: Personal characteristics (continued)**

Marital status				
Married	197 (60.4)	160 (59.5)	37 (64.9)	ns
Single	129 (39.6)	109 (40.5)	20 (35.1)	
Has children				
No	117 (36.3)	92 (34.8)	25 (43.1)	ns
Yes	205 (63.7)	172 (65.2)	33 (56.9)	

*Note.* All variables have some missing values from non-response. <sup>a</sup> Chi Square performed on composite dummy variable of non-male which grouped female and transgender. <sup>b</sup> Chi Square performed on composite dummy variable of non-heterosexual which grouped homosexual, bisexual, transsexual, and queer. Pearson's Chi Square was used to measure association of variables of interest between those living with HIV for 10 – 19 years and 20+ years. *P*-values indicate observed variation is not due to chance. ns = not significant.

### *Socio-economic characteristics*

The majority (73%) of participants had a high level of education with 10 years or more years of formal education. Almost 4 in five participants were working, although almost half (48%) reported poor job security. More than 1 in ten reported previously been sacked from their jobs because they were HIV positive. More than 3 in five (64%) owned their homes but the majority (60%) was currently in debt, and over one-third (35%) reported not having had enough money for food in the past 3 months. Most (88%) of the participants had previous experience working or volunteering in an HIV-related organisation, and most (88%) reported having emotional support. Job status and having previously worked or volunteered in an HIV-related organisation were significantly associated with living 20 or more years with HIV. See Table 2 below.

**Table 2: Select socio-economic characteristics of people living with HIV in the Asia Pacific and associations with living 20 or more years with HIV (N = 360)**

Participant Characteristics	Total N (%)	Living with HIV		<i>P</i> -value
		10-19 years n (%)	20+ years n (%)	
Education level				
High	242 (73.1)	203 (74.6)	39 (66.1)	ns
Low	89 (26.9)	69 (25.4)	20 (33.9)	
Job status				
Working	256 (77.6)	217 (79.5)	39 (68.4)	< .1
Not working	74 (22.4)	56 (20.5)	18 (24.3)	

**Table 2: Select socio-economic characteristics (continued)**

Job Security				
Good	130	115	22	ns

	(52.2)	(54.2)	(59.5)	
Poor	119	97	15	
	(47.8)	(45.8)	(40.5)	
Sacked from job because of HIV				
No	267	220	47	
	(82.9)	(82.4)	(85.5)	ns
Yes	55	47	8	
	(17.1)	(17.6)	(14.5)	
Home ownership				
Own home	204	162	42	
	(63.6)	(61.6)	(72.4)	ns
Rented home	117	101	16	
	(36.4)	(38.4)	(27.6)	
In debt, current				
No	121	103	18	
	(39.9)	(41.0)	(34.6)	ns
Yes	182	148	34	
	(60.1)	(59.0)	(65.4)	
Has enough money for food, past 3 months				
No	111	89	22	
	(34.9)	(33.8)	(40.0)	ns
Yes	207	174	33	
	(65.1)	(66.2)	(60.0)	
Working/volunteering in HIV, ever				
No	37	26	11	
	(11.6)	(9.8)	(20.0)	< .05
Yes	283	239	44	
	(88.4)	(90.2)	(80.0)	
Has emotional support				
No	36	32	4	
	(11.7)	(12.5)	(7.8)	ns
Yes	271	224	47	
	(88.3)	(87.5)	(92.2)	

*Note.* All variables have some missing values from non-response. Pearson's Chi Square was used to measure association of variables of interest between those living with HIV for 10 – 19 years and 20+ years. *P*-values indicate observed variation is not due to chance. ns = not significant.

## HIV Treatment and Risk Behaviour

Almost 2 in five participants were not currently on HIV treatment. Of those currently accessing treatment, almost than 2 in ten (18%) say they are currently facing difficulties in accessing HIV treatment. Less than half (47%) of those currently on HIV treatment have undetectable viral loads, and similarly less than half (44%) reported CD4 counts above 500 copies/ml<sup>3</sup>. Almost a third (31%) of participants reported a history of drug use, and 6 individuals (4.7%) were currently injecting drugs. More than 1 in ten (11%) participants who had a history of using drugs had also previously used drugs to enhance sex. The majority of participants was sexually active (defined as having had sex in the past 3 months), and more than half (56%) of whom had a regular sex partner. More than 2 in five of those who were sexually active had unprotected sex the last time they had sex. The majority (72%) of participants was comfortable discussing sex issues with their doctors. Using drugs to enhance sex was significantly associated with living 20 or more years with HIV. See Table 3 below.

**Table 3: HIV treatment and risk behaviour characteristics among people living longer with HIV in the Asia Pacific and associations with living 20 or more years with HIV (N = 360)**

Participant Characteristics	Total N (%)	Living with HIV		P-Value
		10-19 years n (%)	20+ years n (%)	
<i>HIV treatment</i>				
On HIV treatment, current				
No	124 (39.0)	105 (39.6)	19 (35.8)	ns
Yes	194 (61.0)	160 (60.4)	34 (64.2)	
Facing difficulties in accessing HIV treatment				
No	159 (82.4)	132 (83.0)	27 (79.4)	ns
Yes	34 (17.6)	27 (17.0)	7 (20.6)	
Has undetectable viral load, current				
No	100 (52.9)	86 (55.5)	14 (41.2)	ns
Yes	89 (47.1)	69 (44.5)	20 (58.8)	
CD4 level, current				
500 and above	100 (56.2)	81 (54.7)	19 (63.3)	ns
Below 500	78 (43.8)	67 (45.3)	11 (36.7)	
<i>Drugs and sex</i>				
History of drug use				
No	211 (68.3)	172 (67.2)	39 (73.6)	ns
Yes	98 (31.7)	84 (32.8)	14 (26.4)	
Injecting drugs, current				
No	121 (95.3)	95 (96.9)	26 (89.7)	ns*
Yes	6 (4.7)	3 (3.1)	3 (2.4)	
Using drugs to enhance sex				
No	176 (88.9)	148 (91.9)	28 (75.7)	< .01*
Yes	22 (11.1)	13 (8.1)	9 (24.3)	
<b>Table 3: HIV treatment and risk behaviour characteristics (continued)</b>				
Sexually active				
No	82 (26.2)	69 (28.4)	13 (25.0)	ns
Yes	231	192	39	

	(73.8)	(73.6)	(75.0)	
Regular sex partner				
No	136 (44.4)	109 (43.1)	27 (50.9)	ns
Yes	170 (55.6)	144 (56.9)	26 (49.1)	
Unprotected sex, last time				
No	154 (54.4)	129 (55.1)	25 (51.0)	ns
Yes	129 (45.6)	105 (44.9)	24 (49.0)	
Comfortable discussing sex issues with doctor				
No	87 (28.0)	71 (27.4)	16 (30.8)	ns
Yes	224 (72.0)	188 (72.6)	36 (69.2)	

*Note.* All variables have some missing values from non-response. Pearson’s Chi Square was used to measure association of variables of interest between those living with HIV for 10 – 19 years and 20+ years. *P*-values indicate observed variation is not due to chance. ns = not significant. \* Fisher’s Exact Test.

## Stigma and Disclosure

Two hundred and forty participants completed all 40-items on the Berger Stigma Scale, with an average score of 5.79 and a range of 2.69 to 8.94. This is indicative that on average, participants have reported moderate levels of stigma. However, when separated into the components of stigma, disclosure concerns scored the highest average of 6.14, with a range of between 2.5 and 9.25. See Table 4 below.

**Table 4: Berger stigma scale minimum, maximum and average scores**

Components of Stigma	N	Minimum	Maximum	Average
Personalized Stigma	266	2.50	10.00	5.71
Negative Self Image	274	2.71	9.38	5.83
Disclosure Concerns	273	2.50	9.25	6.14
Concerns of Public Attitudes	265	2.50	9.38	5.84
<b>Composite Stigma Score</b>	<b>240</b>	<b>2.69</b>	<b>8.94</b>	<b>5.79</b>

*Note.* Scoring is from 0 – 10, where 0 is no stigma, and 10 is extreme stigma. N = sample size

Even though disclosure concerns rated highly, the majority of participants have disclosed their HIV status to regular sex partners, work colleagues, friends and family. Disclosure to work colleagues and family were marginally significantly associated with living 20 or more years with HIV. See Table 5 below.

**Table 5: Disclosure of HIV status to others among people living with HIV in Asia Pacific (N = 360)**

Participant Characteristics	Total	Living with HIV		<i>P</i> -Value
		10-19 years	20+ years	
	N (%)	n (%)	n (%)	
To regular sexual partners <sup>a</sup>				
No	12	9	3	ns

	(7.9)	(7.0)	(13.6)	
Yes	139	120	19	
	(92.1)	(93.0)	(86.4)	
To someone at work <sup>b</sup>				
No	39	37	2	< .1
	(15.9)	(17.7)	(5.4)	
Yes	207	172	35	
	(84.1)	(82.3)	(94.6)	
To friends				
No	23	21	2	ns*
	(7.8)	(8.5)	(4.1)	
Yes	273	226	47	
	(92.2)	(91.5)	(95.6)	
To family				
No	15	10	5	< .1*
	(4.9)	(3.9)	(9.8)	
Yes	294	248	46	
	(95.1)	(96.1)	(90.2)	

*Note.* <sup>a</sup> Only asked among participants with regular sexual partners (n = 170). <sup>b</sup> Only asked among currently working participants (n = 256). All variables have some missing values from non-response. Pearson's Chi Square was used to measure association of variables of interest between those living with HIV for 10 – 19 years and 20+ years. *P*-values indicate observed variation is not due to chance. ns = not significant. \* Fisher's Exact Test.

## Comorbidities

**Table 6: Comorbidities of people living longer with HIV in the Asia Pacific and associations with living 20 or more years with HIV (N = 180)**

Comorbidities	Total	Living with HIV		<i>P</i> -Value
		10-19 years	20+ years	
		(n = 144)	(n = 36)	
	N (%)	n (%)	n (%)	
<i>Ever diagnosed with:</i>				
Syphilis	43 (23.9)	32 (22.2)	11 (30.6)	ns
Gonorrhea	41 (22.8)	30 (20.8)	11 (30.6)	ns
Chlamydia	29 (16.1)	19 (13.2)	10 (27.8)	< .05
Herpes simplex	65 (36.1)	51 (35.4)	14 (38.9)	ns

**Table 7: Comorbidities (continued)**

Depression	78 (43.3)	57 (39.6)	21 (58.3)	< .05
Other psychological conditions	55 (30.6)	42 (29.2)	13 (36.1)	ns
Hypertension/high blood pressure	56 (31.1)	46 (31.9)	10 (27.8)	ns
Kidney disease	27	22	5	ns

	(15.0)	(15.3)	(13.9)	
Cancer	19 (10.6)	16 (11.1)	3 (8.3)	ns

*Note.* Participants chose all that applies in a multiple-choice question. Pearson’s Chi Square was used to measure association between those living with HIV for 10 – 19 years and 20+ years. *P*-values indicate observed variation is not due to chance. ns = not significant.

With reference to Table 6 above, the single most common comorbidity reported by participants was depression (43%). This was followed by herpes simplex (36%), hypertension or high blood pressure (31%), other psychological conditions (31%), syphilis (24%), gonorrhea (23%), chlamydia (16%), kidney disease (15%) and cancer (11%). Chlamydia and depression diagnoses were respectively significantly associated with living 20 or more years with HIV.

### Predicting economic, social, physical and mental wellbeing

Proxy Indicator 1: Using having enough money for food as a proxy indicator for wellbeing, we predicted key participant characteristics that will increase the odds of wellbeing. In univariate analysis, high education and working were significant factors that contributed to the odds of having enough money for food in the past three months. These factors remained significant after adjusting for potential confounders in multivariable analysis. In the final model, high education significantly increased the adjusted odds of having enough money for food by almost 6 times, and working significantly increased the adjusted odds by more than 2 times. See Table 7 below.

**Table 7: Predicting having enough money for food in the past 3 months among people living longer with HIV in the Asia Pacific (N = 294)**

Characteristics	Univariate Analysis		Multivariable Analysis	
	OR	95% CI	AOR	95% CI
Younger than 35 years	.85	.50, 1.43		
Female	.79	.49, 1.28		
Non-heterosexual	1.45	.84, 2.49		
Single	1.37	.84, 2.23		
High education	6.21***	3.60, 10.71	5.83***	3.27, 10.40
Working	2.14**	1.26, 3.63	2.11**	1.16, 3.85
Emotional support	.81	.38, 1.71		

*Note.* OR = odds ratio; AOR = adjusted odds ratio; CI = confidence interval. Logistic regression was used to predict having enough money for food in the past 3 months. Multivariable logistic regression was performed back-step with maximizing likelihood ratio.

<sup>†</sup> *p* < .1. \* *p* < .05. \*\* *p* < .01. \*\*\* *p* < .001.

Proxy Indicator 2: Using currently being on HIV treatment as a proxy indicator for wellbeing, we predicted key participant characteristics that will increase the odds of wellbeing. In univariate analysis, being younger than 35 years, female, non-heterosexual, single and had high education were significant factors that contributed to the odds of currently being on HIV treatment. After adjusting for potential confounders in multivariable analysis, the following participant characteristics increased the adjusted odds of being on HIV treatment. These were being younger than 35 years (by more than 2 times), being single (by almost 2 times), and having high education (by more than 7 times). Being female reduced the adjusted odds of being on treatment. See Table 8 below.

**Table 8: Predicting currently on HIV treatment among people living longer with HIV in the Asia Pacific (N = 296)**

Characteristics	Univariate Analysis		Multivariable Analysis	
	OR	95% CI	AOR	95% CI
Younger than 35 years	1.75*	1.02, 3.00	2.24*	1.17, 4.30
Female	.45**	.28, .72	.39**	.22, .69
Non-heterosexual	1.69 <sup>†</sup>	.99, 2.89		
Single	1.53 <sup>†</sup>	.96, 2.56	1.92*	1.10, 3.35
High education	6.81***	3.89, 11.94	7.03***	3.80, 13.03
Working	.85	.50, 1.47		
Emotional support	.99	.48, 2.04		

Note. OR = odds ratio; AOR = adjusted odds ratio; CI = confidence interval. Logistic regression was used to predict currently on HIV treatment. Multivariable logistic regression was performed back-step with maximizing likelihood ratio.

<sup>†</sup>  $p < .1$ . \*  $p < .05$ . \*\*  $p < .01$ . \*\*\*  $p < .001$ .

**Proxy Indicator 3:** Using ever being diagnosed with depression as a proxy indicator for not being well, we predicted key participant characteristics that will increase the odds of not being well. In univariate analysis, not having enough money for food and not currently being on HIV treatment increased the odds of being diagnosed with depression. After adjusting for potential confounders in multivariable analysis, only not having enough money for food remained as a significant predictor, increasing the adjusted odds of being diagnosed with depression by almost 2 times. See Table 9 below.

**Table 9: Predicting ever being diagnosed with depression among people living longer with HIV in the Asia Pacific (N = 169)**

Characteristics	Univariate Analysis		Multivariable Analysis	
	OR	95% CI	AOR	95% CI
Younger than 35 years	.63	.31, 1.28		
Female	1.31	.70, 2.48		
Non-heterosexual	.82	.43, 1.57		
Single	.88	.47, 1.62		
Low education	1.70	.88, 3.29		

**Table 9: Predicting ever being diagnosed with depression (continued)**

Not working	1.41	.69, 2.89		
Not enough money for food	2.00*	1.08, 3.68	1.93*	1.03, 3.62
Not on HIV treatment	2.04*	1.11, 3.73		
No emotional support	.88	.38, 2.03		

Note. <sup>a</sup> Some missing data from non-response. OR = odds ratio; AOR = adjusted odds ratio; CI = confidence interval. Logistic regression was used to predict being diagnosed with depression. Multivariable logistic regression was performed back-step with maximizing likelihood ratio.

<sup>†</sup>  $p < .1$ . \*  $p < .05$ . \*\*  $p < .01$ . \*\*\*  $p < .001$ .

**Proxy Indicator 4:** Using high levels of stigma as a proxy indicator for not being well, we predicted key participant characteristics that will increase the odds of not being



well. In univariate analysis, not working increased the odds of experiencing high levels of stigma. After adjusting for potential confounders in multivariable analysis, not working remained a marginally significant predictor, increasing the adjusted odds of experiencing high levels of stigma by more than 2 times. See Table 10 below.

**Table 10: Predicting high levels of stigma among people living longer with HIV in the Asia Pacific (N = 171)**

Characteristics	Univariate Analysis		Multivariable Analysis	
	OR	95% CI	AOR	95% CI
Younger than 35 years	.82	.34, 2.01		
Female	.87	.39, 1.93		
Non-heterosexual	1.04	.45, 2.37		
Single <sup>a</sup>	.97	.46, 2.05		
Low education	1.57	.71, 3.46		
Not working	2.25*	1.02, 4.93	2.28 <sup>†</sup>	1.00, 5.19
Not on HIV treatment	1.14	.54, 2.43		
No emotional support	1.54	.53, 4.36		

*Note.* <sup>a</sup> Some missing data from non-response. OR = odds ratio; AOR = adjusted odds ratio; CI = confidence interval. Logistic regression was used to predict occurrence of high stigma (score 7 or more). Multivariable logistic regression was performed back-step with maximizing likelihood ratio.  
<sup>†</sup>  $p < .1$ . \*  $p < .05$ . \*\*  $p < .01$ . \*\*\*  $p < .001$ .

## DISCUSSION AND CONCLUSION

The study highlighted important concerns for people living longer with HIV in the Asia Pacific region. Three trends in particular deserve special mention because of their enduring influences emerging from our analyses. These are, economic concerns, HIV treatment access, and depression as comorbidity.

Economic issues were important factors and concerns among people living longer with HIV in the Asia Pacific region. As Russell (2004) made clear in the literature, the economic burden of HIV can be catastrophic for families. This would be compounded by the fact that in most Asia Pacific countries, there are either not any social safety nets or they are insufficiently robust to cover those most at need. Among participants living 10 or more years with HIV in our sample, almost half reported poor job security, and more than 1 in 10 have previously been sacked from their jobs because of HIV. Crucially, more than one-third said they didn't have enough money for food in the past three months. In predicting having enough money for food, we found that having a high level of education and being currently working were significantly factors, increasing the odds of having enough money for food by almost 6 times and more than 2 times respectively. This finding showed the importance of education and job status for the health of people living with HIV in this region, and complements findings by Paxton (2005).

Almost two in five people living longer with HIV are currently not on medication and more than one in 10 face difficulties accessing treatment. For those currently on treatment, less than half have achieved undetectable viral loads, and more than two in five have CD4 below 500. Given that almost one-third had a history of drug use, more than 1 in ten used drugs to enhance sex, and just under half of the sample had unprotected sex the last time they had sex, getting people living longer in treatment and reducing their viral loads to undetectable levels are important goals if treatment as prevention is to be properly enabled. These findings corroborate the results from an APN+ treatment access study among HIV positive men who have sex with men in Asia Pacific countries (2010, 2012). In predicting currently being on HIV treatment, we found that being younger than 35 years, being single and having a high level of education would significantly increase the odds of being in treatment. Crucially, being female significantly decreased the odds of currently being on HIV treatment. On the surface, this finding complements the discrimination faced by women that was reported in Paxton (2005). However, more research is needed to further explore the interaction between HIV treatment and gender.

Depression was the most common mental health concern among people living longer with HIV. This is not surprising given that many of the health services in the Asia Pacific do not have the capacity and well-developed mechanisms to identify, link into care, and provide adequate counseling and psychological care on mental health issues. Given that depression was significantly associated with living 20 or more years with HIV, there is a palpable concern that people living longer with HIV would suffer from poor mental health with little recourse for medical and psychological assistance. In predicting ever being diagnosed with depression, our analysis found that not having enough money for food and not being on HIV treatment both significantly increased the odds of being diagnosed with depression respectively by 2 times. On the surface, this corroborates findings by Wasti (2012) who indicate the intricate relationship between mental health and HIV treatment. However, after controlling for other

factors, only not having enough money for food remained significantly associated with being diagnosed for depression, increasing the odds by almost 2 times. This finding indicates a more important interconnection of factors exists between mental health and economic concerns.

Indeed, factors predicting social, economic, physical and mental wellbeing indicate that many of the health outcomes were socially determined. Working, having enough money to buy food and having a high level of education were key features in most of the models predicting proxy indicators for health. However, unlike findings from the literature that highlighted concerns of high levels of stigma, our results found stigma to be moderate (score of 5.79 out of 10) in this sample of people living 10 or more years with HIV. Similarly, while on the surface our finding on disclosure concerns, which were higher than the rest of the stigma components was consonant with the literature, the majority of participants in this study had disclosed their status to regular sexual partners, work colleagues, friends and family. The majority of participants also reported being able to obtain emotional support when they needed it.

This study has a couple of important limitations. First, the sampling of the study relied heavily on APN+ affiliates and networks which could be capturing those who were most empowered to participate. Given that more than 8 in 10 participants have previous experience working or volunteering in HIV-related organisations, this limitation is realistic. Second, the study was only made available on an online platform. Those without internet access, were computer illiterate, or severely marginalized that they were not connected to the HIV social network would not have known about the survey, or been able to participate without help. We must therefore accept the caveat that the study presents the best scenario of people living longer with HIV in the Asia Pacific region.

In conclusion, even with its limitations, this study is an important first step that fills a gap in the literature on the wellbeing of HIV positive individuals as they live longer with HIV in the Asia Pacific region. Given that the study is likely reaching positive individuals who were most empowered and socially connected in the region, the findings are a stark reminder that those who are marginalized would likely have worst outcomes in terms of economic and social wellbeing, treatment access and health outcomes, and on mental health and stigma than the findings presented here. This study is a timely reminder that there is still much to be done for people living with HIV in the Asia Pacific region. As nations shift their focus from HIV at the end of Millennium Development Goals in 2015, findings in this study highlight that health and wellbeing are multifaceted. These findings point to the need to include sufficient effort to enable and empower people living with HIV if gains in HIV treatment and services scale-up, as well as human and health rights, are to be held on to and expanded in the future. As a way forward, it is clear that advocacy needs to be targeted towards achieving better health and socio-economic outcomes for people living longer with HIV in the Asia Pacific.

### Options for future action

From the foregoing discussion and conclusion, the authors would like to suggest the following options for future action:

- Advocate for more community involvement in providing HIV treatment and improve linkages into treatment and care. This has to be balanced with sufficient effort in the creation of enabling environments and increased community mobilization as critical enablers for better treatment access and adherence. More effort is needed to better understand why there are such large proportions of those on treatment not achieving undetectable viral loads and higher CD4 counts. Factors causing the late presentation for treatment need to be assessed and addressed.
- Advocate to train community groups to identify mental health issues among its members and provide peer-led counseling services and link them into care. As the current cohort of people living longer with HIV age, it is highly likely that mental health issues will start to move higher on the agenda of public health. Community networks and groups should pre-empt this possible surge in mental health issues by preparing themselves with the necessary skills and knowledge to detect and diffuse these concerns.
- Advocate for more equitable employment practices and setup a hotline for people living with HIV to seek redress for unfair dismissal and conduct help address some of the concerns of those living longer with HIV in the region. A possible job placement clearing system that links potential HIV positive job applicants with industry that have been carefully desensitized to HIV might provide better job prospects to HIV positive individuals in the Asia Pacific.

Where possible, these interventions should include components of independent evaluation so that their efficacy can be properly assessed and the necessary improvements put in place. Assessments should also reflect effects on key indicators highlighted in this study.