DOI: 10.1111/hiv.12391
HIV Medicine (2017), **18**, 73–79

ORIGINAL RESEARCH

A global survey of HIV-positive people's attitudes towards cure research

R Simmons,[1] M Kall,[2] S Collins,[3] G Cairns,[4] S Taylor,[5] M Nelson,[6] S Fidler,[7] K Porter[1] and J Fox[8] on behalf of the Collaborative HIV Eradication of viral Reservoirs (CHERUB) Survey collaboration

[1]MRC, Clinical Trials Unit University College, London, UK, [2]Public Health England, London, UK, [3]i-Base, London, UK, [4]NAM, London, UK, [5]Birmingham Heartlands Hospital, Birmingham, UK, [6]Chelsea and Westminster Hospital, London, UK, [7]Imperial College, London, UK and [8]Guy's and St Thomas' Hospital, London, UK

Objectives

Involvement of people living with HIV (PLHIV) in the design of HIV cure studies is important, given the potential risks to participants. We present results of an international survey of PLHIV to define these issues and inform cure research.

Methods

PLHIV were recruited in June–November 2014 through HIV websites, advocacy forums, social media and 12 UK HIV clinics. The survey included questions concerning demographics, HIV disease history, the desirability of types of cure and the patient's willingness to accept potential toxicity and treatment interruption (TI). We examined factors associated with TI and willingness to accept substantial risks.

Results

A total of 982 PLHIV completed the survey; 87% were male, 79% white and 81% men who have sex with men (MSM). Fifty-one per cent were aged 25–44 years and 69% were UK residents. The median time since diagnosis was 7 years [interquartile range (IQR) 2–17 years]. Eighty-eight per cent were receiving antiretrovirals (91% reported undetectable viral load). Health/wellbeing improvements (96%) and an inability to transmit HIV (90%) were more desirable cure characteristics than testing HIV-negative (69%). Ninety-five per cent were interested in participating in cure studies, and 59% were willing to accept substantial risks. PLHIV with a low CD4 count [201–350 cells/μL *vs.* $\geq$ 350 cells/μL; odds ratio (OR) 2.11; 95% confidence interval (CI) 1.11–4.00] were more likely to accept risks, whereas those with limited knowledge of HIV treatments *vs.* excellent/good knowledge and those aged $\geq$ 65 years *vs.* 45–64 years were less likely to accept risks [OR 0.58 (95% CI 0.37–0.90) and OR 0.18 (95% CI 0.07–0.45), respectively]. TI was acceptable for 62% of participants, with the main concerns being becoming unwell (82%), becoming infectious (76%) and HIV spreading through the body (76%).

Conclusions

Cure research was highly acceptable to the PLHIV surveyed. Most individuals would accept risks, including TI, even in the absence of personal benefit. An optimal cure would improve health and minimize onward transmission risk.

Keywords: clinical research, HIV cure, patient perceptions, treatment interruption.

Accepted 15 January 2016

Introduction

Combination antiretroviral therapy (cART) for HIV infection has been immensely successful at reducing mortality and morbidity and prolonging life expectancy [1–4] but requires lifelong adherence to medication which might have unknown long-term side effects. The prospect of taking treatment for decades drives the strong community interest in an HIV cure, to remove the necessity for continuous drug adherence and to limit side effects while also reducing the risk of onward transmission.

Correspondence: Dr Julie Fox, Guy's and St Thomas' Hospital, London, UK. Tel.: 02071886234; fax: 02071886245; e-mail: julie.fox@kcl.ac.uk

To date, a sterilizing cure, that is, elimination of HIV, has been achieved only once, by a Berlin patient who has remained virus free since 2007 [5]. However, remission of HIV infection has been observed in a number of small groups of individuals in the Viro-Immunological Sustained CONtrol after Treatment Interruption (VISCONTI) study who initiated cART in primary HIV infection (PHI), where 15.6% of individuals maintained viral suppression for a number of years after interrupting therapy [6], and most recently in a child receiving ART from birth [6].

A number of phase I/II clinical trials are currently underway to investigate novel interventions, in addition to cART, that may act to limit the viral reservoir and hence confer either remission or sterilizing cure modalities [7]. These are "proof-of-concept" studies which aim to assess the safety and efficacy of a novel intervention, and are not intended or expected to cure HIV infection in the research participants [8]. Moreover, trials may require treatment interruption to allow assessment of the intervention.

The prospect of asking healthy people living with HIV (PLHIV) to enter a research study without any expectation of a medical benefit and often with highly uncertain risks raises ethical questions [9–11]. Finding an acceptable risk–benefit balance is important in order for a clinical trial to proceed. Consultation with HIV community groups and PLHIV is vital to inform the design of cure studies, so that participant needs are met, the ability to enrol is assessed and an understanding is gained of the knowledge base of targeted groups and what risks they would deem acceptable.

We conducted a broad-ranging web-based survey asking PLHIV to address key issues in HIV cure research in order to gain an understanding of the beliefs about cure, motivations and concerns about taking part in cure studies. We aimed to identify factors associated with willingness to participate in cure research and willingness to interrupt cART within a cure study.

Methods

Between June and November 2014, a self-completed, web-based, cross-sectional survey was designed by the Collaborative HIV Eradication of viral Reservoirs (CHERUB) group in collaboration with HIV-positive and other community groups, clinicians and government organizations. The survey recruited PLHIV online through national and international HIV websites, advocacy forums and social media. This involved key UK HIV organizations (the British HIV Association (BHIVA), HIV i-Base, NAM, NAZ, Terrence Higgins Trust (THT), Positively UK, Saving lives, and Living Well). International networks included community forums (PozHealth, European AIDS Treatment Group (EATG), International Treatment Preparedness Coalition (ITPC) and AIDS Treatment Activists Coalition- USA (ATAC-USA)) and Washington University. In addition, 10 UK clinics in London and Birmingham distributed paper versions of the survey, which represented approximately 50 surveys.

The survey collected information on PLHIV demographics, HIV disease history, desirability rating of types of HIV cure, current health, willingness to take part in HIV cure research, previous clinical trial participation, and knowledge about HIV research. Questions primarily used a Likert scale answer format. Medical information (such as CD4 count and viral load) was self-reported.

The survey asked respondents to indicate their interest in HIV cure research and what a cure meant to them from a predefined list of potential outcomes. Participants rated the acceptability of risks, including treatment interruption (and associated viral rebound and CD4 count decline) and severity of side effects of investigational drugs. The effect of year of HIV diagnosis on interpretation of what a cure meant was examined using the χ^2 test for trend. Using logistic regression models, the association between a number of factors and two separate outcomes was examined. The first outcome was the willingness to accept substantial risks, with risk defined as severe/moderate side effects without personal benefit, and the willingness to have detectable HIV RNA for $\geq$ 6 months and/or for CD4 count to fall to $<$ 200 cells/μL during treatment interruption. The second outcome was the willingness to stop HIV medication (participants answering "yes, definitely" or "probably"). The following factors were included in models: age group, sex, sexual orientation, ethnicity, country of birth, year of HIV diagnosis, current and nadir CD4 cell counts, cART status, level of adherence, experience of ART-related toxicities, and knowledge of HIV. All two-way interactions were examined. Finally, in addition to the survey questions, respondents were given the opportunity to provide comments through free text.

Survey responses were considered complete if persons responded to all three key questions on cure interest, cure function and treatment status; only complete responses were included in analyses. The study was funded through the UK National Institute for Health Research (NIHR) Biomedical Research Centres.

No ethical approval was sought for the study as no identifiable information was collected on participants. The survey was freely accessible online with no obligation to complete it, although online surveys typically do not require consent; information was given to the participant about the survey before completion, with a completed survey by virtue taken as consent.

Table 1 Characteristics of HIV-positive people self-completing the HIV cure survey between June 2014 and November 2014 (n = 982)

	Completed survey *n* (%)
Age group (years)	
16–24	29 (3.0)
25–44	485 (50.5)
45–64	414 (43.1)
≥65	33 (3.4)
Not reported	21
Sex	
Male	832 (87.2)
Female	122 (12.8)
Not reported	28
Country of birth	
UK	504 (54.1)
USA	133 (14.3)
Other	295 (31.7)
Not reported	50
Country of residence	
UK	616 (69.0)
USA	129 (14.4)
Other	148 (16.6)
Not reported	89
Ethnicity	
White	757 (78.9)
Nonwhite	203 (21.1)
Not reported	22
New diagnosis	
Yes	252 (28.3)
No	639 (71.7)
Unknown	91
Sexual orientation	
MSM	753 (80.6)
Heterosexual	179 (19.2)
WSW	2 (0.2)
Not reported	48
Ever injected drugs	
Heroin	20 (6.1)
Recreational drugs	101 (30.6)
Drugs for a medical condition	209 (63.3)
Not reported	652
HIV knowledge: science of how HIV and treatment work	
I understand a lot about HIV and treatment	376 (38.9)
I have good general knowledge about HIV and treatment	416 (43.1)
I know a little bit about HIV and treatment	155 (16.0)
I do not know about HIV and treatment	19 (2.0)
Not reported	16
Current CD4 count	
<200 cells/μL	58 (6.7)
201–350 cells/μL	75 (8.6)
≥350 cells/μL	739 (84.7)
Not reported	110
Lowest CD4 count	
<200 cells/μL	370 (43.2)
201–350 cells/μL	228 (26.6)
≥350 cells/μL	258 (30.1)
Not reported	126
Currently on cART	
Yes	861 (87.7)
No	121 (12.3)

cART, combination antiretroviral therapy; MSM, men who have sex with men; WSW, women who have sex with women.

Table 2 HIV treatment status for HIV-positive persons currently on combination antiretroviral therapy (cART) responding to the cure survey (n = 861)

	Completed survey *n* (%)
Undetectable viral load	
No	71 (9.4)
Yes	687 (90.6)
Not reported	103
HIV medication combinations	
First regimen	287 (37.7)
Second regimen	210 (27.6)
Third regimen	124 (16.3)
Fourth regimen	46 (6.0)
Five or more regimens	95 (12.5)
Not reported	99
Adherence	
Never missed a dose	328 (42.1)
Missed a dose a few times a year	327 (41.9)
Missed a dose once a month	97 (12.4)
Missed a dose once a week	28 (3.6)
Not reported	81
Feeling about taking HIV medication	
Very positive	372 (47.4)
Somewhat positive	257 (32.8)
Undecided	65 (8.3)
Somewhat negative	65 (8.3)
Very negative	25 (3.2)
Not reported	77
Current side effects from HIV medication	
Very serious	9 (1.1)
Serious	20 (2.5)
Moderate	99 (12.6)
Mild	222 (28.2)
None	436 (55.5)
Not reported	75
Past side effects from HIV medicine	
Very serious	67 (8.6)
Serious	131 (16.8)
Moderate	243 (31.1)
Mild	222 (28.4)
None	119 (15.2)
Not reported	79

Results

Respondent characteristics

A total of 1703 PLHIV accessed the cure survey, with 982 complete responses: 87% (832 of 954) were male, 79% (757 of 960) were white, and 81% (753 of 934) were gay men [men who have sex with men (MSM)]. The majority were aged 25–44 years (51%; 485 of 961). Fifty-four per cent (504 of 932) were UK-born and 69% (616 of 893) were UK residents (Table 1). The UK residents represented London (49%), northwest England (11%), the southeast coast (8%), the east of England (6%), and other regions (26%). Among those born outside the UK (428 of 932; 46%), the majority were from the USA, Europe (excluding the UK) and Africa: 31%, 31% and 18%, respectively.

This distribution was similar for country of current residence.

The median time since diagnosis was 7 years [interquartile range (IQR) 2, 17], with 28% (252 of 891) of participants diagnosed in the preceding 2 years. Eighty-five per cent (739 of 872) reported a current CD4 count of ≥350 cells/μL, and 43% (370 of 856) reported a nadir CD4 count of <200 cells/μL (Table 1).

Overall, 88% (861 of 982) were on cART, 91% of whom had an undetectable viral load. cART was viewed positively by 80% (629 of 784). Four per cent (29 of 786) reported current ART-related toxicities, and 84% (655 of 780) reported less than three missed doses in the preceding year (Table 2).

Ninety-five per cent (929) of respondents (with no sex difference) were willing to participate in a cure study, with no significant difference in willingness between sterilizing and remission cure studies (92% and 87%, respectively). Seventy-one per cent (697 of 979) of respondents would participate in a cure study even if there were no personal benefits. Over half (55%) of respondents believed a cure was likely within 10 years. Participation in a study was more likely if a cure was believed to be likely within 5 years compared with 10 years (92% *vs.* 86%, respectively; $P < 0.001$).

Perceptions of a cure

The most desired cure outcomes were: 'no risk of HIV-related health problems' (96%), 'never need to take HIV medications' (91%), 'no longer having HIV in your body' (91%) and 'no risk of passing HIV to sexual partners (even off treatment)' (91%). The least desired cure outcomes were: 'stopping HIV medications for a number of years but possibility of restarting' (62%), 'ability to inform people that they did not have HIV '(67%), and 'testing HIV negative' (69%) (Fig. 1). Individuals diagnosed within the past 2 years were more likely to find the following categories extremely desirable compared with those diagnosed earlier: 'testing HIV negative '(P-trend <0.001), 'telling people that you do not have HIV' (P-trend < 0.001), 'no longer having HIV in your body' (P-trend = 0.007), 'no longer having to see a doctor for regular monitoring' (P-trend = 0.04), and 'no longer feel bad or worry because you have HIV' (P-trend = 0.03).

Factors associated with accepting substantial risks

Overall, 59% (576 of 982) of participants were willing to accept substantial risks. Twenty-three per cent (227 of 978) would agree to allowing their CD4 cell count to drop to 200 cells/μL, 39% (379 of 978) would allow their viral load to be detectable for 6 months or more (15% would allow both), and 34% (332 of 981) would accept severe or extremely severe side effects without personal benefit.

The only factors associated with accepting substantial risks were a current CD4 count of 201–350 cells/μL ($P = 0.001$) and a detectable viral load ($P = 0.04$), whereas older respondents ($P = 0.001$), those diagnosed in the past 2 years ($P = 0.03$), those with limited knowledge about HIV or HIV treatments ($P = 0.008$) and those who had never had a CD4 count <350 cells/μL ($P = 0.006$) were less likely to accept substantial risks.

After adjustment for all factors in multivariable logistic regression models (Table 3), factors associated with being willing to participate in, and accepting extreme outcomes as part of, cure research were having a current CD4 count of 201–350 cells/μL compared with a current CD4 count

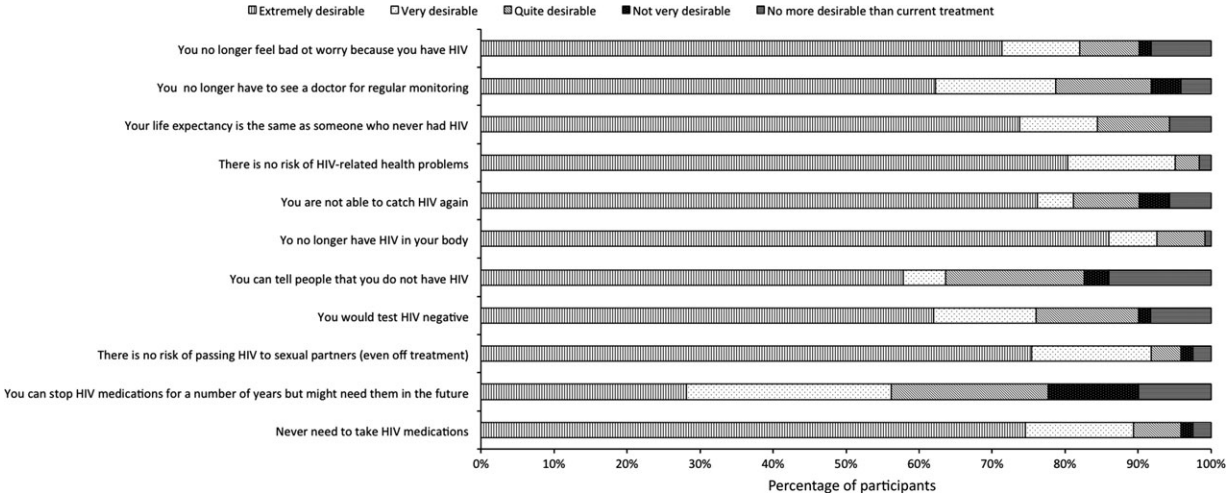

Fig. 1 Percentages of participants rating the suggested HIV cure outcomes in terms of desirability.

Table 3 Factors associated with people living with HIV (PLHIV) participating in HIV cure research and taking risks

	Univariate model			Multivariate model*		
	OR	(95% CI)	*P*-value	OR	(95% CI)	*P*-value
Current CD4 count						
<200 cells/μL	1.67	(0.94, 2.97)	0.001	1.67	(0.85, 3.30)	0.028
201–350 cells/μL	2.38	(1.37, 4.12)		2.11	(1.11, 4.00)	
≥350 cells/μL	1			1		
Lowest CD4 count						
<200 cells/μL	1		0.006	1		0.107
201–350 cells/μL	1.08	(0.77, 1.53)		1.22	(0.82, 1.81)	
≥350 cells/μL	0.64	(0.46, 0.88)		0.76	(0.50, 1.16)	
HIV knowledge: science of how HIV and treatment work						
Excellent/good knowledge	1		0.008	1		0.015
Little/no knowledge	0.64	(0.46, 0.89)		0.58	(0.37, 0.90)	
Age group (years)						
16–24	0.36	(0.16, 0.78)	0.001	1.10	(0.18, 6.56)	0.002
25–44	0.81	(0.62, 1.06)		0.90	(0.62, 1.29)	
45–64	1			1		
≥ 65	0.25	(0.12, 0.55)		0.18	(0.07, 0.45)	
Sex						
Male	1		0.407	1		0.240
Female	0.85	(0.58, 1.25)		0.74	(0.45, 1.22)	
Undetectable viral load						
Yes	1		0.039	1		0.382
No	1.73	(1.01, 2.97)		1.31	(0.71, 2.41)	
Country of birth						
UK	1		0.048	1		0.041
USA	1.56	(1.04, 2.34)		1.68	(1.00, 2.83)	
Other	0.93	(0.69, 1.24)		0.84	(0.58, 1.21)	
New diagnosis						
Yes	0.72	(0.54, 0.97)	0.031	0.89	(0.58, 1.37)	0.611
No	1			1		

*Adjusting for all factors in the table.
CI, confidence interval; OR, odds ratio.

of ≥350 cells/μL [odds ratio (OR) 2.11; 95% confidence interval (CI) 1.11, 4.00] and being USA-born compared with UK-born (OR 1.68; 95% CI 1.00–2.83). Those with little or no knowledge about HIV or HIV treatments compared with excellent/good knowledge were less likely to agree to accept substantial risks (OR 0.58; 95% CI 0.37–0.90), as were those aged ≥ 65 years compared with those aged 45–64 years (OR 0.18; 95% CI 0.07–0.45).

Factors associated with accepting treatment interruption

A treatment interruption of some months as part of a clinical trial was reported as acceptable ("yes, definitely" or "probably") for 62% (606 of 979) of respondents. No single factor was identified as being associated with willingness to have a treatment interruption. The major concerns with a treatment interruption were: becoming unwell (82% reporting being "very or moderately concerned"), CD4 T-cell count decreases (72%) and viral load becoming detectable (72%). Irrespective of sex, becoming unwell was the leading concern; however, a higher proportion of women were more concerned than men about CD4 count decrease (76% *vs.* 71%, respectively), a detectable viral load (78% *vs.* 71%) and HIV spreading through their body (81% *vs.* 76%) (Fig. 2).

Twenty-eight per cent (278 of 982) of respondents left a free-text comment, the majority of whom expressed a desire for a cure, with little preference for the type of cure outcome.

Discussion

Our results indicate a high level of interest in HIV cure research among self-selected survey respondents, regardless of demographic or immunological status, personal benefit or risk and the type of cure offered (sterilizing or remission). An optimal cure was linked with personal health and reduced infectiousness. Notably, eliminating the risk of HIV-related health problems was more desirable than testing HIV negative or informing persons of their status. Treatment interruption was considered acceptable by the majority, with over half of respondents willing to accept risks much greater than would be expected as part of a structured treatment interruption.

Little difference was found in the willingness of persons to participate in a sterilizing or remission cure study, which is reassuring given current progress skewed towards a functional cure [12]. This contrasts with a small Australian survey (n = 20) of persons participating in a cure clinical trial who indicated a strong preference for a sterilizing cure [13].

Our results suggest that participation in cure research irrespective of personal benefits can be anticipated to be high, despite risks, which may include a treatment interruption. These findings were similar to responses among PLHIV at a Food and Drug Administration (FDA) meeting on drug development and HIV cure research [14]. Two in five respondents were willing to allow a detectable viral load, one in three were willing to endure side effects, and one in five were willing to have a low CD4 count. Those less likely to participate in cure trials were older individuals, consistent with other areas of research such as cancer research [15], and those more likely to participate were those with a good knowledge of HIV science and HIV treatments.

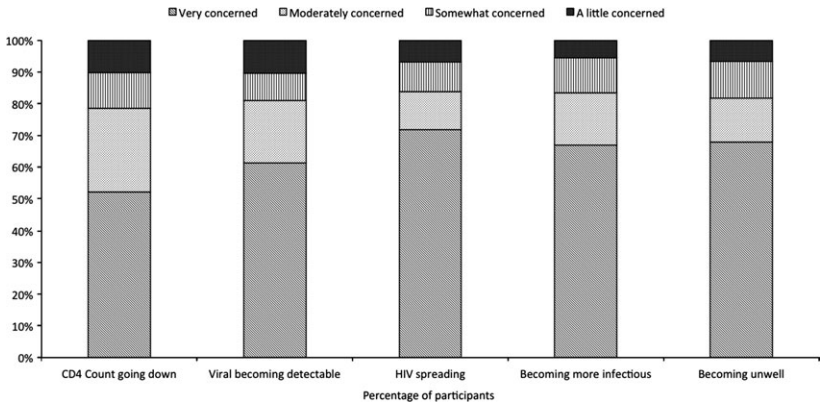

Fig. 2 Level of concern regarding the potential risks involved in stopping treatment.

The most clinically relevant cure trial requires a treatment interruption. A much larger US survey identified that participation in treatment interruption studies was linked to altruistic and health resource considerations [16]. With uniform health care in our primarily UK-based survey, high levels of acceptability of treatment interruption as part of cure research were found regardless of age group, immune status and treatment history, with no independent predictors for participating in a treatment interruption identified. The main concern with treatment interruption was becoming unwell rather than CD4 cell count decline or viral load becoming detectable. In reality, treatment interruption in cure studies involves intensive viral load monitoring with immediate intensification upon viral rebound, which should be explained to participants at enrolment.

Peay *et al.* suggested that the term 'cure' could result in unrealistic expectations, particularly in regard to personal benefit, and careful consideration should be given to the language when recruiting persons for research purposes [10]. However, our findings contradict this view, with participants reporting a realistic expectation of the time to a cure and a willingness to take part in cure trials with no personal benefit. Interestingly, participants were less interested in testing negative than they were in personal health benefit and being noninfectious, consistent with findings among the Australian respondents [13]. However, the responses in this study are a reflection of time since HIV diagnosis, with those recently diagnosed being more likely to focus on emotional/social aspects rather than personal health.

Our study tried to reflect the views of PLHIV towards cure research to improve study design and recruitment processes, and to focus on patient-led outcomes. The high proportion of respondents taking the time to complete the free-text field suggests enthusiasm for research in this field, which represents an opportunity to engage the community in cure research development.

The main limitation of the study was the lack of diversity in terms of gender, ethnicity and sexual orientation, which is common in such research and may reflect the predominately online recruitment method. Respondents were, however, geographically representative among PLHIV resident within the UK [17]. In contrast to previous surveys, however, respondents were not heavily treatment experienced, had relatively high CD4 counts and were relatively recently diagnosed, which makes this survey more aligned to potential cure trial participants than previous studies. Further work is needed to reach women and nonwhite populations to determine whether the factors associated with their participation differ.

Overall, there are high levels of enthusiasm for HIV cure research among PLHIV. Cure programmes aimed at a functional cure (which includes a health benefit and reduced infectiousness) are desired as much as a sterilizing cure. Clinically relevant cure outcomes that PLHIV can relate to must be incorporated into HIV cure research strategies and surrogate markers of these factors included as outcomes.

Acknowledgements

We would like to thank all those who participated in the HIV cure survey. We also thank those who helped design the questionnaire, in particular patient representatives; those who were involved in recruitment; BHIVA, HIV i-Base, NAM, NAZ, THT, Positively UK, Saving Lives, Living Well and Washington University; and those at the 10 UK clinics who distributed paper versions of the survey: including Mark Nelson and Sheena Nneka (Chelsea and Westminster), Sarah Fidler (Imperial College NHS Trust), Steve Taylor (Birmingham Heartlands), Mike Brady

(King's College Hospital), Jane Anderson (Barts and the London), Laura Waters (Mortimer Market Centre), Sabine Kinloche (Royal Free) and John Frater (University of Oxford).

Author contributions

RS undertook the analysis and had access to the complete data set; JF and KP supervised RS; RS wrote the first draft of the manuscript; JF initiated the survey; JF, SC, GC, ST, MN and SF designed the survey; MK and JF supervised the facilities used to distribute the questionnaire. All authors provided critical input to the manuscript and approved all revisions.

References

1 Nakagawa F, May M, Phillips A. Life expectancy living with HIV: recent estimates and future implications. *Curr Opin Infect Dis* 2013; **26**: 17–25.
2 Nakagawa F, Lodwick RK, Smith CJ *et al*. Projected life expectancy of people with HIV according to timing of diagnosis. *AIDS* 2012; **26**: 335–343.
3 Lohse N, Hansen AB, Pedersen G *et al*. Survival of persons with and without HIV infection in Denmark, 1995-2005. *Ann Intern Med* 2007; **146**: 87–95.
4 Collaboration Antiretroviral Therapy Cohort. Life expectancy of individuals on combination antiretroviral therapy in high-income countries: a collaborative analysis of 14 cohort studies. *Lancet* 2008; **372**: 293–299.
5 Hutter G, Nowak D, Mossner M *et al*. Long-term control of HIV by CCR5 Delta32/Delta32 stem-cell transplantation. *N Engl J Med* 2009; **360**: 692–698.
6 Saez-Cirion A, Bacchus C, Hocqueloux L *et al*. Post-treatment HIV-1 controllers with a long-term virological remission after the interruption of early initiated antiretroviral therapy ANRS VISCONTI Study. *PLoS Pathog* 2013; **9**: e1003211.
7 Frater J. New approaches in HIV eradication research. *Curr Opin Infect Dis* 2011; **24**: 593–598.
8 Dube K, Henderson GE, Margolis DM. Framing expectations in early HIV cure research. *Trends Microbiol* 2014; **22**: 547–549.
9 Sugarman J.HIV Cure Research: expanding the Ethical Considerations. *Ann Intern Med* 2013; **159**: 490–491.
10 Peay HL, Gail EH. What motivates participation in HIV cure trials? A call for real-time assessment to improve informaed consent. *J Virus Erad* 2015; **1**: 51–53.
11 Lo B, Grady C. Working Group on Ethics of the International AS. Ethical considerations in HIV cure research: points to consider. Curr Opin HIV. *AIDS* 2013; **8**: 243–249.
12 Frange P, Faye A, Avettand-Fenoel V *et al*. HIV-1 virological remission for more than 11 years after interruption of early initiated antiretroviral therapy in a perinatally-infected child. 8th IAS Conference on HIV Pathogenesis Treatment & Prevention; Vancouver, Canada 2015; **A36**: MOOAA0105LB.
13 McMahon JH, Elliott JH, Roney J, Hagenauer M, Lewin SR. Experiences and expectations of participants completing an HIV cure focused clinical trial. *AIDS* 2015; **29**: 248–250.
14 US Food and Drug Administration. The Voice of the Patient: Human Immunodeficiency Vircs (HIV) patient-focused drug development and HIV cure research. FDA. Available at http://www.fda.gov/downloads/ForIndustry/UserFees/PrescriptionDrugUserFee/UCM389379.pdf (accessed 20 December 2014).
15 Murthy VH, Krumholz HM, Gross CP. Participation in cancer clinical trials: race-, sex-, and age-based disparities. *JAMA* 2004; **291**: 2720–2726.
16 Arnold MP, Evans D, Vergel N. Recruitment and ethical considerations in HIV cure trials requiring treatment interruption. *J Virus Erad* 2015; **1**: 43–48.
17 Health Protection Agency. Numbers receiving HIV care. Available at http://www.hpa.org.uk/web/HPAweb&HPAwebStandard/Page/1201094588844 (accessed 5 July 2012).