

Thank you for agreeing to complete this confidential survey. Please answer all the questions as fully as you can. You are free to leave out any question you do not want to answer.

Please do NOT write your name or clinic number on this survey. Your answers will NOT be seen by doctors and nurses in the clinic, and your answers will NEVER be recorded in your clinic notes.

If you have any questions or need any help, please ask the person who gave you this survey.

Please place your completed survey in the envelope, seal the envelope and give it back to the staff member who gave it to you.

Thank you for your help!

Date: / /	_
Unique study number:	

SECTION A: GENERAL INFORMATION

A1. Are you:	
☐ Male ☐ Transgender male	☐ Female ☐ Transgender female
A2. What is your date of birth?	
Month:	Year:
A3. What is your ethnic group? then tick one box to best desc	Choose one section from A to E, ribe your ethnic group or background
A White ☐ English / Welsh / Scottish / Northern Irish / British ☐ Irish ☐ Gypsy or Irish Traveller ☐ Any other White background B Mixed / multiple ethnic groups ☐ White and Black Caribbean ☐ White and Black African	□ Arab
□ White and Black African□ White and Asian□ Any other mixed / multiple ethnic background	☐ Hispanic / Latino ☐ Any other ethnic group
C Asian / Asian British ☐ Indian ☐ Pakistani ☐ Bangladeshi ☐ Chinese ☐ Any other Asian background	

A4 .	Were you bor	n in the UK?		
_ \ _ \	Yes → IF YES, F No	PLEASE GO TO	QUESTION	I A5
lf	NO, which cou	ntry were you	born in?	
Ir	which year did	d you first arri	ve in the l	JK?
V	/hat is your imr	nigration statu	us in the U	JK?
	British citizen Citizen of anoth country	er European U	nion	☐ Student visa ☐ Refugee / seeking asylum
	Right to stay for time (Indefinite			☐ No papers to be in the UK
	Right to stay for	a fixed amoun	t of time	☐ Work permit
(Exceptional Leave to Remain – ELR)		□ Other		
A5.	What is your	main languag	je?	
	English Other (please wr	ite in):		
A 6.	_			ationship with a partner irlfriend / boyfriend)?
□ `	No, I am not curr → IF NO, PL Yes, I am in a rel Yes, I am in a rel	EASE GO TO Q lationship and l	UESTION A iving with	my partner
lf	YES, how long	have you bee	n in this r	relationship? (please write in)
Y	ears:	N	onths:	
lf	YES, does you	r partner have	HIV?	
	∃ Yes	□ No	□ Don	't know / unsure

A7. Do you ha relationsl	ave any children f nips?	rom current o	r prev	ious	
□ Yes	□ No				
If YES, how r	many children do y	ou have?	□ 1	□ 2	☐ 3 or more
A8. FOR WON	IEN ONLY: are yo	ou currently pr	egnar	nt?	
□ Yes	□ No	□ Don't kno	w / uns	sure	
A9. FOR WOM months?	IEN ONLY: have y	ou had a bab	y in th	e last	12
□ Yes	□ No				
A10. What is yo	our current work	situation?			
☐ Employed or ☐ Full-time stud ☐ Unemployed ☐ Unemployed ☐ Permanently ☐ Temporarily ☐ Looking after ☐ Retired	self-employed FUL self-employed PAF dent / education / tra and registered for I , NOT registered for sick / disabled (for sick / disabled (for I r home / family / dep	RT-TIME (less the control of the con	ore) ths)	hours	•
A11. How man you were	y years in full-time 16?	e education ha	ave yo	u had	since
☐ None ☐ Up to 2 years ☐ 3 years or m					

A12. What is your religion?	
□ No religion → PLEASE GO TO QUESTION □ Christian □ Buc □ Hindu □ Jew □ Muslim □ Sikh □ Any	ldhist rish
How important is religion in your life?	☐ Very ☐ Somewhat ☐ Not very ☐ Not at all
A13. Which of the following options best of yourself?	t describes how you think
 ☐ Heterosexual or straight → PLEASE GO T ☐ Gay or lesbian ☐ Bisexual ☐ Other ☐ Prefer not to say 	O QUESTION A14
How open are you about your sexuality	/? □ Completely open□ Open to most people□ Open to some people□ Not open
A14. Do you currently have enough mon needs (eg food, clothes, heating, a	
☐ All of the time ☐ Most of the time ☐ Some of the time ☐ No	

	the following descondation? (please tic		ent
□ Own my owr	n home (including mo	ortgage / loan / sh	ared ownership)
☐ Renting from	the council / a hous a private landlord housing benefit	sing association	
☐ Staying with	ccommodation (eg h partner / friend(s) / f PLEASE GO TO QU	amily	d & breakfast)
How long ha	ve you lived or stay	yed in your curre	nt accommodation?
☐ Less than☐ 6 months t☐ 1 to 5 year☐ 5 years or	to 1 year rs		
What is your	postcode? (please	write in):	
A16. Thinking	back over the past	FOUR weeks	
	ever no food to eat esources (eg mone	_	
□ Never	☐ Sometimes	☐ Often	☐ Rather not say
did you go enough foo	to sleep at night hu	ungry because th	ere was not
☐ Never	☐ Sometimes	☐ Often	☐ Rather not say
	a whole night and eere was not enoug		ng anything at all
□ Never	☐ Sometimes	☐ Often	☐ Rather not say

SECTION B: LIFE WITH HIV

B1.	When did you	i first find out	you were HIV positive?				
If yo	u are unsure of t	the month, plea	ase give the year only:				
Mon	Month: Year:						
B2.	FOR WOMEN during pregna	-	ou find out you were HIV positive				
ΠY	'es	□ No					
B3.	Where were y	ou first diagn	osed with HIV?				
☐ GP / family doctor ☐ Doctor in private practice ☐ Sexual health clinic ☐ Antenatal clinic ☐ Hospital as an in-patient			 □ While donating blood □ Community venue □ Used a home testing / sampling kit □ HIV testing service □ Prison □ Elsewhere 				
B4.	At your last to	est, what was	your CD4 count?				
□ 2 □ 3 □ N	□ Less than 200 □ 200 - 350 □ 351 - 500 □ More than 500 □ Don't know / can't remember						
B5.	At your last to	est, was your	viral load undetectable?				
□ Y	'es	□No	☐ Don't know / can't remember				

B6.	Does your HIV a	affect your da	y-to-day a	ctivities?
□N	0	□ Yes, a little	;	□ Yes, a lot
B7.	Apart from heal have HIV?	th care staff,	have you	told anyone that you
ПΥ	es 🗆 No	→ IF NO, PLEA	SE GO TO	QUESTION B8
If Y	ES, who have yo	ou told that yo	u have HI\	<i>!</i> ?
11	nave told my part	ner / wife / hu	sband	☐ Yes ☐ No ☐ Not applicable
	nave told other fa g children, parer			☐ Most or all☐ Some☐ None☐ Not applicable
11	nave told my friei	nds		☐ Most or all☐ Some☐ None☐ Not applicable
11	nave told my emp	oloyer		☐ Yes ☐ No ☐ Not applicable
1	n the last 12 mo feelings because (please tick all tha	of your HIV	•	nced any of the following
	feel ashamed blame myself have low self-este feel suicidal	em	☐ I feel gu ☐ I blame ☐ I feel I s	others should be punished

B9. Please indicate you	r agreem	ent with	the follow	ing sent	ences:
	Strongly disagree	Disagree	Uncertain	Agree	Strongly agree
The demands of everyday life often get me down					
I am quite good at managing the many responsibilities of my daily life					
In general, I feel I am in charge of the situation in which I live					
neighbours or others? (do not count anything you do as part of your paid employment) □ Yes □ No → IF NO, PLEASE GO TO QUESTION B11					
your paid employmen	nt)				
If YES, how often have you missed your HIV clinic appointments because you had to look after children, a family member, neighbour or others?					
□ Never □ Rarely □ Sometimes □ Often					
B11. Within the last year, have you been humiliated or emotionally abused in other ways by your partner or your ex-partner?					
□ No □ Yes	□Р	refer not t	o say 🛭 🗆	l Not app	licable
B12. Within the last yea ex-partner?	r, have yo	ou been a	afraid of y	our part	ner or

☐ Prefer not to say ☐ Not applicable

□ No

☐ Yes

B13. Here is a list of some things that other people do or use that may be helpful or supportive. Please tick the column that is closest to your situation:

	As much as I would like	Almost as much as I would like	Some, but would like more	Less than I would like	Much less than I would like
I have people who care what happens to me					
I get love and affection					
I get chances to talk to someone I trust about my personal problems					
I get invitations to go out and do things with other people					
I get help when I am sick in bed					
B14. Has anyone at an HIV clinic ever given you information about					
support groups		_	_		ii about
□ Yes □ No	□ No □ Don't know / can't remember				
B15. Have you been to your local area?	a suppo	rt group	for people	who hav	ve HIV in
 ☐ Yes, more than once ☐ Yes, but only once ☐ No, but I would like to ☐ No, and I do not want to ☐ I am not aware of a local support group PLEASE GO TO QUESTION B16					
If YES, have you fou	nd it help	ful?			
☐ Yes, definitely	☐ Yes, to	some exte	ent 🗆 N	0	

B16. Have you ever other substant	injected yourself with non-prescribed drugs or ces?
□Yes	□ No → IF NO, PLEASE GO TO QUESTION B17
	the last time you injected yourself with ugs or other substances?
☐ Between 4 wee	s and 4 weeks ago eks and 1 year ago r and 5 years ago
(this includes dr amphetamines,	years, have you taken any recreational drugs? ugs such as heroin, cocaine, crystal meth, marijuana or steroids, but does not include any drug octor's instructions)
□ Yes	□ No → IF NO, PLEASE GO TO QUESTION C1
If YES, in the last (please tick all that a	12 months, have you used apply)
☐ Crystal meth☐ Heroin☐ GBL	□ Crack cocaine□ Ketamine□ Mephedrone□ Other

SECTION C: YOUR HEALTH AND HEALTH CARE

C1. Overall, how would weeks?	you rate y	our health	during the	past 4				
☐ Excellent ☐ Very goo	od 🗆 C	Good 🗆	Fair □	Poor				
C2. Over the past 2 wee problems?	eks, have y	ou been bo	thered by t	these				
	Not at all	Several days	More days than not	Nearly every day				
Feeling nervous, anxious or on edge								
Not being able to stop or control worrying								
Feeling down, depressed or hopeless								
Little interest or pleasure in doing things	Little interest or pleasure							
C3. In the last 12 months, have you received support from any of the following, to help you cope with your HIV? (please tick all that apply)								
□ Specialist HIV doctor □ Specialist HIV nurse □ Counsellor or psychologist □ Psychiatrist □ Health adviser □ Community nurse □ Patient representative □ Social worker □ Peer mentor □ Telephone helpline □ Other								

C4. Has the doctor ever (please tick all that a		ve any of the following?			
☐ Asthma (as an adult) ☐ Depression ☐ Diabetes (any type) ☐ Heart condition ☐ Hepatitis B ☐ Hepatitis C ☐ Arthritis	I Depression ☐ Kidney failure I Diabetes (any type) ☐ Stroke (any form) I Heart condition ☐ Sickle cell anaemia I Hepatitis B ☐ Tuberculosis (TB) I Hepatitis C ☐ Neuropathy I Arthritis ☐ None of these				
	g-standing condition thildings, streets or vehic	nat causes you difficulty cles?			
□ Yes	□ No				
C6. Do you experience occurrence of speciappointments etc)	cial events even the m				
□ Never	☐ Hardly ever	☐ Yes, definitely			
C7. Do you feel that yo or solving problem		soning, planning activities			
□ Never	☐ Hardly ever	☐ Yes, definitely			
C8. Do you have diffice book or a movie)?	ulties paying attention	(eg to a conversation, a			
□ Never	☐ Hardly ever	☐ Yes, definitely			

UK?								
☐ Yes ☐ No → IF NO, PLEASE GO TO QUESTION C10								
If YES, have you told y	our GP tl	hat you h	ave HIV?					
□ Yes □ N	No							
C10. When was the last time you attended a GP's surgery in the UK (for your own health needs)?								
 □ In the last year □ 1 to 5 years ago □ More than 5 years ago □ I have never attended a GP's surgery in the UK □ Don't know / can't remember 								
C11. Have you ever stay	ed in a h	ospital ir	n the UK a	s an in-	patient?			
☐ Yes ☐ No → IF NO, PLEASE GO TO QUESTION C12								
If YES, when was the la	ast time y	ou staye	d in a hos	pital in t	he UK?			
□ In the last □ 1 to 5 year ago	☐ In the last ☐ 1 to 5 years ☐ More than 5 ☐ Don't know /							
C12. Thinking about you of agreement with		· -		ate your	degree			
	Strongly disagree Disagree Uncertain Agree Strongly agree							
I can figure out how and where to get the								
I feel that I am in control over how and what I								

SECTION D: YOUR HIV CARE

D1. Since your HIV diagnosis, have there been any periods of a year or more when you have <u>not seen</u> a doctor about your HIV?							
□ No □ Yes □ Don't know / can't remember □ I have been diagnosed for less than a year							
D2. Since your HIV diagnosis, appointments at the HIV c				your			
	Never	Rarely	Sometimes	Often	1		
Simply forgot							
Felt too sick or ill							
Felt too tired							
Felt depressed / overwhelmed							
Felt well							
Didn't want to think about Deing HIV positive							
Didn't have enough money □ □ □ □							
Didn't have transport							
Were afraid of being seen at the clinic							
Didn't think a doctor could help							
Had not followed the doctor's advice							
Had enough medication							
Couldn't get time off work							
D3. Have you ever missed an appointment at the HIV clinic because of drinking alcohol?							
□ Yes □ No		Don't kn	ow / can't rei	member			

D4. Have you ever missed an appointment at the HIV clinic because of taking recreational drugs?						
□ Yes	□ No	☐ Don't know / can't remember				
D5. Since you clinic in t		ave you attended more than one HIV				
□Yes	□ No → I	F NO, PLEASE GO TO QUESTION D6				
If YES, how r (please write		ave you attended in the UK?				
Thinking a attend	bout the HIV cli	inic that you currently				
D6. When did you last see a doctor or nurse at this clinic?						
	and 6 months ago months and 1 year a	ago				
	was the gap betw his clinic and the	een the last time you saw a doctor or time before that?				
☐ Longer than	and 6 months months and 1 year n 1 year	ctor or nurse at this clinic				

	How long have you been r (please write in)	receiving medical care at this HIV clinic?
Year	"S:	Months:
	In the last 12 months, how this HIV clinic?	v many appointments have you missed at
Plea	se write in:	
D10.		el to the clinic? Tick the box for the f your usual journey to the HIV clinic:
	Public transport Car Motorcycle, scooter, moped Taxi, minicab	☐ Hospital transport☐ Bicycle☐ On foot☐ Other
D11.	If you usually travel by ca	ar, have you ever had difficulty with near the clinic?
	lever Rarely Sometimes Often Iot applicable	
D12.	. How long does it usually	take you to get to the clinic?
□ 3 □ 1	Jp to 30 minutes 0 – 60 minutes – 2 hours Vore than 2 hours	

D13. How convenient for you are the opening hours at the clinic?
☐ Very convenient ☐ Fairly convenient ☐ Not very convenient ☐ Not at all convenient
D14. What additional opening hours would be convenient for you? (please tick all that apply)
□ Early morning opening (Monday to Friday) □ Evening opening (Monday to Friday) □ Saturday opening □ Sunday opening □ Other (please specify):
D15. In the past, have you had consultations with a doctor or nurse at this clinic using (please tick all that apply)
□ Face-to-face communication □ Telephone □ SMS / text messaging □ Email □ Skype or other web-based communication
D16. In the future, would you like to have consultations with a doctor or nurse at this clinic using (please tick all that apply)
□ Face-to-face communication □ Telephone □ SMS / text messaging □ Email □ Skype or other web-based communication

D17. How often do you expect to have a <u>routine</u> consultation with a doctor or nurse at this clinic?
□ Every month □ Every 3 months □ Every 4 months □ Every 6 months □ Every year □ Other (please specify):
D18. How likely are you to recommend this HIV clinic to friends and family if they needed similar care or treatment?
□ Extremely likely □ Likely □ Neither likely nor unlikely □ Unlikely □ Extremely unlikely □ Don't know
D19. The last time you made an appointment at this HIV clinic, how did you book your appointment?
 □ In person □ By telephone □ By SMS / text message □ By email □ Online booking system □ Don't know / can't remember → PLEASE GO TO QUESTION D20
How easy was it for you to book your last appointment at this clinic?
☐ Very easy ☐ Fairly easy ☐ Not very easy ☐ Not at all easy

Thinking about the <u>last ting</u> or nurse at this clinic	ne you cam	ie to see a	doctor	
D20. Were the reception staff fri	endly and ap	proachable?	•	
☐ Yes, ☐ Yes, to some definitely extent	e □ No	□ Don't k can't r	know / remember	
D21. Last time you came to see	a doctor or n	urse at this	clinic	
did you book an appointment before you came?				
at tills clillic.				
	Very important	Somewhat important	Not at all important	
I wanted advice / information on my HIV				
I wanted advice / information on something other than my HIV				
I needed practical support (eg letter for housing, benefits etc)				

D23.	. Did the doctor or nurse explain the re	easons for any	treatment
	or action in a way that you could und	lerstand?	

☐ Yes, completely
☐ Yes, to some extent
□ No
☐ Did not need an explanation
☐ No treatment or action was needed
☐ Don't know / can't remember

I needed more HIV medication

Thinking about the last time you saw <u>a doctor</u> at this clinic...

D24. Was the doo	ctor you saw friendly	and appro	achable?
☐ Yes, definitely	☐ Yes, to some extent	□No	☐ Don't know / can't remember
D25. Did the doct	tor listen to what yo	u had to sa	y?
☐ Yes, definitely	☐ Yes, to some extent	□ No	☐ Don't know / can't remember
D26. Did you hav	e confidence and tr	ust in the d	octor?
☐ Yes, definitely	☐ Yes, to some extent	□ No	☐ Don't know / can't remember
Thinking about this clinic	ut the last time y	ou saw <u>a</u>	<u>nurse</u> at
D27. Was the nur	se you saw friendly	and approa	achable?
☐ Yes, definitely	☐ Yes, to some extent	□ No	☐ Don't know / can't remember
D28. Did the nurs	se listen to what you	had to say	?
☐ Yes, definitely	☐ Yes, to some extent	□ No	☐ Don't know / can't remember
D29. Did you hav	e confidence and tr	ust in the n	urse?
☐ Yes, definitely	☐ Yes, to some extent	□ No	□ Don't know / can't remember

SECTION E: MEDICINES

E1. Please indicate your degree of agreement with the following sentences:

	Strongly disagree	Disagree	Uncertain	Agree	Strongly agree
Medicines help many people to live better lives					
Medicines help many people to live longer					
Doctors use too many medicines					
Natural remedies are safer than medicines					
Doctors place too much trust in medicines					
If doctors had more time with patients they would prescribe fewer medicines					

E2. Are you currently taking HIV medicine (HIV treatment / antiretroviral therapy / HAART)?

☐ Yes → IF YES, PLEASE GO TO SECTION F	
□ No – but I have taken HIV medicine previously	→ IF NO, PLEASE GO
☐ No – I have never taken HIV medicine	TO SECTION G

SECTION F: FOR PEOPLE WHO ARE CURRENTLY TAKING HIV MEDICINE

F1. Does your HIV Some HIV clinic treatment / antire place or a local	s pro etrov	vide a ser iral therap	vice which	ch delivers H	IIV medi	cine (HIV	
☐ Yes - I am currentl☐ Yes - I have used☐ Yes - but I haven't☐ No☐ Don't know / can't☐	it but used	I am not	currently	using it			
F2. Many people fi For each of the applies to you:	foll	_	_				
		Always	Often	Sometimes	Rarely	Never]
I forget to take them							1
I alter the dose							1
I stop taking them for while	а						
I decide to miss out a dose							
I take less than instructed							
							-
F3. During the pas		ays, on h	now mar	ny days hav	e you n	nissed ta	king
□ None □ 1 day □ 2 days □ 3 days			□ 4 da □ 5 da □ 6 da □ 7 da	ays ays			

F4. Thinking about taking HIV medicine, please indicate your degree of agreement with the following sentences:

	Strongly disagree	Disagree	Uncertain	Agree	Strongly agree
My health, at present, depends on these medicines					
My health in the future will depend on these medicines					
These medicines are my best hope for the future					
These medicines keep me alive					
Having to take these medicines worries me					
I sometimes worry about becoming too dependent on these medicines					
These medicines give me unpleasant side effects					
The taste of this medicine makes me feel unwell					
You have finished all the questions for you, please go to Section H				se go	

SECTION G: FOR PEOPLE WHO ARE NOT CURRENTLY TAKING HIV MEDICINE

G1.	Has your doctor advised you to take HIV medicine?	
□ Ye	es → IF YES, PLEASE GO TO QUESTION G2	
□ No	lo → IF NO, PLEASE GO TO SECTION H	

G2. If your doctor has advised you to take HIV medicine, how important were the following factors in deciding not to take HIV medicine at this time?

	Very important	Somewhat important	Not at all important
Side effects of medication			
Feeling depressed or overwhelmed			
Don't want to think about being HIV positive			
Using alcohol or recreational drugs			
Don't want anyone to see the medication			
Homelessness			
Taking alternative or complementary medicines			
Medication is too complicated to take			
Medication is harmful			
Information from friends or support groups			
Information from media (eg TV, newspapers, internet)			

SECTION H: Please use the space below for any further comments or information that you feel may be relevant to the survey



Thank you very much for completing this survey

Please seal the survey in the envelope provided and give it back to the staff member who gave it to you.

Thank you

Support, advice and information about living with HIV is available from:

THT Direct

10am to 8pm - Monday to Friday Information can also be found on the Terrence Higgins Trust website at: www.tht.org.uk

This project is run by

Research Department of Infection and Population Health University College London