A Multicenter, Non-interventional Study to Assess the Barriers to Initiation of Antiretroviral Treatment in Treatment-naïve HIV-1 Infected Subjects

bART Patient's questionnaire

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Year of birth ☐☐☐☐ (Y Y Y Y) Date of completion ☐☐ (D D) ☐☐☐ (M M M) ☐☐☐☐ (Y Y Y Y)

Patient's questionnaire

Part 1 – Stages of readiness to start HIV medication

The following statements are about your feelings towards starting HIV medication. Please tick the statement that is closest to the way you feel.

Tick one statement that best fits your situation:

1. I don't need HIV medication at the moment ❑
2. I'm giving serious thought to the advantages and disadvantages of starting HIV medication It is not an easy decision to make. ❑
3. I have made the decision to start HIV medication and plan to start ❑
4. I have considered all the information available and have decided to decline HIV medication ❑

Tick one of the options below:

My feeling about starting HIV medication (as indicated above) has been most influenced by:

1. My friends and/or family ❑
2. Other people who are HIV-positive ❑
3. My current state of health ❑
4. My own research ❑
5. My own beliefs ❑
6. A community treatment program ❑
7. My current HIV doctor ❑
8. Another healthcare provider (please specify their role in your care, e.g. nurse, psychologist, GP or former HIV doctor) ❑

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9. Another source (please specify if possible) ❑

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Part 2 – Numbers around HIV

Please tick the answer below that applies to you.

Tick one answer for each section:		
I was first tested HIV positive	1. Within the last 12 months	❑
	2. Between 1-5 years ago	❑
	3. 6-10 years ago	❑
	4. Longer than 10 years ago	❑
	5. I don't remember	❑
In general, would you say your health is	1. Excellent	❑
	2. Very good	❑
	3. Good	❑
	4. Fair	❑
	5. Poor	❑
	6. Very poor	❑
Last time measured, my CD4-cell count was	1. Above 500	❑
	2. Between 350 and 499	❑
	3. Between 200 and 349	❑
	4. Below 199	❑
	5. I don't remember	❑
	6. My doctor did not tell me	❑
Last time measured, my viral load (HIV) was	1. Undetectable	❑
	2. Below 10,000 copies/ml (‘Low’)	❑
	3. Between 10,000 and 100,000 copies/ml (‘Middle’)	❑
	4. Above 100,000 copies/ml (‘High’)	❑
	5. I don't remember	❑
	6. My doctor did not tell me	❑
Please indicate the number of appointments you have had at this HIV clinic in the last six months	1. None	❑
	2. One	❑
	3. Two	❑
	4. Three or more	❑
	5. I don't remember	❑
How many different HIV doctors have you seen here in the last six months?	1. Always the same doctor	❑
	2. Two doctors	❑
	3. Three doctors	❑
	4. More than three doctors	❑
	5. I don't remember	❑

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Part 3 –All around HIV medication

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The following statements from other HIV-positive people describe beliefs about HIV and HIV medication. These statements are based on opinions of people with HIV taken from research literature. Even though positive and negative feelings toward HIV medication have been described, the following section will predominantly focus on negative statements.

Please tick one answer to each of the following statements that best fits your current situation. You have five options: 1. applies to me a lot; 2. applies to me a little; 3. does not apply to me very much; 4. does not apply to me at all, or 5. I don't know.

	Applies to me a lot	Applies to me a little	Does not apply to me very much	Does not apply to me at all	I don't know
Health Beliefs					
1. I prefer to rely on complementary and alternative medicine (including traditional and herbal medicine) rather than conventional HIV medication					
2. My positive attitude and healthy lifestyle is enough to control my HIV-infection; I won't need HIV medication					
3. My viral load has been low for years, it will continue to stay low without HIV medication					
4. I believe in my body's ability to control HIV without medication					
Body awareness and symptoms recognition					
1. As long as I feel good I don't have to take HIV medication					
2. I trust my body to tell me when I need to start HIV medication					
3. Advice about the best time to start HIV medication is always changing. Doctors now recommend starting medication earlier after infection, but I have my own ideas					

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	Applies to me a lot	Applies to me a little	Does not apply to me very much	Does not apply to me at all	I don't know
Current social circumstances					
1. My current living conditions make it difficult for me to take HIV medication					
2. Problems within my family or relationship make it difficult for me to take HIV medication					
3. Difficulties at work make it difficult for me to take HIV medication					
4. My alcohol consumption or drug use makes it difficult to take HIV medication					
5. Right now there are more pressing needs in my life than taking HIV medication					
Finances and immigration status					
1. The financial implication of taking long term HIV medication puts me off starting medication					
2. If I start state-funded HIV medication it may affect my immigration status in this country					
3. If I start, I may not be able to continue, due to my pending asylum decision					
Understanding my HIV					
1. I cannot believe I have HIV, even though my doctor says I do					
2. I don't want to think about HIV, I prefer to get on with my life					
3. I do not want to take HIV medication because it will be a constant reminder that I have HIV					
4. I do not want to take HIV medication because I do not want to be used as a 'guinea pig' by doctors and drug companies					

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	Applies to me a lot	Applies to me a little	Does not apply to me very much	Does not apply to me at all	I don't know
Meaning of Life and Death					
1. My belief is that God will heal me and I will not have to take HIV medication					
2. HIV cannot be cured, so HIV medication will not help me					
3. I don't want medication keeping me alive to the bitter end; I would rather live a short and happy life without chemical HIV medication					
4. There must be a deeper meaning to being HIV positive; HIV medication will hinder me from finding out about it					
Ability to manage					
1. I do not have the right support network to help me manage HIV medication					
2. I do not have the ability to take HIV medication as regularly as needed					
3. My lifestyle does not allow me to take HIV medication as regularly as needed					
4. Taking HIV medication means more clinic visits and this will not fit into my lifestyle					
5. I will not take HIV medication because I refuse to have my life dictated by pills					
6. If I take HIV medication every day, I will no longer feel in control of my own life					
Social comparison					
1. I do not want to start HIV medication because I know others who are more unwell than me and have not started HIV medication yet					
2. Having to take large numbers of pills like some other people puts me off starting HIV medication					
3. I don't want to take pills every day for the rest of my life; like other people on HIV medication do					

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	Applies to me a lot	Applies to me a little	Does not apply to me very much	Does not apply to me at all	I don't know
Stigma/ Disclosure					
1. I don't want to take HIV medication in case people find out I am HIV positive					
2. I don't want to take HIV medication because my partner, family, friends or another person close to me does not know that I am HIV positive					
3. I don't want to take HIV medication because people may question my sexual orientation					
4. I don't want to take HIV medication because people may think that I inject drugs					
5. I don't want to take HIV medication because I have to travel home to visit my family/relatives from time to time					
6. I don't want to take HIV medication because I cannot store it in the fridge					
Treatment beliefs					
1. I worry about how HIV medication may react with the medication I take for other health conditions					
2. I worry that HIV medication will make my other health problems worse					
3. If I start HIV medication I am admitting that I have HIV and am ill; I want to delay this for as long as possible					
4. I see HIV medication as a last resort so I will not start it until I really need it					
5. Taking medication means I am progressing quickly; I want to delay this for as long as possible					
6. Once I am on HIV medication I will have to take it forever and can't stop, this puts me off starting					

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	Applies to me a lot	Applies to me a little	Does not apply to me very much	Does not apply to me at all	I don't know
7. I am convinced that HIV medication will not work for me					
8. I do not want to start taking HIV medication because I am scared of the side effects it may cause					
9. I am worried my body shape might change if I start taking HIV medication					
10. HIV medication is toxic and I don't want to get poisoned by taking it					
11. I will start HIV medication so that I am less likely to transmit HIV to another person					
12. I will start HIV medication as soon as possible because I think I need it					
Healthcare provider communication					
1. Doctors don't have to take HIV medication. They don't appreciate how difficult it will be for me to take HIV medication					
2. I cannot follow my doctor's reasons for why I need to start HIV medication					
3. I don't have all the information I need about HIV medication					
4. I'm not convinced that the doctors have given me the right advice about starting HIV medication, so I am not going to start					
5. I'm not convinced that the doctors will look after me well if I start HIV medication, so I am not going to start					
6. When I am with my doctor the reasons to start HIV medication seem clear, but afterwards when I am on my own it seems more confusing					

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	Applies to me a lot	Applies to me a little	Does not apply to me very much	Does not apply to me at all	I don't know
7. When I see my doctor there is never enough time to discuss all the important issues about HIV medication					
8. The more the doctor pressures me to take HIV medication, the more I feel I have to resist his/her advice					
9. I hear different opinions from all the healthcare providers looking after me; this makes it difficult for me to decide whether or not to start HIV medication					
10. I would be happy to start HIV medication as soon as possible but my doctor has advised me to wait					
11. My doctor has not yet offered HIV medication to me					
Additional thoughts					
1. If there is another reason or argument for or against starting HIV medication that we did not ask please write it down here and rate it as you did before:					
2.					
3.					
Questions regarding pregnant women only					
1. I have been advised to take HIV medication to help me and my unborn baby but I think it is too risky to my baby's health					
2. I don't want to take HIV medication, because I am scared it will make my nausea and dizziness worse					

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Part 4 – General questions

Screening Depression: Patient Health Questionnaire-9 (PHQ-9)

PATIENT HEALTH QUESTIONNAIRE-9 (PHQ-9)

Over the **last 2 weeks**, how often have you been bothered **by any of the following problems?**	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tiered or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself – or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3
FOR OFFICE CODING	*0*	+___	+___	+___

=Total Score: ___

If you checked off **any** problems, how **difficult** have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all	Somewhat difficult	Very difficult	Extremely difficult
❑	❑	❑	❑

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Screening Harmful Alcohol Use

CAGE Assessment (Alcohol Use)

For most people who drink, alcohol is a pleasant addition to eating and to other social activities.

For most adults drinking a moderate amount of alcohol (up to two drinks per day for men, and one drink per day for women and older people) is not harmful. But, many people get into serious trouble because of their drinking.

This short assessment will help you determine if you might have a problem with alcohol.
(The name "CAGE" is an acronym formed by taking the first letter of key words from each of the following questions.)

	Yes	No
Have you ever felt you should **c**ut down on your drinking?	❑	❑
Have people **a**nnoyed you by criticizing your drinking?	❑	❑
Have you ever felt bad or **g**uilty about your drinking?	❑	❑
Have you ever had a drink first thing in the morning (as an “**e**ye opener”) to steady your nerves or get rid of a hangover?	❑	❑

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Screening Cognitive Problems

Ref: Simioni et al AIDS 2010, 24:1243–1250.

Please tick one answer to each of the following statements that best fits your current cognitive function. You have three options: 1. never; 2. hardly ever; or, 3. yes, definitely.

	Never	Hardly ever	Yes, definitely
Processing information			
1. Do you experience frequent memory loss (e.g. do you forget the occurrence of special events even the more recent ones, appointments, etc.)?			
2. Do you feel that you are slower when reasoning, planning activities, or solving problems?			
3. Do you have difficulties paying attention (e.g. to a conversation, a book, or a movie)?			

Heath insurance situation

	Yes	No	Don't know
Tick one answer:			
Do you currently have health insurance or other government funding that would cover the costs of HIV medication			

Thank you for completing this questionnaire. If you have been worried by the statements you have read here, or are concerned about the best treatment for you, please discuss this with your doctor or nurse as soon as possible.