



Assessment of needs and expectations regarding the education of Persons living with HIV aged 50 and more.



Thanks to the support of
Gilead, ViiV, MSD



- **Background:**

The purpose of this study was:

- to identify and quantify needs and expectations among Persons living with HIV aged 50 years and more
- with a view to improve, develop and implement a therapeutic education and positive health program.

- **Methods**

- A quantitative study based on a questionnaire was conducted online through the HIV Reference Centers and HIV associations in Belgium.
- This questionnaire comprises 4 sections:
 1. **HIV and its treatment,**
 2. **the relationship with healthcare professionals and organizations,**
 3. **the emotional life of PLHIV**
 4. **the social life and professional life of PLHIV**



1. HIV AND MY TREATMENT - Q1-Q15

Q1. How much do you know about HIV and your treatment?

Nothing	2%
Somewhat	12%
Sufficient	46%
A lot	40%

Q2. How much information do you need about HIV and your treatment?

I don't need any information	12%
I need a little information	21%
I need some information	27%
I need a lot of information	37%

1. HIV AND MY TREATMENT - Q1-Q15

Q3. Please rate how important HIV information is to you on the following topics.

	Important	very important
• Preventing HIV transmission	21%	62%
• How HIV affects my body	26%	58%
• What can I do to stay healthy with HIV	13%	74%
• Telling others I have HIV	27%	12%
• Personal experiences/stories of people with HIV	36%	20%
• Getting older with HIV	19%	61%
• Available help and support for people with HIV	33%	47%
• Taking care of my mental and emotional health	22%	62%
• Having a healthy sex life	28%	47%
• Preventing and treating other sexually transmitted diseases	21%	57%
• What I need to know if I use drugs (chemsex)	19%	13%
• What I need to know if I have hepatitis C, diabetes or	20%	51%
• other health conditions (<i>hypertension, renal insufficiency, depression, ...</i>)		

1. HIV AND MY TREATMENT - Q1-Q15

Q4. Of these topics related to HIV, which are the 3 most important ones to you?

- What can I do to stay healthy with HIV 56%
- How HIV affects my body 55%
- Getting older with HIV 48%
- Preventing HIV transmission 40%
- Taking care of my mental and emotional health 20%
- What I need to know if I have hepatitis C, diabetes 11%
- or other health conditions (*hypertension, renal insufficiency, depression, ...*)
- Having a healthy sex life 9%
- Available help and support for people with HIV 9%
- Preventing and treating other sexually transmitted diseases 8%
- Personal experiences/stories of people with HIV 2%
- Telling others I have HIV 2%
- What I need to know if I use drugs (chemsex) 1%

1. HIV AND MY TREATMENT - Q1-Q15

Q5.a. When seeking HIV-related information, from whom or where do you prefer to obtain it?

- | | |
|---|-----|
| • Doctor | 83% |
| • Community HIV organization | 34% |
| • Nurse | 22% |
| • Internet | 19% |
| • Other people with HIV | 13% |
| • Media (for example, brochures, radio, newspapers) | 12% |
| • Support groups | 7% |
| • Family | 1% |

1. HIV AND MY TREATMENT - Q1-Q15

Q6. for how long have you been receiving antiretroviral treatment?

20 years or more	22%
15-20 years	16%
10-15 years	13%
5-10 years	24%
Less than 5 years	17%

Q7.a. Have you experienced one or several undesirable effects of the medication?

Yes	40%
No	48%

Q7.b. Have the healthcare professionals suggested any remedies to relieve the undesirable effects of your medication?

Not at all	2%
Not really	34%
Partly	27%
Totally	23%

1. HIV AND MY TREATMENT - Q1-Q15

Q8.a. Have you experienced one or several undesirable effects of the medication?

- Excessive fatigue, loss of energy 50%
- Loss of libido, reduced sex drive 40%
- Trouble sleeping and/or nightmares 38%
- Changes in fat distribution (lipodystrophy) 35%
- Muscle pain 34%
- Neuropathic pain 17%

Q8.b. Which undesirable effects of the medication were you told about? Please give an answer for each undesirable effect.

- Excessive fatigue, loss of energy 30%
- Loss of libido, reduced sex drive 15%
- Trouble sleeping and/or nightmares 38%
- Changes in fat distribution (lipodystrophy) 40%
- Muscle pain 23%
- Neuropathic pain 16%



1. HIV AND MY TREATMENT - Q1-Q15

Q9.a. Generally speaking, how worried are you about growing old?

- not at all 12%
- a little 22%
- a fair amount **29%**
- a lot **24%**
- extremely **12%**

Q9.b. Do you think that growing old is any different for people living with HIV than people who don't?

- Yes **49%**
- No 31%
- I don't know 16%

Q10. How aware are you of the progression and possible complications (comorbidities) of HIV?

- Not at all **21%**
- Not really **38%**
- Somewhat 21%
- Fully 14%

Q11.b. How concerned are you about the following complications (comorbidities) with regard to your current health?

Somewhat Extremely

My Physical health

Liver	17%	13%
Kidneys	21%	17%
Cancer	30%	10%
Heart	26%	13%
Bones	21%	9%

My Mental health

Memory	26%	20%
Concentration	24%	17%
Dementia	26%	12%
Depression	26%	15%
Anxiety	27%	13%
Insomnia	30%	12%

My Sexual health

Erectile dysfunction	27%	21%
Loss libido	34%	19%
Vaginal dryness (F)	33%	17%
Pain during sex (F)	8%	8%
Orgasm problems	14%	7%
Being infected by other Sexually Transmitted Diseases	22%	17%
Sexual dissatisfaction	27%	9%
Inappropriate sexual behavior	5%	11%

Q11.c. Would you like to learn more about possible HIV complications (comorbidities)?

- Not at all 4%
- Not really 15%
- **Somewhat 29%**
- **Fully 44%**

Q11.d. How would you rate your current **physical health**?

- Excellent 9%
- Good 49%
- Satisfactory 34%
- **Poor 5%**
- Very poor 1%

Q11.e. How would you rate your current **mental health**?

- Excellent 16%
- Good 42%
- Satisfactory 27%
- **Poor 12%**
- Very poor 1%

Q11.f. How would you rate your current **sexual health**?

- Excellent 9%
- Good 22%
- Satisfactory 31%
- **Poor 24%**
- Very poor 6%

1. HIV AND MY TREATMENT - Q1-Q15

Q12. Have you adapted your **lifestyle due to HIV or are you taking other steps to improve your long-term health?**

- I lead a healthier lifestyle because of HIV 49%
- I believe I have improved my diet 45%
- I did not change my lifestyle. I don't anything 33%
- I think I have enough physical exercise for my health 31%
- I avoid stressful situations 30%
- I have adapted my professional life 22%
- I do more physical exercises due to HIV 15%
- I do relaxation exercises (meditation, yoga, Tai Chi, ...) 12%

Other changes:

physiotherapy, rest not going out, volunteer work _____

Q13.a. Do you smoke?

- Yes, I smoke 11%
- I don't smoke now, but I used to 27%
- No, I have never smoked 37%



1. HIV AND MY TREATMENT - Q1-Q15

Q14. How many times in the last 12 months have you used any of these substances?

	Not at all	Every day	Every week	Monthly
Alcohol	27%	9%	29%	34%
Tobacco (smoking)	79%	16%	1%	4%
Cocaine	86%	-	-	8%
Cannabis (marijuana)	87%	-	1%	7%
Ecstasy (Ext)	88%	-	-	1%
Methamphetamine	95%	-	-	-
Heroin	96%	-	-	-
Viagra, Cialis, other similar medication	64%	-	10%	16%
Poppers	70%	-	12%	12%
Cristal meth (Crack,Tina)	93%	-	-	1%
Other: speed, 4mec,3mmc, painkillers, ...				

Q15. Do you need more help regarding drugs (chemsex)?

No 91%

Yes, I would like help with: **8%**



2. The RELATIONSHIP of PLHIV WITH HEALTHCARE PROFESSIONALS – Q1-Q5

Q1. Which healthcare professionals do you talk to about your HIV?

	Never	Sometimes	Often	Very often
Nurse	20%	33%	5%	9%
Hospital doctor	7%	24%	40%	24%
General Physician	7%	42%	20%	12%
Psychologist	41%	15%	4%	2%
Social worker	38%	19%	4%	4%
Dietitian				

Other(s): psychiatrist, home care, dentist



2. The RELATIONSHIP of PLHIV WITH HEALTHCARE PROFESSIONALS –Q1-Q5

Q2. How much attention was paid to the following aspects DURING YOUR LAST CONSULTATION at the HIV Referral Centre?

No attention Little attention A fair amount A lot of attention

Your physical health 2% 8% 51% 29%
 (bones, heart or kidney conditions, hypertension, hypercholesterolemia, ...)

Your mental health 14% 28% 33% 9%
 (depression, anxiety, concentration, memory, ...)

Your sexual health 33% 26% 14% 4%
 (erectile dysfunction, loss of libido, sexual dissatisfaction, ...)

Your medical treatment 4% 16% 47% 22%
 (side effects, changes in medication, simplification of the medication, ...)

Your treatment adherence 9% 9% 41% 30%
 (taking the medication regularly as prescribed)

Other aspects, please specify: physical activity, vaccines, weight gain, discussion not possible as partner is present .

2.  The RELATIONSHIP of PLHIV WITH HEALTHCARE PROFESSIONALS –Q1-Q5

Q3. Do you have the impression that your opinion is taken into account in the medical decision-making regarding your treatment?

- Never 4%
- Sometimes 8%
- Often 19%
- Always 44%
- I leave it to the doctors to make the decisions 17%**



2. The RELATIONSHIP of PLHIV WITH HEALTHCARE PROFESSIONALS –Q1-Q5

Q4. Are there subjects other than your treatment that you would like to talk more about?

- | | Yes | No |
|---|-----|-----|
| | 54% | 37% |
| • The complications (comorbidities) linked to HIV | 31% | |
| • Your sexual health/sex life | 30% | |
| • Your experience of the illness | 26% | |
| • Your mental health | 22% | |
| • Your emotional life | 15% | |
| • The risk of transmission | 13% | |
| • Your financial difficulties | 11% | |
| • Your life’s ambitions | 9% | |
| • Your professional problems | 6% | |
| • The illness of relatives due to HIV | 6% | |
| • Being diagnosed as seropositive | 6% | |
| • Your childhood dreams | 2% | |

2.  **The RELATIONSHIP of PLHIV WITH HEALTHCARE PROFESSIONALS –Q1-Q5**

Q4. Are there subjects other than your treatment that you would like to talk more about?

	Yes 54%	No 37%
• The complications (comorbidities) linked to HIV	31%	
• Your sexual health/sex life	30%	
• Your experience of the illness	26%	
• Your mental health	22%	
• Your emotional life	15%	
• The risk of transmission	13%	
• Your financial difficulties	11%	
• Your life's ambitions	9%	
• Your professional problems	6%	
• The illness of relatives due to HIV	6%	
• Being diagnosed as seropositive	6%	
• Your childhood dreams	2%	



2. The RELATIONSHIP of PLHIV WITH HEALTHCARE PROFESSIONALS –Q1-Q5

Q5. Do you talk to other professionals outside the hospital about your HIV?

	Never	Sometimes	Often
Nurse	70%	14%	2%
General practitioner	27%	45%	14%
Psychologist	67%	17%	4%
Social worker	80%	4%	-
HIV organization representative	64%	17%	4%
Others: pharmacist, home care			

comment :

“PLHIV seem to find it difficult to find support outside the HIV department/hospital”

3.



The EMOTIONAL LIFE of PLHIV - Q1-Q9

Q1. Among those people close to you, who is aware of your HIV-positive status?

My current stable partner	58%
My friends and close friends	55%
My brother(s) and sister(s)	43%
My child/children	26%
My mother	19%
Other family members	15%
My father	15%
My occasional sexual partners	15%
Nobody knows my HIV status	12%
My work colleagues	11%

Q2. Do you receive support from your close friends and relatives?

Not at all	8%
Not really	26%
Somewhat	33%
Fully	23%

3.



The EMOTIONAL LIFE of PLHIV- Q1-Q9

Q3. Are you able to talk to those close to you about your HIV status?

	Never	When necessary	Occasionally	Freely
Family	49%	16%	15%	11%
Friends	33%	34%	17%	5%

Others: sex partners, medical professional

Q4. Have you ever been rejected in a relationship because of your HIV status?

Not at all	33%
Not really	24%
Occasionally	20%
Often	17%

Do you have a relation with a partner at the moment?

Yes 58%

No 41%

3.



The EMOTIONAL LIFE of PLHIV- Q1-Q9

Q5. How difficult was it for you to tell your partner about your HIV status?

Not at all	28%
Not really	15%
Somewhat	8%
Extremely	4%
I did not announce	4%
Not concerned	42%

1/3 have difficulties to talk about

Q6. Do you talk about the risk of HIV transmission with your partner?

Not at all	4%
Not really	11%
Somewhat	12%
Fully	33%
Not concerned	42%

3.



The EMOTIONAL LIFE of PLHIV- Q1-Q9

Q7. Does your HIV make it difficult for you to find or stay with someone?

Yes 12% No 45% Not concerned 42%

If yes, what are the problems? suspi to be contaminated by my partner, anxious to be infectious, difficult to find a partner

Q8. As HIV positive, are you satisfied with your current sex life?

Not at all	9%
Not really	33%
Somewhat	19%
Completely	22%
I no longer have a sex life	12%

Q9. Which subjects would you like to talk about regarding your relational and emotional life?

Sexuality	43%
HIV-related death	33%
The secret	31%
Transmission risks	30%
Undetectable viral load	29%
HIV diagnosis	22%

4.  **The SOCIAL AND PROFESSIONAL LIFE of PLHIV – Q1-Q9**

Q1. Regarding your social life, do you feel isolated from day-to-day life?

No, not at all	41%
Not really	38%
Somewhat	12%
Yes, completely	7%

Q2.a. Do you think you have been discriminated against because of your HIV status?

Yes 76%

No 24%

Q2.b. If yes, how often have you experienced this discrimination?

Rarely	Several times	Often	Very often
6%	12%	2%	1%

4.  The SOCIAL AND PROFESSIONAL LIFE of PLHIV – Q1-Q9

Q2.c. If yes, in what context have you experienced or are you experiencing this discrimination? (multiple answers are possible)

Seeking treatment/care	12%
In your social life	11%
Applying for insurance	8%
Applying for a loan (bank loan)	8%
Travelling	5%
At work	5%
Applying for a job	2%
Finding/keeping accommodation	1%
Other subjects: _____	appointment at dentist at fixed hours

Q3. What is your professional status?

Retired	29%
Working full-time	27%
Working part-time	13%
Disability allowance	11%
Unemployed	4%

4.  The SOCIAL AND PROFESSIONAL LIFE of PLHIV –Q1-Q9

Q4. Do you need help in any of these contexts (administrative, legal, medical, ...)?

Seeking treatment/care 24%

Travelling 22%

Applying for insurance 21%

In your social life 13%

Finding/retaining accommodation 11%

Applying for a loan (bank loan) 7%

Applying for a job 2%

Other subjects: __financial, home work (garden)_____

Q5. Do you think the general public is sufficiently informed on the subject of HIV?

Not at all 34%

Not really 42%

Somewhat 19%

Very well 4%



4.  The SOCIAL AND PROFESSIONAL LIFE of PLHIV – Q1-Q9

Q6.a. Do you know of any organizations that offer help to HIV patients?

No 21%

Yes 78%

Q6.b. Do you visit or have you ever visited an organization that fights against HIV or an HIV support group in Belgium?

Yes, currently 17%

Yes, in the past 9%

No, never 72%

If your answer is “No, never” or “Yes, in the past”, please explain why

Multiple answers are possible

I don't know of any other organizations 24%

I have no/no longer need 22%

I don't have/no longer have the time 15%

They don't/no longer meet my expectations 9%

Other reason: ..discretion, too far away.....



4.  The SOCIAL AND PROFESSIONAL LIFE of PLHIV – Q1-Q9

Q6.d. Do you currently feel the need to visit an HIV organization or support group in Belgium?

Not at all	26%	No: 64%
Not really	38%	
Somewhat	19%	Yes: 31%
Very much	13%	

Q7. Today, what are your main needs to make living with HIV easier:

- Medical information on HIV 56%
- A friendly and welcoming place (support group, etc.) 38%
- Information on existing support structures 30%
- Psychological help (by professionals) 26%
- Information on claiming benefits and compensation 20%
- Financial support 13%
- Home help 7%
- Legal advice 6%

Other: ...list of medical specialists with HIV knowledge,



4. The SOCIAL AND PROFESSIONAL LIFE of PLHIV – Q1-Q9

Q8. During the last 12 months, have you used the services of, or had contact with, any of the following organizations

Hospital/Clinic	70%
Social security	15%
Local HIV organization	8%
Support group	6%
Mental healthcare	5%
Legal advice	2%
Employment centre	1%

Q9. People living with HIV sometimes find it difficult to get help. Tell us if you have experienced any of the following problems when seeking help.

	Yes	No
1. You could reveal your HIV status with the appropriate help.	30%	16%
2. You don't know where to find this help.	28%	21%
3. Asking for help is too complicated or difficult.	26%	24%
4. You think that this help is not available near you.	19%	30%
4. The people who should be helping you, are not doing so or are not motivated.	5%	31%

6. Other problems, please specify:

_____shy, general practioner said he was the only PvVIH in GP practise_____



- **LEARNING MORE ABOUT YOU**

You are: Male 83% Female 14%

What is your sexual orientation?

- **Gay or Lesbian 57%**
- Heterosexual 30%
- Bisexual 9%

Your ethnic origin:

- **Europe 84%**
- East Africa 1%
- **Central black Africa 11%**
- North Africa 2%
- Asia 1%
- Middle East 1%

Your marital status:

- **Single 31%**
- In a relationship (living together) 47%
- In a relationship (living apart) 7%
- Open relationship 7%

Other: _____ widower , divorced _____



- **LEARNING MORE ABOUT YOU**

Do you have children?

Yes 50%

No 49%

To you live with them?

Yes 14%

No 27%

No respons: 59%

What is your level of education?

Primary 5%

Secondary 30%

Higher 44%

University 23%

For how many years have you been living with HIV?

Over 25 years 24%

20-25 years 7%

15-20 years 11%

10-15 years 16%

Less than 10 years 41%

1/3 LTS



- **CONCLUSIONS**

The results suggest the need to improve patients' ability to express their needs, particularly those who are not members of an association. In addition to the implementation of a **therapeutic education program**, a **mental, sexual support** program is also needed.

Messages:

- We cannot reduce the well-being of PvHIV its real to everything that is quantifiable (blood results, 90_90-90,...).
- PUTTING THE **HEART** IN THE TREATMENT AND MONITORING OF HIV PEOPLE
- It is possible today technically to reduce inequalities, but much less on a mental, social and sexual level.

We must work together so that well-being, overall health, comes first.

Vivre pleinement, c'est vivre pour vivre.