

E-health. Patterns of use and perceived benefits and barriers among people living with HIV and their physicians. Part 1: Information retrieval on the Internet and social networks

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E-health. Patterns of use and perceived benefits and barriers among people living with HIV and their physicians. Part 1: information retrieval on the Internet and social networks.

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Abstract

***Objectives*.** To identify patterns of use, perceived benefits, and barriers among people living with HIV (PLHIV) of online searches for health information and via social media. ***Methods*.** Online multicenter observational survey (October 15-19, 2018).

***Results*.** Study participation was accepted by 838/1,377 PLHIV followed in 46 centers, of which 325 (39%) responded online: 181 (56%) had already used the Internet to search for health information; 88/181 (49%) on HIV infection and 78 (43%) on nutrition. These 56% were characterized by a higher educational level (OR=1.82 ±0.50; p=0.028) and more often consulted other specialists (OR=3.14 ±1.26; p=0.004). A subset of 87/180 (48%) PLHIV had changed the way they looked after their health based on their online research, and were more often in material/social deprivation (p=0.02) and diabetic (p=0.02). A small subset of 19/180 (11%) had already asked or answered a question on a forum; these people tended to be women (p=0.03) in material/social deprivation (p=0.009). 296/322 (92%) PLHIV trusted their physician whereas only 206 (64%) trusted information sourced on medical websites. 238/323 (74%) PLHIV expected their physicians to recommend websites if asked, whereas only 23/323 (7%) had actually been given this guidance.

***Conclusion*.** More than half of PLHIV surveyed had already searched for health information on the Internet, and one in two had changed their behavior based on the online search. PLHIV did not see the Internet as an alternative to physicians but they wanted their physicians to guide them on how to find quality health information to better self-manage their condition.

Introduction

The World Health Organization defines eHealth as "the use of information and communication technologies in support of health and health-related fields including healthcare, health surveillance and health education, knowledge and research". eHealth therefore also encompasses searching for information on websites, online discussions on collaborative platforms, community forums and social media, using email exchanges, apps to collect data, or smart devices with telemonitoring to collect health parameters, and on telemedicine where physicians hold electronic consultations or deliver care interventions remotely. Though it is geared to working towards personalized care, eHealth also opens up new opportunities for epidemiological research to leverage statistical analysis on huge and even heterogeneous data resources (Big Data) and opportunities for diagnostic decision support to leverage artificial intelligence using self-learning systems [1,2].

Trend analysis shows that people living with HIV (PLHIV) now have an estimated life expectancy approaching that of the general population [3]. However, HIV-positive people will tend to age faster as they develop metabolic disorders, cardiovascular disease, and cancer. Clinicians will therefore more aggressively screen them and implement primary and secondary preventive measures [4], especially if patients already have the 'classic' associated risk factors. Could eHealth help streamline this care pathway? The EmERGE project, which is currently ongoing in a number of European cities, sets out to answer this question [5-6]. What are the eHealth practices of PLHIV, and do these practices engage and empower PLHIV?

The main objective of this work was to capture the year 2018 patterns of use and perceived benefits and barriers to e-health among PLHIV and their physicians. We primarily focused on how PLHIV use the Internet and social media to look for health information.

Websites used for informational queries to confirm a disease or find answers on its course and/or treatment are extremely popular: a study from 2013 reported that 49% of French people used online health information [7]. HIV and sexually transmitted infections were the leading 'hotspots' of online health research queries in 2015 worldwide [8]. However, a person using the Internet may not necessarily find dependable-quality information, as online content may be skewed by commercial interests, by authors overreaching to garner impact, or by antiscientific sectarian bias. Furthermore, even if patients look up and learn about their disease on the Internet, they may still struggle to confront physicians with health information they found – out of fear physicians may feel challenged and react defensively with disgrace [9]. However, Mazuez [10] has already shown that patients appreciated having their physician help them judge the quality of information found online, and that feeling expedited was a far bigger threat to the physician-patient relationship than challenging the physician's medical expertise.

Is there a need to use informational health websites and social networks to promote behavioral change and new opportunities for learning, and can they help improve the quality of the care pathway for PLHIV?

Methods

We conducted an online multicenter observational 'random-week' survey from October 15 to 19, 2018 on all HIV-positive patients referred for outpatient consultation via regional coordinated care organizations (COREVIH care pathway coordinators). We also surveyed the physicians.

The inclusion criterion was patients aged over 18 years. Exclusion criteria were patients unable to complete the questionnaire, unable to speak French, and refusal to participate.

This observational study was pre-designed to comply with French research standard MR003 (health research without collection of consent), and the protocol was filed with the French data protection authority (French acronym CNIL) (study #M18009).

Concerning data security and safe storage, both patients and practitioners self-generated their anonymized personal data using a REDCap web app purpose-created for this study [11]. Access to the survey was via a QR code or a web link followed by access-code authentication. Access to data was restricted exclusively to the Clinical Research Center—Clermont-Ferrand University Hospital responsible for data stewardship, security, confidentiality, and control.

Statistical analysis was performed using Stata software suite v13 (StataCorp, College Station, TX). Descriptive statistics on the population sample are reported using patient numbers with percentages for qualitative categorical variables and means [± SD] or medians with interquartile ranges [IQR] for quantitative variables according to statistical distribution (after running the Shapiro-Wilk test for normality). Independent between-group comparisons (including patients who had or had not searched for health information online) were performed using Student's *t*-test or a Mann–Whitney test if Student's *t*-test conditions failed to hold (after using a Fisher-Snedecor test for homoscedasticity). Independent between-group comparisons on qualitative variables were performed using the Chi² test or Fisher's exact test where appropriate. In multivariate settings, we used logistic regression models to account for the variables that were considered statistically significant ($p<0.1$) in univariate analysis or clinically relevant based on the literature. The significance threshold for all statistical tests was set at a 5% risk of error.

Results

The survey was conducted in 51 clinics throughout the territory, and 255 physicians who had managed 1,377 PLHIV attending consultation during the study period were surveyed. Of these 1,377 PLHIV, 144 were ineligible, 395 refused to participate, and 838 were given login details to complete the survey. A total of 325 PLHIV attending 46 of the centers (including 191 [59%] hospital outpatients and 117 [36%] in the Ile-de-France region) completed the online questionnaire.

Table 1 reports the reasons for exclusion and refusal to participate. There was a significant difference in survey participants *vs* non-participants on gender make-up (72% men *vs* 65%, respectively; p=0.03) and mean age (52.6 ±11.9 years *vs* 50.6 ±12.1, respectively; p=0.01).

Tables 2 and 3 report the sociodemographic and medical characteristics of PLHIV who took part in the survey. The subset of 287/325 respondents who completed these items were predominantly men, mean age 53 ±12 years, born in France (77%). Half were living with their long-term partner. Nearly 66% were educated to university entry level or had been through higher education, 46% were in stable employment, and 46% were in material/social deprivation. They had been HIV-positive for an average of 17 ±10 years and had been on antiretroviral treatment for an average of 14 ±8 years, with 92% having undetectable viral load (<50 copies/mL) and an immune system regaining strength with a mean CD4 T-cell count of 620 ±375/mm³. Furthermore, 45% were also on other associated treatments. Most saw their primary care physician one, two, or three times a year and their HIV specialist twice a year, and only 29% did not also see other specialist physicians. At the time the survey was completed, mean fitness status of PLHIV was 77 (±20), self-reported on a 0–100 scale.

Searching for health information online

Over half of the PLHIV surveyed (188/341; 55%) had already used the Internet to search for health information or guidance. Univariate analysis found that these 188 web-users were younger (52 ±13 years *vs* 54 ±10 years; p=0.02) and had fewer children (56 [36%] with at least one child *vs* 65 [51%]; p=0.004) and higher educational attainment (74% had university entry qualification *vs* 57%; p=0.003), used geolocation-based dating apps more often (41 [26%] *vs* 20 [16%]; p=0.04), had more often a history of hepatitis B or C (8 [5%] *vs* 1 [1%]; p=0.046) and saw three other specialists more often than their HIV specialist (35 [22%] *vs* 15 [12%]; p=0.03). Multivariate analysis found that they had more often pursued education to at least university entry level (OR=1.82 ±0.50; p=0.028) and saw three other specialists more often than their HIV specialist (OR=3.14 ±1.26; p=0.004) (Tables 2–4).

Table 5 details the topics researched by more than 5% of the 181 respondents who answered the item: the leading topics were HIV care (half of the sample, n=88 [49%]) and nutrition (n=78 [43%]). The latest information researched by these 181 respondents was on a medical information website (n=92, *i.e.* half of the sample; 51%) rather than a nonprofit outreach website (n=22; 12%) or more rarely on Facebook, Twitter, and/or Instagram (n=8; 4%), but around 1 in 4 respondents (n=49; 27%) did not register which channel they had used. The websites visited were Doctissimo (n=89; 49%), ahead of sante.gouv.fr (n=38; 21%), basic national health insurance platform ameli.fr (n=34; 19%), Wikipedia (n=34; 19%), AIDES/Remaides (n=39; 22%), Magazine de la santé (n=22; 12%), Sidaction (n=17; 9%), and Actions Traitement (n=19; 5%). More than three out of four PLHIV (138/180; 76%) were satisfied or very satisfied with the answers they found. A small subset of 19 respondents (11%) had already asked or answered a question on a forum because they were looking for

exchanges with peers who had been through the same experience. They tended to be women (p=0.03) in material/social deprivation (p=0.009). Of those who had not used forums, more than a third stated that information on forums was either inaccurate (n=60; 37%) or unreliable (n=57; 35%), and a quarter reported that they had not dared to 'go public' (n=42; 26%). Nearly half (87/180; 48%) of those who searched for health information on the Internet (*i.e.*, 87/325 PLHIV surveyed) stated that they had changed the way they look after their health/wellness after having found information and guidance online. This subset of change-adopters tended to be in material/social deprivation (p=0.02) and diabetic (p=0.02).

To assess patients' trust in different information sources, we analyzed the results of the 322 PLHIV who answered this item: 92% fully or fairly trusted information sourced from their physician, 79% from their pharmacist, 63% from paper-print leaflets, 53% from outreach groups, and 27% from friends and family, while online, 64% fully or fairly trusted information sourced on medical websites, 45% on mass-audience websites, 14% on mass-audience forums, and 9% on social media.

Asked about guidance given on where to find reliable health information online, very few (23/323; 7%) had already been coached by a health professional – more often than not, a specialist (n=14) – without being able to pin down any 'go-to' website, and 34 (11%) had already been coached by nonprofit outreach staff, most often from AIDES (n=27). However, 55/323 (17%) thought that physicians should systematically point them towards reliable authoritative websites, and 238 (74%) thought physicians should point patients to websites if requested. More than three quarters (223; 77%) thought that guidance on good online sources was not the role of outreach groups.

Only around one in six PLHIV (54/323) knew what a COREVIH was for, and 13/43 PLHIV who answered this item had already visited a COREVIH website. Of the remaining 310

PLHIV who had not visited their COREVIH website, 41 (13%) would be interested to look it up.

Social media

Among the 318 respondents, 200 (63%) had at least one Facebook, Twitter, Instagram, Linked-In, or similar social media account that 83% of them checked up on several times a week, and 98 (49%) had several accounts. They were more often in employment (p=0.02), had spent less time HIV-positive (p<0.001) and less time on treatment (p<0.001), were more often smokers or ex-smokers (p=0.01), more often users of bars (p=0.03) and sex bars (p=0.04), more often users of geolocation-based dating apps (p<0.001), more often took illegal recreational drugs (p=0.02), and had fewer lipidemic problems (p=0.007), and fewer problems with arterial hypertension (p=0.003). Multivariate analysis found that they were younger (OR=0.95 ±0.01; p=0.001), more often smokers (OR=2.27 ±0.81; p=0.022), and more frequently used geolocation-based dating apps (OR=2.96 ±1.24; p=0.01). Lastly, more than a third (75/200; 38%) claimed that their trust in the Internet had been shaken by the recent confidentiality issues, for example charges of Russian interference in the 2016 US presidential election.

Only 27 (14%) followed an HIV outreach group on social media, and 13 (7%) had posted a comment on their health via these channels in the past 6 months. We learned that 161/199 (81%) did not talk about being HIV-positive on any online platform, in most cases not to reveal their serostatus (n=125; 63%). The 38 HIV-positive people who did talk about it did so to feel better about themselves (63%), to belong to a community (55%), to meet people (53%), to feel less isolated (47%), to learn more about their infection (47%), and to help improve STI prevention effort (47%).

Discussion

This study on health information research online and on social media met with lower mobilization than previous surveys [12–14], but the 38% return rate is a perfectly good engagement figure for an online survey. Our respondents had different characteristics from other PLHIV cohorts in France: they were more often older men, although this is not a generational difference [15]. Respondents who had already used the Internet for health information probably did so out of self-concern or a need for self-care and empowerment, given that the leading topics researched were HIV care and nutrition.

In a survey conducted in France in 2012, 30% of people interviewed stated that they had already used the Internet to look up medical or health information for themselves or friends/family [16]. By 2013 the rate was 49%, rising to 61% among people who are affected by or close to someone affected by serious or chronic disease [7]. Our findings on a population of PLHIV reveal that seeing several different specialists and having more risk factors or comorbidities effectively increases the drive to find out more information online. However, the fact that people who have a higher level of education are also more likely to have used the Internet for medical information raises the issue of equity in access to health information. The reality is that collating information requires patients to invest and organize time, thought, money and effort, which can even run to enrolling on a higher education course via a Patient University Program [17]. This warrants moves to address the challenges of health 'literacy', *i.e.* how to communicate clear and inclusively understandable health information and health messages (health culture) and how to evaluate that capability [18].

Nearly a quarter of the PLHIV who answered this item did not check the source of their information and the date it was published. France did not have an institutional agency in charge of the quality of medical information available online until the HONcode certification

was created [19], but there are now evaluation platforms such as the EU-funded Health Curator platform that allow a community of users to provide feedback on online health-related content [20].

The survey found that 48% of PLHIV respondents who search for health information and advice online (*i.e.*, a quarter of the total PLHIV sample) had changed the way they look after their health based on their online research. This is what prompted Hardey [21] to premise an emerging battle to defend power positions in which the proponents of what he describes as 'modern' medicine feel threats on key strategic fronts, because their expert knowledge is dangerously being put on a level with all kinds of other – sometimes antiscientific –knowledge, and because there are a number of market-driven agents bypassing them to speak directly to patients. Reluctance to discuss Internet searches with their physician has laid the ground for calls to make policing the quality of health information a focal priority for patient support groups, as patient online searches manifestly lead to self-diagnosis and/or self-medication [21–23]. The concept of 'expert patient' already encompassed the concept of 'informed consumer' back in 2005 [24], yet even today Fainzang [25] notes a persistent form of 'pharmacovigilant democracy' that continues to crystallize great resistance.

Participation in forum discussion boards was very low, which probably reflects the risk of discrimination facing PLHIV, that people with other chronic diseases do not have to face [7]. Online interactions and exchanges between patients first appear to proliferate in an uncoordinated mess, but a deeper look finds they are in fact relatively well structured by self-organizing community-level learning [26]. Online patient communities cover everything from mutual support to building expertise. This kind of collaborative networked 'participatory medicine' is set to bring patient empowerment and emancipation in relation to health professionals. For some, this new paradigm does not threaten the credibility of physicians

[27]. For others, the Internet has always been a subversive space, and is now challenging the power position held by the medical profession. This disconnect between the utopia of perfect health and the uncontrolled spread of medical information was studied in depth by A. Casilli [28].

Here, we observed that forum contributors tended to be women in material/social deprivation and with metabolic comorbidities. A video-conferencing-based intervention was successfully delivered at community-based intervention sites in a single-group pilot test among women living with HIV in poor areas in the United States [29]. This type of initiative also serves to build skills among young adults living with HIV. A systematic review of advances made by eHealth in the continuum of care for PLHIV found as many published intervention studies and funded projects underway via social networks as via smartphone apps or websites [31]. However, the recent issues with confidentiality on social media have hurt exchanges concerning personal health, and particularly HIV, and the consequences emerge in our survey.

The fact that a huge majority (92%) of PLHIV respondents trust information sourced from their physician means that they do not see the Internet as an alternative to their physician but more as a way to pinpoint questions to ask or as a second opinion. Most PLHIV want to improve their knowledge and to know where to find better-quality health information in order to better self-manage their condition – and there is no mistrust involved, as 74% of PLHIV would like to ask their physician to give them useful websites or HTML links. Medical knowledge has now been transformed into information that is “specialized, technicalized, largely dissociable from the medical expert” and “largely desacralized”, creating tension or even conflict between expert/medical and lay knowledge [32–33]. Against this backdrop, it is easy to understand the demand for more knowledge through access to educational websites. The strength of the bond of trust between PLHIV and their physicians means that trust could

transitively spill over to any credible or even officially-sponsored online resources recommended by the physician. This transitive trust in physicians who guide their patient towards good-quality websites is now redefining the physician-patient or patient-caregiver relationship. It manifestly also requires fresh work and effort from practitioners to improve their knowledge of good-quality websites [34]. This effort from physicians is expected to further empower PLHIV patients while protecting core patient-physician trust and keeping potential conflict in check. It would also help to repair the physician-patient relationship, which has become strained by technical and institutional requirements, squeezed by cuts in the number of caregivers, and damaged by the inflation of visits to different physicians [10]. Other health professionals – typically pharmacists – could also guide patients towards health-focused websites.

A pitfall of this research is that we did not study how 'lay' knowledge is actually constructed, which involves a number of different systems, sensemaking processes, media, and more [36]. We also did not assess whether online health research effectively grows patient empowerment compared to usual care or face-to-face interventions, as has already been done in diabetes care with positive results but ultimately minor clinical outcomes [37].

The old boundaries between 'knowers' (those who have acquired and sometimes even invented new knowledges) and 'learners' (those who have experiential knowledge that they have picked up or forged in response to a problem) are now blurred, giving way to a new shared knowledge paradigm. Our findings argue for widening the frame of care delivery: extending upstream of the consultation if the patient has already researched information or by giving opportunities to self-inform by providing reliable pre-validated links to web-based resources; extending downstream of the consultation by giving more qualified answers, adopting the stance of independent third-party expert to objectively analyze the information

sourced and help empower patients to self-manage their health. This would be the only sound basis on which to work towards the real 'personal medical file' that patients and physicians could co-manage, and rebuild their relation.

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Table 1. Breakdown of the respondent population (people living with HIV [PLHIV] and their physicians)

Number of physicians who agreed to the survey, n=255	
Number of physicians who completed the online questionnaire, n=227 (89%)	
Number of PLHIV who attended visits, n=1,377	
Number of ineligible PLHIV, n=144	
No spoken French	45
No written French	28
Unable to complete the questionnaire	54
Underaged	3
Several reasons	14
Number of eligible PLHIV, n=1,233	
Number of PLHIV who refused to participate, n=395	
Against participating in studies in general	41
Not interested in eHealth	71
No Internet access	92
Not computer literate	50
No time	40
Wary about providing personal data online	31

Other	14
Several reasons	56
Number of PLHIV who agreed to participate, n=838	
Number of PLHIV who actually participated, n=325 (39%)	
Number of PLHIV who answered all items, n=287	

Table 2. Sociodemographic characteristics of PLHIV who have already used the Internet to search for health information or advice, n=181 versus others, n=144

Variable		**n (%)** **Mean ±SD**	**Internet users**	**Non-users**	***p*-value**
Age[1]	Years	53 ±12	52 ±13	54 ±10	0.02
Gender[1]	Male	204 (71)	116 (73)	88 (69)	0.51
	Female	82 (29)	42 (26)	40 (31)	
	Transgender	1 (0.4)	1 (0.4)	0	
Life situation[1]	Long-term relationship	145 (51)	78 (49)	67 (52)	0.58
Sexual orientation[1]	Heterosexual	130 (45)	66 (41)	64 (50)	0.25
	Homosexual	123 (43)	75 (47)	48 (38)	
	Other/Refuse to identify	34 (12)	18 (11)	16 (12)	
Children[2]	At least one child	121 (42)	56 (36)	65 (51)	0.01
Country of birth[1]	Born in France	220 (77)	121 (76)	99 (77)	0.81
Department of birth[1]	Ile-de-France	55 (25)	33 (27)	22 (22)	0.39
Department of residency[1]	Ile-de-France	91 (32)	56 (35)	35 (27)	0.15
Educational attainment[1]	Baccalaureate (university entry qualification) or	190 (66)	117 (74)	73 (57)	0.003

	higher				
Occupational status[1]	Stable employment	133 (46)	71 (45)	62 (48)	0.82
	Retired	61 (21)	32 (20)	29 (23)	
	Incapacity	36 (13)	22 (14)	14 (11)	
	Jobseeker	32 (11)	20 (13)	12 (9)	
Material and social deprivation[3]	EPICES score	31 ±23	32 ±23	30 ±23	0.59
	Non-precarious	153 (54)	83 (52)	70 (55)	0.62
Meeting places[1]	Bars–clubs (non-sex-oriented)	81 (28)	52 (33)	29 (23)	0.06
	Sex clubs	40 (14)	25 (16)	15 (12)	0.33
	Online	61 (21)	41 (26)	20 (16)	0.04

[1] 287 respondents (159 Users, 128 Non-users)

[2] 285 respondents (157 Users, 128 Non-users)

[3] 286 respondents (159 Users, 127 Non-users)

Table 3. Medical characteristics of PLHIV who have already used the Internet to search for health information or advice, n=181 versus others, n=144

Variable		**n (%)** **Mean ±SD**	**Internet users**	**Non-users**	***p*-value**
Last HIV viral load measure[3]	Undetectable viral load	262 (92)	147 (92)	115 (91)	0.56
Last CD4 cell count[4]	/mm³	620 ±375	606 ±337	639 ±420	0.83
Time to HIV test[5]	Years	17 ±10	17 ±11	18 ±9	0.55
Time on antiretroviral treatment[5]	Years	14 ±8	14 ±9	15 ±7	0.45
Smoking[1]	Yes	79 (28)	45 (28)	34 (27)	0.67
	Ex-smoker	64 (22)	38 (24)	26 (20)	
Alcohol use[1]	Once or more than once a week	137 (48)	77 (48)	60 (47)	0.79
Recreational drug use[1]	Yes	39 (14)	26 (16)	13 (10)	0.28
	Ex-user	17 (6)	10 (6)	7 (5)	
Lipodystrophy[6]	Presence	58 (20)	35 (22)	23 (18)	0.43
Other associated treatments[1]	Presence	129 (45)	67 (42)	62 (48)	0.29
	Antihypertensive	59 (21)	36 (23)	23 (18)	0.33
	Psychiatric help	45 (16)	27 (16)	18 (14)	0.50

	Cardiovascular	29 (10)	16 (10)	13 (10)	0.98
	Antidiabetic	26 (9)	12 (8)	14 (11)	0.32
	Hyperlipidemia	16 (6)	9 (6)	7 (5)	0.94
	Osteoarticular	16 (6)	9 (6)	7 (5)	0.94
	Neurological	13 (5)	6 (4)	7 (5)	0.49
	Hepatitis B or C	9 (3)	8 (5)	1 (1)	0.046
	Renal	8 (3)	4 (3)	4 (3)	1.00
	Cancer	5 (2)	1 (1)	4 (3)	0.18
Monitoring[1]	In-hospital	246 (86)	138 (87)	108 (84)	0.56
Primary care physician[7]	None	40 (14)	20 (13)	20 (16)	0.52
	One, two, or three	168 (59)	91 (58)	77 (60)	
	Four or more	78 (27)	47 (30)	31 (24)	
Consultations with an HIV specialist[1]	One or two over the year	165 (57)	92 (58)	73 (57)	0.89
	Three or more	122 (43)	67 (42)	55 (43)	
Consultations with other specialists[1]	None	82 (29)	38 (24)	44 (34)	0.03
	One, two, or three	155 (54)	86 (54)	69 (54)	
	Four or more	50 (17)	35 (22)	15 (12)	

[1] 287 respondents (159 Users, 128 Non-users)

[3] 286 respondents (159 Users, 127 Non-users)

[4] 282 respondents (157 Users, 125 Non-users)

[5] 285 respondents (158 Users, 127 Non-users)

[6] 285 respondents (159 Users, 126 Non-users)

[7] 286 respondents (158 Users, 128 Non-users)

Table 4. Factors associated with seeking health information or advice online: multivariate analysis

People living with HIV who have already used the Internet to search for health information or guidance	**OR [95% CI]**	***p*-value**
Age	0.98 ±0.01 [0.96–1.00]	NS
At least one child	0.69 ±0.18 [0.41–1.16]	NS
Resident of the Ile-de-France region	0.89 ±0.25 [0.52–1.53]	NS
Baccalaureate (university qualification) or higher	1.82 ±0.50 [1.07–3.12]	0.028
Use of geolocation-based dating apps	1.42 ±0.47 [0.74–2.72]	NS
One, two, or three consultations with other specialists over the year (*vs* none)	1.56 ±0.45 [0.89–2.76]	NS
Four or more consultations with other specialists over the year (*vs* none)	3.14 ±1.26	0.004

	[1.43–6.91]	

Table 5. Topics researched online by more than 5% of people living with HIV, n=181

Variables	**n (%)**
HIV care	88 (49)
Nutrition	78 (43)
Adverse events, drug–drug interactions	60 (33)
All-round medical care/other health issues (essentially cancer, diabetes, heart conditions, STIs)	60 (33)
Sexual health	53 (29)
Vaccinations	39 (22)
Discrimination, rights and freedoms, equity and access to treatment	33 (18)
Psychological support	27 (15)
Detox	26 (14)
Love and relationships with friends and family	25 (14)
Ageing	21 (12)
Antiretroviral therapies	19 (11)
HCV	18 (10)
Chemsex	18 (10)
Cannabis	18 (10)
Buying medication online	17 (9)
Smoking, vaping	15 (8)
HBV	13 (7)
Pansexuality, prostitution	13 (7)

HIV: human immunodeficiency virus, STI: sexually transmitted infections, HCV: hepatitis C virus, HBV: hepatitis B virus.