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Original article

# E-health. Patterns of use and perceived benefits and barriers among people living with HIV and their physicians. Part 2: Health apps and smart devices



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## ARTICLE INFO

### Article history:

Received 30 April 2019

Accepted 7 April 2020

Available online 14 April 2020

### Keywords:

HIV

e-health

Mobile applications

## ABSTRACT

**Objectives.** – To evaluate patterns of use and perceived benefits and barriers to health/wellness applications (apps) and smart devices among people living with HIV (PLHIV) and their physicians.

**Methods.** – Online multicenter observational survey (October 15–19, 2018).

**Results.** – Study participation was accepted by 229 physicians and 838/1377 PLHIV followed in 46 centers, of which 325 (39%) responded online. Overall, 83/288 (29%) PLHIV had already downloaded at least one app: these 'downloaders' were younger (OR 0.96 ± 0.01,  $P=0.004$ ), educated to at least university entry level (OR 2.27 ± 0.86,  $P=0.03$ ), and more frequently used geolocation-based dating websites (OR 3.00 ± 1.09,  $P=0.002$ ). However, 227/314 (72%) PLHIV claimed they were ready to use an app recommended by a physician. For the 60/83 PLHIV who answered, the ideal app would be a vaccination tracker (76%) to better communicate with their physician (68%). However, 96/277 (42%) physicians were unable to answer this question and for 94/227 (41%) of them, the ideal patient app would be for schedule management. Although PLHIV used smart devices, 231/306 (75%) would want to report the data to their physicians and 137/225 (61%) of physicians would welcome this exchange. The main physician-side barrier to this exchange was concerns over data security.

**Conclusion.** – mHealth apps and smart devices have failed to garner adoption by PLHIV. There is a case for good-quality health data sharing and exchange if PLHIV are provided with appropriately secure tools and physicians are backed up by adapted legislation.

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## 1. Introduction

Digital technologies have invested every aspect of our lives. A survey conducted by specialists pollsters Opinion Way to coincide with the Distree #Connect 2017 smart tech forum found that 45% of French people see smart devices as "a revolution, much like the Internet a few years back" [1]. A recent BVA survey found that the French put health ahead of safety: 64% of people surveyed claimed that smart device development research should focus first on health applications, against 60% for safety [2].

Digital health industry analysts and strategy consultants Research 2 Guidance reported an estimated 259,000 health apps in 2016 against 100,000 just a year before [3]. eHealth, particularly through mHealth-enabling smart devices, poses a number of challenges for prevention and management of HIV infection. The emergent cultural phenomenon of 'quantified self' goes in tandem with the spread of increasingly ubiquitous wearable smart devices (sensors, wristbands, watches plus mobile apps). The movement extends and revisits ways to measure body, mind, and activity patterns [4]. This first 'quantified self' step teaches practitioners better self-analysis and self-surveillance of their own health indicators. It is claimed as an easy, inclusive, and readily accessible step towards better preventive care or better-coordinated care pathways [5]. It may lead to a second phase called 'modified self' where practitioners learn

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to modify their behaviors and routines and better manage the ageing process, which is a major issue for PLHIV [6]. There is already an array of practical apps, like the HIV prevention apps for men who have sex with men that have been rolled out by the European Center for Disease Prevention and Control (ECDC), or like the Canadian mHealth app HIVSmart that guides people through the process of getting HIV-tested, with links to healthcare facilities and counsellors [7,8]. Others like Hiv/Aidstestapp and Seronet/L'info en + have been created by a French nonprofit called AIDES [9–11]. The systematic reviews that identified HIV-related apps have also shown that they register few downloads [12,13]. Ethical questions have emerged and, over time, mistrust, misinformation, and concern over unwelcome surveillance and unsafe data protection have surfaced. In France, it was only in 2016 that the French National Authority for Health (French acronym HAS) finally issued long-overdue guidelines on information to users, health-related content, technical media, security/reliability, and uses/utilization [14]. Furthermore, caregivers today rarely make use of the data collected by smart devices and mobile apps. Swendeman et al. studied HIV-clinic healthcare providers' attitudes to apps, focusing on their goal to deliver better quality-of-life, and identified a number of barriers, chiefly organizational barriers [15].

We report a survey conducted in 2018 on PLHIV and their physicians that set out to identify patterns of use and perceived benefits and barriers to eHealth in France. The question addressed is whether mHealth, defined as “the practice of medicine and public health supported by mobile devices such as mobile phones, patient monitoring systems, personal digital assistants, and other wireless-enabled devices” serves PLHIV and their physicians as part of a wider self-managed care offer?

## 2. Methods

We carried out an online multicenter observational ‘random-week’ survey on all HIV-positive patients referred for consultation at short-stay outpatient clinics from October 15–19, 2018 via regional coordinated care organizations (COREVIH care pathway coordinators), as described and reported elsewhere [16].

## 3. Results

The survey was led at 51 clinics throughout France, and 255 physicians who had seen 1377 PLHIV attending consultation during the study period were surveyed [16]. Of these 1377 patients, 144 were ineligible, 395 refused to participate, and 838 were given login details to complete the survey. A total of 325 patients attending 46 of the centers, including 191 in-hospital outpatients (59%), completed the online questionnaire. The Île-de-France contingent counted 117 PLHIV (36% of the sample). 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 ( $52.6 \pm 11.9$  years vs  $50.6 \pm 12.1$ , respectively;  $P=0.01$ ).

Table 1 reports the sociodemographic and medical characteristics of patients who took part in the survey. The subset of 287/325 respondents who completed these items had a mean age of  $53 \pm 12$  years and a majority were men, including 77% born in France. 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 precarious employment. They had been HIV-positive for  $17 \pm 10$  years and had been on antiretroviral treatment for  $14 \pm 8$  years, with 92% having undetectable viral load ( $<50$  copies/mL) and a mean CD4 T-cell count of  $620 \pm 375/\text{mm}^3$ . 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

**Table 1**  
Sociodemographic and medical characteristics of patients ( $n=287$ ).

Variable	$n$ (%), mean $\pm$ SD
Age	
Years	$53 \pm 12$
Gender	
Male	204 (71)
Female	82 (29)
Transgender	1 (0.4)
Life situation	
Long-term relationship	145 (51)
Sexual orientation	
Heterosexual	130 (45)
Homosexual	123 (43)
Other	12 (4)
Children	
At least one	121 (42)
Country of birth	
Born in France	220 (77)
Department of birth <sup>a</sup>	
Île-de-France	55 (25)
Department of residency	
Île-de-France	91 (32)
Educational attainment	
Baccalaureate (university entry qualification) or higher	190 (66)
Occupational status	
Stable employment	133 (46)
Retired	61 (21)
Incapacity	36 (13)
Jobseeker	32 (11)
Precarious employment	
EPICES score	$31 \pm 23$
Non-precarious	153 (54)
Meeting places	
Bars-clubs (non-sex-oriented)	81 (28)
Sex clubs	40 (14)
Online	61 (21)
Last HIV viral load measure	
Undetectable viral load	262 (92)
Last CD4 cell count	
/mm <sup>3</sup>	$620 \pm 375$
Time to HIV test	
Years	$17 \pm 10$
Time on antiretroviral treatment	
Years	$14 \pm 8$
Smoking	
Yes	78 (28)
Ex-smoker	64 (22)
Alcohol use	
More than once a week	137 (48)
Recreational drug use	
Yes	39 (14)
Ex-user	17 (6)
Lipodystrophy	
Presence	58 (20)
Other associated treatments	
Presence	129 (45)
Antihypertensive	59 (21)
Psychiatric help	45 (16)
Cardiovascular	29 (10)
Antidiabetic	26 (9)
Hyperlipidemia	16 (6)
Osteoarticular	16 (6)
Neurological	13 (5)
Hepatitis B or C	9 (3)
Renal	8 (3)
Cancer	5 (2)
Monitoring	
In-hospital	246 (86)
Primary care physician	
None	40 (14)
One, two, or three	168 (59)
Four or more	78 (27)
Consultation with an HIV specialist	
One or two over the year	165 (57)
Three or more	122 (43)

Table 1 (Continued)

Variable	n (%), mean ± SD
Consultations with other specialists	
None	82 (29)
One, two, or three	155 (54)
Four or more	50 (17)
Self-reported patient fitness status <sup>b</sup>	
0–100	77 ± 20

<sup>a</sup> 220 respondents.

<sup>b</sup> 325 respondents.

29% did not also see other specialist physicians. At the time the survey was completed, mean patient fitness status self-reported on a 0–100 scale was 77 ± 20.

Mean age of the physicians who took part in the survey was 48 ± 10 years, and 57% were women. A large majority (72%) worked full-time at hospital, with 71% working in an infectious disease clinic.

#### 4. Questionnaire surveying PLHIV

##### 4.1. Apps

A total of 9 out of 10 PLHIV (i.e., 279/314; 89%) owned a smartphone and a little less than half (132/314; 42%) owned a tablet computer.

Stated opinions on mHealth apps by the 311 respondents were as follows: three-quarters (232; 75%) were comfortable with technology, 188 (60%) trusted the technology, 212 (68%) found the time to use the apps, and half (156; 50%) trusted their scientific value credentials, while 137 (44%) stated that using the apps helped them feel in tune with the times and a third (103; 33%) stated that the apps gave grounds to talk technology with friends. However, the dominant concerns were that their data would be used for marketing purposes (250; 81%) or by unauthorized people (241; 78%), and 74% did not want to share their data. Other concerns voiced by PLHIV were that the apps may become overly intrusive (173; 56%), may have hidden costs (119; 39%), or may become addictive (80; 26%).

Nearly a third of respondents (83/288; 29%) had already downloaded 'mHealth/wellness' apps (Tables 2 and 3). Compared to non-downloaders, this 'downloaders' subset was significantly younger ( $P < 0.001$ ) and more educated ( $P = 0.002$ ), spent more time in sex bars ( $P = 0.01$ ) and on geolocation-based dates ( $P < 0.001$ ), were active users of recreational drugs ( $P = 0.02$ ), and had spent less time HIV-positive ( $P = 0.002$ ) and on antiretroviral treatment ( $P = 0.02$ ). Multivariate analysis found that these downloaders were younger (OR 0.96 ± 0.01,  $P = 0.004$ ), educated to at least university entry level (OR 2.27 ± 0.86,  $P = 0.03$ ), and more frequently used geolocation-based dating apps (OR 3.00 ± 1.09,  $P = 0.002$ ) (Table 4).

At the time of the survey, only 10% (30/288) used wellness apps and 18% (52/288) used fitness tracking apps. Only 12 patients (4%) used health-related apps (HIV and/or others) to feel more confident in their health and have more firmly documented discussions with their physician (67%), or to improve their general health and be more self-managing (58%).

Only 9/314 (3%) PLHIV had already been advised on mobile apps by a healthcare professional, but the app functions and features failed to meet the needs of one third of them. However, 227/314 (72%) claimed they were ready to use an app recommended by a physician, far more than by a pharmacist (74/314; 24%) or a non-profit organization (57/314; 18%).

A total of 60 PLHIV answered the question investigating the role that apps play or may play: 75% responded better tracking of their bodyweight, fitness and sleep, 68% responded better

communication with their physician, 67% responded better self-surveillance of comorbidity, and 65% responded as a disease prevention tool, whereas 35% saw using apps as a way to reduce the number of appointments needed with physicians. Note that 46/60 (77%) were against sharing this data, while those who were for sharing this data would prefer to share with their physician (79%), pharmacist (50%), or a nurse (29%).

For around three quarters of the 310 respondents, the ideal app would serve primarily for monitoring vaccinations (235/310; 76%), general all-round health (234/310; 75%), and adverse drug effects (232/310; 75%), as well as for keeping track of blood test appointments (221/310; 71%) and as a record of treatments (210/310; 68%).

Respondents attached very little value to buying drugs and medication online – only 8% (24/310) of PLHIV had already bought over-the-counter products through online channels.

##### 4.2. Smart devices

Although 236/306 PLHIV respondents had already heard about smart devices, only 66 (22%) owned one – in most cases a step counter, smart watch, and sleep quality tracker. Most had owned their device for more than a year, and 11% continued to use them today. These 66 respondents were younger ( $P = 0.009$ ), had spent less time HIV-positive ( $P = 0.003$ ), and more often used geolocation-based dating apps ( $P = 0.003$ ) than the other 224 respondents. Of the 34 respondents that used these smart devices today, 65% reported that the devices helped them stay fit and be more efficient in their efforts to get fitter, but only 26% reported that they served for better-informed discussions with their physicians. The majority (88%) stated that they will continue using them unless they are paid-subscription services. Only 12% consulted their physician less often than recommended, and 70% of them would like to be able to send their data to their HIV specialist and/or primary care physician, against only 12% to their pharmacist, 15% to their basic health insurance, and 8% to their supplemental health insurance.

If they had to get mHealth-equipped, 201/306 (66%) PLHIV would need technical support and 215/306 (70%) would need medical support: either from their HIV specialist (204/233; 88%) or their primary care physician (155/233; 67%) ahead of their pharmacist (70/233; 30%), a nurse (42/233; 18%), a purpose-dedicated website (25/233; 11%), or the health insurance system (26/233; 11%).

#### 5. Questionnaire surveying physicians

The physicians had ubiquitously adopted smartphones – nearly all of them (216/227; 95%) owned one. Practically all of these physicians used their smartphone to browse the Internet (214; 99%), and 212 of them (93%) had downloaded apps: 77 (34%) used wellness apps and 92 (41%) used fitness tracking apps. Half of them in total (117/227; 52%) used these apps, and this subsample had no differentiating sociodemographic characteristics.

Ninety-four (41%) physicians thought their patients used mHealth apps, but only 41 (18%) could give an idea of how their patients used the apps, and 24 of these 41 (56%) thought that less than 10% of their patients were actually health-app users.

According to the physicians' opinion, what patients look for most in an HIV support app is schedule management (94/227; 41%), social connectivity (65/227; 28%), peer testimonies (53/227; 23%), psychological well-being (30/227; 13%), and keeping track of adverse events (30/227; 13%), blood test results (23/227; 10%), and physical and psychological HIV-related parameters. A little short of half (96/227; 42%) were unable to answer this question.

However, for 165/227 (73%) physicians, apps were adjunctive tools, and for 127/227 (56%), apps empowered and informed patients to self-manage their infection. Only 18% thought apps

**Table 2**  
Sociodemographic characteristics of people living with HIV who have already downloaded health/wellbeing apps ( $n = 83$ ) versus others ( $n = 205$ ).

Variables	$n$ (%), mean $\pm$ SD	Downloaders	Non-downloaders	P-value
Age <sup>a</sup>				
Years	52 $\pm$ 12	48 $\pm$ 13	54 $\pm$ 11	<0.001
Gender <sup>a</sup>				
Male	188 (71)	55 (73)	133 (72)	0.38
Female	73 (28)	20 (26)	53 (28)	
Transgender	1 (1)	1 (1)	0	
Life situation <sup>a</sup>				
Long-term relationship	133 (51)	38 (50)	95 (51)	0.87
Sexual orientation <sup>a</sup>				
Heterosexual	118 (45)	28 (37)	90 (48)	0.16
Homosexual	114 (44)	40 (53)	74 (40)	
Other/refuse to identify	30 (11)	8 (10)	22 (12)	
Number of children <sup>b</sup>				
At least one child	108 (42)	26 (35)	82 (44)	0.15
Country of birth <sup>a</sup>				
Born in France	200 (76)	56 (74)	144 (77)	0.52
Department of birth <sup>a</sup>				
Île-de-France	50 (25)	17 (30)	33 (23)	0.28
Department of residency <sup>a</sup>				
Île-de-France	85 (32)	29 (38)	56 (30)	0.21
Educational attainment <sup>a</sup>				
Baccalaureate (university entry qualification) or higher	177 (68)	62 (82)	115 (62)	0.02
Occupational status <sup>a</sup>				
Stable employment	124 (47)	41 (54)	83 (45)	0.20
Retired	54 (21)	13 (17)	41 (22)	
Incapacity	32 (12)	5 (7)	27 (15)	
Jobseeker	28 (11)	11 (14)	17 (9)	
Precarious existence <sup>c</sup>				
EPICES score	31 $\pm$ 23	28 $\pm$ 24	32 $\pm$ 22	0.14
Non-precarious	143 (55)	48 (63)	95 (51)	0.08
Meeting places <sup>a</sup>				
Bars-clubs (non-sex-oriented)	77 (29)	28 (37)	49 (26)	0.09
Sex clubs	39 (15)	18 (24)	21 (11)	0.01
Online	59 (23)	32 (42)	27 (15)	<0.001

<sup>a</sup> 262 respondents (76 downloaders, 186 non-downloaders).

<sup>b</sup> 260 respondents (75 downloaders, 185 non-downloaders).

<sup>c</sup> 261 respondents (76 downloaders, 185 non-downloaders).

could help strengthen the physician – patient relationship and only 24% thought apps could make patient encounters more efficient. Note that 209/227 (92%) physicians stated that the law was too lax on the collection and use of this data.

For 176/227 (75%) physicians, really useful apps would empower patients with better information and therapeutic education: for 40%, the apps would serve for clinical decision support and for 37% they would enable better monitoring, but only 46 (20%) thought it feasible to allow online data entry in the patient's health record.

A majority of the physicians (150/226; 66%) did not know whether their patients used smart sensors. Among just 24 who did know, the majority asserted that no more than 5% of patients used them. However, 137/225 (61%) physicians would welcome mainstream use of smart devices, as they ready their patients for the digital health revolution (71%) and educate their patients on how to sensibly use emerging technologies (53%). Those physicians who were against essentially cited data security issues (57/88; 65%) and information overload (49%) rather than issues tied to data confidentiality (40%), medical liability (26%), inadequate data (26%), or trustworthiness (17%).

## 6. Discussion

Nearly a third of the 325 PLHIV respondents had already downloaded mHealth/wellness apps – including just 3% on the advice of their physician – but only 10% reported using the apps at the time of the survey. These active users were younger and more highly educated, and they already used apps socially. This 10% mHealth app user rate is the same as the rate estimated by the few physicians

who claimed they knew the app. Only 22% of PLHIV surveyed owned at least one smart device, with no differences in sociodemographic characteristics to active app users, and 11% continued using them today. This converges with the numbers estimated by the 24/299 physicians who stated that they knew their patients' patterns of mHealth device use. On top of the gap between patient-reported practices and physician-reported perceptions, there is another gap between patient-reported needs and physician-reported needs: 76% of the 310 PLHIV stated that the ideal app would be a general health and vaccinations tracker for the purpose of better communicating with their physician, whereas 42% of the 227 physicians surveyed said they had no idea how PLHIV would find use for an app.

A French survey led by Odoxa in 2015 reported that 29% of people regularly used mainstream smart devices and only 5% of patients had been recommended a connected technology solution by their physician [17]. We observed that PLHIV are timid mHealth users: they make disappointingly few downloads of HIV-related apps and are even turning away from using them. The early hope and promise of new health information technologies has given way to mistrust due to insecurity surrounding data confidentiality and personal data protection. The 'innovative biotechnology packages' that were designed to improve quality of life across the board had offered a 'framework' and 'horizon' for hope and a less uncertain future [18]. These researches fueled belief that life was improvable and promised to perform 'miracles' in the field of medicine – at a cost of desubjectivizing the body and disembodiment of the conscious subject. However, the surrounding economy selling the promise of a new 'biotechnological regime' is ultimately a 'commerce and industry-driven' vision grounded in a triangle

**Table 3**  
Medical characteristics of people living with HIV who have already downloaded health/wellbeing apps (*n* = 83) versus others (*n* = 205).

Variables	<i>n</i> (%), mean ± SD	Downloaders	Non-downloaders	<i>P</i> -value
Last HIV viral load measure <sup>b</sup>				
Undetectable viral load	238 (91)	70 (92)	168 (91)	0.74
Last CD4 cell count <sup>c</sup>				
/mm <sup>3</sup>	613 ± 366	620 ± 352	610 ± 373	0.28
Time to HIV test <sup>d</sup>				
Years	17 ± 10	14 ± 11	18 ± 10	0.002
Time on antiretroviral treatment <sup>d</sup>				
Years	14 ± 8	11 ± 8	15 ± 8	0.002
Smoking <sup>a</sup>				
Yes	70 (27)	23 (30)	47 (25)	0.54
Ex-smoker	61 (23)	19 (25)	42 (26)	
Alcohol use <sup>a</sup>				
Once or more a week	126 (48)	36 (47)	90 (48)	0.88
Recreational drug use <sup>a</sup>				
Yes	37 (14)	15 (20)	22 (12)	0.02
Ex-user	15 (6)	8 (11)	7 (4)	
Lipodystrophy <sup>d</sup>				
Presence	55 (21)	17 (23)	38 (21)	0.76
Other associated treatments <sup>a</sup>				
Presence	111 (42)	29 (38)	82 (44)	0.38
Antihypertensive	50 (19)	12 (16)	38 (20)	0.39
Psychiatric help	38 (15)	13 (17)	25 (13)	0.45
Cardiovascular	23 (9)	4 (5)	19 (10)	0.20
Antidiabetic	22 (8)	6 (8)	16 (9)	0.85
Hyperlipidemia	13 (5)	4 (5)	9 (5)	1.00
Osteoarticular	13 (5)	3 (4)	10 (5)	0.76
Neurological	11 (4)	3 (4)	8 (4)	0.90
Hepatitis B or C	8 (3)	4 (5)	4 (2)	0.24
Renal	6 (2)	1 (1)	5 (3)	0.68
Cancer	5 (2)	1 (1)	4 (2)	1.00
Monitoring <sup>a</sup>				
In-hospital	226 (86)	64 (84)	162 (87)	0.54
Primary care physician <sup>a</sup>				
None	36 (14)	6 (8)	30 (16)	0.10
One, two, or three	158 (60)	45 (59)	113 (61)	
Four or more	68 (26)	25 (33)	43 (23)	
Consultations with an HIV physician <sup>1</sup>				
One or two over the year	152 (58)	47 (62)	105 (56)	0.42
Three or more	110 (42)	29 (38)	81 (44)	
Consultations with other specialists <sup>3</sup>				
None	76 (29)	25 (33)	51 (27)	0.22
One, two, or three	142 (54)	35 (46)	107 (58)	
Four or more	44 (17)	16 (21)	28 (15)	

<sup>a</sup> 262 respondents (76 downloaders, 186 non-downloaders).<sup>b</sup> 261 respondents (76 downloaders, 185 non-downloaders).<sup>c</sup> 257 respondents (76 downloaders, 181 non-downloaders).<sup>d</sup> 260 respondents (76 downloaders, 184 non-downloaders).**Table 4**  
Characteristics of people living with HIV who have already downloaded health/wellbeing apps (multivariate analysis).

Patients who have already downloaded mHealth/wellness apps	OR [95% CI]	<i>P</i> -value
Homosexuality (vs heterosexuality)	1.14 ± 0.48 [0.51–2.58]	NS
Refuses to identify their sexual orientation (vs heterosexuality)	1.32 ± 0.75 [0.43–4.01]	NS
Age	0.96 ± 0.01 [0.94–0.99]	0.004
At least one child	1.35 ± 0.53 [0.63–2.90]	NS
Resident of the Île-de-France	0.71 ± 0.24 [0.37–1.38]	NS
Baccalaureate (university qualification) or higher	2.27 ± 0.86 [1.08–4.77]	0.031
Precarious employment	0.60 ± 0.19 [0.32–1.12]	NS
Use of geolocation-based dating apps	3.00 ± 1.09 [1.48–6.12]	0.002
One, two, or three consultations with their primary care physician (vs none)	1.99 ± 1.07 [0.69–5.73]	NS
Four consultations with their primary care physician (vs none)	3.86 ± 2.23 [1.24–11.99]	0.019

of ‘market forces, self-determination and public health’ [18]. Connected medical devices (CMD) come with a legal obligation to protect all personal health data, but note that not all connected mobile apps and smart devices are qualified as CMD – the others are smart devices that have no stated medical purpose, for which France has nevertheless issued good-practice guidance to industry to ensure that personal data remains secured and reliable [14]. Furthermore, the sponsors of technoscience-driven promises are arguably in the business of selling hope and may well be overselling the possibilities of solving psychosocial-medical problems with technology solutions [19]. In this sense, their promises equate to speculative bubbles.

Are these app tools overly intrusive, as claimed by 56% of the PLHIV surveyed? On the one hand, without a firm command of the information produced, knowing the state of one’s body is liable to generate stress and anxiety [20]; yet on the other hand, app-based ‘self-healthcare’ may create an illusion of some kind of body-health control. This self-led health assessment may give the illusion of escaping avoidable morbidity and premature death [21]. This biometric data could open the door to intrusive body-health control by service providers or even health insurance companies, which would have acute social and psychological repercussions [22]. Mathieu-Fritz & Guillot [23], in a paper on the ‘patient work system’, showed that the ‘price to pay’ for using self-care tools entails more work, more uncertainty, and – crucially – an ‘experimental mindset’ geared to testing the value and reliability of new devices.

The landmark market approval for the world’s first digital pill – called Abilify, indicated to treat chronic psychosis – to track medication adherence raises tricky ethical questions [24]. On one side of the equation, carer responsibility dictates tight control of perfect medication adherence for the good of the patient. On the other side, the patient becomes dispossessed of their disease, with efficacy overriding patient autonomy since wider community principles dictate the provision of care for all and care to keep scarce health resources cost-effective, and so this digital system ultimately raises the issue of individual freedom.

General disinterest for HIV mHealth may also be induced by inadequate follow-up, gaps in counselling or gaps in personalized status analysis, due to a lack of appropriate health education. Our findings point to distortion in the end-purpose of mHealth apps. Note that the 310 PLHIV respondents stated that the ideal app would be a general health and vaccinations tracker for the purpose of better communicating with their physician, whereas 42% of the physicians surveyed said they had no idea how PLHIV would find use for an mHealth app. The other half of the physicians surveyed thought that their patients see utility in schedule management and for creating social exchange among peers. Less than one in five physicians thought an mHealth platform could strengthen the physician – patient relationship, as suggested in the EmERGE project [25]. Physicians today are routinely struggling with tight time schedules and poor working conditions, especially in hospitals, which puts the physician – patient relationship under strain [26,27]. These new connected devices thus need to find room and space in an already-crowded organization/ecosystem. Furthermore, published findings on the use of digital technologies in medical practice were long a source of controversy [28]. Many of the papers were not fit for analysis as they failed to meet robust methodological evaluation standards [29], and a majority of them failed to demonstrate any real medical service to patients, except for CMDs which enabled ‘live’ telemonitoring that brings significant benefits in heart failure prevention and diabetes management, chiefly through appropriate professional organizational-level service delivery and appropriately-trained professionals [30–32]. The disorganized use of smart health tech and the lack of cooperation between industry, patients, and healthcare providers to ensure data remains secure and reliable have since been addressed and

trial methodologies have since been adapted, with encouraging results [33]. There are now some apps purpose-designed for PLHIV outreach, to support engagement in prevention and medication adherence, or to support continuity of care [34–36]. mHealth solutions could also address inequity in access to care for larger segments of the HIV-positive population in low-income countries. A study in South Africa found that mHealth could address the lack of communication in sharing patient health information between clinics, community health workers, and patients, as well as improve health information transfer to government officials to better allocate healthcare resources, and maybe even enable better patient identification [37], yet nation-wide adoption of mHealth has still not occurred [38].

PLHIV used smart devices that were useful adjunctive tools for managing their care, but three quarters of them would like to send their data to their physician. This fits with the 61% of physicians who would welcome routine use of smart devices, which they see as a vector for delivering health education or a way to empower patient self-management, in line with the conclusions of the national evaluator of health apps and smart devices that certifies medical devices [13]. The main barriers to adoption cited by physicians arise from concerns over data security and information overload, as already signaled by Dr J Melchior from Louvain University in Belgium [39]. In terms of data sharing and confidentiality with ‘health/wellness’ apps that do not strictly host health data, a recent study surveying PLHIV captured the situation well [40]. The authors found that more and more community-member outreach workers are using in-community mobile apps and websites, which raises a number of ethical challenges on four fronts:

- managing personal and professional boundaries with clients;
- disclosing personal or identifiable information to professionals;
- maintaining client confidentiality and anonymity;
- security and data storage measures for online information.

Discussions under the EmERGE project surrounding network exchange platforms converged towards a critical need to implement the highest level of data security/privacy, as there is still strong stigmatization around HIV-positive people, and unlike when a bank account gets hacked, the social damage done is impossible to repair [25].

To conclude, mHealth apps and smart devices have failed to garner adoption by PLHIV. The reason appears to be a combination of marketing-related mistrust raising data security, confidentiality, and privacy fears, and an absence of adequate personalized monitoring and medical analysis – which physicians lack the time and perhaps even the motivation to deliver. These barriers to uptake of mHealth apps and smart devices could be removed if physicians, with legislative backing and better hospital-side organization, engaged in promoting them. If app certification could become one of the roles and responsibilities of scholarly societies working in concert with patient advocacy groups, and if the lead ‘eHealth’ specialists could produce the requisite technical assistance, then data sharing and exchange could become adopted within a new conception of the HIV care pathway.

#### Disclosure of interest

The authors declare that they have no competing interest.

#### Funding

None.

## Acknowledgements

CJ, PB, FL, ROT, and PD drafted the protocol, JP put the two surveys online, CL performed the statistical analysis, CJ interpreted the findings and drafted the article, and FL, ROT, and PD reread and reviewed the draft. The surveys were organized, coordinated, and delivered on-site with help from the following physicians and CRTs: C. Faudon, T. Allegre Aix-en-Provence; M. Lombard, J.L. Schmit Amiens; S. Rehaïem, V. Rabier Angers; A. Valran, E. Piet Ancey; J. Gerbe, F. Caby Argenteuil; E. Chevalier, A. Foltzer Besançon; L. Traore, O. Bouchaud Bobigny; J.C. Duthe, S. Ansart, L. de Saint Martin Brest; P. Goubin, R. Verdon Caen; J. Prouteau, C. Jacomet Clermont-Ferrand; C. Chesnel, L. Richier, S. Gallien, B. Elharrar Créteil; I. Calmont, A. Cabié Fort-de-France; M. Marcou, P. de Truchis Garches; C. Sautron, MP. Moiton La Réunion Saint-Denis; L. Lainé, S. Leautez-Nainville La Roche-sur-Yon; P. Camps, M. Roncato-Saberan La Rochelle; D. Bornarel, A. Greder-Belan Le Chesnay; AS. Keita, A. Cheret Le Kremlin Bicêtre; F. Dangeul-Potier, H. Hitoto Le Mans; B. Montoya, JJ. Laurichesse Mantes-la-Jolie; S. Tassi, E. Frogel Marne-la-Vallée; A. Suzel-Ritleng, O. Zaegel-Faucher Marseille Sainte Marguerite; C. Fernandez, J. Reynes Montpellier; M. Benomar, G. Beck-Wirth Mulhouse; A. Soria, F. Raffi Nantes; I. Toutitou, P. Pugliese Nice; P. Gougeon, S. Sunder Niort; MJ. Dulucq, L. Slama Paris Hôtel-Dieu; C. Louisin, C. Duvivier, PH. Consigny Paris Necker Institut Pasteur; M. Pauchard, D. Beniken, C. Katlama, A. Simon Paris Pitié-Salpêtrière; C. Tran, D. Bollens Paris Saint-Antoine; A. Adda Lievin, G. Thibaut, P. Pialoux Paris Tenon; L. Pinheiro, H. Aumaitre Perpignan; L. Gerard, H. Masson Poissy; D. Plainchamp, G. Lemoal Poitiers; J.C. Duthe, P. Perfezou Quimper; I. Kmiec, F. Bani-Sadr Reims; C. Guennoun, C. Arvieux Rennes; G. Unal, A. Lesourd Rouen; V. Ronat, A. Fresard Saint-Étienne; B. Montoya, Y. Welker Saint-Germain-en-Laye; C. Grand Courault, C. Michau Saint-Nazaire; P. Fisher, D. Rey Strasbourg; V. Lambry, A. Lafeuillade Toulon; M. Digumber, O. Robineau Tourcoing; E. Racamier, H. Champagne Valence; L. Richier, S. Dellion Villeneuve-Saint-Georges.

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