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Original article

# E-health. Patterns of use and perceived benefits and barriers among people living with HIV (PLHIV) and their physicians – Part 3: Telemedicine and collection of computerized personal information



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## ARTICLE INFO

### Article history:

Received 30 April 2019

Accepted 9 April 2020

Available online 19 April 2020

### Keywords:

HIV e-health

Telemedicine

Collection of computerized personal information

## ABSTRACT

**Objectives.** – To evaluate the patterns of use and perceived benefits and barriers among people living with HIV and their physicians concerning telemedicine and the collection of computerized personal information.

**Methods.** – Multicenter online observational survey from October 15 to 19, 2018.

**Results.** – Study participation was accepted by 229 physicians and 838/1,377 PLHIV followed in 46 centers, of which 325 (39%) responded online. We found that while 226/302 (75%) PLHIV accept online prescription renewals and 197/302 (65%) accept online medical certificates, 182/302 (60%) PLHIV – who were more often in material/social deprivation (OR = 1.70 ± 0.45; P = 0.045), less often born in Île-de-France (OR = 0.43 ± 0.15; P = 0.018), with lower CD4 T-cell counts (OR = 0.999 ± 0.0004; P = 0.038), and less often on psychiatric treatment (OR = 0.50 ± 0.18; P = 0.047) – were receptive to teleconsultations. However, 137/225 (61%) physicians would be uncomfortable teleconsulting due to inadequate data security without it reducing the number of consultations or offering economic benefit. Asked about collection of computerized personal information, 197/296 (67%) PLHIV and 139/223 (62%) physicians agreed it improved quality of care, but 144 (49%) PLHIV and 94/222 (42%) physicians thought it was not sufficiently framed by the law. eHealth was seen as improving coordination between health professionals by 240/296 (81%) PLHIV and seen as a good thing by 181/225 (81%) physicians.

**Conclusion.** – More than half of PLHIV were ready for telemedicine. PLHIV and physicians endorsed the advantage of e-health in terms of better coordination across health professionals but mistrust the data collection factor, which warrants either clarification or stronger legal protections.

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## 1. Introduction

The eHealth concept was introduced in 1999 by John Mitchell at the 7th International Congress on Telemedicine and Telecare in London, where he defined the term as “the combined use of electronic communication and information technology [...] for clinical, educational and administrative purposes, both at the local site and at distance” [1]. The following year, the European Directive of 8

June 2000 stipulated, under Article 8, that “Member States shall ensure that the use of commercial communications which are part of, or constitute, an information society service provided by a member of a regulated profession is permitted subject to compliance with the professional rules regarding, in particular, the independence, dignity and honor of the profession, professional secrecy and fairness towards clients and other members of the profession” [2]. eHealth was thus umbrellaed under the same legal framework as e-commerce, which was not tight enough to ensure data security. In November 2008, the European Commission finally recast telemedicine services as healthcare services rather than information society services [3].

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France legalized the practice of clinical telemedicine in its 2009 “Hospital–patients–health–territories” law, and framed the conditions governing implementation under government decree 2010-1229 [4,5]. Videoconference-based telemedicine procedures were made possible in France through pilot trials started in 2014 and extended to the general population in September 2018 [6]. A recent survey on 1,000 respondents found that more than one in two French people were receptive to the idea of teleconsulting, with most citing convenience, but 18% feared that exchanges would not stay confidential and worried that their personal information would be unprotected [7]. Moreover, telemedicine can also take other forms, such as medical professionals monitoring a patient remotely (telemonitoring) or physicians sharing and exchanging medical opinion (tele-expertise).

This means the boundary between primary-care (general practice) and secondary-care (hospital) ‘health’ information systems is permeable, which is what paved the way to the interoperable electronic health record (French acronym DMP) and health insurance smartcard system [8]. In France, it was only in 2016 that the French National Authority for Health (French acronym HAS) finally issued long-overdue guidelines framing information to users on health-related content, technical media, data security/reliability, and access/utilization [9]. This prompted the creation of ‘digital health vaults’ – secure tools for archiving, indexing, filing, and finding digital health files and patient-owned records, and offering an extremely high level of confidentiality and protection for all stored files.

In companion papers we explored patterns of use and perceived benefits and barriers among people living with HIV (PLHIV) and their physicians concerning health information searches online and via social media and health services via smart devices (mHealth) [11,12]. Here we examine our results on perceptions of telemedicine and readiness to share health data.

## 2. Methods

We conducted an online multicenter observational ‘random-week’ survey from October 15 to 19, 2018 on all HIV-positive patients referred for consultation at short-stay outpatient clinics via regional coordinated care organizations (COREVIH care pathway coordinators) [11].

## 3. Results

The survey was led at 51 clinics throughout the territory, and 255 physicians who had seen 1,377 PLHIV in consultation during the study period were surveyed [11]. A total of 325 PLHIV attending 46 of the centers, including 191 in-hospital outpatients (59%), completed the online questionnaire. The Île-de-France region recruited 117 patients, i.e. 36% of the total 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;  $P=0.01$ ).

The sociodemographic and medical characteristics of the PLHIV and physicians who took part in the survey have been described elsewhere [10]. The PLHIV were predominantly men, mean age  $53 \pm 12$  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 (EPICES score). They had been HIV-positive for an average of  $17 \pm 10$  years and had been on antiretroviral treatment for an average of  $14 \pm 8$  years, with 92% having undetectable viral load ( $<50$  copies/mL) and an immune system regaining strength with a mean CD4 T-cell count of  $620 \pm 375/\text{mm}^3$ . 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 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  $77 (\pm 20)$ .

Mean age of physicians was  $48 \pm 10$  years, and 57% were women. A large majority worked full-time at hospital, with 71% working in an infectious disease clinic.

## 4. Questionnaire surveying PLHIV

The 182/302 PLHIV who were ready for certain primary care physician consultations to be done remotely were more often men ( $P=0.009$ ) and men who have sex with men ( $P=0.02$ ), with fewer children ( $P=0.02$ ), more often born in the Île-de-France region ( $P=0.02$ ), had more often been through higher education ( $P=0.01$ ), had more sex dates through geolocation-based apps ( $P=0.001$ ), were less often on psychiatric treatment ( $P=0.04$ ) and neurological treatment ( $P=0.005$ ) to support their antiretroviral therapy, and had more history of hepatitis B or C ( $P=0.09$ ) (Tables 1 and 2). Multivariate analysis found that these PLHIV were more often in material/social deprivation ( $\text{OR}=1.70 \pm 0.45$ ;  $P=0.045$ ), less often born in the Île-de-France region ( $\text{OR}=0.43 \pm 0.15$ ;  $P=0.018$ ), had less elevated CD4 T-cell counts ( $\text{OR}=0.999 \pm 0.0004$ ;  $P=0.038$ ), and less often received psychiatric treatment ( $\text{OR}=0.50 \pm 0.18$ ;  $P=0.047$ ) (Table 3). However, a higher number of respondents wanted to adopt online prescription renewals (226/302; 75%) or online medical certificates (197/302; 65%) and get quick medical advice online (180/302; 60%). Their perception was that these are simple basic services, not medical consultations.

A physical face-to-face consultation with the physician remains the first-choice format for care on acute signs and symptoms (246/302; 81%), for raising intimate-life issues (244/302; 81%), for emergency consulting (181/302; 60%), and for ongoing HIV management (198/302; 65%). Opinions were more mitigated on relatively benign symptoms ( $n=170$ ; 56%). For 60/320 (20%) respondents, it remained the ideal consultation solution because it is face-to-face, but 238/303 (79%) respondents thought that eHealth represents an advancement in delivering patient care. The benefits cited were faster access to care (167/238; 70%), convenience of not losing time getting to a health service (161/238; 68%), and access to care in remote rural communities.

At the time of the survey, 118/303 (39%) respondents had already used email to liaise with a health professional: 86/303 (28%) with their HIV specialist, 40/303 (13%) with their primary care physician, 16/303 (5%) with other physicians, 7/303 (2%) with their psychologist, 6/303 (2%) with a therapeutic education counsellor. However, 246/303 (81%) would like to be able to contact a health professional via a secure email client, including 45/303 (15%) citing a therapeutic education counsellor, and 87/303 (29%) respondents would expect a response within three days.

An Internet kiosk in their point-of-care setting where they could enter data directly into their hospital medical record to flag up important information ahead of the consultation would be a good thing for 31/301 (44%) respondents, as it would save time and give them better ownership of and structure to their information. This subset had fewer children ( $P=0.03$ ) and either never or, conversely, very often saw their primary care physician ( $P=0.03$ ). Multivariate analysis found that they more often had no children ( $\text{OR}=0.61 \pm 0.12$ ;  $P=0.05$ ). For 170/301 (56%), a kiosk option was seen as a bad idea, citing difficulty using it and choosing what kind and quality of information to give, fear of losing privacy, and ending the valuable personal relation with the physician.

Asked about the collection of personal information, 242/306 (82%) PLHIV thought it was set to rise in the coming years, but

**Table 1**  
Sociodemographic characteristics of people living with HIV who endorse having certain consultations with their specialist physicians online,  $n = 182$  versus others,  $n = 120$ .

Variable	n (%), mean $\pm$ SD	Proponents	Opponents	P-value
Age <sup>a</sup>				
Years	53 $\pm$ 12	52 $\pm$ 12	53 $\pm$ 12	0.38
Gender <sup>a</sup>				
Male	203 (71)	132 (77)	71 (62)	0.009
Female	82 (28)	39 (22)	43 (38)	
Transgender	1 (1)	1 (1)	0	
Life situation <sup>a</sup>				
Long-term relationship	145 (51)	95 (55)	50 (44)	0.06
Sexual orientation <sup>a</sup>				
Heterosexual	129 (45)	69 (40)	60 (53)	0.049
Homosexual	123 (43)	84 (49)	39 (34)	
Other/refuse to identify	34 (12)	19 (11)	15 (13)	
Number of children <sup>b</sup>				
At least one child	120 (42)	63 (37)	57 (50)	0.02
Country of birth <sup>a</sup>				
Born in France	220 (77)	135 (78)	85 (75)	0.44
Department of birth <sup>a</sup>				
Île-de-France	55 (25)	41 (30)	14 (16)	0.02
Department of residency <sup>a</sup>				
Île-de-France	91 (32)	62 (36)	29 (25)	0.06
Educational attainment <sup>a</sup>				
Baccalaureate (university entry qualification) or higher	190 (66)	124 (72)	66 (58)	0.01
Occupational status <sup>a</sup>				
Stable employment	133 (47)	78 (45)	55 (48)	0.63
Retired	61 (21)	39 (23)	22 (19)	
Incapacity	36 (13)	21 (12)	15 (13)	
Jobseeker	32 (11)	22 (13)	10 (9)	
Material and social deprivation <sup>c</sup>				
EPICES score	31 $\pm$ 23	30 $\pm$ 23	32 $\pm$ 23	0.46
Non-precarious	153 (54)	95 (56)	58 (51)	0.44
Meeting places <sup>a</sup>				
Bars-clubs (non-sex-oriented)	81 (28)	49 (28)	32 (28)	0.94
Sex clubs	40 (14)	27 (16)	13 (11)	0.31
Online	60 (21)	47 (27)	13 (11)	0.001

<sup>a</sup> 286 respondents (172 proponents, 114 opponents).

<sup>b</sup> 284 respondents (171 proponents, 113 opponents).

<sup>c</sup> 220 respondents (135 proponents, 85 opponents).

only 197 (66%) agreed that it would improve quality of care and patient monitoring, 168 (57%) that artificial intelligence would bring progress in diagnosis, and 152 (52%) that it was the price to pay for using apps today. On the downside, 178/306 (60%) had no trust in how data might be used, and while 105/306 (35%) thought there was enough legal protection framing the collection and use of this data, 137/306 (46%) were skeptical.

Asked about a digital vault for health records, 144/296 (49%) respondents stated they would prefer all of their digital health data to be stored on their own computer, while 107/296 (36%) would prefer storage on health insurance system servers. People in this subset of respondents were more often in material/social deprivation ( $P = 0.005$ ) and more frequently consulted specialists ( $P = 0.02$ ). Multivariate analysis confirmed that these people were more often in material/social deprivation (OR = 1.99  $\pm$  0.51;  $P = 0.007$ ) and consulted specialists more frequently, i.e. at least four times a year, rather than never (OR = 2.74  $\pm$  1.05;  $P = 0.009$ ). There were 96/296 (32%) PLHIV who wanted to have access to a digital vault hosting their health records, and people in this subset were men ( $P = 0.001$ ) and men who have sex with men ( $P = 0.001$ ), younger ( $P = 0.05$ ), with fewer children ( $P = 0.005$ ), more highly educated ( $P = 0.01$ ), and used geolocation-based dating apps more often ( $P = 0.003$ ). Multivariate analysis did not find any clear factor associated with wanting health data hosted by a purpose-dedicated health data facility. Lastly, 21/296 (7%) would prefer this digital health data to be stored on their email client, and 12/296 (4%) by their top-up health insurance.

The development of eHealth was ultimately seen as a good thing by 208/296 (70%) of the people surveyed. The benefit of eHealth was cited as improving coordination of care between healthcare

professionals (240/296; 81%) and combating medically underserved areas (66/296; 56%) more than reducing the need to travel (144/296; 49%), more regularly tracking the course of HIV infection (133/296; 45%), improving quality of medical care delivery (121/296; 41%), self-surveillance of health indicators (114/296; 39%), or empowerment through more self-managed care (93/296; 30%).

## 5. Questionnaire surveying physicians

For 182/225 (81%) physicians surveyed, the development of eHealth was seen as a good thing. However, among these 182 proponents, only 49 (27%) cited benefit in terms of coordination of care between healthcare professionals, 36 (20%) cited better surveillance of health indicators, 35 (19%) better quality of care delivery, 18 (10%) combating medically underserved areas, and 32 (18%) increasing the volume of epidemiological data. Note too that for 174/182 (96%) physicians, eHealth would not help cut the social security deficit. A very large majority of physicians (188/223; 84%) asserted a need for specific training on using and working with new communication practices.

Asked about the interface with the hospital information system, 187/225 (83%) physicians agreed it improved information exchange between providers, 181/225 (80%) agreed it improved the value of electronic health records, and 78/225 (79%) agreed it improved the provision of patient care. Deployment of the hospital information system offered better work tools for 142/225 (63%), improved patient safety for 133/225 (59%), and improved information exchange with the city hospital for 126/225 (56%). However, the majority did not see any improvement in communication from

**Table 2**Medical characteristics of people living with HIV who endorse having certain consultations with their specialist physicians online,  $n = 182$  versus others,  $n = 120$ .

Variable	n (%), mean $\pm$ SD	Proponents	Opponents	P-value
Last HIV viral load measure <sup>a</sup>				
Undetectable viral load	261 (92)	156 (91)	105 (92)	0.79
Last CD4 cell count <sup>b</sup>				
/mm <sup>c</sup>	617 $\pm$ 372	569 $\pm$ 326	688 $\pm$ 424	0.06
Time to HIV test <sup>c</sup>				
Years	17 $\pm$ 10	17 $\pm$ 10	17 $\pm$ 10	0.94
Time on antiretroviral treatment <sup>c</sup>				
Years	14 $\pm$ 8	14 $\pm$ 8	14 $\pm$ 8	0.65
Smoking <sup>d</sup>				
Yes	78 (27)	51 (30)	27 (24)	0.47
Ex-smoker	64 (22)	39 (23)	25 (22)	
Alcohol use <sup>d</sup>				
Once or more than once a week	137 (48)	89 (52)	48 (42)	0.11
Recreational drug use <sup>d</sup>				
Yes	39 (14)	28 (16)	11 (10)	0.24
Ex-user	17 (6)	11 (6)	6 (5)	
Lipodystrophy <sup>c</sup>				
Presence	58 (20)	35 (21)	23 (20)	0.93
Other associated treatments <sup>d</sup>				
Presence	128 (45)	69 (40)	59 (52)	0.053
Antihypertensive	59 (21)	32 (19)	27 (24)	0.30
Psychiatric help	45 (16)	21 (12)	24 (21)	0.04
Cardiovascular	29 (10)	16 (9)	13 (11)	0.56
Antidiabetic	26 (9)	16 (9)	10 (9)	0.88
Hyperlipidemia	16 (6)	9 (5)	7 (6)	0.74
Osteoarticular	15 (5)	7 (4)	8 (7)	0.27
Neurological	13 (5)	3 (2)	10 (9)	0.005
Renal	8 (3)	7 (4)	1 (1)	0.15
Cancer	5 (2)	2 (1)	3 (3)	0.39
Hepatitis B or C	9 (3)	8 (5)	1 (1)	0.09
Monitoring <sup>d</sup>				
In-hospital	245 (86)	148 (86)	97 (85)	0.82
Primary care physician <sup>a</sup>				
None	40 (14)	29 (17)	11 (10)	0.22
One, two, or three	167 (59)	97 (57)	70 (61)	
Four or more	78 (27)	45 (26)	33 (29)	
Consultations with an HIV physician <sup>d</sup>				
One or two over the year	165 (58)	102 (59)	63 (55)	0.50
Three or more	121 (42)	70 (41)	51 (45)	
Consultations with other specialists <sup>d</sup>				
None	82 (29)	47 (27)	35 (31)	0.20
One, two, or three	155 (54)	100 (58)	55 (48)	
Four or more	49 (17)	25 (15)	24 (21)	

<sup>a</sup> 285 respondents (171 proponents, 114 opponents)<sup>b</sup> 281 respondents (168 proponents, 113 opponents)<sup>c</sup> 284 respondents (170 proponents, 114 opponents)<sup>d</sup> 286 respondents (172 proponents, 114 opponents)

the city hospital back to the local hospital, in diagnostic decision support, or in skill transfer, nor any real socioeconomic gain.

Asked about video-based consultation, only 29/225 (13%) had already tried it and 22/29 (76%) were fairly satisfied with the experience, but 119/196 (61%) would not want to teleconsult by video. Physicians who endorsed video-link teleconsulting were more often men ( $P = 0.047$ ).

Even if 161/224 (72%) thought that 'eHealth' procedures represented a technological progress, 155/224 (69%) flagged up a data security risk and 119/224 (53%) flagged up a data quality risk, 98/224 (44%) thought e-Health procedures threatened the principle of confidentiality governing medical information, 147/224 (66%) thought e-Health procedures will not reduce the number of consultations and as many again cited no benefit for the health insurance system. However, 133/224 (60%) physicians thought it could improve the efficiency of patient care delivery and 117 (53%) thought it could improve quality of care.

Finally, while practically all physicians (209/223; 94%) saw the collection of personal health data as set to rise, 146/222 (66%) claimed there was not enough legal protection framing either the collection or use of personal health data, 157/223 (70%) voiced concern over how personal data is used, and 120/223 (54%) had no trust

in how personal data might get used. In total, 145 (65%) disagreed that the use of personal health data was a price to pay to benefit from the utility brought by eHealth apps, but 139/223 (62%) did agree it would improve quality of care and patient monitoring, and they were younger ( $P = 0.09$ ) and used apps more often ( $P = 0.05$ ).

## 6. Discussion

This survey revealed that 60% of PLHIV respondents – more often in material/social deprivation, born in the Île-de-France region, with weaker immune system defenses, and taking less psychiatric treatment – were receptive to teleconsultations, whereas 61% of their physicians would be uncomfortable teleconsulting due to inadequate data security, quality and confidentiality without it reducing the number of consultations nor offering economic benefit. Asked about the collection of personal information, 67% of PLHIV and 62% of their physicians accepted the fact that it improved quality of care and patient monitoring, but just over half PLHIV and physicians distrusted how personal data might get used and only just over a third thought there was enough legal protection framing data collection. eHealth was ultimately seen as a good thing by 70% of the PLHIV and 81% of the physicians surveyed, as it improves the

**Table 3**  
Factors associated with endorsing online consultations for people living with HIV. Multivariate analysis.

People living with HIV who are proponents of teleconsultation	OR [95% CI]	P-value
Male gender	1.37 ± 0.47 [0.70–2.69]	NS
Material and social deprivation	1.70 ± 0.45 [1.01–2.85]	0.045
Homosexuality (vs heterosexuality)	1.25 ± 0.46 [0.61–2.57]	NS
Refuses to identify their sexual orientation (vs heterosexuality)	0.89 ± 0.39 [0.38–2.08]	NS
At least one child	0.73 ± 0.23 [0.39–1.37]	NS
Born in the Île-de-France	0.43 ± 0.15 [0.21–0.86]	0.018
Baccalaureate (university qualification) or higher	1.55 ± 0.43 [0.90–2.69]	NS
CD4 count	±0.0004 [0.998–0.999]	0.038
On psychiatric treatment	0.50 ± 0.18 [0.25–0.99]	0.047

coordination of care between healthcare professionals and helps resolve medically underserved areas. A majority of physicians did, however, argue that they would need appropriate medical and scientific training and an enabling environment.

The survey was conducted at a time when the national health insurance system had only just started covering telemedicine procedures. The acceptability of telemedicine, which 40% of physicians rated as low, depended on a perceived benefit for the patient and for the healthcare system as a whole. We found that over and above public health and finance concerns, telemedicine also reconfigures many aspects of work organization [13]. The telemedicine model is a convergence of technologies, practices, codes, and interests that requires structured adapted organizational change of the hospital information system [14,15]. However, this deep restructuring and reorganization of work routines is only in its early days in France [4,16]. Furthermore, the organizational change hinges on ushering in new forms of cooperation and coordination that need to be introduced between health professionals at every echelon (physician-to-physician and between physicians and nursing staff, caregivers, physiotherapists, and so on) that have implications for their activity, expertise, and professional identity. However, in France, the governance committees running hospitals very often struggle to allocate the necessary time to project coordination, which is why the first telemedicine trials tend to fail [17]. There are also other barriers to the adoption of telemedicine, such as the training and learning required [18]. To allay the sometimes-acute patient-side concerns over the use of these telecare technologies, practitioners need to learn to create a kind of ‘tele-intimacy’ [19,20].

PLHIV may well have a role to play in removing these barriers, as more PLHIV than physicians were receptive to these care relations (60%), and far more PLHIV than physicians would welcome simple basic eHealth services that they see as different to medical consultations, such as online medical certificates and online prescription renewals (75%). We found that many of the PLHIV surveyed seemed ready to accept a shift in the ‘geography of responsibilities’ – in other words, to take on a more proactive medical self-surveillance role [21]. However, figures from January 2019 already showed that 52% of people were ready for consultations to be done remotely and 8 out of 10 were receptive to the idea of teleconsulting in some cases [7]. Teleconsulting physicians are nevertheless stripped of their senses and so may feel unable to formulate firm clinical opinion without being able to pull together all of the diagnosis-relevant

cues and clues that are in the hands of the patient, who may or may not want to divulge the information [22]. Furthermore, the quality of the information communicated, which affects their judgement, may also explain their resistance to change. How to assign the responsibility involved is another sensitive issue surrounding the use of telemedicine solutions: “in complicated cases, a GP would rather delegate responsibility down to the patient” [23].

The physicians also voiced reticence over data privacy and data ownership. The ownership of ‘sensitive’ personal data is governed under article 34 of the French Data Privacy law of 1978. Patients do not ‘own’ their personal data – they only have usufructuary rights (usus but no fructus: no right to enjoy the fruits generated, and no abusus: no right to sell them) [24]. A collector of data, however, is free to commercialize an anonymized file, such as if the purpose is to inform medical research. In 2016, the French law ‘for a digital republic’ enshrined the principle of free title – with all appropriate confidentiality protections – to electronic correspondence [25]. In May 2018, the surge in cybercrime prompted a move towards tighter data protection and privacy measures, with a pan-European law implemented through the General Data Protection Regulation (GDPR) [26]. The stigma surrounding HIV exposes HIV-positive people to discrimination, so a majority of PLHIV and their physicians are understandably sensitive to data privacy issues, as confirmed in our survey. The issue of sharing highly personal information that is protected under physician–patient privilege is a topic that France has also addressed through the 2018 national consultative forum on bioethics [27]. The upshot is that France operates a grey area between the patient and the organization or business collecting personal data, which a majority of the PLHIV and physicians surveyed found uncomfortably ambiguous. It is undeniable that collecting data from several database sources (healthcare-system insurance, hospital data, smart sensors, mobile apps, and more) and cross-referencing the data, even if it has been anonymized, will necessarily facilitate patient re-identification [28,29]. Note too that in a context where the French healthcare insurance system is pushing hard to promote the electronic health records (French acronym DMP) system, these concerns connect to the fact that only one in three patients accept letting the health insurance system hold and store their health data [30]. On the physicians side of the equation, Mathieu-Fritz [31,32] has elegantly illustrated how electronic health records fuel tension between data transmission and preserving physician–patient privilege, and this tension was found to pollute practice in a study on e-record rollout in a region of northernmost France. That said, more than 5 years have passed since Mathieu-Fritz’s research, and both the DMP electronic health record and the allied digital service practices have since evolved.

The inter-insurer national healthcare claims information system (French acronym SNIIRAM) is the world’s biggest healthcare database, hosting more than 1.2 billion care flow sheets, 500 million medical procedures, and 15 million hospital stays every year. Policymakers and health professionals alike both need this data to inform and adopt healthcare system reforms, and the health industry is proposing new solutions and a long-term contracts-driven vision. PLHIV and their physicians need further clarifications on the current protections before they can gauge whether or not the legal protections in place need to be strengthened. It is important to disambiguate how some areas of eHealth are ruled as within the scope of the EU directive on commerce whereas telemedicine is ruled out. This ambiguity persists today, both in France and some other European countries [33].

The second focal issue for physicians concerns data quality. In parallel, more than half of PLHIV claimed they cannot enter data directly into their hospital medical record to flag up important information ahead of the consultation. At the same time, in 2013, less than one in four French patients were ready to complete a medical record online [34]. Barriers can be removed. In New York

for example, the most disproportionately poor PLHIV belonging to ethnic minority struggle to access their health information online due to cost barriers, negative attitudes through social norms, and a lack of the necessary confidence, skills and self-efficacy in computer/internet use [35]. However, once informed about the benefits, the vast majority (86%) would like to be able to access their data and talk to their caregiver via a (more confidential) point-of-care tablet PC, and 70% would like to get training to do it. The development of patient-centric services is one of the core challenges of the third national eHealth strategy plan for France (e-santé 2020), which sets out to narrow patient information asymmetry with the physician [36].

Both PLHIV and physicians recognized that improved coordination of care between healthcare professionals is a key argument for growing eHealth. This objective is at the foundation of the French health insurance reform, along with improving access to care and the care pathway, and possibly also delegating care tasks [37]. This possibility of reducing geographic distance – and by extension, the prospect of reducing inequity in access to care – was pictured at the outset as a lead factor in the deployment of eHealth technologies [38]. As communities are forced to contend with an exodus of caregivers, results have been registered in terms of preventive medicine, consultation adherence, and hospital admissions in diabetes care through a single telemonitoring platform integrating multiple web-enabled tools (health apps, smart devices, telemedicine, artificial intelligence with real-time decision support) [39]. The innovations in diagnosing and/or therapy that are driving the ongoing remodel of the French healthcare system also force a recast of stakeholder roles, including educating patients and creating new professions in the medical and social care sectors.

Our survey found that while more than half of patients and physicians are ready for telemedicine services and endorse the clear advantages of eHealth in terms of coordination between care professionals, there is a still persistent mistrust in the data collection factor, both for PLHIV and their physicians, that warrants either clarification or stronger legal protections in place.

### Disclosure of interest

The author 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, JL. Schmit Amiens; S. Rehaïem, V. Rabier Angers; A. Valran, E. Piet Annecy; J. Gerbe, F. Caby Argenteuil; E. Chevalier, A. Foltzer Besançon; L. Traore, O. Bouchaud Bobigny; JC. 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. Touitou, 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. Katalama, A. Simon Paris Pitié-Salpêtrière; C. Tran, D. Bollens Paris Saint-Antoine; A. Adda Lievin, P. Thibaut, G. Pialoux Paris Tenon; L. Pinheiro, H. Aumaitre Perpignan; L. Gerard, H. Masson Poissy; D. Plainchamp, G. Lemoal Poitiers; JC. 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-Etienne; 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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