## Group Survey Study

Anonymised research data extracted from the three-rounds group survey study conducted online via the REDCap secure web application.

**Round 1 (November 2020)**

***Q1. How do you think people living with HIV feel about sharing personal information about their activities and experiences with their HIV clinicians?***

[P1]: I think it is quite a relief to share personal details with healthcare professionals as it also provides closure and understanding of what one would have gone through, what they are feeling and their future fears. This also makes one to have confidence, positivity and improved self-esteem.

[P2]: I'm not sure what is meant by activities and experiences but I and most people I know are fine answering any questions asked by our clinicians. If you mean about relationships/sex then no problem whatsoever as HIV clinicians are amongst the least judgmental people anyone could meet in this respect. Can be a different case with GPs and other clinicians however through lack of knowledge.

[P3]: It is hard at first because you do not know how people perceive status. If one is among other people living with HIV, it is easier.

[P4]: I think there is initially a reluctance to share information with your consultant until you've built a relationship of trust and confidence with them. This takes quite some time to develop. It is very important to me that I see that same consultant, so that I don't need to discuss my experiences and mental health with a stranger.

[P5]: I think it very much depends on the patient's relationship with their clinician. I expect some are very open and willing to share without filters whereas others may be more cautious in what they share.

[P6]: Think many do not tell the full truth. Like how they actually feeling, if the missed/late taken medication ect. Their sexual behaviour.

[P7]: From my experience with clients, some of them are totally open and some are very secretive. I myself only tell my HIV clinician what i feel they need to know in order to help me. Some of the lifestyle questions are very intrusive. Generally though, I would say that HIV clinicians (certainly in my area) have developed a very non-judgmental approach to their patients, and even though i don't tell them everything, i don't feel they would judge me if i did.

[P8]: I think if people have a good relationship with their consultant then they have no problem sharing their activities and experiences. I think it may be difficult to share things when people are expecting to be judged but that just means they are judging themselves. A consultant needs to know as much information as possible so that they can provide the right care. I think patients are also worried they are taking up too much time, or the appointment is to short for the patient to go into detail.

I think that it depends on how well the patient and doctor relationship is. I have no problems sharing my problems with my consultant although I think it often throws him if I start crying. If you generally see the same clinician and have that continuity it is easier to share information about live and experiences whether they are good or bad. It is best to be as honest as possible. I think that we all find it easier to say everything is fine rather than go into details about what is wrong or what problems you may be having. Our clinic is great as you do not feel rushed by the consultants at our clinic and I have been present with peers who have needed far more than a 10 minute appointment and they get it. They have all the time to talk about what it is that is bothering them or things they may be experiencing again good or bad.

[HCP1]: Generally open and honest with their HIV physicians. Especially if they have developed a good professional relationship with them.

[HCP3]: I think people typically trust their information will be kept safe and not shared with other organisations without their knowledge. Typically, they trust us to store and process it securely.

[HCP4]: My answer is limited to my practice and small population of clients I work with. From my experience this differs across the population of clients I work with, but in general clients tend to me open about their personal information and experiences with HIV clinicians than they are with other professional. Feedback I often hear from clients is that they come to us first before thinking about speaking to GP - as they feel we are more approachable and know them more (even if their issue is not related to HIV - I.E. around domestic abuse).

[HCP2]: Depends on clinician and patient personality traits to be honest - former specifically relating to communication skills and latter on whether they are an open or closed person. Also dependent on how long the patient has known that clinician for, do they only see them in which case probably more likely to discuss more openly. Finally dependent on stage of diagnosis - ie new or long term and how they are coping with it. One thing is patients do tend not to want to talk about and more so get examined for genital health issues even though we are sexual health doctors.

I think this depends on two main factors - individual person and the clinician - personality traits of being open and unbothered about activities and experiences, and clinician's communication/personal traits. Also depends on whether newly diagnosed vs had HIV for many years. Generally I would say they are fine as they become comfortable with the same person or comfortable with their diagnosis with then any person. I have found some patients embarrassed to discuss genital health things even though we are trained in sexual health!

***Q2. Could you describe any barriers that an individual living with HIV might experience to sharing such personal information with their HIV clinical team?***

[P1]: 1. Individual might be having a low self-esteem 2. The clinician might also be impatient with them as they seem to be "too busy" 3. fear of being discriminated fear of being judged

The patient might uncomfortable to share because of fear of being judged or discriminated. The clinician attitude or distraction (eg. If they act like they're in a rush and have something else they'd be rather doing than talking and listening to patients) can also discourage the patient from sharing.

[P2]: I have been tempted to not be entirely truthful at times with my consultant due to them not seeing me as an individual. For example the sort of exercise I do to that they feel inappropriate for my age rather than what I enjoy and am used to doing. Another was the suggestion that I should abstain from any alcohol whatsoever rather than drink in moderation and the feeling that they didn't believe information i was sharing with them. I find my nurse easier to chat to.

[P3]: In my case, I do not see any barrier as these are the people who should be helping you. Some barriers could be language, especially for non-english speaking people. For BAME it is cultural boundaries of sharing information with a stranger especially if they are male.

[P4]: I personally experienced enormous internal stigma after my diagnosis. I felt ashamed, somehow i blamed myself for becoming infected. It took me a long time to become comfortable to be open with my consultant.

[P5]: Barriers to sharing might include language; perceived judgment on the part of the clinician; gender differences i.e. female patients may feel uncomfortable sharing more intimate information with male clinicians; or as I have experienced a male clinician did not want to deal with 'women's issues!'.

[P6]: Embarrassment over their behaviour. fear of feeling like the failed in follow the guidelines for medication, not feeling comfortable with the doctor they seeing.

[P7]: I have always had an issue with my HIV treatment being done with a folder that is shared with the GU clinic. I find the sexual health approach to HIV treatment unnecessary. Maybe its a "british" thing, but i dont like my HIV doctor knowing if i picked up a dose of clap. People that acquire HIV through non-sexual means are subjected to this as well. Women with cervical cancer needs do not attend a GU clinic (as far as I am aware). As to other conditions, some clients do not recognise the connection to their condition and HIV and so do not report it to the HIV clinic. Others are so concerned about privacy and confidentiality that they forbid their HIV doctors from talking to their GP's, because their GP is unaware of their status.

[P8]: Time, is a big factor, out clinic is great and for the more complex patients the time limit becomes more flexible but a patient like me is normally in and out so quick it gives more time to the patients that need it. So hopefully that levels it out. Continuity i also think is a big barrier, if you see a different person every time then its like you have to tell your story over and over. Self-stigma and self judgement also are barriers to a patient sharing personal information with the HIV clinical team.

[HCP1]: Administrative barriers, for example knowing who to email to share letters/ previous records, documents if transferring care. Recall and memory over the last 6 months to a year - may not be accurate. May feel time pressured to cover everything in an appointment.

[HCP3]: They may not understand how we process, store and share information. Past experiences may influence them to struggle with trusting the clinical team. Lack of information and understanding.

[HCP4]: There might be many barriers around this, and most are, and not limited to: cultural and religious beliefs, self-stigma about HIV/sexuality/mental health/gender identity, fear (i.e. in domestic abuse cases), worry about confidentiality and information sharing.

[HCP2]: Concern about stigma, discrimination, clinician personality and patient personality, worried about disclosure to others.

***Q3. – A) If you are a person living with HIV, can you describe how your experience of collecting and sharing personal information related to your HIV care, health and wellbeing, has changed since the COVID-19 pandemic? (This may include, but is not limited to sleep, medication adherence, mood, exercise or anything else that may impact your wellbeing.)***

[P1] As a person living with HIV, due to the pandemic, I've struggled to sleep. Whenever my body manages to sleep, I get to sleep more than necessary (more than 10 hours of sleep per day) I'm also getting anxious and get easily frustrated. I tend to disconnect myself from friends and prefer to be on my own. With regards to taking medication, i have as much as possible managed to stick to the routine. I also struggle to eat and rarely get to exercise.

[P2]: Collecting information for results of previous blood tests has not changed as other than my HIV consultant sending an annual update to my GP (with my permission) then I don't tend to hear anything else from them until my next appointment 6 months later. Even then nothing was mentioned results wise as I guess there was nothing to mention. Focus from my clinician is now more on mood, sleep, exercise etc and feels more regimented via phone. As I have experienced changes to these (adherence - I missed a dose for the first time) I have shared my thoughts not just with my clinician in my last phone consult and nurse when I saw her for bloods taken following the phone appt, but also with friends and other people living with HIV.

[P3]: The pandemic has meant being put on hold, whether accessing the clinic or the GP. The anxiety is not good for already fragile mental health. In my case, I have learnt to take long walks and be involved in a lot of community groups chats and activities. I have not had any problems with adherence or problems sleeping.

[P4]: Because I have a good relationship with the clinical team in my HIV clinic, COVID-19 hasn't impacted me. I have a good support network, but this has now become over the phone rather than face to face. My personal well-being hasn't suffered as a result of this. Lockdown restrictions have resulted in an increased alcohol consumption and consequently some weight gain. Medication adherence has not been affected at all, I have always been extremely adherent.

[P5]: Participating in two online studies related to covid has meant that I have been recording aspects of my well being such as exercise, sleep, mental health more than I would ordinarily do for my routine HIV care. Interestingly I have not shared that information with my HIV clinician as I don't see it has much relevance to my HIV well being.

[P6]: I feel it's harder to take medication on time since daily routine has been mixed up. irregular sleep pattern and food intake. been feeling more lethargic and tired. More lonely since less social interaction which seems to be escalating as it goes on.

[P7]: The only real change was initially the cancelling of my 6 month face to face. I still had the bloods done, but just got an email to say all was fine. I also have had a blood test and a flu jab at my GP clinic, and some investigation into gout. These were conducted via phone calls and video calls. It worked well. I would say that I have missed out on the opportunity to talk about my health. I seem to think it's not important enough to tell my GP or HIV doctor that i have gained weight or that my sleep pattern is severely disrupted. Something in me is saying this isn't important in the time of covid.

[P8]: The pandemic has had its ups and downs for me. I have worked as safely as possible and did shopping for people, picked up medication etc but forgot about myself in all of it. So my self care slipped. I did start being less adherent to my medication, i couldnt be bothered to move to get it or i slept through my meds alarm so missed it then as well. I was aware that it was a bit of an issue but i also know i have normally have great adherence so not to overthink why it was happening or give myself a hard time about it. That made it easier to start to be mindful and if i couldn't be bothered to move i would make myself. I am 14 in years of living with HIV and it feels like i am a teenager in terms of living with, and teenagers do rebel but they do also get back on track and that is where i am now back on track. I do miss having a real appointment as opposed to a phone call but i have had the same consultant for years so it's not the worst experience in the world. My sleep is all over the place as for both lockdowns i have suffered with extreme toothache i have periodontitis (gum disease) and my teeth are coming out one by one and becoming weaker but as we know lots of services are disrupted and dentists are certainly one of them. It's been agony and i have taken too many mixtures of different painkillers where i have made myself ill, i have mixed mouth gels together so that they burn then i did not feel the teeth pain. But it made me not sleep, it made me agitated and i found it so very hard to concentrate. I do have generalised anxiety disorder so this weekend i am up writing speeches and things and worried about my teeth and how they look when i talk, and what will i wear because i have put on winter weight but there are no shops open to buy the next size up, I have been in agony, with my back, something called cervical neuropathy and having physio for that. In fact my health is all over so that affects my mood. I do not get depressed i get despondent and this impacts on my self care. Exercise is a goal not yet achieved. As a support worker i normally have more contact with our clinic as i advocate for service users and accompany them to appointments so it has meant that i spent way less time there which feels odd. Our clinic also moved recently and people ring us if they have any worries or queries about the clinic and services during covid restrictions.

***Q3. – B) If you are a healthcare professional, can you describe how your experience of sharing patient health information in the context of providing care has changed since the COVID-19 pandemic?***

[HCP1]: Much more information shared by telephone, relient on email, and SMS also to send virtual patient information. Sending emails to GP with clinic letters about patients, and copying patients in. - although emailing letters began prior to covid19.

[HCP3]: We use more email contact with patients than before.

[HCP4]: I am not a person living with HIV. As a healthcare professional working with clients who are HIV positive, I noticed that not a lot of information sharing has changed since COVID-29 pandemic. We continue to remain open and see patients face to face (although have moved more towards telephone work too). We continue to share patient information as before - via phone or email (i.e. when we speak to client's GPs, social workers, care coordinators ect - that has not changed). One change I noticed, was clients who have not disclosed their HIV status to GP were contacting us to find out whether they are meant to shield because of their HIV as they were unable to approach GP.

[HCP2]: Hasn't.

***Q4. What are your views on how personal information is communicated between people living with HIV and healthcare professionals?***

[P1]: I think communicated personal information should be shared to a healthcare professional when the person living with HIV has developed "trust" with the healthcare provider. I also think that healthcare providers advise or inform in understandable language terms.

[P2]: I have no issues with phone consultations with my HIV clinician. However touching base with the clinic nurse when giving blood in particular was helpful in staying grounded and feeling a sense of normality through having a general chat and sharing experiences. Better sense of wellbeing afterwards. I feel that care needs to be taken to ensure those who are struggling are not missed by moving more services online. It can be easy to miss the cues that seeing someone in person might show up, not to mention the reassurance for them in being listened to properly and in person. There can also be issues with digital poverty and privacy for some with might mean disengagement with their clinic.

[P3]: Some are professional but some need a lot of training so as to know whether a person is infectious or not.

[P4]: I am a member of [National HIV advocates network anonymised], so this is a great resource for anyone living with HIV and healthcare professionals. This of course relies on someone being willing to receive HIV related emails to their personal email accounts.

[P5]: I still find that many letters sent between health professionals and copied into me as the patient are written very much in medical language so inevitably I have to get the dictionary out to work out what is actually being said about me.

[P6]: Personally I find it non-judgmental when I talk to the health time.

[P7]: Difficult question for me to answer as my personal experience is that i have no problems (normally) discussing treatments and medication with anyone. But as an HIV caseworker, i see a lot of hesitation by clients in talking to doctors generally. They are also often not sure who is responsible for the different aspects of their care. The biggest stumbling block for PLWHIV is definitely GP's. Patients can never be sure who they will be seeing at many practices, and for sure the GP doesn't know their history or much about HIV. A long term survivor will have multiple comorbidities yet only allowed 10 mins to talk about 1 thing. Clients are fed so many drugs in the hope they keep pain away. GP's need to understand a lot more about the complexities of living with HIV and the many different aspects of one's health that can be affected. HIV doctors encourage interaction and talk to other HIV care services. GP's dont.

[P8]: I think people need to be open when communicating with healthcare professionals. However some healthcare professionals (not those working in sexual health) need to learn things not to ask somebody living with HIV, not to make assumptions about them, not to judge and not to see just the HIV. Personal information should be shared especially if it is relevant to the care pathway but it should be shared correctly and respectfully using HIV friendly terms when possible.

[HCP1]: It is essential that patients feel confident in confiding personal information to their HIV team. As we ask directly either face to face or on telephone about very sensitive issues around sexual behaviour and function, drugs/alcohol etc, people are often open in other areas, as a result of having the expectation that they will be asked about more personal private things of a sexual nature, by their HIV team, compared to with other health care teams. HIV positive patients are more likely to be open with their health care teams, then they would be with GPs. I still have many patients that refuse to disclose their HIV status to their GPs due to fear of being treated with prejudice due to their HIV status. We are also being cautious about making sensitive enquiries of the telephone, to ensure patients are safe to disclose information, without someone listening in. Most people prefer to speak by phone or face to face, than share information in writing. Most people prefer telephones at the moment due to COVID.

[HCP3]: I think it's generally communicated cautiously to ensure that information isn't shared with third parties without consent.

[HCP4]: From my experience, as HIV professionals we are very good at asking personal questions, and hopefully make clients feel comfortable about sharing their personal information. We tend to believe in a holistic care approach with clients - and so we ask about their lifestyle, not just their HIV: i.e. their living and financial situation. My view is that we do a good job and ask these questions appropriately. Most important thing is to always explain why we ask these questions and explain when we have to share information with other agencies before asking these questions.

[HCP2]: By asking for permission we add to stigma and discrimination but it's needed because of the real stigma and discrinimation out there. More education is needed for patients and healthcare professionals, including around confidentiality. Perhaps it shouldn't be a choice as with other chronic conditions.

***Q5. What, if anything, could be improved with regards to communication between people living with HIV and healthcare professionals?***

[P1]: Efficient and effective follow up on patients who fail to attend healthcare appointments or adhere to taking their medication. Effective communication.

[P2]: I would like to see all my blood results online in secure format as I do from my GP on patient access. Options if we wish to see someone rather than having a phone appointment. Having a dedicated number to phone if we are struggling. (It's nigh on impossible to contact anyone other than the receptionist at my clinic, despite being told to phone the nurse to get bloods done). Signposting to online peer support and other services offered by trusted charities and organisations given to all. This last should be regardless of whether we need it at the time. If we move to in person consults once a year that is a long time to wait if struggling.

[P3]: They should receive mandatory training on HIV, so as to raise awareness amongst them.

[P4]: On a personal level I do not see how anything can be improved. I am a board member of the patient forum at my clinic. This allows other patients to share their opinions/concerns with the forum and escalate issues directly to the healthcare professionals if they don't feel comfortable to raise issues directly.

[P5]: Timely communication e.g. not waiting months after a procedure to receive a report of what was found. I very much value being able to email my consultant and I get a prompt response but I know that I am incredibly fortunate to have the relationship with my clinician. Perhaps there could be a standard response time if a clinician allows patients to email rather than thinking you are being ignored.

[P6]: Maybe have a form to be filled in about wellbeing, mood, behaviour. Some people might be more comfortable with not having to do it verbally.

[P7]: Generally, the HIV docs seem to have it organised. GP surgeries ought to have an HIV specialist GP who works with patients and understands the effects HIV has on people both mentally and physically. That specialist GP would then hook into the other HIV services to further understand client/patient needs. In professional meetings about clients, the GP is never there.

[P8]: As a patient when attending healthcare appointments, when they ask you do you have any other health conditions and i say HIV positive with an undetectable viral load, i would like them to recognise that and not feel the need to ask me if i was or am an intravenous drug user because i maybe do not fit the bill of somebody living with HIV. HIV does not discriminate people do but unless you are taught something how are you supposed to know. I think sometimes it would just be nice to be a patient being treated the same as any other patient and not having to provide an education session when i introduce myself. I am not expecting everyone to suddenly become HIV experts but at least to become HIV friendly.

[HCP1]: For patients easier direct access to communicate to the team e.g. a direct email, or a messaging service. However they have access to a nurse mobile, and can easily book an appointment for a call back.

[HCP3]: It would be helpful if we could interact with people via text or WhatsApp rather than always relying on email. We can send people text messages but they can't text us back.

[HCP4]: I am sure there is always a room for improvement, and if we had more time with clients that could be beneficial.

[HCP2]: See previous answer.

***Q6.—A) We view 'trust' as an understanding between two parties, in which one party opens themselves up to the other party by sharing something with the other, with the expectation that the other party will behave appropriately. Thinking about 'Trust': in your view, what are the current barriers to sharing personal information online with healthcare professionals?***

[P1]: Mistrusting or doubting how secure the sharing platform is. Sometimes not trusting how the information passed is going to be handled and shared.

Psychological barriers might emanate from fear of shared personal information "leaking" to the public or to unauthorised organisations. There also fear of being criticised as.

[P2]: Some HCPs do not have sufficient knowledge of HIV or personal judgement, so by sharing information related to HIV either stigma, or perceived stigma, might be experienced. Where such information is shared via digital services this can be exacerbated from a psychological viewpoint as we can only guess at the thoughts on the other end. For reasons of stigma (experienced or perceived) many people prefer not to share their status with HCPs outside of their clinic. In my view, as long as we can choose what and with whom and can maintain control of this then this is a good thing, but might take a while for many to trust this - if ever. There can also be issues with trust in getting the best treatment. Do other HCPs know about possible drug interactions and other medications?

[P3]: I do not trust sharing such sensitive information online unless it is password protected. If such information falls in the wrong hands, this is a breach of the human rights of the person involved.

[P4]: Website security mainly. The risk of my identity being disclosed if a website is hacked. I know through the patient forum that NHS communications are secure, so that personally offers me reassurance. In terms of trust, I have total confidence in my clinic and healthcare team.

[P5]: Barriers I would consider would be the inability to control who has access to online information and the risks of electronic communications being hacked or accidently shared due to human error.

[P6]: The safety of the platform that is used to communicate.

[P7]: There are too many different ways to potentially share information, email, text, whatsapp, app voice mail and each has its own confidentiality procedure and standards. It can be overwhelming to get to grips with each different policy and method. Potentially it can feel that everyone knows. On top of that we hear a lot about systems being hacked and confidentiality breached, and confidence falls.

[P8]: Virtual platforms seem to be the way forward for a lot of services but for some of the people I support, this just won't work for them. And it does come down to trust, trust in technology and if it is safe to use. Some people I support also do not have the technology for these platforms they have basic phones and no internet or computer. We provide and support these people accessing electronic prescriptions for example. Telling somebody and talking about your health is so different then it floating around in some cloud. Also the media never print happy stories about technology or data and security so that also makes people worry and during this pandemic we have so many new scams trying to take advantage of people. This has impacted on the psychological barriers and made them more fearful. Some people I have spoken to also think that there is the possibility for them to be being spied on for want of a better word and that people will hear what they are talking about. An HIV status is so personal to the person it is theirs to share or not to share and the problem with technology is once it's out there it's there.

[HCP1]: Knowing who else might have access to that information other than the healthcare professional it is aimed at. 'trusting' the security of the software from being hacked, or misused.

[HCP3]: Patients don't feel services are competent to securely process and store their information. Patients may doubt that a service really cares about protecting their data.

[HCP4]: [left blank]

[HCP2]: Nil per se but trust from a perspective of if you left phone or laptop unlocked/without a password.

***Q6. – B) We use the term 'identity' to refer to how a person represents themselves or is represented to others online. This can include the properties that a person defines themselves by, and which distinguish them from others. It can also refer to properties that are associated with a person in order to authenticate themselves and interact with systems, services and processes, either in the physical or digital world. Thinking about 'identity': In your view, what are the current psychological barriers to sharing personal information online with healthcare professionals?***

[P1]: Fear of being discriminated, labelled or being associated with a 'socially unacceptable' behavioural group.

[P2]: Personally I have no issue with this, although feel from an identity point of view I can represent myself better in person rather than online but see above re stigma and perceived stigma which is experienced by many. Some people might have digital issues with language barriers and not being able to explain themselves well online, might need an interpreter.

[P3]: Not knowing who else is going to see that information.

[P4]: I suppose the only barrier I feel that I might have relating to identity is being judged by the recipient. When it is face to face you generally know the person you're talking to or if you haven't met them before then you make an instant assessment of what to say/share with a healthcare professional. When it is online, there is an element of not knowing who is reading what you've written and being judged by that.

[P5]: Psychological barriers I would have include fear of sharing more intimate personal information online; I'm fine with my HIV status being known but more detailed information about my current health issues I would only want to share in a face to face or phone consultation.

[P6]: Fear of being judged, the information being seen by non-related parties.

[P7]: I think the barriers are again confidentiality (as in previous question). But now we also have to label ourselves. Often using words we personally don't like. eg: I dont like to call myself homosexual. But its often there as a box to be ticked. People who have not yet settled on the gender-identity are also put in boxes. In the organisation i work in, all these questions are asked, yet the information is never used. Psychologically perhaps people may turn away from a service rather than have to identify themselves?

[P8]: Because its harder to share things online, I think. Online you can create a persona that does not represent how you are really feeling.

[HCP1]: Patient's 'online' subjective persona may be quite different from how they are perceived as being by others, objectively. Some of this will be lost in an online information exchange compared to face to face. Patients may be used to interacting differently online compared to in person. They may have had negative experiences online, such as previous cyber bullying, that makes them reluctant to share information. Psychologically online portals for information sharing, can give patients more anonymity, but also less accountability to someone else, to reach their health potentials.

[HCP3]: Minorities are more likely to be living with HIV (e.g. ethnic minorities, LGBTQ+). They are likely to experience phenomena like minority stress or homophobia which may predispose them to greater perceived or actual risk of harm should information be mishandled.

[HCP4]: [left blank]

[HCP2]: Nil

***Q6 – C) The term 'privacy' concerns a person's ability to choose how their data are revealed to others. Thinking about privacy, in your view, what are the current psychological barriers to sharing personal information online with healthcare professionals?***

[P1]: 1. One might be having concerns with regards to breach of confidentiality. 2. Being worried of the onward sharing of confidential information that they would have shared. They may also be worried on how such information will be shared to the receiving end.

[P2]: Some people might have language barriers, privacy and having something written down, other people having access. Poor mental health can also be an issue.

[P3]: Hearing news of sensitive data being lost and ending up in the wrong hands and being published for the world to see.

[P4]: The only barrier I feel about privacy is being judged on the information I'm choosing to share.

[P5]: To me online is not a space to share more detailed information regarding my health as I have no control then of who may see that information.

[P6]: The data being accessible by "wrong" staff.

[P7]: Trust. Do we really trust that our private information isn't being shared? Do we really know how far our private information is circulated? Can we trust the security of the systems on which the data is held. When trust breaks, anxiety follows.

[P8]: Fear of your information being leaked. People may also not have a safe space to be able to share personal information online.

[HCP1]: Understanding of how the online system works and security around it. For older less digital patients, 'trust' in the privacy of online portals are less, due to unfamiliarity with them.

[HCP3]: Previous experiences of friends/family sharing their HIV diagnosis without their consent. Predisposes to more anxiety about sharing again.

[HCP4]: [left blank]

[HCP2]: Nil per se but privacy from a perspective of if you left phone or laptop unlocked/without a password.

***Q6. – D) We view 'security' as referring to the safety of a person's data and protection against unwanted access. In your view, what are the current psychological barriers to sharing personal information online with healthcare professionals, related to personal security?***

[P1]: Fear of data being insecure as there is a possibility of hacking some anonymous information if shared online might be easily tracked back to the person.

[P2]: Psychological or real? These can include being in abusive relationships, others having/gaining access to digital resources, lack of knowledge on maintaining digital privacy, safely secured data and lack of trust that this can be maintained.

[P3]: Stigma is a big issue. It holds people back and causes one not to trust the system.

[P4]: I don't have any concerns relating to security of my data. I'm confident that NHS systems protect my information from unauthorised access.

[P5]: Lack of belief in ability of healthcare organisations to actually keep online information 100% safe from potential unwanted access.

[P6]: Being assured that the data is kept within GDPR guidelines. being offered alternative communications routes that might feel safer for the person.

[P7]: Anxiety that when you tell someone something private, that they keep that privacy. I dont think it's made clear enough to clients that when they say "please don't tell anyone else this", this can't be guaranteed. But the information will be kept within the confidentiality of the institution.

[P8]: That the information provided can be accessed by others. How safe is it? Trust in general in sharing information online.

[HCP1]: There have been publicised leaks of information, and hacking. This would make some people anxious about sharing personal information electronically.

[HCP3]: Awareness of data breaches that have happened in other contexts. Predisposes them to the risks of sharing personal information.

[HCP4]: [left blank]

[HCP2]: Nil.

***Q7. What types of digital information, or 'data', do you think would be useful to share in a consultation for the purpose of supporting overall HIV care, including the self-management of HIV and self-care for achieving wellbeing?***

[P1]: One's lifestyle or day to day routines and habits that are unfavourable when it comes to living with HIV.

[P2]: I'd like to see all blood test results online perhaps in graph format for some to show the trend rather than individual result of each for ease. This to be shareable with other HCPs and information vice versa from them where relevant. Links to other online support services - peer support like local charities, THT's My Community Forum and Plushealth for 1-2-1 peer support, counselling, NHS websites, say for eating/exercising healthily, mental health services, treatment knowledge (BHIVA guidelines), info for eg someone who might be thinking of starting a family, U=U, links to trusted resources (i-base, aidsmap, Plushealth, menopause booklet produced by Sophia forum). There is so much good reliable info online - also dated stuff but good to signpost.

[P3]: Password protected emails and links to the HIV clinic, to keep one up to date with their care and appointments.

[P4]: I'm not entirely sure.... maybe links to websites with HIV news and treatments, apps that support physical and mental wellbeing.

[P5]: For someone newly diagnosed I can imagine it would be helpful to record more emotional/mental health information. I think for someone newly on treatment it would be useful to share adherence data. For long term survivors with co-morbidities I think an overarching framework for sharing multiple health issues would be beneficial so that all disciplines involved with care have access to that information.

[P6]: Adherence of medication. Mood, food and sleep pattern. Changes in behaviour pattern.

[P7]: Basic info such as name, dob, address, contact details. NHS ID GP surgery details and gp name Next of kin Physical conditions/ailments Medication Mental health status (WEMWBS) Other agencies involved. I know its a list, but i'm just thinking about the information I need when I'm working with a client. As well as the actual information, it would be useful to know what the client thinks and who they feel does NOT need to know about their status. Currently its overwhelming for clients who have 5 or 6 different agencies working with them. Part of my role is helping clients understand who the agencies involved in their care are and what their role is and what they can expect from them. Clients are often left to work out for themselves who does what and its difficult for them to manage.

[P8]: General information like CD4 count, viral load and if any problems with kidneys, liver, cholesterol weight blood pressure.

[HCP1]: Diet, and exercise data, height, weight, smoking, and alcohol intake. Co-medication and medication adherence. Mood monitors. Menstrual cycle data/contraception use.

[HCP3]: Questionnaires about mood that can be easily entered online or via text message and to look at change over time. Feedback forms about individual psychology sessions to gauge how helpful the sessions were.

[HCP4]: [left blank]

[HCP2]: Social history aspects.

***Q8. In your view, what might be the best ways for people living with HIV to collect and share these data with healthcare professionals at the clinical consultation?***

[P1]: Through writing down and openly share them on consultation. if its something making them uneasy, seeking immediate relevant appointments may also help. Through one on one consultations.

[P2]: Probably easiest to share online as a record can then be kept. Consultations can be rushed and things not written down forgotten. Alternatively, if the consultation is in person write it out beforehand and leave it with them.

[P3]: Everything is password protected.

[P4]: If a secure app was created that had the ability to share data anonymously.

[P5]: I think this will be specific to individuals - some would be very happy to collate in an app or online form; others would prefer a written journal type option. Others may want to make notes and just have bullet points to jog memory to convey information.

[P6]: Directly to the person eg face2face, online media, by form eg questionnaire.

[P7]: The simple answer is an app i guess which would suit the majority (eg: Emerge in Brighton). But even so, how is the data collated into an app that the client has on their phone. It also doesn't help the clients who are in crisis and would not be capable of collating all the data. So maybe, the answer is actually an app that is capable of receiving the data from different organisations, stored on the clients device and then the client can authorise clinics or other healthcare professionals when they choose to.

[P8]: Video calls would be good if you have the facility or safe space to do it. Accessible page that is accessed by doctor and patient and you can upload information and is visible to both.

[HCP1]: Using mobile apps, that communicate directly with medical software.

[HCP3]: An online platform where people can enter their mood and feedback questionnaires and change over time can be visualised (e.g. https://www.fit-outcomes.com/; https://www.myoutcomes.com/fit-elearning).

[HCP4]: [left blank]

[HCP2]: I'm quite a traditionalist so prefer the face to face real time discussions. Having dates such as last menstrual period on hand, or dates of events happening are useful but even then a rough idea is fine. Knowing how much medication they have!

***Q9. Do you have any further comment to make about taking part in the study or in relation to the questions that have been asked in this survey?***

[P1]: None.

[P2]: I found it a little difficult to understand the questions initially and the responses to some were the same. Quite time consuming in giving enough thought to answers and easier to do a little at a time - perhaps 3 sections. Other than that it I found it useful and interesting.

[P3]: Not at the moment.

[P4]: Very thought-provoking questions.... i had to read a few questions several times to understand what exactly i was being asked. Some of the wording was very similar and it was difficult to differentiate between some of the questions. Maybe try to simplify the questions for round 2.

[P5]: Appreciate the opportunity to have an input into to the research. I'm always slightly anxious that there will be a push to more healthcare delivered in an electronic way rather than in face to face consultations. Acutely aware that not everyone has access to digital means of communication and that can't be ignored.

[P7]: I found some of the questions to be difficult to answer as they weren't clear enough about what you are looking for. So, I answered how I understood. Also, my comments as a person living with HIV are very different to my comments as an HIV case worker working with people who are having difficulties. The biggest single issue we have is GP's. They simply are not involved enough and do not know enough about HIV. I myself was prescribed a drug by my GP that i really shouldn't have been on...even though they know my HIV status.

[P8]: I enjoy doing these studies, it makes me think more about how to survive in a digital world and how we need to trust in how our data and personal information is stored and how we interact with healthcare. Covid has highlighted this immensely.

[HCP1]: None

[HCP3]: None

[HCP4]: None

[HCP2]: None

**Round 2 (March 2021)**

***Theme 1: Patient-clinician relationship***

*Sharing is dependent on the patient’s relationship with the clinician. Patients may feel reluctant to share personal information with their clinicians until they have built a relationship of trust and confidence with them. Seeing the same person over time makes the patient feel more comfortable and confident in confiding personal information to their HIV team. It also provides a continuity so that patients don’t have to tell their story over and over again.*

*Participant’s quote: In the context of sharing personal information with HIV clinicians, a person living with HIV commented:*

*“I think there is initially a reluctance to share information with your consultant until you've built a relationship of trust and confidence with them. This takes quite some time to develop. It is very important to me that I see that same consultant, so that I don't need to discuss my experiences and mental health with a stranger.” [P4]*

***Do you have any comments on the theme summary, anything else you would like to add?***

[P1]: I strongly agree that it's important to see the same consultant if possible. I believe that it also makes the patient confident to share unfiltered information about their health worries or changes to their health and wellbeing. It is also easy for practitioners to also have that perspective to tell if anything is wrong with the patient even if the patient doesn't say it especially when there are concerns of safeguarding.

[P2]: Both statements sum this up very well and I agree with it. However just because someone builds a relationship up with a clinician might not mean they have any more confidence in them if they have differences of opinion, say as regards lifestyle factors. This can be worked on perhaps in becoming more accepting each of the others ideas. If not, does this pose a problem in being able to see another clinician instead?

[P3]: [left blank]

[P4]: I wholeheartedly agree with this. When I was diagnosed, I saw a few different doctor's and I found it difficult to open up about my feelings with someone i'd just met, as I was still struggling to come to terms with my diagnosis. I found it difficult to build any trust with my doctor as it kept changing. I then (by chance) saw the lead clinician and he commented on the fact I'd seen so many different doctors and asked me if I would like to stick with him. He had worked in HIV since the 80's and recognised the importance of building a relationship with your clinician.

[P5]: Additionally I think sharing can only happen if the right sort of questions are asked by the consultant (if they ask any at all). I had many years with a consultant who never asked me about anything other than how many months worth of meds I needed. It was a revelation to switch consultants and find one who actually asked how I was feeling about all aspects of my life not just HIV. Also with patients who have co-morbidities it is often necessary to repeat your story with yet another appointment - often wondered whether joint consultations could take place for those patients.

[13]: Also find it tedious to having to explain it all again from the beginning if not with the same person.

[P7]: I agree fully with the participants comments.

[P8]: I think that continuity is important but unfortunately it’s not always as simple as that. Building up a relationship with your local support network can help immensely for example if your doctor is on holiday and you find it hard to speak to the doctor they have booked in with. Do not suffer in silence, taking a peer mentor or HIV support worker with you may make it easier to explain what is going on without having to go over everything again. A consultant just wants the best for you and if you do not tell them you are suffering in some way then they are just not going to know. I always suggest to people to put the consultants in order of preference so that if your first choice is not available with a bit of luck your second choice might be. That way then you are building up a wider support network, it may not be ideal but in the long run you will have a couple of consultants that you feel able to talk to.

[HCP1]: Agree each subsequent contact with a patient, in long term follow-up enables a richer, deeper information exchange, and familiarity and trust can enable you to expand on topics with patients, especially in a time limited appointment. In sexual health clinics however I think anonymity can also be helpful, as people can disclose things if they feel non-judged, without a pressure, of having to see this clinician again.

[HCP3]: I believe this is a fair summary of how I think about the patient-clinician relationship.

[HCP4]: I wholeheartedly agree with this statement as a clinician working with HIV positive clients. Having continuity with a clinician, particularly for more vulnerable clients can make a very big difference to their confidence, care and self-esteem. I found that clients who see the same clinician are more likely to disclose social issues (i.e. domestic abuse) than those who see different clinicians on each visit. I appreciate seeing the same clinician might not always be possible (due to leave, staff leaving ect) but the benefit of continuity of seeing the same person should not be undervalued.

[HCP2]: 100% agree. It's a no brainer. I think there is not only the building of a relationship of trust and confidence, but also managing potentially complex physical, psychological and social health between different doctors can lead to things being missed and limited understanding of things that can negatively impact patients. I think it's also helpful for the clinician when building up the relationship as a gauge for symptoms that may or may not be of concern, if you feel the patient will flag the concern if it's worse (or not) and therefore whether to allow them get in touch as needed or proactively follow up with them. Also, makes a consultation easier, quicker, more efficient. A colleague, felt we did a disservice to patients who saw the same doctor, but I think it's actually nonsensical! Rationale was different expertise but actually we all know our limits and when to check with other colleagues via MDTs or otherwise. The only thing that I've noted within HIV is some patients being shy about sexual health examinations as they have known us for years! Also, HIV is a journey for many patients, from new diagnosis, to finding a partner to having children. As a clinician it's nice to go on this journey with them too.

***Theme 1 – Q1. At a time when most conversations are held online or remotely, how could patients and clinicians build a relationship of trust and confidence between each other?***

[P1]: By making the conversation a bit more engaging and a bit open so that the patients can feel open and trust the clinician. There is also a need for reassurance that the clinician is doing the best they can in terms of the patient's interest.

[P2]: By listening. It's more important now for any engagement between patient and clinician to be a two way thing. As there are no visual cues in a phone conversation it becomes more important to listen to different voice inflection. Also important is allowing questions on both sides and not rush the appointment, as has been experienced by some patients.

[P3]: There is a problem developing a relationship online, for me, it feels very impersonal. It is easier to have that rapport if you speak to the same person and have also had some kind of relationship before. Having different voices will upset the connection.

[P4]: My relationship already exists, so I won't face this issue. What I would say is that body language is incredibly important, so as we are having to adapt to online conversations, I would strongly recommend consultations to be conducted by a video platform like zoom, teams, webex or google meet.

[P5]: Personally I think this makes building relationships a lot harder. Many people may not have the privacy at home to be able to have open conversations; or even have the remote appointment in the first place if they are not open about their status with others in their household. I think this would be even harder to achieve if you were 'meeting' a new clinician for the first time. I think there would always be an element of fear that online conversations are not as secure as being face to face in clinic and might therefore lead to patient's not sharing or being as open for fear of information being accessed or heard by someone else.

[P6]: I find video chat helps building up trust. Also making sure the clinician using a private room so no other people or voices in background to make sure conversation is private and confidential. I think you get a better and more open chat with your clinician if it's via video chat and not just voice. Also having the same person each time. Also having 1 clinician they know your background instead of having to "defend"/explain my behaviour each time.

[P7]: To start with, use first names. Then if the Dr is able to remember personal things about the client and use them in the conversation to show they have an interest. Like motivational interviewing (sort of), it shows the dr cares about the person and not just the virus. As a caseworker, I use this technique a lot to remind myself about who clients are. I even write down the names of peoples dogs (possibly slightly extreme).

[P8]: Time, I think it is harder for people to talk online or on the phone so the conversation needs to be able to warm up. So more time should be allocated to the patients that may struggle with this type of communication. I do know however think that some people do not trust online platforms. It will just take a bit longer for some people to get used to the new changes.

[HCP1]: Using telephone calls to ask about general well being, and activities, chatting less clinically and more 'humanly' about coping strategies during lockdown, as loneliness and boredom is common, and a significant problem to people's health. Showing that you care and empathise with someones situation, and then conducting their routine care/consultation by telephone, possibly in a separate call, can be a powerful and important way of connecting to you patients, at a time when people are feeling isolated and disconnected from community.

[HCP3]: I think it's the same as above: continuity.

[HCP4]: I think services (especially HIV) should make space to see patients F2F, even during the pandemic. The service I work for continues to see patients who are more complex (i.e. new HIV diagnosis, young people ect) in person. If not possible, and client can only be seen online (either via phone or video), it is important that the clinician takes their time with the consult to go over everything (taking medical, social and psychological histories).

[HCP2]: I think as they would with face to face - communication, but also taking their time and following up as required. Don't think it's really different?

***Theme 2: Sharing information remotely***

*There is value for patients to share personal information with their clinical team. Sharing can help the team better understand what the patient is managing. Healthcare professionals also need to know as much information as possible, in order to provide patients with the right care. During the COVID-19 pandemic, clinicians have asked patients more questions about their psychosocial wellbeing (e.g. how they are feeling). Patients don’t always see the relevance of sharing such information with their HIV clinician and find that some questions are very intrusive, which can make them feel embarrassed to answer.*

*Participant’s quote: In the context of collecting and sharing personal information during the COVID-19 pandemic, a person living with HIV commented:*

*I seem to think it's not important enough to tell my GP or HIV doctor that I have gained weight or that my sleep pattern is severely disrupted. Something in me is saying this isn't important in the time of Covid. [P7]*

***Do you have any comments on the theme summary, anything else you would like to add?***

[P1]: I think it's important for the to[team?] to know especially when the weight gain is as a result of lack of exercise and diet. I think this can also lead to the patient being at high risk of Coronary Heart disease and diabetes. However some patients may conclude that it may just be a side effect due to their medication that they are taking.

[P2]: Regarding the last sentence in the statement I'm not sure how the patient would regard being asked questions about psychosocial wellbeing as being intrusive as it's something they should always have done, even pre COVID. If they haven't and are only now doing it, this is great but they should explain the relevance if the patient seems confused by the line of questioning. Regards the participant's quote, I don't agree with this. The whole well being of a patient should be paramount as if issues related to this aren't addressed then they might develop mental health issues and not be adherent to treatment.

[P3]: [left blank]

[P4] I would partly agree with the participant's quote. Weight gain during lockdown my doctor referred to as 'corona kilos' and reassured me that most people, him included, had gained some weight. He pointed out that my cholesterol was raised, so that made me consider what 'treats' i was having. In terms of a disrupted sleep, I would definitely find that relevant to raise, as there could be a number of causes. He knows me very well, so will have records of previous sleep issues and would ask more probing questions to help identify the root cause.

[P5]: I think there is likely to be a reluctance on many patients to not 'bother' their GP or consultant with what are seen as minor issues during the current covid crisis. I would also be more inclined to minimise my feelings so as not to add any additional pressure on NHS staff that I perceive as being under tremendous stress. In the phone consultations with my GP and HIV consultant I have had during lockdown I don't remember being asked about my well-being as the focus was on the health issues I was dealing with at the time.

[P6]: [left blank]

[P7]: [left blank]

[P8]: In light of the pandemic it seems that people feel bad for bothering their hcp's with things like weight gain and a sleepless night. Also it may not seem important to mention or the person may not just think that they are linked. The importance of psychosocial wellbeing gets forgotten, for some people if things are going ok then they do not want to rock the boat.

[HCP1]: Everyone's struggles and situation is unique. It is important to enquire about diet, exercise, weight and sleep directly with patients, especially over the phone, as the question has to be vocalised, as you can not rely on the visual cues we are use to. I have had patients reflect back to me on how 'lucky' they have been to feel well, and then still list a number of issues that are affecting them, and we have still spent time to explore these issues, which hopefully made a difference. Important that patients feel they can talk about all lifestyle issues openly.

[HCP3]: I think that this indicates the importance of clinicians "broadcasting their intentions" when speaking to patients. In other words explaining why they are asking these kind of questions.

[HCP4]: I appreciate the participant's quote, but would stress asking about our client's mood, sleep and wellbeing it is even more so important during pandemic. Perhaps we need to improve the way we ask these questions so they don't feel intrusive. Getting a picture of our clients in terms of mood, social situation helps us provide best care possible to them.

[HCP2]: Very interesting that it states during the pandemic it's being asked as far as I'm aware most of us ask this whether there is a pandemic or not. But it's about all asking about relevant things to the world around us? We care as well! Very interesting that patients responded this way. Firstly, its relevant on many levels, as psycho-social factors can actually be a clue to physical issues, but also can impact self management of their healthcare. For example, competing interests of social care with taking medication not becoming a priority. With the specific things mentioned, gaining weight and then being overweight can be a cardiovascular risk factor and medication side effect, sleep patterns can be a sign of depression which can impact adherence, but also can be a medication side effects. It might not be important in the time of COVID19 but it is important, and we are able to still address it and prevent it getting worse. The quote had made me quite "frustrated"! For want of another word. Healthcare professionals get a lot of criticism, and I think this pandemic has really given a lot of people an honorary medical degree via the internet (!). So when we ask or want to try and help with a holistic approach we are damned and if we don't we are damned. I know this definitely isn't a one size fits all but....

***Theme 2 – Q2 In your view, how can patients be supported with communications, for sharing information about changes to their well-being remotely (e.g. on the phone or via email)? Types of shared information might include patients’ mood, sleep patterns, exercise, diet and relationship.***

[P1]: Patients can be supported by being provided printouts of guidances on how to monitor and self assess themselves. If in any case they find something worrisome they should consult the clinician who will guide them through conversation and provision of more information if necessary.

[P2]: This should be done by listening to the patient and asking questions as needed. Patients should continually be reassured that HIV well being is seen as part of whole well being, this to include mental health, sleep, diet, relationships and anything related to how they feel. How about a questionnaire ahead of the appointment that can be submitted online or if not possible gone through at the appointment?

[P3]: It is good to share the information of the current trends so that you can receive the relevant help.

[P4]: This is a very good question, however I don't have the answer. I am a peer mentor for people living with HIV. Most HIV+ people I know find it easier to talk to 'people in the same boat' so this forms part of general conversation with my mentees. If I felt that someone's well-being was suffering, I would signpost them the their CNS (clinical nurse specialist) to start a conversation. In my clinic there is a multidisciplinary 'viral load' meeting each Friday to discuss newly diagnosed patients and various support mechanisms. Existing patients with known issues also get discussed that that meeting.

[P5]: Unless someone is already keeping a record of this sort of information I think it wouldn't really give the clinician an insight into their well being with say a monthly or quarterly email check-in. Something like a questionnaire completed for 2 weeks prior to phone/remote consultation might be more manageable for a patient and will capture what has happened in the most recent period of time.

[P6]: asking open questions, follow up on what is said, explain what could be relevant like asking; have your sleeping pattern changed? ect. I would prefer they asked me directly. also follow on questions on what I said if it is not clear enough on how I feel.

[P7]: I think the dr's need to be more specific in their questioning. Its no good just asking about generic mental health. Ask specifically about diet, weight gain, exercise, tv habits, dietary health etc etc. Be specific.

[P8]: Patients should be encouraged to talk about their mood or sleep (well lack of it) etc. Emails could be sent out prior to appointments then patients could answer a set of questions which may help the hcp base the call around. For patients who may not have email access, a few simple questions at the beginning of the call may help also dictate the consultation.

[HCP1]: asking open questions to include all these things, with explanation and validation of why they are important. Self reported on an app, to log trends over time, would be interesting.

[HCP3]: I think it can be helpful to send them a summary of what we'll be asking in a consultation or at least explaining it at the start of a call.

[HCP4]: I would always encourage patients to pay attention to their wellbeing and any changes in it, but I am not sure how feasible the idea of logging these things regularly would work for some of my clients (i.e. those without access to smartphone apps ect). I would not like to exclude anyone from having the opportunity to discuss those things.

[HCP2]: Definitely not email. Imagine sending an email, getting a response three hours later, needing to ask further details, getting a response a week later, then needing further information because a straight answer isn't given and then getting a response that day with an urgent issue, but you then don't check email till later in the day or next day. Nightmare. If stable, that's different, but if a medical issue, I don't think it's actually safe for clinical care. Assessing a patient requires a real time dialogue to ensure no red flags, concerns etc that require urgent attention, and phone or face to face offer this, but email can delay this or make it difficult to put the pieces together. But also, imagine doing this for 40 patients a day?

***Theme 3: Online trusted sharing***

*Patients fear sharing more intimate and detailed information about their health online. They doubt that the system (e.g. online platforms and services) is competent enough to securely process and store their personal health information. Previous online experiences, like cyberbullying, might make people feel anxious and may predispose them to the risks of sharing personal health information online. Negative experiences with the clinical team may also prevent patients from trusting healthcare professionals with this information. Patients question how their information might be circulated once shared, and whilst the health organisation might attempt to protect their data, some fear that their information will end up in the wrong hands or be seen by other members of staff.*

*Participant’s quote: A person living with HIV reflected on the psychological barriers to sharing personal information online with healthcare professionals:*

*When it is face to face you generally know the person you're talking to or if you haven't met them before then you make an instant assessment of what to say/share with a healthcare professional. When it is online, there is an element of not knowing who is reading what you've written and being judged by that. [P4]*

***Do you have any comments on the theme summary, anything else you would like to add?***

[P1]: I agree with the patient thoughts however, there is a need for patients to trust the health care system in terms of data protection. If patients at are worried about anything they should put their health first instead of putting themselves at risk just because of fear of being judged.

[P2]: Regarding the statement I disagree with the 1st paragraph. There are online medical apps where patients information can be viewed that are trusted. The 2nd paragraph might be more of an issue for some. The 3rd paragraph can be resolved by being able to see who has accessed the records (sharing record kept) and also by log on restrictions placed on who has access (nurse/consultant only). Regarding the participants quote this is true but see above re restriction placed on who can view what they have written. Another thought is that the written word can be more poorly interpreted than the spoken word. Therefore this is open to misinterpretation whoever is reading it, especially if given without context. There are more limitations to sharing something in writing.

[P3]: [left blank]

[P4]: I totally agree with this statement.

[P6]: [left blank]

[P5]: I think anyone who has had experience of data breaches in any other arena will always have some trust issues and the potential that anything shared online may reach unauthorised personnel and I'm not sure if there is anything that can be done to overcome that. Also historical experience of your status being shared without your consent (mine was written in large red letters on the front of my file and left on a counter top on a ward when I had a non HIV related procedure) may hinder someone from sharing more detailed information online.

[P7]: personally, i dont have these kind of security issues. My issues are more about prying into my sexual life.

[P8]: I think the only thing the hcp can do is ensure the patient how their information is going to shared if needed and who to. (if they are just taking a message) It is very hard to convince people who do not trust the internet to trust it. But by reassuring them, this should help to ease the feelings of anxiety. HCP's should say who they are and take a bit longer with the call which I know is not always easy but some people just need a little bit more time.

[HCP1]: [left blank]

[HCP3]: This resonates with my experience. I think that this is why its important to explain confidentiality e.g. that my notes go onto the same system that my colleagues use.

[HCP4]: Lack of security would worry me too.

[HCP2]: I think email is different to online platform/services as you can get a personal response with the other, as opposed to the other going into a blackhole and channeled to the right portal. I would agree with concerns the patient mentioned but thoughts on reading this are around feeling "judged" is a subjective thing/stigma/discrimination concern - so leans to me think more word needs to be done on this. There are many portals used and safety is paramount within the NHS so I feel it would be safe, but personally thinking the online aspect is taking away the art of medicine - communication, clinical assessment, history taking etc. I became a doctor for the patient contact not for computer contact. I think with online pre screening and other similar online platforms/services, what's the point of having doctors? I wouldn't be concerned re cyberbullying unless an open forum so seems like an odd comment. I also can just imagine the IT nightmare to sort this out...Clinical assessment is about putting all the information together, so unless it does and asks everything then? But also then what is the point of a doctor? WE might be moving with the times but is it the right thing for all?

***Theme 3 – Q3 What, if anything, could be implemented to reassure patients about the trusted sharing of their personal health information with healthcare professionals online?***

[P1]: There is need for the health care professionals to assure patients with how much they value data protection and as professionals, health care providers do not discriminate or judge patients no matter the information shared. I believe, patients need reassurance inorder to trust the 'system'

[P2]: Restricted access, Viewable record of who has viewed anything shared.

[P3]: There is a need for due notice of this appointment, be it a call or video chat. Then the recipient will be expecting the call.

[P4]: I haven't been asked to share any information online, however, if requested to do so, I would seek assurance that any identifiable information I provided would be seen only by my doctor.

[P5]: Some sort of 'lock' symbol on any documents or consultation notes that are shared; or documents requiring a password/code to be able to read them when shared.

[P6]: as said having a video chat helps and shows they talking to someone in a secure place. eg no other staff or people around. explain how and where the date is stored and how will have access to it

Explain on how and who has access to the records. also every online contact is done directly to one person and not overseen/heard by coworkers.

[P7]: If its online, then all communications should be done by only using reference numbers that cannot be translated into names. Along with transparency of what happens to the information and who has access it to it. If people dont trust who can access their data and believe they are being "spied" on, no amount of reassurance will change that.

[P8]: I think it is going to be really hard to reassure some people, due to their huge mistrust of the internet. I think just reassuring the patient at the beginning and the end of the call may help. We are living in times of change and it I think acknowledging that will also help.

[HCP1]: Perhaps patients could be in charge of accessing that information with the healthcare professional, or releasing that information. Patients can be advised that this is not shared with GPs, or the wider health community. Patients can password protect their information. clear lay details about encryption of online data, can be explained so people understand it is secure, and can only be accessed by the appropriate healthcare professional and patient.

[HCP3]: I guess explaining to patients how information is stored and used.

[HCP4]: Has not written anything

[HCP2]: Clear explanations of the security used but also a reminder about GMC codes of practice.

***Theme 4: Maintaining privacy***

*Patients wish to be able to control who their information is shared with, but there are challenges in enabling people to control what happens to their information once it is shared for maintaining their digital privacy. Some patients have total confidence that their clinic (and wider NHS) will protect their information from unauthorised access. But others are concerned about how private their shared information will remain within the organisation.*

*Participant’s quote: A person living with HIV reflected on the psychological barriers to sharing personal information online with healthcare professionals:*

*Anxiety that when you tell someone something private, that they keep that privacy. I dont think it's made clear enough to clients [patients] that when they say 'please don't tell anyone else this', this can't be guaranteed. But the information will be kept within the confidentiality of the institution. [P7]*

***Do you have any comments on the theme summary, anything else you would like to add?***

[P1]: I believe that there is in no case where I would expect the health care professional not to tell anybody what we shared especially if it raises concerns about my well-being. Information shared between health care professionals and patients can always be taken further within the institution for patient's interest. Private information shared between a health care professional and the patient can also be kept secret if it does not in any way affect the patients health and wellbeing.

[P2]: Fair statement. Regarding participant quote, they shouldn't have to even say "please don't tell anyone this" for confidentiality to be maintained. It should be a given and patients should be reassured from the start that by whatever means they share information - face to face, phone, video or written - that confidentiality is paramount. However we know that sometimes this isn't the case with information shared with GP without consent and also pharmacists mentioning HIV status in hospital wards in front of other patients.

[P3]: [left blank]

[P6]: [left blank]

[P4]: I don't have that anxiety as I have a total trust with my clinician. I know from experience with him, that if I really didn't want something shared, then I would say that to him and I have confidence that he wouldn't.

[P5]: The quote highlights the range of knowledge of patients about the extent to which information is confidential; having worked in the education sector I know that safeguarding may mean that confidential information may be shared by the recipient of that information to others in order to protect a child's welfare. However there are clearly many patients who will believe that confidentiality can't be broken and therefore it needs to be more explicitly explained to a patient if they ask for information to remain private. However, that may then lead to a patient not disclosing more intimate details.

[P7]: Is this a statement just about HIV ? We should all know that any information about ourselves that's given to an organisation is available to multiple people in any organisation. Any professional that is asked "please dont tell anyone else", should always reply that this cannot be guaranteed as it may become collusion.

[P8]: I think just reassuring the patient over and over is the only thing. Building up a new way of trusting how our information is shared and help is going to take a while for some people.

[HCP1]: We also need to make clear limitations to confidentiality with safeguarding issues. No healthcare professional can guarantee complete confidentiality before they know what a patient is about to disclose, in case confidentiality needs to be breached for safety, to safeguard in their best interest or that of someone else's.

[HCP3]: It comes up fairly often that patients want us to keep things private and we have to explain that we can't guarantee that, that we have to write notes to be accountable to the activities of a psychology session.

[HCP4]: [left blank]

[HCP2]: At the end of the day, confidentiality is quite simple. You don't break it UNLESS it's a risk to the patient or others, in which case you would need to disclose to the patient first, go through a discussion at a MDT and even GMC/MPS - it doesn't just happen just like that. In addition, I think we need to start challenging sharing information where relevant, e.g. another healthcare profession knowing about HIV and vice versa - it's otherwise potentially dangerous e.g drug interactions, it impacts the possible causes of someone's presentation etc which could be (without being dramatic) life saving. Also, the issue comes down to stigma - real vs perceived - this needs to be addressed.

***Theme 4 – Q4 In your view, to what extent can the privacy of patients’ information be maintained within a health institution? Patients’ information may describe their lifestyle, their other health conditions, and their mental and physical health.***

[P1]: I think there is a limit to patients information held within an institution. If it's something that can be handled within the institution therefore the institution deals with it. However if it is something beyond the institution they should therefore inform the patient,talk to the patient about it (if there is need) and forward to relevant authorities or departments.

[P2]: By access only to those directly involved in a patient's care with records kept of who has viewed any information.

[P3]: Privacy of patient information is of utmost importance. The clinic should make it a priority. I would not feel comfortable if my personal information is leaked. The clinic should make me feel confident that my information is kept safe.

[P4]: I would hope that access to such information is limited to healthcare professionals on a 'need to know' basis. i.e. who your doctor shares this formation with based on its content.

[P5]: I actually don't think 100% guarantee can be given and therefore patients will always have to weigh up the risks of fully sharing personal information.

[P6]: I always have had trust its been kept safe and not shared, either it was in a face2face or digital conversation. Also reassure the digital conversations is not recorded or monitored might help a few people. Give clear guidance on who what information is shared and with whom. also explain when some part cant to totally confidential and has to be shared and why and how it would benefit the patient.

[P7]: Any questioning session should begin with an explanation of who might access the information. Also, that confidentiality relates to the organisation and not just the individual.

[P8]: If not seeing the same hcp all of the time to have some record of other conditions etc helps any hcp who is new to the patient have some background.

[HCP1]: It is common to review patient informations, records in a multidisciplinary team meeting. where numerous professionals make decisions about care, based on professional experience and evidence, to do this, it is important to have a good understanding of the individual and their needs, but my experience, is this information can be presented and shared (what is essential to know) by the professional who knows the patient best, drug history, medication, other diagnoses could be shared with the wider team, and viewed at such a meeting, but other areas on the record, could automatically be hidden and only accessed with the patient, or by a specific professional, as this may not need to be seen by the wider healthcare team, to make decisions on treatment for example.

[HCP3]: I try to write notes that are as brief as possible and contain information relevant to the problem and help being offered.

[HCP4]: The confidentiality of our patients should always be respected, unless they are safeguarding concerns: I.e. we are seriously worried about their safety. Any breaking of confidentiality needs to be discussed at MDT level as a whole to ensure this is the best decision for client's wellbeing.

[HCP2]: Easily. It always is. Depends on the privacy definition. I don't think as a clinician I need to get consent to discuss the best ARV regimen, for example, with another colleague. Ultimately discussing information would be in their best interests and about bettering their health. There are guidelines/policies about these things. And if a clinician breaks this, they can get into serious trouble.

***Theme 5: Protecting my identity***

*Being able to share data anonymously is important. With online communication, people can create a ‘persona’ that is subjective and not representative of someone’s self-identity and feelings. The ways that people interact online, and what they express, can be different to how they are, how they behave, and how they feel in person. In the context of sharing information online, there are concerns about data breaches and the risk of identifiable information being traced and disclosed if the online platform is hacked or misused.*

*Participant’s quote: In the context of sharing personal information with healthcare professionals, an HIV clinician commented about the use of online portals:*

*Psychologically, online portals for information sharing can give patients more anonymity, but also less accountability to someone else, to reach their health potential. [HCP1]*

***Do you have any comments on the theme summary, anything else you would like to add?***

[P1]: I think the ability to be anonymous online can also be a tool for patients to disclose what they are going through, their experiences and feelings without fear of being directly linked to whatever they share. This can bring about positive results as they feel that the person doesn't know who they really are hence are able to openly share their worries without fear of being judged, laughed at or being discriminated. However some people can also use the platform to 'mask' whatever they are experiencing. Thereby limiting relevant help to achieve their health potential. I think the online portals can be provided to a patient and a health care provider who would have officially met prior to engaging online. I believe that this would be an advantage for health care provider to pick up any abnormalities in the patient's communication and behaviour.

[P2]: Regarding the statements I'm unsure of the connection between the 2 points mentioned. One is about being more easily able to be someone we're not online than in person - fair enough. the other is about data breaches and hacking. I agree with the participants quote. We can feel more accountable when seen in person than online. As previously mentioned it's because online cues can be missed.

[P3]: [left blank]

[P4]: I agree with this statement.

[P5]: Allowing someone to be anonymous could lead to someone being more open with the information they share in the knowledge they cannot be identified; however I'm not sure that would be achievable without some data capturing who that person really is in order to set up an anonymous persona. The quote needs more explaining for me, I am not clear what it is saying.

[P6]: [left blank]

[P7]: Tough question. But basically, make sure that identifiable information is not kept with sensitive information.

[P8]: Anonymity is ok but not if it means a person is not reaching their health potential. but the fear of data breach may be be more about being identified as someone living with HIV. This could be for a variety of reasons.

[HCP1]: [left blank]

[HCP3]: This seem pretty self-explanatory.

[HCP4]: [left blank]

[HCP2]: There are repercussions for misuse - we have to go through mandatory training and serious consequences. Hacking can't be controlled - can it? Donald Trump’s Twitter account was hacked!

***Theme 5 – Q5 Can you describe what you think is meant by ‘accountability to someone else’ in the above quote, and how you make sense of this in terms of your own experience?***

[P1]: I think the quote refer to some one who does not want to have any responsibility in terms of honouring themselves. They don't want to take the blame should anything don't work out for them or if they don't meet expectations.

[P2]: This comment sounds odd and wrong in context of accountability of patient to HCP, but sounds ok is the other way round (HCPs are accountable to patients in giving them the best support and information they can, though can only do so with proper engagement from patients. The word accountable infers some sort of blame attached. I don't like it. Perhaps responsible is a better word. Ideally both HCP and patient are accountable/responsible. One has a duty to support the other and the other has a duty to be up front in responding to questions.

[P3]: Numbers and not names are usually used to ensure the anonymity of an individual. From my own experience, I do not see how it affects accountability to reach potential. I actually feel that we are held back by our own perceptions of a situation.

[P4]: I think that anonymity gives a patient the freedom to be totally honest and share information that could potentially be harmful in the long term, such as excessive alcohol intake and/or poor diet. The 'accountability to someone else' means that I wouldn't be obliged to discuss this with a doctor/dietician

[P5]: This was the one part of the quote that I didn't understand! Are patients ever accountable to anyone but themselves? I can't make sense of it as I am unclear what it means.

[P6]: understand it as you can say things about something you done or happened with someone which probably should be followed up. due to the anonymity it cant and therefor maybe create further effects on both parts.

The clinician has a duty to report and being over viewed by someone to make sure they are doing the correct things or in the patients best interest.

[P7]: nope...dont know what this means.

[P8]: I think it means by remaining unknown, it means they may get general advice but not advice that is accountable to a hcp, making it real.

[HCP1]: Accountability to someone else can have a big impact on supporting someones motivation over time, particularly if a behaviour change is required to improve health. Having no accountability, can mean people have to be self-motivated, and this can wain, if people are fully left to their own devices. It is important to have regular check -ups with a trusted professional to keep people motivated and on track, to maintaining their good health overall.

[HCP3]: I'm afraid I don't know what this means!

[HCP4]: I feel that the worry here might be about whether a client might disclose something worrying (I.e. feeling suicidal) and we might not be able to act on it if they did not leave any other details. If there is an appt being developed for clients to track their mood and wellbeing, I would be very mindful of ensuring there are some mechanisms there, which ensure safety of our clients.

[HCP2]: Means the patient is in control of their own health, but won't get the medical/psychological expertise to really truly benefit? It also comes down to be subjective in the former vs objective in the latter. Again what's the point of a healthcare professional then?

***Theme 6: Sharing data for achieving wellbeing***

*Some patients value sharing information about their lifestyle or day-to-day routine to discuss their wellbeing with their HIV clinician. To help patients manage their wellbeing, HIV clinicians may ask patients about their lifestyle (e.g. alcohol intake) and social history (e.g. relationships and family). Information about accessing peer support and other services offered by trusted charities should be signposted to all patients regardless of whether they need it at the time.*

*Participant’s quote: One person living with HIV comments on the types of information that might be useful to share at the consultation for supporting patients’ HIV care and wellbeing:*

*For someone newly diagnosed I can imagine it would be helpful to record more emotional/mental health information. I think for someone newly on treatment it would be useful to share adherence data. For long term survivors with co-morbidities, I think an overarching framework for sharing multiple health issues would be beneficial so that all disciplines involved with care have access to that information. [P5]*

***Do you have any comments on the theme summary, anything else you would like to add?***

[P1] For someone newly diagnosed, record keeping helps in terms of keeping track of when and what needs to be done interns of looking after themselves. It also helps in picking up on abnormalities or changes which they may also encounter along their journey. I think having long term survivors to share their personal experiences also provides a 'practical guide' to issues relating to challenges that one might encounter. It may also provide practical solutions or provide a direction of where to get help when in need.

[P2]: Statement - all perfect, especially the last paragraph during the COVID pandemic. Online peer support is easy to access. Participants quote - also all good and relevant. It is true that for the majority of newly diagnosed the emotional side is very important in getting support with. However this is very generalised. Some who have been newly diagnosed might be diagnosed late with one or more other health conditions that might need addressing. Those further down the line (long term diagnosed) might have drug fatigue or MH conditions or alcohol/drug related issues that mean adherence is not good. Those diagnosed in later years might already have co morbidities that need taking into account.

[P3]: [left blank]

[P4]: I agree with this statement.

[P5]: I wonder how knowledgeable clinicians in some parts of the country are about services that patients can be signposted to? I get a sense that outside of major areas the choices available for patients are limited. In 30 years of being a patient I have never been asked about lifestyle issues such as drug or alcohol use or social history so not sure if that is a common question patient get or whether my consultant was not interested in those aspects of my life. From memory I think that is one of my quotes! Today I think emotional/mental health information should probably be captured at all appointments in light of the stresses brought on by covid. For patients with co-morbidities it is so important for joined up communication between clinicians and GPs.

[P6]: [left blank]

[P7]: Its not easy to share information between different organisations. We all have different databases, we uses different forms of ID and different processes and admin. When we do work together we share information through secure portals. The framework is a good idea, but whos responsibility is it?

[P8]: I think by having a peer mentor based in clinics all of these things could be addressed

[HCP1]: [left blank]

[HCP3]: I guess that sharing some of this data is important for accessing services. For example, issues with adherence may facilitate quicker access to psychology services.

[HCP4]: [left blank]

[HCP2] Agree with the summary statement. Participant quote is a bit contradictory to the other questions previously where someone was saying why did they ask me about weight gain and sleep patterns. Everyone is different, so patient centred approach is crucial. Also we do record this stuff for a new patient. Not sure what they mean about adherence data - this wouldn't/shouldn't make a difference. In the first review as well there is so much to cover but also patients can guide the consultation as well as the doctor. We tend to also ask if there is anything else? They also almost always see a HA or peer who goes through this in more detail but equally I know I've spent whole new dx consultations just discussing mental health and how they're coping with their diagnosis. Saying all disciplines involved with care is crucial - contradictory to previous questions. This is what all clinicians ultimately want, but patients overide this. So are we actually saying that they need to also take more control of their health?

***Theme 6 – Q6 How can online tools cater for different people with HIV at different stages of their personal journey with HIV (since diagnosis)?***

[P1]: I think online tools like support groups with different people at different stages would empower patients to feel encouraged in cases where they feel demotivated. Some online tools also manage to tackle challenge uncertainty and fears especially that of being discriminated because of HIV status. For those who feel lonely, it would be a way to socialise and realise that there is a community out there which does not care of whatever your HIV status is. People are also able to share information, personal experiences (with newly HIV diagnosed individuals) and also how they've managed to get through certain challenges.

[P2]: signposting to different sections related would help - MH, lifestyle, menopause, bone health, support services etc. Some charities already do this - uses resources already available. Try not to reinvent the wheel too much but look at what works already.

[P3]: Questions should be asked at any level of a person being diagnosed so as to ascertain the correct regime for them. It's not just about questions, but person centered questions.

[P4]: There are many support groups and websites giving information to people such 'nam AIDSMAP. This is a huge resource and offers support at every stage of your journey from diagnosis, treatments, transmission and prevention, healthy living and legal issues. It also has help with health problems and ageing with HIV. This is therefore perfect for people to dip in and out of for help and guidance at any point in their life.

[P5]: My experience with say online forums that have separate sections for different stages of one's HIV journey is that I tend to look/engage with those at the same stage as myself; and if there is little activity within that section then I stop using the forum. I think there is value in having separate sections that reflect different people/stages but those sections should allow anyone to read them and engage with them. Peer support does not necessarily have to come from someone in the same position on their journey.

[P6]: Younger or newly diagnosed people often have a greater knowledge of online tools where of older longtime survivors (prefer calling them warriors) might not find it easy to use so more traditionally methods or phone contact might reach out to a larger %. Also many with complex needs (as alcohol, drug misuse) does not have all the gadgets (smart phone, laptop ect) to actively benefit from online support.

[P7]: At the moment I dont see how this can be done. There are so many different organisations involved in both speciality services and geographic location. This sounds negative from me. I think it would be great if all organisations involved in a persons care were able to work more closely together (and not concentrate on their own power base). Many are charities and struggling for funding and therefore protective if their own sphere and client base. losing clients = losing funding.

[P8]: By finding and listening to other people living with HIV talk about their experiences in the different stages of living with HIV.

[HCP1] I think breaking things up, so that different areas in the journey become relevant at different times, but that the patient can see the overall road -map of care, and can access things at different times when needed. For example, can 'unlock' adherence support section only after patient has started ARVs, or 'unlock' side effects 3 months after starting ARVs. This way it is clear what may be relevant, at what stage. But to remember that you can go back to areas at any point in the health continuum.

[HCP3]: Any tool needs to include info about when the patient was diagnosed with HIV. This means that if the data is reviewed by, say, a psychology team we can work out if issues with adherence may be better directed to health advisors rather than a psychologist.

[HCP4]: [left blank]

[HCP2]: General information. I only refer to websites e.g NAM/ibase/THT for information. Personally I'm not a fan of apps, graphs of results and all that. I think it takes away the human side of things, makes care of a patient more "cold" and "non personal"?

***Theme 7: Two-way communication***

*Communication should be timely and effective so that patients don’t feel they are being ignored by healthcare professionals. There is value for patients to be able to reach out directly to their clinical team (e.g. via email or phone), but not all patients have the same access. Two-way communication is one thing that could be improved with regards to communication between patients and healthcare professionals.*

*Participant’s quote: An HIV healthcare professional [psychologist] commented on how communication could be improved with patients:*

*It would be helpful if we could interact with people via text or WhatsApp rather than always relying on email. We can send people text messages but they can't text us back. [HCP3]*

***Do you have any comments on the theme summary, anything else you would like to add?***

[P1]: I'd suggest patients to have as many platforms offered to them when in distress. It can be in any form including text especially in a situation where by the patient has no secure access to email or phone. I also think it's a challenge to use applications like WhatsApp as the data is shared on a third party platform. This can also be a data safety concern if not handled correctly.

[P2]: Statement - absolutely agree (wry laugh - email?!). Clinics are all very different in services they provide. eg some send test results via text or someone can phone up after bloods have been done - or someone gets no notification till the next appt. 6 months later. Re participants quote - not sure a clinic could or would keep up if all their patients were on WhatsApp. I personally would be happy via any media I might be assured of a response. I currently only have direct phone call to clinic which rarely connects me to who i need to ask a question of. WhatsApp is a bit too "social". I would prefer email.

[P3]: [left blank]

[P4]: While text messages are generally automated, i find that if a follow up is needed then the text message usually includes a number to call.

[P5]: I am fortunate to be in a position where I can and do email my consultant and can guarantee I will get a prompt response; however another patient that I know has sometimes never had a response to his email to his consultant so I think there is probably a wide range of experiences in this area. I would definitely agree there is value in being able to reach the clinical team directly, particularly in this era where consultations may be 6 months apart. I had not realised that some HCP can text patients - if that is the case it would make sense for the patient to be able to reply back.

[P6]: [left blank]

[P7]: Firstly, some of our clients dont have smart phones (true), some wont use apps like whatsapp. Text isnt secure. We dont see much interaction from clinical professionals via email anyway.

[P8]: Emails are ok but some people do not have access to emails, Text communication or whats app could be a great addition to a clinic.

[HCP1]: I think this could be really helpful and important for younger patients. It is the way most people communicate quickly, reliably, directly every day, it is immediate and accessible information. It especially demonstrates accessibility to the professional, showing the patient, that they are there when needed, and that they can be contacted. too often patients face multiple barriers to receiving health care, being referred to the right place, and people give up trying to be heard. This can be really frustrating and demotivating. SMS, text whatsapp, is the way we need to communicate to keep us technologically up to date

[HCP3]: WhatsApp would be good as it's a bit quicker than email and avoids things getting lost in an inbox. However I'd only use this to arrange appointments or send links to online psychometric forms.

[HCP4]: Many healthcare professionals have work mobiles for that reasons so that clients can text them back directly (i.e. Health advisers).

[HCP2]: Strongly disagree - I think our cohort have every possible way to contact us (some perhaps not all) - but they can have secretarial/booking numbers, with appointments often available on the day with a clinician, walk in service (literally walk in pre covid19), a dedicated mobile phone, and some have their clinicians email address and some find the email for consultant email inbox meant for healthcare professionals and some even call the consultant on call mobile. The only thing missing is patients just pitching up and knocking on our doors? I think when we compare this to other non HIV services, it's zero. Text or watsapp I think is crossing boundaries. Imagine 4000 patients texting a mobile or watsapping, getting the message to the right person, then they start messaging about other random things etc etc. It's slightly dangerous??? Plus we need to prioritise according to clinical need. What's urgent for a patient might not be urgent for a clinician, and when compared to another patient? I think the only merit I can see with a mobile contact is for adolescent patients. In addition, within clinical care we are also trying to do other things during working hours - e.g. meetings, service, QI/audits/research, self directed learning etc.

***Theme 7 – Q7 What are your views on a two-way communication between healthcare professionals and patients (e.g. being able to respond to each other)? How could this improve quality of care? What are the challenges for patients and healthcare professionals?***

[P1]: In my personal opinion, I support two way communication in the form of feedback, consultations and advise, feedbacks always help in terms of issues relating to areas that may require improvement in quality of care. Being able to respond to each other brings about effective communication between the parties however, there I need for health care professionals to be extremely cautious as they engage with patients on these platforms. There is need for both parties to maintain professionalism in such engagements.

[P2]: Would be good. I'd be happy with secure online format or email. Would increase engagement between patient and clinic. Challenge to HCPs is if/when they have time to respond. Patients would need reassurance of a response within a certain time frame.

[P3]: The texts I have been receiving are just for appointments and far as I am concerned, that does not need a two-way system.

[P4]: Two-way communication is essential. If I felt uncomfortable answering a question, I would tell my doctor this. He could then tailor his questions, so that I'm more likely to open up and respond. It would improve the quality of care because he could then gain an understanding of what issues I had difficulty discussing and could offer me reassurances and encouragement to open up. This also reinforces the trust i have with him.

[P5]: I have found it invaluable to have a relationship with my new consultant that allows for two-way communication via email. I suppose the key in this is that I don't abuse that privilege and email constantly but use it for specific issues arising from my clinical care. One of the challenges for developing this more widely would be the time constraints that consultants would have to be able to reply and the level of engagement that some patients may then want. A one or two word answer from a consultant may leave the patient feeling their needs are not being met.

[P6]: feeling "at ease" with you healthcare professional it vital for an open an honest conversation, if this the not established the option to change healthcare person should be offered. also vital the healthcare person suggest this if the conversations are struggling or not working.

[P7]: As a caseworker, I use text, whatsapp, email, zoom, snail mail...anything the client accepts. The clinical professionals in my arena firstly rarely communicate with clients (I include myself here as a patient), and when they do write to them its in a foreign scientific language that only they understand. Mental health professionals project a very superior attitude in their writing and are often condescending to those of us further down the support ladder.

[P8]: I think by having an easier way to communicate would be great, but also could become very time consuming for the hcp. It would also have to be managed and a peer mentor based in clinic could help with this being a link between the patient and the hcp

[HCP1]: Improves accessibility, which can improve trust and rapport. It can make information much easier to access, and give confidence to patients, that they can reach out to their health teams easily. The volume of patients and messages needs to be manageable. People will need to be aware that they may not get an instant response from a professional, but they will get one as soon as possible. It might be limited to people that need additional support, motivation, or are vulnerable, initially, then to everyone, so that work load is manageable. For patients who do not have privacy at home, such a young people, this could be a really helpful way of staying connected with their healthcare team.

[HCP3]: I think it generally works pretty well by email - it's how I contact most of my patients. It's especially good when you don't have a secretary to take messages or call patients for you and avoids 'phone tennis'!

[HCP4]: I had excellent feedback from client who found texting back so much easier, in case they missed a call from us. Particularly younger clients (under 25s) feedback that arranging appt via texting us back was much easier!

[HCP2]: Please see comments above. Strongly disagree. I think we already have good care and access to patients, and when we compare it to other services it's really a trilion per centre above and beyond to the power of infinity! I've had patients say it's like private healthcare. I like to think I ensure I respond to patient but we need to manage other patients who might be more complex, require referrals, discussions with other colleagues etc etc. Challenges are a plenty - mainly expectations, understanding of what we do as well.

***Theme 8: Being treated like any other patients***

*Language is very important for communication with patients. Healthcare professionals should use understandable and HIV friendly terms. More education is needed for non-HIV healthcare professionals to understand what it means to have an undetectable viral load. Patients would like this to be recognised more so they don’t have to educate their doctors when saying that they live with HIV. They want to be treated like any other patients.*

*Participant’s quote: HIV clinicians have to ask their patients before they contact their patients’ healthcare team with medical results (e.g. GPs.) This is what one HIV clinician thinks about this:*

*By asking for permission we add to stigma and discrimination but it's needed because of the real stigma and discrimination out there. More education is needed for patients and healthcare professionals, including around confidentiality. Perhaps it [permission] shouldn't be a choice as with other chronic conditions. [HCP2]*

***Do you have any comments on the theme summary, anything else you would like to add?***

[P1]: I believe that asking for permission should be done as it empowers the patient with whom they want their health records shared with. The patient must also be well informed about the benefits and risks involved when such records are shared. We cannot ignore that there is still stigma and discrimination including from the non- HIV healthcare professionals. I strongly believe that it should be a personal choice.

[P2]: True statement. The problem is that the patient does not know how much HIV knowledge the Dr/consultant has which can make them unwilling to share their status with them. It's not just U=U but also things like drug interactions and where to check against other prescribed medication. Participants quote - I totally agree with the HIV clinician, but then why do they ask for that extra layer of permission to test for HIV compared to other STIs when doing testing at the start. The stigma starts there! ditto with different clinic identifiers to NHS numbers as many clinics have. Once this is addressed then yes, it should become the norm for the HIV clinician to write to the GP just as any consultant a patient might be seeing for another health condition might.

[P3]: [left blank]

[P4]: I totally agree with this. Undetectable doesn't mean much to anyone that doesn't have an awareness of HIV. Within the global HIV community, the term U=U (undetectable equals untransmittable) is far clearer. I think there is a definite need for primary healthcare to be educated.

[P5]: Not sure what an 'HIV friendly' term is? Of course we would all love non HIV professionals to understand more but then that adds to the 'otherness' of HIV, do we expect other health care professionals to understand issues for say cancer; diabetes patients? Personally I relish the opportunity to educate far and wide about issues like U=U but that is because I live openly as a person with HIV. With regard to contacting a patient's other health care team I do think it should be an assumed opt in unless a patient explicitly opts out of correspondence being shared - if they opt out it needs to be explained that they may not receive optimum care if all parties are not privy to the same information.

[P6]: [left blank]

[P7]: I really disagree with this response. HIV patients have a lot of bad experiences and distrust of GPs. Also a string of incidents of stigma and ignorance towards them from NHS staff. By asking for permission, you show respect. You don't add to the stigma thats already there. Fix the existing stigma first. Educate NHS staff. The education needed isn't about confidentiality, its about HIV and respect.

[P8]: Fear and self stigma may stop a patient from wanting their HIV status shared with a GP, but also stigma and discrimination from GP's themselves. More education is needed to improve this situation.

[HCP1]: [left blank]

[HCP3]: I think that we need to ask permission until stigma is reduced. Stigma is, unfortunately, a real issue including amongst other health services. I think that addressing stigma in other services is a very broad issue but should probably be a part of the commissioning remit of a HIV service like ours. This way it can be properly funded and prioritised.

[HCP4]: I agreed with the statement above re stigma. I think that particularly other medical specialisations (i.e. GPs need more training around HIV).

[HCP2]: Agree. In fact it looks like something I'd say! Education definitely needed around HIV. But it's also a two way thing - patients need the education about why it's important and confidentiality rules when they are concerned about it. But it's not just clinicians, also non clinicians working in healthcare environments.

***Theme 8 – Q8 What will it take for people living with HIV to feel that they are treated like any other patient? What could be improved, especially in the context of remote or online communication, and with regards to protecting patients’ confidentiality? Please use this space to answer the question and/or add any comments or thoughts.***

[P1]: I think there is need for patients not to be identified by their HIV status so as for them to feel treated differently. Taking basic security check before sharing confidential information can also be an extra shield in order to protect and maintain patient's confidentially and data. In addition to protecting patients confidentiality, I would suggest using number codes such as designated clinical number or NHS number instead of using patients registered names on online platforms.

[P2]: See my response above. This is the only way to normalise HIV - treat it like any other health condition right from the start. ensure that GPs are knowledgeable as they would be expected to be about any other condition. Offer a mode of communication that patients are comfortable with - plus secure access. Remote or online communication - would be good to have any. Joined up care is very important and engagement with patients - being able to see our results for all health conditions in one place. I'm not sure how this can be done with different app access depending on hospital, clinic, GP practice.

[P3]: I have never felt that I was treated differently because someone asked a question. Actually, I would rather have them ask questions than presume the wrong thing.

[P4]: I think hospital trusts need to review their policies. I had a biopsy an hospital a few years ago. I was told that I would have to wait until the last appointment due to infection control. I was angered by this, as I was being singled out and being treated differently. As I am undetectable I am zero risk to anyone. All of the patients before me were not asked if they knew what their HIV status was, so surely they were a far greater risk. I posed this to the nurses and they totally agreed and apologised, but said it was the trust policy.

[P5]: I already feel that I am treated like any other patient but that has come about through years of being open with the other healthcare professionals and educating them where needed. I have always believed being proactive would ensure I got the best care but I guess not everyone has those skills. Not sure what can be improved other than access to up to date information for non HIV HCP in some format that allows them to understand the needs of their positive patients better.

[P6]: I think full medical history should be disclosed to involved healthcare people. thou it should not be brought up (HIV status) if its not relevant. othen many healthcare professionals seem to think HIV is the main topic,

[P7]: 1) Educate all NHS staff about HIV 2) Remind all NHS staff that they are breaching their own contracts when then they stigmatise HIV clients. 3) Acknowledge you still have a massive problem in the NHS. 4) Include dentists in this as well. They are the worst.

[P8]: Up to date information for other HCP's to stop stigma and discrimination that people still experience in some settings. HIV is cared for by HIV consultants and other health care is for GP'S etc. If knowledge was widely available their would be no need to worry about confidentiality as the GP or hcp would not be having to even look at your HIV, because that is already being cared for and has no bearing on other health care issues.

[HCP1] Routine testing of HIV like any other viral condition, so that it is normal to consider this infection in all patients. Normalising HIV, and reducing stigma associated with it. Explaining U=U. Explaining that in sexual health we deal with confidentiality, but living with HIV, however it was acquired, is living with a long term condition, that will at times need to be managed by various specialist. Changing all these messages about stigma around HIV, will give people more confidence in sharing their information with the wider health community if necessary.

[HCP3]: Great awareness of U=U will be the biggest factor I think. Until then I think that sharing of HIV status should be done very, very carefully.

[HCP4]: It is hard to write this from a perspective of HIV positive person as I am not one. I would think that many would feel more comfortable with their details being shared if they had confidence that dentists, GPs and other medical professionals would be non judgmental about their HIV. I think th

[HCP2]: People who stigmatise & discriminate to have a brain transplant??? Education patients on why communication is needed to other healthcare professionals, and educating healthcare professionals and others in the healthcare environment about HIV,.

**Round 3 (April 21)**

***Theme 1: Service user-clinician relationship***

*Participants agreed that there is value in seeing the same clinician over time, for building relationships of trust and confidence, and for providing a continuity of care. One clinician commented:*

*“Agree each subsequent contact with a patient, in long-term follow-up, enables a richer, deeper information exchange, and familiarity and trust can enable you to expand on topics with patients, richer, deeper information exchange, and familiarity and trust can enable.” [HCP1, Round 2]*

*In some cases, feeling comfortable about sharing personal health information with a clinician can be more complex than just seeing the same person over time. Service users and clinicians may have differences of opinion and if this poses a problem then service users should be given the option to see another clinician.*

*Seeing the same clinician can also make people feel uncomfortable and reluctant to share some more personal or intimate information. For example, people might feel shy about sexual health examinations if they have known their clinician for a long time. In the case of sexual health, one clinician commented that not seeing the same person can be helpful “as people can disclose things if they feel non-judged, without a pressure, of having to see this clinician again.”*

***Do you have any comments on the theme summary, anything else you would like to add?***

[P1]: I strongly relate to the value of seeing the same clinician over time. Seeing the same clinician has the effect of patients developing trust and feel secure. I think that in most cases there is the "sense of belonging" whereby a patient can be free to share their worries with some of the information that the patient may not feel comfortable sharing with their family and friends. I also believe that it provides a tried and tested confidentiality to the patient thereby they will be willing to share their concerns without any fear or limitations

[P2]: I agree with the clinician quoted comment. clinicians will know us better than anyone else at our clinic - except possibly our nurse. We also get used to others idiosyncrasies (for want of a better word) – i.e. what individual clinicians like to focus on and what particular concerns each patient has. I don’t agree with the statement that seeing the same clinician can make us more uncomfortable in sharing new information unless we're already uncomfortable with that clinician. However I understand that over time some patients see their clinicians more as friends and for them to have to examine them might prove uncomfortable. The last bit is interesting and gives a different perspective and a valid point. It really shows how different we all are and what different scenarios there might be.

[P3]: I agree that it is good to have the same clinician so as to establish some kind of rampart. With the high turnover in the NHS, one will find themselves with a new clinician, so in this situation, one should be confident enough to be able to share anything. I guess more people struggle with fear of being judged but we should be able to trust the one who is giving care to us.

[P4]: I totally agree with this. You build a relationship with your clinician which I can only describe as a professional friendship. He knows me inside out, my strengths, my weaknesses and my values. I have total [confidence] in him, but because of the good relationship I have, sexual health examinations feel embarrassing, so I would always prefer a Doctor I'm less acquainted with or indeed a Doctor I've never met.

[P5]: I wonder whether now with 6th monthly appointments appearing to be the norm whether any useful long term relationship can be built up between patient and consultant. In the past when you saw your HIV doc every 3 months it felt much easier to build up a relationship; I worry that people being diagnosed today may not have that opportunity with less contact.

[P6]: I find it easier if I know the clinician cause I built up a trust between us. thou is cause I personally got a good connection with her. I can understand others might feel the opposite, so being able to choose who to see is vital.

[P7]: Another thing to bear in mind is that we (service users) will almost always out live the careers of our consultants, so we ought, from an early stage, be aware that we will be service users for the rest of our lifetime, and our clinicians will naturally come and go. We service users need to be prepared for change along the way.

[P8]: I think what is important is what works for the patient as an individual. When you have been going to the same clinic for a number of years, most will probably had to have seen different doctors or nurses. A peer mentor can also be beneficial to helping somebody tell a hcp something that they be embarrassed about or think that it's not worth bothering the hcp.

[HCP1]: [N/A]

[HCP3]: I agree

[HCP4]: [left blank]

[HCP2]: Have noted that it's interested with HIV patients I've managed for years they are shy/embarrassed about sexual health examinations yet we are sexual health physicians - only a handful. Completely understandable. Also, same clinician more beneficial for patients and helpful, but 100% agree they should ALWAYS have the option of seeing someone else - both clinician and patient should feel comfortable to discuss/suggest this without offence! This is a crucial skill really for doctors to have and recognise when this might be appropriate but also, in the sense of discussions with other doctors to getting them to actually see someone else. There might be differences of opinions for patients and doctors in this, but both should understand/discuss pros/cons.

***Theme 2: Remote interactions with clinicians***

*Participants shared their concerns about attending remote consultations with clinicians. Online or phone communication can feel impersonal and make a lot harder to build a relationship, especially if meeting a clinician for the first time. Face to face consultation should always be available for people who really need it even during a pandemic.*

*In remote consultations (conducted via phone or online), there are ways to increase trust and make conversation more engaging, for example, by reassuring and listening to what people share, and by making sure that questions can be asked on both sides. Video calls can be helpful because they support real-time feedback and visual cues. But most participants reported having remote consultations over the phone.*

*In practice, more time should be allocated to the ‘remote’ consultation, because it takes more time to “warm up” the conversation and go through everything when consultations are held online or over the phone. Showing personal interest is important and one clinician highlighted the need to show care and empathy when using the phone for her consultations:*

*“Using telephone calls to ask about general well being, and activities, chatting less clinically and more 'humanly' about coping strategies during lockdown, as loneliness and boredom is common, and a significant problem to people's health. Showing that you care and empathise with someone's situation, and then conducting their routine care/consultation by telephone, possibly in a separate call, can be a powerful and important way of connecting to you patients, at a time when people are feeling isolated and disconnected from the community”. [HCP1, Round 2]*

***Do you have any comments on the theme summary, anything else you would like to add?***

[P1]: Remote consultations need to be given more time as there is need to build humane relationship between patients and clinician. Video calls are helpful in consultations as they provide visual cues which the clinician might not pick up in a voice call.

[P2]: I'm not sure I understand the quote - it is suggesting that 2 different phone calls might be beneficial to the patient? If so I don't agree as might cause more stress. However they're done it can be helpful to share information perhaps about something mutually experienced – i.e. lockdown. Empathy and care is always a fantastic quality in any clinician. However appointments are held, whether in person or at clinic, it would be great if the patient isn't made to feel rushed - something I've never experienced but I know other have, including those newly diagnosed. On the statements, I absolutely agree with the 1st paragraph. On the 2nd paragraph, yes, all valid points.

[P3]: Most clinicians have been giving telephone interviews, for me, this is rather impersonal but we also have to consider the circumstances. At least we have someone to talk to. For the newly diagnosed it can feel strange and difficult.

[P4]: I totally agree. Online video consultations are much better than phone calls. If you know your consultant then you generally catch up during the first ten minutes about non-clinical things. My last consultation was remote and not with my regular Doctor, but with another one that I also know reasonably well and we had a general catch up before discussing my results. This is definitely the right approach, you feel they're concerned for your well-being rather than delivering your blood results.

[P5]: Personally I really hope this is not the way of the future; I did not find telephone consultations during lockdown were as beneficial to me as seeing my consultant face to face. The quote illustrates an ideal way of reaching a patient with a remote consultation - I like the idea of chatting more generally before discussing routine care but wonder if time constraints/workload would make that realistic for all doctors.

[P6]: I find remote interaction an efficient way for routine appointment. If there was any major changes in my result I would prefer to be told face2face. I think the remote routine appointment is great and efficient way and would say time money for both parts since not having to travel or take time off. I hope the keeping this option after the pandemic. I dont find it to take longer time since i already have a good report [rapport?] with my clinician (i see the same each time) so no need for "warm up" time .

[P7]: I like the idea of a welfare call in between consultations. As we move to yearly appointments, things that concern us can mount up and a single remote appointment always feels a bit rushed. The welfare calls do not have to be conducted by the consultant, but maybe by the healthcare workers in the unit. (I using the [name of HIV care unit] as an example, and the [Name of HIV Charity] as well that does conduct welfare calls).

[P8]: Yes be more human on the phone being clinical does not really work.

[HCP1] [N/A]

[HCP3]: Makes sense to me

[HCP4]: [left blank]

[HCP2]: Nothing much to really add here. As time goes on, I do feel stronger that virtual shouldn't replace f2f, should be an options/mixed available/option. Need to be fully aware of the FULL pros and cons of this for patient and doctors.

***Theme 3: Preferences & considerations for two-way communication***

*There should be many options offered to service users for reaching out to their clinical team but clinics are all very different in the services that they provide. Participants were unsure about how the clinics and staff would keep up with a model that would support two-way communication (e.g. clinicians and service users communicating directly via text messages or emails). Two-way communication could be envisaged for people who may be more vulnerable or need additional support and motivation at particular times.*

*Participants had different preferences with regards to using emails or text messages. Whilst some saw the potential of using mobile applications like WhatsApp, others were concerned about sharing personal health information via third party platforms. Being able to text directly would also cross professional boundaries and raise a number of implications. For example, engagement between service users and clinics would significantly increase; facilitators would need to be brought in to support communication flow; service users’ expectations would have to be managed e.g. in terms of receiving a response within a certain time frame.*

*Some clinics already provide good access to healthcare professionals, as one clinician described:*

*“I think our cohort have every possible way to contact us (some perhaps not all) - but they can have secretarial/booking numbers, with appointments often available on the day with a clinician, walk in service (literally walk in pre covid19), a dedicated mobile phone, and some have their clinicians email address and some find the email for consultant email inbox meant for healthcare professionals and some even call the consultant on call mobile.” [HCP2, Round 2]*

***Do you have any comments on the theme summary, anything else you would like to add?***

[P1]: I think providing helplines, booking appointments and walk in services (if possible) are effective ways currently available. They also maintain professionalism.

[P2]: All good valid points and observations. On the quote, it sounds great but also keep in mind that if contact details are given, any contact made should be responded to. In my experience, being able to contact the clinic reception is excellent whereas having been given the nurse's phone number with the ability to text, although response was immediate in the first couple of weeks, on the rare occasion I've needed information since my text/message left on answering machine has gone ignored. An example being I needed to know my CD4 number where still taken and previously under 500 when purchasing holiday insurance. I ended up having to guess. As I don't tend to know results till 6 months later my only other option would have been a walk in to ask.

[P3]: Two-way communication is good. I feel that this should be tailored according to the patient. I do not think professionalism will be lost by texting your clinician, this only shows how accessible your Consultant is to you.

[P4]: [left blank]

[P5]: The management of two way communication is key; I can envisage some patients getting more stressed/anxious if their texts or emails are not responded to promptly so expectations would need to be managed. Similarly clinicians or their secretaries would need to at least acknowledge each communication to avoid unnecessary follow ups from patients wondering why they had not got a response.

[P6]: I don't myself see it as a worry using 3rd party apps for communication but I can understand some do. Using a patient number instead of name might put some at ease, but then again the phone number is linked to the person so I dont see how they can get around that, unless they have a spec pay as go phone. I just think people has to learn that nothing that is going through digital media is safe from hacking, they just have to realize that who would actually be interested in their medical record (unless you very famous).

[P7]: I don't think we should have 24/7 access to our consultants via sms, whatsapp or facebook. I think a telephone all or an email should suffice. Sort out what other agencies can support clients and REFER to them. I put this in capitals as sometimes it is really hard to get referrals from clinics to third party services. ([name place of care, South East], peer mentoring).

[P8]: Since our clinic has moved people say its harder to make contact especially during covid As peers we have become that communication point in between linking patients with their hcp.

[HCP1]: [N/A]

[HCP3]: Makes sense to me

[HCP4]: Agreed with statement. My team also uses a mobile which clients can text - this works particularly well with younger cohort (18-25 year olds), as few commented they prefer this over calling to book an appt. I do not feel that this increased communication with clinic as boundaries are set from the beginning (i.e. telling clients do call or text our work mobile for this and this purpose, and we are only available to text back 9-5).

[HCP2]: 1) Being offered many options to for service users is private healthcare. 2) Where do you draw boundaries with this. 3) How could you have a safe model to accommodate this. 4) How could a clinician be expected to progress with services, management, audit, quips, academia, education etc etc etc. 5) Are there any other specialities that do this? 6) Does this not potentially add to stigma? 7) If using computers for work, and then a phone for communication would lead to constantly being on a laptop, having your phone ring, beeping with texts. 8) Messages get heavily misinterpreted or limited by characters, over text or email, Talking would be way more efficient (think about typing out what you want to say vs saying it), than text or email. Dialogues over these mediums may then be replied to if clarification needed until a few days and you end as a clinician with half information that might concern you but not nec the patient and all sorts of chaos ensues.

***Theme 4: Asking people about psychosocial wellbeing***

*It is critical for service users to talk about their lifestyle issues openly, and psychosocial wellbeing should be part of the routine consultation whether there is a pandemic or not.*

*It is important for the clinical team members to know information about weight gain, for example, because it can help prevent service users from developing additional conditions (e.g. heart disease) that could put them at risk over the long-term.*

*At the consultation, questions about psychosocial wellbeing can be asked in a different way so that they don’t feel intrusive. Explaining why those questions should be asked is also important. However, it is not always straightforward, as one clinician observed:*

*“Healthcare professionals get a lot of criticism, and I think this pandemic has really given a lot of people an honorary medical degree via the internet (!). So when we ask or want to try and help with a holistic approach we are damned and if we don't we are damned. I know this definitely isn't a one size fits all …” [HCP2, Round 2]*

*To facilitate a holistic approach, questionnaires could be used ahead of a consultation to collect useful information about service users’ wellbeing and lifestyle. This could also help both parties (service users and clinicians) with planning and communication at the consultation.*

***Do you have any comments on the theme summary, anything else you would like to add?***

[P1]: In as much as it is not straight forward to apply holistic approach to everyone, I think questionnaires pre appointment helps to uncover some of the details that the service user might not reveal at the appointment. It also pre empty user's well being that can be vital for the consultation.

[P2]: The pandemic has I think caused a massive change in lifestyle measures for some, whether for better or for worse. Of course it's not all about weight gain - some people have built up muscle mass through resistance exercise, potentially meaning they are healthier than before. However I understand that this will bring it's own challenges for clinicians and care needs to be given in questioning. A questionnaire ahead of the appoint might well prove helpful as it might give more complete information.

[P3]: It is important to discuss your psychological well-being as this can affect your adherence to the drug regime.

[P4]: I haven't personally felt like this, but do see the benefits of gaining this info ahead of consultations.

[P5]: I don't ever remember being asked about psychosocial wellbeing throughout my 30 years of consultations. I was paying to see a therapist for 5 years to deal with a number of issues and my HIV consultant never knew about that because he had never asked. A questionnaire prior to a consultation may be beneficial but it would always depend on the right questions being asked I guess.

[P6]: a pre questionnaire would prob not give an accurate result since many would not consider their problem as a concern. Also i think including to many angles to you HIV clinician would derive from their work. They are there to look after your HIV and HIV related health not being your weight management person or guide you through a drinking problem for ex. That should be referred to specialist branches.

[P7]: I am no longer convinced this will happen. My clinic is moving to once yearly consultant appointments. I don’t think a once a year appt will be able to facilitate any kind of holistic service. So, I have put 10kg on, you wont see me again for another year!

[P8]: Get a peer mentor in the clinic who can act like social prescribers.

[HCP1] [N/A]

[HCP3]: I agree

[HCP4]: Agree with majority of statement. Not sure if checklist/questionnaire set allows for good flow during consult. I ask my patient in conversation style about other areas of their life rather than reading off the screen, I think it feels less rehearsed.

[HCP2]: I think generally we are good at asking about other things. I do it routinely - any physical concerns (and then run through symptoms) or psychological concerns (feeling down etc). Plus we ask about alcohol/drugs/smoking and domestic abuse. If someone questions it I explain it's about a whole approach and while we may not be a mental health specialist we can still advise and signpost.

***Theme 5: Adopting a patient-centred approach***

*Everyone’s journey and struggles are unique. Visual resources or tools could be designed to better support a patient-centred approach, as one clinician imagined:*

*“I think breaking things up, so that different areas in the journey become relevant at different times, but that the patient can see the overall road -map of care, and can access things at different times when needed. For example, can 'unlock' adherence support section only after the patient has started ARVs, or 'unlock' side effects 3 months after starting ARVs. This way it is clear what may be relevant, at what stage. But to remember that you can go back to areas at any point in the health continuum.” [HCP1, Round 2]*

*Participants also highlighted the role of peer support in relation to delivering patient-centred care and empowering people at different stages of their personal journey with HIV. Peer support does not necessarily have to come from someone at the same stage in their journey with HIV.*

*It is not always easy to signpost people to the relevant organisation or services that coincide with where they are on their journey. There are many organisations offering a wide range of services in different parts of the country but outside of major areas, the choice available to service users may be limited.*

***Do you have any comments on the theme summary, anything else you would like to add?***

[P1]: I think support groups or organisations are there to provide guidance on individuals journey there s need for individuals to accept that not everyone has the same journey. They should seek relevant support from professionals when facing some challenges especially when it comes to medication or physical challenges.

[P2]: On the comment, not sure I agree or see the point. eg what would be the point of unlocking side effects of meds 3 months after starting? Perhaps it's the way it's written. Having access to resources that show a journey, on the other hand, may well be helpful - eg this website that has different sections on newly diagnosed, starting treatment, being undetectable, wellbeing etc. https://www.plushealth.org.uk/index.html. On peer support - very relevant as offering this to patients. Knowing that it is there if needed can be so helpful to wellbeing and should be embedded as part of the service that clinics offer in signposting either locally or online. On the last paragraph, there are online services that cover the whole country that can be accessed by anyone eg THT My Community Forum, Positively UK (currently) and Plushealth who offer a range of services that include all stages of our journey. However in person meeting are I agree severely lacking outside the major areas.

[P3]: Everyone's journey is different, thus the need of the patient-centred approach is vital. Peer mentoring help where the patient is still trying to come to terms with their diagnosis or fear stigma and disclosure.

[P4]: I am a peer mentor and offer this via clinics to other patients. Peer support is something that was not offered when I was diagnosed and would have been so beneficial. I had many dark days of depression, anxiety and fear and to have been able to speak to someone that has lived through the same experience would have helped me enormously.

[P5]: As a long term survivor I have not used any peer support services so cannot testify to their benefits; I do know that for me should I ever want to use that sort of service I would want someone at the same stage i.e. another long term survivor. I also think there is a tendency to forget that many patients are not engaged at all with HIV organisations and therefore never get to hear or know about the services they offer.

[P6]: I think a "road map" is great. It gives the person information and support relative to the problem they do have at the time. Often for a newly diagnosed person all the info can be overwhelming and off putting. Also a great collaboration between the clinic and other organisations would build up a network and understanding between the different parties of what "help" and support is available. Many people with problem for ex never get referred to occupational health which prob would be a more beneficial channel then bounced back and forth as often happen.

[P7]: It should be very easy for clinicians to signpost clients. All they need to do is engage with the services on offer in their local area to easily fit the client with the correct service.

[P8]: Peer mentors based in the clinic.

[HCP1]: [N/A]

[HCP3]: I agree

[HCP4]: [left blank]

[HCP2]: I think this could help with the previous question about why we ask what we ask. Agree with peer support aspect BUT there needs to be objectivity and also not be used as a fast track for things, again boundaries.

***Theme 6: Being reassured and informed***

*In relation to trust, privacy and security concerns, healthcare professionals and wider health organisations have the responsibility to reassure and inform service users. For example, information and clear guidance should be communicated about what information is shared and with whom, and how it is intended to benefit the service user.*

*Features could be implemented to help reassure people, for example, a viewable record of who has accessed anything shared, or controlling restrictions on who can access the records. One clinician also commented on ways to address mistrust in online sharing:*

*“Perhaps patients could be in charge of accessing that information with the healthcare professional, or releasing that information. Patients can be advised that this is not shared with GPs, or the wider health community. Patients can protect their information with a password. Clear, accessible details about the encryption of online data, can be explained so that people understand that information sharing is secure, and can only be accessed by the appropriate healthcare professional and patient.” [HCP1, Round 2]*

***Do you have any comments on the theme summary, anything else you would like to add?***

[P1]: I believe that patient information is more secure if kept within the clinician intranet, making it available to authorised personnel only. Patients can be allowed access to their information upon request. I think making it available to the "wide web" can result in information being exposed to hacking and other malicious online activities.

[P2]: I think this is suggesting something similar to patient access or PKB? I'm up for anything where I can access my records online with the facility to share if needed and relevant with other HCPs.

[P3]: Information could be password protected. Sharing information with your GP is important as this helps when you develop other health challenges and they need to prescribe medication.

[P4]: This would be excellent

[P5]: I think a viewable record would be reassuring for patient's who have concerns about who knows what; for me personally as someone who lives openly with HIV I have no worries about information being shared with any other health care provider if it means everyone involved in my care is fully informed; particularly now as I have other health issues being addressed by non HIV consultants.

[P6]: I would have expected this to be in place already, my personal data should not be shared without consent.

[P7]: This is maybe more about procedures than anything else. Patient data is already highly confidential. Its up to the clinicians to follow the strict guidelines already set out by their trusts. What i would like to see is what happens if the procedures are not followed. Its one thing for the systems to be robust, but another thing for staff to adhere to guidelines.

[P8]: I think some people may feel too anxious having a password for themselves as they are very suspicious of the internet.

[HCP1]: [N/A]

[HCP3]: I agree

[HCP4]: [left blank]

[HCP2]: At the end of the day a clinician is not going to share something with someone for the fun of it, and there can only be a benefit. Also, making a big issue of this adds to stigma. In other specialties this isn't an issue. The major difference is stigma. Also, all staff within healthcare are bound by confidentiality.

**Theme 7: Remaining anonymous**

Being able to share personal health data anonymously is important because it gives service users more freedom to share their feelings and experiences. However anonymity can prevent a person from reaching their health potential., It may be harder due to anonymity for healthcare professionals to follow up with service users. This also raised safeguarding concerns, for example: if someone disclosed something worrying then a healthcare professional may be unable to act if they do not have enough information.

A Health Advisor reflected on what anonymity might mean in the context of using digital technology for people to self-report about their mood and wellbeing:

“If there is an app being developed for clients to track their mood and wellbeing, I would be very mindful of ensuring there are some mechanisms there, which ensure safety of our clients.” [HCP4, Round 2]

***Do you have any comments on the theme summary, anything else you would like to add?***

[P1]: I think that although some individuals choose to share their wellbeing and mood anonymously, they can also get help on such platforms without their identity exposed. The moment they give away their anonymity, they might hold back some of the challenges that they may be going through.

[P2]: [left blank]

[P3]: It is difficult to follow up on an anonymous tip. Maybe some kind of safeguarding could be developed to protect the vulnerable. This again could be tailor-made for the patient.

[P4]: While this statement is true, some people would only complete if anonymity was guaranteed.

[P5]: I think 100% anonymity carries an element of risk but if someone needs that reassurance to be able to share honestly then that has to be taken into consideration. Ideally there should be systems built into place to signpost a user to human support systems for example the Samaritans phone number could pop up if someone mentions suicide or suicidal thoughts.

[P6]: I think it would be very hard to reach out and help the person who is anonymous. It would create a much harder work environment for the health care staff to actually get the help through to the person needing it.

[P7]: when a client decides to access health care anonymously, they should be told very clearly how that may impact on the service offered. At the same time, maybe clinic should try and find out why that person wants to be anonymous and refer appropriately. ? Mental health issue, safeguarding, misunderstanding how the information is stored and used?

[P8]: I think it would need some sort of way of raising a flag to ensure safety of patients. But this should be made obvious to users

[HCP1]: [N/A]

[HCP3]: I agree

[HCP4]: [left blank]

[HCP2]: Not sure I understand this. On the note, of the safety of our clients - safety for any patient using it.

**Theme 8: Breaking confidentiality**

Maintaining privacy cannot be 100% guaranteed, therefore service users will always have to weigh up the risks of fully sharing personal information.

Overall, participants were aware that confidentiality can be broken, for safeguarding reasons or for the service user’s best interests. For example, information shared between a clinician and a service user might be acted on within the institution if there are safeguarding concerns, in the service user’s best interests.

One clinician reflected that “breaching confidentiality” does not just happen there is a process where clinicians inform service users first before sharing the information with others in the institution.

It is also common for healthcare professionals to review service users’ information and records in a multidisciplinary team meeting where numerous professionals make decisions based on their expertise and experience for the service users’ wellbeing. One clinician commented on ways to share and present information in the context of staff meetings and in a way that maintains service users’ privacy within the organisation:

“[What is essential to know] could be shared with the wider team, and viewed at such a meeting, but other areas on the record, could automatically be hidden and only accessed with the patient, or by a specific professional, as this may not need to be seen by the wider healthcare team, to make decisions on treatment for example.” [HCP1, Round 2]

***Do you have any comments on the theme summary, anything else you would like to add?***

[P1]: I support that breaking patients confidentiality is justified if the confidentiality is broken for the sake of safeguarding patients interest and when it's done to enable patients with continuity of care.

[P2]: All good valid points and safeguarding is a priority where there are concerns. Thoughtful comments from the clinicians.

[P3]: This comes down to the patient, whether to give the go-ahead for their information to be shared. In the team meetings, patients' names can be replaced by numbers. This can be rather impersonal but it protects the patient.

[P4]: Great idea

[P5]: It probably is worth re-emphasising this with a patient, as and when, they have more people than just their HIV doctor involved in their care. I don't ever remember formally being told it could happen but assumed it would be possible.

[P6]: I find that common sense, also in multi team meeting there is no need for the team to know who the person is more than what is relevant to the case. so keeping a patient confidential would not be a big problem and something i would expect to be in place already.

[P7]: These breaches happen routinely in muti disciplinary meetings where some organisations do understand how confidential some information is. It is not uncommon for me to receive unsecured emails with clients names in the subject line. These come from council departments, the probation service, and the NHS. Some people just cant be bothered to use secure email like Egress.

[P8]: No further comments I like this approach.

[HCP1]: [N/A]

[HCP3]: I agree

[HCP4]: [left blank]

[HCP2]: I think the quote can complicate things to be honest with technology. At the end of the day what would be considered as oversharing? Relevant things shouldn't or wouldn't be discussed? For example if discussing a case about domestic abuse, someone wouldnt need to discuss if they had chlamydia in the past. For example if discussing a case about switching treatment, chlamydia is irrelevant. Just giving random examples here. So again not sure I fully understand but I'm struggling to think what would be SO confidential for another healthcare profession to see that would impact an issue to be discussed that would be of benefit to the patient or someone else that might be affected by the patient. Do no harm is one of the pillars of ethics.

**Final thoughts & feedback: Do you have any further comments or reflections on the statements set out in this round of the survey? Do you have any feedback about your experience of taking in the INTUIT survey?**

[P1]: No

[P2]: I felt comments/quotes seemed weighted more from the clinician's perspective rather than the service users - though this might not have been the case. However on the whole some good points raised with only a couple of things I found ambiguous. It was an interesting, thought provoking survey - the longest I've taken part in, perhaps due to needing to engage my brain more! Many thanks for the Amazon voucher :)

[P3]: I guess there should be a patient-centered approach in the way clinicians deal with patients. There is no fit for all approach that can ever work. This has really been good, it has made me to look subjectively relationship between Clinicians and patients.

[P4]: Thank you for inviting me to take part. I hope my responses have of benefit

[P5]: I have valued the opportunity to see a project develop and to know that I have played a small part in it.

[P6]: been a very interesting study and in depth of some subject. though some questions were hard to answer. otherwise easy to complete and understand. Also easy to follow and understand how to use the form.

[P7]: nothing more to say...thank you for listening. it was very interesting.

[P8]: No apart Ii thoroughly enjoyed this. Was interesting.

[HCP1]: [N/A]

[HCP3]: They seem a fair summary of some points that I made. I appreciated the follow-up emails when I failed to respond - the nudge was much appreciated as I believed this to be a valuable study and the emails sometimes got lost.

[HCP2] Nil. It's been therapeutic in some ways! :)