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## Perspectives of healthcare professionals and people living with HIV in dialogue: on information sharing to improve communication at the consultation

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### ABSTRACT

We report on a qualitative Group Survey study involving four healthcare professionals (HCPs) and eight people living with HIV who were recipients of care in the United Kingdom (UK). The survey aimed to bring participants' perspectives into dialogue and establish consensus about how communication between HCPs delivering HIV care and their patients could be improved in the context of the routine care consultation. Responses from both parties were anonymously collated, thematically analysed, and shared back with participants in two subsequent survey rounds to support consensus-building on matters of concern and identify thematic insights. In this paper, we report three themes for informing future designs of tools and services to support communication between patients and HCPs: Patient-clinician relationship for trusted sharing; Self-reporting psychosocial information to support Whole-person care; and Perceived barriers for online trusted sharing with HCPs. Our findings highlight key areas of concern and further investigation is needed to understand how self-reported information may be meaningfully captured, interpreted and processed by HCPs in ways that are trusted by patients who voice privacy and security concerns.

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### KEYWORDS

Qualitative survey; whole-person care; health data; privacy; security; trust

## Background

Through effective treatment, the Human Immunodeficiency Virus (HIV) has been transformed into a long-term condition (LTC) with normal life expectancy for the majority of people on treatment (May et al., 2014). The focus of HIV care has shifted towards maximising Quality of Life (QoL) in ageing (Lazarus et al., 2016; Kall et al., 2020). A key treatment is Antiretroviral Therapy (ART) that reduces how much virus there is in the body so that people have an undetectable viral load, meaning that they cannot pass the virus to someone else (Pebody, 2020). Most people take one or two tablets a day, but symptoms or side effects are commonly reported because HIV is often managed alongside other health conditions, making it a complex socio-medical context for living and ageing well (International HIV/AIDS Alliance, 2018; Terrence Higgins Trust, 2017). This entails life-long treatment adherence and monitoring with complex health and social care needs (Hasse et al., 2011). In England, most people access primary care with a Generalist Practitioner (GP) for non-HIV-related health and attend an HIV

clinic for routine appointments with a HIV Clinician and Specialist Nurse to monitor their viral load and check how the ART treatment is working (Baylis et al., 2017; Carter, 2020). The long-term management of patients with stable HIV is typically supported by 20–30 min face-to-face routine clinical consultations with an HIV clinician once or twice a year. These consultations are informed by blood test results, biomedical readings at clinic attendance (e.g., blood pressure), and self-reported information from patients communicated verbally during the consultation.

A central concern of UK Government's Five Year Forward View of the National Health Service (NHS) is to address the burden of an ageing population through "Patient-involved care" (NHS, n.d.-a). This has highlighted the role Patient Generated Data (PGData) can play for clinical routine care, which constitutes "any health-related data which are created or collected by patients or designated proxies to address a health concern" (Hewitt et al., 2021, p. 2). Self-reported information like PGData can be used to capture information about medication adherence, pain experience, quality of sleep, physical activity, or lifestyle

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behaviours (i.e., smoking). It has the potential to improve self-management of LTCs, and when shared with healthcare providers it can improve the care received (Brown et al., 2022). However, previous research shows that PGData shared at the consultation present both opportunities and challenges including the risk to disrupt patient-provider communication (West et al., 2018). Most recently, research on Patient Reported Outcomes Measures (PROMs) for HIV shows how PROMs can support self-reporting at the routine consultation, and in turn improve communication with healthcare professionals (HCPs) (Bristowe et al., 2020; Seguiti et al., 2022; Short et al., 2022; Wen et al., 2022) and encourage Patient-involved care (Harding et al., 2022).

However, concerns related to the sharing of self-reported information have been highlighted particularly for people with potentially stigmatising LTCs like HIV (Brown et al., 2022; Claisse et al., 2022; Hewitt et al., 2021). Identified barriers for sharing PGData include trust, security and privacy concerns (Bussone et al., 2020; Ramanathan et al., 2013). These have gained new significance with the COVID-19 pandemic as there has been a significant increase in Telemedicine and mediated communications between patients and HCPs. During and following multiple national lockdowns in response to the pandemic, UK HIV populations were shielding and routine consultations sometimes shifted to remote modes of communication either online or via phone, creating new complexities for care management and, in turn, for broader wellbeing and QoL (BHIVA, 2021; Blandford et al., 2020).

Given the recent changes in service provision and the impetus towards encouraging Patient-involved care through self-reporting information, we contribute further empirical understandings in this space by reporting on the views of both people with HIV and HCPs on sharing personal health information for supporting HIV care. We report on a Group Survey study, which helped us bring into dialogue different perspectives to establish consensus about how communication between HCPs delivering HIV care and their patients could be improved in the context of the routine care consultation.

## Materials and methods

We conducted a Group Survey using the Delphi Technique (Brady, 2015; Hsu & Sandford, 2019) to generate qualitative evidence about challenges related to tele- or online communications between patients and HCPs. This study was part of the INTUIT project (<https://intuitproject.org/>) and conducted as part of a wider research programme, which received ethical approval

from the Health Research Authority Research Ethics Committee (reference 19/YH/0417). The protocol was developed with HIV clinicians and experts in the lived experience of HIV who were project advisory group members, and conducted with a peer researcher employed by the Terrence Higgins Trust – a core project partner.

## Methodology

The Group Survey study was part of the INTUIT project, which takes a qualitative and design-led approach to research for technology innovation. The objective of our study was to bring different perspectives together in dialogue to achieve shared consensus on the subject matter, and to identify how the design of interactive services supported by Internet-enabled and digital tools may be improved to strengthen communication between patients and HCPs. We initially planned to conduct an in-person focus group with both HCPs and people living with HIV, but revised our plan in light of the COVID-19 pandemic. We chose the Delphi technique, which can be adapted for qualitative research with stakeholders who have different expertise on a specific topic (Brady, 2015), for envisioning what could or should be (Hsu & Sandford, 2019). This approach offers anonymity, control feedback and iteration; providing participants with the opportunity to comment on substantial inter-group differences (Fletcher & Marchildon, 2014). In our case, it offered flexibility for engagement as participants were able to engage remotely and asynchronously. This was critical for our participants at the time of this study due to having relatively limited availability: HCPs were under additional pressure working on the COVID-19 front-line, some in Infectious Diseases; some charity representatives needed to navigate staff members being on the UK Furlough scheme; some participants were shielding from the pandemic or managing COVID-19 infection. The Delphi technique is also found to facilitate the sharing of views or experiences in an ethically safe way, “without the fear of responses being impacted by unequal power dynamics, in-person group think, difference in social identities and values, or past history with one another” (Brady, 2015, p. 3). This fitted well our research context whereby power relationships between patients and HCPs may have influenced participation.

## Methods and recruitment

The Group Survey was administrated by a REDCap secure web application, through three rounds of data collection between November 2020 and February 2021. Administration of Rounds 2 and 3 of the survey were

**Table 1.** HCPs demographic information.

Role	Participant ID	Gender
HIV and Sexual Health Speciality Registrar	HCP1	Female
Consultant HIV Physician	HCP2	Female
Clinical Psychologist	HCP3	Male
Sexual Health Adviser	HCP4	Female

further delayed due to the second and third waves of COVID-19, and were completed in May 2021. In total, 12 participants took part: Four HCPs and eight people living with HIV. HCPs participants were recruited through a professional network: one HIV and Sexual Health Speciality Registrar, one Consultant HIV Physician, one Clinical Psychologist and one Sexual Health Adviser who worked in the NHS as part of a multi-disciplinary team based in a Sexual Health Clinic (Table 1).

Eight people living with HIV were recruited through a national HIV advocates network. A purposive sampling strategy was used for selecting participants aiming to represent a diverse range of demographics and experiences: Five participants identified as Female, three as Male, and three as Gay or Lesbian and five as Heterosexual or Straight. Seven were diagnosed with HIV between 2002 and 2017 and one participant was diagnosed pre-treatment in 1991. Six participants reported seeing their HIV doctor every 6 months and two of them once a year. Other characteristics are presented in Table 2. All participants with lived experience received a £20 shopping voucher for their contribution to the survey.

### Analysis

Our adaptation of the Delphi technique was highly qualitative (Brady, 2015). Responses from both parties were anonymously collated, thematically analysed (Clarke & Braun, 2021), and shared back with participants in subsequent rounds to support consensus-building on matters of concern, and to further consolidate thematic insights.

**Table 2.** Demographic information for participants with lived experience.

Participant	Age	Gender	Ethnicity	Location
P1	33	Female	Black/African/Caribbean/ Black British	East of England
P2	60	Female	White British	East Yorkshire
P3	58	Female	Black/African/Caribbean/ Black British	East of England
P4	47	Male	White British	West Midlands
P5	51	Female	White British	Central London
P6	48	Male	White Other (European)	South West
P7	64	Male	White British	South East
P8	53	Female	White British	South West

The structure for the three-round Group Survey was organised as follows: In Round 1, participants were invited to answer eight open questions informed by our background work and main research questions. Our initial questions covered the following topics: experiences and potential barriers for sharing health information with HIV HCPs; sharing health information during the COVID-19 pandemic; understanding of concepts of Trust, Identity, Privacy and Security (TIPS) for sharing health information online with HCPs, and the types of information (i.e., data) that are valued for supporting HIV care and self-management. Data were extracted from the survey into a Word document and coded by the first author to identify common views and differences in participants' responses to the questions. The document was then shared with the second and third authors who commented on the codes. Thematic clusters of participants' responses were then organised into a new document and a round-table between the three authors informed the development of eight provisional sub-themes. Then, the lead author worked closely with the peer researcher (second author) to develop a summary for each sub-theme, which was then shared in Round 2 of the survey, together with selected quotes and new questions for participants to further contribute. The sub-themes generated in Round 1 were refined based on participants' responses in Round 2. In the last round (Round 3), refined summaries of the themes were shared with participants for capturing any additional comments and final thoughts. Following Round 3, the sub-themes were further critically reflected upon by the three authors, refined, and consolidated into three overarching themes: *Patient-clinician relationship for trusted sharing*; *Self-reporting psychosocial information for supporting Whole-person care*, and *Perceived barriers for online trusted sharing*.

### Results

#### *Patient-clinician relationship for trusted sharing*

Both parties agreed on the value of seeing the same clinician over time, for building relationships of trust and confidence, and for providing continuity of care. Seeing the same clinician was perceived as increasing patients' confidence and encouraging them to share personal health information more openly: "I believe that it [seeing the same person] also makes the patient confident to share unfiltered information about their health worries or changes to their health and wellbeing" (P1). Participants also commented on the process of building a relationship with their clinicians in terms of establishing

“some kind of rapport” (P3) and building a “professional friendship” (P4). HCPs participants added that seeing the same person over time could also help with managing complex physical, psychological and social health issues; by helping clinicians gauge symptoms and proactively follow up with patients, making the consultation “easier, quicker, more efficient” (HCP2).

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. (HCP1)

We also gained nuanced understandings about the patient-clinician relationship whereby feeling comfortable about sharing health information with a clinician was more complex than just seeing the same person over time. Patients and clinicians may have differences of opinion, and seeing the same person overtime and building that “professional friendship” (P4) can also make patients feel uncomfortable and reluctant to share some more personal or intimate information. HCP participants reported that patients would sometimes feel embarrassed to discuss their sexual health. Having the option to see someone that patients feel less acquainted with was important; “as people can disclose things if they feel non-judged, without a pressure, of having to see this clinician again” (HCP2). Whilst not all participants could relate to this, they empathised with each other’s experiences and agreed that patients should always have the option of seeing someone else. Participants also highlighted the recent changes in care provision and questioned the ability to build that long-term relationship:

I wonder whether now with sixth-monthly appointments appearing to be the norm whether any useful long-term relationship can be built up between patient and consultant... I worry that people being diagnosed today may not have that opportunity with less contact. (P5)

### **Changes in care provision**

In Round 1, participants were asked to describe any changes related to care provision since the COVID-19 pandemic. Participants with lived experience shared their concerns about attending remote consultations with clinicians; “Telling somebody and talking about your health is so different then it floating around in some cloud” (P8). Tele-communications (online or by phone) were found to be impersonal, making it a lot harder to build a relationship, especially if meeting a clinician for the first time. It was agreed that face-to-

face consultation should always be available, particularly for people who were identified as vulnerable (e.g., newly diagnosed); “I think services (especially HIV) should make space to see patients face-to-face, even during the pandemic” (HCP4). HCP2 further emphasised her concerns in the last round: “As time goes on, I do feel stronger that virtual shouldn’t replace face-to-face, [there] should be mixed available options. [We] need to be fully aware of the FULL pros and cons of this for patients and doctors”.

In subsequent rounds, participants were prompted to suggest ways to facilitate remote communication. Suggestions included the potential of video calls for supporting real-time feedback and visual cues; allocating more time for remote consultations because it takes longer to “warm up” the conversation when consultations are held remotely; and finally, the importance of listening and making sure that questions could be asked on both sides. One HCP participant expanded on this:

Using telephone calls to ask about general wellbeing, and activities, chatting less clinically and more “humanly”, [...] (s)howing 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 your patients, at a time when people are feeling isolated and disconnected from the community. (HCP1)

### **Self-reporting psychosocial information for supporting whole-person care**

Consensus was established on the value of sharing psychosocial information (i.e., mood, social histories) with HIV HCPs to support Whole-person care. Sharing information about mood, diet, sleep patterns and social histories was seen as necessary to help the clinical team members better understand what patients are dealing with and to provide them with “the right care” (P8). From all HCPs’ perspectives, asking patients about their lifestyle was critical for providing holistic care:

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. (HCP4)

Asking about psychosocial wellbeing was found even more important during the COVID-19 pandemic as the consecutive lockdowns critically impacted people’s wellbeing and routines with consequences for health



self-management. Changes in lifestyle were reported by participants such as “an increase in alcohol consumption and consequently some weight gain” (P4). Four participants also observed how the lockdown disrupted their routines, which impacted their medication adherence: “my self-care slipped. I did start being less adherent to my medication ...” (P8).

In relation to delivering Whole-person care, participants highlighted the role that HCPs have in signposting patients to peer support resources. In the context of the consultation, peer-based information and resources for physical, mental and social wellbeing was found critical to support self-management particularly as patients are seen less frequently:

Signposting to online peer support and other services offered by trusted charities and organisations given to all. This 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. (P2)

Three participants observed that there is already a large amount of peer resources available to support people at every stage of their journey; however, P5 raised a question: “I wonder how knowledgeable clinicians in some parts of the country are about services that patients can be signposted to”. Overall, there was consensus that health organisations could work more closely with HIV charities, particularly outside of the big cities so that everyone gets to hear about additional support. In the last round, P5 re-emphasised: “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”.

### **Supporting communication of psychosocial information at the consultation**

Barriers for sharing psychosocial information were also reported. Participants with lived experience of HIV described feelings of embarrassment and their fear of being judged; cultural differences, self-stigma, and mental health issues, which could prevent patients from sharing personal information with their clinicians. It seems that these feelings gained new significance during the pandemic as sharing was found to be more difficult when mediated and remote. Three participants also observed that they were less likely to share information because they did not want to add more pressure on NHS staff; for example, P5 commented:

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-19 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 Round 2, participants were asked about their views on how patients could be supported with self-reporting about their wellbeing (i.e., mood, sleep). The use of questionnaires was suggested by four participants to support monitoring and self-assessment of health and wellbeing, and also to support planning and communication at the routine clinical consultation. In Round 3, participants were invited to further comment on the use of questionnaires for facilitating planning and communication at the consultation. Four participants saw the benefits of using a questionnaire ahead of the consultation as it could help provide “more complete information” (P2) and “uncover some of the details that the service user might not reveal at the appointment” (P1) – however, it would depend on “the right questions being asked” (P4). HCP participants expressed mixed feelings towards the use of questionnaires. HCP2 highlighted the value of having dialogue with patients, and HCP4 was concerned it would disrupt communication flow at the consultation and added: “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”.

### **Perceived barriers to online trusted sharing**

In Round 1, we asked participants about trust-related barriers for people with HIV to share personal information online with HCPs. The main barriers that participants reported were associated with the security of online platforms; “patients don’t feel services are competent to securely process and store their information” (HCP3). In relation to this, participants described the risk for information “being hacked or leaked to the public or unauthorised organisations” (P1), and falling “into the wrong hands [...] and being published for the world to see” (P3). Both parties commented on how those concerns may be exacerbated by the awareness of data breaches published in the media, the lack of familiarity with digital technologies and previous negative experiences like cyberbullying, which may make people reluctant to share information online.

Participants described psychological barriers like thinking about how the information is handled and shared “on the other end” (P2), and “the inability to control who has access to online information” (P5). This connects to issues around the transparency of the system and “not knowing who else is going to see that information” (P3); “other than the healthcare professional it is aimed at” (HCP1). Participants with HIV were unsure how private their shared information would remain within the wider health organisation:

confidential information could be accessed by the “wrong staff” (P5) or shared across departments and during multi-disciplinary team meetings with people from outside of the organisation (i.e., social worker). This was further unpacked in Round 2 where participants expressed contrasting views regarding confidentiality: Sharing information about a patient across the whole healthcare team was an “assumed opt in” for P5 whilst P1 and P2 expected permission to be asked. Overall, there was a consensus that confidentiality could be broken for safeguarding reasons or for people’s best interest but this should be clearly explained to patients beforehand:

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. (P5)

### Addressing concerns for online sharing

In Rounds 2 and 3, participants were asked about what could be implemented to reassure patients about online sharing with HCPs. There was a consensus across both parties that information and clear guidance should be communicated about what data including PGData is shared and with whom, and how it is intended to benefit the patient. Participating HCPs highlighted the importance to reassure and inform patients, particularly in the context of HIV care, which requires the expertise of various specialists and therefore sharing information across departments. All HCPs commented on the need to address stigma and to raise awareness in non-HIV healthcare settings; a greater awareness of the Undetectable = Untransmittable (U = U) campaign is need but until then, the sharing of HIV status should be done “very, very carefully” (HCP3). Two other HCPs also commented that education should be considered as a two-way practice; “Educating patients on why communication is needed to other healthcare professionals, and educating healthcare professionals and others in the healthcare environment about HIV” (HCP2), “changing all these messages about stigma around HIV, will give people more confidence in sharing their information with the wider health community if necessary” (HCP1).

Other suggestions for leveraging trust barriers included restricting access to patients’ information on a “need-to-know” basis (P4); having a “viewable record” (P2) of who has accessed the information, encryption of

shared information and password-protected features. It was also suggested for patients to have more control on their shared information. The majority of participants positively commented on those suggestions but concerns around security of the wider system were re-emphasised by most participants in Round 3.

## Discussion

Our findings show the value for patients to see the same clinician over time to support relationship building, which can in turn support self-reporting and overall communication at the routine clinical consultation. This also helps ensure continuity of care, which is critical for the management of LTCs like HIV. In England, HIV care has a track record of clinical outcomes (Baylis et al., 2017); however, participants observed how recent changes in care provision may hinder health outcomes, preventing patients from building that critical relationship with their clinical team members. Indeed, current UK models of care provision do not, arguably, reflect the complex and long-term nature of HIV care. Reports have described the health system as fragmented and not supporting the need for integrated and coordinated care (Baylis et al., 2017; NAT, 2020). HIV clinics are no longer funded to coordinate non-HIV care (Baylis et al., 2017), which arguably makes it challenging to deliver Whole-person care. This is problematic as poor coordination of services can significantly impact people’s engagement in care and prevent from Patient-involved care (NAT, 2020). Recent recommendations include moving towards a place-based approach and for clinics to link in with peer support organisations to help self-management of HIV and broader health (Baylis et al., 2017).

Further to this is the impact of the COVID-19 pandemic on routine care (BHIVA, 2021; Blandford et al., 2020), and the move towards the digitisation of service provision (NHS, n.d.-b), which have encouraged more remote communications between patients and healthcare providers. Findings from our survey evidence the challenges for self-reporting and communicating with HCPs remotely, and highlight the need for further investigations to understand the opportunities but also the barriers of remote and virtual modes of communication for delivering person-centred care. Responses from participating HCPs echo a recent commentary that highlights the human and relational qualities of care provision (Blandford et al., 2020), and whilst digital and online technologies may offer new opportunities, telepresence will never be the same as seeing patients in-person for coordinating Whole-person care (Samuel, 2020). In addition, people living with stigmatising

health conditions like HIV have unique TIPS-related needs and concerns with regards to using online and digital technologies for self-management (Bussone et al., 2020; Ramanathan et al., 2013). Sharing self-reported personal health information digitally and online amplifies such concerns, demonstrating the need for robust systems to protect personal health data. In the context of sharing with HCPs, we found that people were concerned about how private their personal information would remain within the broader health organisation. Previous research shows that people with HIV may feel less comfortable sharing self-reported information with non-HIV HCPs like their GPs (Carter, 2020; Claisse et al., 2022). HIV as a LTC remains misunderstood and stigmatised in society and the healthcare setting is not an exception (Hedge et al., 2021). Currently, patients in the UK are offered exceptional confidentiality meaning that HIV clinicians do not share patients' HIV-related information with GPs without patients' informed consent. However, recent debates have questioned how this may further challenge the provision of integrated and coordinated care (Cairns, 2023), demonstrating the need to further investigate how best to navigate the disclosure of sensitive information across health settings and organisations.

Finally, it is widely acknowledged that good care provided at the consultation should go beyond focusing on viral suppression whereby clinicians ask patients about other aspects of their life apart from their health. Findings from our survey illuminate the value of capturing psychosocial information as part of the routine care consultation and this was found even more important during the pandemic as participants described significant changes in their daily routine. However, barriers for sharing such information were highlighted and participants suggested the use of questionnaires for facilitating patient-HCP planning and communication at the consultation. Here we highlight a design opportunity for developing appropriate tools and communicative mechanisms for collecting and processing PGData to contribute to routine HIV care management. We connect to HIV research that evidences the value of using PROMs for improving patient-provider communication (Seguiti et al., 2022; Short et al., 2022; Wen et al., 2022) and Patient-involved care (Harding et al., 2022). Recent innovation in this space includes digitally-administered PROMs showing the potential for digital technology to improve efficiency, engagement and customisation of self-reporting tools like PROMs (Churruca et al., 2021; Short et al., 2022). Priorities for future work include exploring the development of digital tools for PROMs (Harding et al.,

2022) and considering the increasing growth of Artificial Intelligence (AI) health technology incorporating PROMs (Pearce et al., 1997), and what this may afford for developing and administering PROMs as part of routine HIV care.

## Conclusion

We contribute empirical insights from a Group Survey study whereby we captured the views of HCPs who deliver HIV care and people living with HIV on the sharing of personal health information for supporting care provision. We have highlighted key areas of concerns and further investigations needed for designing appropriate tools and communicative mechanisms for collecting and processing PGData to contribute to routine HIV care management. UK models of care provision are rapidly changing and this may have a significant impact on the trusted sharing of information between HIV HCPs and their patients. Whilst the sharing of psychosocial information by patients is found valuable for Patient-involved and Whole-person care, more research is needed to investigate how this information may be meaningfully captured, interpreted and processed by HCPs in ways that are trusted by patients who voice TIPS concerns and for whom the process of sharing can be burdensome.

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## Disclosure statement

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