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# BMJ Open Measuring the prevalence of autistic traits in a cohort of adults living with HIV or taking HIV pre-exposure prophylaxis and mapping safer-sex barriers and facilitators: a study protocol

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## ABSTRACT

**Introduction** Autistic individuals identify with a wider range of sexual orientations than non-autistic individuals, including higher rates of bisexual orientation in autistic men. Gay, bisexual and other men who have sex with men are at greater risk for HIV. Prevalence data of autistic traits in people living with HIV or using Pre-Exposure Prophylaxis (PrEP) for HIV are lacking so far. Such data, combined with insights in barriers and facilitators for safer sex in autistic people living with HIV or using PrEP, are a first step to improve health support for autistic people in HIV clinics. This support is crucial since autistic individuals have worse physical and mental health outcomes. The objective of this research is to determine the prevalence of autistic traits within the group of people living with HIV or using PrEP in Belgium and to describe specific facilitators and barriers for sexual safer behaviour in people living with HIV and PrEP users with autistic traits.

**Methods and analysis** The research is a cross-sectional, observational and multicentre study with recruitment of individual participants. The research consists of two phases. In phase 1, adults coming for HIV/AIDS care or HIV PrEP in participating Belgian HIV Reference Centres will be invited to fill in the validated Autism Spectrum Quotient questionnaire. In phase 2, participants with a score above the predefined cut-off for autistic traits (>26), who agreed to be informed about this score, will be invited to complete an additional survey, inquiring facilitators and barriers for sexual safer behaviour.

**Ethics and dissemination of results** Institutional Review Board Institute of Tropical Medicine Antwerp, 25 July 2022, REF 1601/22 and University Hospital of Antwerp, 12 September 2022, Project ID 3679: BUN B3002022000111. Study results will be published in peer-reviewed journals and presented to Belgian HIV Reference Centres and at conferences.

## INTRODUCTION

Autism is described as a neurodevelopmental condition with ‘persistent challenges in communication and social interaction across multiple contexts’, and ‘restricted,

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Data collection about autistic traits in people living with HIV and Pre-Exposure Prophylaxis (PrEP) users is unprecedented and might create awareness.
- ⇒ Focuses on an ‘invisible’ group in HIV clinics, with an elevated likelihood for mental health problems.
- ⇒ Maps specific safer-sex barriers and facilitators in people living with HIV and PrEP users with autistic traits.
- ⇒ Participation bias cannot be excluded.
- ⇒ Autism screening tool is used as a proxy for clinical diagnosis.

repetitive behaviour, interests or activities’, with early childhood onset.<sup>1</sup> Hyperreactivity or hyporeactivity to sensory input may be present.<sup>2–3</sup> In this article, both identity-first language (autistic person) and person-first language (person with autism) will be used to comply with the different language preferences of the autism community.<sup>4–6</sup>

Global autism prevalence is estimated at 1%<sup>7</sup> and has been rising over the past decades.<sup>8</sup> This can largely be attributed to an increasing autism awareness and a broadening of the diagnostic criteria, introducing the concept of ‘autism spectrum’.<sup>9–12</sup> Also, specialised professionals are now trained to recognise more subtle manifestations of autism.<sup>10</sup>

Despite this awareness and broadened diagnostic criteria, autism in adults often remains undiagnosed.<sup>13–15</sup> Indeed, nowadays’ adults grew up in times with lower awareness and more narrow diagnostic criteria. Also, obtaining a developmental history—crucial in diagnostics—in adults is challenging, with adults’ caregivers being deceased or having only vague memories of the adults’

childhood.<sup>13 14</sup> Furthermore, autistic individuals without intellectual disability often develop social compensating skills, making them appear non-autistic for unexperienced observers (including many health professionals).<sup>16–18</sup> Finally, diagnostic overshadowing of autism by co-occurring mental health conditions is a major obstacle.<sup>19</sup> Mental health problems occur more frequently in people with autism than in the general population, with reported prevalences of 20% for anxiety disorders and 11% for depressive disorders in autism.<sup>13 19–22</sup> Often, only these co-occurring problems capture the health worker (HW)'s attention, while the underlying autism is missed.

The considerable likelihood of undiagnosed autism in adults leads to missed opportunities to increase quality of life. Indeed, many late-diagnosed adults describe the postdiagnosis era as a shift from being self-critical to self-compassionate, with a better appreciation of individual needs<sup>23 24</sup> and better access to specific care,<sup>25</sup> all improving quality of life.

Given the potential positive aspects of receiving a diagnosis,<sup>24 26</sup> vigilance for undiagnosed autism in adults is needed. In the context of HIV clinics, this vigilance is challenging. A long-standing yet incorrect perception that autistic individuals are uninterested in sexual relationships, and thus less at risk for HIV, can negatively affect autism awareness.<sup>27</sup> Moreover, numerous people living with HIV suffer from depression and anxiety<sup>28–34</sup> and, intuitively, HWs might consider the person's HIV status as the predominant or unique cause of these mental health conditions, thereby overlooking an underlying autism as an alternative or complementary cause.

Though autism remains greatly hidden in adult HIV clinics, we hypothesise that the prevalence of autism within the population of people living with HIV and users of HIV Pre-Exposure Prophylaxis (PrEP) is similar to, or even slightly higher than the prevalence in the general population. First, most autistic individuals report having been sexually active.<sup>27 35–37</sup> Additionally, autistic individuals identify with a wider range of sexual orientations than non-autistic individuals, including higher rates of bisexual orientation in autistic men.<sup>27</sup> Gay, bisexual and other men who have sex with men (GBMSM) are at greater risk for HIV.<sup>38 39</sup> Furthermore, the elevated rates of sexual victimisation described in autistic individuals<sup>40–43</sup> might be associated with sexual risk behaviour later in life.<sup>44–47</sup> Besides the above-mentioned theoretical arguments supporting our hypothesis regarding the autism prevalence in people living with HIV and PrEP users, little published data support or contradict this hypothesis, since within the group of people with autism, both sexually transmitted infections (STI) rates higher,<sup>48</sup> similar or lower<sup>27 49</sup> than in the general population have been reported.

Although autism prevalence data in HIV clinics are missing to date, such data are useful to demonstrate the number of people living with HIV or using PrEP that could benefit from autism-friendly support. Such support is imperative to tackle the manifestly poorer outcomes

in physical and mental health in autistic individuals compared with their non-autistic peers.<sup>15 19–21 50–58</sup> These poor health outcomes cannot be explained by social and biological factors alone; the lack of autism-friendly healthcare plays a crucial role.<sup>20</sup>

To tackle the health disparities, guidance on installing autism-friendly healthcare has been issued,<sup>15 59</sup> but despite these recommendations, we remain at loss when it comes to autism-friendly sexual health provision.<sup>60</sup> One of the aspects of sexual healthcare with a particularly profound knowledge gap is safer-sex counselling, which promotes the ability to have sexual experiences with a minimal risk for (recurrent) STI or sexual victimisation.<sup>59–61</sup>

Safer-sex counselling is an integral component of care offered to people living with HIV and PrEP users and strongly considers specific safer-sex barriers (SSB) of the counselled individual. Several theoretical arguments generate the hypothesis that SSB in autistic individuals differ from SSB observed in their non-autistic peers. First, communication about intentions, sexual boundaries and safer-sex wishes is a corner stone of sexual safety,<sup>62</sup> yet communication might be challenging in autism.<sup>1</sup> These challenges may be even more pronounced in the sexual context, where an indirect communication style is often used, and where knowledge of how to negotiate conflicting sexual wishes (eg, about safety) is crucial.<sup>63</sup> Additionally, a lack of autism-friendly sexual education may lead to a lower actual knowledge on sexual risks,<sup>40</sup> thus increasing vulnerability for non-consensual sex. Furthermore, challenges in impulse control observed in certain autistic individuals<sup>64</sup> may increase the frequency of health-related unsafe behaviours.<sup>48</sup> Finally, the difficulties in the ability to monitor one's own internal states sometimes observed in autism<sup>65</sup> may lead to unclear perceptions of own sexual boundaries, making some autistic individuals an easy-to-convince person for partners seeking hazardous types of sex.

Currently, publications concerning specific SSB in autism are scarce, however<sup>40 48 66</sup> and many questions remain unanswered. For example, unpublished work with 10 autistic people living with HIV (*Huyst, Sexual Risk Behaviour in Autistic Patients in follow-up in the HIV clinic*), showed that the majority mentioned using sexual contacts (obtained through dating apps) as a remedy against loneliness, and declared to be reluctant to demand safer-sex measures in that specific situation, by fear of scaring off potential dating partners. An answer to the question of how frequent such an SSB is in larger groups of autistic people living with HIV or using PrEP cannot be found in published research so far. Additionally, participants of the sparse publications about SSB often differ in age, sexual orientation or IQ from Belgian people living with HIV or using PrEP, who are often above 50 years old, identify as GBMSM and do not have an intellectual disability.<sup>67</sup> More research regarding sexuality counselling for autistic individuals in HIV clinics is therefore urgently needed.<sup>59 61</sup>

Considering the knowledge gap on how and on which scale to provide autism-friendly safer-sex counselling in

HIV clinics, this research aims to obtain data on prevalence of autistic traits in HIV clinics and on SSB in people living with HIV or using PrEP with autistic traits.

## STUDY AIMS

The primary aim is to determine the prevalence of autistic traits among people living with HIV and PrEP users in Belgian HIV clinics. Secondary objectives are (1) to describe sociodemographic characteristics of people living with HIV and PrEP users with and without autistic traits; (2) to describe facilitators and barriers for sexual safer behaviour in people living with HIV and PrEP users with autistic traits.

## METHODS AND ANALYSIS

### Participant and public involvement

The study protocol and the SSB questionnaires were reviewed for input by autistic adults (both individuals and autism advocacy groups).

### Study sites

The study will be conducted in Belgian HIV clinics, which are termed HIV Reference Centres (HRCs). Belgium has one HRC (plus satellite sites) in each of its 10 provinces. The study was initiated by researchers from the Institute of Tropical Medicine (ITM), the HRC of the Antwerp Province. Other HRCs will be invited to participate. The HRC's mission is to keep people living with HIV, or people with substantial risks of acquiring HIV, in an optimal medical and psychological condition. HRC teams provide medication to prevent or treat HIV and associated diseases, support adherence to treatment and monitor the occurrence of treatment side effects. HRC teams consist of medical doctors, psychologists, dietitians, sexologists, and nurses.

### Study design and timetable

The study consists of two phases and will run from November 2022 till November 2023. Information will be presented per phase.

#### Phase 1

Phase 1 aims to determine the prevalence of autistic traits among people living with HIV and PrEP users in Belgian HRCs and is a cross-sectional, observational, multicentre study, with recruitment of individual participants. Sociodemographic characteristics of people living with HIV and PrEP users with and without autistic traits will be determined.

#### Participants

People living with HIV and PrEP users coming to participating HRCs in the study period are eligible to participate. Individuals below 18-years-old and persons not understanding Dutch, English, French or Spanish are ineligible. Intellectually disabled adults under guardianship

are ineligible as well, and so are individuals with a noticeable alcohol or drugs intoxication.

In October 2022, ITM's HRC had 4798 persons in active follow-up (HIV=3127, PrEP=1671). All Belgian HRCs combined had—according to national data available at the time of protocol design—21 001 individuals in follow-up in HRC, of which 17 018 for HIV treatment and 3983 for PrEP.<sup>67</sup> More recent data show that 22 899 individuals are in follow-up in HRCs (HIV=17 622, PrEP=5277).<sup>68</sup>

### Sample size

A prevalence of 3% was used to determine the sample size. Several reasons for choosing a prevalence higher than the global prevalence of 1%<sup>7</sup> can be put forward. First, the currently accepted male-to-female sex ratio for autism is 4.2:1,<sup>7</sup> and most individuals in follow-up in Belgian HRC are men (66% of people living with HIV, 99% of PrEP users).<sup>68</sup> Second, the wider range of sexual orientations observed in autism<sup>27</sup> could increase the risk for HIV.<sup>38 39</sup> Third, high rates of sexual victimisation<sup>40–42</sup> reported by autistic people could increase risks for acquiring STI.<sup>44–47</sup>

We chose a precision of 1% in the CI. The sample size was calculated using the formula  $n = z_{\alpha/2}^2 \frac{p(1-p)}{d^2}$ , where  $p$  is the expected prevalence of 3% and  $d$  is the precision of the CI (1%). The final sample size was adjusted for the total population available. A sample size of 1059 persons was calculated.

### Procedure

Staff of participating HRCs will join a research information session. Besides background and practical information, the management of research-induced emotional stress in participants will be discussed.

HRC receptionists or HWs will then briefly introduce the study to all eligible adults coming for HIV-treatment or PrEP-related consultations. They will explain that individuals are invited—on a voluntary basis—to participate in a scientific study by filling in a questionnaire, which is expected to take about 15 min. They will then provide the envelope to the person—unless the person refuses or declares prior participation in this study—and mention that all study information can be found in the envelope. HWs will respond to basic study-related questions, but will contact the investigator if more in-depth information is required. Illiterate people will be able to ask nurses to read and explain the documents.

The envelope will contain an information leaflet, informed consent form (ICF) and autism screening questionnaire (in Dutch, French, English or Spanish). The information leaflet mentions that participation is voluntary and a decision not to participate will not impact on attendance at the HRC. To prevent potential participation bias, the leaflet states the usefulness of participating even if one is sure of not having autistic traits. Participants will be able to fill in their phone number if they want to be informed in case their questionnaire results suggest the presence of autistic traits. All documents describe



risks and benefits of being informed of these results. Also, it is mentioned that an autism screening does not equal a formal autism diagnosis and that participants may be autistic even if the screening is not suggestive and may not be autistic even if the screening is suggestive for autism.

Participants will be able to complete documents on paper or online, accessed through a QR-code included in the information package. Individuals choosing participation on paper will be able to fill in ICF and questionnaire immediately and give the closed envelope to the HRC receptionist or HW, who will store it in a locked box. People choosing to fill in the documents at home, will receive a prepaid envelope and send back the documents later. Individuals preferring digital participation will use their own electronic device to fill in ICF and questionnaire. Participants will be allowed to withdraw from study participation at any moment.

Phase 1 is expected to take at least 8 months (or longer, depending on the start of inclusion in other HRC). This should give the opportunity to approach all people in active follow-up since most people living with HIV have 6-monthly consultations, but some postpone consultations.

### Measures

Cost, waiting lists and the need for multiple visits with a specialised team, make the commonly used diagnostic path unsuitable for screening large groups for autistic traits. A screening tool, the Autism Spectrum Quotient (AQ) questionnaire will therefore be used. The AQ assesses the degree to which an adult without intellectual disability has autistic traits.<sup>69</sup> It has been validated in several languages,<sup>69</sup> including the languages used in this study. The AQ consists of 50 statements, assessing social skills, attention switching, attention to detail, communication and imagination. Participants indicate to which extent they agree or disagree with the statements on a 4-point Likert scale.

The ideal cut-off to obtain a good discriminative validity and good screening properties with the AQ lies between 26<sup>70</sup> and 32.<sup>69</sup> The sensitivity for a cut-off of 32 is 0.79, and the specificity is 0.98<sup>69</sup> in a setting where individuals with autism in the strictest sense are compared with a non-autistic group without any other diagnoses. Yet, when the same cut-off of 32 is used in clinical practice, where differentiating between individuals from the broader autism spectrum and individuals with psychiatric conditions whose manifestations can overlap with autism is needed, the sensitivity decreases to 0.41, with a specificity of 0.90.<sup>71</sup> When a cut-off of 26 is used in clinical practice settings, sensitivity is 0.76 and specificity 0.72.<sup>71</sup> Using the AQ with a cut-off of 26 is thus a valid option for screening large groups for autism in clinical practice.

Individuals already having an official autism diagnosis, established by certified specialised teams, will be able to indicate this in the questionnaire. Such participants will be counted as autistic, whatever the AQ score is, since the

sensitivity of the AQ is lower than the sensitivity of a full diagnostic investigation.

A minimal number of questions about sociodemographic factors will be joined to the AQ (see electronic annex 1) such as age, sex, sexual orientation and reason for follow-up in the HIV clinic (PrEP or HIV-positivity).

### Data management

Data will be collected through Research Electronic Data Capture (Redcap, [redcap.vanderbilt.edu/consortium/library/search.php](http://redcap.vanderbilt.edu/consortium/library/search.php)), a secure web application for building and managing online surveys and databases (compliant with Good Clinical Practice and GDPR). Scores will be generated automatically. Data collected on paper will be transferred to Redcap by research collaborators.

Questionnaires will be pseudonymised. Only participants wanting to be informed about an AQ score above the cut-off will fill in their phone number. After telephone contact about the score, the direct identifiers will be removed from the questionnaire.

Data will be stored and archived in a secure and appropriate location for 20 years.

### Data analysis plan

The percentage of respondents with either a score above 26 on the AQ questionnaire or with a reliable self-reported autism diagnosis will be calculated for the PrEP group, the group of people living with HIV and both groups combined. Additionally, the proportion of participants with a score above 32 will be determined.

Incomplete AQ questionnaires will be excluded.

Comparisons of sociodemographic factors (eg, sexual orientation) between groups of interest (with and without autistic traits) will be made whenever possible using the Mann Whitney U test for continuous characteristics and the  $\chi^2$  or Fisher's exact test for categorical characteristics.

Software used will be R.

### Phase 2

Phase 2 aims to describe facilitators and barriers for sexual safer behaviour in people living with HIV and PrEP users with autistic traits and will have a cross-sectional, observational, multicentre design, with recruitment of individual participants.

### Participants

Recruitment will occur in the group of people living with HIV and PrEP users in Belgian HRCs, who: (1) participated in phase 1, and (2) had a score above 26 or a reliable reported diagnosis of autism and (3) formally agreed (during phase 1) to be contacted.

### Sample size

If 3% of the sampled 1059 individuals (or 31 persons) score above the cut-off of 26, we would expect half of them (approximately 15 persons) to agree to participate in phase 2.

## Procedure

Participants scoring above the cut-off of 26, who consented to be notified about the result, will receive a brief explanation about study phase 2.

Participants willing to learn more about phase 2 will be asked to provide their e-mail address so that the investigator can send a QR code and web link giving access to: (1) an information section; (2) a new ICF and (3) a questionnaire about safer-sex facilitators and barriers (electronic annex 2), in the desired language. Participants will also be able to choose to receive the documents by regular mail. The investigator will ask the participant's name and address over the phone, and write it directly on the envelope. These identifiers will not be stored. A prepaid envelope will be added to return completed forms.

This second phase is expected to take at least 8 months.

## Measures

A written survey was chosen because this communication type is less volatile than spoken language and gives autistic individuals more time to process the questions (as opposed to oral interviews where an answer must be given quickly). This aligns with the communication preferences of many autistic people.<sup>15 26</sup> Moreover, participants can complete the survey at home at a convenient moment rather than fixing an appointment with an interviewer. Concrete unambiguous language, understandable for adults with a secondary school diploma, was used. Sexual terms were defined.

Most questions are yes/no, scale and multiple-choice questions, which meets the preference for closed questions commonly observed in autism.<sup>15</sup> Two open questions were added at the end, to discover barriers or facilitators missing in the questionnaire. Though some autistic individuals find broad open questions challenging, understanding the objective of such questions is easier when the open questions are preceded by closed questions covering the same topic.<sup>15</sup>

To decide which barriers and facilitators to include in the questionnaire, a structured hypothesis generating process was performed. This process builds on the specificities in information processing and socioemotional status in autism and on how these specificities could affect sexual safety (table 1). Also, elements from the clinical experience with people living with HIV already diagnosed with autism were used to determine barriers and facilitators to include.

Two autistic adults (not in follow-up in the HRCs) reviewed the questionnaire. A pilot study was then done, in which 10 autistic people living with HIV voluntarily tried out the reviewed questionnaire (after informed consent). Half of these individuals gave oral feedback on the language used and the type of barriers enquired. Based on the pilot study experience, questions were added or omitted, and further revisions were made by the researchers.

Table 1 shows an overview of the included SSBs or facilitators.

## Data management

Phase 2 data will be collected through Redcap.

## Data analysis

The presence of barriers and facilitators will be described by using counts and percentages for categorical characteristics. The analysis of the open questions will focus on gaining insights into participant's barriers and facilitators rather than on theory building. The descriptive texts will be analysed by open thematic coding (seeing which broad themes or ideas emerge from the text).<sup>72 73</sup> Text passages will then be linked with one of the identified themes.

## ETHICAL ISSUES

The Institutional Review Board of the ITM and the ethical committee of the University Hospital of Antwerp provided ethical approval. For other HRCs willing to participate, additional ethical approval will be asked from the local ethical committee. The study will be conducted according to the principles stated in the Declaration of Helsinki, all applicable regulations and according to established international scientific standards.

This study raises specific ethical issues which deserve to be reported.

### Linking autism with sexual risk behaviour

There is no evidence at all that autism as such is related to a higher frequency of sexual risk behaviour, only untested hypotheses that SSB in autistic individuals may differ from SSB reported by non-autistic people. All efforts will be made to clarify this during research-related communication, to avoid creating stigma.

### Potential risks in terms of breach of sensitive personal information

This study examines sensitive research topics. Participants may be identified as belonging to multiple minority groups which are at risk for stigma: living with HIV or being at risk to acquire an HIV infection, being GBMSM and being a person with autistic traits. A breach of such study information could have a major impact on the risk for discrimination.<sup>74-78</sup> Appropriate technical and organisational measures have been taken to safeguard the confidentiality of the participant personal data in compliance with the EU General Data Protection Regulation. All procedures have been reviewed and approved by ITM's Data Protection Officer.

### Potential benefits of disclosing a high AQ score to participants

Many autistic individuals have a history of sexual victimisation, bullying, depression and/or anxiety.<sup>19 40 43 79</sup> Autism-friendly support aiming at reducing the probability for these events and supporting individuals to deal with their impact are necessary. However, in the absence of a (suspected) autism diagnosis, initiation of such support often comes late. A (suspected) diagnosis can help to find adequate support, reduce the chance for re-occurrence of such problems<sup>80</sup> and avoid wasting time being

**Table 1** Barriers and facilitators for sexual safer behaviour

Barriers for sexual safer behaviour in the questionnaire and the rationale for including the barriers		Facilitators for sexual safer behaviour in the questionnaire
► Situational GBMSM sex in men with a heterosexual orientation	► Oral communication with autistic people living with HIV about situational GBMSM sex, combined with the fact that GBMSM sex is associated with higher risks for HIV. <sup>38 39</sup>	Community and work ► Expansion of social network, including participation in peer support activities targeting autistic individuals
► Challenges in sociosexual communication with sex partners, influencing safer sex	► Known communicational challenges in a non-autism-friendly environment reported by certain autistic individuals <sup>1</sup> and the importance of communication in safer sex <sup>62</sup>	► Having a paid, autism-friendly, professional activity
► Challenges to gain insights in own sexual boundaries, leading to situations in which the autistic individual is overly compliant with the partner's wishes, even if these wishes entail risks	► Certain autistic individuals desire support in the domain of Theory of Own Mind <sup>65</sup>	Health and social services ► Access to safer-sex counselling by a professional trained in specificities of sexuality in autism
► Obstacles in recognising the degree of trustworthiness of sex partners	► The need for support in terms of Theory of Mind <sup>65</sup> has been reported by autistic individuals	► Access to reliable sexual services by sex workers trained in autism
► Sexual victimisation, giving physical and/or psychological risks*	► Known elevated rates of sexual victimisation in autism <sup>40</sup>	Individual ► Expansion of sociosexual communication skills
► Commercial sex work	► Obstacles to maintain a regular paid employment in the Belgian context, <sup>86</sup> possibly leading to the need for other income-generating activities such as commercial sex work, which is associated with HIV risks <sup>97</sup>	► Expansion of adequate (non-sexual) stress-coping skills
► Using sex as an outlet for stress, combined with increased risk exposure when sex is used as an outlet for stress	► Known elevated stress levels in autism, <sup>79 98</sup> and oral communications with autistic people living with HIV mentioning riskier sex when using sex as an outlet for stress	► Expansion of knowledge on personal sexual boundaries
► Using sex as a means for social contact, combined with increased risk exposure when sex is used in this situation	► Elevated rates of feelings of loneliness described in autism <sup>87 88</sup> and descriptions of increased risk exposure when having sex if feeling lonely <sup>86</sup>	
► Using sex to increase self-confidence, combined with increased risk exposure when sex is used for this purpose	► Oral communication with autistic people living with HIV	
► History of chemsex to reduce the impact of certain autism-related challenges	► Positive impact of two types of illicit drugs on certain autism-related challenges, <sup>99 100</sup> and the association of chemsex with sexual risk exposure <sup>101–103</sup>	

\*The possibility of sexual offence by autistic individuals, linked with factors such as misinterpreting consent of partners, is not discussed here, as this research focuses only on safer-sex barriers from the perspective of the autistic person.

GBMSM, Gay, bisexual and other men who have sex with men.



### Box 1 Counselling session content

- ⇒ Assess emotional reaction.
- ⇒ Assess manifestations of previous and current challenges in sensory hyper-reactivity or hyporeactivity, central coherence, theory of mind and executive functions and the associated degree of distress.
- ⇒ Provide a brief, personalised explanation of what autism is.
- ⇒ Address possible false beliefs about autism.
- ⇒ Discuss advantages, disadvantages and practicalities of going for a formal diagnostic exploration after a high Autism Spectrum Quotient score.
- ⇒ Where appropriate, provide information about autism peer support initiatives (often accessible without a formal diagnosis).
- ⇒ Where appropriate, help to identify good-quality autism coaches (often accessible without a formal diagnosis).

misdiagnosed and feeling misunderstood by HWs. Finally, getting the diagnosis is often reported as life-changing for adults, who mention to be relieved to get an answer on the question why they felt different all their lives.<sup>23 24</sup>

#### Potential risks of disclosing a high AQ score to participants

Disclosing a high AQ score might cause emotional distress. Therefore, these individuals will be able request support from the HRC's psychosocial team or request one counselling session provided by the investigator, who is trained in autism. All support is free of charge. **Box 1** shows the content of the counselling session.

#### Potential risks of enquiring safer-sex facilitators and barriers in individuals with autistic traits

Difficult personal experiences may be brought up. When participants feel emotional burden and need support, they will be able to cancel the participation and/or ask for (free) support by the HRC's psychologist, sexologist, or social nurses.

#### DISSEMINATION OF RESULTS

Results will be published in peer-reviewed journals, presented at conferences and discussed with relevant organisations. Participants can get a summary on request. HRCs will receive a research summary.

#### DISCUSSION

To date, many autistic individuals in HIV clinics are probably 'invisible' due to the limited capacity of non-specialised HWs to recognise less obvious manifestations of autism,<sup>15</sup> and due to diagnostic overshadowing of autism by its frequent co-occurring conditions such as depression and anxiety.<sup>19–22 50 53 54 56</sup> Attributing the commonly seen mental health problems in people living with HIV<sup>28–34</sup> too quickly to the HIV status, rather than to underlying autism, can add to the situation. Finally, a long-standing yet incorrect perception that autistic individuals are uninterested in sexual relationships may contribute to this state as well.<sup>27</sup>

Though autism may be unrecognised in HIV clinics, we hypothesise that its prevalence might be comparable or higher than in the general population. First, most autistic individuals report partnered sexual activity.<sup>27 35–37</sup> Second, a wider range of sexual orientations, including higher rates of bisexual orientation in autistic men, has been reported.<sup>27</sup> GBMSM are more at risk for HIV.<sup>38 81</sup> Finally, the elevated rates of sexual victimisation observed in autism<sup>39 42 43 82</sup> might be linked with subsequent sexual risk behaviour<sup>44–47</sup>

The hoped-for study impact is situated on several levels.

On a microlevel, screening large numbers of people living with HIV and PrEP users for autism and providing a personalised postscreening counselling to participants with an AQ score above the cut-off, can help these participants to find adequate support, to create a better self-understanding and provide an explanation for past life experiences.<sup>15 23–25 83</sup>

Furthermore, informing HRC staff about the prevalence of autistic traits can generate a much-needed awareness. This awareness for the possibility of underlying autism in the numerous people with HIV and PrEP users with depression and anxiety<sup>28 29 84 85</sup> is key to direct individuals timely towards proper screening and care and to avoid considering the person's HIV status as the principal or sole origin of mental health problems for too long. The Joint United Nations Programme on HIV/AIDS recommends a better integration of mental health and HIV services.<sup>31</sup> A better awareness for and identification of autism, which is so often associated with mental health morbidity, especially when unrecognised, seems a useful strategy to adhere to these recommendations.

This research can also contribute to shaping autism-friendly sexual healthcare provision in HIV clinics, which is key considering the vast knowledge gap on ways to support sexual health in the autistic population,<sup>61</sup> and the demands for autism-friendly STI service-provision expressed by autistic individuals.<sup>59</sup> Indeed, while HRC prevalence data will demonstrate the number of people that could benefit from autism-friendly care, data on SSBs and facilitators will help to model this care. For instance, the use of sex as a means for loneliness-compensating social contact in autistic individuals is investigated in this research, since sex under these circumstances is often associated with unsafe practices<sup>86</sup> and since loneliness is common in autism.<sup>87 88</sup> If our data reveal high rates of loneliness-driven unsafe sex in autistic people living with HIV or PrEP users, HW should proactively enquire and manage this in future safer-sex counselling sessions. Another example of how study data could shape sexual health provision lays in the domain of (adult) sexual victimisation. When testing and discussing the phase 2 questionnaire with known autistic patients in our clinic, seven out of the 10 test patients reported (young) adult sexual victimisation; some even mentioned they acquired HIV like this. If our research confirms this tendency, HRC staff should enquire sexual victimisation more proactively,



provide adapted support for past victimisation events and counsel to prevent revictimization.

A last potential study impact is an improved comprehension of specific needs of the subgroup of autistic lesbian, gay, bisexual, transgender or queer (LGBTQ) individuals in HIV clinics. Autistic LGBTQ individuals in HIV clinics are particularly vulnerable, since they are exposed to a triple minority stress due to stigma against people living with HIV or taking PrEP, being LGBTQ and being autistic.<sup>75–78 89 90</sup> Moreover, a knowledge gap concerning (sexual) health provision in autistic LGBTQ currently deters the development and accessibility of proper support for this subpopulation,<sup>59 74 91</sup> which is deplorable since the poor health outcomes observed in autistic individuals<sup>15 50 52</sup> are even worse in autistic LGBTQ.<sup>60 74</sup> Since Belgian HIV clinics serve important rates of LGBTQ individuals,<sup>68 92</sup> we expect LGBTQ to be well represented in both phases of our research, which could contribute to a better understanding on how to serve this subpopulation within HIV clinics more adequately in the future.

Our study has several limitations. As the study is autism-related, people with self-suspected autism might be more inclined to fill in the survey, causing a participation bias. Conversely, autism is stigmatised,<sup>90</sup> so persons with self-suspected autism could be reluctant to participate, leading to a reverse participation bias. A second limitation is the use of an autism screening instrument as a proxy for diagnosis. The specificity and sensitivity of the AQ screening in detecting autism—with a cut-off of 26 or 32—should always be considered when interpreting and communicating study data.<sup>69 70</sup>

As for the mapping of SSBs and facilitators, the use of closed-question questionnaires has intrinsic limitations. However, the questionnaire builds on our prior explorative clinical experience and our unpublished pilot project with 10 autistic people living with HIV (*Huyst, Sexual Risk Behaviour in Autistic Patients in follow-up in the HIV clinic*). Nevertheless, the findings of the current study will have to be completed with additional in-depth research. Another point to consider is that this research only focuses on SSBs from the perspective of the autistic person, while factors such as misinterpreting consent could also put partners of autistic individuals at risk for events such as non-consensual sex.<sup>93</sup> However, since available research does not indicate a higher prevalence of sexual offending by autistic individuals compared with the general population,<sup>94</sup> this barrier was not included in this research.

Despite the limitations, we hope to gain insights in the prevalence of autistic traits in HIV clinics, sociodemographic characteristics of people living with HIV and PrEP users with autistic traits and SSBs faced by this subpopulation. This knowledge is an essential step to design future sexual health support for people living with HIV and PrEP users with autistic traits, ultimately aiming at empowering non-intellectually disabled autistic adults of various sexual orientations to have safe and noncoercive sexual experiences, if desired.

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