

HIV/STBBI Testing Survey and Forum Final Report July 2018

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HIV/STBBI Testing Survey and Forum Final Report

Background

In January 2018 Substance Consulting was contracted to work on a project that explores the strengths and challenges of STBBI testing and education in Winnipeg, MB. This project was developed based on a previous report that identified an existing opportunity to coordinate HIV/STBBI prevention education activities and improve access to testing for those who need it most. A new proposal was developed to take advantage of this identified opportunity with the following anticipated outcomes:

1. To identify populations currently accessing testing services and to compare with local epidemiological data to identify gaps.
2. Enhanced opportunities for collaboration between STBBI Testing Clinicians and Sexual Health Educators to maximise resources and target populations that are being missed.
3. Sharing tools, case reviews and best practices to increase comfort in completing sexual health assessments

The following report will provide an overview of the project, trends and themes arising from the survey and recommendations on initial next steps.

Project Overview

This project involved three components:

1. *HIV/STBBI Participant Survey* – A participant survey about testing behaviours and people’s rationales for accessing testing (or not) was developed by the consultant in consultation with Nine Circles, Klinik Community Health Clinic, Mount Carmel Clinic and the Healthy Sexuality and Harm Reduction Team at the Winnipeg Regional Health Authority (WRHA) (Appendix 1). The goal was to get a sense of who is currently being tested in clinic to determine whether the right people were accessing care. Additionally, learning more about how people want to access testing and HIV/STBBI information was another priority of this survey. 4 sites (9 Circles, Klinik, Street Connections, and Mount Carmel Clinic) participated in this process by completing 20-30 participant surveys each over the course of the month of April 2018. The data was compiled and analyzed for trends and themes.

2. *HIV/STBBI Forum for Health Educators and Clinicians who do HIV/STBBI testing* – A forum took place on May 25th, 2018 to share the results of the survey, learn from a panel of PEERS about their thoughts around education and testing, and work towards improvement opportunities moving forwards.
3. *Final and Interim Reports*: Each of these reports describes the project approach and provides some analysis of the data collected. This final report includes a summary of the findings of both the survey and the forum, key themes that emerged from both, and a set of recommendations for improving access to testing for those who need it most.

Summary of Findings and Key Themes

Part 1: HIV/STBBI Participant Survey

Demographics (N=80):

The following describes the demographic profile of the people who are accessing care. Each site had a slightly different profile and so site specific quality improvement approaches should be based on the specific site data (Appendix B).

Age:

- 14-29 (43)
- 30-40 (24)
- 41-51 (5)
- 52+ (6)
- n/a (2)

Sexual Orientation:

- 49 participants identify as Heterosexual
- 12 participants identify as Bisexual
- 12 participants identify as Gay
- 1 participants identified as Two-Spirit
- 1 participant identified as Transgender
- 2 participants identify as Queer
- 3 participants did not respond

Gender:

- 52 respondents identified as male (65%)
- 25 respondents identified as female (31%)
- 1 respondent identified as genderqueer (1%)
- 2 prefer not to say (2%)

Race/Ethnicity:

- 42 respondents identified as White or Eastern European (62%)
- 26 people identified as Indigenous or Metis (23%)
- 3 people identified as Black (1), African (1), or African Caribbean (1) (4%)
- 5 people identified as South East Asian (3), South Asian (1), or Filipino (1) (6%)
- 4 did not say/prefer not to say (5%)

Testing Data

The following describes some of the sexual health practices of those who responded to the survey.

First HIV/STBBI Test:

- 23 was the average age for a first STI test, while 25 was the average age for a first HIV/AIDS test.
- 10 people were getting testing for the first time. (12.5%)

In terms of frequency of testing, folks identified in the following ways:

- 13 said they access testing once a year
- 24 said they access testing 2/3 times a year
- 11 said they access testing 4 times or more/year
- 17 they access testing less than once a year
- 15 participants did not answer*

*Many of the people who stated that they test less than once a year were making that choice based on perceived risk factors and actual risk factors. Many of these people test less because of fair and reasonable assumptions about their STI risk levels and that as soon as they got information that changed their perceived risk they came in for testing.

*****48 (60%) respondents are getting regular STI testing¹.

The top 2 presenting issues identified by participants were:

1. I get tested regularly as part of my sexual health/drug using routine
2. I have a new sex partner

¹ 'Regular' is based on anyone getting tested more than once a year.

Data Analysis/Key Themes

After a review of the 80 completed surveys from all four sites (9 Circles, Klinik, Street Connections, and Mount Carmel Clinic) the following three key themes emerged:

The 'Worried Well'

- Most survey participants identified HIV/STBBI testing as a normal and routine part of their sex lives and regular health care.
- Most people were not feeling negatively about getting tested. Most identified feeling calm, neutral, prepared or even happy about being at the clinic for testing.
- 77.5% of respondents mostly (7) or completely (55) agreed that getting tested is about showing respect for themselves and their partners.
- Discussion about STI testing with partners was common among participants.

People Who Use Drugs

- Only 9 people out of 80 identified drug related activity as their reason for presenting for care.
- Of those 9, only 4 people identified sharing drug use supplies as a reason for testing. All other responses were related to sexual contact.
- 6 of these people were seen at Mount Carmel Clinic
- given the higher rates of HIV and HCV infection among injection drug users, lack of representation from this community among survey participants is of concern.

Racism and Homophobia Within the Healthcare System

We asked survey participants whether homophobia, racism or concern about how they would be treated by their Health Care Providers had prevented them from testing in the past.

- Only two people identified homophobia or racism as a factor in their decisions not to test.
- Three were worried about how they would be treated by their Health Care Providers.

Initial Considerations Based on the Survey Data

- *Missing from Care:* A critical reflection for sites, clinicians and educators is around who is missing from care. If there are significant populations of people missing (for example, people who use drugs, Indigenous people, Newcomers, LGBT2SQ people), we are not creating enough opportunities for intervention among these priority populations.

- *Opportunity for quality improvement measures:* Based on this survey data, it appears we are not testing the people who are most likely to test positive for HIV/STBBIs. This survey is not enough to make a determination regarding this, but it does provide enough to explore potential quality improvement opportunities to see if they support a shift in who is accessing care. More research and chart review may help to tease out specifically who sites should be targeting for quality improvement projects related to improving access.
- *Systemic Homophobia and Racism in Healthcare:* We know that homophobia and racism entrenched in healthcare systems, and providers themselves, prevents people from accessing care. In Canada, “research shows that racism against Indigenous peoples in the health care system is so pervasive that people strategize around anticipated racism before visiting the emergency department or, in some cases, avoid care altogether.”² For this survey, we asked people whether racism or homophobia had prevented them from accessing care. Only two people stated that racism and/or homophobia had prevented access, and another three stated that they were worried about how they would be treated by their Health Care Providers. Given what we know, the natural query based on this survey data is ‘If people are experiencing racism and homophobia within the health system and only 5 people surveyed identified this as an issue, are we missing people because of concerns related to homophobia and racism?’. Testing sites need to look critically at how they create safety for Indigenous people, Black people, People of Colour, and LGBT2SQ people. This is of importance given that because of various systemic factors, including colonization, systemic racism, and homophobia these priority populations may face an increased risk of HIV/STBBI’s.³
- *Nothing About Us Without Us:* Learning about how to create services that are responsive to people who use drugs is critical. This means ensuring that people who use drugs are consulted, engage, and lead at every step of program development.
- *Sharing tools with other sites that are doing HIV/STI testing:* It may be worthwhile for sites not included in this survey to explore whether they are testing the people who are most in need of testing— we may be running busy clinics, but knowing if we are successfully addressing the needs of underserved populations would help support sites in targeting our resources.

² Allan, B. & Smylie, J. (2015). First Peoples, second class treatment: The role of racism in the health and well-being of Indigenous peoples in Canada. Toronto, ON: the Wellesley Institute.

³ Canadian Public Health Association. Factors Impacting Vulnerability to HIV and other STBBIS
https://cpha.ca/sites/default/files/uploads/resources/stbbi/FIV_EN.pdf

- *Comfort level of those we do test:* The population of people currently accessing testing are very satisfied with the care they receive. And many identified community health clinics as the best places to go for thorough testing that feels comfortable.
- *Increased interest in technology:* The vast majority of participants are accessing site information on-line. Many identified improved use of technology to learn about sexual health and local resources, book appointments, get results, and access treatment or prescriptions as a priority. The more we can manage this group of people efficiently through use of technology and self-testing, the more space and time we free up to target priority populations and other people we may be missing.
- *Intrinsic Motivation:* The majority of people in this sample are those most likely to diagnose and treat any HIV/STBBI transmission quickly. We know that an area of focus for most sites participating in this survey is becoming more streamlined and targeted in their testing practices. Quality Improvement approaches may help shift practice in clinic to better serve priority populations.

Survey Summary

For the population currently accessing care who responded to this survey, the service and approach is working effectively. That said, those surveyed for this report are likely to access testing regardless of services, given their intrinsic belief that testing is an important part of sexual health and self-respect. This creates a condition where shifting practice should not be a deterrent to those currently accessing care and could then allow for those we are not reaching to be better served. We should pay careful attention to how our current systems and approaches could shift to improve access for people who use drugs, Black/Indigenous and other People of Colour, women, sex workers, and Queer and Trans people.

Part 2: HIV/STBBI Forum for Health Educators and Clinicians who do HIV/STBBI

Employing a healthcare Quality Improvement process, a forum was held which focused on clinician and educator driven recommendations for improvements to practice and how testing could look moving forward.

A key consideration for those working in HIV/STBBI testing in community health is ensuring that practitioners approach quality improvement with a sense of how to improve equity, especially within the context of a client population that is nearly universally facing barriers to care. If clinicians and educators center quality improvement that *delights* the most marginalized and underserved of client communities, they will be successfully attending to their core values and meaningful organizational change.

Following a presentation of the survey data findings and an Indigenous Peer-led panel discussion about gaps, challenges, and ideas for moving HIV/STBBI testing forward

meaningfully, forum participants engaged in a quality improvement group discussion exploring how to best strategize around gaps in service and propose a range of possible interventions. (Appendix C)

Aims of the discussion were two-fold:

1. Based on the survey data, identify potential processes, areas of concern, problems related to HIV/STBBI testing that could be improved with a QI Initiative (asking the question “BUT WHY” until we can drill down to the crux of the issue and develop QI hypotheses based on this).
2. Develop opportunities for solutions by focusing on improved care and how to DELIGHT clients (asking the question, “HOW could we shift to accommodate the realities of people’s lives/issues in care provision?”).

Regarding the first aim of the discussion, four interrelated themes emerged concerning gaps in service.

People Who Use Drugs (PWUD):

- Lack of representation among this group was identified as one of the major oversights of the survey data.
- Practitioners felt that PWUD faced several barriers, including not being able to access treatment while high, and encountering policy restrictions because of their drug use when engaging with the health care system.

Legal System Implications:

- The perceived and actual lack of privacy around sharing client information could also be viewed as a legal concern for clients who avoid health care settings because they are worried about clinicians reporting them to child welfare, the police, parole officers etc.
- Forum Participants thought that clients might not feel safe at the point of access to care.
- A point of discussion also arose around people who are accessing healthcare from within the justice system (i.e. people who are being tested in jail). This could be another underserved population who are not accessing health care once they leave prison.

Health Care System Imposed Discrimination:

- When accessing health care services, many participants believed that clients might encountering negative experiences that were the result of interactions within the system.
- These negative experiences included feelings of judgement, stigma, and a lack of trust and respect, particularly in their encounters with care providers.
- Participants believed that negative encounters in the system were acutely felt by PWUD, newcomers, Indigenous people, people with disabilities and mental health concerns, single parents, and people without housing.

Accessibility:

- There were many barriers that were identified as limiting accessibility for clients, particularly affecting single parents and people without housing or identification.
- Limited clinic hours and no offer of 24-hour services was seen as a stumbling block, as was a lack of timely access to lab services.

Following this portion of the forum, participants attended to the second objective of the Quality Improvement discussion. During this portion of the session, another four broad themes emerged around opportunities for solutions and *delighting* clients who come to us for care.

The group of Peer participants also spoke to these subsequent four emerging themes and their insight will be highlighted in the following analysis.

Focus on Culturally Relevant Care:

- Clinicians and educators recognized that more Indigenous nurses and testers were needed, as well as the involvement of Elders in health care settings.
- Peers called for better integration of traditional health practices and medicines.
- Peers also expressed concern about “cultural safety” rhetoric without the implementation of meaningful practices.
- In keeping with the TRC’s 94 Calls To Action, any new programs or approaches that serve Indigenous people should be developed and lead by Indigenous people.

Change on the Part of the Health Care Professional:

- Forum participants felt that a shift was needed on the part of health care professionals to act more as client advocates who could assist in navigating the system, educate clients on health care and safe drug use, and be willing to modify their approach to meet their clients’ needs.
- Engaging more directly with communities that providers serve was also seen as a potential area where connections could be made, for example attending bingo, attending drop in spaces, and malls – essentially setting up testing sites where people already are. This conversation emerged after a comment from a nurse who works out of targeted locations where the clients he serves already gather. This was seen as an added benefit by clients and a very effective way to ensure that people who need testing get it.
- Participants also thought that providers could work more collaboratively amongst themselves and with government to build capacity and improve communication.
- The Peers felt that the way health care providers and clients are educated about HIV/STBBI should be critically investigated, and that educators should take on a “guide/navigator” role.
- The Peers also felt that providers’ attitudes that position their clients as the “other”, relegating them to an us/them, good/bad binary should be addressed.

Changes to How Health Care Services are Administered:

- Making the experience of clients who access services more meaningful could be achieved by making services within the clinic more accessible (for example, drop in, extended hours, providing a kiosk rather than paper, booking appointments online, safe waiting/discussion areas) as well as outside the clinic. Participants discussed holding pop-up clinics, increasing home visits, and expanding outreach initiatives.
- Participants felt they should be maintaining the highest level of client privacy or as close to anonymity as possible with respect to minimizing the collection of personal information (including contact tracing), limiting required discussion of risk factors, and reducing collection of demographic information to the essentials.
- The Peers also felt that more outreach options or testing options should be made available, for example self-test kits and home/community visits.

Incentives:

- The final point of discussion around delighting clients was a seemingly simple one: offering incentives for getting tested. This included providing transportation (i.e. bus tickets, rides), child care, food and drinks (e.g. water, suckers, cookies), and making Traditional medicines available.

Forum Summary:

Moving beyond what the PEERS referred to as the rhetoric of “cultural safety” without meaningful solutions will be the challenge going forward. Health care clinicians and educators will need to challenge themselves to think outside the conventional models of care to reach the populations that are currently being underserved. While it is encouraging to note that those currently accessing services are pleased with current approaches, more must be done to address the gaps. Improving accessibility, service provision, and the role of clinicians and educators must include consideration for underserved populations and the communities they live in. The next steps in the Quality Improvement process should build on the opportunities identified by forum participants and Peers, testing these solutions, and evaluating their effectiveness. Peer driven community engagement and leadership in the provision of services is strongly encouraged.

Recommendations

This survey provided an informal overview of who we are testing and opened a conversation that allowed clinicians, educators, and peers to reflect on current practices, and brainstorm opportunities for quality improvement measures that may support testing sites in reaching those that are most in need of care. The following are recommendations that emerged based on the conversation and survey data.

Improving Access to service for those that we currently see for testing

Even though the majority of the people who responded to the surveys are not necessarily those that we would be targeting, especially given the emphasis on equity approaches in community health, the fact remains that these folks also need access to safe STI testing, and this is an area where community health clinics have important expertise for other potential HIV/STBBI testing sites. For a significant proportion of respondents ease and accessibility was a core need. The following recommendations offer suggestions that could allow this group to continue to access care in a way that makes most sense for them while also creating room for clinicians and testing sites to target those folks we are missing.

1. Use of technology: Explore how sites can use online technology to book appointments, get results, and have prescriptions phoned in to pharmacy etc.
2. Quality Improvement: Testing Sites should explore where within, current practices, time could be saved from an appointment. People are looking for quick and competent care and Quality Improvement initiatives that test the testing process to streamline appointments for participants who get tested regularly may be of benefit.
3. After hours, quick access STI testing sites: Other provinces have developed free-standing STI testing sites that are fast and convenient and open after traditional business hours. Exploring what this could look like in MB may be beneficial.
4. Work with Family Practitioners, the Department of Medicine at the University of Manitoba, and the province to increase the inclusion of HIV/STBBI testing in family doctor's routine care related to overall physical health. If family docs were required to provide this care to their clients and offer it routinely, clients would not be put in the position of having to ask for a test or be worried about the reaction of their family doctor. Many of the people who responded to the survey indicated that they have a family doctor, but are uncomfortable accessing testing from them. This creates an offloading of care onto community health clinics which prevents targeted, health equity based, testing initiatives. It may be worth it to increase/create billing amounts for fee for service clinicians to encourage HIV/STBBI testing.
5. Advocate for access to home HIV/STI testing. While this is not currently an option in Canada, there is evidence to support the introduction of home testing or self-testing in

clinic settings.⁴ The healthcare system overall needs to eliminate its' history of paternalism and gate-keeping and move forward to meet our clients where they are at on this issue. The vast majority of people consulted (between 74-96% of folks in priority populations AND the general population, depending on the study) found home testing to be acceptable to them as an alternative to clinic testing.⁵

Improving Access to Care for Priority Populations

HIV/STBBI testing efforts should be targeted at those communities that have been marginalized from traditional health care models. We have a responsibility to turn the lens away from the person being served and back onto the systems, clinics, and models that need to shift to meet the needs of the people who most need the care. We need to think about how we can shift our approaches and practice (indeed, the only thing we can control) to be what the people we care for need us to be. Safety and trustworthiness need to be so explicit that everyone knows where the safe HIV/STBBI testing is available and how they will be treated when they present for care.

1. **In consultation with, and led by people who use drugs**, in particular, those who use injection drugs, site based strategies for increasing testing access for people who use drugs should be developed.
2. Increase Clinician comfort and knowledge of illicit and recreational drugs, how people use their drugs, and how to connect and provide harm reduction oriented care to people who use drugs.
3. Increase basic accessibility to testing – locations, hours of operation, access to childcare, transportation (especially in winter).
4. Tailor education efforts to support people to weigh the risks and benefits to testing. Build system navigation skills that can keep people safe and knowledgeable about how they can disclose personal health information and practices, and the safest way to access testing in a system that is not always safe for people who are underserved (criminalized by substance use, impacted by homophobia and racism etc.).

⁴ 'HIV Home Based Testing: Potential Benefits and Ongoing Concerns'. CAITE.
<http://www.catie.ca/en/pif/spring-2014/hiv-home-based-testing-potential-benefits-and-ongoing-concerns>

⁵ 'HIV Home Based Testing: Potential Benefits and Ongoing Concerns'. CAITE.
<http://www.catie.ca/en/pif/spring-2014/hiv-home-based-testing-potential-benefits-and-ongoing-concerns>

5. Review and evaluate current human resources processes to ensure that applicants that self-identify as a part of a priority population are interviewed and wherever possible supported for employment.
6. Increase off-site testing opportunities and increase outreach that includes HIV/STBBI testing.
7. Create intentional clinic spaces that go above and beyond to make people who are often unwelcome in other settings, feel welcomed.
8. Develop a collaborative, Winnipeg based, testing strategy that can inform lobbying efforts.
9. Consider the benefits of a stand-alone STI site that is open in off-hours and targets specific priority populations. Ensure that clinicians staffing this site have specific and meaningful expertise working with priority populations.
10. Create the context and opportunity for nurses to work to scope, including doing their own blood draws.

Conclusion

Ensuring that HIV/STBBI testing meets the needs of those we are currently serving, while also prioritizing communities that are underserved is an important challenge in Winnipeg and one that requires a willingness to shift current practices, test new ideas, and truly innovate around how healthcare could truly embody healing and wellness. While traditional models and approaches often hold back clinicians and educators who want their care to be meaningful and effective, we still have a responsibility to practice in a way that centers our values and ethics, and clinical expertise. Walking alongside those who are directly impacted, we need to create a path forward that allows us to engage in system change that makes sense and challenge approaches that do not honour and respect the needs and identities of those we serve.

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IMPROVING STI/HIV/HEPATITIS C TESTING
FOR PEOPLE IN WINNIPEG SURVEY



A FEW QUESTIONS
ABOUT YOU:

How old are you? _____

I identify as:

- Queer
- Bisexual
- Gay
- Lesbian
- Two-Spirit
- Straight/Heterosexual
- Prefer not to say
- You don't have an option that applies to me. I identify as: _____

Gender:

- Nonbinary
- Genderqueer
- Woman
- Man
- Two-Spirit
- Prefer not to say
- You don't have an option that applies to me. I identify as: _____

Would you describe yourself as transgender?

- Yes
- No
- Prefer not to say

I identify as:

- Indigenous
- African
- African Caribbean
- Black
- Indian Caribbean
- Latin American/Latinx
- South Asian
- East Asian
- South East Asian
- Middle Eastern
- Mixed (please specify): _____
- White
- Prefer not to say
- You don't have an option that applies to me. I identify as: _____

PLEASE ANSWER EACH QUESTION AS BEST YOU CAN. IF A QUESTION DOESN'T APPLY TO YOU, OR YOU PREFER NOT TO ANSWER, PLEASE FEEL FREE TO WRITE 'NOT APPLICABLE', OR 'NA'

1. Is this your first Sexually Transmitted Infection (STI) Test?

- Yes
- No
- Not Applicable

Is this your first HIV Test?

- Yes
- No
- Not Applicable

Is this your first Hepatitis C (HCV) test?

- Yes
- No
- Not Applicable

↳ If not, how regularly do you get tested?

- 4 times a year
- 2-3 times a year
- Once a year
- Less than once a year
- More than four times a year

2. How old were you when you got your first STI test?

How old were you when you got your first HIV test?

3. What brought you here today? (check all that apply)

- I get tested regularly as part of my sexual health/drug using routine.
- I have symptoms that are bothering me.
- Someone I have slept with tested positive for an STI.
- Someone I share drug equipment with tested positive for HIV or HCV
- I have a new sex partner(s).
- I shared drug use supplies (needles, water, cookers, pipes) with someone.
- Sex Work related (unprotected sex with a john, a condom broke etc).
- Public health nurse told me I needed to come in for testing.
- I think I'm pregnant
- I had sex with someone I don't know very well/at all and I don't feel comfortable talking/don't want to talk to them.
- I had sex that was not consensual.
- Someone I use with injects my drugs for me, and I'm not sure whether they use new supplies each time.
- Condom broke
- I got high and had unprotected sex
- I blacked out and I think I may be at risk for an STI, HIV, and/or Hepatitis C.
- Other: _____

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4. How did you feel about coming here today?

- happy sad angry
- worried neutral shy
- uncomfortable awkward calm
- prepared other _____

5. Do you worry about how you will be treated by clinic staff when you ask for an STI test or HIV test? YES NO

6. Has (institutionalized) homophobia or racism within healthcare prevented you from getting tested in the past? YES NO

7. Why have you avoided testing in the past (if you have)?

8. If you have avoided getting tested in the past, what changed to get you here today?

9. Why do you think some people avoid testing?

10. How did you prepare to come here today (for example, talked to a friend, googled things on-line, looked up the clinic website etc.)?

11. How much do you agree with the following statements?
1=not at all 2=somewhat 3=not sure 4=mostly 5=completely 6=Not Applicable

- 1 2 3 4 5 6 STI testing is a regular part of my healthcare
- 1 2 3 4 5 6 STI testing is a normal part of my sex life
- 1 2 3 4 5 6 I talk about STI testing openly with the people I have sex with.
- 1 2 3 4 5 6 I am private about getting an STI test.
- 1 2 3 4 5 6 If I share safer drug use supplies, I come in for testing.
- 1 2 3 4 5 6 If I get high/drunk and forget what I have done while high/drunk, I come in for testing.
- 1 2 3 4 5 6 Getting an STI/HIV/HCV test is about showing respect for one's self, their sexual partners and the people they may use drugs with.

12. What kind of information makes it easier to come get an STI/HIV/HCV test? (check all that apply)

- Knowing what will happen at the appointment.
- Knowing what treatment exists for STI's/HIV/HCV
- Knowing who will be doing the test
- Knowing whether the test will hurt.
- Knowing I have support if I get bad news (test positive for an STI, HIV, or HCV)
- Knowing what type of test I can get (urine [pee] test, rapid HIV test, or blood test).
- Other _____

13. How do you like to get information about testing and STI's/HIV/HCV? (for example: on line, from my doctor, nurse or nurse practitioner, books or articles, phone line etc.)

14. What could make this experience easier for you?
