

“Click yes to consent”: Can we achieve informed consent for online testing for sexually transmitted infections?

Amanda Bonnell,¹ Devon Haag,² Mark Bondyra,² Janine Farrell,² Melanie Achen,² Elizabeth Elliot,³ David Unger,⁴ Mark Gilbert^{2,5,6}

1. Provincial Health Services Authority

2. BC Centre for Disease Control

3. College of Registered Nurses of British Columbia
4. Providence Health Care

5. University of British Columbia

6. Ontario HIV Treatment Network

BACKGROUND:

- Achieving informed consent is fundamental when offering testing for HIV and STI
- The BC Centre for Disease Control has developed a new online STI/HIV testing service in British Columbia (getcheckedonline.com, GCO)
- In developing GCO, we included core pre-test concepts necessary for informed consent according to provincial guidelines
- If and how informed consent can be achieved in an online environment is not well understood - this is a key gap given increasing availability of self-directed e-health diagnostic services
- We also need to distinguish between procedural knowledge (e.g., how website or process works) and substantive knowledge (e.g., potential harms of testing, window periods)

OBJECTIVE:

- To assess acceptability and perceptions of the informed consent webpage on GCO and understanding of core pre-test concepts

METHODS:

- Eligible if English-speaking, age > 18 years, completed GCO usability testing
- Recruited from Craigslist and among STI clinic clients
- Structured interview guide, including copy of GCO consent webpage (Figure 1)
- Detailed review of transcripts and thematic analysis conducted in inVivo by single investigator (JF)
- Coding framework was initially based on informed consent theory, high-level themes identified by the interviewer (AB), and investigator input and refined iteratively

Figure 1: GetCheckedOnline informed consent page

Create Lab Form

Assessment 12Your TestsConsentPrint Lab Form

Consenting to Testing

Before you print your lab form, there are a few things you need to know before you can consent to get Sexually Transmitted Infection (STI) testing. Click on the <more> for more information about each statement.

☐

I understand that if I have any questions about the STI testing I can get more information from ??? before proceeding with STI testing.

☐

I understand that getting tested for STIs is voluntary.[More](#)

☐

I know what STI tests I am getting.

☐

I understand that the STI tests recommended require a urine sample for chlamydia and gonorrhea, and a blood sample for syphilis, HIV and hepatitis C. If the test is done too soon, it may not be able to detect the infection and I will need to be retested after the "window period" for each STI. I understand that GetCheckedBC does not offer all of the STI tests I might get if I went to an STI clinic.

☐

I know the benefits of getting STI tests.[More](#)

☐

I know the potential harms of getting STI tests.[More](#)

☐

I know a public health nurse will contact me with any positive results.[More](#)

☐

I understand GetCheckedBC is similar to, but not the same as, seeing a health care provider in person.[More](#)

☐

Want to learn more before you consent?

☒

I understand and would like to proceed with testing

RESULTS:

Table 1: Participant characteristics (N=13)

Characteristic	n (%)
Age (mean, range)	36 years (22-56)
Self-reported gender/sex	
Female	4 (31)
Male	9 (69)
Self-reported ethnicity	
White	7 (54)
Mixed	2 (15)
First Nations	1 (8)
Korean	1 (8)
Chinese Canadian	1 (8)
Canadian	1 (8)
Born in Canada	11 (85)
English as first language	10 (77)
Self-reported sexual orientation	
Heterosexual/straight	9 (69)
Bisexual	1 (8)
Gay	2 (15)
Missing	1 (8)
Highest level of education completed	
College or University	9 (69)
High school	2 (15)
Graduate School	1 (8)
Trade/vocational school	1 (8)
Ever tested for HIV or STI	13 (100)
Tested for HIV or STI in the past year	12 (92)

ACKNOWLEDGEMENTS:

The authors would like to thank the individuals who participated in this study. This study was funded in part by the Canadian Institutes of Health Research. The authors have no conflict of interest to disclose.

Theme 1: Meaning of informed consent

While perceived as important, participants explained the purpose of the consent page in different ways. Overall, the reason for the page was attributed to individual or agency protection (often for legal purposes).

For some, the content was at odds with their idea of what consent meant or should be.

And what this says to me is “we are protecting you” or “we are trying to protect you”, right? We’re here to help you, we’re not here to hurt you. And so I actually think just overall, especially this page, but the whole structure really defined the process of getting tested and the process of finding information. *Male, 30 years, gay*

I think people should consent to that “I understand that in rare cases there could be problems with the test and I may need to go for re-testing”. That is something all by itself. I don’t think you have to consent to saying that you may feel anxious waiting, etc. I don’t think that’s something you need to consent to because I don’t see how that protects. *Female, 42 years, straight/heterosexual*

Theme 2: Role of one’s experience on understanding consent

Participants understood the differences between online and in-person testing, drawing from prior experience. More experienced testers generally demonstrated greater understanding.

Participants who had previously experienced or anticipated potential harms showed a more nuanced understanding of informed consent.

Interviewer: Um, have you seen any of these questions before in other situations?
Participant: I think I’ve done the, well when I’ve done STI tests before I’ve come across some of these questions like saying that yes I know what I’m getting into, yes I know what I’m getting tested for, this and that, I had to fill out a form for that. So it wasn’t that new to me, these questions. *Female, 22 years, bisexual.*

Yeah, um it made me feel safe because it made it seem like you guys really wanted me to be protected. And wanted me to know what I was getting involved with and not trying to [...] to confuse me or trick me or coerce me into getting tested, it really pushed the whole feeling of free will. I’m here because I want to be here, and I’m here for myself not because I’m being tricked or coerced into it. Um and that’s really profound. This actually was one of my favourite pages of them all, I had a great emotional reaction because consent, confidentiality, like I’ve known people who’s lives that were destroyed because someone outed them as pos, right? I’m HIV positive, I have lots of friends who are [...]. And even similar stuff’s happened to me and it just, confidentiality is so important, and consent, um and like free will. *Male, 30 years, gay.*

Theme 3: Role of website design

The need for participants to check every box was seen as disrupting speedy “click-throughs”, increasing understanding, and conveying a sense of importance.

Drop-down features allowed participants to understand confusing statements, although hiding information also had its drawbacks.

Whenever iTunes updates it you just scroll to the bottom and you check this off and go. If you had to go through and check all of this stuff off you probably would be a little more cautious and read some of this stuff. So I think having all of the individual check marks as far making sure that the person who’s having the testing done is more educated as opposed to scrolling to the bottom, checking it off and proceeding. *Female, 22 years, bisexual.*

Yeah and if I was kind of um you know if it was my first time testing and I’m kind of shy and I’m not necessarily hyped to like go through and thoroughly explore the webpage. I would probably just fill out the form, you know, just click click click and then just assume okay I’m getting tested for everything. Unless it was like, you know, I would like, it would almost be like this would almost, the consent page would almost be a good place to remind people what’s not, what you’re not getting tested for. *Male, 33 years, straight.*

CONCLUSIONS:

- Principles of informed consent apply equally to online testing programs
- Overall, participants recognized the purpose of informed consent as being for individual and/or agency protection, although specific explanations varied
- Experienced testers, and individuals with prior experience or anticipation of testing harms demonstrated better understanding
- As online testing models evolve, understanding how better to meet the informed consent needs of less-experienced testers is critical.
- We found website design considerations to be highly influential on the consent process
- Achieving informed consent can be effectively achieved without detracting from the user experience – in fact, including a detailed informed consent step was valued and contributed to trust of the service

NEXT STEPS:

- GetCheckedOnline is now live and includes this consent page
- Further research is underway to:
 - Compare knowledge of pre-test concepts for individuals testing through GCO to individuals testing in-person
 - Interview GCO users about their perceptions of the consent page
- In this work, we will specifically examine differences based on testing experience (including first-time testers)

FOR MORE INFORMATION:

To talk during or after the conference please email mgilbert@ohtn.on.ca. To find out more about our research projects including this one please visit our website www.lovebytesresearch.ca or use the QR code for the full report

