

# Should your visuals be wearing blue, pink or yellow pants (or no pants at all)?

## Developing specimen self-collection instructions that are more sensitive to the needs of traditionally marginalized and underserved client populations

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### BACKGROUND:

- Self-collecting specimens for sexually transmitted infections (STI) and HIV testing is increasingly common, at home and in clinical settings.
- In British Columbia, self-collection will be recommended for some clients of a new online STI/HIV testing platform (*GetCheckedOnline*; *GCO*), however there is no existing protocol for self-collection of anal, pharyngeal, or vaginal swabs.
- We set out to develop self-collection protocol and accompanying materials effective and sensitive to the spectrum of bodies, genders, identities, experiences and sexualities of our client population.

### METHODS:

- We conducted focus groups to gauge acceptability of self-collection and review existing examples of instruction guides and test kits.
- Participants were recruited from STI/HIV clinics in Vancouver BC, and from Craigslist.
- Two focus groups were conducted at the BC Centre for Disease Control. One focus group was conducted with five self-identified men ranging from age 31 – 60 years old (average age 47.2 years old). The second focus group was conducted and one focus group with five self-identified women ranging from age 24 – 64 years old (average age 35.8 years old).
- Participants represented a range of education levels, ethnicities, and STI testing histories.
- Following focus group analysis, draft instructions were created with the feedback in mind, which were then usability tested with 11 new participants: these participants used the materials try the entire self-collection process, then debriefed the experience with a researcher.
- Usability testers ranged in age from 18 to 48 YOA with all but one under the age of 35; participants varied in gender identity including gender-variant, cisgender men and women and transgender men and women, all with a range of sexual identities.

#### Questions guiding usability testing with draft instructions

1. What are participants' initial perceptions of self-collection before and after doing the self-collection?
2. How do participants respond to each set of instructions (visuals, text, etc.) in practice?
  - Are the pictures that make specific direction on how and where to swab clear enough?
  - Do the pictures and instructions line up with/contradict how the participant sees, understands, relates to their body and/or sexuality?
  - Are the instructions professional and easy to read?
3. What steps do the participants take to make the process run smoothly and stay organized?
4. How do participants respond to the self-collection materials/kit in practice?
5. Do the participants feel confident in the quality of the swab they produced?
6. Would participants choose to do self-collection again?
7. After trying self-collection, what needs or additional information do participants request?

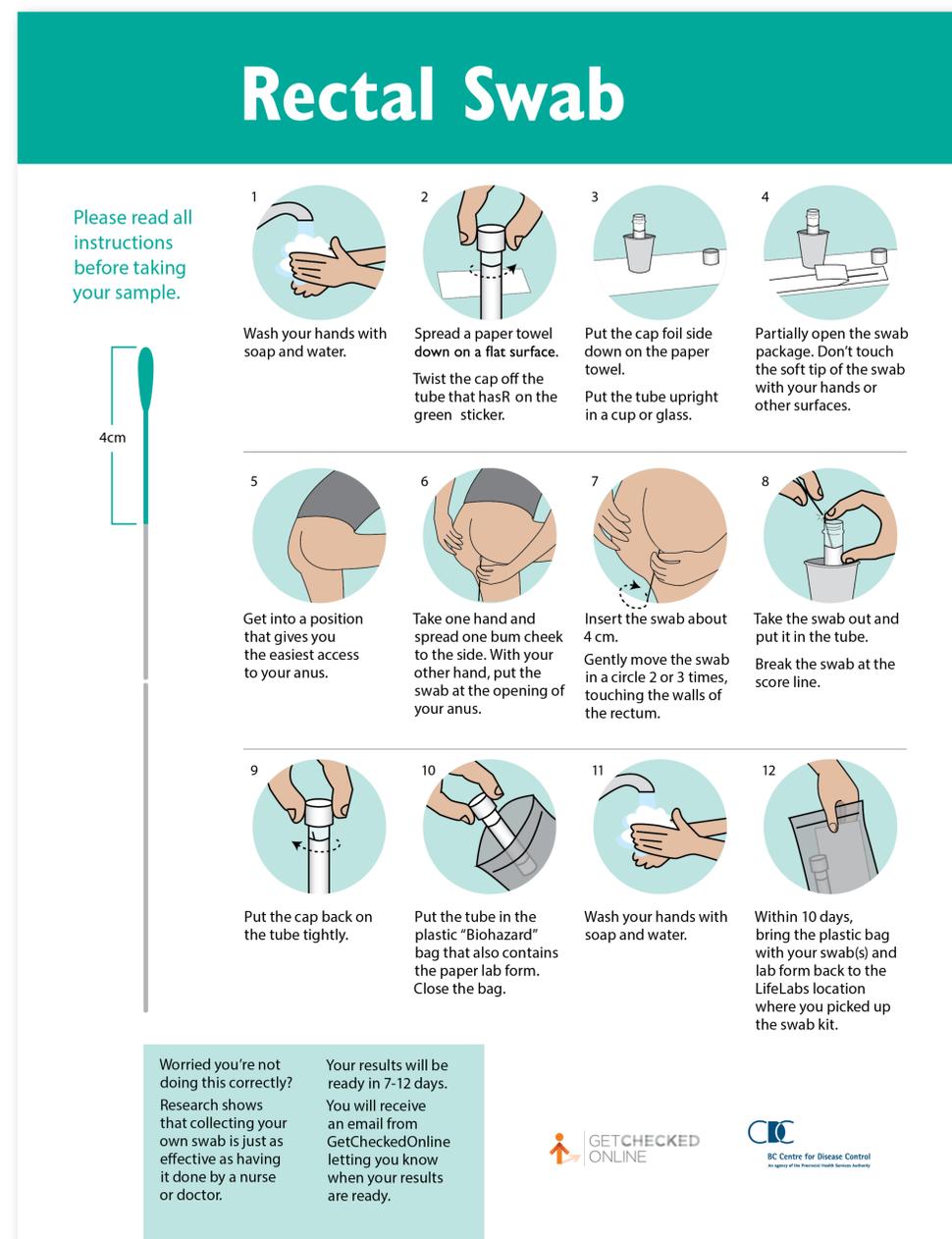
### RESULTS:

- Overall self-collection was acceptable to the initial 10 focus group participants; however, existing examples of kits/guides elicited distaste due to being overly gendered (pink/blue; girls/boys), complex, busy, wordy, hard to understand, and for having intimidating medical diagrams and visuals that depict genders that didn't necessarily match clients' genders or bodies.
- The 11 participants usability testing the final instruction guides testing kits considered them easy to read and understand, sensitive to various genders and sexual identities, and conducive to successful self-collection; many participants worried about the quality of their specimen which the researcher noted was most related to participants general clinical knowledge and experience as well as comfort with their own body.

#### Table 1: Responses to Focus Group Questions

Self-collection topic	Focus group responses
Acceptability	Overall high level of acceptability; Self-collection seen as a way to 'take control' of one's health, know one's own body; Clinics too dirty, busy, rushed, to do self-collection on site.
Preferred self-collection site	Strong preference for testing at home; Home is more comfortable; Some concern about losing relationships with health care providers (i.e., not needing to go to the doctor's office), particularly for people new to testing or with language/literacy challenges; Collecting specimens at the lab difficult due to cramped space, don't want to carry specimens through the waiting area; Mailing samples seen as useful in rural areas, but some uncertainty about cost and reliability of delivery.
Instructions	Initial fear about being able to collect specimens correctly, particularly among women, however once instructions were shared participants felt very confident; Suggested having instructional posters in the lab bathrooms (if collecting at the lab) to avoid clients having to carry in one more thing; Not much support for online instructions – participants did not think they would read these online ahead of time or print them out.  Visually participants liked a clear description of where to swab; Thought an institutional logo added legitimacy; Clear, anatomically correct language was not considered embarrassing; Written instructions most effective when paired with pictures.
Materials and kit	Having one package for both sexes (with both urethra/cervical instructions on the swab) was confusing; Colour-coding was considered ideal; It was important to participants to have clear labeling between the swab and self-collection instructions.
Additional considerations	Participants wanted to know how long results would take – instructions that included this information were preferred; Instructions should provide information about privacy and what to do in the case of a positive result; Refer to other more familiar procedures (e.g., PAP smear, urethral swab) to help clients understand how to collect their specimens; Provide instructions ahead of when they will be asked to provide specimens.

Figure 1: Self-collection instructions created for GetCheckedOnline



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### FOR MORE INFORMATION:

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