


# “They Should Be Asking Us”: A Qualitative Decisional Needs Assessment for Women Considering Cervical Cancer Screening

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## Abstract

In this study, we examine from multiple perspectives, women’s shared decision-making needs when considering cervical screening options: Pap testing, in-clinic human papillomavirus (HPV) testing, self-collected HPV testing, or no screening. The Ottawa Decision Support Framework guided the development of the interview schedule. We conducted semi-structured interviews with seven screen-eligible women and five health care professionals (three health care providers and two health system managers). Women did not perceive that cervical screening involves a “decision,” which limited their knowledge of options, risks, and benefits. Women and health professionals emphasized how a trusted primary care provider can support women making a choice among cervical screening modalities. Having all cervical screening options recommended and funded was perceived as an important step to facilitate shared decision making. Supporting women in making preference-based decisions in cervical cancer screening may increase screening among those who do not undergo screening regularly and decrease uptake in women who are over-screened.

## Keywords

decision making screening and prevention, cancer; women’s health, gender; agency; qualitative research; screening, health care

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High-quality health care is based on person-centered and evidence-based philosophies. In particular, health decisions should reflect individuals’ preferences among the best available options that are supported by research and available resources (Haynes, Devereaux, & Guyatt, 2002; Hoffmann, Montori, & Del Mar, 2014; Lang et al., 2018; Umscheid, 2009). Shared decision making provides an opportunity to implement evidence-based practice that accounts for patient preferences, such that when multiple options are available to patients regarding a specific health decision, individuals’ personal characteristics and values will influence the best choice for them (Hoffmann et al., 2014; Stacey et al., 2017). However, the use of shared decision making in cancer screening is seldom used and such approaches that have been used are diverse (Elston Lafata, Brown, Pignone, Ratliff, & Shay, 2017; Hoffmann et al., 2014).

Traditionally, cancer screening decisions are made through a population health lens in which clinical practice guidelines have been developed, with individual health care providers

promoting the recommendations therein. Individuals, however, are considered compliers if they decide to accept the offer of screening recommended in the guidelines, but usually are not presented the opportunity to make an informed decision about participation (The Lancet, 2016; Sandman, Granger, Ekman, & Munthe, 2012). With new technologies developed to screen for cancer, there are more cancer screening decisions leading to more options presented to individuals

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and health care professionals (Lillie et al., 2014). Decisions about screening modality, frequency of screening, and starting and stopping age are inherently preference-sensitive, suggesting that individuals and health care professionals could use shared decision making to identify the optimal option.

The most recent cervical cancer screening guidelines at a national level in Canada (Dickinson et al., 2013) and provincial level in Ontario (Murphy et al., 2011; Murphy et al., 2012) recommend that the long-standing Papanicolaou (Pap) primary screening test be replaced by testing for high-risk strains of human papillomavirus (HPV), of which have been found to be a causative factor in the development of cervical cancer. Compared to the Pap test, HPV testing of samples obtained by a health care professional offers increased sensitivity, a slightly decreased specificity, and different rates of false positive and false negative test results (Koliopoulos et al., 2017). HPV testing can be conducted on self-collected samples with slightly decreased sensitivity and specificity compared to samples collected by a health care professional (Arbyn et al., 2014). These different options are also associated with different recommended intervals between screens (e.g., 3 years for a Pap test, 5–6 years for an HPV test), and different ages to start and stop screening. Recent systematic reviews suggest that most women find self-sampling preferable to clinician-collected sampling (Braz et al., 2017; Nelson et al., 2017; Racey, Withrow, & Gesink, 2013; Verdoodt et al., 2015) because of factors related to ease, ability to conduct the testing without a health care professional or by themselves, privacy, and lack of embarrassment.

These three screening modalities (e.g., Pap testing, HPV testing in-clinic, self-collected HPV testing) and the option not to participate in screening are associated with distinct trade-offs between the benefits (e.g., ability to predict cervical cancer risk) and harms (e.g., false positives and false negatives). As these options differ in convenience, privacy, and invasiveness, individuals should actively participate in discussions with their providers to decide their best option. HPV testing modalities also differ from other cancer screening options because of implications of testing for a sexually transmitted virus; stigma surrounding this type of testing may affect how individuals make trade-offs in these decisions. However, provincial and national guidelines have not addressed individuals' values or preferences among these cervical screening options (Sawaya & Kuppermann, 2015), and have not provided explicit guidance for eliciting preferences. Table 1 presents the existing options for cervical cancer screening in Ontario. In the shared decision-making literature, there are no decision support tools relating to these options (Jimbo et al., 2013; Lillie et al., 2014; Stacey et al., 2017).

Evidence-based guidelines use a utilitarian approach to creating population-based recommendations (National Collaborating Centre for Healthy Public Policy, 2016). Health care professionals (HCPs) who use these guidelines often feel obligated to promote the recommendations, despite individuals' preferences for alternative options (Jepson, Hewison,

Thompson, & Weller, 2005; Petrova, Dale, & Fulford, 2006; Trevena, 2009). The divide between population and individual perspectives may be augmented for cancer screening programs or policies because of the requirements of a mass screening program (i.e., a defined, long preclinical phase, need for accurate and reliable tests, demonstrable effective early treatment; Salmi, Coureau, Bailhache, & Mathoulin-Pélissier, 2016). Shared decision-making processes can reconcile individual and population perspectives for cancer screening by addressing the individual acceptability of tests in the context of HCP values and evidence-informed recommendations (Grad et al., 2017; Lang et al., 2018). Therefore, a shared decision-making framework can guide processes to elicit preferences in cancer screening, aligning with person-centered and evidence-informed practice (Hoffmann et al., 2014; Zhang et al., 2017). To support preference elicitation and shared decision making in cervical cancer screening, we need to know how stakeholders, including women eligible for screening and HCPs, perceive the decision.

## Theoretical Framework

The Ottawa Decision Support Framework (ODSF; O'Connor, Jacobsen, & Stacey, 2002; O'Connor et al., 1998) is a decision support framework incorporating expectancy value, social support, cognitive, and psychology theories (Ajzen & Fishbein, 1980; Feather, 1982; Fischhoff, Slovic, & Lichtenstein, 1980; Janis & Mann, 1977; Keeney & Raiffa, 1993; Norbeck, 1988; Orem, 1995; Tversky & Kahneman, 1981). This framework was validated in previous research involving individuals and families making health and social decisions (Feenstra, Lawson, Harrison, Boland, & Stacey, 2015; O'Connor et al., 1999; Poirier et al., 2016). The goal of shared decision making is to promote a well-rounded decision process rather than a particular action (Lillie et al., 2014); therefore, assessment of shared decision-making processes would consider decision-relevant outcomes. Shared decision-making processes are separated into three constructs: decision quality, decision impact, and decision action. Good decision support would assure that individuals feel informed and that they can clearly articulate the characteristics that are most important in making a decision (i.e., decision quality; Fischhoff et al., 1980; Llewellyn-Thomas & Crump, 2013; O'Connor, 1995; O'Connor et al., 2002; O'Connor et al., 1998; Tversky & Kahneman, 1981). In addition, individuals would feel that they are satisfied with the decision process and do not experience decisional conflict (i.e., decision impact; Llewellyn-Thomas & Crump, 2013; O'Connor, 1995; O'Connor et al., 2002; O'Connor et al., 1998). There is no ideal cancer screening action or intended behavior; instead outcomes focus on making decisions consistent with individuals' preferences and values (Lillie et al., 2014; Sepucha et al., 2013; Stacey et al., 2017). At a population level, a 2017 review found that decision support increased under-use and decreased over-use of some

services, for example, prostate cancer screening (Stacey et al., 2017). Patients who are active in decision making are more likely to have better health outcomes and care experiences, at a potentially lower cost to the system (Hibbard & Greene, 2013; Hoffmann et al., 2014; Stacey et al., 2017).

Cervical cancer screening promotion and programming often occurs in a multi-disciplinary primary care team environment, following the broader shift in primary care toward patient-centered medical homes (Bryant-Lukosius et al., 2015; Kiran, Kopp, Moineddin, & Glazier, 2015). Because nurses play a key role in facilitating communication between patients and their interprofessional care team, they are well-positioned to support women who are making cervical cancer screening decisions (Légaré et al., 2011; Registered Nurses' Association of Ontario [RNAO], 2015; Stacey, Légaré, Pouliot, Kryworuchko, & Dunn, 2010). Furthermore, nursing professional standards in Ontario highlight the role that nurses play in advocating for patient-centered care (RNAO, 2015), including shared decision-making approaches.

According to the ODSF (Llewellyn-Thomas & Crump, 2013), *values* refer to individuals' informed attitudes about relative desirability or undesirability of the characteristics of a decision's options. Instead of considering values as the underlying ethical, religious, social, or political principles that guide how individuals judge different situations (Pieterse & Stiggelbout, 2016), values are associated with how individuals assess the specific attributes of each option. *Preferences* are constructed from individuals' informed attitudes toward the detailed characteristics of each option, in which the preference is the most-favored option.

Decision support interventions can address decision quality through five steps: (a) Recognition that a decision needs to be made; (b) Understanding information related to the decision; (c) Clarification of values and identification of preferences according to these values; (d) Consideration of resources, including social influences, that affect the decision; and (e) Formation of an action plan (Lillie et al., 2014; Llewellyn-Thomas & Crump, 2013).

## Research Objective

The objective of this study was to examine, from multiple perspectives, women's needs for shared decision making when considering available cervical screening options: Pap testing, in-clinic human papillomavirus (HPV) testing, self-collected HPV testing, or no screening. Understanding women's knowledge needs and the values that shape their cervical screening decisions is important for shared decision making. Because shared decision making involves bilateral flow of information, nurses, physicians, and professionals (HCPs) who develop or administer cervical cancer screening guidelines can offer alternative perspectives on how women make decisions in cervical screening, sources of decisional conflict

for women, and methods for implementing decision support in practice.

## Method

Using a qualitative, semi-structured interview approach, we interviewed multiple stakeholders, including women and HCPs to determine what women need to identify their preferences among cervical cancer screening modalities, based on a shared decision-making framework. This study was approved by the Ottawa Health Science Network Research Ethics Board (Protocol #20,160,134-01H). All respondents provided informed consent at the beginning of the interviews.

## Participants

Participants were eligible if they were 18 years or older, had knowledge of the Ontario health care system (as a patient or HCP), and could participate in an English-speaking interview. Study participants included two groups of stakeholders. The first group comprised women who would be eligible to consider participation in the Ontario cervical screening program; previous experience with screening was not required. Screening participants were selected purposively based on age categories (e.g., <35, 35–54, 55+) and ethnicity (e.g., European descent, First Nations/Inuit/Metis, immigrant or another minority population). The second group comprised of health care professionals (HCPs) including primary care providers who provide cervical cancer screening to their patient population (i.e., *providers*) and non-clinical professionals who develop and administer cervical cancer screening recommendations (i.e., *managers*). These individuals were purposively selected based on their role within the cervical cancer screening program (e.g., through local policy/management, through provincial guidelines and policy, through direct clinical care). These professional groups play substantially different roles in how cervical cancer screening is delivered but share a common role as “health experts.” In this context, HCPs were familiar with cervical cancer etiology, population-based cancer screening and guidelines, and the organization of the Ontario health system.

HCPs were recruited by contacting clinics in the Champlain Local Health Integration Network region in Ontario, Canada, and relevant cancer screening agencies. Clinics were purposively based on geographic area (urban and rural) and targeted communities with high proportions of Indigenous or Francophone clients and/or vulnerable populations, including newcomers to Canada, those affected by mental illness, or low-income residents. The research team worked with the clinics and HCPs to identify screen-eligible women who met the aforementioned age and ethnicity criteria. Researcher contact information was also shared with community groups and patient advocacy groups to recruit screen-eligible women.

**Table 1.** Existing Cervical Cancer Screening Options in Ontario.

Option	Guideline Recommendation	Funding Status
Cervical cytology/Pap test	Recommended by Cancer Care Ontario in interim guidelines Recommended by the Canadian Task Force on Preventive Health Care	Screening according to Cancer Care Ontario guidelines is covered by public insurance
Provider-administered HPV testing	Recommended by Cancer Care Ontario	2017 provincial budget allocated funding toward HPV testing, but not implemented
Self-collected HPV testing	Recognized as an option for HPV testing, no explicit mention in guidelines	No funding; can be privately purchased online
No screening	Not applicable	Not applicable

Note. HPV = human papillomavirus.

**Table 2.** Overview of Needs Assessment.

ODSF Steps to Shared Decision Making	Guiding Questions
Recognize the decision to be made	What do you perceive as important decisions for you/women in cervical cancer screening? Have you considered options in cervical cancer screening modalities? How might you/women feel making decisions about cervical screening? What difficulties might you/they have? What will make the decision difficult for you/women? Knowledge Expectations Values clarity Support Resources
Information comprehension	What do you see as the main options? What do you see as the main benefits and risks of these options?
Values clarification and preference elicitation	What qualities about these screening options are most important to you? (Potential screening participants only) For example, convenience, process of test, length of time to get results, costs, invasiveness, access, follow-up procedures, sensitivity/specificity
Identifying necessary social support and material resources	What supports do you or other women need to make this decision? What will help/hurt the decision-making process? What will help overcome some of these issues? What are the barriers and facilitators to offering options in cervical screening? What options are available to support women in making decisions about cervical cancer screening? What might be the “best” option for a cervical screening decision tool (e.g., Internet, phone app, etc.)?
Forming an action plan	What do you perceive as implementation facilitators and barriers? (HCPs only) What personal, clinical characteristics are important in decision making?

Note. ODSF = Ottawa Decision Support Framework; HCP = Health care professionals.

Recruitment continued until data saturation was reached for all guiding categories (further details in Analysis section).

In-person or phone/video interviews were arranged between July 2016 and November 2016. At the beginning of each interview, the project was explained to each respondent, and respondents' questions were answered before obtaining written informed consent. Contact cards were provided to the respondents if they wished to follow-up with the interviewer after the interview. Interviews lasted between 30 and 60 minutes and were conducted by Brianne Wood (BW), a researcher trained in the ODSF who was familiar with cervical screening guidelines.

### Data Collection

Semi-structured interview guides were developed separately for women and HCPs based on the ODSF and its Population Needs Assessment guide (Jacobsen, O'Connor, & Stacey, n.d.; see Table 2 for an overview of the interview guide). The interview guides contained open- and close-ended questions based on these steps, eliciting from screen-eligible women and HCPs what cervical screening decisions women face, what information women may need to make decisions, values that affect their decision, and the support and resources women may need to make a screening decision among

cervical screening modalities. Demographic data on each participant were also collected during the interview. Respondents were asked if they wanted to receive communication about the project, following the interview; those who expressed interest received an email with a high-level summary of the analysis findings. Feedback or comment on the interpretation of the data was invited.

## Analysis

The interviewer took field notes during each interview and composed interview summaries afterward, allowing for reflexive analysis (Alley, Jackson, & Shakya, 2015). All interviews were audio-recorded using a tablet with an external microphone. Digital recordings were transcribed using an intelligent verbatim process, which includes light editing to correct sentences and grammar to improve overall readability. Before interviews were conducted, a coding dictionary was created using the ODSF overarching steps (Table 2) as guiding categories (Jacobsen et al., n.d.), and the codebook fields outlined by Guest, Bunce, and Johnson (2006, p. 64). In particular, each code definition contained a code overview, a full definition, a “when to use” section, a “when not to use” section, and an example of the code. Transcripts were analyzed chronologically during data collection (NVivo qualitative data analysis Software; QSR International Pty Ltd. Version 11, 2016), using deductive content analysis (Hsieh & Shannon, 2005; Varpio, Ajjawi, Monrouxe, O’Brien, & Rees, 2017) with respondents as the unit of analysis. During the analysis, additional codes were developed and added to the codebook, and current code definitions were updated to reflect the nuances presented in the interviews (Hennink, Kaiser, & Marconi, 2017). Previous coding was reanalyzed to assess consistency with the new code definition, and a new code was added if necessary. The iterative approach was important to help determine when saturation was reached. A categorization matrix (Elo et al., 2014) was created to depict which categories were communicated by stakeholder groups, and to indicate when code definitions were added or changed to document saturation. Another member of the study team (Virginia Russell [VR])—an expert in qualitative research—reviewed the codebook to assure clarity of the definitions. VR independently analyzed each transcript to ensure complete and appropriate coding of important themes. Coded segments were assessed and refined further to concisely represent the data. Discrepancies in how segments were interpreted were resolved through dialogue between BW and VR.

In this study, we sought to triangulate different stakeholder perspectives (Fusch & Ness, 2015; Légaré et al., 2007) to gain an in-depth understanding of women’s needs to make an informed decision among cervical screening modalities. In particular, we elicited multiple perspectives on women’s decisional needs for cervical cancer screening modalities, to understand how women’s decisional needs are influenced by individual, provider, and health system

factors. We looked for convergence in how ODSF steps were interpreted by stakeholders to identify opportunities to support women’s decisional needs. Any diverging interpretations were explored in further interviews. The sample size was considered adequate once a diverse sample of stakeholders had been recruited (Guest et al., 2006), and study authors considered that no further interviews would generate insight to help address the research objective (O’Reilly & Parker, 2013; Varpio et al., 2017). A category was considered saturated when the code meaning was determined stable for each of the stakeholder groups (Varpio et al., 2017).

## Results

### Participant Characteristics

In total, seven women eligible for screening and five HCPs were interviewed—three providers and two managers. Of seven screen-eligible respondents, women’s ages ranged between 24 and 63 years. Two Indigenous respondents participated, as well as one Francophone respondent, and two women who identify as immigrant or first-generation Canadian. Most screen-eligible respondents had previously had a Pap test. Among HCPs, two nurses and a general practitioner represented clinical providers, and a director of a health center and a provincial cancer agency director were interviewed as managers. Among the HCPs, one respondent identified as male.

Three screen-eligible respondents who were recruited from the same organization (an Indigenous health organization) were interviewed in a group setting, when they identified at their interview session that they preferred a group interview instead of separate one-on-one interviews. As the interview was the first time that the respondents had met in-person with the interviewer, they communicated that they felt more comfortable discussing some of these sensitive health topics together. One respondent (Woman 1) recruited the two other respondents (Woman 2, Woman 3) and organized the interview space, but did not dominate the interview conversation. There was a large focus on HPV and cervical cancer information in this session, with the discussion exploring opportunities for them to choose among cervical cancer screening options.

The main themes are organized below by the ODSF steps to shared decision making.

#### 1. Recognition that a decision needs to be made

Most screen-eligible women had not considered participation (or non-participation) in cervical screening as a *decision*. Instead, a Pap test was perceived as an obligation for women of a certain age, thus women would not actively choose to avoid a Pap test. Rather, women might defer cervical screening, or they might want to attend screening but face

barriers accessing the health care system. When asked about decisions that they had faced with cervical screening, most respondents expressed confusion; they had not considered “no screening” a viable option:

It was just sort of best practice or recommended by the doctor to have it done, so I really didn't give it much thought and just had the procedure. (Woman 6)

I thought it was maybe about the right time to get a Pap test done. So, that was just my reason—like my age. (Woman 7)

Both groups of stakeholder respondents identified that women may prefer a female health care provider, although the choice among options still was not perceived as a decision.

In 2012, Ontario cervical screening guideline extended intervals between screens from annual Pap tests to 1 every 3 years, and some respondents—including female HCPs—preferred more frequent screens than recommended. Despite this preference, respondents felt they could not act on their preferred options because they were limited by the provincial guidelines and funding:

OHIP [Ontario Health Insurance Plan] doesn't [sic] cover Pap smears once every 3 years now. For women, not every 6 months . . . that's the law now. (Woman 3)

When it's due, I want it done. And I prefer it actually be done more often than [chuckles] is recommended now, but I'm okay with that. (HCP 3)

Manager HCPs felt strongly that women's options in cervical screening should be governed by guidelines developed by cancer agencies, which was echoed by provider HCPs who currently decide the types of tests to offer women for cervical screening:

So it is confusing to make the choice once there is more of a choice because there's not too much of a choice yet, right? . . . Central and national guidelines [are important] because they give individuals as well as primary care providers some framework around the decisions that they make. (HCP 5)

Despite their perceived lack of choice, screen-eligible women wanted to choose between options. Although they wanted to know more about these options, they also wanted to engage with their primary care provider to make a decision. Interestingly, most of the potential screening participants focused on the self-collection option of the test, paying less attention to new diagnostic processes, suggesting that having options that differ in sample collection process as well as diagnostic performance might make decision making more complex:

I like the idea of having multiple options, but I think if you say that, for example, if I decided I have my Pap test but I still decided to do the HPV test and I realized that it was positive, then you said well sometimes you can have a virus but it's not a

big deal because it's going to go away on its own. . . . So I guess it has two sides, like it's good because that would be something convenient. But at the same time, we are not doctors. We don't know those things so maybe it would create more people going to the clinic that we really need. (Woman 5)

## 2. Understanding information related to the decision

Most respondents did not know that several options were available for cervical screening in Ontario, or that they faced a decision between in-clinic Pap testing, in-clinic HPV testing, self-collected HPV testing, no screening. A portion of each interview involved communicating what is known about HPV, cervical cancer, and current initiatives for prevention, detection, and treatment of cervical cancer to screen-eligible respondents. Three of the screen-eligible respondents had not heard of HPV previously, although they had previously participated in cervical screening. Except for one woman who had learned about self-collection through work, six screen-eligible respondents had not realized a self-collection option existed:

I think the questions I would ask and stuff, like, oh, how does it work and what's the process it's going to be like? Does it hurt? Especially like for myself when you've never got screened before. I'll probably feel like very anxious and like scared of doing it myself for the first time. (Woman 4)

HCPs were more aware of the connection between HPV and cervical cancer, although three HCPs wanted further information about new cervical screening options, suggesting that more work in knowledge translation with professionals in the health field is needed. A provider argued that these options were hypothetical at this point because HPV testing is not yet funded, so communication opportunities might be premature. As a result, HCPs were concerned about communicating options that were not universally available:

Because so far there isn't that option [for self-collected HPV testing], so there isn't any discussion like that. It's just me explaining you could get cervical cancer. It can be detected before it becomes cancer. This is how it's done and it's recommended to start at age 21. We do it every three years. So I explain that and then they say okay. And they go for it. (HCP 2)

I would imagine there would be some of our clients, patients, who would ask about it [the HPV test] because they would have heard about it, known about it . . . you know, you really would have to ask them [the clinicians who administer the Pap tests] if they raise it [the options for cervical cancer screening] with women who they know could not pay for the test. (HCP 1)

Although options other than Pap tests are accessible through private payments, clinicians may not engage in knowledge exchange with their clients because the options are not addressed in the practice guidelines, nor are they funded by the public system. HCPs conveyed a sense

of paternalism—that women’s decision making should be contained within the evidence-based guidelines—which coincided with a desire for women to have the autonomy to make informed decisions. Some HCP respondents recognized this contradiction throughout the interview and struggled with balancing autonomy of women versus the population-based goals of a screening program:

‘I’m a very big believer in clients making choices . . . And if it’s a bad choice, it’s still their choice and they have all the right in the world to make that choice.’ (HCP 4)

I think most screening programs, not just in Canada but definitely in the U.K. [United Kingdom] and the Nordic countries have moved towards a more balanced message. I do struggle a little bit with that because okay, so I want women to have a balanced message about the benefits and harms of cervical cancer screening, right? (HCP 5)

Both screen-eligible women and HCPs identified that all stakeholders (i.e., women, providers, managers) need more information about the cervical screening modalities, the processes, the risks, and benefits of these options, and how these options appeal to individual women. Women wanted more information so that they could weigh the cervical screening options and consider what aspects of screening are most important to them:

I guess like if you’re going to a clinic and an expert is helping you screen it, then I think the information you would want is, like, oh what are you going to do and, like, how does it work in general and the process and like how long or how often does it come back to get screened? Whereas for like, if you’re doing a self-test, for me I would want to know, like, more information, I would probably have to like want to reassure myself that I’m doing things correctly. (Woman 4)

### 3. Clarification of values and identification of preferences according to these values

Because in Canada we balance, an individual’s choice with what’s good for the population and what we can afford as a society, right? (HCP 5)

Attributes that respondents thought would affect women’s screening decision were organized into three main categories: characteristics of the sample collection process, characteristics of result follow-up and communication, and importance of cervical cancer and early detection. As mentioned previously, women and HCPs tended to focus on the decision between in-clinic cervical screening versus self-collected (e.g., “at-home”) cervical screening versus no screening, expressing less concern about a change in diagnostic procedure. (i.e., cytology vs. HPV testing).

Screen-eligible women were primarily concerned with sample collection and the convenience among the different modalities. Women’s comfort with the sample collection pro-

cess often related to prior traumatic or painful screening experiences, and their confidence to collect a sample themselves:

But they’re kind of similar, I think the questions I would ask and stuff, like, oh, how does it work and what’s the process it’s going to be like? Does it hurt? Especially like for myself when you’ve never got screened before. I’ll probably feel like very anxious and like scared of doing it myself for the first time. (Woman 4)

HCPs expressed more concern about the socioeconomic impact of offering cervical screening modalities that require women to pay out-of-pocket and the implications of varying laboratory quality of the screening tests:

So you have to understand that the clientele that we have here are low income is over 50 per cent. We have some low income and our mandate is to serve low income seniors and new immigrants. So it is a huge consideration for them not going forward with that. And a lot of females with low income don’t mind coming in for Paps and testing. I’m generalizing, but I don’t want to generalize in any way. So it’s not about the testing itself and feeling uncomfortable with doing it. It’s just about the cost. (HCP 4)

Women and HCPs expressed concern about communication and follow-up of results. Both groups of stakeholders were concerned about privacy when communicating results, noting that current Pap test results are shared via letters from a central provincial agency. The lack of personalization of these letters and potential for ambiguity was worrisome for providers and women, although not mentioned by managers. In the following excerpt, a provider communicates frustration with the current result communication system in Ontario, suggesting that the letters to participants do not clearly articulate what screening results mean, and might cause distress:

Like they [women eligible for screening] know what they would want if they think it through is for their doctor to tell them and to not have to wait for the doctor to say it is not normal and then tell them what that means and not get this message that it’s not normal. Then have to wait for whatever length of time to find out what it means and in the meantime being scared to death of the implications. (HCP 2)

The change in approach to detection of cancer and precursor lesions—from looking for cellular abnormalities with Pap testing to detecting the presence of a high-risk sexually transmitted virus with HPV testing—was considered important because of stigma associated with sexually transmitted infections. Women and HCPs suggested that methods to follow-up positive results would require careful communication with women. Unsurprisingly, women were concerned with the privacy and confidentiality of how results, including HPV positivity, would be communicated. The following interaction occurred in the first interview with three women, who had recently learned about the connection between HPV

and cervical cancer, and how cancer screening would involve testing for a sexually transmitted infection:

Confidence is the main thing. Because there's a stigma related [to a] sexually transmitted . . . (Woman 3)

Oh you whore or whatever. (Woman 1)

A moral responsibility to be healthy and participate in healthful behaviors influenced how women contemplated cervical cancer screening options, which was reiterated by HCP and screen-eligible women respondents. The inherent "good" value of cancer screening was emphasized as many respondents described cancer screening participation as healthful. Most respondents ignored the "no screening" option because it was implied that when someone was appropriately informed, they would choose to participate in cervical screening. This conviction that any cervical screening would necessarily improve one's health was also related to certain risk expectations of cervical cancer; women were more enthusiastic about cancer screening when they perceived themselves at a higher risk of developing cancer:

But if it [other option's diagnostic performance] was different or the sensitivity or the results were different between the options, obviously it would be my first deciding factor. (Woman 7)

A manager HCP agreed that public health enthusiasm for cancer screening could be responsible for an automatic acceptance of screening:

I imagine that's how most women make their decisions and I think a lot of it is probably not evidence based and not balanced and not good quality information. And screening programs used to be part of that because we were like you should be screened no matter what. (HCP 5)

While women and HCPs seemed to identify similar attributes that could influence cervical screening decisions among modalities, they judge them differently. Women focused on decision making at an individual level and were concerned about personal risks and benefits, while HCPs often spoke of patient populations and collective risks and benefits, reinforcing the population perspective of cancer screening programs.

#### 4. Consideration of resources, including social influences, that affect the decision

Respondents indicated that primary care providers were most likely to influence women in their decisions among cervical screening modalities. Notably, it seems that screen-eligible respondents who had a consistent primary care provider were more likely to turn to a clinician for input into their decisions. Screen-eligible respondents explained that they rarely involved friends or family in cervical screening

decisions, although one HCP noted that women from certain religious groups might prefer to involve their husbands because of the invasive nature of the sample collection:

Anybody's welcome to stay as long as the client wants them to. So we found that East Indian women very uncomfortable with it and need almost that family support around for them. (HCP 4)

Women and HCPs recognized the counseling that primary care providers can offer women in preventive health care. Screen-eligible respondents emphasized the importance of access to a provider whom they trust, explaining that would influence how they or others choose to participate in screening:

I was very lucky because . . . it took no time to have a family doctor first of all. Because one thing I find is that I wouldn't want just any doctor to do the Pap test. (Woman 8)

Screen-eligible women wanted to feel comfortable with the person who is administering the invasive cervical cancer screening; some women mentioned that a lack of familiarity with a provider made self-sampling more appealing. HCPs agreed that cervical cancer screening with the Pap test requires a lot of trust because of the pelvic exam but added that providers help their patients feel supported if abnormalities are found.

More broadly, screen-eligible women "trusted" their primary care provider to offer them any screening tests or preventive health care for which they are eligible. Provider HCPs also noted that their patients will frequently accept cervical cancer screening when they are introduced to it opportunistically. A manager HCP identified that women who are more likely to participate in preventive health care, such as cervical screening, will already have a trusting relationship with a primary care provider; conversely, women who are not attached to a primary care provider are less likely to participate in screening:

[I]t's almost like a bit of a catch-22 because if you're a woman and you're in a position to have that somewhat personal conversation with someone, you're also in a position to be more likely to be screened. (HCP 5)

All respondents communicated that women need some external support to make a decision among screening modalities, with suggestions ranging from educational campaigns to public funding of all options. Some respondents suggested that tailored approaches are needed to reach women from different populations. For example, two Indigenous respondents indicated that they would prefer learning about cervical screening through an online source, and they feel most comfortable accessing health care that is tailored to Indigenous women. Another woman indicated that "clear instructions in both languages [French and English]" were important for



communicating the cervical screening options. A manager HCP seconded this bilingual preference and emphasized the importance of structuring support for immigrant and refugee women, as well as women who have experienced sexual trauma.

Most women considering screening felt confident that they could choose their preferred screening modality if they received more information, in the absence of primary care provider input. While discussion groups (e.g., at a public health unit) were considered a satisfactory option by a few women, most women preferred to learn about the options independently through materials they could find online or in a public space, or through a one-on-one conversation with a health care provider. Several of the women mentioned wanting “several sources” of information before deciding on a screening modality:

I would say the website, kind of getting different information from different sources, only because the majority of us have access to like internet. . . . I also sometimes look at different experiences . . . I used to go for different sources because you just want to check the facts and one website might cover something that you never thought about before. (Woman 4)

#### 5. Formation of an action plan

They [health care professionals] should be asking us. (Woman 2)

Overall, respondents acknowledged women do not perceive that undergoing cervical cancer screening involves a decision, which women attributed to a lack of awareness and HCPs attributed to the context of a population-based screening program. As new modalities are implemented, screen-eligible women and HCPs identified provider-patient encounters as an optimal environment to have a conversation about screening options. Subsequently, respondents identified that women and primary care providers need support from the cancer screening program to ensure that they have sufficient information and resources to engage in these conversations. HCPs looked to clinical practice guidelines and funding organizations to catalyze this change:

What’s available, if we don’t have the funding then they [policy-makers] can’t recommend it. (HCP 2)

Most respondents emphasized that support from cancer agencies and funding bodies was important to make cervical cancer screening options accessible. Having all options covered under the public insurance plan was important to implicitly establish that the screening options and entire program were trustworthy. For screen-eligible women, public funding would reinforce the notion that governments are not solely concerned about saving money and that all options

were “good.” For HCPs, public funding of all options symbolized confidence in the scientific evidence behind these options. Having multiple options available within the organized cancer screening program would allow screen-eligible women to make preference-based decisions in cervical cancer screening, while meeting the objectives of a population-based program:

[I]f it’s [the screening modality] well explained, if the price is good . . . If it’s something that’s accessible anywhere that anybody can buy anywhere, why not? (Woman 5)

So I think by doing all of these things through an organized screening program and having that structure, you have the opportunity to ensure that women are not over screened or at least help to make sure women aren’t over screened and to try to target unscreened women (HCP 5)

## Discussion

In this qualitative interview study, we observed that screen-eligible women and HCPs do not perceive participation in cervical cancer screening as a health decision, but rather, it is an opportunity or an obligation. Most respondents were reluctant to identify “no screening” as an acceptable option. Recognizing that a decision among cervical screening modalities exists for women is crucial for high-quality shared decision making, according to the Ottawa Decision Support Framework (O’Connor et al., 2002; O’Connor et al., 1998). Other decisional needs identified in this study include women’s knowledge of cervical screening options and associated risks and benefits, and resources to support them in decision making, most notably a trusting relationship with a primary care provider.

Cancer screening decisions are thought to be inherently preference-sensitive (Lillie et al., 2014; Stacey et al., 2017), although cervical cancer screening has been under-represented in shared decision-making literature (Jimbo et al., 2013; Lillie et al., 2014; Stacey et al., 2017). In Canada, Pap testing had long been the only screening option available for early detection of cervical abnormalities and cervical cancer. Consistent with the health messaging by media campaigns, Pap testing might have seemed like the *correct* option. Even now, as the Pap test is the only publicly funded option among available modalities aside from not screening, respondents asserted that informed women would choose to participate in screening. This public and professional enthusiasm for cancer screening has been discussed previously (Schwartz, Woloshin, Fowler, & Welch, 2004; Shieh et al., 2016) and likely contributes to the perceived imperative to participate in cervical cancer screening.

With regard to eliciting preferences among Pap testing, in-clinic HPV testing, self-collected HPV testing versus no screening, most women and some HCPs were unaware of

any type of HPV testing, for example, modalities that are not funded by the Ontario health system. However, some organizations, like the United States Preventive Services Task Force (U.S. Preventive Services Task Force, 2017), already recommend that women make a choice among modalities, although implementation and decision support for individuals is unclear. This study's findings are timely because it seems that awareness and knowledge of the cervical screening options stand out as women's primary decisional needs in cervical screening. Although values played an important role in how women make the decision (e.g., how women make trade-offs between the costs of different options, the convenience of the procedures), screen-eligible women felt confident that they could make the decision if they had more information. However, it is possible that because women have not faced this type of decision-making in cervical cancer screening, that they may miss some of the nuances around the different trade-offs (Pieterse & Stiggelbout, 2016). Value clarification methods—strategies to help individuals assess the desirability of attributes of different options—will be important help women identify which option they prefer among cervical screening modalities (Llewellyn-Thomas & Crump, 2013; Pieterse & Stiggelbout, 2016).

HCPs worried that multiple options may cause worry or anxiety in women deciding among cervical screening modalities. The HCP concern of decisional conflict may reflect worry that women may not participate with *medicine's* preferred screening modality (i.e., making the “wrong” choice by selecting a less sensitive option). The belief that there is an ultimate “good” decision suggests that HCPs may have values that differ from their patients. Respondents also believed that if women recognized the decision and were informed of the options, they would choose the option that corresponds with population health objectives. However, it may be challenging for women to act on their preferred option for cervical screening if it deviates from their clinician's preferred option (Adams, Elwyn, Légaré, & Frosch, 2012). Nurses will play a key role in fostering an environment that allows women to learn about their cervical cancer screening options in an unbiased and comprehensive way. By fulfilling the role of decision coaches (Stacey et al., 2012; Stacey et al., 2008), nurses prepare individuals to have conversations with their practitioners about screening decisions (Grad et al., 2017; Lang et al., 2018; RNAO, 2015; Stacey et al., 2008). However, providers also face organizational barriers such as performance quality metrics that might impede shared decision-making (Elston Lafata et al., 2017; Walter & Lewis, 2007).

Some authors have discussed perceived challenges of autonomous decision-making within the context of a population-based cancer screening program (Elston Lafata et al., 2017; Jepson et al., 2005; Salmi et al., 2016; van Dam, Kuipers, Steyerberg, van Leerdam, & de Beaufort, 2013). In the cervical screening situation, many HCPs were concerned

about offering modalities to patients that were considered inferior to the modalities recommended by clinical practice guidelines. Findings from this study demonstrated an interesting paradox that HCPs and individuals trusted cancer agencies and networks to know the “best” options for cervical screening for individuals, yet, some respondents also expected system-level institutions to prioritize financial or other system prerogatives above an individual's wellbeing. As test acceptability is a crucial component of a successful screening program (Dobrow, Hagens, Chafe, Sullivan, & Rabeneck, 2018; Salmi et al., 2016; Wilson & Jungner, 1968), women want confirmation from HCP stakeholders that the options are valid.

One respondent—a HCP—vocalized concern for potential harms with over-diagnosis and overtreatment when women decide to participate in cancer screening, possibly related to their contribution to guideline development. As knowledge of the decision and its options is a key decisional need identified in the interviews, a balanced presentation of risks and benefits for each option is necessary. Two previous systematic review demonstrated that individuals and health professionals tend to overestimate the benefits and underestimate the harms associated with screening (Hoffmann & Del Mar, 2014; Hoffmann et al., 2017), suggesting that tools to elicit preferences or support shared decision-making need to carefully communicate that cervical screening can directly benefit a small number of women through early detection, and potentially introduce harmful consequences through over-diagnosis and overtreatment (Salmi et al., 2016; Sawaya & Kuppermann, 2015; Shieh et al., 2016). Not only are women's *informed* preferences among cervical screening modalities (and other decisions) integral to patient-centered care, but they may lead to more appropriate use of health care resources. The 2017 Cochrane review of decision aids (Stacey et al., 2017) found that some options may be under-used and others over-used, which was usually related to inadequate information comprehension. Hence, supporting women in making preference-based decisions in cervical cancer screening may increase screening among those who do not undergo screening regularly, and decrease uptake in women who are over-screened, which is consistent with utilitarian public health campaigns. This research highlights an opportunity for nurses and other health professionals to empower women to make autonomous cervical cancer screening decisions.

This study is the first to consider women's decisional needs among multiple cervical screening modalities—Pap testing, in-clinic HPV testing, self-collected HPV testing, and no screening—from the perspectives of women who are eligible for screening as well as health care professionals. However, it has some limitations: some respondents perceived this decision among screening modalities as a hypothetical; sometimes, the way individuals perceive and act in a hypothetical decision may vary from that in real world circumstances (Feldman-Hall et al., 2012; Kuhberger,

Schulte-Mecklenbeck, & Perner, 2002). However, because the decision to screen for cervical cancer is ongoing and the modalities are available, most respondents perceived the decision as real. We determined that twelve respondents provided sufficient data to identify decisional needs using the ODSF, and we will integrate this analysis with the findings of a systematic review to further validate the main categories. Although many studies tend to have larger number of interviews, many do not explain why or how they reached saturation at that sample size (Guest et al., 2006; Mason, 2010; Varpio et al., 2017). Inquiring about women's decisional needs from women and HCPs, using two independent coders to analyze the ODSF categories, and a clear description of the data collection and analysis methods (Satu Elo & Kyngäs, 2008; O'Reilly & Parker, 2013) helped to ensure rigor in this project. These results may not be transferable to contexts outside of Ontario, although these findings might apply to other publicly funded health care systems where quality metrics and remuneration are determined by adherence to clinical practice guidelines. In addition, similar decisional needs were identified across a sample of women with diverse socio-demographic backgrounds which suggests that most women may benefit from some form of decision support.

## Conclusion

Women and health care professionals did not perceive cervical cancer screening participation as a decision for women to make. When considering available modalities—Pap testing, in-clinic HPV testing, self-collected HPV testing, and no screening—women and health professionals wanted to know more information about these options. Women wanted to make a choice among available options, although health professionals were hesitant to engage in shared decision-making because some of the options are not funded by the public-payer system, and some options might not be consistent with population-based screening goals. Women and health professionals emphasized the importance of a trusting relationship between women considering screening and their primary care providers for shared decision-making. Subsequently, adequate access to primary health care may play a significant role in women's decision-making process. A tool that addresses some of these decisional needs might support women and their health care providers in cervical screening encounters, which is important for person-centered, evidence-based care. Supporting women in making preference-based decisions in cervical cancer screening might increase screening among those who do not undergo screening regularly, and decrease uptake in women who are over-screened, which is consistent with utilitarian public health campaigns. As advocates for person-centered care on interprofessional teams and health promotion settings, nurses are well-positioned to facilitate preference-based decision-making in cervical cancer screening.

## Author Contributions

B.W., J.L., and I.D.G. conceptualized the study. B.W. conducted the interviews, analyzed the data, and wrote the first draft of the manuscript. V.L.R. helped to analyze the data and contributed to the first draft of the manuscript. All authors contributed to the interpretation of the data and provided editorial feedback on drafts of the manuscript. All authors read and approved the final manuscript.

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The authors declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: B.W. is a PhD student in Epidemiology at the University of Ottawa School of Public Health and Epidemiology who is investigating methods to elicit women's cervical cancer screening preferences. Her research is funded by a Mitacs Accelerate fellowship in partnership with Eve Medical—a self-sampling device company in Toronto. B.W. has received an educational travel grant from Roche Canada (Research Canada partner) to attend a Research Canada meeting. These companies had no input on the conduct, analysis, or reporting of the research. The remaining authors declare no conflicting interests.

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## Supplementary Materials

For further information on the data and interpretation of this study, please contact the corresponding author of this study.

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## References

- Adams, J. R., Elwyn, G., Légaré, F., & Frosch, D. L. (2012). Communicating with physicians about medical decisions: A reluctance to disagree. *Archives of Internal Medicine*, 172, 1184–1186. doi:10.1001/archinternmed.2012.2360
- Ajzen, I., & Fishbein, M. (1980). *Understanding attitudes and predicting social behavior*. Prentice Hall. Retrieved from [https://books.google.ca/books/about/Understanding\\_attitudes\\_and\\_predicting\\_s.html?id=AnNqAAAAMAAJ](https://books.google.ca/books/about/Understanding_attitudes_and_predicting_s.html?id=AnNqAAAAMAAJ)
- Alley, S., Jackson, S. F., & Shakya, Y. B. (2015). Reflexivity: A methodological tool in the knowledge translation process? *Health Promotion Practice*, 16, 426–431. doi:10.1177/1524839914568344

- Arbyn, M., Verdoodt, F., Snijders, P. J. F., Verhoef, V. M. J., Suonio, E., Dillner, L., . . . Anttila, A. (2014). Accuracy of human papillomavirus testing on self-collected versus clinician-collected samples: A meta-analysis. *The Lancet: Oncology*, *15*, 172–183. doi:10.1016/S1470-2045(13)70570-9
- Braz, N. S. D. F., Lorenzi, N. P. C., Sorpreso, I. C. E., Aguiar, L. M., Baracat, E. C., & Soares-Júnior, J. M. (2017). The acceptability of vaginal smear self-collection for screening for cervical cancer: A systematic review. *Clinics (Sao Paulo, Brazil)*, *72*, 183–187. doi:10.6061/clinics/2017(03)09
- Bryant-Lukosius, D., Cosby, R., Bakker, D., Earle, C., Fitzgerald, B., & Burkoski, V., & Advanced Practice Nursing Guideline Development Group. (2015). *Effective use of advanced practice nurses in the delivery of adult cancer services in Ontario: Guideline recommendations* (Program in Evidence-based Care Guideline No. 16–4). Toronto. Retrieved from <https://www.cancercareontario.ca/en/guidelines-advice/types-of-cancer/2166>
- Dickinson, J., Tsakonas, E., Conner Gorber, S., Lewin, G., Shaw, E., Singh, H., & McLachlin, M. (2013). Recommendations on screening for cervical cancer. *Canadian Medical Association Journal*, *185*, 35–45. doi:10.1503/cmaj.121505
- Dobrow, M. J., Hagens, V., Chafe, R., Sullivan, T., & Rabeneck, L. (2018). Consolidated principles for screening based on a systematic review and consensus process. *Canadian Medical Association Journal*, *190*(14), E422–E429. doi:10.1503/cmaj.171154
- Elo, S., Kaariainen, M., Kanste, O., Polkki, T., Utriainen, K., & Kyngas, H. (2014). Qualitative content analysis: A focus on trustworthiness. *SAGE Open*, *4*(1). doi:10.1177/2158244014522633
- Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, *62*, 107–115. doi:10.1111/j.1365-2648.2007.04569.x
- Elston Lafata, J., Brown, R. F., Pignone, M. P., Ratliff, S., & Shay, L. A. (2017). Primary care physicians' support of shared decision making for different cancer screening decisions. *Medical Decision Making: An International Journal of the Society for Medical Decision Making*, *37*, 70–78. doi:10.1177/0272989X166660547
- Feather, N. T. (1982). *Expectations and actions: Expectancy-value models in psychology*. Lawrence Erlbaum. Retrieved from [https://books.google.ca/books/about/Expectations\\_and\\_Actions.html?id=\\_ox9AAAAMAAJ&redir\\_esc=y](https://books.google.ca/books/about/Expectations_and_Actions.html?id=_ox9AAAAMAAJ&redir_esc=y)
- Feenstra, B., Lawson, M. L., Harrison, D., Boland, L., & Stacey, D. (2015). Decision coaching using the Ottawa family decision guide with parents and their children: A field testing study. *BMC Medical Informatics and Decision Making*, *15*, Article 5. doi:10.1186/s12911-014-0126-2
- Feldman-Hall, O., Mobbs, D., Evans, D., Hiscox, L., Navrady, L., & Dalgleish, T. (2012). What we say and what we do: The relationship between real and hypothetical moral choices. *Cognition*, *123*, 434–441. doi:10.1016/j.cognition.2012.02.001
- Fischhoff, B., Slovic, P., & Lichtenstein, S. (1980). Knowing what you want: Measuring labile values. In D. E. Bell, H. Raiffa, & A. Tversky (Eds.), *Cognitive processes in choice and decision behavior* (pp. 398–421). Cambridge, UK: Cambridge University Press. doi:10.1017/CBO9780511598951.020
- Fusch, P., & Ness, L. (2015). Are we there yet? Data saturation in qualitative research. *The Qualitative Report*, *20*(9). Retrieved from <http://nsuworks.nova.edu/tqr/vol20/iss9/3>
- Grad, R., Légaré, F., Bell, N. R., Dickinson, J. A., Singh, H., Moore, A. E., . . . Kretschmer, K. L. (2017). Shared decision making in preventive health care: What it is; what it is not. *Canadian Family Physician Medecin de Famille Canadien*, *63*, 682–684. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/28904031>
- Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods*, *18*, 59–82. doi:10.1177/1525822X05279903
- Haynes, R. B., Devereaux, P. J., & Guyatt, G. H. (2002). Clinical expertise in the era of evidence-based medicine and patient choice. *ACP Journal Club*, *136*(2), A11–A14. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/11874303>
- Hennink, M. M., Kaiser, B. N., & Marconi, V. C. (2017). Code saturation versus meaning saturation: How many interviews are enough? *Qualitative Health Research*, *27*, 591–608. doi:10.1177/1049732316665344
- Hibbard, J. H., & Greene, J. (2013). What the evidence shows about patient activation: Better health outcomes and care experiences; Fewer data on costs. *Health Affairs*, *32*, 207–214. doi:10.1377/hlthaff.2012.1061
- Hoffmann, T. C., & Del Mar, C. (2014). Patients' expectations of the benefits and harms of treatments, screening, and tests. *JAMA Internal Medicine*, *175*, 274–286. doi:10.1001/jamainternmed.2014.6016
- Hoffmann, T. C., Del Mar, C., Brandt, L., O'Leary, J., Iannone, L., & Waldhausen, J. (2017). Clinicians' expectations of the benefits and harms of treatments, screening, and tests. *JAMA Internal Medicine*, *177*, 407–419. doi:10.1001/jamainternmed.2016.8254
- Hoffmann, T. C., Montori, V. M., & Del Mar, C. (2014). The connection between evidence-based medicine and shared decision making. *Journal of the American Medical Association*, *312*, 1295–1296. doi:10.1001/jama.2014.10186
- Hsieh, H.-F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, *15*, 1277–1288. doi:10.1177/1049732305276687
- Jacobsen, M., O'Connor, A., & Stacey, D. (n.d.). *Decisional needs assessment in populations*. Ottawa. Retrieved from [https://decisionaid.ohri.ca/docs/implement/Population\\_Needs.pdf](https://decisionaid.ohri.ca/docs/implement/Population_Needs.pdf)
- Janis, I. L., & Mann, L. (1977). *Decision making: A psychological analysis of conflict, choice, and commitment*. Free Press. Retrieved from [https://books.google.ca/books/about/Decision\\_making.html?id=YgRHAAAAMAAJ&redir\\_esc=y](https://books.google.ca/books/about/Decision_making.html?id=YgRHAAAAMAAJ&redir_esc=y)
- Jepson, R. G., Hewison, J., Thompson, A. G. H., & Weller, D. (2005). How should we measure informed choice? The case of cancer screening. *Journal of Medical Ethics*, *31*, 192–196. doi:10.1136/jme.2003.005793
- Jimbo, M., Rana, G. K., Hawley, S., Holmes-Rovner, M., Kelly-Blake, K., Nease, D. E., & Ruffin, M. T. (2013). What is lacking in current decision aids on cancer screening? *CA: A Cancer Journal for Clinicians*, *63*, 193–214. doi:10.3322/caac.21180
- Keeney, R. L., & Raiffa, H. (1993). *Decisions with multiple objectives: Preferences and value tradeoffs*. Cambridge University Press. Retrieved from [https://books.google.ca/books/about/Decisions\\_with\\_Multiple\\_Objectives.html?id=GPE6ZAqGrnC&redir\\_esc=y](https://books.google.ca/books/about/Decisions_with_Multiple_Objectives.html?id=GPE6ZAqGrnC&redir_esc=y)
- Kiran, T., Kopp, A., Moineddin, R., & Glazier, R. H. (2015). Longitudinal evaluation of physician payment reform and team-based care for chronic disease management and preven-

- tion. *CMAJ : Canadian Medical Association Journal/Journal de l'Association Médicale Canadienne*, 187(17), E494–502. doi:10.1503/cmaj.150579
- Koliopoulos, G., Nyaga, V. N., Santesso, N., Bryant, A., Martin-Hirsch, P. P., Mustafa, R. A., . . . Arbyn, M. (2017). Cytology versus HPV testing for cervical cancer screening in the general population. *Cochrane Database of Systematic Reviews*, (8), Article CD008587. doi:10.1002/14651858.CD008587.pub2
- Kuhberger, A., Schulte-Mecklenbeck, M., & Perner, J. (2002). Framing decisions: Hypothetical and real. *Organizational Behaviour and Human Decision Processes*, 89, 1162–1175. Retrieved from <http://www.schulte-mecklenbeck.com/pubs/Kuhberger2002.pdf>
- The Lancet. (2016). Balancing the benefits and risks of choice. *The Lancet*, 388(10050), 1129. doi:10.1016/S0140-6736(16)31641-5
- Lang, E., Bell, N. R., Dickinson, J. A., Grad, R., Kasperavicius, D., Moore, A. E., . . . Stacey, D. (2018). Eliciting patient values and preferences to inform shared decision making in preventive screening. *Canadian Family Physician*, 64, 28–31.
- Légaré, F., Stacey, D., Dodin, S., O'Connor, A., Richer, M., Griffiths, F., . . . Tapp, S. (2007). Women's decision making about the use of natural health products at menopause: A needs assessment and patient decision aid. *The Journal of Alternative and Complementary Medicine*, 13, 741–750. doi:10.1089/acm.2006.6398
- Légaré, F., Stacey, D., Gagnon, S., Dunn, S., Pluye, P., Frosch, D., . . . Graham, I. D. (2011). Validating a conceptual model for an inter-professional approach to shared decision making: A mixed methods study. *Journal of Evaluation in Clinical Practice*, 17, 554–564. doi:10.1111/j.1365-2753.2010.01515.x
- Lillie, S. E., Partin, M. R., Rice, K., Fabbri, A. E., Greer, N. L., Patel, S. S., . . . Wilt, T. J. (2014). *The effects of shared decision making on cancer screening—A systematic review* (VA ESP Project #09-009; 119). Retrieved from <http://www.ncbi.nlm.nih.gov/books/PMH007888/>
- Llewellyn-Thomas, H. A., & Crump, R. T. (2013). Decision support for patients: Values clarification and preference elicitation. *Medical Care Research and Review : MCRR*, 70(Suppl. 1), 50S–79S. doi:10.1177/1077558712461182
- Mason, M. (2010). Sample size and saturation in PhD studies using qualitative interviews. *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research*, 11(3). Retrieved from: <http://www.qualitative-research.net/index.php/fqs/article/view/1428/3027>. <http://dx.doi.org/10.17169/fqs-11.3.1428>.
- Murphy, J., Kennedy, E. B., Dunn, S., Fung Kee Fung, M., Gzik, D., & McLachlin, M. C. (2011). *Cervical screening: Guideline recommendations* (Program in Evidence-based Care Evidence-based Series No. 15-9). Toronto. Retrieved from <https://www.cancercareontario.ca/en/guidelines-advice/types-of-cancer/2156>
- Murphy, J., Kennedy, E. B., Dunn, S., McLachlin, C. M., Fung Kee Fung, M., Gzik, D., . . . Paszat, L. (2012). HPV testing in primary cervical screening: A systematic review and meta-analysis. *Journal of Obstetrics and Gynaecology Canada /Journal d'obstétrique et Gynécologie Du Canada*, 34, 443–452. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/22555137>
- National Collaborating Centre for Healthy Public Policy. (2016). *Utilitarianism in public health*. Montreal. Retrieved from [http://www.ncchpp.ca/docs/2016\\_Ethics\\_Utilitarianism\\_En.pdf](http://www.ncchpp.ca/docs/2016_Ethics_Utilitarianism_En.pdf)
- Nelson, E. J., Maynard, B. R., Loux, T., Fatla, J., Gordon, R., & Arnold, L. D. (2017). The acceptability of self-sampled screening for HPV DNA: A systematic review and meta-analysis. *Sexually Transmitted Infections*, 93, 56–61. doi:10.1136/sextrans-2016-052609
- Norbeck, J. S. (1988). Social support. *Annual Review of Nursing Research*, 6, 85–109. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/3291918>
- O'Connor, A. M. (1995). Validation of a decisional conflict scale. *Medical Decision Making*, 15, 25–30. doi:10.1177/0272989X9501500105
- O'Connor, A. M., Drake, E. R., Fiset, V., Graham, I. D., Laupacis, A., & Tugwell, P. (1999). The Ottawa patient decision aids. *Effective Clinical Practice*, 2, 163–170. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/10539541>
- O'Connor, A. M., Jacobsen, M. J., & Stacey, D. (2002). An evidence-based approach to managing women's decisional conflict. *Journal of Obstetric, Gynecologic, & Neonatal Nursing*, 31, 570–581. doi:10.1111/j.1552-6909.2002.tb00083.x
- O'Connor, A. M., Tugwell, P., Wells, G. A., Elmslie, T., Jolly, E., Hollingworth, G., . . . Drake, E. (1998). A decision aid for women considering hormone therapy after menopause: Decision support framework and evaluation. *Patient Education and Counseling*, 33, 267–279. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/9731164>
- O'Reilly, M., & Parker, N. (2013). “Unsatisfactory saturation”: A critical exploration of the notion of saturated sample sizes in qualitative research. *Qualitative Research*, 13, 190–197. doi:10.1177/1468794112446106
- Orem, D. (1995). *Nursing: Concepts of practice* (5th ed.). Toronto: Mosby. Retrieved from <https://trove.nla.gov.au/work/6247247>
- Petrova, M., Dale, J., & Fulford, B. K. W. M. (2006). Values-based practice in primary care: Easing the tensions between individual values, ethical principles and best evidence. *The British Journal of General Practice : The Journal of the Royal College of General Practitioners*, 56, 703–709. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/16954004>
- Pieterse, A. H., & Stiggelbout, A. M. (2016). What are values, utilities, and preferences? A clarification in the context of decision making in health care, and an exploration of measurement issues. In M. A. Diefenbach, S. Miller-Halegoua, & D. J. Bowen (Eds.), *Handbook of health decision science* (pp. 3–13). New York: Springer. doi:10.1007/978-1-4939-3486-7\_1
- Poirier, N., Légaré, F., Stacey, D., Lemieux, S., Bégin, C., Lapointe, A., & Desroches, S. (2016). Postmenopausal women with abdominal obesity choosing a nutritional approach for weight loss: A decisional needs assessment. *Maturitas*, 94, 58–63. doi:10.1016/j.maturitas.2016.08.011
- Racey, C. S., Withrow, D. R., & Gesink, D. (2013). Self-collected HPV testing improves participation in cervical cancer screening: A systematic review and meta-analysis. *Canadian Journal of Public Health /Revue Canadienne de Santé Publique*, 104(2), e159–e166.
- Registered Nurses' Association of Ontario. (2015). *Person-and family-centred care clinical best practice guidelines*. Toronto. Retrieved from [http://rnao.ca/sites/rnao-ca/files/FINAL\\_Web\\_Version\\_0.pdf](http://rnao.ca/sites/rnao-ca/files/FINAL_Web_Version_0.pdf)
- Salmi, L. R., Coureau, G., Bailhache, M., & Mathoulin-Pélissier, S. (2016). To screen or not to screen: Reconciling individual and

- population perspectives on screening. *Mayo Clinic Proceedings*, 91, 1594–1605. doi:10.1016/j.mayocp.2016.07.017
- Sandman, L., Granger, B. B., Ekman, I., & Munthe, C. (2012). Adherence, shared decision-making and patient autonomy. *Medicine, Health Care and Philosophy*, 15, 115–127. doi:10.1007/s11019-011-9336-x
- Sawaya, G. F., & Kuppermann, M. (2015). Identifying a “range of reasonable options” for cervical cancer screening. *Obstetrics & Gynecology*, 125, 308–310. doi:10.1097/AOG.0000000000000670
- Schwartz, L. M., Woloshin, S., Fowler, F. J., & Welch, H. G. (2004). Enthusiasm for cancer screening in the United States. *Journal of the American Medical Association*, 291, 71–78. doi:10.1001/jama.291.1.71
- Sepucha, K. R., Borkhoff, C. M., Lally, J., Levin, C. A., Matlock, D. D., Ng, C. J., . . . Thomson, R. (2013). Establishing the effectiveness of patient decision aids: Key constructs and measurement instruments. *BMC Medical Informatics and Decision Making*, 132(Suppl. 2), S12. doi:10.1186/1472-6947-13-S2-S12
- Shieh, Y., Eklund, M., Sawaya, G. F., Black, W. C., Kramer, B. S., & Esserman, L. J. (2016). Population-based screening for cancer: Hope and hype. *Nature Reviews Clinical Oncology*, 13, 550–565. doi:10.1038/nrclinonc.2016.50
- Stacey, D., Kryworuchko, J., Bennett, C., Murray, M. A., Mullan, S., & Légaré, F. (2012). Decision coaching to prepare patients for making health decisions: A systematic review of decision coaching in trials of patient decision aids. *Medical Decision Making*, 32(3), E22–E33. doi:10.1177/0272989X12443311
- Stacey, D., Légaré, F., Lewis, K., Barry, M. J., Bennett, C. L., Eden, K. B., . . . Trevena, L. (2017). Decision aids for people facing health treatment or screening decisions. In D. Stacey (Ed.), *Cochrane database of systematic reviews*. Chichester, UK: John Wiley. doi:10.1002/14651858.CD001431.pub5
- Stacey, D., Légaré, F., Pouliot, S., Kryworuchko, J., & Dunn, S. (2010). Shared decision making models to inform an interprofessional perspective on decision making: A theory analysis. *Patient Education and Counseling*, 80, 164–172. doi:10.1016/j.pec.2009.10.015
- Stacey, D., Murray, M. A., Légaré, F., Sandy, D., Menard, P. O., & Connor, A. (2008). Decision coaching to support shared decision making: A framework, evidence, and implications for nursing practice, education, and policy. *Worldviews on Evidence-Based Nursing/Sigma Theta Tau International, Honor Society of Nursing*, 5, 25–35. doi:10.1111/j.1741-6787.2007.00108.x
- Trevena, L. (2009). Cancer screening—Pros, cons, choice, and the patient. *Australian Family Physician*, 38, 188–192. Retrieved from <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=med5&NEWS=N&AN=19350066>
- Tversky, A., & Kahneman, D. (1981). The framing of decisions and the psychology of choice. *Science*, 211, 453–458. Retrieved from [https://www.uzh.ch/cmsssl/suz/dam/jcr:fffff-fad3-547b-ffff-ffffe54d58af/10.18\\_kahneman\\_tversky\\_81.pdf](https://www.uzh.ch/cmsssl/suz/dam/jcr:fffff-fad3-547b-ffff-ffffe54d58af/10.18_kahneman_tversky_81.pdf)
- Umscheid, C. A. (2009). Should guidelines incorporate evidence on patient preferences? *Journal of General Internal Medicine*, 24, 988–990. doi:10.1007/s11606-009-1055-0
- U.S. Preventive Services Task Force. (2017). *Draft recommendation statement. Cervical cancer: Screening*. Author. Retrieved from <https://www.uspreventiveservicestaskforce.org/Page/Document/draft-recommendation-statement/cervical-cancer-screening2>
- van Dam, L., Kuipers, E. J., Steyerberg, E. W., van Leerdam, M. E., & de Beaufort, I. D. (2013). The price of autonomy: Should we offer individuals a choice of colorectal cancer screening strategies? *The Lancet. Oncology*, 14(1), e38–e46. doi:10.1016/S1470-2045(12)70455-2
- Varpio, L., Ajjawi, R., Monrouxe, L. V., O’Brien, B. C., & Rees, C. E. (2017). Shedding the cobra effect: Problematising thematic emergence, triangulation, saturation and member checking. *Medical Education*, 51, 40–50. doi:10.1111/medu.13124
- Verdoodt, F., Jentschke, M., Hillemanns, P., Racey, C. S., Snijders, P. J. F., & Arbyn, M. (2015). Reaching women who do not participate in the regular cervical cancer screening programme by offering self-sampling kits: A systematic review and meta-analysis of randomised trials. *European Journal of Cancer*, 51, 2375–2385. doi:10.1016/j.ejca.2015.07.006
- Walter, L. C., & Lewis, C. L. (2007). Maximizing informed cancer screening decisions. *Archives of Internal Medicine*, 167, 2027–2028. doi:10.1001/archinte.167.19.2027
- Wilson, J., & Jungner, G. (1968). Principles and practice of screening for disease. *The Journal of the Royal College of General Practitioners*, 16, 318. Retrieved from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2236670/>
- Zhang, Y., Coello, P. A., Brożek, J., Wiercioch, W., Etxeandia-Ikobaltzeta, I., Akl, E. A., . . . Schünemann, H. J. (2017). Using patient values and preferences to inform the importance of health outcomes in practice guideline development following the GRADE approach. *Health and Quality of Life Outcomes*, 15, Article 52. doi:10.1186/s12955-017-0621-0

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