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# Understanding Patients' Perspectives and Information Needs Following a Positive Home Human Papillomavirus Self-Sampling Kit Result

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## Abstract

**Objective:** We explored patient perspectives after a positive human papillomavirus (HPV) self-sampling result to describe experiences and information needs for this home-based screening modality.

**Materials and Methods:** We recruited women who tested high-risk (hr) HPV positive during a pragmatic trial evaluating mailed hrHPV self-sampling kits as an outreach strategy for women overdue for Pap screening in a U.S. integrated health care system. Telephone interviews were conducted from 2014 to 2017. Five independent coders analyzed transcripts using iterative content analysis.

**Results:** Forty-six women (61% of invited; median age 55.5 years) completed a semistructured interview. Six themes emerged: (1) convenience of home-based screening, (2) intense feelings and emotions after receiving positive kit results, (3) importance of seeing provider and discussing kit results, (4) information seeking from various sources, (5) confusion about purpose and meaning of HPV versus Pap tests, and (6) concern that HPV self-sampling is inaccurate when the subsequent Pap test is normal.

**Conclusions:** Although women liked the kit's convenience, discussion about discordant home HPV and in-clinic Pap results led them to question the accuracy of HPV self-sampling. Patient-provider communication around home HPV kits is more complex than for reflex or cotesting because clinician-collected Pap results are unknown at the time of the positive kit result. Patients need education about differences between HPV and Pap tests and how they are used for screening and follow-up. To reassure patients and keep them interested in self-sampling, education should be provided at multiple time points during the screening process.

**Keywords:** human papillomavirus DNA tests, early detection of cancer, uterine cervical neoplasms, mass screening, qualitative research

## Introduction

ALTHOUGH LARGELY PREVENTABLE with screening, >12,000 incident cervical cancers occur in the United States annually.<sup>1</sup> In 2015, 18.9% of women aged 21–65 years were underscreened (*i.e.*, no Pap test in prior 3 years).<sup>2</sup> Most invasive cancers arise because of failure to screen.<sup>3</sup> Underscreening is attributed to lack of time due to competing de-

mands (*e.g.*, childcare and work), embarrassment about the procedure, worry about cancer, and poor access to care.<sup>4,5</sup>

Expanded use of tests that detect infection with high-risk human papillomavirus (hrHPV), a necessary cause of cervical cancer,<sup>6</sup> has changed U.S. screening and management guidelines. Current guideline-recommended options include Pap, hrHPV, or combined Pap/hrHPV testing on clinician-collected samples.<sup>7–10</sup> Although not yet guideline recommended, home

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hrHPV kits that allow women to collect their own sample (*i.e.*, “self-sampling”) may improve screening adherence.<sup>11</sup> A meta-analysis of European trials showed mailing self-sampling kits to underscreened women doubled screening participation compared with invitation for in-clinic screening.<sup>12</sup> Kits with HPV genotyping enable immediate triage of HPV 16/18 positive women to diagnostic evaluation with colposcopy (mirroring triage guidelines for clinician-collected samples,<sup>13</sup> whereas those with other hrHPV strains (*e.g.*, 31, 33), which have a lower risk of progression to high-grade precancerous lesions and invasive cancer,<sup>14</sup> can be referred to in-clinic follow-up for a Pap test (Fig. 1).

For home hrHPV kits to be successful, women with positive results must complete diagnostic evaluation.<sup>15</sup> However, adherence to follow-up can be negatively influenced by failure to understand abnormal test results, anxiety, and distress, as demonstrated in women receiving abnormal Pap results.<sup>16,17</sup>

Although several studies have documented acceptability of self-sampling,<sup>18,19</sup> no study has examined women’s experiences and health system interactions after receiving a positive kit result. This information is essential to minimize negative perceptions about this screening modality. Therefore, we conducted a qualitative study nested within a large pragmatic trial of mailed hrHPV kits to describe patients’ attitudes, emotional responses, and informational needs after receiving a positive kit result and having the opportunity to complete recommended follow-up. We also explored whether women’s reactions differed by timeliness of completing follow-up procedures.

## Materials and Methods

### Study population and setting

We conducted semistructured telephone interviews with a subset of women who were randomized as part of a pragmatic trial to receive an unsolicited mailed hrHPV self-sampling kit, returned the kit, and tested positive. Trial details including intervention materials and follow-up protocols are described elsewhere<sup>20</sup> (ClinicalTrials.gov: NCT02005510). In brief, the trial evaluates whether mailed hrHPV kits to women overdue for screening are effective in increasing screening uptake, early detection, and treatment of cervical neoplasia compared with usual care. The trial included 16,590 women aged 30–64 years who were not screened in at least 3.4 years and were members of Kaiser Permanente Washington (KPWA; formerly Group Health), an integrated health care delivery system.

The intervention arm received an invitation letter, kit, instructions, and a prepaid return envelope addressed to KPWA’s laboratory (Supplementary Appendix A; Supplementary Data are available online at [www.liebertpub.com/jwh](http://www.liebertpub.com/jwh)). According to KPWA’s standard protocol for results reporting, laboratory staff entered the kit result into the electronic health record (EHR) that notified the woman’s primary care team. Providers and staff were informed about the trial and on how to counsel patients.<sup>20</sup> Patient notification method depended on the result:

- For HPV-negative women who subscribed to the patient web portal, electronic results were released immediately; the primary care team contacted non-subscribers by telephone (no results were mailed).
- For HPV-positive women, the team called women to relay results and schedule in-clinic follow-up. For portal subscribers, electronic results were delayed 24–48 hours to allow time for telephone contact (see Supplementary Appendix B for results). Recommended follow-up was colposcopy if hrHPV 16/18 positive and in-clinic cotesting if other hrHPV positive.
- For indeterminate/unsatisfactory results, provider received an EHR message to schedule the patient for a Pap or cotest.

### Eligibility and recruitment

Interview recruitment began in August 2014 and stopped in March 2017. We used the trial database and EHR to identify, on a weekly basis, eligible subjects from the trial who (1) were randomized to the intervention arm, (2) returned the kit, and (3) tested positive for any hrHPV type. We invited participants immediately after completing timely diagnostic follow-up (*i.e.*, received cotest and/or colposcopy within 6 months after a positive kit result). Women not completing diagnostic follow-up were invited after 7 months to ensure that main trial results were not impacted.<sup>20</sup> If treatment was indicated, we tracked whether excisional procedures were completed within 12 months of positive kit result.

We used a two-stage invitation process. First, research staff mailed invitation letters and information sheets describing the qualitative study with a telephone number to opt out or ask questions. Second, if potential participants did not opt out, interviewers (L.S. and K.K.) made up to 12 call attempts over a 4-week period, leaving up to three messages. After confirming eligibility and interest, interviewers obtained oral consent and either conducted the 15–20-minute interview or scheduled an interview time. Upon completion, participants received a cash incentive, based on the response rate and to encourage participation; we increased the incentive mid-enrollment from \$25 to \$50.

### Interview guide

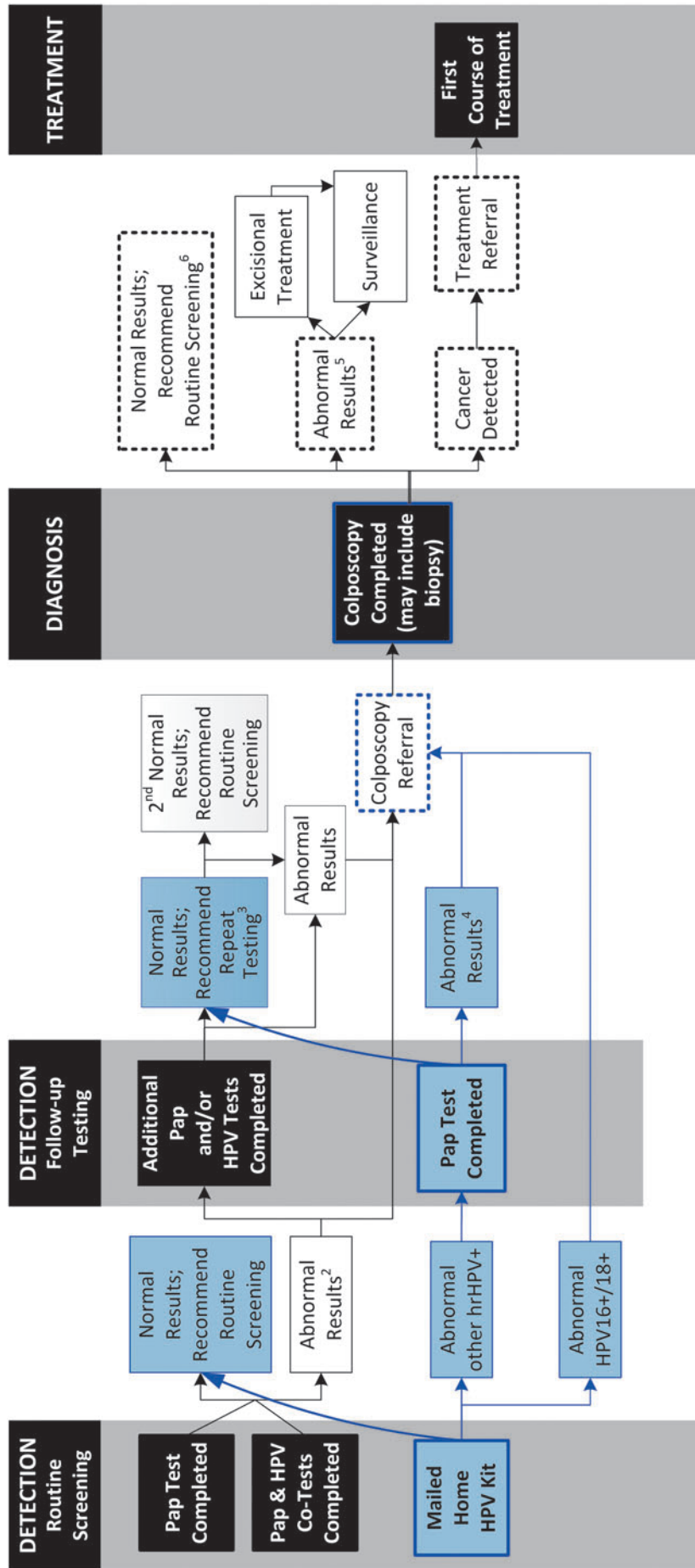
Because we were interested in specific points in the screening process starting at kit receipt (Fig. 1), we structured the interview guide (Supplementary Appendix C) around the following topics:

- (a) HPV knowledge;
- (b) reaction to unsolicited mailed kit;
- (c) feedback about results reporting process (including comprehension and emotions about results text);
- (d) communication with provider during diagnostic evaluation; and
- (e) reasons for not completing timely follow-up.

The guide also included a quantitative measure about participants’ experience with the kit (8-item scale) and survey items measuring beliefs about and willingness to use the kit in the future. Items used a 5-category Likert scale (strongly disagree to strongly agree). Interviews were audio recorded, transcribed verbatim, and anonymized.

### Analyses

Transcripts were concurrently analyzed by five coauthors with prior qualitative coding experience (J.A.T., K.K., L.S.,



**FIG. 1.** Conceptual model of the cervical cancer screening process (adapted from Beaber et al.<sup>15</sup>). Boxes and arrows in blue illustrate how the home hrHPV kit was integrated with other screening modalities (Pap, cotesting). hrHPV, high-risk human papillomavirus.

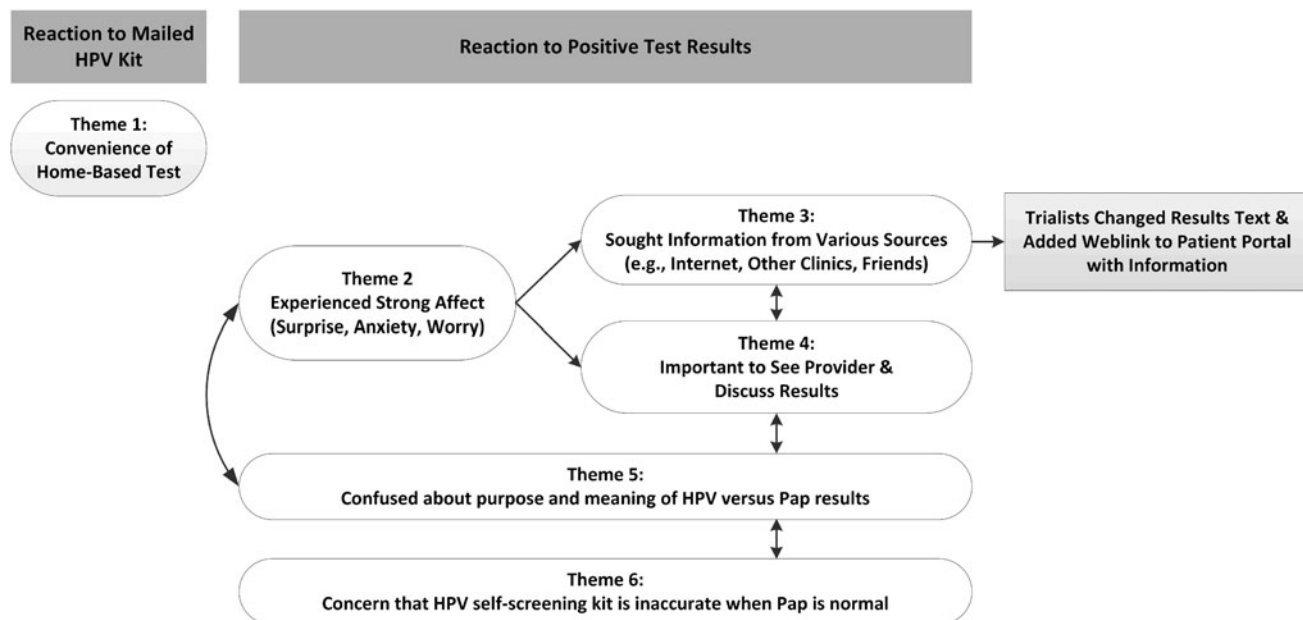


FIG. 2. Depiction of themes and how they relate to each other.

A.B., and C.M.) using iterative content analysis.<sup>21</sup> Concurrent data collection and analysis allowed for modification of probes in subsequent interviews. Coders independently reviewed three transcripts and suggested codes based on the screening process continuum (Fig. 1).<sup>15</sup> Through discussion, codes were grouped by step in the process (e.g., kit receipt, result receipt, and communication with provider). Codes were applied to the remaining transcripts. Coders met periodically to discuss uncertainties and achieve consensus.

Themes were identified using the framework approach<sup>21</sup> in which a matrix of rows (patient quotes) and columns (codes mapping onto emerging themes) was placed in adjacent columns. The matrix systematically organized data and conceptualized associations among themes (Fig. 2). From the EHR, we obtained sociodemographic characteristics, prior Pap utilization, and determined timeliness of completing follow-up procedures. Timely was defined as cotest or colposcopy within 6 months; if biopsy findings warranted treatment, women had up to 12 months to receive excisional procedures. We used chi-square or Fisher exact test to compare invited potential participants and interview completers. We calculated mean scores for the 8-item kit experience scale and frequencies for the belief and willingness items.

**Results**

We identified 75 eligible women who had a positive kit result during our recruitment window. Of these, 46 women (61%) completed an interview, 7% refused and 32% were unreachable (latter two categories were classified as nonresponders). Compared with nonrespondents, interview participants were more likely to be white, have had ≥1 prior Pap tests documented in the EHR, and have a hrHPV 16/18 positive kit result (Table 1). Most interview participants were ≥50 years of age (median age 55.5 years), white, commercially insured with low insurance deductibles, and had been enrolled in the health plan for at least 10 years. Most had a

Pap test 3.4–5 years ago and the most recent Pap result was normal. Almost one-third of interviewed women (15 out of 46) had a HPV 16/18 positive kit result. Among those with timely follow-up, only one woman was diagnosed with a high-grade lesion, warranting excisional treatment (e.g., CIN 2 or higher). Eight interviewed women did not receive timely follow-up.

*Findings from the thematic analysis*

Six themes emerged: (1) convenience of the home-based kit, (2) intense affect (feelings and emotions) after receiving positive kit results, (3) importance of following up with a provider to discuss kit results, (4) information seeking from various sources, (5) confusion about purpose and meaning of HPV versus Pap tests, and (6) concern that HPV self-sampling is inaccurate when the subsequent Pap test is normal (Fig. 2).

**Theme 1: Convenience of HPV kit.** Women liked the convenience of a mailed hrHPV kit. They thought it was “pretty cool you could do something like that at home. It was easy. It was painless. I just got to drop it in the mailbox and be done” (age 43; timely follow-up). They liked how the kit was “a substitute for actually going into the doctor’s office and getting a Pap” (age 41; not timely follow-up). One woman stated, “The only reason I did it was so I wouldn’t have to go in and get tested,” (age 53; timely follow-up) suggesting that visiting a clinic was a screening barrier. Findings from our 8-item scale echoed this positive kit reaction with a mean score of 4.39 indicating strong agreement (Table 2).

**Theme 2: Intense affect after receiving positive kit results.** Most participants reported experiencing intense affect (feelings and emotions) after receiving positive kit results. A number of women were surprised by the result because they believed themselves at low risk due to their age

TABLE 1. SOCIODEMOGRAPHIC AND HEALTH CARE UTILIZATION CHARACTERISTICS OF WOMEN INVITED TO A QUALITATIVE INTERVIEW AFTER RECEIVING A POSITIVE HUMAN PAPILLOMAVIRUS SELF-SAMPLING KIT RESULT IN A PRAGMATIC TRIAL, BY INTERVIEW STATUS (N=75), 2014–2017

Characteristic	Qualitative interview status	
	Invited, nonrespondent, n = 29 (38.7%)	Completed interview, n = 46 (61.3%)
Age group (years)		
30–39	5 (17.2)	5 (10.9)
40–49	7 (24.1)	7 (15.2)
50–64	17 (58.6)	34 (73.9)
Race*		
White	22 (75.9)	41 (89.1)
Black	2 (6.9)	2 (4.3)
Asian/Pacific Islander	4 (13.8)	0 (0)
Multiple race/other/unknown	1 (3.4)	3 (6.5)
Ethnicity		
Hispanic	1 (3.4)	3 (6.5)
Non-Hispanic	28 (96.6)	42 (91.3)
Unknown	0 (0)	1 (2.2)
High deductible plan (insurance measure) <sup>a</sup>		
Yes	8 (27.6)	10 (21.7)
No	21 (72.4)	36 (78.3)
Length of health plan enrollment <sup>b</sup>		
≥3.4 to <5 years	11 (37.9)	11 (23.9)
≥5 to <10 years	8 (27.6)	10 (21.7)
≥10 years	10 (34.5)	25 (54.3)
Pap history documented in electronic health record*		
No prior Pap	11 (37.9)	7 (15.2)
≥1 Pap	18 (62.1)	39 (84.8)
<i>Characteristics of women with a prior Pap</i>	<i>n = 18</i>	<i>n = 39</i>
Time since last Pap <sup>c</sup>		
≥3.4 to <5 years	14 (77.8)	25 (64.1)
≥5 to <10 years	2 (11.1)	12 (30.8)
≥10 years	2 (11.1)	2 (5.1)
Most recent Pap result		
Normal	16 (88.9)	29 (74.4)
Abnormal (ASC-US or higher)	0 (0)	1 (2.6)
Unsatisfactory	0 (0)	1 (2.6)
Unknown result <sup>d</sup>	2 (11.1)	8 (20.5)
<i>Home hrHPV kit result*</i>	<i>n = 29</i>	<i>n = 46</i>
HPV 16/18 positive	3 (10.3)	15 (32.6)
Positive for other hrHPV types only	26 (89.7)	31 (67.4)
Completed timely diagnostic follow-up <sup>e</sup>		
Yes	24 (82.8)	38 (82.6)
No	5 (17.2)	8 (17.4)

\**p*-Value for chi-square or Fisher exact test was <0.05.

<sup>a</sup>High deductible plan is defined as meeting one of these three criteria: (1) individual annual deductible ≥\$1350; (2) family annual deductible ≥\$2700; (3) specialty visit copayment >\$30.

<sup>b</sup>Continuous enrollment for at least 3.4 years before randomization (allowing for gaps of up to 2 months) was an eligibility criterion for the main trial.

<sup>c</sup>An eligibility criterion for the main trial was no Pap documented in the EHR for at least 3.4 years before randomization.

<sup>d</sup>Pap performed outside of health care system and results were not documented in the EHR.

<sup>e</sup>To be counted as timely diagnostic follow-up, women had to receive cotest (Pap and HPV tests) and/or colposcopy within 6 months. If biopsy findings warranted treatment, women were allowed up to 12 months to receive excisional procedures.

ASC-US, atypical squamous cells of undetermined significance; EHR, electronic health record; hrHPV, high-risk human papillomavirus.

TABLE 2. SURVEY RESULTS OF WOMEN WHO COMPLETED A QUALITATIVE INTERVIEW AFTER RECEIVING A POSITIVE HUMAN PAPILLOMAVIRUS SELF-SAMPLING KIT RESULT IN A PRAGMATIC TRIAL (N=46), 2014–2017

	Respondents, N=46
Scale scores	Mean (SD)
Experience using HPV kit (8-item scale)	4.39 (0.55)
Individual items	% strongly agree/agree
Believe HPV kit result is correct	58.7
Trust HPV kit result	65.2
Felt in control of health after using HPV kit	82.6
Using the HPV kit is a good thing for my health	89.1
Would recommend HPV kit to friend	84.8
Prefer provider administer Pap test in-clinic than use HPV kit at home	13.0

and marital status—“I’m 60 years old. It’s not like I’m running around. I’ve had the same partner for 27 years—I was quite shocked” (age 60; timely follow-up). Understanding HPV is transmitted *via* sexual behavior, another stated, “I haven’t even had sex in three or five years... I was like whoa” (age 56; timely follow-up).

In addition to surprise, many felt fear, anxiety, and worry about what kit results meant—“It was just scary, because they were saying I was positive... a possible link or cause of cervical cancer” (age 42; timely follow-up). Although the information sheet explained the purpose of the home HPV kit, some women did not remember that information when reading their results.

It was an alarming email and I had no understanding of HPV... it could mean [cancer]? Perhaps it was in [the directions], and I didn’t read it, but I believe I read everything in there... But I needed the education ...after I got the alarming email (age 52; timely follow-up).

**Theme 3: Information seeking from various sources.** - Shock and fear about the kit findings triggered many questions. One woman stated, “The most confusing thing was getting results but not getting a packet or something that answers questions. Like I had to do all the information [seeking] on my own or with my provider” (age 40; timely follow-up). Several women searched the Internet for information to “get a better sense of the terminology” (age 59; timely follow-up). One woman stated,

I actually googled it... it was confusing whether it was urgent or not... I was just trying to assess the severity of the situation and... why I would have positive results (age 41; not timely follow-up).

Others consulted friends—“I looked on WebMD and then talked to different people. I had a friend who had cervical cancer so I got a lot of information from her” (age 42; timely follow-up). Even though women knew they were participating in a research study, research is oftentimes hard to dis-

tinguish from usual primary care outreach; thus, they were concerned about contradictory information from the Internet and other clinics. For example, one woman reported, “Afterwards I talked to my doctor and he was shocked. He said, well, who did you get that from?... I said I got it from Group Health.” (age 60, timely follow-up). Using existing KPWA infrastructure for educating providers, we sent clinical update emails immediately before trial launch and again halfway through the 2.5-year enrollment period.<sup>20</sup> Some providers may have forgotten that home HPV kits were being distributed to some of their patients, or missed the statement in the electronic results text, indicating the kit result was part of a research study.

**Theme 4: Importance of following up with a provider to discuss results.** Among women completing timely follow-up, many felt an urgency to discuss results with their provider—“Yes, it [results message] made me make my appointment and go see my doctor (laughs)... instead of putting it off like I usually do” (age 54; timely follow-up). Women not completing follow-up had the opposite reaction—“I mean it [the results] didn’t make me feel anything. Am I concerned? No. I figured if it was something really important they’d still be calling me” (age 58; not timely follow-up). These women were either not worried about the test or had other health/life issues that were more important to address.

Most women (38/46, 82.6%) completed timely follow-up and felt reassured after communicating with their provider during the follow-up evaluation—“I freaked my own self more than I probably needed to. She definitely made everything feel more at ease and not as big of a deal” (age 37; timely follow-up).

**Theme 5: Confusion about purpose and meaning of HPV versus Pap results.** After receiving kit results and talking with their provider, many women remained confused about HPV and Pap tests. Women did not understand how they could be HPV positive and have a normal Pap test (and vice versa)—“If it’s contradictory to my regular Pap smear, I don’t know—or maybe it’s more specific. I just don’t understand why they were different” (age 58; timely follow-up). Others believed the tests checked for the same thing—“Well, basically what a Pap smear does, is testing for cancer cells and then I didn’t realize at the time that it was checking for the HPV, but after the fact I know that now” (age 53; timely follow-up). Others thought a positive kit result automatically meant they have cancer—“When I went in to see the doctor, she was like, ‘Just because you’re having an abnormal Pap smear doesn’t mean you’ve got cancer.’ Well, I don’t know, because I got an email that says I think I have cancer” (age 52; timely follow-up).

**Theme 6: Concern that HPV self-sampling kit is inaccurate when subsequent Pap is normal.** Despite the study information sheet, several women reported poor understanding about the purpose and meaning of the tests. Women questioned hrHPV kit accuracy when the kit and Pap/biopsy results were discordant (*i.e.*, latter result found no abnormal cells or dysplasia). A number of participants expressed concern about the “false positive” rate of the kit and were not interested in using self-sampling again. One woman

explained, “In my case I had a false positive so that’s a little startling, but nonetheless that’s what you do for screening and then you go get checked and everything looked fine ... I would hope that in the future (laughs) I don’t have more false positives because that would increase your fear factor and defeat your interest in trying them [new screening tests]” (age 58; timely follow-up). Another was adamant about the kit not being ready for widespread use until accuracy was improved. Women wanted to prevent others from having a similar experience—“It [Pap test] came back—nope, you don’t have it at all, it came back negative. I was literally pissed at you guys [study investigators]... because I thought oh my God, how many other women are feeling like I felt at that time?” (age 56; timely follow-up). This concern mirrored women’s survey responses to items about HPV kit accuracy and trust (Table 2). Only 59% agreed that the HPV kit result was correct and only 65% agreed they trusted the HPV kit result. Yet only 13% of women preferred a clinician-collected Pap over a home hrHPV kit. Survey responses were similar regardless of hrHPV result type (16/18 positive vs. other hrHPV).

Our interview guide (Supplementary Appendix C) probed about whether women distinguished between having a 16/18 positive result versus other hrHPV types. Across themes 2–6, women did not comment about (1) how the follow-up procedures differ or (2) risk of progression. This may be due to recall or because providers did not explain how triage strategies vary based on hrHPV type. Our ability to explore differences between women with timely and nontimely follow-up was limited by the small number in the latter category.

## Discussion

This is the first qualitative study examining women’s experiences with positive hrHPV kit results. Underscreened women generally had positive reactions to the unsolicited kit, finding it convenient and preferable to an office visit. However, many ultimately did not trust the kit, particularly when HPV and subsequent Pap results were discordant. Lack of understanding about how HPV and Pap results are used in conjunction undermined women’s experiences, and provider encounters did not always resolve misperceptions. Given that lack of knowledge of cervical cancer screening and HPV is common,<sup>17,22</sup> our results indicate a critical need to educate women on the purpose and meaning of each test and result if an HPV self-sampling program is to be successful. As one woman stated, “[Provider] actually went and printed out a printout explaining exactly how my results came back and what the meaning was behind those results and then what the next steps would be as far as preventive or follow-up care” (age 53; timely follow-up). It is essential to educate health care systems on how to integrate kits with management protocols for other screening modalities, and train providers on effective communication practices that meet patient information needs.

Some participants interpreted positive kit results as an indicator of cancer. Others<sup>23,24</sup> found HPV results were less concerning than cytology results when an abnormal Pap preceded the hrHPV test; however, we found when hrHPV testing was the first step in the screening process, some participants reported intense emotions after receiving positive kit results. A woman’s reaction may differ by initial screen-

ing modality or if a clinician is present to explain the test’s purpose. When subsequent Pap results found no abnormality, some viewed the kit result as a “false positive.” With co-testing and reflex HPV testing, providers know both Pap and hrHPV results when communicating with the patient. For self-sampling, Pap results are delayed; thus, succinct straightforward communication must help patients distinguish (a) HPV from cancer and (b) how the two screening modalities are used in conjunction, without undermining the importance of screening and perceived benefits of the home-based screening. Evidence-based frameworks, for example,<sup>25</sup> should guide development of patient education materials and provider communication training.

Patients often express the greatest desire for information upon receipt of an abnormal result when it is most salient.<sup>26,27</sup> This desire was evidenced in our study; results receipt spurred women to seek information *via* the Internet, family, friends, and providers. Based on iterative analyses of the interviews, investigators modified the patient web portal’s results text mid-trial (May 2015), adding a web-link (Supplementary Appendix D) explaining the kit’s purpose, a few HPV facts, and a reminder to follow-up with their provider.

Our findings are consistent with past studies on understanding of women’s feelings about abnormal Pap tests and colposcopic evaluations.<sup>17,28–30</sup> Receiving an abnormal screening result commonly triggers anxiety,<sup>31</sup> which may impair certain cognitive functions including working memory<sup>32</sup> and is associated with lack of understanding<sup>28</sup> and dissatisfaction with result explanations.<sup>33</sup> Ours and others’ findings suggest that the timing of patient education is important to manage these feelings.<sup>17,29,30</sup> Thus, consistent education should be provided at multiple time points—introduced at screening invitation, reiterated with results text, and reinforced during clinic follow-up. To maintain engagement in screening, communication should reassure women that an HPV positive result does not necessarily indicate cancer, follow-up testing is needed to identify whether any precancerous cells are present, and timely excisional treatment of precancerous lesions can prevent cancer development. Although anxiety may deter follow-up in some women, we found anxiety was commonly accompanied by an urgency to discuss findings with their provider. Conversely, most women not receiving timely follow-up expressed either little anxiety upon receiving the result or decreased anxiety after talking with family and friends.

In general, conversations with providers eased patient worry but did not facilitate long-term understanding of the difference between Pap and HPV results as many participants voiced misconceptions. For some, lack of provider awareness about mailed hrHPV kits may have compounded patient confusion and test distrust. Health care systems should invest resources on provider and staff education when introducing new screening modalities such as home hrHPV kits to ensure positive patient experience and willingness to use the test again.

Although our results highlight the need to educate women about HPV versus Pap testing, HPV-specific concerns were also relevant. Among participants of older age and/or in monogamous relationships, surprise at positive kit results and low perceived risk for HPV suggests a need to educate patients about persistent infection and relevance of HPV screening for women up to age 65 years. Education



concurrent with result communication should also address concern about partners and reduce stigma associated with sexually transmitted infections.

Regarding limitations, this qualitative study was conducted in the Pacific Northwest among mostly white middle-aged commercially insured women with prior Pap experience. Future studies should explore whether experiences differ for women of different race/ethnicity, age, geography, and socioeconomic status as well as among never screened women. It may be important to assess women's experiences with transportation barriers to care, among whom HPV self-sampling may pose greatest appeal and benefit. We only interviewed women with positive results; therefore, potentially more favorable experiences of women with normal results are not represented here. Also, few of the interviewed women did not complete timely follow-up. Thus, additional studies to understand barriers to follow-up are needed. Successful HPV self-sampling programs require women (1) believe in the kit's accuracy and efficacy and (2) are willing to follow recommended screening intervals; thus, perspectives from women with a positive kit result may be most critical to refine program protocols. Messages addressing unique informational needs and misperceptions should be tested to improve knowledge and beliefs about HPV self-sampling programs.

### Conclusion

Although women liked the kit's convenience, some questioned the accuracy of HPV self-sampling when kit and in-clinic Pap results were discordant. Patient-provider communication around home HPV kits is more complex than for reflex or cotesting. In the latter two cases, results for both tests are available at the same time and can guide clinical decisions, whereas for positive kit results, providers' communication goal is that patients come in for follow-up Pap testing or colposcopy. Lack of patient understanding about how HPV and Pap results are used in conjunction is problematic. Interventions to better educate patients and train providers on how to communicate about Pap and HPV tests are needed.

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### Author Disclosure Statement

No competing financial interests exist.

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