

Additional File 3. Themes and quotes from interviews with physicians

Label used and rationale

Theme	Bladder	Cervix	Prostate
Pre-Cancer	I will say abnormal cell that is pre-cancer (16, family physician, bladder)	<p>Yah will describe it as a precancer but I like to sort of avoid the cancer word when possible (18, OB/GYN, cervix)</p> <p>So if they have a biopsy that says that they have precancer on their cervix, I think that's the best label to use. (24, OB/GYN, cervix)</p>	---
Rationale for using pre-cancer	<p><u>Differentiates condition from cancer</u> So I will say pre-cancer and we have to treat earlier because it can become a cancer. (16, family physician, bladder)</p>	<p><u>Suitable for higher-grade lesions (e.g. HSIL)</u> Well it depends; if it was, if it was precancerous or whether it was...carcinoma but I think yes, I'd probably put precancerous. (17, family physician, cervix)</p> <p>Why don't we talk about a precancer when we're talking about a CIN-3 or an AS, like a lesion that is true precancerous lesion. (18, OB/GYN, cervix)</p> <p>If it's high-grade then I do typically refer to it as precancer... I would use precancer, again trying to communicate the more clinically significant severity of it, if its HSIL or something like that. (20, gynecologic oncologist, cervix)</p> <p>So for the higher-grade ones then I also say that they've been diagnosed with, with slightly abnormal cells of the cervix and we call them; we call them high-grade and those ones I would tell the patient they are considered precancerous. (21, OB/GYN, cervix)</p> <p><u>Ensures patients understand why follow-up or treatment are needed</u> And if you use precancerous, I find it's a little more effective in communicating this is the step before cancer and if we don't do something about it, you might end up having a cancer....Most people are quite accepting of treatment when you explain that you've got a fairly high chance of cancer if we</p>	---

		<p>don't do anything but that this kind of minor procedure can take that risk away almost completely. (20, gynecologic oncologist, cervix)</p> <p>But I do find that I'll use the word precancerous with the high-grade changes because I think it suggests, or it helps the patient to understand a little bit more about why we would treat those ones with either a LEEP or a resection. (21, OB/GYN, cervix)</p> <p>I think the benefits are that people understand where in the spectrum of changes on the cervix they've been found to have and that way they're better informed about what their prognosis is and what opportunities they had to improve their health outcome and prevent future morbidity related to that. (24, OB/GYN, cervix)</p> <p><u>Precancer matches what patients will see online</u> So I use the term precancer cells or dysplasia which are abnormal precancer cells so that they understand what it is they're looking at. So when they go home and they read on the internet which they do, they understand the terminology that's being used and they're not confusing it for what does not apply to them. (24, OB/GYN, cervix)</p>	
Rationale against pre-cancer	<p><u>Label causes alarm and fear</u> I think pre-cancer shouldn't; we shouldn't say that because its, it scares patients. So we should use only the word cancer when its cancer. (16, family physician, bladder)</p>	<p><u>Patients perceive advanced cancer</u> Precancer is generally speaking a phrase that I don't think should be used because people don't hear the pre part. They don't hear the "ous" part. They just hear the cancer part and the reality is that the majority of patients; again I'm speaking to the colposcopy population, will not go on to have cervical cancer. And so therefore, to call it precancerous it almost implies that this person will get cancer. And that, and that's what they hear, if anything they hear that they already have cancer. And that I think is actually in some ways misleading. Now it's not misleading to know that if left unchecked, untreated that individual is at a much higher risk than the general population of developing cancer but it's not a guarantee. I know</p>	---

		<p>that many patients hear and interpret that term precancerous to be like I have cancer, I have an early form of cancer which means it's developing further. It really alarms them in a way that I actually think is not true. (19, OB/GYN, cervix)</p> <p>I think that for some patients the idea that we're following a precancer sort of implies like that there's a high probability of conversion to cancer even when the chances are very low...I don't disagree with the use of precancer but I think we have to be a little bit careful about how we use that because I think that's similarly has the potential to evoke the idea that like; how do you know its not cancer? (18, OB/GYN, cervix)</p> <p>I think the downsides are for sure that some people become fearful or anxious when they hear the word cancer because they assume that precancer means they already have cancer that we haven't detected yet or that they're automatically going to develop cancer because they have precancer. (24, OB/GYN, cervix)</p>	
Non-aggressive and Non-invasive cancer	So typically if I have someone with a low-risk cancer I tell them that they have a non-aggressive, non-invasive cancer that hasn't gone to the deeper layers of the muscle. (23, urologic oncologist, bladder)	----	---
Rationale for non-aggressive and non-invasive cancer	<u>Patients understand condition is not aggressive</u> I use this terminology because it is more patient-centred, so people understand what aggressive cancer is and what's not aggressive cancer is and then I see them before we do the surgery. (23, urologic oncologist, bladder)	---	---
Rationale against non-aggressive and non-invasive cancer	<u>Suggests treatment or follow-up is not needed</u> I guess a potential harm would be that they don't take the tumor seriously, so they think 'I don't have to come to follow-up appointments. I'm not at risk of this harm in my life or causing problems in the future'. And so, potentially they don't feel like they actually have a cancer they need to be worried about. (23, urologic oncologist, bladder)	---	---

Abnormal or atypical cell	---	Or just refer to it as abnormal cell (18, OB/GYN, cervix) I guess depending on the result I might use the word atypical if that's more appropriate (19, OB/GYN, cervix)	---
Rationale for abnormal cell	<p><u>Better than pre-cancer, which alarms patients</u> Sometimes I will say abnormal cell if I know that my patient are nervous or they have anxiety I will say abnormal cell and we need to treat that soon. So it depends. Some people that I know that they will understand well and will be able to manage that [pre-cancer term]. But some people sometimes are very stressed and they have a lot of anxiety so I will use more abnormal cell... I think abnormal cell is better than pre-cancer because when my patients hear cancer they don't like that although it is pre-cancer or cancer they, yah. So I think it will be better if there is no cancer to say that abnormal cell and when its cancer, cancer but yah, so. (16, family physician, bladder)</p> <p><u>Preferred over inflammation, which may suggest treatment or follow-up is not needed</u> I think abnormal cells is a good term because if I say that, oh don't worry, it's only inflammation in the cells, sometimes people won't take that seriously and they will say, oh okay, so I don't want you have a treatment because it's not serious. So I always say that although it is only abnormal cells we need to treat that (16, family physician, bladder)</p> <p><u>Easy to understand</u> They understand pretty good and, yah they understand that their cell are not normal so they have to treat that. (16, family physician, bladder)</p>	<p><u>Better than pre-cancer, which alarms patients</u> When I started my practice I actually used to use precancer a lot more liberally and when I found that both patients that I had seen and patients that my colleagues have seen will leave colposcopy clinics thinking that they have a cancer. And in reviewing histories in patients that have been treated for cervical dysplasia or even seen in colposcopy that they were told that they have a cervical cancer. I think that's the biggest harm is patients leaving with a higher level of anxiety than it is due; thinking that they actually have cancer. (20, gynecologic oncologist, cervix)</p> <p>I do use the word abnormal because it does send a clear message that it's not normal but at the same time it doesn't have that worrisome anxiety provoking connotation that the word cancer does even if its within like precancerous... I prefer abnormal because I want to be able to communicate clearly but at the same time without alarming them. (19, OB/GYN, cervix)</p> <p>I don't want people to get too worried. They hear the word cancer and they get very worried. But I do need for them to be concerned enough to know why they're going to colposcopy or to be compliant about following up with me. So it's abnormal cells if they're going to follow-up with me. (17, family physician, cervix)</p> <p><u>Better for low-grade conditions</u> If it is low-grade then I tend to just say abnormal cells... I prefer to use abnormal cells with patients for low-grade lesions. (20, gynecologic oncologist, cervix)</p>	---

		<p>So for the LSIL ones, so the lower grade one's, I would usually just tell people they have been diagnosed with mildly abnormal cells of the cervix and we call those low-grade changes. (21, OB/GYN, cervix)</p> <p><u>Better than precancerous which is inaccurate</u> I use the word abnormal. With patients I don't use the word dysplasia or I definitely don't use the word precancerous. And if a patient uses the phrase precancerous I specifically spend some time to explain how I don't use that phrase, almost calling it like a misnomer. (19, OB/GYN, cervix)</p> <p><u>Enforce appointment importance without overly concerning patients</u> I give them enough alarm or urgency; just get them to understand why the importance of them coming to their visits because compliance can be an issue with colposcopy patients; get them to follow-up on their results. Like meaning I see the patients in follow-up but sometimes just to book them in for their follow-up could be difficult or they; or they no show at a high rate. But at the same time is I don't want to alarm them into them tuning out and not hearing anything else I'm saying because I; as in like terms of like health teaching or anything like that. I also don't want them to have this fear that leads to them not coming to the appointment. But at the same time I don't want to mislead them to make it so nonchalant that, oh there's no issue here, and therefore they can be nonchalant about whether or not they're compliant with coming to visits, following up on results. (19, OB/GYN, cervix)</p> <p><u>Better than atypical cells or cervical dysplasia which patients do not understand</u> Sometimes I will say the same thing that it's in their report such as atypical cell. So this word patients do not understand all the time but abnormal is better. It's a better term instead of atypical cell (16, family physician, bladder)</p>	
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		<p>I would literally call it some abnormal cells of the cervix because they wouldn't understand cervical dysplasia. (17, family physician, cervix)</p> <p><u>Use term "abnormal" to supplement medical term</u> I think I will use the word abnormal cells but then I'll explain which one it is because I think people kind of you know, we have; I can show them a graph. I can show them; like I'll often; I will draw a picture that LSIL usually goes to HSIL which goes to cancer but a lot of LSIL's will get better, they may go back to ASC-US or they may go to normal. So I think that I always use the actual terminology and laymen's terms at the same time, right? (26, family physician, cervix)</p>	
Rationale against abnormal cell	---	<p><u>Too general – does not clarify risk of cancer</u> And the converse is true that, you know if you just to refer to something that's abnormal cells I think its very hard to conceptualize and if you have a high-grade lesion, I worry that patients might not necessarily return for follow-up if they just think, oh its an abnormal cells. (20, gynecologic oncologist, cervix)</p> <p>I tend not to like to use abnormal cells just because I think it's a bit too vague in terms of like what's abnormal about it; what does that mean for me. And I find patients tend to want to have more information than less and so it's a bit vague for them. (18, OB/GYN, cervix)</p> <p>I don't think the term means anything. So I don't, I don't typically use that term. I think because again, a pap smear is not a diagnosis and a pap smear can't say the cells on your cervix are abnormal. A pap smear says, it's concerned there maybe some changes on your cervix but it can't confirm anything... It maybe a simple error or over call on the pap smear; simply like the medical detector in the airport that beeps all the time even though we don't have the gun in our pocket. But a pap smear can't tell us that you have abnormal</p>	---

		<p>cells or precancer cells on your cervix. (24, OB/GYN, cervix)</p> <p><u>Term abnormal cells may cause stigma/shame</u> I think the possible harm would be is almost like patient kind of self-stigmatizing themselves. Like okay that means they're not normal. It could impact their relationships like in terms of whether or not they feel that they need to divulge certain aspects to their partner or future partners. (19, OB/GYN, cervix)</p> <p><u>Term abnormal cells causes anxiety</u> Even just by using the term abnormal it could cause them some sort of fear and anxiety. The reality is they have an abnormality that we need them to take it serious, and at the same time, I think we have a responsibility to inform a patient without over alarming them, like scare them. I don't want to use a scare tactic into compliance but at the same time I think it would be overly paternalistic to book someone in for medically necessarily appointments but not really tell them about what the importance is in their health, so why they should come. (19, OB/GYN, cervix)</p>	
Medical Label	---	<p><u>Matches what patients hear in later appointments</u> <i>RE: ASC-US, LSIL, HSIL</i> You need to use a medical label because a person's gonna hear that later, right? If you're gonna go to colposcopy you're gonna hear that you were sent for an abnormal pap smear; that was called LSCIL or ASC-US. I think that we need to be really clear that I'm trying to use; I'm trying to give a definition of what they are so in a non-medical way. And I also at the end of all conversations, you need to keep asking me questions. (26, family physician, cervix)</p> <p><i>Intra-epithelial lesion</i> So I do use the intra-epithelial lesion. Like I'm careful, I always relay the diagnosis. I relay what's on the pathology report and I use the term abnormal. But I then focus on where I feel that</p>	---

		<p>the patients understanding needs to be. I definitely use the term that's on the pathology report because I want to make sure I'm relaying to them exactly what I know about their health but at the same time (19, OB/GYN, cervix)</p> <p><i>Cervical Dysplasia</i> I tend to describe what the word dysplasia is and then I use that word with them. (18, OB/GYN, cervix)</p> <p>I tell them the word dysplasia. I tell them that the word simply means abnormal cell growth in Latin and so that they're not afraid of the word and they understand what it really is. I then spend time talking to them about what their real implications are of having dysplasia on their cervix. (24, OB/GYN, cervix)</p> <p><u>Term Dysplasia is more precise</u> The more precise you can be with a diagnosis the more helpful that can be with patients. So they feel like they have certainty of the diagnosis and they're not worried about as not being sure or a lack of, of kind of definitive diagnosis that's with them. (18, OB/GYN, cervix)</p> <p><u>Matches what is on patient charts/online</u> I like the idea that patients sort of can use some of the language that we use in the clinic. Dysplasia is a word that like they can conceptualize, that we can use when they have access to the charts for example, they can see we're using those same words. (18, OB/GYN, cervix)</p> <p>I think in terms of benefit, because people now have access to their, their charts through MyChart you know giving them the language that we use helps them to be able to interpret some of those reports because we know they look at their results and they're trying to understand what they mean. (18, OB/GYN, cervix)</p>	
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		<p>So I think that those are the big potential risks. In terms of benefits, giving people the most accurate diagnosis can be helpful when people Google these terms. They can find you know patient-level language that helps them to understand what that diagnosis is (18, OB/GYN, cervix)</p> <p><u>Term cervical dysplasia differentiates condition from cancer alleviating stress</u></p> <p>Patients can understand that there's a diagnosis that's not cancer and so by using a cervical dysplasia, it helps them to understand they have like a separate condition that we're worried about. So I think it kind of like cancers the diagnosis which I think can help alleviate stress. (18, OB/GYN, cervix)</p> <p><i>RE: Atypical cells</i></p> <p><u>Understandable with physician explanation</u></p> <p>I guess depending on the result I might use the word atypical if that's more appropriate and I do explain the different kind of cell lines whether like squamous or granular cells that might be the source (19, OB/GYN, cervix)</p>	
Rationale against medical label	<p><u>Complex, clear only after more discussion</u></p> <p><i>RE: Non-invasive papillary carcinoma, Stage 0 Grade 1 Bladder Cancer</i></p> <p>For my patients because they do not understand this, this type of word so I'm very simple (16, family physician, bladder)</p> <p><i>RE: Non-muscle invasive bladder cancer</i></p> <p>Yah I try to avoid medical jargon that patients are not going to understand. So telling them that they have high-grade pathology or muscle invasive bladder cancer or different terms that we see on pathology reports. Let me think of another example, like invading into the lamina propria. I think none of that a patient will understand and so I try my very best to avoid overly using medical jargon. (23, urologic oncologist, bladder)</p> <p><i>RE: Papillary Urothelial Neoplasia, Non-Muscle</i></p>	<p><u>Complex, clear only after more discussion</u></p> <p><i>RE: Cervical Dysplasia</i></p> <p>I think the biggest risk or harm is sort of a lack of understanding of what that means. It's not a term that's used colloquially, so the potential for them not to understand that, obviously because dysplasia and precancers can happen in other parts of the body. (18, OB/GYN, cervix)</p> <p>I don't think patients will understand the word cervical dysplasia, so I don't think that would be an appropriate word. (21, OB/GYN, cervix)</p> <p><i>Intraepithelial lesion (HSIL + LSIL)</i></p> <p>So I can't say whether or not squamous, intra-epithelial lesion is a helpful term or not. To me that's a pathologic term, that's medical jargon. It has its place within pathology, within medicine but I don't think it has its place in helping to explain a</p>	---

	<p><i>invasive Bladder Cancer</i> Those questions; no, these are all medical terms. It doesn't mean anything to the patient. So while you can use it, you have to definitely make sure you put it in a simpler way so they understand what it means. (27, urologist, bladder)</p> <p><u>Patients do not understand label</u> Example, carcinoma in-situ. Like that means nothing to a patient (23, urologic oncologist, bladder)</p>	<p>patient what's going on with their health. (19, OB/GYN, cervix)</p> <p><i>RE: HSIL</i> I think it's very hard for patients if you use medical terminology too much. Like if I was to start referring to things as HSIL, they're not gonna have any idea of what I'm talking about. So I try to stay away from that... But I think anytime we start using medical terminology it does patients a disservice for the vast majority. (20, gynecologic oncologist, cervix)</p> <p><u>Too general – does not clarify risk of cancer</u> <i>RE: Cervical Dysplasia</i> I think for cervical dysplasia it can be quite misleading if people have a low-grade abnormality that really has no cancer risk to call it precancer. So I try really hard not to do that because I find that it helps improve communication. (20, gynecologic oncologist, cervix)</p>	
Grade Group 1 Prostate Cancer	---	---	<p>Typically, would say a low-risk prostate cancer and would use the Grade Group I as another description for them. (22, radiation oncologist, prostate)</p> <p>I usually start with that just to let them know that I'm telling them they have a one out of five on a five-point scale and that we don't recommend treating those ones and that we would plan to keep an eye on them (25, urologist, prostate)</p>
Rationale for Grade Group 1 prostate cancer	---	---	<p><u>Language doctor was trained to use</u> I guess for me its been what's used from when I was trained and have been practising as one of the risk groups for, for men who had been diagnosed with prostate cancer. (22, radiation oncologist, prostate)</p> <p><u>Easy to understand that Grade Group 1 of 5 grades is low risk</u> So the Grade Group classification; I think because there's 5 Grade Groups; seeing it as a one can feel that kind of fits with it being a lower group or an earlier group. (22, radiation oncologist, prostate)</p>

			<p>The biggest benefit is that [Grade Group] 1/5 is meaningful to people in terms of being small. It's the lowest and it's also small. So I mean if I'm feeling a sports analogy I'll use something like batting average or something like that. Otherwise, I'll just say that it's the lowest number on the scale of aggressiveness. (25, urologist, prostate)</p> <p>I mean I think Grade Grouping is simpler and better in a sense that like a scale of 1-5 makes a lot more sense than a scale of 6 to 10. So I do think that Grade Grouping is better nomenclature and its likely just due to president that Gleason Score is so used a lot at least where we are. We use both but it still; it is still certainly used a lot (28, urologic oncologist, prostate)</p>
Rationale against Grade Group 1 prostate cancer	---	---	<p><u>Patients perceive advanced cancer</u></p> <p>For some people knowing that there is a cancer and abnormalities, something that could impact their length of life or their quality of life, their focus maybe is on having it taken out, of having it removed, of having it treated regardless of it being at the early point of a disease course when at intervention may not have a significant effect on the length of time with their disease. They would have more time for side effects for the impact on their quality of life with that because of the lead time bias of a diagnosis until when their condition may worsen and then require treatment where. So even calling it a Grade Group I Prostate Cancer may still have that effect on, 'I need to have a treatment for this cancer'. (22, radiation oncologist, prostate)</p>
Rationale against Gleason Score (prostate)	---	---	<p><u>Patients perceive advanced cancer</u></p> <p>The challenge with using the Gleason number, so like a Gleason VI, 3 + 3 = 6; it feels like its farther along that range than with the Grade Group; the Grade Group it looks like, no its right at the beginning whereas the Gleason VI only because it; its between the 6 and a 10, it feels like its farther along then. (22, radiation oncologist, prostate)</p>

			And when I say, a 1/5 there's another way of naming it and that way is an older; an older way called the Gleason Score. Lots of them will then sort of nod because they've looked things up. And I'll say, in this case the score is a 6/10 and I'll acknowledge 6/10 sounds like a lot but that the scale starts at 6 and that it is a; it is a sum of two numbers and it starts; it starts at six. (25, urologist, prostate)
Uses Gleason Score and Grade Group terminology	---	---	I more commonly use the Gleason Score, like 6 to 10 but I also do use Grade Group I; both. Depends on the patient and what depth of detail they're requesting... So patients have often seen their pathology result or they can pull it up if they haven't and that's like the Gleason Score is still what is; like primarily reported. And so sometimes I'll translate that to Grade Grouping, again depending on how the conversation is going and the patients looking for. (28, urologic oncologist, prostate)
Prefers to use terms "low-grade" and "high-grade"	<p>And grade wise I usually just simplify it, say aggressive, non-aggressive and are comparing to low-grade, high-grade. (27, urologist, bladder)</p> <p><u>Complex, clear only after more discussion</u> I don't use the word Grade because they; I feel like it makes it too complicated or say there's like a; like a scoring system. It starts with one goes to three for Grade or stage wise. And if they ask; what's my stage, I say that it's very low, it's not even Stage I, so it's Stage 0. (27, urologist, bladder)</p>	<p><u>Matches tests results</u> I tend to sort of say like not worrisome or worrisome, more in keeping with like a low-grade change or a high-grade change. And again, I like to use that language because that's what a pap result; a cytology result will be. Like that it's low-grade versus a high-grade... I might say like that this is not worrisome or not suspicious. (18, OB/GYN, cervix)</p> <p>I really like to include the term low-grade and high-grade because I think a lot of patients after we chat will go to the internet and look things up. So those are consistent with what a patient would find if they Googled something. (21, OB/GYN, cervix)</p> <p><u>Patients perceive advanced cancer</u> So I do feel that sometimes when you attach the word grade to something, the low-grade or high-grade, that's when the general public thinks about grade they usually connect it to true malignancies or cancers. And if they went and just looked up</p>	---

		something like high-grade or low-grade on the internet it would be associated with a malignancy. So it may induce more anxiety in that patient (21, OB/GYN, cervix)	
Carcinoma in situ (cervix)	---	<u>Complex, only clear after more discussion</u> You know we still see people talking about carcinoma in situ and I think any language like that is very confusing for patients because is when you search the term carcinoma and without the follow-up words you know you find cancer. (18, OB/GYN, cervix)	---
Low-risk cancer	Basically say you have a low-risk cancer of the bladder usually these are kind of a mellow cancer. They tend to come back but they don't get worse (27, urologist, bladder)	---	<i>RE: Low risk + Non-aggressive</i> I would say that they have a low-risk or a non-aggressive prostate cancer. (28, urologic oncologist, prostate)
Rationale for low-risk cancer	<u>Ensures patients understand condition is low-risk/non-aggressive</u> Mostly to ensure them that this is not something serious because the moment somebody hears cancer they are thinking, oh I'm gonna die from this. So we basically... basically, immediately interrupt that this is a low risk cancer and usually it doesn't act aggressive but we need to just keep an eye on it. (27, urologist, bladder) <u>Cancer label prevents loss to follow-up</u> I think the benefit is they still know this, like using the word cancer still gives the patient enough; basically worry in a sense that they don't forget about it and they just don't say it's nothing and if; get lost in follow-up. (27, urologist, bladder)	---	<u>Ensures patients understand condition is low-risk/non-aggressive</u> <i>RE: Low risk + non-aggressive</i> I think its one that patients understand and hopefully it communicates that their cancer is not gonna harm them in the near future. I would say unlikely to spread...I mean I think it's beneficial hopefully and communicating the patients that although they can identify to have a cancer diagnosis that they are unlikely to be harmed by it at least in the near future. (28, urologic oncologist, prostate)
Rationale against low-risk cancer	<u>Label causes anxiety</u> I think just using cancer alone without kind of; that are defining it and putting conditions on it is not a good thing because patients usually over interpret. On the other hand, you don't want to make it too; basically give them so much; basically confidence that this is not a thing that they would basically forget about it. So that's a balance we have to find as a physician so that patient knows that this condition exist, patient forget about it but it's probably not gonna harm them in the long	---	<u>Label causes anxiety</u> And the harm of it, I mean like anytime someone has a label or a diagnosis of cancer it can cause anxiety and concern for the patient and their family and so part of our responsibility is to explain to them in a bit more detail and contextualize the diagnosis. (28, urologic oncologist, prostate)

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How do patients understand or react to labels

Theme	Bladder	Cervix	Prostate
Relieved or reassured	<p><i>RE: Abnormal cells</i> They understand pretty good that their cells are not normal so they have to treat that (16, family physician, bladder)</p> <p><i>RE: Non-invasive, non-aggressive cancer</i> I think often patients still are not surprised, they still hear the word cancer and so they still understand that they have a malignancy that needs to be monitored. I often find that they're relieved when they hear that it is a non-aggressive, non-invasive cancer and that they won't need to go onto surgery to remove their bladder or treatment into their bladder where they have to come back to the hospital every week. So I feel that they do take it seriously but I find that they're quite relieved that it's not being aggressive or a muscle invasive tumor (23, urologic oncologist, bladder)</p> <p><i>RE: low-risk bladder cancer</i> I ask them; as you say, well this no risk...you probably can actually tend to react in a positive way that's, okay so I just have to kind of live with it rather than suffer from it. (27, urologist, bladder)</p>	<p><i>RE: Precancer/Precancerous cells</i> I think it's generally relatively well received, and I think for the most part they understand that. If I'm explaining it for the first time, I'll often say precancer is what you have and if we don't do anything about it, it likely could turn into cancer so that they understand that language a little bit better. I haven't had anybody say that they didn't like it. I think sometimes precancer can come across as a little bit shocking to people if they weren't sure where they were with things. But sometimes I think that's not necessarily a bad thing. I think if they are a little bit surprised by that word, I think it does convey understanding. I haven't had anybody react really badly to that sort of terminology. (20, gynecologic oncologist, cervix)</p> <p>When I tell them that I think they have a high-grade change and its precancerous, as long as I reassure them that there's absolutely no cancer there and we'll be able to remove it, they respond I think well, and I think are reassured by that...people are usually pretty happy with you just telling someone that it's precancerous which means just a mildly abnormal cell and it hasn't turned into cancer. (21, OB/GYN, cervix)</p> <p><i>RE: ASC-US, LSIL, HSIL</i> I think that they understand because we have a good conversation about it and we make sure that their questions are answered. (26, family physician, cervix)</p> <p><i>RE: Cervical Dysplasia</i> I have the benefit, in cervical dysplasia, of having a very good intervention to offer people before it</p>	<p><i>RE: cancer (i.e. Grade Group 1 cancer)</i> So when they end up seeing myself, they've had some of these conversations and they are quite well researched on what their options are and have a strong opinion on what direction they want to take. The ones that come to see me they either have an interest on the radiation-based treatments or uncertainty on what to find out about their options. So often I don't have the immediate reaction as to how they think of it being a Grade Group I Prostate Cancer compared to an advanced cancer. (22, radiation oncologist, prostate)</p> <p>They seem to be happier with Grade Group I because it's not always in their preparation. Lot's of people have done some searching and they'll usually come across the Gleason Grading. So I would say on the net they seem reassured by the Grade Group I. In my practice I would say that my conversations around recommending surveillance and describing Grade Group I Cancer are generally met with positivity. I don't usually have people raising their eyebrows or getting frustrated... overwhelmingly people take the visit as an acknowledgment of a lower-risk situation that requires monitoring. (25, urologist, prostate)</p>

		gets to precancer and once you talk through that and next steps in how long it takes for cervical dysplasia to become cervical cancer. Then most people tend to be quite reassured by us. (20, gynecologic oncologist, cervix)	
Anxious about severity or health implications	<p><i>RE: low-risk bladder cancer</i></p> <p>The first thing they want to know is, is it gonna kill me or not? Is it aggressive? Has it spread? (27, urologist, bladder)</p>	<p><i>RE: precancer</i></p> <p>Some people tear up a little bit if they're really worried about it and I tell them it is what we were worried about (20, gynecologic oncologist, cervix)</p> <p><i>RE: precancer, abnormal cells, cervical dysplasia</i></p> <p>I think it is a very individual response and I think patients who are very worried about cancer or who have health anxiety are generally speaking kind of anxious regardless of what we tell them or what the diagnosis is right? (18, OB/GYN, cervix)</p> <p><u>Concerned about future fertility</u></p> <p>What impacts that it's gonna have on trying to have a baby in the future... Not just that it's cancer, the risk of it passing on to their children, and how do they get it is another thing and have a whole other questions. (17, family physician, cervix)</p> <p>And probably the third kind of concern within a specific patient population is the impact to future fertility. Like not necessarily just from the abnormality but abnormality at treatment. (19, OB/GYN, cervix)</p> <p>And what this means in terms of future health outcomes for them in terms of future fertility and/or concern about future development of cancer in the cervix or in other areas of their body as we've started to learn. (24, OB/GYN, cervix)</p>	<p><i>RE: cancer</i></p> <p>Certainly there are some that you really can't wrap their heads around the concept. Some have significant anxiety and its very detrimental to their mental and physical health due to fear of what the cancer could do to them (28, urologic oncologist, prostate)</p>
Confused if it's cancer	<p><i>RE: pre-cancer</i></p> <p>They will ask me if it is cancer. It is the first question. So this is the main concern. Patients are very concerned about cancer. When I say, no it is just before but we have to treat; they always happy about that... for all the organs when I say that there is an abnormal cells they will ask me if</p>	<p><i>RE: abnormal cells</i></p> <p>The biggest question is, what do you mean by abnormal? Does this mean I have cancer? (19, OB/GYN, cervix)</p> <p>Particularly with the low-grade changes, I would say that a lot of people don't really understand</p>	<p><i>RE: Grade Group 1, Low-risk cancer</i></p> <p>So it is not an uncommon thing for people to wonder if they have to be declaring that they have cancer of if they believe that their life insurance or travel insurance for snowbirds will be compromised by their label. (25, urologist, prostate)</p>

	<p>there if it is cancer. (16, family physician, bladder)</p> <p><i>RE: stage 0 bladder cancer</i> The patients do ask me, well does it mean that we say Stage 0? (27, urologist, bladder)</p>	<p>that its not necessarily considered precancerous. There's confusion about the low-grade changes, we will commonly just do repeat pap tests or will do more expectant management where they're not treated. So a lot of people have; have confusion about if there is something there that's abnormal why are you not treating it? They don't understand the natural regression or progression of the low-grade changes. (21, OB/GYN, cervix)</p> <p>"Do I have cancer? Why aren't we doing this sooner? Should I go and see a specialist now?" (26, family physician, cervix)</p>	
<p>Confused about why they don't need more testing or treatment (when active surveillance is recommended)</p>	<p><i>RE: cancer</i> I guess telling people that they don't need to do anything else right now, that we're just going to follow-up and do a cystoscopy in 3-months and then in 12-months. For some people that's a big relief. For other people who have just been told that they have cancer that is nerve racking because they expect that they're gonna need more surgery or radiation or chemotherapy but when you're told that they're not, especially younger patients, I find that they're a little bit more hesitant that that's all that they need. (23, urologic oncologist, bladder)</p> <p>It comes down to the personality of physician and also personality of the patient. It is; it is at times necessary to tell the patient just relax, let's give it at least a bit bigger and just kind of watch it. And especially because of risk of the spread or the evidence is low; that could be a good option. But the main thing that causes patients to become concerned about and then say no, I don't want to do that, is the word cancer, and no worries, they have symptoms looks such a...they usually prefer that something is done about those tumors. (27, urologist, bladder)</p>	<p><i>RE: abnormal</i> They want to do pap smears more often. They don't believe that 3 years is adequate. They feel like abnormal cells are going to be abnormal for life and that they shouldn't revert back into normal screening (17, family physician, cervix)</p>	<p><i>RE: cancer</i> Uncertainty about if the cancer will progress and uncertainty about their management choice especially when most of these patients are asymptomatic (28, urologic oncologist, prostate)</p>
<p>Shocked by the diagnosis</p>	<p><i>RE: cancer</i> Generally speaking, when you tell them it's cancer, the first thing is shock (27, urologist, bladder)</p>	<p>---</p>	<p>---</p>

What language or approaches do you use to explain risk or uncertainty

Theme	Bladder	Cervix	Prostate
Used plain/lay language	<p>So I will say usually in a healthy body the cells always regenerate for a new one when there is another; and I always explain that their macrophage, it's like a big soldier that eats the bad cell. But when you have abnormal cell, you have more than expected and the soldiers are not able to destroy them. That is why there is a multiplication of these abnormal cells and we need to stop that with treatment to be sure that the good cells will grow and the bad cells will die. But it's after; apoptosis but I don't say this kind of word to my patient because it's too complicated. (16, family physician, bladder)</p> <p>I often explain that the main risk of tumors that they have was not aggressive, non-invasive; is that the risk of it coming back and forming another tumor in the bladder which is why we have to monitor closely with cystoscopy, so a camera testing the bladder. And that if it does come back, typically its very treatable and we can either do another minor surgery to scrape it out or to burn it but it's important to catch it early so that it doesn't become a higher risk type of a tumor; typically what I say is the risk is mostly that it comes back, this tends not to become a more invasive tumor but we do need to keep an eye on things to ensure that we're not missing a period of time where we could cure any tumor that does come back. (23, urologic oncologist, bladder)</p> <p>So the first thing is actually discussing what it is; the next would be to tell them what it means and how it's gonna affect them during their daily lives. Usually these tumors don't change to become aggressive or become a higher stage. Always say the risk of them getting worse is really low and risk of dying from these are extremely low. But unfortunately these tend to come back, so that's</p>	<p>But I tell them that the, the low-grade and the high-grade are also put together in groupings not just because of what it looks like under a microscope but because of what happens and that low-grades tend to go away on their own and not require treatment. Whereas in high-grades tend to linger and worsen with time and therefore those are the ones that we treat. So when a pathologist looks under a microscope for instance, they look at characteristics that help them decide whether or not this is low-grade or high-grade. I wouldn't say that's an analogy to a patient. I think that's just a kind of simplifying of how we make the pathological diagnosis. (19, OB/GYN, cervix)</p> <p>They [patients] might not know what it is on a cellular level but most people if you say, you have a cancer then they understand that. And so, I will often say, this is not a cancer, this is the step before cancer. And if we weren't to do anything about it then you likely would end up with a cancer. (20, gynecologic oncologist, cervix)</p>	---

	<p>why every so often we look inside and if there's a sign of recurrence we have to go back and scrape the tumor again. (27, urologist, bladder)</p>		
Used analogies	<p>I will say also that if have a wound on your skin, there is a rash and it is not cancer. But if you don't treat your wound on your skin that can get worse. So it's the same inside of your body but you don't see that, but it is inside inflammation and if you don't treat, like the wound on your skin that you can see, it can have infection, it can grow, it can form cancer, so it's the same thing. It's only the thing that you don't see because when my patients comes for like a tiny pimple they will be a very scared about that. Should I treat that? But inside of the body they don't see that. So sometimes I will make a parallel with the wounds are inflammation of the skin for the patient to help them to better understand the serious of treating abnormal cells that are pre-cancers. (16, family physician, bladder)</p> <p>I'll use analogies that patients can use; can think of, like the; your bladder tumor is only into the first layer of the bladder which is kind of like the lining of your cheek, so that they can understand what the inside of their cheek is like and that is just in the first layer, it's not going deep (23, urologic oncologist, bladder)</p>	<p>We use the shades of grey analogy on the white to black analogy. (18, OB/GYN, cervix)</p> <p>I do use an analogy when it comes to HPV. I use that analogy in terms of like freezing rain and I tell them that we know HPV does not mean abnormal cells. HPV means it's a risk factor for developing an abnormality. But in a similar way, freezing rain doesn't mean you are gonna get into a car accident, but we all know that it does increase your chance of getting into a car accident. And then I draw that analogy to getting HPV testing is like looking at the weather forecast for whether or not it's gonna be freezing rain. In that, you may still head out on your trip regardless, but you're gonna take that into consideration. You're gonna use precautions. You're gonna say do I really need to take this trip? Can I put it off until tomorrow when the freezing rain thawed, like whereas with HPV it's a similar manner. It gives patients the knowledge to know whether there's an importance for them to come to these visits, come for their check-ups because they're at higher risk of developing an abnormality. (19, OB/GYN, cervix)</p> <p>It's like the metal detector at the airport. They're screening for guns before we let anybody on the plane because we really don't want anybody on the plane with a gun. In their case, the pap smear is like the metal detector, we're screening for precancer cells on the cervix, not cancer. I'm doing that because we want to find precancer and treat people that have precancer before it turns into cancer. And so when their pap smears not normal, I tell them it's just like going through the metal detector at the airport; you beeped. Your pap smear is not normal. This does not mean that you have precancer. It means you need to be checked more closely to ensure that you're not at</p>	---

		<p>risk for developing cancer; that you don't already have precancer and therefore you need further testing. Just like at the airport where they pull you aside and the guy with the wand comes along and scans you more closely til you see if we're really concerned about the possibility of there being some abnormal cells there. (24, OB/GYN, cervix)</p> <p><u>Compare to other conditions</u> So the best way to really educate is to say that almost everyone's exposed to it somehow. So that's so important somehow to get across to people; that there's no stigma in it. I always talk to people about walking around a pool and your feet are exposed to a wart virus that someone left there but 100% of the people walking through that pool area did not get the wart. Only maybe one might actually come out with that; with that, what that wart despite all these people being exposed to it. And the other one is likely had COVID and only some people got really, really sick. Other people were somehow able to, to get over it. (17, family physician, cervix)</p> <p>Again, I try to go back to the fact that abnormal cells in it of themselves are likely reflective of HPV infection and when the infection goes away then the abnormal cells will often go away. I will sometimes liken it to a common cold, I use that as a metaphor. That when you have the virus you've got a runny nose and changes to your cells and then when the virus goes away, all that stuff goes away. And I think that seems to lessen anxiety. (20, gynecologic oncologist, cervix)</p> <p>And I explain HPV as that it's more like a flu or a cold virus, so it's very different from the other types of viruses like herpes or HIV where you definitely need to disclose that and it impacts your sexual health. Whereas the HPV is more like a flu or cold and almost everyone gets that it and it can come and go and go between partners very</p>	
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		easily and it's not necessarily something that, that impacts their sexual health. (21, OB/GYN, cervix)	
Described risk of reoccurrence or chance of survival	<p>If they're smokers I encourage them to stop smoking and talk to them about smoking sensation as that; a very high-risk of developing more aggressive types of cancers. (23, urologic oncologist, bladder)</p> <p>If they asked me directly, should I be concerned about this, and most of the time they're referring to this, is it gonna limit my life-expectancy? Do I have limit days left? I generally say no, it's not gonna bother you in that way. But there's a lot of back and forth because we have to look inside, we have to keep an eye on things and we're gonna see each other quite often and probably for another 5, 10 years. So, and then I explain to that and to them that this is basically just surveillance. As long as the tumor doesn't come back, we're all happy. And if it comes back depending on the findings of the procedure and pathology, we will change gears if we need too. Otherwise most of the time it's just look inside, do a scraping or make burning the tumor and that's all we have to do. (27, urologist, bladder)</p>	<p>And that actually is quite helpful for them. That an abnormal finding has sometimes less than 1% chance of becoming a true cancer, and that then is like a pretty reassuring step for them. (17, family physician, cervix)</p> <p>And that's why I also take time to tell patients that they're either precancerous or they're not considered precancerous, like the low-grade ones or and that they can be treated...And I'll usually talk to patients about the chance of there being a high-grade lesion, that there's no problem with waiting one or two months for the colposcopy that the progression; if there is a progression to cancer is extremely slow. (21, OB/GYN, cervix)</p> <p>For the people that do not really have changes that are really precancerous or likely to turn into precancer, I, for people that have been shown to have lower grade changes on biopsy on their cervix; 80-90 percent of those think it's important to reassure them of that...And I go over in detail the statistics from research that have been done to tell them that, for example patients; all those cell changes completely disappear without any treatment on their own within 2 to 3 years. I tell them all that it takes 10+ years in general for precancer cells to turn into cancer. (24, OB/GYN, cervix)</p> <p>The new guidelines are telling me that once you've had one ASCUS, I need to repeat your pap smear in one year and if that's normal we just do it one more year after that. If that's normal you go back to every 3 year screening. If though you get two ASCUS's in a row or you get something that's moved a little farther down the; down the pathway...Most of them get better on their own, 97% of ASCUS and LSIL's will just get; get better without treatment and therefore we simply need</p>	<p>I tend to use terms like 99% likelihood that you're not gonna succumb to prostate cancer in the next 15 years...I present surveillance as the obvious best answer and other treatments are available in rare circumstances and that I don't believe it applies almost ever in those cases. (25, urologist, prostate)</p> <p>I'd explain to them that they have cancer changes identified on their biopsy; most commonly or in their tissue that these types of cancers or this type of cancer that was identified is one that doesn't usually grow quickly or spread and that it requires in most cases monitoring and care to ensure that it doesn't get worse but that there's a good chance that it will not harm them either in the medium to long term or ever depending on their age and other factors. (28, urologic oncologist, prostate)</p>

		<p>to repeat your pap smear yearly for the next two years and if you get an another abnormal, then we're gonna go on to investigate. (26, family physician, cervix)</p> <p><u>Explanation varies on age of patient</u> Now the difference from the counselling perspective will come up depending on their age. In terms of future issues; if it's a high-grade abnormality in a post-menopausal patient, not only are we going ahead with treatment, but we don't counsel on impacts to future fertility. On the flipside is if we see a woman younger than age 25 and has the abnormality, I do counsel them differently because we don't do paps earlier than age 25 by our guidelines; not because those women don't get high-grade abnormalities; is we actually know that they do. It's that the abnormality comes and goes off the body so quickly that the screening and intervening actually doesn't benefit their health, definitely not their long term health but it also has risks associated. (19, OB/GYN, cervix)</p>	
Explain how common condition was		I'll let them know that it's actually quite common to have, or that they'd be abnormal and it's very common as well, that it will go back to normal. So that's sort of reassuring to them. I don't think that that would btie the stage at which they would be overly alarmed but just more safe about following up. (17, family physician, cervix)	
Provided educational material	They're also <national urologic cancer organization> brochures that if handy, I'll just pick them up. If not, I'll usually give the patient one of those brochures and kind of circle what's going on with them. And I'll pretty much almost always say, with different cancers, for example <national bladder cancer organization> or <national prostate cancer organization>; go read these things. These are accurate and the information is reliable if you want to know more, I think that's the best resource. (27, urologist, bladder)	We have hand-outs in our clinic talking about precancer of the cervix and talking about the LEEP procedure. We have them available in a bunch of different languages as well which is really nice. And so that, I think is quite helpful most of the time when patients come in for their LEEP they feel like they've been relatively well informed. I often will start talking about consent, I know the nurse went through it, I read your pamphlet, everything is fine. I think they usually end up with a relatively good handle on what's going on. (20, gynecologic oncologist, cervix)	We do have some booklets or handouts that provide a diagram or a representation of the anatomy of the patient... So try not to just do it by, by verbal terms because that can be challenging. (22, radiation oncologist, prostate) We have a variety of patient education material that are available in my clinic. I don't rely on one in particular. I would refer patients to various reliable resources like the <National Urological Organization> or <National Urological Organization> if they want more information or

	I always refer my patient to the [hospital name]and also we have in <province>, [web site name] and they can click on bladder cancer and they will, they will and there is a picture and they can see stage I pre-cancer risk lesion, stage I, cancerous tumor have spread into connected tissue. Stage II muscular wall, Stage III; so I explain that to the patients and I always say, we don't want that to go in that; like the Stage IV cancer has spread to major organs (16, family physician, bladder)		<Nationale Prostate Cancer Organization>; organizations like that. I don't use a particular analogy I don't think. (28, urologic oncologist, prostate)
Used visual aids	<p><u>Uses diagrams and visuals</u></p> <p>When I explain that I show a picture of the different stages of the inflammation of the cell and I show that to my patient. So for example, I will, I will show an interpreting bladder biopsy result for the bladder and I will show them like low grade picture with that and then high grade and non-invasive and invasive. So I will explain to my patient the different term and I will show an example with a picture because when I show a picture patients better understand... I explain, I draw something on the paper of my exam table so there is a white paper, so I will draw to explain. (16, family physician, bladder)</p> <p>I often draw a diagram with the different layers of the bladder and so I tell them that we're looking to see if it goes into the deeper layers. And so when I tell them that it was non-invasive and not fully into the deeper layer of the muscles; I feel like it correlates with drawings that I've given them in the past and optimal; re-draw them at that time so there's a way that they can visualize what I'm talking about... But if you draw them a diagram, I find that they are much more understanding and receptive to you some of the important terminology that we have to discuss, like invasive, non-invasive, going into the muscle, not going into the muscle. (23, urologic oncologist, bladder)</p> <p>And then when that discussion comes up, I try to</p>	<p><u>Uses diagrams and visuals</u></p> <p>I really like a timeline that shows how it is reversible. I think it's helpful to have stats just to say like your chance, <National Preventative Health Organization> have those lovely pictures and they'll have like a hundred people and how many people will actually get it. And I never give people the words, I only show them the picture so that they understand that the; what that means pictorially. (17, family physician, cervix)</p> <p>In our clinic we tend to use a gradient approach. We tend to use a scale sort of white to black, with basically like moderate high dysplasia being sort of in the middle or as a grey zone. Using some sort of ordinal scale or rating scale to understand the degree of which we're worried the degree to we're concerned about malignancy...We have a visual graph that we use. We sort of have the gradient already drawn out for people. We tend to circle what their diagnosis is kind of on that; that graph between low-grade and high-grades and then again, outside of sort of that bar is cancer. (18, OB/GYN, cervix)</p> <p>My visual aid is drawing. Usually with ASC-US, I sort of say the progress towards cervical cancer which is way over here on the right is usually a progress through LSIL to HSIL to cancer or to cancer in situ to cancer. Whereas ASC-US is something that, we're just saying there's slightly abnormal. We don't really have a good answer</p>	<p><u>Uses diagrams and visuals</u></p> <p>I also show pictures of the range of Gleason I to Gleason V and how their biopsy results were obtained. (22, radiation oncologist, prostate)</p> <p>I will draw a picture of the prostate and by that I mean sort of a; something that kind of looks like a big strawberry cut in half lengthwise and then I'll draw the; some "x's" on it in where routinely I put needles to give them a sense of the prostate and then I'll draw this little angel hair pasta thing about a centimetre long. And I'll often reference a little length along it by filling it in to the tune of the amount or percent of the cores that are involved to give them a sense of the physical literal size of what we're dealing with. (25, urologist, prostate)</p>

	<p>basically use diagram to show them different staging and exactly show them what it means. It's basically localized to the bladder, it's not even invasive and it's low-risk, low-grade. I tell them that too... to make things simplified. Again, the diagram we have in the office. If I don't have them I just basically do out a scratch and draw something and try to show them what's going on. (27, urologist, bladder)</p> <p><u>Uses physical model</u> Sometimes I have a plastic bladder and I show them. (16, family physician, bladder)</p> <p><u>Uses videos in practice</u> So this is the things that I use and sometimes there is video also that I will use. There is a lot of video with my own clinic, so I use that. (16, family physician, bladder)</p> <p>And obviously I've seen some software's on iPad that you can basically put it on an iPad; something and just basically hand it to the patient and say, why don't you watch this 5-minute video or attend that video, it will go through exactly what I just explained to you. And then you can always send them a link to a video as well. (27, urologist, bladder)</p>	<p>for it. It doesn't necessarily mean you're going on that pathway, it's a separate thing. So I'll often kind of put it down below, however if you get ASCUS's its telling me hey, you know what, there maybe something that's happening and we need to look at this. So yah, I usually do a drawing. (26, family physician, cervix)</p> <p><u>Uses physical model</u> I have a model of a cervix to touch the uterus to show them where the anatomy is just to make sure they understand what it is that's actually being tested. (24, OB/GYN, cervix)</p>	
Arrange follow-up visit to discuss further	<p>Often, if people are very anxious about their diagnosis, I will see them back in a month or so just to go through things again, see how they're doing; make sure that they're coping okay...So I would say its just more reassurance from me and then if they; if there's someone who needs it, I will see them back sooner than their usual follow-up. (23, urologic oncologist, bladder)</p> <p>And the next thing would be usually these sessions are; sorry, there's so much information going back and forth and the patient they just forget pretty much everything. Then I set-up another follow-up in a few weeks to say, hey this is what's going on, what do you want to do? Do</p>	<p>This is the way that we usually follow people along and I'm here to have you, if you want to think about this for a little bit and call me back or make another appointment to talk about this, well you are welcome to do this. (26, family physician, cervix)</p>	---

	you have any questions? And that seems to work. (27, urologist, bladder)		
Ask patients to articulate specific concerns	---	What I'll often do, well one, we need to understand what that patients concerns are. Can you please tell me what you're most worried about? And then let's move there. Then I tell them about wasteful worry, right? So if I tell you this; that you have this abnormality and you're gonna worry about it everyday, and then a year from now its normal, you're gonna have wasted a year with worry. So let's look at wasteful worry vs. worry. So how about this, can you think about it once a week or once a month if that helps you out? But this is something that I wouldn't worry about; many of my patients have had this before. Oh so now that we've said this, you still look like you're a little bit anxious. Why don't you tell me what you heard me say?...So it's just not me talking, I need to understand what you heard from my talk. (26, family physician, cervix)	---
Took extra time to discuss concerns and answer questions	After my explanation usually its not so long they; I ask them do you have any question about that and if they know, we understand that we have to treat just to be sure that our; abnormal cell turn not into cancer, so most of my patients understand that very well. (16, family physician, bladder)	---	---
Explicitly state low-risk lesions differ from invasive cancer	And sometimes when I explain with the picture, people will say, oh it's pre-cancerous lesion. Do I have a cancer? And I always say, no it's an abnormal cell in a smaller quantity. So I try to explain that way just to be sure that patient are not too worried about that or scared (16, family physician, bladder) Yah so typically by saying the aggressive types of cancer cells we worry about those spreading to other parts of the body, going into the lymph nodes and typically those types of tumors tend to be ones that we need to do more aggressive types of treatments on; like removing the bladder or doing treatments into the bladder where you	What I find helpful for patients to understand is that the cells that we're looking at are very superficial; they're just sitting on the surface of the cervix, they're not deeply invasive. They're easy for us to detect by biopsy if necessary. So it's not a very invasive exam obviously for some people, it's invasive but the tests are pretty well tolerated by patients. We have a wide range of treatment options that are validated and have been shown time and time again to reduce the risk of a cancer particularly LEEP excision and cone biopsies. (18, OB/GYN, cervix) I'll use the example of a high-grade pap abnormality, probably our most common kind of	I guess I try to provide them with an understanding of how typically cancers progress over time by accumulating more changes which can change how they behave can, make them more aggressive, can also change how it appears under the microscope. And so, with the other aspect of the biopsy is there's also the sense of how much of the prostate is involved with the numbers positive cores for example, as a reflection of the extent within the prostate and what changes have developed in those abnormal cells over time; change in the appearance of subsequent biopsies. (07, radiation oncologist, prostate) I think it is similar to what I've said that the

	<p>need to come to the hospital once a week because they're at higher risk of both coming back into the bladder but also spreading to other parts of the body. However, when these cells are not aggressive we don't worry about that quite as much at this point and that the main way that we monitor to see that the cancers not coming back is with the camera test. However, at some point you might have aggressive cells and need these treatments which is why it's really important that we keep an eye on things and if you develop blood in your urine you call us back at any time. (23, urologic oncologist, bladder)</p> <p>So like very, in the official format saying, you have cancer. The next thing I say, is it low-grade or high-grade and then the next thing I would say is; as it maybe that the wall on the bladder or not. And then kind of summarize everything saying, oh you have a low-grade cancer, it's a small focus, hasn't grown into the wall and doesn't show any aggressive features. (27, urologist, bladder)</p>	<p>high-grade abnormality is high-grade squamous lesion. For that pap abnormality I would talk to someone that this is a high-grade abnormality, it is not cancer. If left unchecked, untreated this could develop into cancer and therefore it's important for the patient to maintain these visits, the treatments, the follow-ups and even after. (19, OB/GYN, cervix)</p> <p>I, yah I can't think of one to absolutely not have except to just really assure them it's not cancer. (21, OB/GYN, cervix)</p> <p>Using the word not cancer is probably how I distinguish it. Abnormal cells are that; they're normally cells look one-way and these ones are just a little bit abnormal or a typical, that need to be followed, again, if; I almost need the person then to ask me the next question to know where I take that, whether, like I don't draw picture of a cell. (26, family physician, cervix)</p>	<p>difference here is that what a pathologist recognizes as cancer is an abnormal group of cells and what a doctor and a patient should be concerned about is the ability of those cells to misbehave and that the 1/5 cancer do not seem to have that ability to misbehave... So it can't really spread and it can't really do harm on its own. But it is something that we have to keep an eye on because it can signal the presence of other or development of a more meaningful cancers in the future. (25, urologist, prostate)</p> <p>I mostly speak to them about the fact that a cancer that is in your prostate most of the time doesn't cause you harm and it doesn't cause you pain or cause you to die for example. But then I explain that if a cancer causes you harm if they grow large or if they spread and I state that this type of cancer doesn't usually do that. That's how I would try to explain the difference between this cancer and an aggressive cancer. (28, urologic oncologist, prostate)</p>
Referred to staging, grade or coninum in relation to risk	---	<p>I often will talk about the spectrum of normal to cancer and let them know how we caught it before it; and they do say that it's the one area where we can catch it before its cancer with some early-stage changes. So I'll often say how that is not cancer, but we have found enough changes that we know it could change to cancer. It doesn't mean it will, but it could and at every stage along that journey it can go back to normal, so that, that really helps them to understand that abnormal can actually revert back to normal. (17, family physician, cervix)</p> <p>So we tend to think of dysplasia sort of more on like a spectrum so its sort of a continuous plain which may not be entirely the reality of how the natural history of a disease works but that's what we tend to use. (18, OB/GYN, cervix)</p> <p>Sometimes I do talk in fairly simple terms; grading things, Grade I, Grade II and Grade III as levels of</p>	---

		<p>severity; using an old numeric system. And again, I think grading it like that does help people understand it a little bit better. (20, gynecologic oncologist, cervix)</p> <p>I think its important to explain to patients where they're actually at in that continuum so that they understand what the risk is that they're actually going to develop precancer, cancer or not. (24, OB/GYN, cervix)</p>	
Explain experts agree that although condition is cancer, patients do not require treatment	---	---	<p>But I sort of immediately say, most of us don't really consider pattern one a true cancer because our pathologists look under the microscope and they define it as a cancer because they know what cancer looks like. But we as clinicians and patients define cancer by its behaviours and grade group I cancer does not seem to have the type of behavioural ability of other cancers...In the broader sense I just say that these; these are technically cancers although there's active debate in our community including debates at every; at every major meeting about how we should be describing these and that there's a universal understanding that the safest and smartest manoeuvre is not to treat them actively. (25, urologist, prostate)</p>
Use pathology or radiology report to supplement explanation	<p>It will be the pathologist or the radiologist report. So it depend of what type of report that I have, I will read the pathologist report and then I will explain that to the patient but with simple words. (16, family physician, bladder)</p>	---	<p>I would go through the pathology results identifying that there is this low-risk prostate cancer and how that terminology; or how that determination was made from (22, radiation oncologist, prostate)</p>

Challenges clinicians face when communicating with patients

Theme	Bladder	Cervix	Prostate
Difficult to distinguish cancer and precancer	---	<p>The concept of precancer and cancer and that kind of switch to invasion is a very hard thing to wrap your head around. I don't know if I've got a really good way to explain it, other than the fact that patients know what cancer is. (20, gynecologic oncologist, cervix)</p>	---
Clinician not familiar with less common	---	<p>The interesting thing when you cross over to other areas of DCIS and so on, we would we</p>	---

conditions		over treat and when you, when you call it HSIL I think I'm more objective about understanding the sequence of retesting and seeing if you need to have it done. I'm not a gynecologist, but on the other hand for primary care and having all these acronyms, I think sometimes people don't recognize as HSIL. We all know HSIL because it's more common and LSIL, but some of the other ones are ones I'm not familiar with. We don't see them as much either (17, family physician, cervix)	
Confusion with low-grade conditions	---	So I would say it's more the low-grade ones that cause more confusion than the high-grade. (21, OB/GYN, cervix)	---
More difficult to explain more high-grade conditions	---	I think where the difficulty comes is when it's some of the other areas that are the other acronyms that are more concerning that that, it gets confusing...We're still in a nice preventative level but if it comes back at a much more worrisome acronym, then that's a little more difficult to explain...And so for me, my biggest difficulty is definitely at the abnormal adeno-carcinoma inset. I find that one a little bit more difficult to explain over HSIL. We're okay up to the HSIL area and then there's this whole glob of high risk ones that I just put into a referral level that I really can't explain very well. They just are an in situ cancer or very close to kind of level; just a high-risk level. (17, family physician, cervix)	---
Confusion among clinicians and patients about screening/management	---	We have a lot of changes at the moment relating to the HPV changes whereas the primary screening test and it's confusing for physicians as well as patients to be honest. So some are ordering too much, some are confused when to order it, some ordering it when they're way too young. Some of the pap smears on everyone is way too young, or they think 25 is too old. (17, family physician, cervix) A pap smear does not make a diagnosis of anything. And unfortunately I think too many people are told or led to believe or	---

		miscommunicated that they have a diagnosis of a precancerous condition based on a screening test result; that's a pap smear for example and that unfortunately leads to many difficulties. So I just like to state off the top that the only time I tell anybody that they have cervical precancer which is by definition dysplasia as if they've had a biopsy of their cervix that confirms that they have high-grade cell changes consistent with CIN II or III on the biopsy results. (24, OB/GYN, cervix)	
Patients believe previous abnormal cells means history of cancer	---	So, I have seen some patients in follow-up either in colposcopy or in my general gynae office where they will tell me that they have a history of cancer. And when you actually explore, you'll find out that they just had a LEEP for precancerous cells or for high-grade changes (21, OB/GYN, cervix)	---
Difficult for patients to access good resources	The problem is good resources are not easily accessible and patients tend to just go Google something and read about it. (27, urologist, bladder)	---	---

What else is needed to help patients understand or address concerns

Theme	Bladder	Cervix	Prostate
Provide patients with, or refer them to print or online resources	I think patient education either a hand-out or it's on-line tool that I talk to the patient in clinic for maybe 10, 15 minutes and then providing them with a link or a hand-out saying, this is the type of cancer you have; here's some additional information in patient-friendly language that they could go home and review and that could answer even more of their questions in a time when they're not sitting in clinic and stress out in front of a physician... an evidence-based on-line resource that a patient could go to afterwards that was vetted by experts but at the same point wouldn't need to sit in the clinic the whole time to go through every detail. (23, urologic oncologist, bladder)	There's so many things that can help the primary care physician explain it or have access to it are that going to be very helpful. So patient guided YouTube. I think it's very, very important to have it on a reputable site. <National Cancer Organization> be a very good one because we all remember that one. You want something that's very easy to remember. (17, family physician, cervix) <u>Websites need to be appropriate for the condition</u> The only trouble with [National Cancer Organization] is it's got the word cancer in it and it's not cancer, its precancer and I think that's	I mean having data and studies that supports how patients should be managed I think is the most important thing. Patients don't actually often use those resources but for physicians to be able to properly counsel, we need to have confidence in what we're stating and therefore research and studies is probably the most important thing. (28, urologic oncologist, prostate)

		<p>really important. Suddenly patients would go into a sweat if I said, go to the <National Cancer Organization Website> because it's precancer. So it's much better to be on a site that's just gynaecology or even better would be a site where you have some focus on prevention and preventative care. (17, family physician, cervix)</p> <p><u>Current website is outdated</u> I think the information on the website is out of date and I think the terminology used on the website and then the letters they send directly to patients; unfortunately sometimes wrong and confusing and that sends bad messages sometimes to patients. So I think those need to be fixed. (24, OB/GYN, cervix)</p>	
Provide clinicians with visual aids or guides to better communicate with patients	---	<p>So if anything, it's going to be PDF that are really useful and animated and easy to understand and not too wordy at all. I prefer pictorial. So I prefer pictures because they're non-language; they're language universal... I think pictures can help, they [patients] will ask questions around pictures whereas the level of understanding with words is so much higher. So I think absolutely something that is animated and pictorial so that people understand what's happening with this and why it isn't cancer yet and the chances that they are able to reverse this. (17, family physician, cervix)</p> <p>But I think also technology nowadays is being underutilized and it could be used in a way that helps our patients with a bit more accuracy about their diagnosis and why they're coming to the clinic. So I think that good patient level videos outlining both what cervical dysplasia is and what happens in colposcopy still are needed... I think that the ability to have videos that are targeted towards specific pap findings that help walk people through what their pap and colposcopy might look like would be very helpful. (18, OB/GYN, cervix)</p> <p>I think professionally done, like centrally, like</p>	<p>But where they'd have like a 100 stick type figures and then you would show; be able to show out of where risks or percentages; how that corresponds with people affected and people not affected as a graphic representation of like a percent. Having, having that type of comparison can...as opposed to just a number; percentage...I mean risks are always hard because you can't say which group they're going to be in and it doesn't mean that; it's also hard because risks or side effects can vary in their severity, so there's a lot of uncertainties. (22, radiation oncologist, prostate)</p> <p>What I'm envisioning is that a grid, a vast grid of tiny squares all green with maybe one little red square out of; out of a thousand or more of people who end up in real trouble after a Grade Group I diagnosis or a histogram showing the likelihood of the next biopsy or a future biopsy being worse or needed; in needing treatment. An interpret; a visual patient-level interpretation of what we would see in our data and in clinical studies about cancer I think would be potentially helpful for some. Lots of patients are informed and if they're either highly educated or one of their family members is very interested in rustling with numbers, having these visuals would potentially be</p>

		<p><provincial cancer organization> or <provincial cancer organization> kind of thing. Not recreating the wheel all over the place at every colposcopy clinic or every physician's office but professionally done, very short kind of videos or graphics, that explain to patients, that are developed with patients... But if you're able to either direct them to because you prescribe it for them. Like a specific link to a short video that the patient has an ability to go to a site and based on questions they ask of themselves or something like that, they're able to then pick out the videos that they want to watch and educate themselves. (19, OB/GYN, cervix)</p> <p>I think we could have better educational videos/tools available to patients that if healthcare workers in their office feel they don't have the time to have these kinds of conversations with people, having well developed videos; almost like <Lecture Series> if you would, which we do all the time, might be a way to help ensure people get reliable information in a way that it addresses some of their questions. (24, OB/GYN, cervix)</p> <p><u>Physician doesn't want physical materials</u> Absolutely no handouts please, because I think we're going to a virtual world and EMR's definitely are the better way to go. (17, family physician, cervix)</p> <p><u>Videos should be developed with patients</u> It should be short and it should be made with patient involvement. Everything down to the language used, the way in which the graphic design is used; that patients are informing that process. I think obviously would be very helpful if we were doing something professional and centrally done to have informally involve patients with that process. (19, OB/GYN, cervix)</p> <p><u>Visuals/Videos should be used during the</u></p>	<p>a positive. (25, urologist, prostate)</p>
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		<p><u>appointment</u> If there's a graphic that helps to explain the treatment, what a LEEP procedure is, or cervical-cone biopsy. I would definitely see myself using those during an appointment to help facilitate the appointment and the patients' understandings. (19, OB/GYN, cervix)</p> <p><u>Visuals/Videos could be prescribed post-appointment</u> I have my own website for my practice and so I would link directly to that easily and my web address is on my business card and it's on the follow-up appointment card that patients get. So it would be very easy to direct patients to that website and almost like prescribe for them, I'd like you to look at these topics (19, OB/GYN, cervix)</p> <p><u>Material should contain QR code</u> On that patient hand-out, not only would I direct them directly to where they would get that information but I would include things like QR codes so it makes it really easy for them, they could lose the piece of paper and using the QR code, go to it on their phone, bookmark the site and then they have it for future reference. (19, OB/GYN, cervix)</p> <p><u>Materials should be available to patients in the waiting room</u> I can even see myself doing that like with the poster in the room so that even while a patient is waiting, they'd have access to those resources. (19, OB/GYN, cervix)</p>	
Connect patients with support services or groups	Potentially also another option would be having some sort of like nurse navigator or a nurse educator or some physician extender that could spend more time with a patient or could; a patient could call in with questions... Probably, I mean ideally it would be an educated nurse that could do it in-person and could educate the patients for a longer period of time. (23, urologic	<p>As much as I love technology and I think patients need more access to that. They still do need some access to a human in some way just to get some of their, their immediate concerns addressed. (18, OB/GYN, cervix)</p> <p>If there was some sort of provincial navigator that kind of just helped answer questions specific to</p>	<p><u>Support groups are helpful for patients</u> There are patient support groups that not all patients but some patients do make use of. I have heard how patients appreciate speaking to others who have had different treatments especially if they're wanting more real-life experiences from patients who have been in similar situations can help them with making decisions. I think that all</p>

	<p>oncologist, bladder)</p> <p><u>Supplement in-person support with online resources</u></p> <p>I think the initial discussing of the diagnosis and discussing what that means and the next steps with your physician is the most important initially. I do think probably patients gain more information from an in-person appointment however, given the limited resources and time crunch and everything that we have, I think people you the way that our society is now I think it is very reasonable to have on-line resources for the majority of patients. (23, urologic oncologist, bladder)</p>	<p>cervical screening that had a bit of a health background or armed with some really robust FAQ's to kind of help a patient understand what's going on. (18, OB/GYN, cervix)</p> <p>I do it in-person but I also do a lot of my follow-up by videoconference. And so the videoconference you're really, really squared in on the person. Like you're really like face-to-face and you can really see how their eyes glaze and stuff like that when you use certain terms like getting that visual feedback. (19, OB/GYN, cervix)</p> <p><u>Diagnoses/screening letters should be given in person</u></p> <p>And I think this is why it's so critical that it isn't just a letter sent from <provincial cancer authority> that says you have precancer, go see your doctor. It needs to be a conversation with your trusted healthcare provider so that at the time they can go on to explain these things and help ease that anxiety and fear on the spot so that you actually have information to address your concerns and your fears...But I think again, the challenge is helping people to understand what they're dealing with as an individual person without unduly creating anxiety. It is a challenge to do in a letter from somebody that you don't know; that's from perceived to be from the government and I think people ultimately rely on their healthcare providers for that. (24, OB/GYN, cervix)</p> <p>We have structured teaching that we do with the nursing staff and they actually do a lot of our health teaching for patients at the first consult... we have nurses who do health teaching on a regular basis and we value that part of their job. (18, OB/GYN, cervix)</p> <p>I am very lucky in my clinic in that I have some excellent nurses who work with me, and they do a lot of patient education around the diagnosis as</p>	<p>factors into having current and accurate information about what, what disease and what treatment is like for other men in their situation as a way to inform their decision. (22, radiation oncologist, prostate)</p>
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Physician's responsibility to share reliable resources	---	---	So I think one of the things as a physician no matter what type of physician, you can do is just at least direct them to the reliable source to get them the names of a website or a book if you have a brochure or something that is easily readable by the patient is to provide it to them. (27, urologist, bladder)

What would help you to communicate with patients about abnormal cells

Theme	Bladder	Cervix	Prostate
Change in label or language	I mean I think if there was like a standardized patient-friendly language that was used to explain for example, carcinoma in-situ. Like that means nothing to a patient but if there was a standardized patient-friendly way that was then used on a patient-friendly website for education, it would help with the confusion; like differences for patients between these different stages and types and aggressive cells and not aggressive cells. So I think a standardized patient-centred language that is consistent across different specialists, but also patient-education materials would be helpful.	<p><u>One comprehensive term for spectrum of conditions</u></p> <p>So sometimes it's quite difficult to interpret all these different acronyms and I would love one single one that had, that could they all just be HSIL. So that we have some, some way of being able to just say you have HSIL...I would very much like this spectrum to be a little bit easier to reproduce. I find there's too many at that high end for me to really understand. (17, family physician, cervix)</p>	I guess currently the discrepancy is the name with it being a Grade Group I Prostate Cancer that I think it can feel like a disconnect. Yah, you have a cancer, but you don't need treatment, that can be challenging for some patients. Where I do think if it was; if there was a different term or different way of conveying that information without it being a cancer then that may buy us more towards or lean more towards not treating than having the term of carcinoma... With active surveillance being more or strongly recommended or becoming more aware of it as a recommended option I think it

	(23, urologic oncologist, bladder)	<p><u>Different labels are needed for spectrum of conditions</u> Well again, I think the problem is they're all thrown around as if they're equivalent and is if they apply to everybody. And I think the problem is we're not precise about who to use these terms for and in what situations. And I think that's what leads to the confusion. So again, if you've got a biopsy that proves that you have precancer, then we should be using the term precancer. If your pap smear is not normal that's not proof you have precancer, well cancer we shouldn't be using those words. We shouldn't; as a diagnosis. We should say, your screening test is not normal and you need further evaluation to understand if there's a concern here... So in a way, we get around all that inducing fear or labelling people with the precancer conditions that don't have one. (24, OB/GYN, cervix)</p> <p><u>Is unsure of a label that would be more effective than what is currently being used</u> I do a fair bit of colposcopy and so I've changed my language a fair bit over years in my practice and I haven't really arrived at anything that's a lot better. I haven't seen anybody else do anything a whole lot better. And I worry if we try to create new systems that always adds to a lot more confusion. So I think, I think the labels that we have currently are; are reasonable. I think the big problem with medical care is that nothing is gonna be perfect for a patient to understand it completely. And nothing is gonna work for every single patient. So you have to kind of make the best of what we've got. (20, gynecologic oncologist, cervix)</p> <p>I don't think if you're trying to land on what term should we use for everybody; I don't think you're gonna be able to come up with a term to tell patients here's what's up with your cells because the only way you'll ever know what's up with someone's cells, really is if they have a biopsy.</p>	<p>does reflect a change in thinking and processing and that a change in the terminology may, may warrant, maybe warranted with, with that increasing information...it will likely be helpful for them to have a term that is better able to reflect whether they need to be making a decision about treating a cancer or whether it's something that I can; an earlier you know there's changes but not at the point. I think when you hear that its cancer then that often feels like I need to have a treatment for it. Whereas if it's something that is develop; potentially becoming a cancer that...different; a different type of mindset. (22, radiation oncologist, prostate)</p> <p>It was termed as for example, precancerous or non-cancerous, some type of other language. The only problem is that it has to be very consistent. So it would have to really be an accepted change throughout the whole community. We can't have some people calling it cancer and some people not calling it cancer. (28, urologic oncologist, prostate)</p> <p><u>Consider grouping Gleason 6 with Gleason 3-5</u> I mean in the current state it, I think it reflects where things are at from a pathological perspective as saying it's a change in its; here in some of the microscope that it does kind of start people on a trajectory of; I feel like it; like I've; I never see anybody who has a Gleason V or III, IV, V, so we don't; and those aren't considered cancers but there's obviously there's changes in them already. So whether the Gleason IV should be incorporated to the terminology used for those earlier variation in appearance. (22, radiation oncologist, prostate)</p> <p><u>Remove "cancer" from label</u> I would celebrate if a term like prosthetic neoplasm of unknown significance or some; some precancer name applied to it, but it doesn't and I respect our pathologists in their, their descriptions. So I think the label of cancer is appropriate but it's</p>
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		<p>And most people never come to have a biopsy because most people never need a biopsy, alright. (24, OB/GYN, cervix)</p>	<p>incumbent on us to communicate that effectively... I think it's a good one both for sort of patients to understand their true risk because the "C" word is ridiculously powerful (25, urologist, prostate)</p> <p><u>Prostatic epithelial neoplasm of indeterminant significance instead of GG1</u> I definitely would celebrate it. I'm just not an evangelist for it. The best one I heard was prostatic epithelial neoplasm of indeterminant significance and I get bubbled up sarcastically on-line a few years ago. I think the less spicy acronyms are probably better. (25, urologist, prostate)</p> <p><u>Prostatic epithelial neoplasm of indeterminant significance is too complicated for patients to understand without explanation</u> I think that that would be okay. Yah I wouldn't be opposed to that. It is a bit confusing. It is a bit long winded and confusing. So I mean I think it could be a pathologic term.... I think that that language like that terminology is okay but I mean; and I think that really at the end of the day though, patients are just gonna say, okay well not like a cancer or not? And does it need to be treated or not? That's really what they will care about. (28, urologic oncologist, prostate)</p> <p><u>Is unsure of a label that would be more effective than what is currently being used</u> I mean we have a similar situation with low-risk breast cancers or ductal carcinoma in-situ which is you know even the name or description of it is contradicts itself as in-situ and carcinoma are contradictory and yet they're part of the name. So I think that's a situation where clarification of the name would be beneficial for patients. What that would look like for prostate entities, I don't know if it would require an expansion of the precancerous entities pathologically versus or whether it's own category itself I don't know. (22, radiation oncologist, prostate)</p>
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<p>More patient education</p>	<p>So it's not a one-man's job and you cannot just expect others to do it for you, so you need a team, you need to basically bring up the issue and suggestions, get ideas from others and try to improve the whole system. And it's just not about patient education about their disease but also about the treatment and what to expect after treatment. So yah, there's always room for improvement. (27, urologist, bladder)</p>	<p><u>General health education</u> I think that general health teaching is important for patients to understand that many but not all cancers have a precancer condition that when treated can kind of result in the reduction of the development of cancer or the early diagnosis. (18, OB/GYN, cervix)</p> <p>Yah so I think that what a gap in this area is around the initial education that is provided to patients and particularly by the family doctors, the nurse practitioners in the community who are doing the screening tests. So first, there are many people who don't even know why they're getting a pap test. (21, OB/GYN, cervix)</p> <p>I think we need better educational tools and I think the system needs to educate people better again long before they ever get into screening. And I think this needs to start in schools and I don't think we do a good job of educating young people in schools about why they need the screening, what it is, what it involves. And especially now that we're vaccinating young people specifically in schools, it just makes no sense to me that we're not also having an educational dialogue run by a healthcare worker about HPV and about prevention of HPV related to future cancers such as cervix cancer and anus cancer, throat cancers; all these other things to young people at the time that they're being offered the vaccine to help with these things. (24, OB/GYN, cervix)</p> <p><u>Education with primary physician before seeing specialist</u> I think that patients do need to be armed with a little bit more information particularly those who are unattached to a primary care provider because the family docs often are doing some of this pre-health teaching for us. If you're just getting a pap in the clinic and getting sent onto the clinic, there's really no pre-education that's</p>	<p>Other things that you know can be helpful is reliable educational guides you know websites, etc. The only challenge with those types of things is that many patients don't fit into a tidy little box. And so those types of tools are usually complimentary to counselling and you know the direct physician to patient discussion. (28, urologic oncologist, prostate)</p>
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		happening before you arrive in the clinic. (18, OB/GYN, cervix)	
More research into conditions and patient experience	---	---	The thing that helps me the most is available research and real-world data supporting how patients perform, if they had this condition or their condition is like this is by far the most important thing (28, urologic oncologist, prostate)
Provide patients with information in advance of visit to discuss diagnosis	---	An opportunity to sort of address any questions that have come up but then provide targeted help information about the patient, their specific diagnosis and the next steps. We use an electronic health record, many of us in the country and the province don't have the technology really enabled in such a way that we can send patients information in advance of their appointments... and most patients aren't set-up on the patient portal yet to make that sort of scalable in a way that's useful... Giving patients the ability to sort of have a bit of information in advance so that they can write questions down and bring them in I think can be very helpful. If I know in advance what the patients concerns are or they know what their concerns are frankly, then I can make the most use of their clinic time (18, OB/GYN, cervix)	---
Existing patient-physician relationship improves communication	---	I also find that there's a difference between whether or not I'm talking to them about their results and the first time I'm meeting them; like the first referral and they've already been referred with for instance like a high-grade abnormality versus if I've been following someone for instance with a low-grade abnormality and it becomes high-grade and I'm talking to that person and I think that the latter group benefit from a patient physician relationship. So they can get to know me or trust me and also then read me. Like so if I'm not coming across as concerned, they can understand that as well as, I tend to speak to my patients from a patient education perspective and I tell them why I'm following for low-grade... So they're a less alarmed when they hear it compared to the patients I'm seeing on day-one whose referred	---

		with a high-grade abnormality and may or may not have had any real counselling from their referring physician. (19, OB/GYN, cervix)	
Longer visits with ample time for discussion and questions	---	<p>I think the best way is by having the educational dialogue that I've just alluded to; that isn't a two second deal... ah I mean providing me with more time to do these things would be great. (24, OB/GYN, cervix)</p> <p>I think that I'm not actually going to say that we never have enough time. We just need to make it...So when you don't have a normal, you actually have to take the time. And it may mean that you go through a little bit of your lunch. It may mean you're gonna be late with the next person. This is not a conversation that takes an hour or even a half an hour or even 20 minutes most often. You can do it in sort of 5 or 6 minutes. So you're gonna be able to catch-up overtime or you give up a little bit of your lunch time, it's not gonna happen everyday. (26, family physician, cervix)</p>	---
Content with current materials/resources	---	<p>I don't know that I need that much more help with this. I've been talking in a very similar way for 36 years. I really like my <Provincial Cervical Screening Program> recommendation summary. So I can always bring that out if people are having more questions or they just kind of; or say, well why aren't you referring me now? I can kind of show them what happens. We can also talk about HPV testing right? It depending on the age of the person and whether that would be a helpful thing or not to do...<provincial cancer organization> has a good website and that I can bring down my screening recommendation sheet and sit down with you. And I think that usually, most people think the feedback that I get from patients is that they understand what I'm saying and they feel comfortable asking me more questions to clarify. (26, family physician, cervix)</p>	<p>I honestly feel like I do a comprehensive job over a relatively short period of time... So if we're capable of communicating low-risk in an acceptable way to patients; I don't feel that I'm lacking for any specific resource. (25, urologist, prostate)</p>