Additional File 2. Themes and quotes from interviews with patients

Labels used for abnormal cells by doctor

Theme	Bladder	Cervix	Prostate
Label Used	Non-muscle intrusive/invasive bladder cancer The name that immediately came to mind was non-muscle intrusive [bladder cancer] (06, patient, bladder) He said that it was non-invasive, low-grade (08, patient, bladder) My recollection is that it was non-muscle invasive bladder cancer (09, patient, bladder) Abnormal precancerous cells For exactly what he said; the first time around was just abnormal cells, precancerous (11, patient, bladder) Low-grade cancer The other piece was over simplified; he said, you have cancer and it's low-grade (11, patient, bladder) Cancerous Tumor It's a tumor and it's cancerous (12, patient, bladder) Mass The first word I heard was a mass (07, patient, bladder) Tumor I had my cystoscopy where we looked at the tumor, he called it a tumor (07, patient, bladder)	Precancerous Cells/Precancer Just precancerous [cells] (10, patient, cervix) I believe that they said, precancerous and I think that's all I can remember. (13, patient, cervix) Abnormal cells So they said, abnormal cells (13, patient, cervix) I don't remember very well but when I was tested the first time, the doctor called me and said, I have abnormal cells, she hadn't proved whether its cancer or not but she told me, you have to do another test for a pap smear. (15, patient, cervix) Atypical squamous cells Atypical squamous cells; I'm not sure how to say that, atypical squamous cells. (14, patient, cervix) Signs of cancer That I have signs of cancer but it's not yet proved. So I'm still doing examinations on Friday; I went and do another pap smear to confirm what exactly is happening. (15, patient, cervix)	Cancer I can recall fairly verbatim because I think I was a little bit shocked but "a little bit of cancer" (01, patient, prostate) The words they used; there was a lot, but they said something about good news and bad news. The bad news is there's cancer cells but it's small and slow growing (03, patient, prostate) Gleason score/Gleason 6 What I remember when I went for the follow-up after the biopsy was him saying well, I have good news and bad news, that the bad news first, you have prostate cancer. The good news is that it's assessed as a Gleason 6 which means that it's an early diagnosis and, in some situations, it may not progress beyond that at all and have no impact, but it also may of course progress and require various levels of treatment. (02, patient, prostate) [They] just mentioned the Gleason scale and that there were a couple 6's and a 7 (04, patient, prostate) Gleason score & Low Risk Cancer I got my first biopsy which was conducted one year ago, it was Gleason score 6 at the time. The doctor called me on my phone and told me I have low-risk cancer (05, patient, prostate) Adenocarcinoma My doctor said what I have now is called adenocarcinoma or something like that. And I asked him, okay what does this mean? He said, it's a lower risk cancer (05, patient, prostate)

Reaction to label used by doctor

Theme	Bladder	Cervix	Prostate
Anxious about severity of health implications	*RE: Non-muscle intrusive bladder cancer* It put a lot of fear in me because I didn't know what it meant… I didn't think to ask what stage it was because honestly when I heard cancer, I didn't even capture what he said to me (08, patient, bladder) *RE: cancerous tumor* Just panic I think was the first thing. Now that I know that it was low-grade cancer, a superficial tumor, the words felt a little much. The words he used were just extremely - the only word I could think of at the moment- is harsh... It just put me in a state of panic...I just felt like the moment he said it [cancerous tumor], I just had trouble remembering anything after that. I just sort of went into a fog and just was having a great deal of difficulty focusing and trying to listen to anything he said after that (12, patient, bladder) *RE: cancer* I didn't have a whole lot of experience personally with cancer. I had lots of family members going through it but that first word; it was instant fear. It was okay, this isn't going to be good, it's not just a little blip on the radar, it's a mass - to me that's just a big word and scared the crap out of me (07, patient, bladder) You tend to shut down because you weren't expecting it to be cancer, or I wasn't, and you shut down at the word cancer. So, I didn't really receive a whole lot of the other discussion. I wasn't processing. It was a shock. (11, patient, bladder)	*RE: pre-cancerous cells* Definitely fearful. I had never had an abnormal pap before so in the moment it was much scarier than what the outcome ended up being (10, patient, cervix) *RE: abnormal cells* I felt bad. Actually I lost weight in few days. I lost weight because I, according to what I know, like me I'm coming from Uganda. First we know that it's not easy to cancer to cure, so I felt like I'm going to die. But when I talked to the doctor, she told me that if anything happened, you're going to be fine. You'll be treated, you'll be okay. But I felt bad. Actually I cried…but they were kind. It was too hard for me to take it, but I had too because you know as a mother, as a woman you know what it means when you just hear something of cervical cancer, it's really hard and it's not easy. So it was a hard experience such hard news. (15, patient, cervix)	*RE: cancer* I kind of went to fear mode fairly quickly I would say because I was being told that I had cancer and didn't really know what that meant...so it was a bit traumatic (01, patient, prostate) I think they sort of said it was an early stage of cancer they found in the cells and it was treatable. So, I was nervous, quite nervous, it's expected from the results (04, patient, prostate) Scared. But I would say not so much [due to] Gleason because Gleason is just something which is just a name or whatever. But the word cancer, that's what scares you the most (05, patient, prostate) I remember after leaving and walking down the street and trying to recall everything he said and I couldn't, and just having trouble recalling anything because all it was 'oh my god I have cancer'. And then my mind leads to end-of-life, end of life cancer, cancer. (02, patient, prostate) Well cancer's quite a powerful word. It's like the nuclear bomb. Cancer, wow. You think right away of how much longer you have to live and all of that. And you know your life is going to be really affected by this cancer. So, in a way it definitely caught my attention. If they had said anything less than that; if they said tumor or something of that thought, maybe I wouldn't have been so concerned. But the term cancer definitely did catch my attention (03, patient, prostate)
Confused if it's cancer	*RE: non-invasive low-grade bladder cancer* I don't know, is it cancer or is it precancer? So there's still things that I don't understand... Is it	*RE: precancerous cells* I really didn't have much education around this, so it wasn't very clear to me what that meant	*RE: cancer* Well I guess a little bit of confusion..a little bit of cancer didn't really mean a whole lot to me…either

	precancer or cancer when it's low-grade non-invasive? (08, patient, bladder) *RE: precancerous cells* It's like, so what does that mean? What's the prognosis? Where do you go from here? (11, patient, bladder)	exactly... that was something that was ambiguous and I don't really know what that means (13, patient, cervix) *RE: atypical squamous cells* I don't know, I guess confusion... Well I don't really know what it means. Like I don't know what an atypical squamous cell is, so I was really confused because I didn't know the vocabulary (14, patient, cervix)	you are or you aren't sick with cancer (01, patient, prostate) The first time he just said, you'll be fine, it's a low-risk cancer, no need to worry, no need to do anything.... That was confusing and scary because you know that you have cancer but at the same time, the doctor tells you don't do anything (05, patient, prostate) *RE: Gleason score* Nothing. Gleason 6 meant nothing. He probably said to me it's a scale from; I forget now, 6 to 9 or 6 to 10 or something. Well no, 6 as a result but 3 plus 3, so you could have a score of less than 6 if you don't have a 3 plus 3. But he said it was a scale and that that was the lowest level at which they diagnosed prostate cancer. (02, patient, prostate) It really didn't mean anything because I didn't know what the Gleason scale was at the time... [The label caused] more uncertainty (04, patient, prostate) The first time I heard about this, it meant nothing to me. I had no idea what Gleason means in prostate cancer. It was quite confusing to be honest (05, patient, prostate)
Shocked	*RE: non-muscle-invasive bladder cancer* I guess I was numb because I've always you know looked after myself health-wise, not that that's an indicator of anything. And I guess I would have been shocked, surprised (09, patient, bladder) *RE: Cancer* That's all I heard, that word. I didn't hear anything else because the world just stopped (11, patient, bladder) *RE: Cancerous Tumor* I just felt like the moment he said it, I just had trouble remembering anything after that. I just sort	---	*RE: Prostate cancer* So that was shocking news because the only words I heard was you're diagnosed with prostate cancer and I didn't know Gleason 6 from anything else (02, patient, prostate) *RE: cancer* I maybe could have been a little more proactive and pursued some of the paths to getting more information. I just was in a little bit of a shock (01, patient, prostate) Well, it definitely caught my attention. Once the word cancer was used, I kind of jumped, (03,

	of went into a fog and just was having great deal of difficulty focusing and trying to listen to anything he said after that (12, patient, bladder) *RE: mass* The first thing that popped into my head was oh crap, I have cancer. I was shocked, I was stunned. I was, like, what do you mean I have cancer? It was just like almost disbelieving is probably the first thing (07, patient, bladder)		patient, prostate)

Opinion of medical labels

Theme	Bladder <Stage 0, Grade I bladder cancer, bladder carcinoma in situ, non-invasive papillary carcinoma, papillary urothelial neoplasia of low malignant potential>	Cervix <Cervical dysplasia, low-grade squamous intraepithelial lesion (LSIL), high-grade squamous intraepithelial lesion (HSIL), precancerous cervical cells	Prostate <Grade Group I prostate cancer, Gleason Grade 6 prostate cancer>
Complex clear only after more discussion	Except for the last one [papillary urothelial neoplasia of low malignant potential], I heard them all and I had a vague idea what they meant, and again…I found optimism... I thought the fairly complicated complex descriptor was something that I could relate to and understand. (06, patient, bladder) *RE: stage 0 bladder cancer* So the actual Stage 0 and all that wasn't used with me until after I had had my bladder cancer surgery. Those words, from a doctor, they weren't given until that time and at that point for me it was okay, he had told me that he got it all and he had done the one dose of chemo and so it was kind of okay, using the low-grade Stage 0 label at that point was really good. It was just like awe, okay, this is not a life-sentence or a death-sentence right now (07, patient, bladder) *RE: Low-grade non-invasive cancer* Others aren't as lucky as I seem to have been. But I don't know that there is a better name. I mean	*RE: HSIL, LSIL, Atypical squamous cells, cervical dysplasia* We know that medical words to someone that's not familiar may not understand it properly... When you were reading those [medical labels] out to me it was just like a different language, other than "precancerous cells." So, if someone were to refer that to me, by that terminology, I would have no idea what they would be talking about... But for most people they don't understand medical terminology unless you have been around it or experienced it. So, I feel like that that could open up a whole area of unknowing and not feeling safe, so just a lot of unanswered questions. (10, patient, cervix) *RE: Cervical Dysplasia* To me that doesn't really mean anything. I don't understand dysplasia and so I don't really have an association with that. (13, patient, cervix) *RE: atypical squamous cells* I guess it's more specific but like I said, it can lead to	*RE: Gleason Score* Now that I understand the grading in the Gleason scoring, I think it's really good. At the time, probably if it was used I would have had a look on my face as to what they were talking about. I did see my family physician and I was later referred to an oncologist at a Cancer Clinic in one of the hospitals and those terms were used somewhere down the line and by then I had done a little bit of reading and was aware of what the references were. And during that first day it probably wouldn't have been particularly helpful to me. I think more of something to penetrate through the shock and fear would have been probably something a little more familiar in terms of rating out of 10, you're this or/and high, medium and low-risk, or something of that nature. (01, patient, prostate) It's scientific. It's difficult to really know what it means. Gleason 6 is a result of a 3 plus 3, it's just gibberish when you hear it for the first time and then to try to teach yourself what it really means.

	low-grade non-invasive is, now that I understand what it is, I guess a good thing. I don't really know what other names you could give it if it's a cancer. If it's a precancer maybe that would be better to hear than just you have cancer (08, patient, bladder) *RE: papillary urothelial neoplasia of low malignant potential* I think that might be a little better than just the abnormal label because it is a little more descriptive and it's saying low potential, which sort of gives you an idea of okay this isn't necessarily going to be a major issue as there's a low potential to it (11, patient, bladder) *RE: all medical label* Well, each of those seems almost a little more qualified than the words that were used [by the physician]. So, I think it might have at least got me asking a question like what does that mean? What is it? Just tell me more in the moment, when the words he used just sort of didn't promote that kind of thought for me.... So those words I think would have been better probably for me (12, patient, bladder) *RE: Urothelial neoplasia of low malignant potential* I consider it too complicated. Now I am a person of scientific background and I pride myself for understanding even complicated words and concepts and this is still something that goes way above my head and doesn't really describe. Not meant as a criticism or anything, it's just silly in its complexity and not bringing any understanding to what actually goes on (06, patient, bladder) So, low malignant potential; for the average individual; malignant, do they understand that? Potential, okay. When you're saying low malignant potential is that like a 10%? Is that like a 2%? Is	confusion for the patient...I think people are confused. I mean they don't; I guess they, they present the results in a way that they understand but it's not very clear for the rest of us who are like non-medical people. (14, patient, cervix)	It takes a lot of effort and one thing I felt disappointed [about] was that when I left there, I was not given any supporting information or documentation, like here - this will help you better understand what this means. (02, patient, prostate) They could have expanded more in laymen's terms rather than more clinically. Explain more what the Gleason meant and implications you know in laymen's terms rather than technical terms... if I hadn't researched the word Gleason, what Gleason scale would've implied, I wouldn't really know. (04, patient, prostate) *RE: Grade Group 1* They're fine if you have an understanding of what they mean. Now it's only getting a little confusing again because the Grade Group is already an attempt, I believe from what I've been reading, at trying to put another label on this. And I don't know because I haven't researched Grade Group I to say…I did Gleason 6. So I don't know whether it's identical or whether it's a combination of something, or an extraction, and therefore you can feel better because Grade Group I is even less than Gleason 6 in the scope of things, I don't know that. So the language has only been, for me, more complicated with another term than simplified. (02, patient, prostate) Grade Group I is the lowest grade. So, it didn't concern me too much. When you use the term, I can say that I'm at the bottom of the scale... When you use a number, it's easily understood. When you use something that's very medical or very complicated then of course nobody understands that; at least not the laymen. So, when you use a number like 1; that is the lowest, that's fine. Now when you use the term; 3+3, again, now a little bit of a Google and you can understand that. Now

	that like a 1% chance? (11, patient, bladder) Papillary urothelial neoplasia of low malignant potential seems so clinical... Just so many big words that mean nothing to me... I think for me, when some of these very clinical terms are used, it does sort of promote some anxiety just in a sense that immediately it's what the heck is that? (12, patient, bladder) *RE: Non-invasive Papillary Carcinoma and Papillary Urothelial Neoplasia of Low Malignant Potential* I like the Stage 0 Grade I; that's okay, but the rest of that gobble goop is useless to me because I'm not familiar with the terminology, and it's something I hadn't had any discussions about, haven't had anybody involved in it before. So, it's so foreign, it's like speaking a foreign language, it's useless (09, patient, bladder) *RE: non-muscle invasive bladder cancer/papillary carcinoma* The names are descriptive to someone, but to me it doesn't describe what it is. Is it in the muscle cell? Is it not in the muscle cell? Is it just floating around inside? I mean what is it doing? I don't know how to describe it better, but I don't think those terms are words that the average individual will understand. I didn't (11, patient, bladder) Patients perceive advanced cancer *RE: urothelial neoplasia of low malignant potential, non-muscle invasive bladder cancer* If anything, those labels are so foreign, it must be very complicated that things are looking pretty grim here. That would be my interpretation... . But I would assume the average person they're just thinking, oh that sounds very serious right? (09, patient, bladder)		the Gleason; 3+4 or 4+3; it's two different things. That was a little bit confusing. (03, patient, prostate) *RE: Grade Group 1 & Gleason Score* I think if you're gonna provide somebody that terminology without the definitions of what it means, at least you can provide a one-pager laypersons interpretation guide of what it's all about. It doesn't mean a whole lot. So if it came along with a reference I would find it helpful, as opposed to what I would have; if we're talking about that first visit to discuss the diagnosis itself I don't know if it's harmful per se but I don't think it's particularly meaningful in and of itself. (01, patient, prostate) If it's a normal person who is not in the medical industry or medical profession, it means nothing to you. It just really means nothing... You don't know if it could be bad or good... He needs to clearly explain to me what type of cancer I have, not in the medical terminology...because it's still quite confusing for a normal person (05, patient, prostate)
Label is self-explanatory	---	*RE: pre-cancer* It's self-explanatory. So, I think any other verbiage	---

		used may not have made sense to me like that simple precancerous cell. (10, patient, cervix)	
Label causes anxiety	*RE: Stage 0, Grade I bladder cancer, bladder carcinoma in situ, non-invasive papillary carcinoma, papillary urothelial neoplasia of low malignant potential* They're really scary. They put almost instant fear like oh crap, is this it? Is kind of where I first went... It's like these are big actual medical words, this is an actual diagnosis. It's not abstract anymore. This is it; I actually have cancer (07, patient, bladder)	*RE: precancer/precancerous cells* Well the precancerous one sounds pretty scary. (14, patient, cervix) I think precancerous feels kind of stressful and anxiety inducing (13, patient, cervix)	---
Too general – does not clarify risk of cancer	---	*RE: Low-grade/High-grade* I think that the high-grade and low-grade was something that they did mention with me and like I think that its hard to know where that threshold is, it's not a lot of clarity of when, how close you are you know to high-grade if you're designated as low-grade or vice-versa. So it feels like that's pretty ambiguous language (13, patient, cervix)	---

Opinion of alternative label

Theme	Bladder <abnormal cells of the bladder>	Cervix <abnormal cells of the cervix >	Prostate <abnormal cells of the prostate>
Easy to understand and can alleviate anxiety	I like abnormal cells of the bladder. It's easier to understand for the common person...Abnormal cells of the bladder makes me feel a little better to be honest...I think abnormal cells of the bladder makes the most sense to kind of ease a person's mind (08, patient, bladder) Those terms, abnormal cells of the bladder, that would have been better...Because it's sort of more laymen. For someone who doesn't know much about clinical terms, it's just easy to understand... there's something there but now let's just talk about it (12, patient, bladder) That one seems a little bit easier or lighter, a little bit more of a calming thing; abnormal cells. The	Definitely not precancerous, but abnormal cells that could be precancerous? I guess a different flipping of the words. You're saying *could be* rather than precancerous cells because that immediately makes someone go down you know the cancer path which is scary… I think that [abnormal cells as a label] is fantastic. It's straight to the point and like I just said, I feel like abnormal cells of the cervix is a much easier term to understand (10, patient, cervix) I do think abnormal cells is helpful because it seems pretty neutral. It's just like this is something that's different and so it needs to be explored. I didn't find that terminology too anxiety inducing. (13, patient, cervix)	That would work, that would be better... I guess more for the laymen... it would be more helpful to a person just starting with the cancer cell issue (04, patient, prostate) I think for simple people like myself, it actually should be abnormal cells. It's an appropriate name.... We don't need to create another medical term for that one. It should be simply called abnormal cell because abnormal cells could be bad, they could be maybe not so bad (05, patient, prostate) In case of the low-risk cancer, especially if it's a Gleason score 6; I would say it would be more benefits than harm; it's totally appropriate to say

	other one [urothelial neoplasia of low malignant potential] just sounds so much worse... With abnormal cells, I can still trick myself that it's not cancer (07, patient, bladder)	I have abnormal cells. According to me, something is unusual. Like something is different, it means to me that I must have a sickness in me...An abnormality is a negative of how you're suppose to be. That means something is going on wrong on your body. (15, patient, cervix) <u>Abnormal cells is appropriate at early appointments</u> I feel comfortable with abnormal cells because it does feel like its; at least when its at the beginning phase when they are starting the process of doing the biopsy and looking into things further. Starting up by calling it abnormal to me feels appropriate. I feel like okay there's something that needs to be checked out but we're not making any assumptions about what it is right now. And perhaps later on in the process it's not as helpful because it's sort of vague. (13, patient, cervix)	just simply abnormal cell versus to right away to call it cancer, Gleason 6 or whatever; something like that. Because, right after that, the doctor told me you don't need to do anything (05, patient, prostate)
Patients perceive advanced cancer	I don't like [it] at all. It is for me, personally, scary… If they start out with abnormal that is already a warning sign, and then probably this sets the tone for the rest of the other words that follow. I would lead with something that is less aggressive (06, patient, bladder)	I don't know...abnormal sounds bad, like there's something wrong when they don't even know if it's cancerous yet. (14, patient, cervix)	---
Too general – does not clarify risk of cancer	Well, when you say abnormal cells of the bladder, I have had that one used, and again, you think, what's abnormal? How common is it? How often does it happen? And what does it lead to?... To say that they're abnormal cells you still question okay, if they're abnormal what does that really mean? (11, patient, bladder)	---	Again, it's a little vague for what I would probably be wanting to know. I want to know if I have cancer or not. I want to know if I have precancerous cells. I want to know what risk I have of it metastasizing. So again, for me it would be just a little bit too generic. There's lots of abnormalities that are benign, that do not put one's health at risk... But I think, for me, abnormal may not have been sufficient. I would have followed up with what does that really mean? (01, patient, prostate) Abnormal cells, that's less terrifying than cancer, but the question that then arises is; are these abnormal cells going to lead to cancer? Or are they just

			something that's abnormal? If it's not cancer, then it is preferable to use that. (03, patient, prostate)

Discussion of meaning of abnormal cells

How doctor explained (to distinguish from cancer or how concerned you should be)

Theme	Bladder	Cervix	Prostate
Offered little to no explanation or other approach	I would honestly say it wasn't really explained all that well. (07, patient, bladder) That discussion about whether to be concerned really wasn't had (08, patient, bladder) I had no discussion with the doctor after that about the treatment...The interaction with the doctor was extremely limited, it's a busy place... the doctor didn't provide a lot of information. So, it's not as though I was sitting across from the doctor at a desk ever having a discussion. I was lying on a bed or moving from the operating room to the recovery room and then there were just words in passing. So, there was very little information provided (09, patient, bladder)	There wasn't really a lot of explanation provided to me...In my situation it felt very mechanical, I just felt like a number, and I was just being processed more than them explaining to me why it could have happened, what causes it, and the procedures moving forward for it. It was done very, very mechanically…As far as the whys or what could happen and what your future entails, that wasn't provided by my primary doctor, that was provided by the doctor who completed the biopsies and explained why they needed to remove them... There wasn't really a lot of explanation provided to me (10, patient, cervix) I wasn't provided with any paperwork or any references or anything, like here's a piece of paper with frequently asked questions… not by my primary doctor or the gynecologist that did the procedures on me (10, patient, cervix) I've seen so many doctors through this process, it started out with a visit to a walk-in clinic and then I went to another hospital and I have a doctor at another hospital, so in between like the healthcare practitioners that do the screening versus the doctor's that called me to discuss the screening, I feel like there was not a lot of clarity that I received about what was happening. (13, patient, cervix) She didn't really explain how it could affect my health. She never mentioned cancer for example, I don't know, tough question. (14, patient, cervix)	Actually, there was nothing talked about. It was a little bit of cancer, I have other patients that aren't doing anything about it, send me back to surveillance, I can monitor you every 6 months and if things change, we can do something different. That was kind of the gist of the 5-minutes that we had with the urologist, my wife and I. (01, patient, prostate) There was really no medical explanation. I was told basically that he had a number of patients that were similar to me in terms of my diagnosis and that they chose not to take any further medical treatment and they had been with him for a number of years, and that he would suggest that I consider doing something similar in terms of that. Or I could be referred to the Cancer Clinic in our city at one of the hospitals. There was no real discussion about; I don't believe the word indolent encapsulated tumor, or any comment of description of the volume or the molecular appearance of the cells was ever really discussed. It was very, very, very basic in terms of; you don't have to really do anything with this unless you feel like you have to or you want to, but I suggest you don't have to. I felt like it was, to be perfectly blunt with you it was; it wasn't a particularly positive experience. (01, patient, prostate) There was no support, and I remember the next time I went back to my urologist I said I've really been struggling (02, patient, prostate) We did not have an in-depth discussion about Gleason 3+3; Gleason 3+4; Gleason 4+3 or anything

			of that sort. We did not discuss that at all...So I kind of felt that they assumed I would know the Gleason scores and Grade Groups. We didn't spend hardly any time discussing that part... They didn't describe the cells in any detail. They did not go deep into the description of the cells (03, patient, prostate) Also, to be honest, the doctor did not spend much time explaining what a Gleason score is...My first communication with my doctor was literally two minutes and it was all over the phone and no explanation whatsoever. He just said, low-risk cancer, Gleason 6, adenocarcinoma or whatever, and you'll be fine. You don't need to do anything. That's it... So, from the doctor's perspective, my personal opinion, it was very poorly done. (05, patient, prostate)
Described risk of recurrence or chance of survival	I felt reassured after the explanation as to the nature and the possible causes of these tumours, and also about the treatment and the chances of survival, because when somebody says cancer the first thing your mind goes to is okay, I will die…I was also lucky that the doctor explained or highlighted the fact that I'm in a high-risk category due to age, gender and general nature of this particular cancer.(06, patient, bladder) He said we caught it probably 3 years earlier than it would have been caught if I hadn't had my first surgery, and there was a chance that it will come back, and we would just track it for 5 or 6 years (07, patient, bladder) It was described to me in much more specific terms, and he used much more qualifying statements than he did initially and explained to me what the treatment would be, and I was much more encouraged and much less anxious after those discussions than I was initially... I think he did a pretty decent job of explaining everything; what I had, what the treatment plan was going to	---	And whereas in previous years the professional might have immediately led to some sort of medical procedure; current belief is that slow spreading prostate cancer can often be tolerated to end-of-life if it's that slow and may require no treatment in a person's lifetime. So, I think that was helpful and provided some comfort in that, okay I don't need to jump into an ambulance and get to a hospital or anything like that (02, patient, prostate)

	be, what the potential outcomes would be, what the chance of recurrence would be. I felt my anxiety levels were extremely reduced after the visit (12, patient, bladder)		
Referred to staging, grade or continuum in relation to risk	The word that I was most worried about was that he used the word high-grade to characterize the tumours and he still explained that this is a categorization that comes from whatever, World Health Organization, and that in his long career he saw hundreds, maybe thousands of tumours and usually they are high-grade so I shouldn't really be afraid of the fact that the official category is high-grade (06, patient, bladder) He just said that it was very low-grade, it was superficial... It was pretty calming at that point because it was almost like, oh okay, it's cancer but it's so minor that it's almost not (07, patient, bladder) He just said that if you're going to have cancer this is the best to have; not that I felt that way at the time. I understand more now but at the time I thought that this doesn't even make sense- if I'm going to have cancer this is the best cancer to have. No one wants to hear that word (08, patient, bladder)	---	[The doctor described whether to be concerned] by indicating that Gleason 6 was the lowest diagnosis level and that it was contained in the prostate and that prostate cancer is recognized as a slow spreading cancer and that you didn't have to jump to any conclusion or serious treatment overnight or anything (02, patient, prostate)
Described treatment options to explain risk	There wasn't a lot of explanation. He just said that it was removed. He's not going to proceed with any further treatments. He said that if it had been I guess a higher-grade tumor that they would have proceeded with BCG but at this point he didn't want to do that and he just kind of wanted to wait and see (08, patient, bladder) I think the piece was that I heard cancer and you know this is the treatment path, this is what we're going to do. (11, patient, bladder) In terms of the words he used, that's when he started using words like low-grade, superficial,	---	He explained that while the cancer is contained within the prostate, if it worsens then there are procedures right up to the removal of the prostate that can be done. But he did not go into any elaboration of what the alternative procedures would be other than the removal at that time and that, should the cancer spread beyond the prostate into other glands or into the bones then it has metastasized and then you're dealing with cancer spreading throughout the body and the treatment would have to be discussed and certainly be more urgent at that time (02, patient, prostate) The only thing I can remember of the family doctor

	easily treatable, how the treatment would work, what it would look like, that it was minor, there was no concern about my bladder being removed; those types of things (12, patient, bladder) <u>Likelihood of treatment success used to explain risk</u> He put the chances of reoccurrence even after successful operation to about 40% (06, patient, bladder)		said not to go for radiation because it messes up everything; to go for surgery instead. Now I did take it that he's a family doctor, not a specialist, so that's as much as he told me. But when I went to the other doctors, they did not explain what a Gleason 6 is. Perhaps they took it upon themselves that I would do the research and it's very simple to understand what each of these grades meant... It was more on what kind of radiation you would do, internal or external and then what kind of surgery you would do, laparoscopic or robotic or conditional. So, I kind of felt that they assumed I would know the Gleason scores and Grade Groups. We didn't spend hardly any time discussing that part (03, patient, prostate) They finally recommended a couple options for treatment. One was because of my age and the heart history, he recommended radiation therapy rather than doing surgery and then because <hospital name I> didn't do any radiation treatment, they referred me to <hospital name II>...[doctor showed] the charts he had produced from the biopsy procedure, showed me a filled-out chart with the Gleason information, but other than that, nothing really (04, patient, prostate) He said, because it's low risk, the probability of expanding this cancer to other organs is very low, I don't need to do anything. Pretty much that's it, and he told me you will be fine. (05, patient, prostate)
Explained how common condition was	---	I think it felt like they were trying to explain that it was a common thing and that it's not unusual for someone to have this experience in that cervical cancer is something that's very easy to detect early on. But I think that kind of conversation is saying like that this is common or normal or to be expected. Like they're trying to make you feel better about it and I think that does work. (13, patient, cervix)	---

Used plain/lay language	I was very lucky my doctor sat me down and, it's not like dumbing down, but explained in laymen terms what the situation is. (06, patient, bladder)	---	---

Additional support doctor provided beyond discussion

Theme	Bladder	Cervix	Prostate
Suggested getting a second opinion	---	---	He did offer me to get a second opinion on the situation...I'm not sure exactly [who it was], but he himself was actually the person who I did the interview with, who gave me the results was actually a urologist who does surgery, the ones that do the surgery on prostates, and he recommended that I not go that route. I'd go...with the radiation route rather than being aggressive (04, patient, prostate) Did NOT endorse second opinion I did ask my doctor; what about a second opinion on the biopsy, but they were saying that it's not going to be much different because they had very competent people. We did the biopsy reports and doctors and so on. And so, I decided not to go out to get a second opinion, third opinions because that sometimes can be more confusing than anything else. Like how do I know the second opinion is better than the first opinion or the third opinion is better than the second opinion? So, I decided not to go that route (03, patient, prostate)
Took extra time to discuss concerns and answer questions	He then sent me out to go talk to my wife about it and again, I was still trying to process what he said, and I couldn't even talk very well. The positive is that he came out and followed up and he asked me "were you able to discuss this with your wife?"...He said, "come with me," and he then took us into his office to discuss it in more detail.... I think that him taking the extra time to then meet with myself and my wife was the game changer mentally for me (11, patient, bladder)	---	So I would say that my urologist was definitely sympathetic, did not rush me. Probably said, do you have any questions at this time? (02, patient, prostate)
Used visual aids	There was even some kind of a sketch that I still have; after four and a half years. (06, patient, bladder)	In-person the gynaecologist kind of gave me a demonstration, not a demonstration of what it actually looked like, but what the cells look like	---

	Visual aids were used during the actual cystoscopy. I was watching the whole thing on the screen, so he was pointing out the tumor and explaining to me where the tumor was in my bladder and then what the surgery was to remove it. So, I was actually seeing it, the actual tumor. (07, patient, bladder) Just the cystoscopy where I actually saw what the tumor looked like. And then after my procedure he told my brother that he found a few other spots which he removed, and they're mentioned on the pathology report as well as low-grade non-invasive (08, patient, bladder) Initially when he used the harsher terms, he physically showed me the tumor up on video (12, patient, bladder)	and why they needed to remove them. But there wasn't much further information than that (10, patient, cervix) When I went there she tried to show me picture of the cervix, [one] which was close to normal and another one which was cancer and the one which was close to cancer. She tried to explain by showing me pictures... She showed me pictures of abnormal cells, like the stages ... there were stages and there were four pictures. The one for cancer and another one for abnormal cells, and the one that was normal. (15, patient, cervix)	
Provided educational material	And then I just got some brochures when I left to read up on and websites to go to and stuff before my surgery which was two months later (07, patient, bladder) He did show a visual aid. I know when I was with him just prior to doing the biopsy he did the scope as well...and gave me <National Cancer Group> booklet (11, patient, bladder)	They did give me a pamphlet... It was a little bit dated in terms of like the graphics and just visually how it was; it was; I mean there weren't really that many visuals I guess. It was more text space. (13, patient, cervix) And then I also find pamphlets get lost easily. And at the time you know you're; there's a lot going through your mind so you're not really thinking about oh I should put this somewhere safe. (13, patient, cervix)	They gave me a book and a few booklets about prostate cancer, about sexual life for people with prostate cancer; about some treatments which exist and are approved. They gave me that information (05, patient, prostate)

How well patients understood explanation

Theme	Bladder	Cervix	Prostate
Understood and was satisfied with explanation	I was perfectly satisfied with the explanation. I understood everything they were talking about, and it made perfect sense to me…I had 100% certainty that I know what it is all about (06, patient, bladder)	I mean I think that they did a good job of explaining to me the two types of procedures so that I felt comfortable with what was happening when I went into the laser procedure. And they did a good job of describing like my after care. (13, patient, cervix)	I had a pretty good understanding of what was happening, of the process. [There's] not really any ways the doctor could have better explained off-hand at the moment that I can think of (04, patient, prostate)

	That's when I was finally able to process what he was saying, and then understand the treatment, and the importance of having caught it early, that the prognosis of longevity was quite high with this type of cancer and catching it early (11, patient, bladder)	I just understood that it's not yet confirmed that I have cancer...I understood that I don't have cancer. And I believe that as long as I get medication I will be fine. According to what she told me. (15, patient, cervix)	I was a little bit reassured by the fact that the doctor did not think it was too serious. In other words, they did not say you have to make a decision, or you have to take action right away. They did say that I have a choice between surgery, radiation, active surveillance, all of that. So that kind of lowered my concerns a bit (03, patient, prostate)
Patients were only comforted by their own research into their condition	*RE: Non-muscle intrusive bladder cancer* I did some research and came off with a conclusion that I'm really very lucky that it was caught early, and I was kind of filled of hope when I look at the alternative, muscle intrusive and so on. Also, I considered myself lucky in that particular situation, that there were technical methods and processes that actually visualized it for the medical team. The actual tumours or growths or masses - they were calling them various different things, and they said that there was a fair chance of this resulting in a successful treatment if I compared it to other cancers of other organs and situations. So I was, in a way, optimistic and relieved by that, although the situation was pretty dramatic (06, patient, bladder)	---	*RE: Gleason 6 Score* There are articles I read that would indicate some urologists blatantly say they would never tell a patient they have prostate cancer due to a Gleason 6. So, I found that interesting. I found that comforting because I decided to, for my own mental health, focus on that until there was a clear indication and concurrent with it all. I have an enlarged prostate, and continuing to grow prostate is not uncommon at my age. (02, patient, prostate)
Did not understand risk or prognosis	---	Am I a person who is like at high risk forever? Or like what do I now identify as having I guess?... And I guess knowing that like HPV is something that you have forever, like what does that mean in terms of abnormal cells? Will I always be at risk of this flaring up? And how; where on the spectrum I am in terms of how at risk I am for cancer because of it? (13, patient, cervix)	It was the absence of description. I understood because it was fairly rudimentary explanation but I didn't have knowledge. I had awareness but didn't have knowledge. An awareness that I had some tumor, but I didn't really know much more than that. A little small tumor I assumed, and one that was, based on what he was telling me, something I shouldn't worry too much about at the present time. Beyond that, nothing. (01, patient, prostate)
Poor understanding or lack of useful resources provided by doctor prompts self-	At the time probably not that well. I sort of understood it, but it was kind of like is it cancer? Is it actually cancer? But it sounded like it was such a minor tumor that it felt like it wasn't really a big deal at all until I started doing a little more research on my own. Google's not your friend (07, patient, bladder)	So, I feel like that that could open up a whole area of unknowing and not feeling safe, so just a lot of unanswered questions… the harms are someone could take that [medical label] and immediately Google it and then come up with the worst-case scenario (10, patient, cervix) Not really well. And I struggle to tell my sons and	*RE: Gleason Grade 6* I didn't know Gleason 6 from anything else and it was only after the fact that I went home and of course spent hours and hours researching whatever that meant and trying to understand it and what the various potential treatments might be...It's scientific. (02, age 75, Male, Prostate)

directed searching that could be harmful	I wouldn't really say there was a description. It was more just him saying that if you're gonna have cancer this is the best one to have and that was basically what I took away from it...Honestly, I had to come home and start Googling things... They may have had some pamphlets in the office, but I didn't look at them when I got home, I just started researching myself and I listen to podcasts (08, patient, bladder) We did our own research to find out about BCG treatments and the options to deal with non-muscular invasive cancer in a bladder. And then I talked to other people that I knew in the medical profession that they all spoke highly of the procedure, and I just put my faith in that and tried to stay away from looking at the worse scenarios that are often described on the internet...Because we got so little information, we did our own or at least my wife did her own searches which sort of heightened the anxiety of the whole concern. (09, patient, bladder) But again, really understanding where the cancer was at, the different types of cancer there, I actually had to look it up afterwards to really understand it (11, patient, bladder)	family about what was going on because I didn't have a great understanding. (13, patient, cervix)	So I did some more research, I looked at my pathology report and it had something they called, could be formed cells and something else, IBC, introductory carcinoma, something like that...Now this was my own research from the pathology report. So they did not go into technical detail about the cells. All they're looking at is the high-level summary which says, 3+4. So 3+4 now is one step ahead of 3+3. So now at 3+4 I have to now make a decision as what I'm going to do next. (03, patient, prostate) I didn't understand what they described...For my second time I was a bit more educated, it's self-education It's where it's kind of the general type of information and you definitely need someone who would sit down with you and explain your situation properly (05, patient, prostate)

Recommendations to improve and supplement communication

Theme	Bladder	Cervix	Prostate
Schedule follow-up soon after delivering news to address concerns	A little bit about the timeline. I understand all the objective causes from resources and so on. But after I knew the stages that we will go through, I was just anxious to accelerate the timeline and there were weeks or months between the steps (06, patient, bladder) The follow-up appointment, I wish that had been closer to the initial exam; there was a couple of weeks between the two which left me feeling very anxious between those two time periods (12,	---	I'd asked for a referral, and I never heard anything and after a month I followed up, and so I haven't heard from the Cancer Clinic and the referral was never made. So, I got dropped through the cracks by that particular medical office…There was no real sort of follow through with anything else and that was kind of the last time I actually had that particular urologist (01, patient, prostate) We will refer you to an oncology clinic and they will explain to you. And while I was waiting almost a

	patient, bladder)		month for that appointment, again, you feel scared, you do your own research, you talk to some kind of support groups, you talk to family physician and so on (05, patient, prostate)
Patients want more detailed explanation of their condition	I had no clue of how things were going to be going forward and what I sort of had, like I have it now so is it going to come back? Do I have 5 years? Do I have 6 years? Am I pretty much cured? Like I didn't know if I was considered cured? Is it curable? Or is it something that I'll always have? Just a little more detail on how it actually will affect me going forward (07, patient, bladder) <u>More explanation about risks and prognosis</u> I just feel still an uneasiness knowing that there's a high reoccurrence rate and I asked the doctor; if it's going to come back; will it happen quickly? Or will it happen later on? And he said, either or. He said it could happen fast or it could be years. So, I feel like there's just so much unknown right? That the urologist doesn't really have the information to give you. He can't because you know, everybody's different... If this is common and if the reoccurrence rate isn't as frequent as I have in my head, that it could be just to live life normally. Live the way you were living before. Just you know carry on and try not to worry about it (08, patient, bladder) Those types of things like how common is this? If I have this diagnosis, should I be worried about cancer elsewhere in my body? (09, patient, bladder)	<u>Patient wants to understand what is actually "abnormal" about the cells</u> I don't know like I guess having some idea of what; a little bit more specifically about what it is that is different about the cells. And like I mentioned these language, like an area lit up in their screening or later on in the process using language like abnormal cells, like those moments where it is a little bit ambiguous it feels a bit scary because you don't know exactly what's being seen. Obviously you can't see it yourself, so you're kind of relying on what the healthcare practitioner is describing to you and they're not really like educating you on what a normal screening looks like versus what they're seeing. So you know I don't if my cervix has; like what percentage of the area is abnormal versus not and I guess like how prevalent these cells are (13, patient, cervix) Like I think just explaining better, just giving me more information but in a way that I could understand, like just talking verbally...Well maybe she could have like compared it to like a normal or a typical test. I don't know how they measure how bad an atypical cell is. Like I guess it would have helped if I knew what the consequences were of having an atypical result... Like what is a squamous cell? How do they determine if its typical or atypical and what are the consequences of that diagnosis. (14, patient, cervix) <u>Explanation specific to their own experience</u> But it also leaves me feeling confused, like where; like where the distinctions are I guess in terms of like they're kind of speaking generally about	<u>More detail on treatment including active surveillance</u> Well I guess describing what an active surveillance model looks like... I'm not a doctor, but I guess a proper preparation for what my treatment options were. (01, patient, prostate) They need to explain to me my timeframe to have some treatments. What treatment I may have and so on (05, patient, prostate) <u>More explanation about risks and prognosis</u> I would have been quite prepared to enter into a little more in-depth discussion... I'm a graduate, an educated person, and I have the ability to read and understand some basic scientific terminology or medical terminology. I know now that I have adenocarcinoma in two of the 12 tissue samples and one; 2/4 in one of the sample areas. So I think I would have been probably a lot more satisfied with a little more definition to what the term means, how much cancer I had. And there was no discussion of any cell or molecular sort of description of as to whether it was a Gleason 3, 4, 5. So that wasn't even part of what we talked about at time. (01, patient, prostate) I think he could have talked about the risk; how much risk there was to delay doing anything or if I required to immediately be taken care of, the options for treatment (04, patient, prostate) I'll tell you what I expected from my urologist; He needs to explain me my risks... Just more explanation and explain every parameter of that cancer type. How quickly it can develop and get

		demographics, who has experiences but like what about me specifically and I don't know if they are able to say specifically my risk versus other people's risk you know? Like comparatively but I think I would love to know really like how bad my situation is or how good it is if they're able to say that. (13, patient, cervix) More information about number and type of persons affected More of the whys and the hows, and how often this happens percentagewise to women, and is it common, is it something that happens after a certain age? I guess more information on a statistical level would have been helpful (10, patient, cervix)	bigger; could it metastasize or not. Something like that should be explained to patients (05, patient, prostate)
Connect patients with support services or groups	I'm still active in <cancer support group> and support groups like this. Unfortunately, we don't meet face-to-face anymore since COVID, but I never thought that I could open up about everything that I go through and went through to other people. I was encouraged by the fact that it was run by people like me; patients diagnosed and some of them had training from <cancer support group> and we formed an instant bond and I'm happy to go to the monthly meetings (06, patient, bladder) There is actually a specific group that is dedicated to just bladder cancer in Canada... I would have liked having that information because they also link you to other cancer care patients who are able to talk to you one-on-one. And so, these are other patients who've gone through similar types of cancer or treatments, and they connect you, and I would have appreciated that information earlier than later (11, patient, bladder)	At first, I told her they sent an email, calling me, so they told me that they have found some abnormal cells in my cervix... email showing that according to the test that they made I need to go back and they talked to me. It wasn't direct. Wish they would have just called me that they need me because I knew something must have went wrong and I started shaking. (15, patient, cervix)	There was no mention of the prostate support network. That information I came about by random chance through a local newspaper. It was actually my wife who picked it up; an announcement for a local meeting. I wasn't even aware it existed, not that I was seeking it out (01, patient, prostate) [I] wish that there would be more information for a patient to have and even a support group and he said we don't have that, and I don't know of any support group. And I told him about the <name of city-based cancer support group>And he said, well that was interesting and maybe I would like to join it because he didn't know anything of this. They're near the north end of <city name>. He said he knew of nothing more local than the centre of the core area [of city]. So I went to a meeting and I followed their information constantly and it perplexes me why something as helpful as it is; you're not made aware of the existence of such a resource. (02, patient, prostate) I know I can always call and say I need an appointment, I'm having trouble handling this, can I have an appointment, but trust me, you try to get an

			appointment with a doctor or urologist these days, even if you're in a panic you're not gonna talk to anybody for several weeks, if not months. So the system is not equipped to provide any kind of psychological support...That's the only thing that struck me as a big gap in terms of support. (02, patient, prostate)
Provide patients with, or refer them to print or online resources	Even just here's some resources that you could look at, just even on a piece of paper. Here are the resources available. This is the word describing what you have, and for your information, please go to these sites so that you'll hopefully have some or at least a better understanding... I guess I was still in shock just from the diagnosis and it would have been nice just to have that; so that I'm not reading everything that's available and related to bladder cancer on the Internet (09, patient, bladder) The piece that I loved about [Nation Bladder Cancer Organization] documentation is that it was day-to-day English, and they went through and described basically the two major types of bladder cancer and linked everything off that; the treatments, the prognosis, the challenges you may have. I would have liked having that information (11, patient, bladder)	Well they give out pamphlets for everything it seems but I don't know if they actually have one for this that might have helped... something where I could get more information. (14, patient, cervix) <u>Resources specific to treatment outcomes</u> Yah I think some resources that are specific maybe to my outcomes would be helpful so there's; like I said, there was pamphlets regarding the procedures, the laser procedure that they did to remove the abnormal cells. And there was a pamphlet regarding HPV but I think if there were digital resources but also a digital resource that was like specific to my situation that would be helpful. Because sometimes I get a little bit confused about where I ended up on the spectrum of high-grade, low-grade and all those things. (13, patient, cervix) <u>Outline steps in treatment and recovery</u> Yah I think if there was almost like a sub-pages to it or ways that you could sort of choose your own adventure kind of style where its like okay, you started at this point and like go through it step by step instead of starting with trying to educate someone on the whole realm of what could be. Maybe just like keeping it really simple at the beginning, so you've had an abnormal pap and what's the next step after that. And then okay, you've been told that there's abnormal cells and what does that mean? And then after your biopsy, like how that plays out and then; there was also two options for the procedure. There's	I really would appreciate walking out of there with some sort of resource document. A few years before that I had a kidney stone and when I went with the same urology clinic; and when I went to that process with the kidney stone they gave me pamphlets, they gave me information. I went home with more information than I could have thought of. They gave me more information than I could have thought of asking about and things that I could do different and where they came from and how. A resource that really helped me through the process; helped me know what I was living with having kidney stones and because that's what I even asked him [doctor]. I said, do you have anything you can give me to help me read and understand this. And he says, oh no we don't and so. So that kind of support in my mind would have been great (02, patient, prostate)

		the laser or the, like physical removal. But if there was almost like a way you could like compare those side by side and then if you had done one of those procedures; what the aftermath is and kind of like a step by step approach I think would be really helpful for me. (13, patient, cervix)	
Follow-up with patients after diagnosis	---	---	I know it's a daily occurrence but for me this is a once in a life-time occurrence and its difficult and nobody follows up to say are you doing okay? You understand a week, a month later what you were told and where you're at. (02, patient, prostate)

Distinguish from cancer or explain likelihood/risk that it will become cancer	I think at the point of the cystoscopy when we diagnosed it that it was a tumor, I think explaining a little bit better about the chances that it was cancer because at that point we didn't know if it was bladder cancer or just a mass. Explain that most likely it will be cancer, the chances of it being non-cancer was so low but explain a little bit more on how early we found it and what my prognosis was. Like is this something that I'm gonna end up having multiple surgeries for and just a little more time and explanation on it; because mine was so superficial. I think that would have made me worry a little less if I'd understood it at that time (07, patient, bladder) With this year's diagnosis of low-grade non-invasive bladder cancer, I'm still labelled I guess with bladder cancer though the tumor has been removed, but I don't understand was it cancer? (08, patient, bladder)	---	<u>Review pathology/radiology report with patients</u> Well what I have now, I'm sitting here looking at my pathology report and I'm assuming that the doctor would have had this at the time. It's 2-pages, and it talks about the source of the specimen and gross descriptions, microscopic description and diagnosis of what it is, and how involved the prostate is, and there's nothing in the glands or vesicle or anything like that beyond the prostate. It would be nice to know that. I was quite capable of looking at this and reading it now with a level of understanding. I think that I would have benefited from an opportunity to go through this 2-page report with him and talk about my treatment options. That would have really been a different starting point to my treatment or active surveillance. (01, patient, prostate) And I don't mind it being called what it's called if; when it's communicated to you, you are given some very clear explanation and ideally a resource or documentation as to what it means in simple English. I read my biopsy report because I could look at it. It's a hospital record and they read my MRI and my eyes blur over with words I can't pronounce and numbers that don't mean anything. (02, patient, prostate)

Provide clinicians with visual aids or guides to better communicate with patients	[For doctors to better explain] I think probably the use of a diagram (08, patient, bladder) So, for me, it would have been a scale of 1 to 10 here you are, you might be at level 1 or even you know just be pre-level 1, but we want to check things out (09, patient, bladder)	---	I think if there's a scale and it's kind of a short, small scale and is part of the profession. Something that was more in the public domain in terms of; and I don't know with other cancers whether there's a scale at all. Cancer is cancer whether you're level I or level 10. That might help somebody understand better where they're at, and I don't know how other types of cancer deal with it. I know the breaking point is if its cancerous, metastasized, that's a serious and difficult stage to be in because the cancer has spread and I think it's certainly critical to understand where you are on that scale if it's possible to make that clear. (02, patient, prostate) I always like the numbers because the numbers will tell me how serious it is. So abnormal cells can mean anything, but a number like 1, 2, 3, 4, 5; that gives me a better idea of how serious this is (03, patient, prostate)

Change in label and language	Think it should be dumbed down, labels are placed by highly educated and informed people. So that doesn't mean anything to people who aren't using that language (09, patient, bladder) *RE: low-grade cancer* He didn't say what that means. And for a first-time cancer patient that's kind of important... They say the terms, but in laymen's, what does that mean? If I don't know the medical terms, why give me a medical term? (11, patient, bladder) I just think that at the initial examination for sure he could have just not used those harsh terms, I guess the only way I can describe it is just a little more gentle, probably explain things a little bit more at that point (12, patient, bladder)	I guess just a little bit striking that balance between not using like anxiety inducing or triggering terminology, like precancerous but also still giving the patient a good idea of what's going on and specific information regarding their case somehow. (13, patient, cervix)	So, like the word generates a whole lot of fear and the active surveillance for me was the term that wasn't used. It was more of the wait and see; it was totally counter intuitive to what my emotional reaction was at the time. It's just something that I was able to, over a period of time and talking to people in the prostate cancer support world, more of a self-study than anything provided at the initial appointment with the urologist. (01, patient, prostate) <u>Due to monitoring as treatment, patient thinks condition should be considered precancerous not cancer</u> In hindsight I almost wish I had urologist who said this; this is not considered to be cancer at this time but we're just gonna have to monitor because it could be down the road an indicator of cancer happening. I equate it to skin cancer when they see a mole and they say oh it's carcinogenic and it hasn't been tested and then you go and you get the result saying, but it's not cancerous and we continue to monitor and assess anything... So you're not labelled with the skin cancer diagnosis just as I think they should be more careful about labelling something with the prostate cancer in a diagnosis. No matter how you look at it, cancer feels like a sentence, just something very unpleasant. (02, patient, prostate) <u>Use precancer label for low-risk prostate cancer</u> For example, blood sugar, sometimes it's a little bit high but they don't tell you that you have Diabetes. They just tell you, your blood sugar is higher than it's supposed to be. My father had diabetes, they told me initially that you have pre-diabetes first, before they give you the diagnosis of diabetes. Perhaps something like that maybe should be used in case of prostate cancer. (05, patient, prostate)
Longer visits with ample time for	Probably just a little more time explaining what bladder cancer entails (07, patient, bladder)	So giving the patient like a little bit of time to absorb and then follow up with more thoughts and questions and discussions would be helpful.	My doctor did not spend too much time with me...He just referred me to an oncology clinic and told me that you will meet with a doctor there and they will

discussions and questions	I just felt after the exam there was other people waiting to have for their exam, so it was very rushed. I wished there had been a little bit more time for me to ask more questions or maybe for me to go to a place where I could talk to someone else or someone else could have explained things to me more (12, patient, bladder)	(13, patient, cervix) They only had like certain amount of time they can spend with each patient and the pap was not like the purpose of my visit but I had just done the pap and she got the results back, so that's why she brought it up with me. So no, not enough time was spent on that particular thing. (14, patient, cervix) <u>Option to ask questions online after appointment</u> I think that having more of like a way to follow up with questions would have been helpful for me. I know it's difficult to get in touch with healthcare providers in general right now. Like its just they're quite busy and even with my family doctor I find, like it's kind of hard to get through. So I don't know, if there was some kind of like portal or forum that questions could be asked that would have been helpful because in the moment I don't; I'm trying to absorb the information that they're giving me and there's a lot going through my mind and anxiety and I don't think that I really was able to absorb what the kind of technical or medical aspects of this experience that I should have. (13, patient, cervix)	explain with the nurse, and they will explain to you (05, patient, prostate)