

Talking with Patients About HPV

Patty Cason, MS, FNP-BC

Envision Sexual and Reproductive Health

Los Angeles, CA USA

patty@envisionsrh.com

Disclosures

ASCCP board member

Objectives

- Discuss relevant facts about HPV with patients
- Demonstrate use of plain language
- Describe an information sandwich

“What really, really bothered me was the lack of consistent clear information ... one clinic in one hospital, they would say this can completely be cleared up. And then I’d speak to someone else and they’d say no don’t be silly it’s a virus you’ve got it for life. And then someone else would say you’re going to get warts and somebody else would say you’re not going to get warts it’s a different strain of the virus. And someone would say a condom will not protect you it’s sexually transmitted.”

Responses to a Positive HPV Test

- Stigma; fear; self- blame; anger; guilt
- Concern about
 - HPV's potential role in disrupting or affecting a pregnancy
 - The physical act of sex would worsen their abnormal cells
 - Fidelity
 - Disclosure

“It just made me feel so dirty ... there’s a sort of shame, there’s a leper type deal to it.”

“Something growing inside”

- Sexually unattractive

Paraphrasing

“It sounds like you’re concerned that you will have HPV for the rest of your life, do I have that right?”

Alternates to Paraphrasing

“Many of my patients say that they have heard that getting a positive HPV test means they will get warts, is that what you mean?”

Disclosure

- For some, the stigma of having an STI has a greater impact than concern about cancer
- Concerns about disclosing are partly due to the stigma, embarrassment, and shame associated with having an STI and how others would respond
- Image of promiscuity attached to sexual transmission

Disclosure

60% of women agreed with the statement; “Disclosing my HPV test result is risky”

Patients Ask--When is Disclosure Necessary?

- Patients often question whether it is necessary to disclose to current and previous partners
- Some feel obligated to disclose the results to current and prospective partners

“And I would say what’s the protocol here? Should I be telling sexual partners that I have this? And one person would say yes of course you must and another would say don’t be silly almost all the population’s been exposed to it. And there was such a conflict of information, that was what really upset me...”

Disclosure to a Sexual Partner

- *"The thought of having it (HPV), deciding when to do it and how and what to say - it was extremely stressful"*
- The prospect of disclosure is challenging, complicated and something many wish to avoid
- Associated with anxiety, worry, fear, and stress
- Some are not worried about disclosing

Disclosure; Specific Concerns

- Being rejected by a partner following disclosure

"If I told men that I had it they might not want to have sex with me"

- The partner would accuse them of infidelity
- Cause harm to their relationship
- Some ended relationships out of fear of rejection following disclosure

Common Strategies Used to Avoid Disclosure

- Some choose not to disclose their HPV result as a way to minimize anxiety and avoid explaining about HPV
- Instead they tell their partners about:
 - their abnormal cytology result
 - their potential cervical (pre)cancer
 - having a gynecological problem
- Others are deliberately vague about how HPV is transmitted playing up their own confusion

Rationale for Avoiding Disclosure

- Perception that HPV does not have serious physical consequences in males
- Do not know what to tell their partner
- They describe a lack of clear, consistent information

The Impact of Testing HPV Positive Varies

- Relationship experience
- Social and cultural norms
- Practices around sex and relationships
- Understanding of key features of the virus

This underlines the need to individualize information and respond to concerns



I can see that
this is hard for you,
can you tell me
what is most
concerning for you
about this?

Empathy with Neutral Words

Use neutral words to transmit empathy rather than labeling feelings like “anxious” or “angry”

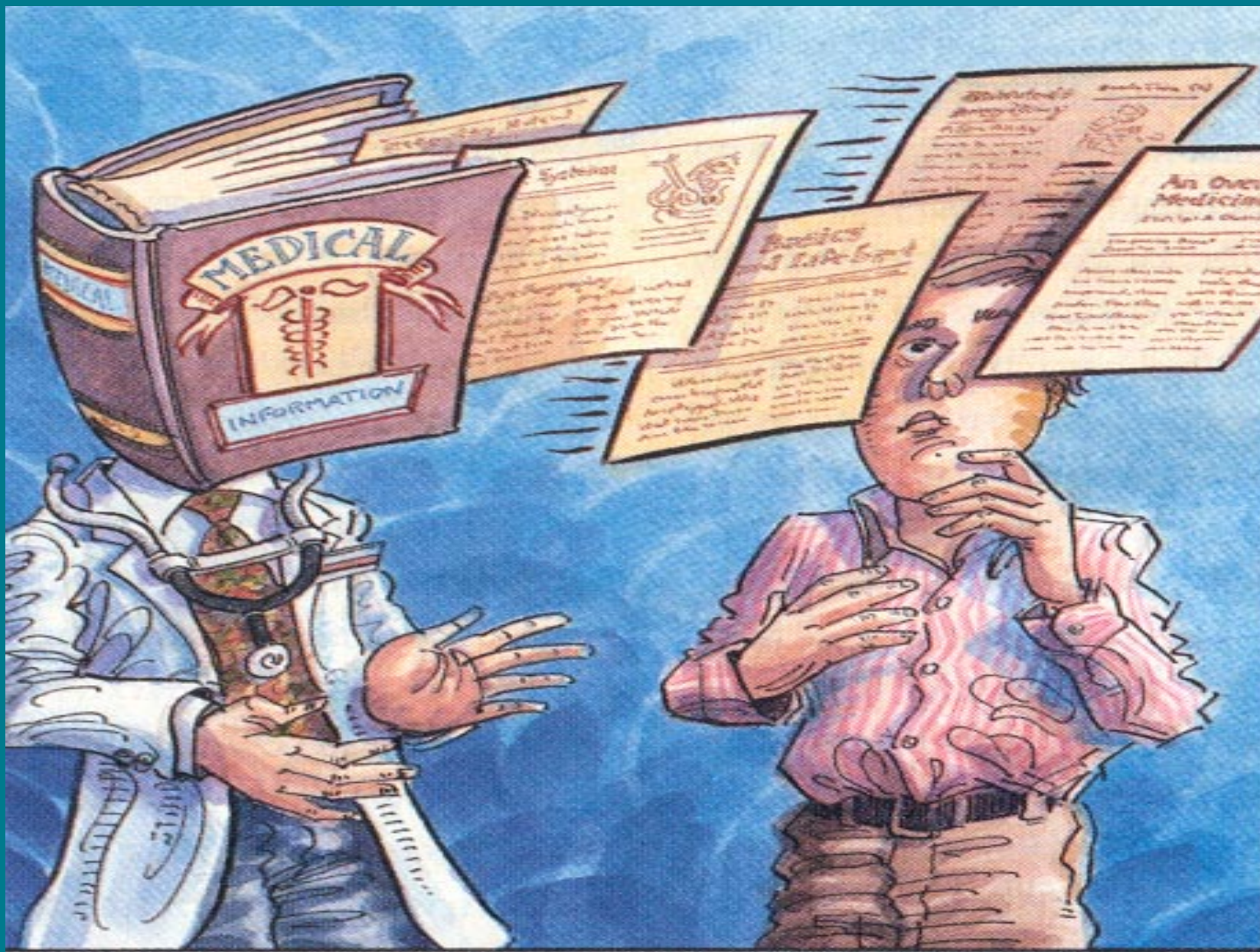
*“That must be really **hard to deal with**”*

“Anyone would find that upsetting.”

*“I can understand why getting another pap is **concerning to you**”*

Health Literacy

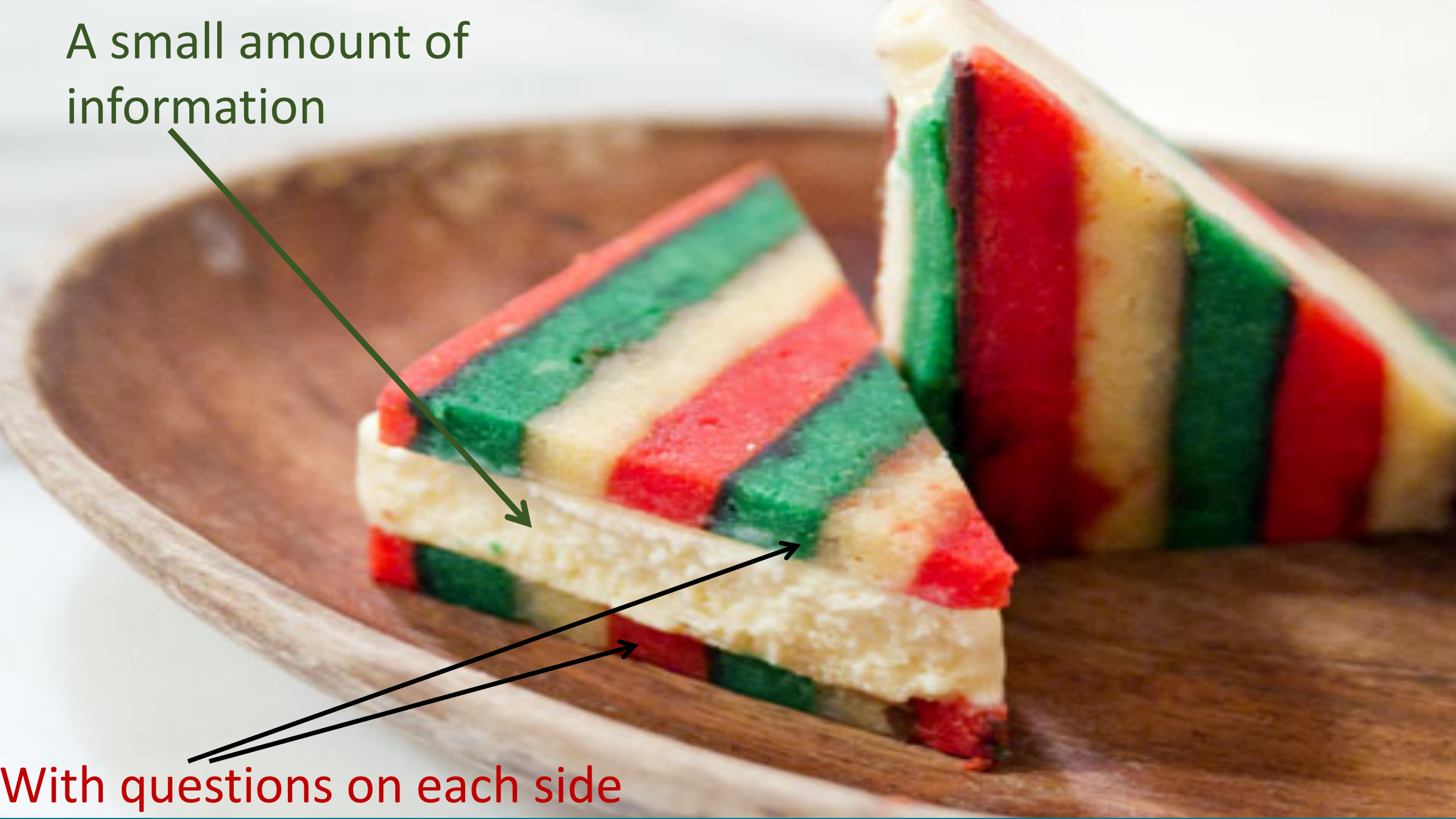
“The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.”



Give Information Effectively

- Humans do not integrate large amounts of information at a time
- Focus on the individual's specific concerns, knowledge gaps, and needs
- Use plain language
- Ask follow up questions

A small amount of
information



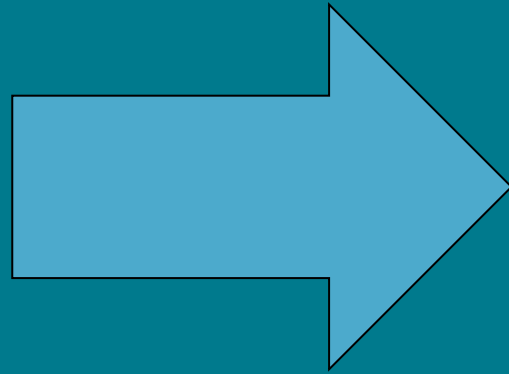
With questions on each side

Types of Questions to Ask After Giving a Fact

- How would that be for you?
- Knowing that, how would it be for you if_____?
- Has something like that ever happened before?
- How did you manage it?

Examples of Plain Language

- Annually
- Topically
- Detect
- Fertility
- Accurate

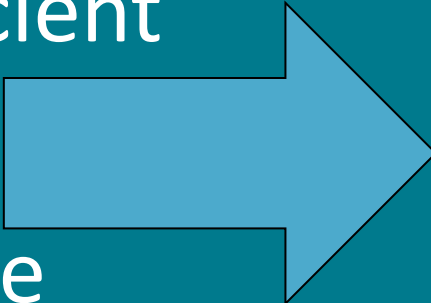


- Yearly or every year
- On the skin
- Find
- Ability to get pregnant
- True, right, correct

The Plain Language Thesaurus for Health Communications

http://depts.washington.edu/respcare/public/info/Plain_Language_Thesaurus_for_Health_Communications.pdf

Examples of Plain Language

- Acute
 - Adequate, sufficient
 - Adhere
 - Efficacy, effective
 - Adjacent
- 
- Sudden start, quick
 - Enough, the right amount
 - Stick to, follow
 - How well it works
 - Beside, next to, near, touching

The Plain Language Thesaurus for Health Communications

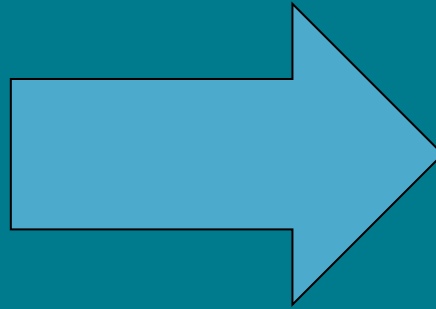
http://depts.washington.edu/respcare/public/info/Plain_Language_Thesaurus_for_Health_Communications.pdf

Examples of Plain Language

- Surveillance

- Susceptible

- Systemic



- Keep a close eye on, watch closely, monitor

- More likely to get, in danger of getting

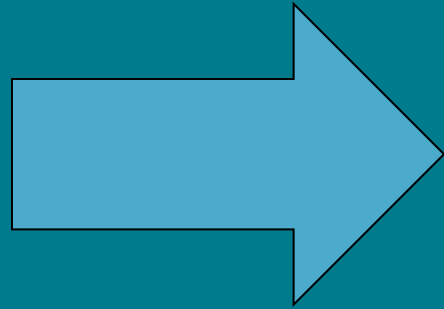
- Through your body, in all parts of your body

The Plain Language Thesaurus for Health Communications

http://depts.washington.edu/respcare/public/info/Plain_Language_Thesaurus_for_Health_Communications.pdf

Examples of Plain Language

- Mitigate
- Monitor
- Prevalence
- Progression



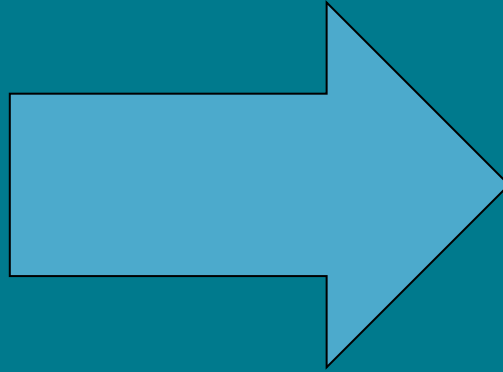
- Make less harmful
- Watch for changes
- Number of people with the infection (e.g. 90 out of 100)
- Get worse, move forward, keep going on

The Plain Language Thesaurus for Health Communications

http://depts.washington.edu/respcare/public/info/Plain_Language_Thesaurus_for_Health_Communications.pdf

Examples of Plain Language

- Risk
- Adverse
- Aggressive
- Asymptomatic infection



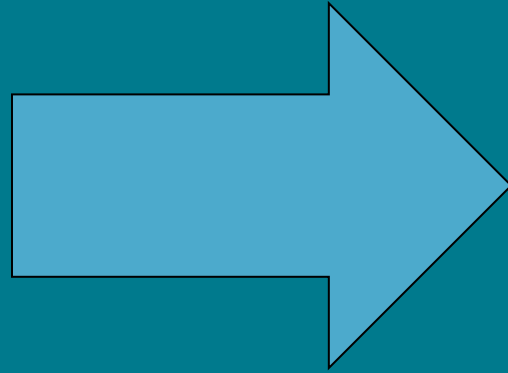
- Chance
- Bad, dangerous, harmful
- Gets worse fast
- You have an infection, but you don't feel bad, no symptoms

The Plain Language Thesaurus for Health Communications

http://depts.washington.edu/respcare/public/info/Plain_Language_Thesaurus_for_Health_Communications.pdf

Examples of Plain Language

- Immunity, Immune system
- Fluctuate
- Localized



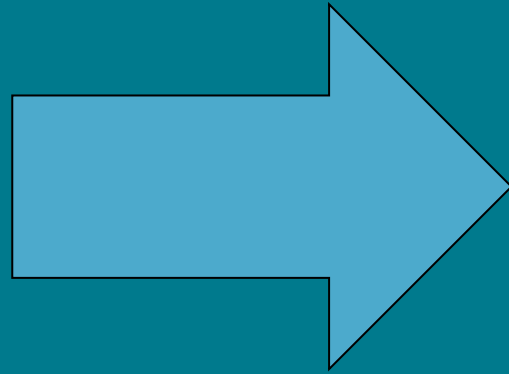
- The way your body fights off infection
- Change, go back and forth from high to low
- Only in one place, in a small area

The Plain Language Thesaurus for Health Communications

http://depts.washington.edu/respcare/public/info/Plain_Language_Thesaurus_for_Health_Communications.pdf

Examples of Plain Language

- Avoid
- Carcinogen
- Uterus
- Cervix



- Do not
- Can cause cancer
- The place where a baby would grow (picture), womb
- Lower part of the uterus

The Plain Language Thesaurus for Health Communications

http://depts.washington.edu/respcare/public/info/Plain_Language_Thesaurus_for_Health_Communications.pdf

HPV Facts that Can Minimize the Potential Negative Impact of HPV+ Results

- High prevalence (Very common)
 - Reduces the perceived stigma
 - Puts the perceived severity of HPV In perspective
- Asymptomatic
 - Knowing that there are no visible symptoms (warts) allows one to “go on with everyday life and not think about it”.

Waller, J., McCaffery, K., Nazroo, J., & Wardle, J. (2005). Making sense of information about HPV in cervical screening: a qualitative study. *Br J Cancer*, 92(2), 265-270.

McCaffery, K., Waller, J., Nazroo, J., & Wardle, J. (2006). Social and psychological impact of HPV testing in cervical screening: a qualitative study. *Sex Transm Infect*, 82(2), 169-174.

“Most everyone gets HPV but most of the time we don’t know it’s there and it doesn’t cause any harm and goes away by itself.”

“Most people get an HPV infection when they first start having sex, unless they have been vaccinated.”

Use
Natural
Frequencies
And Common
Denominators

*8 out of 10 people will
have HPV at some point
in their life*



Beneficial Information

- Spontaneous clearance (it goes away on it's own in most cases)
 - HPV usually “clear ups” on its own without treatment
 - Allows comparison with other trivial infections like colds:

“In the majority of cases the body can fight off the infection and make it go away --like a common cold”

Waller, J., McCaffery, K., Nazroo, J., & Wardle, J. (2005). Making sense of information about HPV in cervical screening: a qualitative study. *Br J Cancer*, 92(2), 265-270.

Beneficial

- Dormancy (may have been around for a long time but didn't cause any problems)
 - Allows patient's to attribute the infection to a previous partner, or to assume that their partner had contracted it during a previous relationship
 - Has been shown to be extremely reassuring

Waller, J., McCaffery, K., Nazroo, J., & Wardle, J. (2005). Making sense of information about HPV in cervical screening: a qualitative study. *Br J Cancer*, 92(2), 265-270.

“Your body gets rid most viruses that you get. With time, it’s likely that your body will fight off the HPV.”

“Almost everyone gets rid of the virus before it does any harm to the cells on the cervix.”

“Most people get rid of the HPV within 2-3 years, on average after 8 months.”

Beneficial

- Treatment for CIN is highly effective
- Distinction between high risk types and genital warts

McCaffery, K., Waller, J., Nazroo, J., & Wardle, J. (2006). Social and psychological impact of HPV testing in cervical screening: a qualitative study. *Sex Transm Infect*, 82(2), 169-174.

HSIL	
HSIL	
CIN 3	
Severe dysplasia	Carcinoma in-situ

VS.



“It’s confusing because the name HPV is used to describe two types of viruses. One type causes warts but can’t cause cancer. The other type can cause cancer and doesn’t cause warts.”

Seeking a clear recommendation

“But nobody’s actually sat down and said ‘Look, you now have to be careful. You now have HPV’ and I think if somebody said ‘Look you really do have to either use condoms or inform future partners’ I would do. If somebody actually said ‘You need to start doing that’. But still nobody’s really told me how serious or little of importance this virus is.”

Waller, J., McCaffery, K., Nazroo, J., & Wardle, J. (2005). Making sense of information about HPV in cervical screening: a qualitative study. *Br J Cancer*, 92(2), 265-270.

How did I get it?

- *Skin to skin contact*
- *Usually through intimate genital contact*
- *Perhaps fingers, mouth, sex toys*

Teach Back

“We have gone over a ton of information and I want to be sure I was as clear as I could be. Can you tell me what your understanding about HPV is?”

“What have you read (or heard, or what do you know) about HPV?”

Use Body Language That Invites Questions

- Sit at the same level as the patient
- Look at patients when talking *and* listening

How to Discourage Questions



~~“Do you have any questions?”~~

~~“Do you understand?”~~



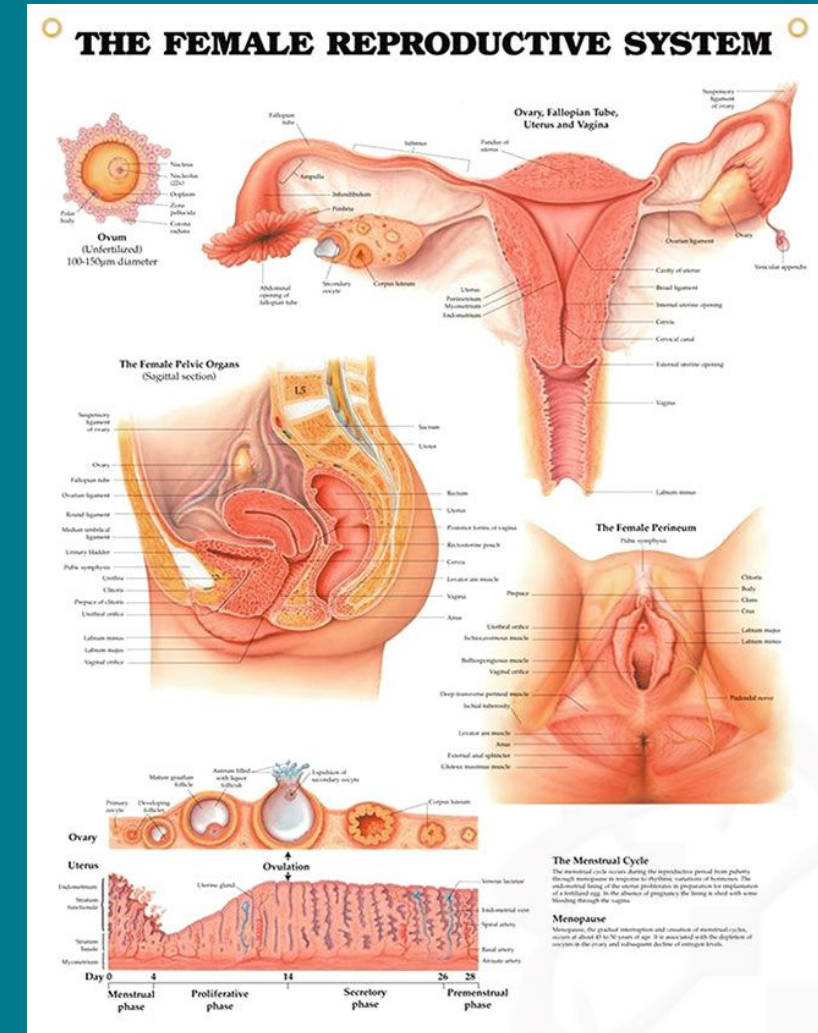
Encourage Questions

“What questions do you have for me about HPV?”

“What other questions do you have about your pap results?”



- Demonstrate/draw pictures
- Clearly written education materials
- Illustrations
- 3-D models



Text Construction

- Write at or below a 6th grade level
- Use 1- or 2-syllable words
- Use short paragraphs
- Use active voice
- Avoid all but the most simple tables and graphs
- Abundant “white space”
- Pictures

Weiss BD. Health Literacy and Patient Safety: Help Patients Understand. American Medical Association 2007

Limit Content and Slow Down

- Limit information to 3-5 key points per visit
- Focus on “Need to Know” and “Need to Do”
- Breakdown complex information
- Repeat content

Slow down and try to use the person's own words

Universal Precautions

- Everyone, no matter how educated, is at risk for misunderstanding health information
- Patients don't always recall health information correctly
- Patients may believe they have understood directions or may be too embarrassed to ask questions to confirm their understanding

The following slides are from:

Talking about human papillomavirus and cancer:
development of consultation guides through lay and
professional stakeholder coproduction using
qualitative, quantitative and secondary data.

- HPV is a virus that is passed from one person to another during sex or physical intimacy.
- It affects both men and women, and it is so common that most of us get it at some point in our lives.
- HPV is usually cleared by the body's own defenses but, in a few people, it stays in the cells of the affected area for months or years. Then it sometimes causes the cells to change, and that may lead to cancer.
- Even if HPV causes cells to change, it can take another 10 years or more for cancer to develop.
- Most people never know they had HPV because there aren't usually any symptoms. It is hard to know when you got HPV or who you got it from.

There is no treatment for HPV but there's now a vaccination to prevent it.

Frequently asked questions

Q: What does this mean for my relationship?

A: You and your partner will have already shared whatever infections you have and no changes in physical intimacy are needed.

Q: What about previous partners?

A: There is no need to tell previous partners you have HPV. There is no test or treatment for it; most people clear the virus without treatment and without even knowing they had it.

Q: Could I have done anything to prevent getting HPV?

A: No, it is so common that nearly all adults get it and condoms would not have given you complete protection.

However, if you are a smoker, giving up smoking may help

Q: Could I have got HPV any other way?

A: This is very unlikely because HPV targets a type of cell found in the lining of parts of the body that only come into contact during sexual intimacy.