An Introduction to Patient Decision Support Tools

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UTMB Minicourse Oct 23 2013
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Decisional Dilemmas

Cancer Treatment
Localized (low risk) prostate cancer
Intermediate risk prostate cancer and short-term ADT

Cancer Screening
Prostate cancer
Colorectal cancer
Lung cancer

Overview

1. The case for IDM and decision support

2. Define IDM / SDM and Patient Decision Support Technologies

3. Demonstrate a few products

4. Some current initiatives for PtDAs and IDM/SDM Research in Cancer
The case for IDM and the need for decision support tools
Patient Engagement Takes Center Stage

- February 2013 theme issue

Patient Engagement Topics

- End-of-life care
- Health costs
- PCOR
- Barriers to SDM
- Data needs of patients
- E-health
- Decision aids

http://www.healthaffairs.org/
The purpose of CER is to assist consumers, clinicians, purchasers, and policy makers to make informed decisions that will improve health care at both the individual and population levels.
Patient Centered Outcomes Research Institute (PCORI)

- Established by Patient Protection and Affordable Care Act of 2010.
- ...to help patients, clinicians, purchasers, and policy makers make better informed health decisions by “advancing the quality and relevance of evidence about how to prevent, diagnose, treat, monitor, and manage diseases, disorders, and other health conditions.

www.pcori.org
Affordable Care Act and SDM

• Funds an independent entity to develop consensus-based standards for certifying patient decision aids.

• Funds development and evaluation of patient decision aids.

• Authorizes CMS to test shared-decision making models.

• Implementation may be mandated throughout Medicare.
Defining IDM / SDM and Patient Decision Support Technologies
Informed Decision Making (IDM)

When an individual:

1. Understands the nature of the disease/condition (core knowledge)

2. Understands the preventive service/treatment, including risks, limitations, benefits, alternatives, uncertainties (core knowledge)

3. Considers preferences and values as appropriate (values)

4. Chooses a level of participation in decision making with which he/she is comfortable (role preferences)

5. Makes (or defers) a decision based on his/her preferences and values (values-based decision)

Shared Decision Making (SDM)

- SDM is defined as decisions that are shared by doctors and patients, informed by the best available evidence and weighted according to the specific characteristics and values of the patient.

Brooks, Cochrane. Introduction to SDM. Dartmouth-Hitchcock Medical Center.
How do we enhance SDM?

- **Patient tools** – ie, decision aids
- Clinician training
- Decision “coaches”
- Change reimbursement
- Practice redesign
What are Patient Decision Support Technologies?

“Decision support interventions help people think about choices they face: they describe where and why choice exists; they provide information about options, including, where reasonable, the option of taking no action. These interventions help people to deliberate, independently or in collaboration with others, about options, by considering relevant attributes; they support people to forecast how they might feel about short, intermediate and long-term outcomes which have relevant consequences, in ways which help the process of constructing preferences and eventual decision making, appropriate to their individual situation.”

Patient Decision Support Technologies

- They are **not** designed to:
  - advise people to choose one option over another
  - replace physician consultation

- Bottom line:
  - Patient decision aids prepare patients to make informed, values-based decisions with their health care providers

When do you need decision aids?

• **For preference-sensitive decisions:**
  – Decisions where there is uncertainty about the optimal course of action
  – There are clear trade-offs between harms and benefits
  – The patient’s preferences are central to determine which option should be pursued
Decision aids have the potential to...

• Save time during the clinical encounter

• Improve quality of “informed consent”

• Decrease practice variation (and perhaps health care costs) – maybe?
Are Patient Decision Aids Effective in Promoting Informed Decisions?
From 2011 Cochrane review

compared to standard care, decision aids...

<table>
<thead>
<tr>
<th>Decision Attributes</th>
<th>Decisions</th>
</tr>
</thead>
<tbody>
<tr>
<td>14% ↑ knowledge</td>
<td>↓ 20% elective surgery, ↓ 15% PSA; ↓ 27% HRT</td>
</tr>
<tr>
<td>74% ↑ accurate risk perceptions</td>
<td>Effect on other decisions was variable</td>
</tr>
<tr>
<td>25% ↑ informed decisions that match values</td>
<td>✗ No/minimal effect on anxiety or health outcomes</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Decision Process Attributes</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>6% ↓ feeling uniformed</td>
<td></td>
</tr>
<tr>
<td>5% ↓ feeling unclear about values</td>
<td></td>
</tr>
<tr>
<td>61% ↓ passive</td>
<td></td>
</tr>
<tr>
<td>57% ↓ undecided</td>
<td></td>
</tr>
<tr>
<td>↑ patient-practitioner communication</td>
<td></td>
</tr>
</tbody>
</table>

Cancer-Related Decision Aids

- 34 RCTs
  - 22 screening
  - 12 prevention/treatment

Context

- Screening
  - Cervical cancer
  - Prostate cancer
  - BRCA 1 / 2
  - Colorectal cancer

- Treatment
  - Prostate cancer
  - Breast cancer

Few aids developed in cancer and evaluated in RCTs

Cancer-Related Decision Aids

The Bottom Line

- Cancer-related decision aids...
  - increase patient knowledge
  - do not raise anxiety (decrease in screening context)
  - reduce decisional conflict

What we do in the **Decision Support Laboratory**

- **Develop patient decision aids**
- **Research decision support methods:**
  - Risk communication
  - Addressing health literacy/numeracy
- **Evaluate implementation and outcomes of decision aids:**
  - Acceptability, usability, credibility
  - Behavioral and/or psychosocial outcomes
Case Examples

1. Paper-based tools

2. Encounter-based tools

3. Entertainment-based tools (multi-media)

4. Web-based tools (multi-media)
Ottawa A-Z Decision Aid Inventory

http://decisionaid.ohri.ca/AZinvent.php

- Hundreds of decision aids for all types of healthcare decisions
- International Patient Decision Aid Standards (IPDAS) collaboration, assessment of quality criteria
Paper-Based about End-of-Life Decisions (Ottawa Patient Decision Aids)

Understanding the OPTIONS
Planning care for critically ill patients in the Intensive Care Unit

- [http://decisionaid.ohri.ca/docs/das/Critically_Ill_Decision_Support.pdf](http://decisionaid.ohri.ca/docs/das/Critically_Ill_Decision_Support.pdf)
American Cancer Society Guideline for the Early Detection of Prostate Cancer

Update 2010

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http://caonline.amcancersoc.org/cgi/content/full/60/2/70
New “Paper-based” Materials from ACS

16-page Patient Decision Aid

Testing for Prostate Cancer

"Should I be tested? Is it the right choice for me?"

Does the American Cancer Society say that all men should be tested for prostate cancer?

Yes, we do. The research that has been done is not clear. Some researchers believe that finding prostate cancer early will stop someone from dying from the disease. Others research does not show this. And treating prostate cancer can have some serious side effects.

The American Cancer Society says that men should make an informed decision. This means that you should learn about prostate cancer and testing. You should think through the risks and possible benefits. Then, after talking with your doctor, you should decide if testing is the right choice for you.

What are my chances of having prostate cancer?

Based on the way prostate cancer testing is done today, about 1 out of every 10 men (10%) below age 50 will be diagnosed with prostate cancer during their lifetime.

17 out of 100 men (17%) age 50 will be diagnosed with prostate cancer during their lifetime.

What is important to you?

There are many reasons why men decide to be tested or not to be tested for prostate cancer. Some reasons are listed below. Listed below are 5 of the main reasons that are important to you.

- Some reasons to be tested

  Check what's important to you

  I will have peace of mind when I know the test results.
  I will know if I have prostate cancer or not.
  I will have a better chance of getting cancer treatment if cancer is found early.

  Other reasons important to you (list them here)

- Get out and talk to your doctor.
How do I decide if testing is the right choice for me?

Know the facts about:
- Prostate cancer and other prostate problems
- What the PSA test and rectal exam can and cannot tell you
- What other decisions you may need to make if you are tested

Ask questions and talk to others:
- Write down your questions and discuss them with your doctor.
- Talk about testing with your family and those who care about you.

Use the balance scale on the next two pages
- To help you weigh how you feel about testing
- To help you make your decision about testing

What is important to you?

There are many reasons men decide to be tested or to not be tested for prostate cancer. Some reasons are listed below. Place a check by the reasons that are important to you.

Some reasons to be tested

Check what’s important to you

I will have peace of mind when I know the test results.

I will know if I have prostate cancer or not.

I will have a better chance of getting cancer treatment if a cancer is found early.

Other reasons important to you (list them here):

Which way are you leaning about being tested?

Want to be tested

Not sure

Do not want to be tested
Patient Education

Lung Cancer Screening
Is It Right for Me?

Lung cancer is the leading cause of cancer death in both men and women in the United States. Cigarette smoking is the major risk factor for lung cancer. Over 85 percent of lung cancer deaths are caused by smoking.

A large research study recently identified a screening test that found lung cancer early and lowered the chance of dying from lung cancer. A screening test is used to find cancer before a person has any symptoms. This can help find cancer at an early stage, when it is easier to treat.
Lung Ca Screening Aid (video)

Design Requirements

- For use with screen-eligible patients at CPC
- Linear
- Video-based with narration
- Delivered on exam room computers or education rooms
- 5 minutes max
- English only
- 8th grade reading level
- Risk communication modules
Selected Screenshots from Lung Ca Video

- Diagnosed with Lung cancer.
- Suspicious result, but no lung cancer.
- Result not suspicious for lung cancer.
Lung Ca Screening Aid Demonstration

http://www3.mdanderson.org/streams/FullVideoPlayer.cfm?xml=cfg%2FLung-Cancer-Screening
Entertainment-based Decision Aids

Telenovelas to promote engagement

Animations to communicate key learner content

Volk – PI (NCI)
**Design Requirements**

- For use with screen-eligible patients
- Use in clinical setting
- Linear
- Video-based
- Delivered on laptops
- Low literacy design considerations
- Entertainment-based
- Culturally-tailored
- Spanish and English language versions
Screenshots of Test Attributes

**Discomfort**
- FOBT
- Flexible Sigmoidoscopy
- Colonoscopy

**Frequency**
- FOBT
- Flexible Sigmoidoscopy
- Colonoscopy

**Complications**
- FOBT: None
- Flexible Sigmoidoscopy: Possible tears or bleeding
- Colonoscopy: Possible tears or bleeding

**Accuracy**
- FOBT: GOOD
- Flexible Sigmoidoscopy: BETTER
- Colonoscopy: BEST
Demonstration

Colorectal Cancer Screening: A Story of Choices
Encounter-Based Decision Aids

(transactional or communication aids)
Mayo Shared Decision Making
National Resource Center

• For use during clinical encounters
• Attribute comparisons (vs option comparisons)
• Some tools only address risk
• http://shareddecisions.mayoclinic.org/decision-aids-for-diabetes/
### SDM Made Easier

**Option Grids**

- Encounter-based tools
- Promote discussion
- FAQs by options layout
- Summary of evidence

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**Option Grids**

**Osteoarthritis of the Hip**

This grid is designed to help you and your clinician decide how to best manage your hip pain and activity level. The first steps are to become as fit as possible, work to approach your ideal weight, and consider trying physical therapy. Surgery is normally recommended only after non-operative treatments have been tried.

<table>
<thead>
<tr>
<th>Frequently asked questions</th>
<th>Non-operative treatment</th>
<th>Hip replacement surgery</th>
</tr>
</thead>
<tbody>
<tr>
<td>Will this reduce the pain I have in my hip?</td>
<td>It depends on who you are and which of the many possible treatments you try. You should talk to your clinician about which treatments might work best for you. Tablets like acetaminophen (tylenol), ibuprofen (NSAID), and tramadol as well as steroid injections may be recommended.</td>
<td>Three months after having surgery, around 84 in every 100 people say they are very satisfied with how the surgery improved their level of pain. One year after surgery, around 87 in every 100 people say they are very satisfied with how the surgery improved their level of pain.</td>
</tr>
<tr>
<td>Will this treatment improve my ability to be active?</td>
<td>It may. As you get pain relief, you should be able to be more active and this in turn can also help to reduce pain. It may help to take pain relievers before being physically active.</td>
<td>Yes, the vast majority of patients experience improvement in their activity level. However, not everyone is satisfied with the improvement in their ability to perform some strenuous activities.</td>
</tr>
<tr>
<td>Are there any risks to this treatment?</td>
<td>All medications have some side effects. For example, codeine may lead to constipation and prolonged use of tablets like ibuprofen (NSAIDs) increases your risk of developing stomach bleeding, high blood pressure, and heart or kidney problems. Around 2 in 100 people who receive a steroid injection will experience joint pain and swelling for a day or so after the injection.</td>
<td>Among those over 65 years of age, roughly 3 in every 100 people experience a serious medical complication after surgery such as infection, bleeding, blood clots in the legs or lungs, heart attack, or death. Rare but possible surgical complications include dislocation, fracture, and leg length inequality. The risks of surgery increase with age and if you have other conditions, such as heart or lung disease, are a smoker or are overweight.</td>
</tr>
<tr>
<td>How long will it take me to feel better after the treatment?</td>
<td>Some people experience pain relief within a few days of starting to take pain relievers but others require a few weeks or longer before they notice a difference in their pain.</td>
<td>Pain relief is gradual and rehabilitation can be challenging. You will stay in the hospital for around two to four days. Most people walk unaided after 1 or 2 months. Full recovery usually takes around 1 year.</td>
</tr>
<tr>
<td>Will I need to have more treatment or surgery?</td>
<td>If things don’t get better with one non-operative treatment, talk to your clinician about other non-operative treatments that might work better for you.</td>
<td>The chance of needing your hip replaced for a second time depends on your age and activity level. Around 10 in 100 people will need a second operation to revise their hip replacement within the first 10 years after surgery.</td>
</tr>
<tr>
<td>What are the long term outcomes for people with arthritis who have this treatment?</td>
<td>Many people cope well by using medication, being as active as possible, and losing weight. Some people are not able to achieve pain relief with non-operative methods alone.</td>
<td>Surgery is usually considered after other options have been tried. Around 95 in 100 people are satisfied with the overall results of their surgery one year after having a hip replacement.</td>
</tr>
</tbody>
</table>

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*Elwyn et al., Pat Ed Counsel 2013.*

http://www.optiongrid.org
Web-based Decision Aids

Taking Control: Non-surgical Treatment Options for Urinary Incontinence in Women

- released by AHRQ
September 17, 2013.

http://www.effectivehealthcare.ahrq.gov/index.cfm/tools-and-resources/patient-decision-aids/
Features of *Taking Control*

- Visually-engaging, flat design
- Simple navigation
- Multimedia (video, graphics, text)
- Normative messaging (quotes)
- Values-prompting questions
- Deliberative messages
- Tailored print-out
Knowing Your Options: A Decision Aid for Men with Clinically Localized Prostate Cancer

- released by AHRQ September 8, 2011.

http://www.effectivehealthcare.ahrq.gov/ehc/decisionaids/prostate-cancer/?EC=BV
Prostate Ca Treatment Aid Flow

Flow Chart: A Decision Aid for Men with Localized Prostate Cancer

Start

LM 1 Introduction
- Who should use this tool?
- Overview of the tool (what this tool does and does not cover).

LM 2 About Prostate Cancer
- Anatomy and functioning of prostate.
- What is prostate cancer?
- What is early stage, clinically localized prostate cancer?

LM 3 Treatments options
What are the options for treating localized prostate cancer?
1. Active surveillance (watchful waiting).
2. Surgery (prostatectomy).
3. Radiation (external beam radiation; brachytherapy).
5. Other, newer treatments

LM 4 Benefits and harms of treatment
2. Treatment side effects (erectile dysfunction; urinary problems; bowel problems).

LM 5 Deciding what’s important to you
Prompting questions
- Treating now versus watching and waiting.
- Additional questions reflecting trade-offs.

LM 6 Getting Ready to Talk with Your Doctor
Normative messaging (importance of partnering in your care; expressing preferences).
Steps in deliberation:
- Get the facts.
- Ask questions.
- Tell your doctor what you are concerned about.
- Tell your doctor about your preferences.

Print Out Option
- Summary information on options and harms.
- Responses to values questions (LM 5).
- Questions for your doctor.
- Other resources.

Glossary

End
Features of the Aid

- Reinforcing messaging
- Simple navigation
- User-entered data
- Animation
- Visually-engaging design
- Values-prompting questions
- Deliberative messages
- Tailored print-out
Future directions for PtDAs and IDM/SDM Research in Cancer
Some current initiatives for PtDAs and IDM/SDM Research in Cancer

• Decision support for questions that involve “doing less”
  – eg, mammography screening for breast cancer in women over 70 years of age (Sheffield)

• Promoting deliberation on a short timeline
  – eg, Fertility preservation in female cancer patients prior to treatment
Some current initiatives for PtDAs and IDM/SDM Research in Cancer

• Delivering decision support “at the point of care”
  – eg, lung cancer screening with CT

• Involving families in ISM/SDM using PtDAs
  – eg, DNR orders for patients at the end of life
Thank you and questions
Current ASCO Decision Aids

- **Lung Cancer**
  - Decision aids for 1\(^{st}\), 2\(^{nd}\), 3\(^{rd}\), and 4\(^{th}\)-Line chemotherapy

- **Breast Cancer**
  - Adjuvant endocrine therapy for hormone receptor-positive breast cancer

- **Prostate Cancer**
  - Prostate cancer screening with PSA testing

[http://www.asco.org/ASCOv2/Practice+%26+Guidelines/Guidelines/Clinical+Tools+and+Resources](http://www.asco.org/ASCOv2/Practice+%26+Guidelines/Guidelines/Clinical+Tools+and+Resources)
Cancer.Net patient education videos

http://www.cancer.net/multimedia/videos
American Cancer Society

- Easy reading for patients
- Dealing with side effects of cancer treatment
- Most available in English and Spanish

ASCO Decision Aids

• Paper-based

• Content
  – What is/how to use a DA
  – Role preferences in decision making
  – Who the DA (or the options) is for
  – Risks and benefits of the options
  – Weighing options, preferences
  – Plans in next steps
DECISION AID TOOL
Adjuvant Endocrine Therapy for Hormone Receptor-Positive Breast Cancer

This booklet is what is often called a decision aid. The goal of decision aids is to help patients better understand their treatment choices and to help them make the best medical decision possible for their situation.

This decision aid is for women who are post-menopausal and who have hormone receptor-positive (ER+ and/or PR+) breast cancer and are trying to decide whether or not to take adjuvant (after surgery) endocrine therapy and what type of endocrine therapy to take. The goal of this decision aid is to help patients and doctors talk to each other in order to make decisions about treatment. It is based on recommendations from the American Society of Clinical Oncology’s updated Clinical Practice Guideline on adjuvant endocrine therapy. Use of this decision aid is voluntary.

The decision aid is divided into two sections:
1. Learning the risks and benefits of adjuvant endocrine therapy
2. Help for thinking through the decision

The first time you read this decision aid, your doctor should be present to help you understand the information, and any family members or friends you would like to include. You may also take this document home after reviewing it with your doctor.

This guide contains numbers or statistics which may predict the course of breast cancer. If you are not comfortable with this type of information, you may prefer not to use this decision aid.

What role do you prefer in making this choice?
☐ I prefer to share the decision with _____________________________
☐ I prefer to decide myself after hearing the views of _____________________________
☐ I prefer that someone else decides
☐ I prefer to decide on my own

If help is desired, from whom?
☐ Doctor ☐ Spouse/Partner ☐ Children ☐ Other family member(s)
☐ Other person _____________________________

This decision aid tool is derived in part from recommendations in the American Society of Clinical Oncology Clinical Practice Guideline Update on Adjuvant Endocrine Therapy for Women with Hormone Receptor-Positive Breast Cancer. This decision aid tool is a practice tool based on ASCO practice guidelines and is not intended to substitute for the independent professional judgment of the treating physician. Practice guidelines do not account for individual variation among patients. This tool does not purport to suggest any particular course of medical treatment. Use of the practice guidelines and this decision aid tool are voluntary. The practice guidelines and additional information are available at http://www.asco.org/guidelines/endocrinoadmin. Copyright © 2010 by the American Society of Clinical Oncology. All rights reserved.

Wrapping Your Options section adapted from the Ottawa Personal Decision Guide Copyright O’Connor, Stacey, Jacobsen 2004

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**BENEFITS**

The first set of pictographs, below, show the chances of breast cancer coming back in the same breast in 5 years.

1. Out of 100 women taking tamoxifen for 5 years, 17.4 had breast cancer return.
2. Out of 100 women taking an aromatase inhibitor for 5 years, 16 had breast cancer return.
3. Out of 100 women who took tamoxifen and switched to an aromatase inhibitor, 16.7 had breast cancer return.

1. Tamoxifen
2. Aromatase Inhibitor
3. Tamoxifen then Aromatase Inhibitor

Therefore, the number of women who had breast cancer come back was quite similar with all three treatments. There were small differences favoring the use of an aromatase inhibitor as either first treatment, or after tamoxifen.

This set of pictographs show the chances of getting breast cancer in the other breast within 5 years.

1. Out of 100 women taking tamoxifen for 5 years, about 1 woman (1.4) had a breast cancer in the other breast.
2. Out of 100 women taking an aromatase inhibitor for 5 years, about 1 woman (1.2) had a breast cancer in the other breast.
3. Out of 100 women who took tamoxifen and switched to an aromatase inhibitor, about 1 woman (1.2) had a breast cancer in the other breast.

Therefore, there was no difference in the number of women who had breast cancer return with any of the three treatments.

**RISKS**

Like all medicines, tamoxifen and aromatase inhibitors have side effects. The pictographs below show the chance of having some of the more serious or more common side effects.

**Blood clots (Venous Thromboembolism)**

When blood forms clots, they block blood flow and this can be dangerous. For example, it can lead to a life-threatening lung problem (called pulmonary embolism), heart attack, or stroke. There are medicines and other treatments for blood clots, if you should get a blood clot.

1. Out of 100 women taking tamoxifen for 5 years, about 5 women (4.9) got blood clots.
2. Out of 100 women taking an aromatase inhibitor for 5 years, about 2 women (2.4) got blood clots.
3. Out of 100 women who took tamoxifen and switched to an aromatase inhibitor, about 5 women (4.8) got blood clots.

Therefore, about 2 1/2 fewer women (2.4-2.5) taking an aromatase inhibitor had a blood clot, compared to those taking tamoxifen or tamoxifen followed by an aromatase inhibitor.

**Bone fracture**

After menopause, a woman can lose bone and her bones may be more likely to break. Aromatase inhibitors may slightly increase the chances of a bone break compared to tamoxifen.

In a woman who is postmenopausal, tamoxifen may help prevent osteoporosis (fragile bones).

1. Out of 100 women taking tamoxifen for 5 years, about 7 women (7.3) had a bone fracture.
2. Out of 100 women taking an aromatase inhibitor for 5 years, about 10 women (9.8) had a bone fracture.
3. Out of 100 women who took tamoxifen and switched to an aromatase inhibitor, about 10 women (9.4) had a bone fracture.

Therefore, about 2 to 3 fewer women (2.1-2.5) taking tamoxifen had a bone fracture, compared to those taking an aromatase inhibitor.
WEIGHING YOUR OPTIONS

The following pages are to help you think about what type of adjuvant therapy (for hormone receptor-positive (ER+ and/or PR+) breast cancer) to have after you have talked to your doctor. You may want to do this on your own or with someone else (for example, family, friends, or other caregivers outside of the doctor’s office).

Your treatment options include:
• Taking tamoxifen or
• Taking an aromatase inhibitor or
• Taking tamoxifen first and then changing to an aromatase inhibitor.

The next two pages include three steps:
1. What decision do you need to make?
2. What information and help do you need to make the decision?
3. What are the next steps?

1. What decision do you need to make?

2. What information do you need to make the decision?

   Do you have enough support and advice from other people to make a choice? 

   If not, who do you want to talk with before making your decision?

   Are you choosing your treatment option without pressure from others?

   Do you have enough facts to make a choice?

   If not, what more would you like to know?

   Do you know the benefits and risks of each option?

   If not, what information do you need?

3. In the following space, write down any additional other concerns and/or issues that you think are important to your decision (for example, other health issues, your age, money issues, family, etc.):

4. Plan the next steps

   Consider planning your next steps based on your needs:

   a. If you feel you do not have enough support and/or if you feel pressure from others—you may want to look for other support. Your doctor, hospital, or clinic may be able to refer you to others who could help you find additional support.

   b. If you feel you do not have enough facts about adjuvant endocrine medicines, you may want to get more. For example, you could visit cancer.net (www.cancer.net).

Please use the space below or another page to write any questions or concerns you have: