Health Literacy
Universal Precautions
Toolkit for
Rheumatology
Health Literacy Universal Precautions
Toolkit for Rheumatology

This toolkit is adapted from the Health Literacy Universal Precautions Toolkit developed for primary care practices. Revisions were made and tested with rheumatology clinics.

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About this Toolkit

The *Health Literacy Universal Precautions Toolkit for Rheumatology* is adapted from *Health Literacy Universal Precautions Toolkit* created for primary care practices. It provides step-by-step guidance and tools for assessing your practice and making changes so you connect with patients of all literacy levels.

**Toolkit Key**

Throughout the toolkit we have used a number of icons and symbols to help you quickly identify different tools, documents and resources:

- **Tools within this toolkit**
- **Resources on the Internet**
- **Document created for this toolkit**
- **Videos from the Internet**

*All blue underlined words* are links to other toolkit documents or Internet resources (e.g., Web sites, videos, publications, articles). Click on the words to connect to the link. Many of the graphics are also links to toolkit documents or Internet resources. Click on the graphic to connect to the link.

**Toolkit Design and Contents**

This toolkit is designed to be used by all levels of staff in a practice providing rheumatology and orthopaedic care for adults and/or pediatric patients. (Please note that references to patients also include caregivers and parents.) This toolkit is organized so that its implementation can fit into the busy schedule of a practice. It contains:

- **Overview** This section provides information about health literacy universal precautions and the tools you can use to promote change and improve patient care.
- **Path to Improvement** This document outlines the steps to follow to implement health literacy universal precautions in your practice and contains tools you can use to raise awareness, assess your practice and plan your changes.
- **Tools** The toolkit contains 22 tools to help you address areas that need improvement.
Quick Start Guides

If you want to try a few proven techniques to improve health literacy, we have developed two brief quick start guides to get you started.

1. **Patient Encounter**—The guide to Promote Health Literacy in Your Patient Interactions presents 3 key strategies that may improve your clinical visits with patients.

2. **Practice Encounter**—The guide to Promote Health Literacy Throughout your Practice presents 3 key strategies that may improve a patient’s overall experience with your practice.

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**Quick Start Guide**  
*Promoting Health Literacy in your Patient Encounters*

**Three Things You Can do Right Now:**

1. Encourage Questions
2. Confirm Understanding
3. Confirm Medication Accuracy

**Why does it matter?**

Low health literacy is associated with:
- Worse health outcomes.
- More hospitalizations.
- Greater use of emergency care.
- Poor medication adherence.¹

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**Quick Start Guide**  
*Promoting Health Literacy Throughout Your Practice*

**Three Things You Can do Right Now:**

1. Welcome Your Patients
2. Walk Through Your Practice
3. Listen to Your Phone System

**Why does it matter?**

Low health literacy is associated with:
- Poor use of health care services.
- Worse health outcomes.
- Medication errors.
- More hospitalizations and use of emergency care.²

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Internet Resources and Toolkit Documents

This is a list of all the Internet resources referenced in the toolkit as well as any documents created for the toolkit, such as forms, PowerPoint presentations, and posters.
Overview of Health Literacy
Universal Precautions

Rheumatologists establish long term relationships with their patients for the management of a variety of chronic diseases. This toolkit is designed to help those in rheumatology practices identify and remove many common barriers to communication, care and action. Small changes in your rheumatology practice can improve patients’ experience and their ability to better manage their disease. The toolkit draws from ten years of research findings in health literacy studies.2-6

Medical care is complicated and many people struggle with understanding medications, self care, instructions, and followup plans. The way we organize our practice and communicate with patients can help to minimize confusion and lead to better health outcomes.

“Before reviewing this toolkit, we had never heard the term ‘health literacy.’ As we assessed our practice and reviewed the tools, we realized that the concerns addressed in this toolkit are things we see and struggle with every day. This toolkit made us more aware of the challenges that our patients face and guided us to make meaningful changes throughout our practice.”
-Office manager, rheumatology practice

What is health literacy?

Health literacy is the ability to obtain, process, and understand health information to make informed decisions about health care.

Seeking medical care, taking medications correctly and following prescribed treatments requires that people understand how to access and apply health information. Health literacy involves using literacy as well as other skills (e.g., listening) to perform health-related tasks. Studies in the rheumatology setting from Australia, Scotland and the U.S. have demonstrated that a significant number of patients have low literacy.2, 7-12
Limited health literacy is associated with:

- Medication errors.
- Increased health care costs.
- Inadequate knowledge and care for chronic health conditions.\(^{13,14}\)

What are universal precautions?

Universal precautions refer to taking specific actions that minimize risk for everyone when it is unclear which patients may be affected.

This toolkit offers practices a means to structure their services and their patient interactions to minimize the risk that any one of their patients will not understand the health information they are given, thus allowing patients to make informed decisions about their health care.

Why take universal precautions when it comes to health literacy?

Experts recommend assuming that everyone may have difficulty understanding and creating a shame free environment where patients of all literacy levels can thrive and everyone feels comfortable and welcomed. In the case of health literacy universal precautions, rheumatology practices should ensure that systems are in place to promote better understanding for all patients, not just those you think need extra assistance.
Does paying attention to health literacy work?

A number of studies have shown that health literacy practices improve health outcomes.\textsuperscript{13, 14} Below are two research studies, as well as a case study from a practice that has used this toolkit, showing how health literacy practices can improve specific health behaviors and outcomes.

Research Studies

- **Inflammatory Arthritis Management:** This study shows that an intervention, designed to reduce low literacy barriers in inflammatory arthritis management, improved management in the intervention group.\textsuperscript{6}

- **Depression Management:** This study shows that when patients who were low literate and depressed were referred to literacy programs, their depression symptoms significantly improved in comparison to the control group.\textsuperscript{16}

Case Study

**Medication Adherence:** During our toolkit testing rheumatologists confirmed that medication errors occur more often with therapies not on a typical dosing schedule such as methotrexate and prednisone. By confirming medication adherence using Tool 9: Brown Bag Medication Review and confirming understanding using Tool 6: The Teach-back Method and Medication Dosing Form, we found that practice staff identified and corrected misunderstandings, which improved patient safety and satisfaction.

How do we address health literacy?

To obtain optimal health outcomes, we have identified four key areas of change that are important for promoting health literacy in your practice:

1. Improve spoken communication.
2. Improve written communication.
3. Improve self-management and empowerment.
4. Improve supportive systems.

We include tools to address topics in each area. All areas are important and should be addressed over time as you make changes in your practice. In addition, we have included 4 tools to help you get started, and suggest you follow the Path to Improvement to guide the process.
Key Change 1: Improve Spoken Communication

Studies indicate patients understand and retain about fifty percent of the information discussed by their physician\textsuperscript{17,18} and often leave the visit misunderstanding what they are supposed to do to manage their condition.\textsuperscript{19} This can have an enormous impact on patient safety and adherence. This toolkit includes seven tools to address and improve spoken communication.

Tools to Improve Spoken Communication

Tool 5: Tips for Communicating Clearly
Tool 6: The Teach-Back Method
Tool 7: Followup with Patients
Tool 8: Telephone Considerations
Tool 9: Brown Bag Medication Review
Tool 10: How to Address Language Differences
Tool 11: Culture and Other Considerations

Key Change 2: Improve Written Communication

Health care providers rely heavily on print materials to communicate with patients. A number of studies have shown that those with limited literacy skills have difficulty understanding written information, including medication dosage instructions and warning labels,\textsuperscript{20,21} discharge instructions,\textsuperscript{22} consent forms for treatment and participation in research studies,\textsuperscript{23} and basic health information about diseases, nutrition, prevention, and health services.\textsuperscript{24} These factors contribute to patient outcomes and practice liability.

Tools to Improve Written Communication

Tool 12: Design Easy-to-Read Forms and Practice Materials
Tool 13: Assess and Use Health Education Material Effectively
Tool 14: Welcome Patients: Helpful Attitudes, Signs and More

Mr. Bowman
Production Inspector
(4th grade reading level)

“I had an abscess in my ear. I had to fill out forms that I couldn’t fill out, so I came back home. I ended up having to go to the emergency room that night because it burst.”

-Excerpt from AMA health literacy video\textsuperscript{15}
Key Change 3: Improve Self-Management and Empowerment

An important part of patient-centered medical care is enabling patients to share responsibility for their health and health care.

Limited literacy has been associated with poor adherence to medications and self-care instructions and with poorer understanding of health information. It is, therefore, not surprising that in a study of Medicare patients, those with low health literacy had worse physical and mental health and significantly higher rates of hypertension, diabetes, heart failure and arthritis. 25

Tools to Improve Self-Management and Empowerment

Tool 15: Encourage Questions

Tool 16: Make Action Plans

Tool 17: Improve Medication Adherence and Accuracy

Tool 18: Get Patient Feedback

Key Change 4: Improve Supportive Systems

All patients need support outside the rheumatology setting to make healthy choices and to adhere to treatment plans, and patients with limited literacy often need more assistance. Rheumatologists and other clinicians, nurses, and practice staff can link patients to community organizations and government agencies to support them in achieving better health.

Tools to Improve Supportive Systems

Tool 19: Link Patients to Non-Medical Support

Tool 20: Medication Resources

Tool 21: Use Health and Literacy Resources in the Community

Tool 22: Communicating Care with Other Physicians
References


Path to Improvement

Follow these steps to mobilize your practice and prepare to change the way you relate to patients.

Step ① Watch a Health Literacy Video.
ACP Health Literacy Video

Step ② Form Your Team.
Tool 1: Form a Team

Step ③ Raise Staff Awareness.
Tool 2: Raise Awareness

Step ④ Assess Your Practice.
Tool 3: Assess Your Practice

Step ⑤ Choose a Tool.
List of Tools

Step ⑥ Plan Your Changes.
Tool 4: Plan your Changes
Form a Team

Overview
Initiating and sustaining health literacy universal precautions in a practice requires strong, effective leadership and a clear strategy. To start this process, a diverse and dedicated team should be formed to lead the practice through these changes. The most effective teams include at least three categories of members: senior leadership, clinical and administrative staff, patients and caregivers. The goal of this team will be to use the tools from the toolkit while working with all facets of the practice to plan, implement and monitor changes that address health literacy in your practice.

Actions

Identify members.
• Chair or Champion
• Employees from each department:
  ◦ Clinicians
  ◦ Nurses
  ◦ Practice manager
  ◦ Front desk/receptionist
  ◦ Lab technicians
• Senior leadership (full or ad hoc)
• Patient and/or caregiver of a patient as a full fledged or ad hoc member.

Establish your team.
• Size of team should be no more than 8 members.
• Meetings should be scheduled regularly, monthly if possible.

Bring members together.
• Introduce them to health literacy by watching the health literacy video (6 minutes).
• Introduce them to this toolkit.

Extra Resources about forming a team are available at: The Institute for Healthcare Improvement.
Raise Awareness

Overview

Limited health literacy is a big concern and affects 77 million Americans.\(^1\) Thus, it likely affects your patients and your practice. Implementing changes to promote health literacy universal precautions in your practice requires that all of your staff are aware of the problem, know how it affects your patients and your practice, and are consistently working to improve communication. This tool contains resources that will increase understanding and awareness, help to engage and motivate your staff to move forward and make changes to improve care.

Actions

Resources for raising awareness.

- **Video:**
  - ACP Health Literacy Video (6 minutes)
- **PowerPoint presentation:**
  - Health Literacy: Barriers and Strategies: This presentation includes 26 slides with speaker’s notes that can be delivered in 30-40 minutes to a group or as a self-study program.

Strategies for raising awareness.

- **Session size:** Groups sessions are optimal but individual self-study sessions are also effective.
- **Group session strategies:**
  - Use this Questions for Discussion and Moderator’s Guide.
- **Include health literacy on the agenda.**
  - **Staff meetings:** Work on or revisit a tool in the toolkit each month.
  - **Orientation:** Have a plan to train new employees about health literacy skills; show each new employee the 6 minute video.

For Extra Resources such as self-study programs for CME credits, other videos, manuals and other tools, click here.

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\(^1\) America’s Health Literacy: Why We Need Accessible Health Information. US Department of Health and Human Services http://www.health.gov/communication/literacy/issuebrief/
Assess Your Practice

Overview

The Health Literacy Assessment Questions will help you assess how your practice is performing in several key areas that affect patient understanding and satisfaction. Completing this assessment process may help to identify opportunities to improve patient care by raising awareness and pointing you to a tool in the toolkit that will help address the issues.

Actions

Print copies of the Health Literacy Assessment Questions.

Hand out to several staff.
• Ask them to complete the survey (10-15 minutes to complete).
• Aim to include at least one person from each area of your practice.
• Have one or more people do a “practice walk-through” whereby a team member acts like a patient and experiences the practice from the patient’s perspective while answering the survey questions.

Collect, tally and discuss the results.
• If you have several surveys you may want to use this tally sheet to help you compile the results.
• Sit down with your team and talk about the results.

Choose a tool.
• Choose a tool you would like to work on. The choice may be based on the results from your assessment or from specific aims that you have developed for your practice.

“The assessment increased our attention to areas not previously identified as concerns, like the signs in our practice. We just don’t think of those things every day.”

-Nurse, rural clinic
Plan Your Changes

Overview

After choosing a tool to implement, you will need a plan to get started for creating the change. The Institute for Healthcare Improvement offers a model to help guide practice change. Start with a very small step. For example, when implementing teach-back, start with one nurse or doctor and have them try it with one patient who is prescribed a new medication and then evaluate. The team can then study the results and quickly make changes to refine the implementation. Once the implementation process has been refined and success has been reached on a small scale, the implementation can be slowly expanded to the entire practice.

When planning and testing change, remember that changes should initially involve:

- A single step of the entire tool implementation.
- A small segment of the practice (e.g., 1 or 2 staff).
- A short duration (e.g., 1-2 hours or maybe 1 day).

Actions

Use the Plan-Do-Study-Act (PDSA) worksheets.

- **Plan:** State the tasks in your small, short test and predict what you think will happen and what measures you are going to use to determine if it happened.
- **Do:** Do the tasks and observe and record what happened.
- **Study:** Study the results against what you predicted would happen.
- **Act:** Refine the process to improve your results for the next PDSA.
- To better understand this process, look at these Examples.

Expand implementation.

- Once a plan has been tested and refined, start to spread the change to the rest of the practice.
- A big part of success will be having those involved in the initial steps of change to talk about their experience and its benefit.
Tips for Communicating Clearly

Overview

Clear oral communication strategies help patients feel more involved in their health care and increase their likelihood of accepting recommendations. When speaking with patients it helps to keep these strategies in mind and practice them routinely.

Actions

Key communication strategies.

- Have a warm greeting.
- Make eye contact.
- Speak slowly and clearly.
- Limit the content to 3-5 key points.
- Repeat key points.
- Use plain, non-medical language.
  Plain language guides may help.
- Use graphics such as skeletons and pictures.
- Encourage patient participation by asking “What questions do you have?”
  Tool 15: Encourage Questions offers more ideas.
- Confirm understanding. Ask patients to explain back a concept or instruction in their own words. Tool 6: The Teach-Back Method explains how.
Remembering and practicing these strategies.

- To help staff assess their communication skills, ask them to fill out the Communication Self-assessment form after a few patient encounters.

- Review these strategies with staff and hang this poster in a non-patient area (i.e., kitchen) as a reminder.

"I had a very complicated visit with a patient who was taking Fosamax. She had been referred to us to see if she could come off it. We talked for a long time about the process of coming off and the risks and benefits. As I was concluding the visit I used teach-back to confirm understanding and quickly realized that I had given her way too much information. I then briefly reviewed the key points she needed to know. This helped me to learn that as a physician I have to get down in the weeds to figure things out but that patients do not need to know all that!"

-Rheumatologist, rural clinic
The Teach-Back Method

Overview

Teach-back is an extremely valuable skill for all staff in a medical practice. Teach-back is asking the patient to state in their own words what they need to know or do in a non-shaming way.

Using teach-back may help you:
1. Improve patient understanding and compliance.
2. Decrease call backs and cancelled appointments.
3. Improve patient satisfaction and outcomes.

Actions

How do you do teach-back?
- After a plan or a concept is discussed, teach-back is done by asking the patient to explain the information back to you in their own words.

Suggested approaches to solicit teach-back.
- “I have noticed that many people have trouble remembering how to take their methotrexate. Can you tell me how you are going to take it?”
- “Tell me what you going to do when you get home?”
- “What are you going to tell your family when you get home about what we discussed today?”

Tips for using teach-back.
- It is not a test of the patient. They are supposed to feel consulted, not insulted.
- Clarify if patients cannot remember. Explain it using a different method and ask them to teach it back again.
- Watch a video to demonstrate the use of teach-back.

Studies have shown that 40-80 percent of the medical information patients receive is forgotten immediately and nearly half of the information retained is incorrect.
The Teach-Back Method

- **As with all change, start small.** Try teach-back on only a few patients until you are comfortable with your approach.

- **Use this self-evaluation tracking log** after each encounter where teach-back was used to help you reflect on the process and the outcome.

- **Use it consistently.** Don’t assume that somebody understands until you confirm it!

**Use handouts with teach-back.**

- **Write down instructions** so patients don't have to remember them. This [Medication Dosing Form](#) is easy to fill out and easy for patients to understand, especially when prescribing methotrexate and prednisone.

**Extra resources** are available such as a teach-back PowerPoint presentation and other teach-back videos.

“I saw a fairly young client who had been prescribed methotrexate. When she came in for a followup visit she was still complaining of pain, and I asked her how she was taking her methotrexate. She explained that she had been taking 1 methotrexate each day, and when I looked at the chart, she was prescribed 6 methotrexate on one day per week. I was surprised that she had misunderstood the instructions because she was young, didn’t ask questions and appeared to understand the information. I learned that you can’t tell by looking and that teach-back needs to be done with everyone, even if you think they have understood the instructions.”

-Nurse, rheumatology practice

**References**

Followup with Patients

Overview

Followup is the act of making contact with a patient or caregiver at a later, specified date to check on their progress since their last appointment. Appropriate followup can identify misunderstandings, answer questions, or provide further opportunity to make an assessment and adjust treatment. In addition, it helps to promote a good working relationship between you and the patient.

Actions

Ask patients to record information.
- Followup tracking forms like this one for a patient with RA, are something a patient can use to report their progress between visits via phone or mail.

Ways followup can be done:
- Phone: Talk with the patient on the phone.
- Email, text or mail can be used by the office or the patient.
- An automated calling system can collect information from patients.
- A visit can be scheduled.

Initiating and tracking followup:
- Systems for tracking followup can be established through the electronic medical record or by using a computer based calendar (MS Outlook).

Extra resources regarding email considerations and automated calling systems can be found here.

“I did a small test of change regarding followup. For a week I planned to have my nurse call patients who had just received a new diagnosis of RA. We followed up with their medication administration and exercise regimen. We found some patients who needed clarification on their medicines, but the real impact of this was the relationship that was formed in those phone calls. Patients really appreciated the extra contact.”

-Rheumatologist, urban practice
Telephone Considerations

Overview

Telephone contact plays an important role in health care, and the efficiency of a telephone system and telephone contact will shape a patient’s impression of your practice. Efficient and courteous call management will benefit your patients and may save your practice time and money. It is important to consider health literacy when assessing your telephone communications.

Actions

How is your telephone system?

- Call your practice as if you were a patient (during business hours and after hours).
- Ask your patients about your system.
  - Is the menu easy to understand? (see example menu).
    - No more than 5 menu choices, such as: (1) speak to a person directly; (2) repeat the menu; (3) hear a menu in a specific language; (4) direction for medical emergencies; (5) dial “0” for operator.
- Is the tone a friendly, conversational voice that uses plain language?
- A toll-free number so patients can call you without a charge.

How is your telephone etiquette?

- Encourage questions by asking, “What questions do you have?”
- Teach-back. For example, “I know some people have trouble remembering. So that I know that I explained it right, tell me what you are going to bring to your next appointment?”
- Scripts for frequently asked questions, such as directions to your office and hours of operation.
Educate your patients.

- **Talk with patients** during their visit or at check-out. Tell patients exactly how to get to services they need (e.g., “Dial our main number and press 3 to leave a message for my nurse”).
- **Brochures**: Create a brochure that explains the practice and its phone system.
- **Posters**: Put up posters in the waiting room.
- **After hours answering systems** are sometimes different than business hours and can require an explanation.

For additional information refer to “How Does Your Practice Sound on the Phone?”.
Brown Bag Medication Review

Overview

The “Brown Bag Review” of medications is a common practice that encourages patients to bring all of their medicines and supplements to their visit for review and assessment. Performing a medication review with the patient and their pill bottles provides the opportunity to discuss not only WHAT medications they are taking, but also HOW they are taking them. This process can help to identify medication errors and misunderstandings that otherwise might have been overlooked. It also provides an opportunity to educate the patient and answer questions regarding their medicines. Medication reviews can be especially helpful in a rheumatology practice that often prescribes medicines that are not taken on a typical dosing schedule.

Testimonials from Practices:
- “Out of 10-15 brown bag reviews, only 2 were accurate.”
- “Out of 5 brown bag reviews, we found 3 that had duplicate medicine bottles resulting in double dosing and 1 where discontinued medicine was still being taken.”

Actions

Review Medicines.
- **Review** with the patient each medicine they are taking by:
  - **Set out all medicine bottles:** Patients need to bring all of their medicine bottles to the appointment (prescription pills and creams, over-the-counter medicines, herbal medicines, vitamins and supplements).
  - **Ask** the patient with each medicine in hand:
    - “When do you take this medicine?”
    - “How do you take this medicine?”
    - “What do you take this medicine for?”
  - **Reviewing all vs. some of the medicines:** It may be necessary for a sub-specialty to review only the medicines they prescribe unless the patient rarely sees their primary care physician.
**Brown Bag Medication Review**

**Tool 9**

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**Tips for successful brown bag reviews.**

- **Set out medicines:** Have the nurse set out the medications at the beginning of the visit.
- **Offer praise** to the patient for bringing medications.
  - Note: If a patient brings in their medicines and they are not reviewed, the patient may not bother to bring them in again.
- **Helpful questions to ask:**
  - “Are you taking any new medicine since our last visit?”
  - “Have you stopped taking any medicines since our last visit?”
- **Provide a medicine schedule** by using mymedschedule.com. 
- **Schedule refills** at the same time.

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**Remind patients to bring in their medicines.**

- The most successful strategy for getting patients to bring their medications to each appointment is to conduct a full-scale campaign. Everyone in the practice stresses its importance and many different tactics are employed, such as reminding patients:
  - On the appointment card.
  - During the appointment reminder call.
  - On a personal call from the physician or the practice staff.
  - During the visit.
  - On posters displayed throughout the practice.
  - On a bulletin board: Display a bulletin board with anonymous case studies and persuasive reasons for bringing in their medicines.
  - By providing a carrier such as a bag with the practice name on it.
  - By emphasizing the benefits (i.e., reduced medicines, review refills).

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Research currently supports that patients with limited literacy have poorer skills when managing their medications. Therefore, it can be very productive to ask patients how they are taking each of their medicines.


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What do most practices do?

- **Reconcile:** Many practices will attempt to reconcile the medicines a patient is taking with what is listed in the medical record. This is sometimes done by relying on:
  - Patient’s memory.
  - Patient’s list of medicines.
  - Patient’s pill bottles.

Unfortunately these methods are not as accurate as a brown bag review (see below):

<table>
<thead>
<tr>
<th>Less</th>
<th>More</th>
</tr>
</thead>
<tbody>
<tr>
<td>Through patient memory</td>
<td>Through a patient list</td>
</tr>
<tr>
<td>Using patient medicine bottles</td>
<td>Review of medicines over the phone</td>
</tr>
<tr>
<td>Review of only medicines prescribed by practice</td>
<td>Review of all medicines</td>
</tr>
</tbody>
</table>

### Resources

- The American Medical Association manual **“Health Literacy and Patient Safety: Help Patients Understand”** offers information on medication reviews.

- [Brown Bag Toolkit](#) is a toolkit from the Ohio Patient Safety Institute that contains information for practices with pharmacies to plan a brown bag event.
How to Address Language Differences

Overview

Patients who speak English as a second language or who are deaf or hard of hearing often do not get the health information they need. Addressing language differences is an important part of addressing health literacy universal precautions and is also a requirement by law. As part of the Civil Rights Act of 1964 and subsequent Federal and State laws and policies, a practice participating in Medicare or Medicaid is legally required to provide equal access to services for patients who do not speak or understand English well.

Actions

Welcome and assess language preference.

- Display “I Speak” cards and Interpreter Services Poster in the lobby to convey your willingness to accommodate other languages.
- Hand the “I Speak” cards to non-English speaking patients to determine their language.
- Ask patients what language they prefer to speak in and if they would like an interpreter.

Acceptable language assistance services.

- On-site trained interpreters (see extra resources for interpreter companies).
- Telephone or video medical interpreter services.
- Bilingual clinicians and staff trained as interpreters.

Unacceptable language assistance services.

- Untrained staff: Using untrained staff to interpret may lead to clinically significant medical errors.
- Family and friends: Using family or friends poses a problem with patient privacy. In addition, family may impose their view of the patient and their health.

Minor children should never be used as interpreters. Using minor children to interpret puts the child in a very vulnerable position and puts the practice at risk for liability if something were to go wrong. Patients may be less likely to discuss more personal health topics when using children as interpreters.
Translating written material.
- What to translate:
  - Practice forms, letters, and signage.
  - Health education material (see extra resources for websites containing rheumatology and orthopaedic health education material in other languages).
- How to translate:
  - Direct, word-for-word translations do not always work because nuances of culture are thereby ignored.
  - Apply plain language guidelines.

Other things to think about.
- Work with family interpreters:
  - Patients may insist that staff communicate with bilingual family or friends and that request should be respected, but a trained interpreter should be in the room to assure that the information is accurately relayed.
- Organize language services:
  - For small populations of diverse patients, consider scheduling appointments and having call-in hours on specific days when appropriate interpretation services are available (e.g., Latino clinic, Thursdays 1-5PM).
- How to pay for language assistance services:
  - Investigate whether Medicaid and other insurance plans will pay for interpreters or have negotiated discounts (e.g., Medicaid reimbursement is available in 13 states).
  - Coordinate with other practices to develop contracts with language assistance vendors.
  - Contact community organizations for possible volunteer trained interpreters.
  - Consider separate flexible funding sources such as grants or fundraisers to help subsidize these services.
  - Consider partnering with local hospitals and sharing language services.

Not appropriately addressing language differences can result in medical errors, and violations of health privacy, and can put the practice at increased risk for lawsuits.
Culture and Other Considerations

Overview

Religion, culture, and ethnic customs can impact the health of patients and how they take care of themselves. But without proper training, a clinician can sometimes deliver medical advice without fully understanding how health beliefs and cultural practices may influence how that advice is received. Learning about patients’ ethnic backgrounds, cultures and religions should not lead to stereotyping or assumptions, but should help clinicians deliver good patient-centered care.

**Things that can effect the healthcare of patients:**

- **Health beliefs and customs:** e.g., Some patients treat empacho (indigestion) by pinching the skin.
- **Ethnic customs:** e.g., the roles of women and men in society.
- **Religious beliefs:** e.g., contraception or blood transfusions.
- **Dietary customs:** e.g., fasting or ethnic foods and cooking.
- **Interpersonal customs:** e.g., eye contact or physical touch.

Actions

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**Learn from patients.**

- **Ask patients** about their health beliefs and customs.
  - “I am not familiar with your culture and beliefs. Can you teach me what I might need to know so I can better treat you?”
  - “What do you call your illness? What do you think caused your illness? How do you think it should be treated?”
  - “Do any traditional healers advise you about your health?”

- **Avoid stereotyping.** Understand that each person is an individual and may or may not take on certain cultural beliefs or practices.

**Cross-cultural education courses and websites.**

- **Continuing education:** The Department of Health and Human Services offers an on-line course to educate staff. See [extra resources](#) for more information.
- **Websites and videos:** See [extra resources](#) for some websites that offer information on specific ethnic and cultural groups.
Design Easy-to-Read Forms and Practice Materials

Overview

Patients are often asked to fill out forms or read written material. But, are practices sure that patients can read this information? Practices that are conscientious about developing written material that is easier to read may increase the chance that patients will use it correctly, thereby saving staff time and possibly improving patient outcomes.

Considerations for developing material.

- **Organization:**
  - Use bullets and headings to group related information.
  - Limit information included so essential items are stressed.
- **Writing Style:**
  - Include little or no technical jargon.
- **Appearance:**
  - Page is uncluttered, and includes ample white space.
  - Font size 12 point or larger.
- **Appeal:**
  - Have patients read material and give you feedback.
When designing forms.

- Use check boxes as much as possible.
- Include ‘don’t know’ or ‘not sure’ options to give patients a choice when they are unsure.
- Bold key words.
- Use medical words first with a common word explanation in parentheses, for example: ‘arthritis (joint pain)’.

See extra resources for forms that practices can adapt and use.

Train staff to evaluate and create written material.

Have one person take responsibility for learning how to design simple, easy-to-read written materials that will be appropriate for everyone, including people with limited health literacy.

Help patients with forms and written material.

- The best designed form still might not be enough, so have a system in place to offer ALL patients help with forms.

References:
Assess and Use Health Education Material Effectively

Overview

The effective use of well-designed educational material can help your patients manage their health. If the material you use contains too much information or medical words that are difficult to understand, it will likely be thrown out. In addition, simply handing your patient a pamphlet is not enough to promote understanding or behavior change. The goal is to select appropriate well-designed material that you review with the patient and follow up on at subsequent visits.

Actions

How to use health education handouts.

- Review/read the handout with the patient at the visit.
  - Circle or highlight important points as you talk about them.
  - Personalize the materials by adding the patient’s name, medicines, or specific care instructions.
- Use teach-back to confirm understanding and draw the patient's attention to the handout: Refer to Tool 6: The Teach-Back Method.
- Repeat: Refer to the material again in follow up phone calls and appointments.

Choose appropriate material for your patient.

- A newly-diagnosed patient may prefer more general, brief information.
- A patient who has adjusted to their diagnosis may then desire more comprehensive, disease management information.
Considerations for choosing material.

- **Organization:**
  - Use bullets and headings to group related information.
  - Limit information included so essential items are stressed.
- **Writing Style:**
  - Include little or no technical jargon.
- **Appearance:**
  - Page is uncluttered, and includes ample white space.
  - Font size 12 point or larger.
  - Graphics are simple and reinforce text.
- **Appeal:**
  - Have patients read material and give you feedback.

Brief health education material.

**Health Tips, What you can do—Fibromyalgia**

**Health Focus: Osteoarthritis**
Lupus.

National Institute of Arthritis and Musculoskeletal and Skin Diseases.

(For a list of ‘easy to read’ handouts, click here and choose ‘easy-to-read’ on the pull-down menu for ‘Search by Category’).

Rheumatoid Arthritis.

The Patient Education Institute, Inc. through Medline Plus.

Comprehensive disease management material.

Bone Health and Osteoporosis, what it means for you, which contains extractable pages on calcium and Vitamin D and a calcium counter. The 2004 Surgeon General’s Report.

Rheumatoid Arthritis Medicines, A Guide for Adults.

Effective Health Care, Agency for Healthcare Research and Quality (AHRQ).
Other forms of health education material.

- **Videos** with information in simple terms, such as this [RA video](#) or [this video](#) from [Medline plus](#) can be played in the exam room if it has an Internet accessible computer/monitor. Videos can then be discussed during the visit.

- **Websites** offer access to a variety of health information. When referring patients to a Website, make sure it has:
  - Content that is accurate and written using simple, plain language.
  - An A-Z search function.
  - A limited amount of information on each page.
  - Large print size.
  - Information in groups with simple stand-alone headings and in three lines or less.
  - Simple navigation tools such as a “Previous” and “Next” button. An example of a well-designed Website is [healthfinder.gov/prevention](http://healthfinder.gov/prevention).
  - Educate patients about seeking health information on the Internet.
  - Watch this [video](#) about finding health information on the Internet. Consider showing it to patients in your waiting or exam rooms.
Welcome Patients: Helpful Attitude, Signs, and More

Overview

While some patients may feel anxious or intimidated when locating and entering a health care practice, this may be more problematic for patients who are new to your practice and for those with limited literacy. Creating a friendly environment that is easy to navigate may help your patients feel a sense of welcome and encourage their participation in the health care experience.

Actions

Evaluate your practice.

- **Perform a walk-through:** Have someone unfamiliar with your practice walk through as if they were a patient and offer feedback. See [extra resources](#) for more information.

Front desk.

- **A welcome atmosphere:** Front desk staff should be helpful and cheerful.
- **Offer everyone assistance with forms.**
- **Assess language preference** by displaying “I Speak” cards.
- **Offer a practice brochure** that highlights elements of your practice such as:
  - Contact information, including after-hours and emergency.
  - Services provided.
  - Address and directions to your office.
  - What to bring to appointments.

Waiting room.

- **Design bulletin boards** that are easy-to-read, informative and updated regularly.
- **Display photos of staff:** Use current pictures of staff with their title or role.
- **Television** that plays easy-to-understand health-related information.
Confirm that signs throughout your practice:

- Are easy to read and visible.
- Identify locations:
  - From the front of the building to your practice entrance.
  - Waiting room/check-in/check-out.
  - Billing department.
  - Laboratory and/or infusion area.
  - Nursing area or station.
  - Exam rooms.
  - Exits.
  - Restrooms.
  - Pharmacy.
- Identify processes or procedures.
- Use simple, common words.
- Use graphics when appropriate. Hablamos Juntos ("We Speak Together") is an initiative that has created graphic symbols for common medical services, some which may be applicable in the practice setting.
- Use color coding, lines, or symbols.
- Effective, based on patient feedback.
- Are in a language that your patients understand.

Please review these extra resources for more information about actions you can take at the front desk.
Encourage Questions

Overview
An essential part of promoting patient safety and achieving good health outcomes is helping patients to be an active member of their health care team. However, patients can sometimes be embarrassed to ask questions, fearing that they will appear foolish. Creating a shame-free environment that encourages patients to ask questions and gives them the confidence to take ownership of their health is crucial in this effort.

Actions

Encourage patients to ask questions.
- Close your encounter with, “What questions do you have?” instead of, “Do you have any questions?”
  ◊ This creates the expectation that they should ask questions.
  ◊ Patients may pause after hearing this to consider things they may want to ask.
- Other ways to elicit questions:
  ◊ “We discussed a lot of information. What can we review again?”
  ◊ “Rheumatoid arthritis is a new diagnosis for you, and I expect that you have some questions. What would you like to know more about?”

Case Example
To promote patient questions, one practice chose to ask staff to focus on asking the question, “What questions do you have?” during clinic visits. Practice management sent an email to staff discussing this approach and asking them to try it for one week. Email reminders were sent daily and a few notices were posted in staff areas around the office.

At the next staff meeting people started talking about ‘the new question.’ Everyone was very surprised at how well the patients responded. When asked the question, it seemed like they would pause and actually think about what they did not understand or wanted to know, and then ask something. Staff were very pleased at how such a small change in one question could substantially change their patient interaction.
Promote patient participation.

- **Ask Me 3** This program, designed by the National Patient Safety Foundation, encourages patients to know three things before leaving the encounter:
  1. What is my main problem?
  2. What do I need to do?
  3. Why is it important for me to do this?

- **Questions Are the Answer** This campaign, created by AHRQ, encourages patients to get more involved in their health care. It contains videos, handouts, and an online question builder.


Other considerations.

- Start your encounter by asking “What is your goal for this visit?”
- Your body language can help patients feel comfortable to ask questions.
  - Be attentive: Be conscious about presenting yourself as having time and wanting to listen to their questions. Try not to interrupt.
  - Sit vs. stand: Sit at the same level as your patient.
  - Look and listen: Look at patients when talking and listening, rather than looking at the chart or computer.

- Advise all staff to invite questions.
- Encourage patients to ask questions of other physicians, pharmacists, etc.
- Encourage patients to bring a relative or friend to the next visit to help them remember information and include these people in the conversation.
- Managing questions: If patients have many questions, prioritize them and defer some to a future visit.
Make Action Plans

Overview
An action plan outlines small steps a patient can take to attain a larger health goal such as quitting smoking or losing weight. An action plan is created by the patient and the provider and should identify one or more small steps that the patient believes are attainable. Followup on an action plan should show the patient their progress toward their larger goal and motivate them to continue setting goals.

Actions

Watch a video to learn how to set up an action plan.
- This 6-minute American College of Physicians Foundation Video shows three examples of patients and providers creating an action plan.

Steps to an action plan.
- **Patient created:** The patient must determine the goal with the provider’s guidance.
- **Small and realistic steps** should be set that can be re-evaluated over a short time period (e.g., 1 week).
- **One step at a time:** Ask the patient to pick one specific step that they are likely to implement.
- **Fill out the form:** Outline what, how much, when, and how often they will do the step.
- **Assess confidence:** Assess the patient’s confidence by asking:
  - “How sure or confident are you that you can follow this action plan?”
  - A patient should feel confident, stating a 7 or higher on a scale of 0-10.
  - If they are not, revise the goal so the patient feels confident they can succeed.
  - Ask the patient, “What might stop you from following this action plan?”
  - Help the patient problem solve about how to overcome barriers.
- **Make a copy of the action plan** for the patient and file it in the patient’s chart.
Action plan forms

Followup.
- By phone or at an upcoming visit: It lets the patient know that you are interested in them.
- Redefine the goal if the goal was not met.
- Set another goal if this one was met.
- Track progress over time.

Help providers to remember to use an action plan.
- Make action plan forms accessible.
- Talk about action plans in your staff meetings.

Developed by authors of this toolkit.
Developed by UCSF Family Medicine (Spanish, English and Chinese).
Developed by Home Health Quality Improvement.
Improve Medication Adherence and Accuracy

Overview

Taking medication correctly is often an important part of managing illness and symptoms. One specific challenge for rheumatology patients is medications with an atypical dosing schedule such as Methotrexate. Therefore, understanding how your patients are managing their medicines and offering help to set up a system may reduce errors and increase patient satisfaction and compliance, thus improving health outcomes.

Research shows that patients with rheumatic disease miss medicines, have more difficulty taking a large number of medicines and forget to take their medicines if they have to take them at several different times during a day.

Actions

Ask patients how they remember to take their medicines.
- “Do you have a way to remember to take your medicines?”
- “Everyone forgets to take their medicine from time to time. When was the last time you forgot to take any of your medicine?”

Tools to help patients manage their medications.
- MyMedSchedule.com and MedActionPlan.com are free services on the Internet that provide an easy method to offer patients:
  - A pill list with pictures of the pill and times they take them (wallet size and large print).
  - A handout of a list of their medicines and a simple explanation of what each
A health recording form for patients to document things like daily blood pressure, weight, blood sugars, etc.

Email or text reminders to:
  • ‘Take your medicine.’
  • ‘Refill your prescriptions.’

This program is HIPPA compliant.

Medication dosing form You can print this form right now and use to help patients understand when they are to take their medicines, especially medicines on an atypical dosing schedule like methotrexate or prednisone.

Pill boxes: Offer to provide and fill a pill box to help patients manage their medicines, or consult with your local home health agency for the service.

Family members: Solicit help from family members to help remind patients or to set up and fill pill boxes.

Advertise the service.
  • Display this Medication Aid Poster and discuss it with your patients.

Other considerations.
  • When you write a prescription, write precise instructions for taking the medicine. For example, “Take 1 pill in the morning and 1 pill at bedtime.”
  • Consider organizing patient refills so they occur at the same time of the month.
  • When switching from a brand name to a generic medicine, tell your patients that the color, shape, and size of the pill may change and provide a new medicine schedule.

Reference
Get Patient Feedback

Overview

Patients are in the best position to judge if a medical office poses health literacy challenges. Frequently, practices are unaware of the level of difficulty patients encounter in completing routine forms and navigating the health care system. Obtaining patient feedback can provide very valuable information about your systems and areas in need of improvement.

Actions

Select patients to provide feedback.
- Obtain feedback from a group of patients that is representative of your practice.

Use a survey.
- **CAHPS® Clinician & Group Survey—Item Set for Addressing Health Literacy** consists of 29 items that aim to assess the performance of practices regarding health literacy issues. These items are a supplement to the CAHPS® Clinician & Group Survey.
- **About the CAHPS® Item Set for Addressing Health Literacy** gives you an overview of the questions.
- **Methods of administration:** Because patients with limited literacy are unlikely to respond to a mail survey, we suggest that you administer a survey by phone, or in person or offer a phone followup to a mail survey.
- We have also included a **Sample Cover Letter** that can be mailed to patients with the survey.
Patient shadowing.
- Shadow several patients over the course of a week.
  ◦ Stay with the patient throughout the entire time they are in your clinic.
  ◦ Discuss their visit when they are done. Ask about communication, friendliness, navigation, etc.
  ◦ *Navigating the Health Care System: A Health Literacy Perspective Through the Eyes of Patients* is a PowerPoint presentation on shadowing and the walkthrough experience.

Patient walkthrough.
- Have a person who is unfamiliar with your practice walk through it and give you feedback on the feel and navigation.
- For more information, see pages 99-115 of *The Health Literacy Environment of Hospitals and Health Care Centers*.

Patient feedback of written material.
- Ask a variety of patients at the end of their visit or while they are waiting to evaluate one or two of your forms or other written material (also evaluate material that you did not develop). Think about asking them the following questions:
  ◦ Is the information clear and easy to understand?
  ◦ Is it confusing in any way?
  ◦ Are any parts/words hard to read or understand?
  ◦ Is there anything offensive?
  ◦ What is helpful and what isn’t?
- *In Other Words…Can They Understand? Testing Patient Education Materials With Intended Readers* has some great tips on using patients to test materials.
Link Patients to Non-Medical Support

Overview

Limited literacy not only affects the patient’s health care but all aspects of their life. When practices offer help with things like understanding health benefits, transportation to appointments, obtaining medicines and housing, patients may have more time, energy and ability to attend to their health. This process not only requires knowledge of the available resources, but also following through with any referral to ensure that the connection was actually made.

Actions

Assess patients’ needs and support systems.
- Ask patients about things in their life that may be affecting their ability to take care of their health. Take some ownership to help them overcome these challenges.
- Ask about and involve the patient’s current support systems such as family and friends.

Know your community resources.
- Information and Referral (I &R): There are several ways to identify community resources:
  - 2-1-1– Information & Referral Search: In many parts of the country, The United Way and AIRS (Alliance of Information and Referral Systems) can provide you with a phone number to call for information about the social services in your area. You can press 2-1-1 on your phone or access it on the Internet.
  - The Chamber of Commerce in your area can provide a list of services.
  - Ask these agencies to send pamphlets or to give a presentation to your practice. This helps staff to understand their services and referral process and to meet a contact person.
Connect patients with resources.

- **Have a system for organizing resources:** Have one person take on the role of organizing the resources and helping patients get connected.

- **Create a supportive atmosphere:** Make it an obvious priority to support patients in many ways to promote good health.

- **Use a Community Referral Form** to provide essential information about the service.

- **Followup:** Find out if the referral was completed by contacting the patient and the service provider.

- **Notary Public:** Certify one person in the practice as a Notary Public. This can help expedite certain forms and eliminate an additional step for patients.

- Locate a [Notary Public training course](#).

Recognize that patients can sometimes interfere with success. But clearly presenting to the patients and the staff that the practice is willing to support them in a variety of ways may create an atmosphere where patients start to trust in at least one system—the practice.
Medication Resources

Overview

Medicine is often a vital ingredient to maintain health. Unfortunately, some patients may try to save money by going without their medicines or reducing the amount they take. Some larger pharmacies have recently helped the low-income consumer by offering many generic medicines at a lower price. But these programs do not always cover every medicine, and sometimes generic prescriptions are not appropriate for the situation.

Actions

Assess patients’ ability to pay for all of their medicines.
• “It is sometimes hard to afford all the things we need. Are you having any trouble paying for your medicines?”

Review and advise patients on their insurance coverage.
• If they are uninsured, make a referral to an agency that can help them apply for Medicaid or other subsidized insurance.
• For Medicare recipients, make sure they have Part D.
• Explore mail order options as a way to save money.

Connect patients with medication assistance programs.
• Below are assistance programs that connect patients with each pharmaceutical company for each medicine. Separate applications will be required for each medicine requested.
  ◦ NeedyMeds.com provides patient assistance programs, drug discount cards, and a list of disease-based assistance programs.
  ◦ Partnership for Prescription Assistance Offers a single point of access to more than 475 public and private programs, including nearly 200 offered by pharmaceutical companies.
  ◦ RXAssist offers a comprehensive database of patient assistance programs, as well as practical tools, news and articles so that health care professionals and patients can find the information they need.
• **Rheumatology specific medicines:**
  ◊ **Orencia Co-Pay Program.**
  ◊ **Remistart** offers assistance with Remicade.

• **Fee-based programs:** Among other services, these sites may actually help patients fill out the application, but they may charge patients.
  ◊ **RxHope** assists patients with applying for free or low cost medicines and also allows physicians to set up accounts and manage that process as well.
  ◊ **Together RxAccess** claims to save 25%-40% on brand-name prescription products.
  ◊ **Select Care Benefits Network** is a patient advocate agency working with low income patients to help them receive their medicines from pharmaceutical companies.

• **Local programs:** **State Pharmacy Assistance Programs** do exist in some states, and there may be some local agencies that will give financial assistance for medicines.
Use Health and Literacy Resources in the Community

Overview

Your patients’ health outcomes may be improved through their participation in a variety of health and literacy programs. Since it is unlikely that your practice is able to offer all of the resources and services that your patients need, your ability to help them connect to the appropriate organizations in your community is an important part of your practice.

Actions

Identify health resources.
- **Medline Plus Directories** is a nationwide service that helps you find health professionals, services and facilities in your area. Clicking on the service allows you to search for resources in your community.
- **NC Health Info** Use the ‘Go Local’ feature to find a variety of services such as Yoga or weight loss programs (specific to North Carolina.) Look for a similar site in your state.
- **Internet Browser** services such as Google Maps (‘Search Nearby’ feature) and Yahoo Local offer a way to search by typing in the name of your community and searching different services.

Identify literacy resources.
- **LINCS Literacy Information and Communication System** is a site that identifies local resources to provide help with reading, math, GED, and English for speakers of other languages (ESOL).

Call and obtain the following.
- Information about their program(s).
- How to make referrals.
- How to contact them and where they are located.
Approach patients about using literacy resources.
- When asking people about their reading skills let them know that it is a common problem, “Half of Americans have some difficulty with reading.”
- “Have you ever had a problem with reading?”
- “Would you be interested in a program to help you improve your reading?”
- For more guidance on approaching patients about improving their reading skills see the D-I-R-E-C-T approach outlined in the AMA health literacy manual.

### Connect patients with resources.
- **Obtain or develop an easy-to-read handout** such as this [Community Referral Form](#).
- **Make it routine.** During visits, think about community resources that the patient may benefit from.
- **Review the handout with your patient,** including the name of the person to contact.
- **Help with the referral.** Ask staff to help the patient by making the initial phone call.

### Followup.
- By following up with a patient regarding a referral, a practice can:
  - **Confirm** that the patient successfully connected with the resource.
  - **Check the quality** of the resource as a helpful service.
  - **Reaffirm** that you feel the patient could benefit from the resource and that you care enough about the patient to see it through.
Communicating Care with Other Physicians

Overview

Because many patients have one or more specialists that they see on a regular basis, it is important to establish a direct method of communication between the rheumatologist and the primary care provider. When this type of teamwork occurs in a seamless way, fewer mistakes are made, and it gives the patient a sense of confidence about their health care and providers. But when this communication falters, it can be very disheartening and frustrating for the patient, often causing more health care expense, more provider and patient time, and sub-standard care overall.

Actions

Develop networks.

- Develop relationships with some of the referring practices.
  - Invite a representative from that practice to meet with your practice to develop guidelines for sharing information about referred patients.
  - Develop a service agreement that outlines how referrals will be made and how information will be reported back.
  - Offer to hold a mini clinic with another practice once a week or once a month, whereby you go to that clinic and see scheduled patients. This can really improve communication.

Define roles.

- Determine who will be responsible for such things as routine lab work or changing medicines.

Define reporting requirements.

- Develop a standard referral form for other practices that includes:
  - Reason for referral.
  - Relevant history, problem list and list of medicines.
  - Relevant labs or tests that have been done.
  - What information they want you to consult on.
  - One-time consult or ongoing.
Communicating Care with Other Physicians

**Establish plan for communication.**

- **What information** will be transmitted: Does the physician need to know everything in your note or can the visit be summarized? Do they have time to read the entire note? Make sure that the primary care provider has all the information they need and don’t expect the patient to be the primary source of communication.

- **How will it be transmitted:**
  - Electronic medical record system.
  - Faxed.
  - E-mailed.
  - **Phone call or phone message:** It may be advantageous to confer in real time about this patient; determine the best way to do that.
  - **Note copied and sent through mail system.**

- **When:** Within what time period does the other physician expect the communication?

- **Who:** Are there key people involved, such as a nurse in the primary care physician's office, who can help to relay this information? Who in your office will carry out this communication and allot time for this?