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Citation

Published Version
10.1016/j.sapharm.2013.04.016

Citable link
http://nrs.harvard.edu/urn-3:HUL.InstRepos:33973671

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Adaptation of the health literacy universal precautions toolkit for rheumatology and cardiology – applications for pharmacy professionals to improve self-management and outcomes in patients with chronic disease

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Abstract

Over a decade of research in health literacy has provided evidence of strong links between literacy skills of patients and health outcomes. At the same time, numerous studies have yielded insight into efficacious action that health providers can take to mitigate the negative effects of limited literacy. This small study focuses on the adaptation, review and use of two new health literacy toolkits for health professionals who work with patients with two of the most prevalent chronic conditions, arthritis and cardiovascular disease. Pharmacists have a key role in communicating with patients and caregivers about various aspects of disease self-management, which frequently includes appropriate use of medications. Participating pharmacists and staff offered suggestions that helped shape revisions and reported positive experiences with brown bag events, suggestions for approaches with patients managing chronic diseases, and with concrete examples related to several medicines [such as Warfarin©] as well as to common problems [such as inability to afford needed medicine]. Although not yet tested in community pharmacy sites, these publically available toolkits can inform professionals and staff and offer insights for communication improvement.

Keywords

Health Literacy; Brown Bag Review; Medication Adherence; Teach-Back Method

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Introduction

Research has demonstrated links between health literacy skills of patients and health outcomes. Consequently, health literacy is increasingly considered in health policy development. The National Action Plan to Improve Health Literacy (NAPHL) articulates seven goals and priorities for a wide swath of stakeholders (including organizations, professionals, policy makers, and communities) in order to create a more health-literate environment. The plan is based on two principles: that everyone has the right to health information and that health services should be delivered in ways that are understandable and beneficial. This emphasis on accurate and actionable health information is a result of findings from over a decade of health literacy studies. Research indicates a profound mismatch between the structure and content of health information (delivered in writing or in talk) and the average skills of high school graduates. Indeed, as adult literacy surveys and health literacy studies indicate, a majority of US adults have difficulty using everyday materials with accuracy and consistency as they try to accomplish mundane tasks.

Unfortunately, it is not always clear who struggling to understand and use health information. As a result, a clear action plan for health improvement is a call for literacy-related universal precautions: treating everyone as though they have difficulty accessing and understanding health information.

The mismatch between average literacy skills of U.S. adults and complex health information is of particular concern for all health professionals who work with patients with chronic health conditions, such as arthritis, asthma, diabetes, and cardiovascular disease. A recent project studying the domains of communication between patients with heart disease and their physicians showed that physicians were unaware of medication adherence barriers in 38 out of 57 visits (65%) and of psychosocial barriers in 61 out of 88 visits (69%). Low health literacy is related to mortality and hospitalization among patients with heart failure, and its affects may be mutable by practicing appropriate interventions including “appropriate teaching methods, reinforcement of education over time and checking for understanding.” Furthermore, limited health literacy has been found among patients in many rheumatology clinics and proved to be predictive of disease severity.

A number of efforts are underway to mitigate the effects of low health literacy on patient health outcomes. Some programs aim to enhance patient education materials to make them more understandable, using well designed, easy-to-read materials focused on treatment, medications, and general information about particular diseases. In one case, the program included a patient educator to review information with patients. These efforts have been shown to improve clinical outcomes and disease-specific knowledge for patients. Other initiatives have focused on the role of the practitioner in overcoming barriers associated with low health literacy through the development of manuals and protocols to improve clinical interactions and practice re-design. The tools for training health care workers differ from program to program, with some offering educational manuals for clinicians, others providing instructional toolkits for teams to implement in clinics, and still others offering one-time in-person training seminars.

There are several substantial specific efforts to address the concerns of low health literacy that are targeted to pharmacy professionals in both the academic and community settings. The Accreditation Council for Pharmacy Education (ACPE) recognizes communication as an essential professional responsibility of pharmacists by requiring that all schools of pharmacy adequately prepare and document competency in communication with patients for pharmacy graduates. Furthermore, the Agency for Healthcare Research and Quality (AHRQ) acknowledges that pharmacists play a key role in “making sure that patients obtain the maximum positive health outcomes from their medications,” and offers the Pharmacy Health Literacy Center. This online site offers free tools, curriculum modules and resources to promote health literacy for pharmacists in the academic and community setting. One such resource available to address health literacy universal precautions in a comprehensive way is the Health Literacy Universal Precautions Toolkit for primary care practices that was commissioned by AHRQ (HLUPTK-PC) and released in 2010. The toolkit provides a structured approach for all clinic practitioners and staff, including pharmacy professionals, to improve care for all patients regardless of their literacy level. The Toolkit includes 20 tools with practical guidance for conducting a health literacy assessment of the practice, improving written and verbal communication as well as improving self-management and supportive services.

**Study of Toolkits for Specialized Practice and Pharmacy Applications**

This small study is focused on the adaptation, testing, and refinement of two new subspecialty Health Literacy Toolkits and their application for related medical specialists and in pharmacy practice. These toolkits, focused on issues related to rheumatology (HLUPT-R) and cardiology (HLUPT-C) practices, were adapted from the Health Literacy Universal Precautions Toolkit for primary care practices (HLUPT-PC). Heart disease and arthritis are two of the most prevalent chronic conditions and often require patients to adhere to complicated medication regimens. Our Toolkit adaptation team included health educators, a dietitian, pharmacist, internist, rheumatologist, cardiologist, and social scientists. The HLUPT-PC was reviewed to identify possible opportunities for specialty customization. An environmental scan of health literacy literature for rheumatology and cardiology was conducted. Experts associated with rheumatology and cardiology practices and individuals at the Centers for Disease Control and Prevention (CDC), National Institutes of Health (NIH), and voluntary health agencies such as the Arthritis Foundation and American Heart Association were contacted for their advice and input. Gaps in rheumatology and cardiology specific materials were identified and relevant resources, materials, references, and examples were selected.

Based on the results of the scans and input from experts, two new Toolkits were drafted for testing. HLUPT-R additions included references to health literacy in rheumatology, a video using the teach-back method in a patient with rheumatoid arthritis, a rheumatology specific plain language guide, medication aids and handouts for rheumatic disease therapies, and links and examples of easy to understand arthritis and rheumatic disease patient education materials. HLUPT-C additions included cardiology-specific health literacy studies, a teach-back video with hypertension and heart failure examples, medication aids for cardiac disease therapies, and links to cardiology patient education materials that are appropriate for patients.
with all levels of health literacy. An additional tool was added to each subspecialty Toolkit, “Communicating Care with Other Physicians”, which provides guidance for a subspecialty provider to communicate with the patient's primary care physician.

Pharmacists have a key role in communicating with patients and caregivers about various aspects of disease self-management, which frequently includes the appropriate use of medications. Health literacy studies indicate that, regardless of literacy levels, patients have particular difficulty with medication dosing when more than five medications are taken. Patients with chronic disease and especially those with multiple chronic conditions, such as those followed in rheumatology and cardiology practices, frequently take five or more medications, and a recent study identified that patients with low health literacy and coronary heart disease were less likely to identify all of their medications. Therefore, the subspecialty Toolkits were examined for applications for pharmacists.

**Methods**

The study was conducted in two phases. Phase 1 focused on the review, use, and revision of the Toolkits, as modified for specialty customization in rheumatology and cardiology. Phase 2 focused on a qualitative examination of Phase 1 findings to select specific tools and applicable examples of specific interest to pharmacists in clinical settings.

**HLUPT-R and HLUPT-C Testing in Practice Settings**

Eight sites (4 rheumatology and 4 cardiology) in North Carolina were recruited to test and/or review the information and 21 tools in the adapted toolkit designed for their subspecialty. One of the cardiology sites was a cardiac rehabilitation center. The practices varied in size (health system, group, and solo practices), patient population served, and setting (urban versus rural). The Toolkits were designed for use by all staff at a practice, including physicians, nurses, laboratory staff, pharmacists, rehabilitation specialists, receptionists, and administrative personnel. Approval was granted by the Office of Human Research and Ethics at the University of North Carolina to engage the practices in the testing of the Toolkits. The practice profiles of the rheumatology and cardiology sites are presented in Tables 1 and 2. All practices were reimbursed $3000 for their participation in the testing.

A detailed testing plan was prepared to guide our practices in the use of the toolkit. A member of the research team visited each practice in the fall of 2010 to discuss health literacy and provide a brief review of the toolkit prior to the testing. The testing occurred from February through May 2011 with each practice participating for a two-month period. The testing plan was divided into three milestones with each culminating in telephone contact or a conference call with the development team: Milestone 1 – Form and Train your Health Literacy Team; Milestone 2 – Conduct Health Literacy Assessment of Your Practice; Milestone 3 – Implementation of 2 Tools. After completing the milestones, the practices completed forms and returned them to the research team one week prior to the calls. Each practice completed a practice profile and pre and post review questionnaires. The testing was guided by the Plan/Do/Study/Act (PDSA) model. The practices also provided their PDSA worksheets and completed a tool implementation feedback form after milestone 3. Information and feedback from the practices were collected, submitted and reviewed by
team members prior to conference calls. All calls were guided by a structured interview and notes were taken throughout the calls. Calls were also recorded in case team members needed to clarify call notes. The quantitative and qualitative data from the questionnaires and calls were summarized and reviewed by team members. The tools and adapted Toolkits were revised and updated based on the practice testing and recommendations. All results presented are descriptive.

Identification of pharmacy-specific tools and examples

The study team (including a pharmacist) reviewed the tools and all input provided from the practices to determine and select the tools with the most relevance to pharmacists in the clinical setting. Quotes and examples given from the practices were examined and grouped under the tools selected for most relevance. These qualitative findings were summarized.

Results

Phase 1: HLUPT-R and HLUPT-C Testing and Refinement based on Practice Input

All eight practices completed the testing and provided written and oral feedback. Overall, 14 tools were formally tested or reviewed by the practices (Table 3). As part of the testing milestones, all practices completed Tools 1-3. In Tool 1, forming a health literacy team, practices are encouraged to incorporate a patient into the team. One of the practices included a patient on the team. As with the testing of the HLUPT-PC\textsuperscript{25} the Teach-Back Method and Brown Bag Medication Review were the most frequently tested tools that were not required. Seven practices tested the Teach-Back Method and three the Brown Bag Medication Review. One of the practices testing Teach-Back noted that “using teach-back could be spread to all the nurses in this clinic and maybe throughout the practice with the doctors.” Designing Easy-to-Read Material was tested by four practices (Table 3). After re-designing and simplifying a new patient letter, one practice noticed that nearly all of the patients receiving the new letter came prepared and on time for appointments. Telephone Considerations and Communicating Care with Other Physicians were tested or reviewed by two practices and Use Health Education Material Effectively, Welcome Patients, and Medication Resources were each tested or reviewed by one practice (Table 3). Practices were encouraged to informally review all tools in addition to their formal testing/reviewing of two tools. The cardiac rehabilitation site continued to work through all of the tools in the Toolkit after the testing period and systematically focused on implementing one additional tool each month.

This testing format allowed us to have rapid evaluation and feedback on the Toolkits. Overall, the Toolkits were reported to be useful to the practices with one practice stating that “these tools will be a benefit to both staff and patient, and the more I use them the more comfortable I feel with each tool.” Some practices used the toolkits electronically and other practices worked with printed copies. A variety of staff members (physicians, nurses, pharmacists, nursing assistants, receptionists and business managers) participated in the testing process. We asked specifics regarding usage and usefulness about the tools that were tested. The following results were reported: 80% reported reading the entire tool during testing, 20% read parts of the tool; 80% reported that the tool was completely
understandable, 20% somewhat understandable; 50% felt the tools tested were very useful for addressing health literacy issues in their practice, 50% somewhat useful; 100% accessed some of the internet resources in the tools and 30% found the resources very useful and 70% somewhat useful. All practices felt the tools somewhat or very much improved patient care and that the time invested in the tool was worth the benefit. Lastly, all practices said they would sustain the changes made as a result of tool testing over time and planned to use other tools.

Although the practices found the tools useful, many staff members commented that the length of the tools and size of the toolkits was a bit onerous. Based on feedback from the practices, all of the individual tools within the toolkits were shortened and improved design elements, such as more white space, graphics, and specialty specific education materials and links, were added. Furthermore, rheumatology and cardiology specific examples contributed by test sites were added. For example, the rheumatology practices noted that rheumatoid arthritis patients often have difficulty understanding how to take methotrexate properly and the cardiology practices identified problems with adherence to Warfarin© regimens. As a result, handouts were created and added to the resources targeting these issues. Several of the practices participating in the testing did not have experience planning and implementing change ideas. As a result, another tool was added to the subspecialty Toolkits after testing, “Plan Your Changes”, which offers specific guidance for this process. A list of all of the final tools included in the HLUPT-R and HLUPT-C Toolkits after the testing and revision is provided in Table 4.

The revised and refined Toolkits were sent back to all of the practices for final review and were well received. All practices provided either written or oral communication that the refinements based on their input had resulted in more “user-friendly” toolkits. HLUPT-R and HLUPT-C are available free electronically on the NC Health Literacy and Thurston Arthritis Research Center websites. The online PDFs of the Toolkits provide the user with documents that can be easily navigated and contain visual cues and links to additional resources. For users who prefer to work from a printed document, the option to print all or part of the contents of the Toolkits is available.

**Phase 2: Identification of pharmacy-specific tools and examples**

Five tools in HLUPT-R and HLUPT-C focus on promoting patient safety and medication adherence and may be of particular interest to pharmacists working in the clinical setting (Table 4). These tools are useful for improving the management of all chronic conditions and include:

1. The Teach-Back Method (Tool 6);
2. Brown Bag Medication Review (Tool 9);
3. Improve Medication Adherence and Accuracy (Tool 17);
4. Medication Resources (Tool 20);
5. Encourage Questions (Tool 15).
The following are examples of Tool use in rheumatology and cardiology settings that illustrate how and why these tools may be helpful pharmacy professionals:

**The Teach-back Method**

The teach-back or tell-me method entails asking patients to state in their own words what they need to know or need to do (Figure 1). This is an effective method for all health care providers to confirm that they were clear while explaining medical information and to confirm that a patient knows what they need to do when they get home. The teach-back method is not meant to be a test of the patient's knowledge, but instead focuses on testing how well the concept was explained by the health care professional. This method can be used with all patients, including those who appear to understand the information that was discussed during the clinic visit. Practices testing the tool found teach-back especially effective for the following:

- Warfarin© dosing schedule - Cardiology staff used a well-designed handout and teach-back to confirm that patients understood their Warfarin© doses, and subsequently received fewer call backs with questions.
- Methotrexate dosing - Rheumatology staff recognized the importance of using teach-back for all patients starting methotrexate and when patients were dissatisfied with pain relief provided with this medication. After patients explained how they were taking their medications, the staff realized they were not taking the medication correctly because they had not understood dosing instructions.

**Brown bag medication review**

The Brown bag review is the practice of asking patients to bring all of their medications, supplements and vitamins to a clinic visit for review and assessment. Patients are asked several questions about each medication, including when they need to take it, how they take it, and what they take it for. At that time, health care professionals clarify medication instructions, update the medications in the patient's medical record, and provide patients with an updated list of their medications. All of the practices that conducted brown bag reviews found errors, such as:

- Out of 5 reviews conducted in one practice: three patients had duplicate medication bottles and were taking double doses, and one patient was taking a discontinued medication.
- A cardiology patient had stopped her cholesterol medication because she thought it was a second bottle of her potassium supplement.
- A younger patient that a rheumatologist thought would understand how to take her medications was actually taking her methotrexate daily instead of weekly.
- A rheumatology patient was taking the wrong medication to gain additional pain relief.
Improve medication adherence and accuracy

When patients have multiple medications prescribed to them, taking the wrong dose or taking them at the wrong time can be very common. Some patients have difficulty remembering to take their medications, or they have difficulty following complex medication regimens. Providers can use various approaches to help patients manage their medications including MedCard, a printable form that lists the medications and other health information that can be folded and carried in a wallet. Pill charts and pill cards can also be used, which provide pictures of medicines, the purpose for taking them, and instructions on how to take them (Figure 2).

Practices testing the tool reported that:

- ‘It was helpful for the patients if my staff and I wrote precise instructions and gave them reasons for taking the medicine whenever a new medication was prescribed.’
- ‘When a patient switched from a brand name to a generic medicine, it was important to tell them that the color, shape, and size of the pill may change.’
- ‘Patients really appreciated it when the staff made MedCards for them, and it was absolutely worth the time. It was helpful that our Electronic Medical Record could be set up to supply the same information in an efficient way.’

Medication resources

Critical conversations are not always focused on medicine instructions and use. Sometimes patients cannot afford to purchase medications. Thus, the toolkit suggests that it may be helpful to ask patients directly if they are having trouble getting their medicines and if so, to offer information about ways that they can be helped. Providers can begin the conversations by saying:

- ‘In these times it is sometimes hard to afford all the things we need. Are you having trouble paying for your medicines?’
- ‘Taking medicines is important. If you ever have problems affording your pills, please let me know before you run out, and we can try to help you get them.’

Informing uninsured patients about Medicaid, Medicare, and other subsidized insurance options is important. Other patient assistance programs such as Select Care Benefits Network, a patient advocate agency, and RXAssist, a comprehensive database of patient assistance programs, can also help patients afford their medications.

Encourage questions

One of the lessons learned from health literacy and from communication studies is the value of question asking. Creating an environment where patients are comfortable asking questions is an important part of empowering patients to take an active role in their health care and is essential for patient safety. “Ask Questions if you have doubts or concerns” is listed as the first step in the “Five Steps to Safer Health Care,” a patient fact sheet developed by the U.S. Department of Health and Human Services. All members of the health care team can invite questions by changing their approach to patient communication:
• Ask the patient “What questions do you have?” instead of “Do you have any questions?” A small change in wording opens the door to questions much more effectively. Staff testing this tool found that this was a helpful way to close a patient encounter, and were pleased and not burdened by the questions patients asked.

Discussion and Implications

Although most health care professionals agree that improving safety and satisfaction with health care services is important for all patients, finding practical strategies to accomplish these goals can be challenging. HLUPT-R and HLUPT-C provide tested and effective strategies that clinical and administrative staff can use to mitigate the effects of low health literacy in patients with chronic disease. These Toolkits are designed for the clinical or rehabilitation setting and were tested by a range of practice staff and healthcare providers, including pharmacists, physicians, nurses, and administrative personnel. The Toolkits contain links to videos, health education materials, medication adherence handouts, and references applicable to two of the most common chronic conditions, arthritis and cardiovascular disease.

Many patients have difficulty managing their medications as well as their health care. Pharmacists have a key role in communicating with patients and their caregivers about important aspects of disease self-management, and thus are essential partners in achieving the goals of the NAPHL released in 2010. The HLUPT-R and HLUPT-C discussed in this article and especially the five strategies and tools from the Toolkits that were highlighted, help address two goals identified in the Plan: 1. “Promote changes in the health care delivery system that will improve health information, communication, informed decision-making, and access to health services.” and 2. “Increase the dissemination and use of evidence-based health literacy practices and interventions.”

An ideal in rheumatology and cardiology practices is to have a pharmacist on the multidisciplinary team. Because pharmacists have frequent contact with patients, they are in an optimal position to help persons with low health literacy levels. Research indicates that medication instructions and warnings can be complex and may be difficult for patients (especially those with average or below average literacy skills). Incorrect adherence with prescribed medication regimens may compromise patient safety, lead to unnecessary hospitalizations and reduce patient satisfaction. Unfortunately, it is not always clear who is struggling to understand and use health information. Application of strategies to promote health literacy serves as a vital link between the pharmacist and the patient to improve medication adherence. It is the responsibility of everyone who interacts with patients to communicate in a way that the patient can understand. If patients do not understand what they need to do to manage their health, they cannot actively participate in their care.

In addition, several initiatives have aimed to address the health literacy challenge through the creation of pharmacist-specific health literacy toolkits. The Agency for Healthcare Research and Quality (AHRQ) offers an online health literacy toolkit, “Is our Pharmacy Meeting Patients’ Needs?”, to guide outpatient pharmacies in the self-assessment of their practices and the implementation of health literacy universal precautions.
Academy of Family Physicians (AAFP) offers a toolkit that provides guidance on educating patients on medication usage, and although the toolkit is targeted towards physicians, the information is applicable for pharmacists as well. These manuals contain a variety of helpful strategies and suggestions, however, they also require health professionals to be self-motivated to read the content and implement suggestions without additional guidance or support.

This study is limited by the small number of test sites, primarily qualitative and descriptive findings, and the geographical boundaries. In addition, one of the study limitations is the omission of community based pharmacy sites. However, the strategies in these two new toolkits could also be applicable to community pharmacy settings. Communication is a central component of pharmacy practice, regardless of the setting. Thus, employing strategies discussed in this article, including confirming understanding of information, performing medication reviews, improving medication adherence and accuracy, and encouraging questions offers pharmacy professionals practical guidance for structuring encounters to improve outcomes and promote patient satisfaction. Pharmacists may also use the tools in these toolkits to promote health literacy awareness throughout their organization.

HLUPT-R and HLUPT-C, along with the initial HLUPT-PC, offer structured approaches for increasing awareness, assessing current practices, and addressing specific concerns as needed.

Acknowledgments

Funding for the HLUPT-R and HLUPT-C was provided by Novartis. We thank the following for supporting the HLUPT-R and HLUPT-C development: Thurston Arthritis Research Center, Cecil G. Sheps Center for Health Services, and the North Carolina Program on Health Literacy. We thank the following practices for testing the HLUPT-R and HLUPT-C: Appalachian Regional Rheumatology Healthcare, Boone, NC; Arthritis & Osteoporosis Consultants of the Carolinas, Charlotte, NC; Mid Carolina Cardiology, Charlotte NC; Mid Carolina Cardiology, Salisbury, NC; Mountain Medical Associates, Clyde, NC; UNC Center for Heart and Vascular Care, Chapel Hill, NC; UNC Health Care Cardiac Rehabilitation, Chapel Hill, NC; UNC Rheumatology, Chapel Hill, NC. We thank the following UNC colleagues for their assistance with the development of the HLUPT-R and HLUPT-C: Kimberly Brouckou, Deborah MacDonald, Carla Sueta, as well as Cindy Brach from the Agency for Healthcare Research and Quality.

References


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-dooming 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 medications. Can you tell me how you are going to take it?"
"Tell me what you plan 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:
1. It is not a test of the patient. They are supposed to feel comfortable, not ashamed.
2. Clarify if patients cannot remember. Explain it using a different method and ask them to teach it back again.
3. Watch a video to demonstrate the use of teach-back.

Fig 1.
Fig 2.
Table 1

Profile of the Four Rheumatology Practice Sites

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<th>Affiliation</th>
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<th>Location (Urban / Rural)</th>
<th>Number of Providers (MD, NP, PA)</th>
<th>Number of Staff</th>
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Population Served:

X ≥20% of practice population  
AA = African American  
NA = Native American  
Hisp = Hispanic  
W = White

Affiliation:

Y = Affiliated with Health Care Organization  
N = Independent/private practice
## Table 2

### Profile of the Four Cardiology Practice Sites

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* (Cardiac Rehab Clinic included 1 MD, 2 RN’s, 3 Clinical Exercise Specialists, 1 RN Mental Health Specialist, 2 Dieticians)

**Population Served:**

- X ≥20% of practice population
- AA = African American
- NA = Native American
- Hisp = Hispanic
- W = White

**Affiliation:**

- Y = Affiliated with Health Care Organization
- N = Independent/private practice
Table 3

List of Tools

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<td>Assess Your Practice</td>
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<td>Raise Awareness</td>
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<td>Plan Your Changes</td>
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