

June 2006

# Patient Education Best Practice Guidelines eNews

## Welcome new participants:

*Terri Ades, MS, APRN-BC, AOCN  
Director, Cancer Information Health Promotions  
American Cancer Society*

This Initiative is expanding to include disease management associations. We're delighted to have American Cancer Society contributing their expertise

## Let the MetaSearch Begin! Welcome:

*Diana Delgado, MLS  
Pattie Mongelia, MLIS  
CHIS*

We are unbelievably fortunate to have the skills and intelligence of two top medical librarians from Cornell University/Weill Cornell Medical College to begin the meta search toward identifying educational practices for inclusion as a Patient Education Best Practice Guideline.

**Many thanks to Virginia Forbes, NY Presbyterian Hospital, for making the connection with Diana and Pattie.**

Kathy Kastner, Chair  
Patient Education  
Best Practice Initiative

## IS THERE A NEED FOR GUIDELINES?

### A RESOUNDING YES:

- ⇒ **YES: Put a spotlight on education: it's part of every aspect of healthcare**
- ⇒ **YES: To help guide the healthcare system**
- ⇒ **YES: To provide a comprehensive framework that healthcare professionals can refer to**
- ⇒ **YES Particularly as people self manage**
- ⇒ **YES: For those who develop education as well as for the patient**
- ⇒ **YES: For a coordinated multi-disciplinary approach**

**MARCH 20, 2006 TELECONFERENCE**



## 5<sup>TH</sup> ANNUAL HEALTH LITERACY CONFERENCE

Institute for Healthcare Advancement [www.ih4health.org](http://www.ih4health.org)

- ✓ Learning is cumulative, and contextual,
- ✓ Learning is based on a hierarchy of difficulty
- ✓ Improving skills requires practice

*Christina Zarcadoolas PhD*

*Advancing Literacy: A Framework for Understanding and Action*

- ✓ Using stories and metaphors can make all the difference in health education, and understanding a health concept.

*Helen Osborne M.Ed OTR/L, Health Literacy Consulting*

March 20, 2006: Organizational Teleconference Development Panel

**Dr. Richard Croteau** JCAHO **Ray Bullman** NCPIE **Nancy Tuohy** ISMP **Ellen Shapiro** FDA  
**Dr Nancy Ostrove** FDA **Oralia Bazaldua** AAFP/STFM **Linda Golodner** National  
Consumer League **Gloria Mayer** Institute for Healthcare Advancement **Virginia Forbes** NY-  
Presbyterian Hospital **Anne Williams** University of Maryland Medical System **Helen Osborne**  
Health Literacy Consulting **Dr. Jackie Smith** University of Utah **Laurie Reyen** UCLA **Anita**  
**Boles** Partnership for Clear Health Communication **Denis Morrice** Bone and Joint Decade  
**Ray Chepesiuk** Pharmaceutical Advertising and Advisory Board **Elizabeth Sloss** Attorney  
Ethicist **Dr. Cesar Bandera** Reviewer National Science Foundation **Laura Walsh** Marketing  
Consultant **Leanne Worsfold** Policy Consultant College of Nurses **Nida Saleem** NY State  
Dept of Health

**Patient Education Best Practice Listserv in development**

**Thanks for the suggestion: Pattie Mongelia and Diana Delgado  
Weill Cornell Medical College**

**Developing Patient Education Best Practice Guidelines:  
Summary Report and Highlights from  
First Organizational Teleconference: March 20, 2006**

**Introduction:** Interest in health is just behind finances in its importance in our lives. Googled, 'health information' garners 2 *billion* responses. Be that as it may, interest in health is more often general in nature, and theoretical in approach.

This changes when a person (or loved one) becomes a patient, and enters the healthcare system. In the blink of an eye, health becomes excruciatingly personal. The new patient is launched into a substantial learning curve. With emotions running high, and often not feeling well, the patient has to learn a new language, new processes, procedures and treatment options – usually without benefit of medical knowledge or training necessary to sufficient understanding of implications. The impact is immediate and relentless – on emotional, practical and financial levels.

The person-who's-become a patient also has to make the mental shift from deciding as an individual, to making decisions as a member of a team, which includes immediate family, community (real and virtual:) and – of course – healthcare providers (real and virtual). Googled, Patient Education also garners almost 2 billion responses

**Rationale for Developing Patient Education Best Practice Guidelines:** Many would say that education and the educational process are already in place. Organizations, institutions, academics and clinicians are involved in setting standards, developing protocols, materials and course outlines for patient education. Many private sector companies develop and distribute patient education materials. And certainly, within the continuum of the healthcare system, there are many touch-points where education, and not simply information, is a standard requirement\*. For healthcare providers, and within the healthcare system, the intention of education is to affect attitude and effect a change in behavior, with the end result a healthier population and reduced healthcare costs.

As it stands, proof that patient education accomplishes these goals has neither been collected comprehensively nor organized as Guidelines. Further, investment in educational support is often minimal. For this to change, education must be proven to positively affect outcomes and/or change behavior. With the inevitability of each of us eventually needing healthcare (aging, co-morbidities, and sedentary lifestyle) and, since education has proven to positively effect life's outcomes as relates to work, self-esteem, empowerment, general self-advancement, this initiative, Patient Education Best Practice Guidelines, was born.

**Goals of Best Practice Guidelines:** Patient Education Best Practice Guidelines will provide a roadmap for providers and developers of adult education for the ultimate benefit of patients. Since we are each individuals with medical histories, prior knowledge, biases, and communities (whether real or virtual), these Guidelines are intended to be just that: guidelines to help fill individual educational needs. The ultimate objective is to impact all aspects of patient education toward achieving patient-led, patient-centered and patient-directed education.

There may well be studies whose results should be included as a Best Practice Guideline. Searching, analyzing, processing and organizing has not yet been undertaken. Hence this initiative – a multi-phased approach kicked off with the first organizational teleconference, March 20, 2006, which followed talking points in provided slides.

**Teleconference Summary:** Thanks to all participants – representing standards-setting organizations, key consumer advocacy groups, leaders in patient education from teaching hospitals, regulatory bodies, educators and ethicists. The resulting discussion, in which you each gave input and feedback, led to a greater understanding of challenges and common agreement on interpretation of

1. Terminology
2. Expectations
3. Measurement
4. Challenges

Analysis of the comprehensive data gathered in the teleconference led to the conclusion that the first phase of the literature search should be focused on effective communication strategies. Attached are teleconference highlights including search words.

Caveats that emerged from the analysis:

- Not every patient knows what they need
- Reputable sources often give conflicting information
- Available educational materials are inconsistent in their use of language, terminology and definitions
- Consumers turn to their own community (however credible and reliable it may or may not be) for input, advice, direction and education - along with their healthcare providers

Your comments will be welcomed! Please ensure to 'reply all'.

**Kathy Kastner Chair, Patient Education Best Practice Guidelines**

\* Education, by definition, is the transforming of information so the end user learns.

**MONDAY MARCH 20<sup>TH</sup>**  
**FIRST ORGANIZATIONAL TELECONFERENCE**  
**PATIENT EDUCATION BEST PRACTICES INITIATIVE**

**Purpose:** To brainstorm on topics/issues put forward in slides

**Chair:** Kathy Kastner, CEO The Health Television System Inc

**Participants:**

**Dr. Richard Croteau** JCAHO, **Ray Bullman** NCPIC **Nancy Tuohy** ISMP **Ellen Shapiro** FDA  
**Dr Nancy Ostrove** FDA **Oralia Bazaldua** AAFP/STFM **Linda Golodner** National Consumer  
 League **Gloria Mayer** Institute for Healthcare Advancement **Virginia Forbes** NY-Presbyterian  
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 Pharmaceutical Advertising and Advisory Board **Elizabeth Sloss** Attorney Ethicist **Dr. Cesar**  
**Bandera** Reviewer National Science Foundation **Laura Walsh** Marketing Consultant **Leanne**  
**Worsfold** Policy Consultant College of Nurses **Nida Saleem** NY State Dept of Health Intern

**Objective:** For purposes of developing Patient Education Best Practice

Guidelines, input toward agreed upon understanding of

1. Terminology Interpretations
2. Expectations
3. Challenges

**CONFERENCE CALL HIGHLIGHTS:**

**Reinforced during the teleconference:**

The cornerstone of patient education requires putting at the center of all educational strategies: patients' priorities, needs, objectives and agenda.

While this may be self-evident, the thought and detail you each contributed points to the importance of including in *Patient Education Best Practice Guidelines* a mechanism to ensure that every educational undertaking is patient-centered, patient-directed, and patient-led.

In addressing the goals of patient education, articulated were four specific components that education can achieve to help patients:

- Feel more in control in the decision-making process
- Change their attitude
- Change their behavior
- Improve their outcome

**Comments from The Joint Commission and ISMP two standards-setting organizations represented:**

- Standards are just starting point
- Standards don't go into sufficient detail to actually get the job done
- Even if guidelines are prescriptive, they're on a patient by patient basis
- When there's a variation, there's a rationale, and we all learn

**1. Interpretations: HEALTH OUTCOMES**

The development of Best Practice Guidelines as relates to Patient Education will benefit from an understanding of and agreement on terminology and expectations.

The interpretations and definitions of health outcomes resulted in refining and honing criteria for Patient Education Best Practice Guidelines that will help in meeting patient specific educational needs and expectations.

- Depending on patient population, outcomes can relate to:
  - Quality-of-life indicators
  - Functional indicators
  - Morbidity
- These indicators incorporate subsets: e.g. medication compliance
- Intent of education is to inform rather than persuade
- Therapy/recovery strategy will be negotiated with patient
- Patient's expectations of outcomes may be very different from those of the healthcare providers/educators
- Outcome is based on patient's objectives, and the desired benefit that the patient wants to achieve
- Focus must be on patient's perception of and satisfaction with the outcome (i.e .the healthcare provider may think the patient is doing just fine)
- The healthcare provider's outcome expectations and obligations often focus on: 'You must take'/ 'You must do' instead of patients' wants and needs

**Interpretation EVIDENCE-BASED**

**A literature search focusing on patient education guidelines may reveal that patient education does not lend itself to a 'rigorous scientific approach'. More precise search criteria may be more easily established once the literature search has been undertaken. Put forward in the teleconference regarding the definition:**

- Expert consensus
- Case studies
- Personal beliefs
- Whatever works

### Interpretation: **HEALTH LITERACY**

**Health literacy - an increasingly emphasized key factor in providing patient education, promoting and facilitating improved health outcomes - requires heightened sensitivity by healthcare providers**

- Healthcare professionals often use medical language as a matter of course
- Healthcare professionals need to be aware of and sensitive to terms they are using
- Do not assume words are going to be interpreted as intended
- Assess the amount of information provided, and a patients' readiness to learn

### **2. Expectations: PATIENT'S POINT OF VIEW**

**Education must consider that the typical person who's become a patient is faced with overwhelming change, is on a major learning curve, and does not have medical training. Individualized education should include:**

- Providing what the patient feels they need to know
- Ensuring patients feel they're listened to
- Education that is based on condition of patient and their objectives
- Assessing whether the patient has the skills (psychological, physical, intellectual, practical) to manage their responsibilities
- Consideration that education is a team activity and patient has to be part of it
- Awareness that it's not 'education' until it's understood
- Repetition of education

**Providing patient education that meets the articulated goals is a complex proposition.**

- When people are sick and hurting they (we) don't always function like adults
- Self-directed is very individual and dependent on health status
- After diagnosis, there needs to be a period of reconciliation
- Cultural sensitivity is a major consideration
- Fear Factor and the Human factor:
  - Patients who are afraid of what they're encountering
  - There has to be a will to learn
- Educational intervention (can) change attitudes.
- How can education change behavior

### 3. CHALLENGES TO SUCCESSFULLY IMPLEMENTING PATIENT EDUCATION BEST PRACTICE GUIDELINES

Practical, logistical and financial aspects have to be taken into account when ensuring patients receive the education they feel they need, and that the education positively impacts on their desired outcomes. Brought to the table were the following points:

- There is often mistrust in the healthcare system – especially with underserved populations
- Healthcare providers need support and training
- Education often is not allocated sufficient budget
- There may be gaps/inconsistencies in patient education materials currently available
- Available educational resources may not be in formats that fit all learning styles
- Principles of marketing (e.g. repetition) that have proven successful in changing consumer behavior are allocated a more substantial budget than education

**NEXT STEP: LITERATURE SEARCH, USING THE FOLLOWING WORDS:**

Adaptation psychological  
 Anxiety/prevention and control  
 Attitude to health  
 Behavior Therapy  
 Communication  
 Comprehension  
 Consensus Development  
 Consumer Participation/Satisfaction  
 Continuity of patient care  
 Decision-making  
 Education measurement  
 Feedback  
 Guideline  
 Health behavior  
 Health education  
 Health knowledge, attitudes, practice  
 Health promotion/standards  
 Hospital-Patient Relations  
 Interview  
 Medical History Taking

Outcome assessment (healthcare)  
 Outcome and process assessment  
 Patient Acceptance of Health Care  
 Patient Advocacy  
 Patient Care Team  
 Patient Centered Care  
 Patient Compliance  
 Patient Education  
 Patient Participation  
 Patient Satisfaction  
 Physician-Patient Relations  
 Practice Guidelines  
 Professional-Patient Relations  
 Program Evaluation  
 Quality of Life  
 Questionnaires  
 Self-Care/ Self-efficacy  
 Stress, psychological  
 Teaching Materials  
 Treatment outcome  
 Verbal Behavior