

# Using Patient Literacy and Knowledge to Optimize the Delivery of Health Information

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#### Introduction

The recently published “Healthy People 2020” objectives emphasize education so patients can be knowledgeable and proactive members of their healthcare team [1]. To achieve this critical goal, this biomedical information center at Vanderbilt University Medical Center (VUMC) has identified an innovative framework that allows for a personalized approach to health communication: patients can learn in a way that suits them best, how to care for themselves and their families. Leveraging years of expertise in adult education, a strategy has been developed that focuses on two key principles: an understanding of an individual’s health literacy level and an understanding of an individual’s preferred mode of learning (often referred to in the educational literature as learning styles).

While health literacy is often discussed as a means to enhance patient-provider communication, the effect of learning styles has been less explored. This paper presents the first steps of an Institute of Museum and Library Services (IMLS)-funded state-of-the-art intervention for optimizing communication with patients who represent a diverse array of literacy levels, learning styles, and knowledge of their medical conditions.

#### Background

In 2010, the Knowledge Management and Eskind Biomedical Library teams received IMLS funding to create a model for patient-specific information prescriptions tailored to individual health literacy levels and learning style preferences. Across multiple phases, the research team will conduct a series of studies designed to (1) evaluate the effectiveness of the individualized information prescriptions and (2) test their reusability for a variety of healthcare conditions and settings.

Evaluation of the information prescription is being conducted through a randomized trial of hypertensive adult patients in the VUMC emergency department (ED). The primary outcome is knowledge of high blood pressure concepts in a randomly allocated intervention group that receives the tailored health education materials in addition to standard ED discharge instructions; the control group receives only discharge instructions. To assess baseline knowledge, patients are administered a hypertension quiz at the time of their ED visit. Two-weeks after their ED visit, hypertension knowledge is reassessed using the same quiz, and differences between the control and intervention groups are compared.

The use of an effective health knowledge assessment instrument is fundamental for accurately 1) capturing baseline data and 2) assessing knowledge retention. In an earlier feasibility study designed to capture the effect of a learning-style tailored information prescription [2], the team used a non-validated high blood pressure questionnaire, the National Heart, Lung & Blood Institute's (NHLBI) *Check Your High Blood Pressure IQ* [3]. Results from that experience highlighted the need for a more rigorous tool to measure hypertension knowledge. Specifically, study outcomes revealed that at baseline, of the twelve quiz questions, seven were answered correctly by over 80% of study participants (n=76). The high proportion of correct answers prior to study intervention thus minimized the potential to observe statistically significant increases in knowledge gains at follow-up.

### **High Blood Pressure Assessment Development**

In preparation for the IMLS grant starting in December 2010, in November 2010 the Knowledge Management team initiated a process to create and test a novel high blood pressure knowledge assessment for use in the long-term research project.

#### *Knowledge Test Development*

Investigators began by collecting questions from various sources for consideration in the knowledge assessment. Sources included the NHLBI's *Check Your High Blood Pressure IQ* quiz, an online knowledge assessment accessible from the American Heart Association's website [4], questions reported in hypertension research primary literature and contributions from a VUMC emergency department clinician. Eighteen questions were selected from the pool of potential items and then compiled into a knowledge test; some questions were revised from their original format and restructured to include multiple choice response options. For the question selection process, particular attention was given to risk factors (e.g. nutrition) and long term complications. All questions were translated into Spanish.

#### *Knowledge Test Validation*

Using the same patient inclusion criteria as the planned research project, the Knowledge Management and Eskin Biomedical Library teams assessed the content validity of the high blood pressure knowledge assessment. Three rounds of testing were performed; each round consisted of ten hypertensive ED patients. Patients eligible for enrollment in this validation study were aged 18 or older, and able to read and speak either English or Spanish. Additionally, eligible patients had two or more blood pressure measurements taken during the ED visit that met criteria for Stage I or Stage II hypertension as determined by the Joint National Committee on Prevention, Detection and Evaluation and Treatment of High Blood Pressure [5]. Patients were excluded if they had a life-threatening condition as measured by an Emergency Severity Index of 1 (the most severe level), left the ED without being seen by a physician, were transferred to another institution, were imprisoned, had a psychiatric chief complaint, or the medical chart noted cognitive impairment. Knowledge Management Information Specialists performed patient recruitment and the study received exemption status from the Vanderbilt University Institutional Review Board.

The validation process ensured the high blood pressure knowledge quiz reflected key hypertension management concepts and captured knowledge variation among participants. The study team then analyzed data from the three rounds of testing to refine and modify questions. Results from the final round provided standard deviation data to inform the sample size calculation in future phases of the research project.

## Results

Eighteen questions were selected for inclusion in the initial round of testing. Table 1 shows the rate of correct responses for questions revised between Rounds 1 and 2.

Table 1: Patient correct response rate to questions revised between Round 1 and Round 2

Question	Round 1 (n=10)	Round 2 (n=10)	Round 3 (n=10)
<b>Q4</b>	90%	90%	70%
<b>Q5</b>	90%	0%	20%
<b>Q10</b>	80%	50%	30%

Question 4 asked respondents to identify the race with the highest rates of high blood pressure. In Round 1, 90% of patients correctly selected “African-Americans” over the other choices of Caucasians, Hispanics, and Asian Pacific Islanders. Given the high correct response rate, prior to Round 2, the question was changed to ask which race had the highest mortality rate from high blood pressure complications. An additional response option of “American Indians” was added based on data from a National Vital Statistics Report [6]. In Round 2 however, the question was still correctly answered 90% of the time, and 70% of the time in Round 3. The high correct response rate across all rounds of testing demonstrated a widespread understanding of the increased risk of high blood pressure among African-Americans. This question was subsequently eliminated from the final high blood pressure knowledge assessment as the study populations indicated less educational need for this concept.

Question 5 (Figure 1), assessed knowledge of risk for high blood pressure by age.

Figure 1

<b>Original Question:</b>	<b>Revised Question:</b>
<b>If you've never had high blood pressure, are you more likely to as you age?</b>	<b>Which of these age groups have a higher percentage of high blood pressure?</b>
a) Yes b) No c) Do not know	a) 45-54 years b) 55-64 years c) 65+ years d) Do not know

Most respondents seemed to understand that the risk for high blood pressure increases with age, therefore the question format was changed from a Yes/No response to a multiple choice selection. The original question was used in a research study by Egan et al. [7] and response options of the revised question were extracted from data in a National Center for Health Statistics Brief on the prevalence of high blood pressure [8]. Data from Rounds 2 and 3 showed that few patients answered the revised question correctly, thus identifying an important educational need.

Originating from a quiz on the American Heart Association’s website, Question 10 (Figure 2), captured an individual’s understanding of the risk factors for high blood pressure and heart disease [4]. Results from Round 1 showed that many patients correctly selected option “d”. The response options were modified to replace option “d” with the “late-child bearing” statement, which may be familiar to patients who heard news reports of its association with an increased risk for breast cancer. Placing it out of that context and within this question can help assess knowledge of major risk factors for high blood pressure and heart disease. Participants were directed that more than one answer could be selected. Additionally, the option “Do not know” was added to this question and several others to allow the respondent to indicate they do not know the answer rather than guessing.

Figure 2

<b>Original Question:</b>	<b>Revised Question:</b>
<p><b>Major risk factors other than high blood pressure for heart disease and stroke include:</b></p> <ul style="list-style-type: none"> <li>a) High cholesterol</li> <li>b) Smoking</li> <li>c) Family history of the disease</li> <li>d) a, b, and c</li> </ul>	<p><b>Major risk factors other than high blood pressure for both heart disease and stroke include:</b></p> <ul style="list-style-type: none"> <li>a) High cholesterol</li> <li>b) Late child bearing</li> <li>c) Diabetes</li> <li>d) Physical exertion</li> <li>e) Do not know</li> </ul>

After analysis of results from Round 2, the team determined that additional changes were needed for Question 9 (Figure 3). This question was included to capture understanding of important contributors to high blood pressure. During validation testing many participants understood ice cream to be the least likely answer. The team replaced option “d” with a choice focusing on the dietary intake of fruits and vegetables; similarly to Question 10, this new option was included given increased news focus on healthy eating and the high likelihood that study participants would have exposure to media messages.

Figure 3

<b>Original Question:</b>	<b>Revised Question (For Round 3):</b>
<p><b>Which of the following is more likely to contribute to your high blood pressure?</b></p> <ul style="list-style-type: none"> <li>a) Physical activity</li> <li>b) Salt/sodium intake</li> <li>c) High cholesterol level</li> <li>d) Ice cream</li> <li>e) Do not know</li> </ul>	<p><b>Which of the following is more likely to contribute to your high blood pressure?</b></p> <ul style="list-style-type: none"> <li>a) Physical activity</li> <li>b) Salt/sodium intake</li> <li>c) High cholesterol level</li> <li>d) Eating less than 5 servings of fruits and/or vegetables a day</li> <li>e) Do not know</li> </ul>

At the conclusion of Round 3, the two questions with the highest correct response rate were Question 7 and Question 17. These questions were related to the use of high blood pressure medications and warning signs of strokes. Each question was answered correctly by 8 of the 10 respondents. Though these two questions were often correctly answered, they covered critical concepts and the team

determined they were important enough to retain to help educate the 20% of patients that may not answer correctly.

After the elimination of Question 4 as previously explained, the final knowledge assessment consisted of 17 questions. Final results from Round 3 testing showed that 15 of the 17 items on the final version of the quiz were answered correctly less than 80% of the time; the average correct response rate for the entire quiz was 45%. Outcomes from this iterative testing process enabled the design of an instrument that effectively measures knowledge of hypertension in ED patients and identified high blood pressure education needs.

### ***Information Prescription Content Development***

Following the knowledge quiz development and testing, the team created educational information prescription content targeted to different literacy levels; this content was intended for use during the funded phase of the research project. Learning objectives for the material were drawn from concepts covered in the final version of the high blood pressure knowledge instrument. Information professionals with curriculum development and patient education experience created content relevant to each learning objective. Content was selected from various sources including government agencies and national associations (e.g. National Heart Lung and Blood Institute, the Center for Disease Control and Prevention, and the American Heart Association).

Few guidelines were available for mapping educational content to specific health literacy levels. Adapting a tiered model from diabetes education research by Wolff, et al. [9], the team created two tiers of content for the personalized information prescriptions based on grade level. A “core” set of educational content was written at the 5<sup>th</sup> grade reading level. Additional advanced “supplemental” information written at the 8<sup>th</sup> grade reading level included more complex concepts related to high blood pressure and associated health issues. The determination of which material a patient received was driven by the results of the health literacy testing in the first phase of the larger research project; patients with “inadequate” health literacy were provided with the “core” educational materials, patients with “marginal” health literacy received the “core” materials with the option to receive “supplemental” content, and patients with “adequate” health literacy received both the “core” and “supplemental” materials. Design of the information prescription material followed proven guidelines for clear health communication (e.g. larger font sizes, heavy use of pictures and visual elements, etc. [10-11]).

### **Conclusion**

With the proliferation of health information available through different media (e.g. television, radio, and websites), individuals who have not been formally trained in healthcare may misinterpret or incorrectly apply what they have heard or read. To address this, researchers working in healthcare communication must carefully design knowledge assessment tools that are capable of ascertaining potential confusion from media sound bytes.

This paper describes a study that addresses this critical health issue. A team of librarians and information specialists carefully determined which questions were best suited for the knowledge assessment, largely informed by knowledge gained from a previous pilot study. Knowledge testing, combined with the development of individualized educational materials, provides an opportunity to address knowledge gaps as well as patient misunderstanding of health care concepts. Based on this research, a key recommendation for other investigators is to not blindly adapt questionnaires and tests without first doing refinement and evaluation as this type of validation can potentially determine the overall impact of research interventions.

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## References

- 1) U.S. Department of Health and Human Services. Healthy People 2020: Topics and Objectives. [Internet]. Washington DC; [cited 2011 Jun 3]. Available from: <http://www.healthypeople.gov/2020/topicsobjectives2020/default.aspx>.
- 2) Koonce TY, Giuse NB, Storrow AB. A Pilot Study to Evaluate a Learning-Style Tailored Information Prescription for Hypertensive Emergency Department Patients. Journal of the Medical Library Association. Forthcoming 2011.
- 3) National Heart Lung and Blood Institute. Check your high blood pressure I.Q. Bethesda, MD: U.S. Government Printing Office; 1994.
- 4) American Heart Association. Test Your Blood Pressure IQ. [Internet]. Dallas, TX; [cited 2011 Jun 5]. Available from: <http://goo.gl/HCamw>.
- 5) Chobanian AV, Bakris GL, Black HR, Cushman WC, Green LA, Izzo JL Jr, Jones DW, Materson BJ, Oparil S, Wright JT Jr, Roccella EJ; Joint National Committee on Prevention, Detection, Evaluation, and Treatment of High Blood Pressure. National Heart, Lung, and Blood Institute; National High Blood Pressure Education Program Coordinating Committee. Seventh report of the Joint National Committee on Prevention, Detection, Evaluation, and Treatment of High Blood Pressure. Hypertension. 2003;42:1206-52. DOI: 10.1161/01.HYP.0000107251.49515.c2.
- 6) Heron M, Hoyert DL, Murphy SL, Xu J, Kochanek KD, Tejada-Vera B. Deaths: Final Data for 2006. Natl Vital Stat Rep. 2006 April 17; 57(14): 1-134. Available from: [http://www.cdc.gov/nchs/data/nvsr/nvsr57/nvsr57\\_14.pdf](http://www.cdc.gov/nchs/data/nvsr/nvsr57/nvsr57_14.pdf).
- 7) Egan BM, Lackland DT, Cutler NE. Awareness, knowledge, and attitudes of older americans about high blood pressure: implications for health care policy, education, and research. Arch Intern Med. 2003 Mar 24;163(6):681-7.
- 8) Lloyd-Jones D, Adams RJ, Brown TM et al. Heart disease and stroke statistics--2010 update: a report from the American Heart Association. Circulation. 2010 Feb 23;121(7):e46-e215. Available from: <http://circ.ahajournals.org/cgi/content/full/121/7/e46>.
- 9) Wolff K, Cavanaugh K, Malone R, Hawk V, Gregory BP, Davis D, Wallston K, Rothman RL. The Diabetes Literacy and Numeracy Education Toolkit (DLNET): materials to facilitate diabetes education and management in patients with low literacy and numeracy skills. Diabetes Educ. 2009 Mar-Apr;35(2):233-6, 238-41, 244-5. Available from: <http://tde.sagepub.com/content/35/2/233.long>.

- 10) Plain Language Action and Information Network. PlainLanguage.gov. [Internet]. [cited 2011 Jun 3]. Available from: <http://www.plainlanguage.gov/index.cfm>.
- 11) Centers for Disease Control and Prevention. Simply put: a guide for creating easy-to-understand materials. 2009 Apr [cited 2011 Jun 3]. Available from: [http://www.cdc.gov/healthmarketing/pdf/Simply\\_Put\\_082010.pdf](http://www.cdc.gov/healthmarketing/pdf/Simply_Put_082010.pdf).