

*Research Paper* ■

## Informing Patients: A Guide for Providing Patient Health Information

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**Abstract** **Objective:** To understand and address patients' need for information surrounding ambulatory-care visits.

**Design:** The authors conducted two patient focus groups regarding patient education. The first covered general information needs of patients and the second explored their reactions to a computer-generated patient handout that was developed in response to the results of the first focus group and implemented in a clinic.

**Results:** Participants sought information about their health—generally after the encounter with their caregiver. They wanted a permanent record of personal health data and relevant educational information. Participants recommended that the information be concise, clear, and illustrated with graphics if appropriate. Receiving health-related information from their providers favorably affected the participants' trust in, relationship with, and confidence in their physicians. When given printouts with graphic trends depicting their responses to therapy, participants reported that they were more motivated to adhere to a treatment plan and were more satisfied with their care. Based on the results of the focus groups, we developed a set of attributes (P.A.T.I.E.N.T.) to guide the development of patient and consumer health information.

**Conclusions:** Patients participating in our focus groups felt that providing printed summary information to patients at the end of a clinic visit improves their understanding of their care, enhances their relationships with providers, improves their satisfaction with care, and motivates them to adhere to treatment plans. Further empirical studies are necessary to test their perceptions.

■ *J Am Med Inform Assoc.* 1998;5:563–570.

In general, patients want to participate more in decisions regarding their health and health care.<sup>1–4</sup> Although the exact role that a patient wishes to play in decision making will vary from patient to patient, the desire for information about care is high.<sup>5–7</sup> We are

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This work was supported in part by High Performance Computing and Communications contract N01-LM-43509 from the National Library of Medicine and by Micromedix Corporation.

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Received for publication: 4/8/98; accepted for publication: 7/8/98.

interested in developing, as part of a computer-based patient record system project, tools that assist caregivers in providing better health information to their patients. In this paper, we describe results of two patient focus groups regarding patients' information needs. We previously reported the results of a focus group that covered the broad topic of patient information needs following an ambulatory-care visit.<sup>5</sup> We conducted a second focus group to explore patients' reaction to a document (the after-visit summary) designed to meet the information needs identified by the first group. We believe that addressing patients' need for information will allow them to more effectively participate in their own care.

### Background

#### Literature Review

Observational studies of clinicians' activities during ambulatory-care encounters have showed that the amount of time spent on patient education was both

significant and uniform over a wide variety of practice settings. In an observational study of seven diverse clinical practice sites (primary care, specialty care, faculty practice, independent private practice, and urban care for the under-privileged), approximately 60 percent of the time spent in the encounter was devoted to a dialogue between the provider and patient.<sup>8</sup> Of the time spent talking, a remarkably consistent proportion of that time, approximately 37 percent, was dedicated to performing patient education. This was true regardless of the practice observed or the total time spent with the patient during the encounter.

Although physicians spend a significant amount of time performing patient education, understanding and retention of the information has been shown to be modest at best. Calkins et al.<sup>9</sup> found significant disparity between perceptions of physicians and patients regarding patients' understanding of hospital discharge instructions. In a study done at the Mayo Clinic, patients and physicians were asked to report on major health problems and other problems dealt with during an ambulatory-care encounter. Patients failed to report 68 percent of problems that their physicians listed as being addressed during a specific encounter.<sup>10</sup> In addition, 54 percent of the "most important health problems" physicians discussed during the encounter were not even listed among those that patients recounted after the encounter. If patients and physicians do not agree on the subject matter discussed during an encounter, it is unlikely that the instructions and education provided by the clinician would be effective.

Lack of clear understanding can also contribute to a lack of retention of instructions or explanations. Ley found the ability to recall information presented by physicians in outpatient clinics ranges from 50 percent at 5 min to 56 percent at 1–2 weeks.<sup>11</sup> In a study of patients' recall of medication information, 60 percent of patients did not know the names of their drugs and 20 percent did not know the purpose of their medications.<sup>11</sup>

Physicians' perception of the importance of providing patient education may affect the effectiveness of its delivery. In a study of outpatient care, Laine et al.<sup>12</sup> assessed patients' and their physicians' attitudes toward the importance of nine domains of outpatient care. Patients and physicians differed substantially on 58 percent of the elements measured. The most striking difference was in the area of provision of information, which patients thought was second in importance only to their physicians' clinical skills and which physicians thought was sixth in importance of nine domains.

In summary, physicians uniformly spent a significant amount of their clinic time with patients providing patient education, yet documentation of significant benefit is lacking. Our project team explored ways to improve the effectiveness of patient education efforts during ambulatory-care visits.

### Focus Group on Patient Educational Material

We previously reported the results of a patient focus group regarding patient education.<sup>5</sup> The focus group session time was spent on four general discussion topics: 1) opinions about patient education materials that participants had received in the past; 2) reactions to sample patient education handouts on two common health issues (lower back pain and asthma in adults); 3) reactions to a summary document about a patient encounter (including the provider's name, patient's vital signs, active medications, medication allergies, new medications prescribed, new laboratory tests ordered, new consultations requested, graphed laboratory test results, printed instructions from the visit, and follow-up appointments and phone numbers); and 4) desired attributes of patient education material. We review here the major themes that emerged from the first focus group:

- *Patients' need for information.* Participants wanted more information about their illness and treatment plan than they typically received during physician visits. After an outpatient visit, our patients sought information from a variety of information sources, including friends, relatives, pharmacies, public libraries, and the World Wide Web. They also used the information to explain the outcome of the encounter to their family or friends.
- *Custom-tailored information.* Participants preferred to receive information tailored to their own situation. For example, patients with high cholesterol wanted to see their cholesterol results and an explanation of how their results compare with the normal range, what the consequences are, and how they could take steps to favorably affect the results.
- *Timing of questions.* Patients sought answers to their questions at the time they formulated their questions. This was generally after they left the clinic, not during the encounter.
- *Need for physician endorsement.* Although there are a variety of sources from which to get information (e.g., drug store, library, magazines), participants preferred to receive material that their physician had endorsed as credible and applicable to their specific problem.

- *Access to more information.* Participants wanted their physicians to recommend other sources of information as well. Journal articles, URL addresses, or resource telephone numbers are all helpful. These resources give patients additional comfort and confidence that they have ways to answer future questions.
- *Personal medical record.* Participants wanted to accumulate as much information as possible about their own health and health problems. Some patients who had received printed summaries of their encounter, which included personal data, saved them as their own personal medical record.

## Methods

### The After-visit Summary

Northwestern Memorial Hospital (Chicago, Illinois) implemented a computer-based patient record system, EpicCare (developed by Epic Systems Corporation, Madison, Wisconsin), in selected sites of affiliated physician practices. The computer-based patient record system stores patient demographics, provider

schedules, clinician-entered progress notes, prescriptions, orders, laboratory test results, radiology results, and other patient data. The system automatically generates, at the end of each encounter, an after-visit summary (AVS) containing the patient's vital signs, medication allergies, medications and laboratory tests ordered, patient instructions, and patient educational material. Providers may include educational material from an electronic library of health-related information approved or written by members of the clinic. In addition, providers often include personalized instructions for individual patients. Both personalized instructions and general educational material are included in the encounter documentation. This document is given to the patient at the end of the visit as a summary of the encounter. Based on the results of the first patient education focus group, our project team enhanced the AVS patient handout to fulfil more of the desired attributes described in the focus groups. For example, we added graphic trends of blood pressure and other parameters and provided an explanation of the results. A sample output of the AVS is shown in Figures 1 and 2. The accompanying graphic trend, automatically printed for patients with hypertension, is shown in Figure 3 with explanatory text.

**Figure 1** First page of a sample after-visit summary. The summary typically includes the provider seen, the vital signs for this visit, the allergies on record, new medications prescribed this visit, new orders initiated this visit, and other, current medications. It also includes general information (e.g., information about a disease, guidelines for a low-cholesterol diet, guidelines for weight loss), which may be continued on the second page (see Fig. 2).

Patient		HR #	DOB	Sex
TEST, JACK		182955	06/28/22	M
Date	Time	Clinician Seen Today	Clinic/Dept	
03/15/98	12:22 PM	Tang MD, Paul	NMMH/ATT	

During your visit today, we recorded the following information about you:

Temperature	Pulse	Respiration	Blood pressure
98.6 degrees	66/minute	18/minute	130/75

Weight  
195 lbs

Our records show the following allergies:

Allergy Agents	Noted	Allergy Reaction
PENICILLINS	3/14/98	Shortness of breath

Date verified: 3/14/98

**ORDERS/MEDICATIONS**

**Medications Ordered Today**  
SEPTRA DS TABS 800-160 MG OR 1 TABLET EVERY 12 HOURS  
Refills: 0


**CURRENT MEDICATIONS (PRIOR TO TODAY'S ENCOUNTER)**  
FLUVASTATIN SODIUM CAPS 20 MG 1 tablet every day  
ATENOLOL TABS 50 MG 1 tablet every day  
ASPIRIN TABS 325 MG 1 tablet every day

**Instructions related to today's visit**  
--Bronchitis Information--

Bronchitis is an infection in the air passages in your lungs. It commonly develops as a complication of a "cold." Although the bacterial infection generally responds well to antibiotics, the underlying viral infection (your cold) will run its usual course despite taking antibiotics. Hence, not all of your symptoms will disappear with the antibiotic.

Although there are no medications to cure your cold, there are a number of medications available over the counter (OTC) that can help treat the symptoms:

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Most OTC cold medications include a combination of antihistamines and decongestants (e.g., Theraflu, Dimetapp, Extentabs, Contac). These help dry up your runny nose or unclog your sinus congestion.

The antihistamines tend to make you drowsy, so you should try them out at night first. Since you have high blood pressure, you should avoid medications with "decongestants" as part of the ingredients (e.g. pseudoephedrine, phenylpropanolamine).

If you have a fever or muscle aches or sore throat, you can either take Tylenol (acetaminophen=generic name) or aspirin, or check to see if the cold medication already includes these medications as part of their ingredients.


You should:

1. Take the antibiotic to treat the infection in your bronchial passages.
2. You may take OTC medications for your cold symptoms, but avoid decongestants.
3. Drink plenty of fluids to keep well hydrated.
4. Call your physician if you develop a fever, or your symptoms worsen or persist.

If you have questions, call your Primary Care Provider at (312) 908-8630

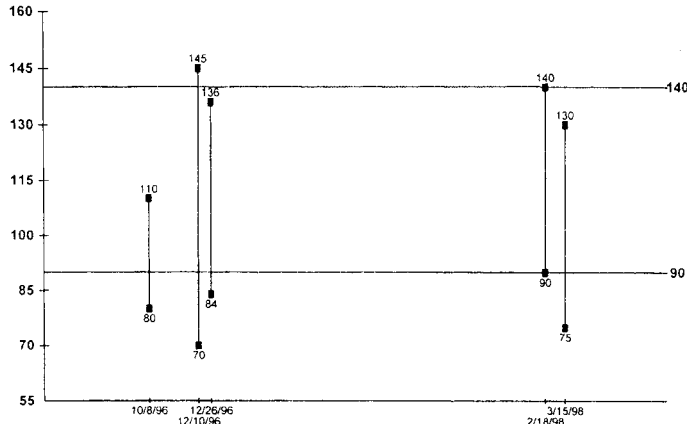
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**Figure 2** Second page of the sample after-visit summary. General information is continued, and patient-specific instructions are included. The phone number of the provider is also given.



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**Blood Pressure for Jack Test**  
03/15/98



Date	Blood Pressure
10/8/96	110 / 80
12/10/96	145 / 70
12/26/96	136 / 84
2/18/98	140 / 90
3/15/98	130 / 75

Blood pressure normally changes with activity and stress. If a person is sitting relaxed their blood pressure is usually less than 140mmHg for the first number (systolic) and less than 90mmHg for the second number (diastolic). When someone's blood pressure is consistently above these numbers we call it high blood pressure or hypertension. Salt restriction and exercise, if appropriate for the individual, are the foundation of treatment.

Medications are used when these simpler measures are not enough. The goal of treatment is to decrease the risk of stroke, heart disease, and kidney disease. Depending on the medications and dosages, the patient's age, other problems, side effects and other individual issues your physician may accept mildly elevated values (160mmHg). The target value for good control is usually a diastolic less than 90mmHg and a systolic less than 140mmHg.

**Figure 3** Sample blood pressure graph included on the sample after-visit summary for a patient with hypertension. The blood pressure recorded on this visit is graphed with blood pressure readings from the preceding four visits. The horizontal lines indicate the upper limits of normal for systolic and diastolic readings. The text at the bottom helps put the "normal limits" in perspective.

### Focus Group on the Enhanced After-visit Summary

After implementing the enhancements to the AVS, we conducted focus groups with patients recently seen in a clinic using the computer-based patient record to get their feedback on the AVS as a patient information document.

Patients sign a release when registering at the clinic. It notifies them that investigators may access their records to conduct research. After obtaining permission from the clinic to use the computer-based patient record for research on quality and patient satisfaction, a list of names and telephone numbers was generated from visit schedules.

Patients were selected from a pool of those with acute and chronic disorders (e.g., hypertension, diabetes, coronary artery disease). For patients with chronic diseases, we selected those who had been seen at least twice in the previous six months and at least once in the previous three months. Acute-care patients were selected from those seen within the previous three months. Patients who attend the internal medicine clinic are over 18 years old. We contracted with an independent market research group to recruit patient volunteers and to facilitate the conduct of the focus groups. The market research firm used an interview script to determine participant eligibility. Potential participants were asked whether they would be willing to discuss health-care-related materials generated from a computer in a group setting. Patients were excluded if they worked in health care, marketing, or advertising, had participated in a qualitative research study within the prior six months, or had participated in a health-care-related study in the past two years. Eligible patients who agreed to participate were arbitrarily divided into two two-hour focus groups of 10 participants each to ensure maximum discussion by each of the participants. There were 11 men and 9 women. The focus groups were led by a trained facilitator, videotaped, and observed by project team members behind a one-way mirror. All observers signed confidentiality agreements. The patients' identities were not revealed. Informed consent was obtained from the participants. An honorarium of \$50 was given to each participant in appreciation of their time.

The characteristics of the focus group participants are summarized in Table 1. The demographics are similar to those of people living in the area near the Northwestern Medical Center in downtown Chicago.

The focus group session time was spent on five general discussion topics: 1) educational materials re-

Table 1 ■

### Characteristics of Participants in the After-visit Summary Focus Groups

	No. of Participants
Sex:	
Male	11
Female	9
Type of visit:	
Acute	5
Chronic	15
Age distribution:	
18–34 years	5
35–49 years	6
50–64 years	5
65+	4
Marital status:	
Married	5
Single/Other	15
Household income:	
<\$25K	4
\$25K–\$49K	10
\$50K–\$74K	2
\$75K+	4
Education level:	
High school	4
Some college	2
College	4
Graduate	10

ceived during an office visit, 2) satisfaction with the materials, 3) use of the materials, 4) suggestions for improvement, and 5) reactions to physicians using computers during the visit. The session was led by a professional facilitator, who used open-ended prompts in general topic areas. The resultant themes were later developed by analyzing the video tapes.

## Results

When asked about information they had received during a recent clinic visit, participants were quick to focus on the AVS. Some of the participants had not received an AVS and were interested in the descriptions of those who had received them. Participants who had not received an AVS did not mention any other methods of "information provided." The participants who had received an AVS were uniformly positive about its value. All the recipients agreed that it was a desirable component of the patient-care experience in the clinic. Several common themes emerged during the discussion, which are summarized below. Many of the

comments validate our findings from the previous focus groups on patient education, either by reiterating points made there or by emphasizing how the AVS addressed patients' information needs.

### Permanent Personal Record

Participants in the focus groups said they wanted information about their health. They appreciated receiving their personal information as a printout they could take home with them and file, which most of them did. The AVS was a helpful tool to answer the inquiries at home:

"When I got home and my wife asked me what happened to me at the doctor's, I pulled out my summary [patient gesticulating] and said, 'Here, read this.'"

"I put [my AVS] by the phone. When my mom called, I told her what my hemoglobin A1c was. When my best friend called, I told him."

"I'm able to take more time absorbing what happened to me."

### Relationship with Providers and Customer Satisfaction

The positive impact of the AVS on the patient-provider relationships and customer satisfaction was pronounced. The quotes below, generated when the participants were asked what they liked about the AVS, illustrate this point.

"I feel like there is more care involved."

"It shows they are paying more attention to you."

"It shows that the doctors are more organized, more professional."

The quality of the patient relationship can also have a positive effect on the personal satisfaction of providers whose professional lives are becoming increasingly burdened with the administrative overhead associated with managed care. Receiving the AVS influenced participants' feelings about the whole encounter. When asked how they would feel if they had to change providers and the new physician did not provide an AVS, one patient replied, "I would ask for it!"

Another goal of the therapeutic relationship is to share decision making with the patient. Providing information to the patient engages the patient in this joint decision-making process:

"When I have this information [in the AVS], I feel like it levels the playing field between the doctor and patient."

"The graphic results help you evaluate yourself."

Patients with a sense of control over their care management are more likely to participate in preventive care, have an improved sense of health, have an increased optimism concerning the efficacy of therapy, and have a reduced number of illness episodes than those with a poor sense of control.<sup>13</sup> In a study examining the emotional response of patients when told they have an abnormal Pap smear, Stewart et al.<sup>14</sup> showed that patients who received an educational brochure reported a reduced level of emotional distress compared with those who did not receive the printed information.

### Adherence with Therapy

The ultimate clinical goal for providing more information to patients is to engage the patient in shared decision making and improve the adherence with jointly agreed-upon treatment plans. Although the health outcome of efforts to improve patient compliance are difficult to measure, we posed the question of how receiving the AVS would affect their adherence with therapeutic plans.

The participants felt that the graphic printouts of trends and identified goals were particularly helpful in motivating them to adhere to prescribed therapy. Their responses included the following statements:

"I didn't care about blood pressure before, but then the graph of my lowered blood pressure after an increase in my medication convinced me. . . . The graph motivates me."

"Seeing a graphic positive trend would be motivating for me."

"The [graphic trend plots] would get you more involved in your own health care. It sets goals for you and makes you pay attention."

### Information in a Computer

Despite the fact that entering information into a computer-based patient record may cause some concern about maintaining confidentiality of patient data, when the topic was deliberately raised, the participants in our focus groups were more focused on the potential benefits to their care:

"Now that my records are on a computer, it should be easier for doctors to find. That is the most important thing."

"Docs using computers. Wonderful!"

As a 72-year-old woman asserted when describing her desire for all her physicians to share her medical data, "They oughta have a server someplace."

## Suggestions for Improving the After-visit Summary

The facilitator also asked for suggestions on ways to improve the AVS. Many participants expressed a desire to include diagnoses on the AVS. Some suggested including even more information on the graphic summaries of their laboratory test results, with personalized "target goals." Because of the perceived value of the graphic charts, participants suggested other enhancements such as using color and indicating borderline abnormal ranges.

## A Guide for P.A.T.I.E.N.T Information

Reviewing the results of two sets of focus groups, the first on the broader topic of patient educational materials and the second covering participants' feedback on an instrument designed to meet patients' information needs, we offer the following guidelines for patient-care educational materials. We call them Personal Articulate Timely Informative Endorsed Next-step Therapeutic (P.A.T.I.E.N.T) guidelines. We describe each attribute here.

- *Personal.* Participants in both focus groups repeatedly emphasized the desirability of having permanent access to specific information about their personal health.
- *Articulate.* Graphic presentations were highly valued for their clarity of presenting information. The clarity of the document was important to its believability and influence on their compliance.
- *Timely.* Like the first focus group, the focus group on the AVS reiterated the value of having a permanent document to review whenever questions arise—when returning home or when needing a reminder or clarification in the future. Another approach to providing access to information when the need arises is to provide patient-specific information over secure Internet connections. Naturally, use of strong authentication methods, such as those employing a physical token, and encryption are requirements for any use of the Internet for transmission of identifiable information.
- *Informative.* As information becomes increasingly accessible over the Internet, and as their interest in self-care increases, participants seek and expect to receive more information from their providers about their health. Educational materials should be as patient-specific as possible. The material should take into account the literacy level and any language barriers that may exist.
- *Endorsed.* Although general information is available from many sources, the accuracy and reliability of recommendations provided are highly variable.<sup>15</sup> Consequently, patients prefer to receive information that is endorsed by their physician.
- *Next-step.* Patients want concise and explicit instructions about the next steps in their care, whether diagnostic or therapeutic.
- *Therapeutic.* Mechanisms to improve understanding and retention of patient information and instructions increase the chance of patients' complying with the instructions.

## Discussion

The results from our focus groups suggest that sharing personal health information with the patient or consumer has a number of potential advantages—improved patient understanding, increased motivation to adhere to treatment plans, and improved patient satisfaction.

We recognize that focus group results are by nature qualitative. One of the limitations of focus group feedback is that when answering hypothetical questions about desirability of one function or another, participants' opinions do not always reflect how they would react if the recommended function were designed and implemented in a real environment. We attempted to overcome this limitation by following up our design focus groups with validation focus groups. Our follow-up groups provided strong validation not only for the original patient information requirements but also for the favorable way in which the AVS document addressed the needs requirements. Further empirical study (e.g., controlled trial) are needed to test the participants' perceptions of the value of receiving information in this manner by measuring their understanding of the material, their compliance with treatment plans, and their satisfaction.

We also recognize that people who volunteer to participate in a focus group may not necessarily represent the broader population of patients of the clinic or the general community of consumers. The consistency of findings between the two sets of focus groups (the focus groups on patient education and the focus groups on the AVS), however, tends to strengthen support of the conclusions within the limitations of the focus group method. We do not know whether the demographics of our focus group participants are representative of the broader community of patients of Northwestern physicians, because many of the socioeconomic characteristics are not systematically ac-

quired during registration procedures at physicians' offices. In general, our participants had a high level of educational background and above-average incomes. Consequently, their information-seeking attitudes and their comfort with printed information may not be generalizable to populations where functional literacy may be more limited, such as those attending inner-city emergency departments.<sup>16-18</sup>

Our experience with the AVS showed that enhancing the health-related information provided to participants in outpatient care favorably affected their trust in, relationship with, and confidence in their physician. Kaplan et al.<sup>7</sup> reported that physicians who spend more time with their patients were rated by their patients as having a more participatory style (they involved patients more in the decision-making process). Unfortunately, the financial pressures of managed care are reducing the amount of time caregivers have to spend with each patient.<sup>19</sup> Our use of a computer-based patient record system to generate an AVS as a byproduct of the routine care process is an efficient method of generating patient-specific material.

The AVS is a tangible example of the potential for a computer-based patient record to benefit patients directly. Although long-term follow-up would be required to prove whether changes in participants' attitudes that resulted from receiving an AVS would translate into a gain in health outcomes, focus group participants report favorable impressions of the AVS and their comments suggest that the AVS may improve the therapeutic relationship. And that is a worthwhile beginning.

The authors thank their NetReach project team colleagues—Barb Boggs, Cindy Fellencer, Susan Gorden, Bill Hamilton, Mary Jaworski, Michael LaRosa, Nancy Kreider, Wendy Marquardt, and Jim Yarnold—who made the use of after-visit summaries a reality for their clinical sites, the clinicians who use the summaries as part of their routine care, and their colleagues in the Information Services Department of Northwestern Memorial Hospital for their contributions to the project.

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