

# THE PERSONAL HEALTH JOURNAL: EMPOWERING PATIENTS BY DESIGN

Rosemary McCaffrey Gill, RN, MS, NP and Nancy Bishop-Abney, RN

One health care system has developed a journal to strengthen the partnership between providers and patients.

**P**roviders and patients often don't see eye to eye in terms of the particular information patients should receive concerning their health and health care.<sup>1-4</sup> Research indicates that patients wish to be informed about key components of their care, including test results, and that this information is more important to patients than providers realize.<sup>2,3,5</sup> If providers take a paternalistic approach to patient information and education—providing patients with what they consider need-to-know information without input from the patients—an imbalance occurs in what patients believe should be a health care partnership.<sup>1-4,6</sup>

Today's patients are more satisfied with their care when they feel they have good communication with their providers and are receiving appropriate information about their health.<sup>1,2,7-9</sup> Without it, patients cannot make appropriate lifestyle changes to improve their health, which may make it more difficult to get the desired outcomes.<sup>1,5-7,10-15</sup>

**Ms. Gill** is the patient education coordinator and **Ms. Bishop-Abney** is a quality management consultant, both at the VA Palo Alto Health Care System, Palo Alto, CA.

Health care delivery increasingly requires sustained treatment of chronic illnesses, especially for the aging veteran population.<sup>16</sup> In order to provide patients with the excellent ongoing primary care and top quality customer service that the VHA is committed to providing, it is essential to foster inclusive relationships by creating provider-patient partnerships.<sup>12,17</sup>

In response to evolving patient needs and concerns, health care organizations are developing better ways to connect with patients. In March 2002, the Joint Commission on Accreditation of Healthcare Organizations initiated the "Speak Up" campaign, which aims to improve patient safety by increasing knowledge and encourages patients to be active and informed health care consumers.<sup>18</sup> Along the same lines, in January 2003, former VA Under Secretary for Health Robert Roswell, MD charged the VHA to find "new ways to partner with patients."<sup>19</sup>

Here at the VA Palo Alto Health Care System (VAPAHCS), Palo Alto, CA, we answered these calls for change while addressing our own patients' grievances. In 1999, we began the Personal Health Journal

(PHJ) project to increase veteran satisfaction with the coordination of primary care visits, to promote a continuum of care, and to create a partnership with patients that would improve their care. In this article, we discuss the conception of the journal, its effectiveness, and how it has helped us develop more inclusive relationships with our patients that better reflect current health care practices.

## ADDRESSING THE PROBLEM

Traditionally, hospitals both within and outside the VA system have been challenged by low rates of patient satisfaction with regard to patient education. At the VAPAHCS, reports of patient discontent, coupled with average to low scores on national and local patient satisfaction surveys, suggested deficiencies in two major areas of ambulatory care: patient education and visit coordination.

On the 1999 national feedback survey, the VAPAHCS's problem score (percentage of patients reporting less than high satisfaction with an indicator) for patient education was 28%, slightly below the VA's national average of 30%. The problem rate for visit coordination was

17%, just above the VA's national average of 16%. Repeated feedback surveys showed that patients wanted to know how they would receive their test results. (In particular, they were unclear as to whether they would get the results by phone or at their next appointment.) Patients also indicated that they wanted to clarify which provider was in charge of their care, what actions to take if their problems or symptoms worsened, the implications of medication changes and test results, and the date and time of pending appointments.

There are few documented studies that have investigated the process through which providers communicate such information to patients. Meza and Webster looked at how patients felt about test result notification. Of 49 patients surveyed, they found that 46 (94%) preferred to be notified of "every laboratory result, whether or not a management change was indicated." They found no correlation between the method of notification and patient satisfaction. There was, however, a positive correlation between being notified and having a higher level of satisfaction.<sup>5</sup>

**DEVELOPING THE PROJECT**

Our concept for a journal arose from our participation in the Patients' Evaluation of Performance in California (PEP-C) project. One PEP-C guest speaker, an executive at a small community hospital in Colorado, described dramatic improvements in patient satisfaction following implementation of a discharge process whereby patients were given a binder containing follow-up information with key contact numbers.<sup>20</sup> When developing our PHJ project and the journal's contents, we used the Colorado

hospital's concept as a starting point upon which to build.

**Journal contents**

We developed the PHJ to contain each patient's personal health information, such as their current maladies and medication schedule, most recent test results, and a list of future appointments (Table 1). In addition, the journal contains the name and contact information for the patient's primary care provider as well as a directory of available services and contact information related to those services. To support educational efforts related to preventive care and the VHA's External Peer Review Program, the PHJ also provides due dates for vaccines, diabetic foot checks, and eye examinations and contains health care system brochures describing the telephone care program, the pharmacy refill system,

and safe medication practices—with key contact numbers.

**Project design**

Staff development was critical to the project. If staff were going to believe in and encourage patients to use the PHJ, leadership support was key. Provider, staff, and patient feedback were used to fine-tune journal contents. For the initial project phase (the pilot study), providers and staff were trained largely by the team members at the pilot site, the San Jose Clinic (SJC), San Jose, CA. The project was designed so that the work involved with the PHJ could be distributed among four parties: clerks, nurses, providers, and patients.

First, the clerks at each primary care clinic print a personalized health summary for each patient at the same time they print the encounter forms for that day. When a

**Table 1. Core elements of the Personal Health Journal**

- **Introductory letter:** Letter to patient from the health care team explaining the journal
- **Personal page:** Personal information sheet on which patient can list emergency contacts
- **General information:** *Telephone Care Program, Primary Care, and Be Safe-Be Informed* brochures; special programs information
- **Advance directive:** Advance directive information sheet with which patient can put a copy of his or her advance directive
- **Future appointments:** Information on what to do if problems return, a sheet on which to list current care providers
- **Medications:** Prescription refill brochure, information sheet on how to take and store medications safely
- **Laboratory and test results:** Sheet explaining common laboratory studies
- **Health maintenance:** Sheet describing common vaccines
- **Patient education:** Blank for patient's use
- **Business office:** Blank for patient's use
- **Notes:** Blank for patient's use

Continued on page 42

Continued from page 38

patient checks in, the clerk gives him or her the personalized health summary along with a cover letter that explains the PHJ process and asks the patient to review the material and formulate any questions for the provider. We estimated that this routine adds only one to two minutes per patient to a clerk's day.

Second, the intake nurse asks if the patient has already received a binder and, if not, gives one to the patient, along with a short explanation. This could take the nurse anywhere from one to five minutes per patient, depending on whether the PHJ has been explained to the patient on a previous visit.

Third, the provider reviews the patient's health summary with the patient during the visit, a process we estimated would take less than 30 seconds per patient.

Fourth, the patient is asked to bring the journal to all clinic appointments and admissions.

The large number of binders required and the time needed to assemble them posed a challenge. Initially, staff and volunteers assembled the binders, but it quickly became clear that it would be more efficient to contract fully assembled journals through the Government Printing Office. At the end of 2002, we purchased 10,000 fully assembled journals, including core contents, at a cost of \$2.55 per item. Funding was provided through the Office of Education with full support of the VAPAHCS director.

## IMPLEMENTING THE PHJ

The first stage of the PHJ project was the pilot study conducted at the SJC between January and September 2001. Using a single site for the study made it easier to modify the journal and the process based

on feedback from staff, providers, and patients. We decided to focus on primary care as the key to a continuum of care because provider-patient relationships are formed in that setting and tend to be more highly developed than in other settings.<sup>21</sup>

The SJC had seven physician primary care providers and 7,100 primary care patients. We began the pilot with one provider and included the remaining providers after several weeks. A six-month,

With the help of the chief nurse for ambulatory care and the nurse managers, we developed a timeline for implementing PHJ procedures at the other clinics. We determined that it was realistic to activate one or two new sites per month and gave priority status to the sites showing the highest patient dissatisfaction rates.

## ASSESSING JOURNAL VALUE

To test the PHJ's effectiveness, we used a quasi-experimental pre-

*Top management supported the PHJ and requested project expansion to include all nine VAPAHCS sites.*

full-time, licensed vocational nurse position was created to launch the project. The team also included the nurse manager and an internist from the SJC. To address staff concerns regarding privacy and release of information, we consulted legal counsel who determined that the contents of the PHJ did not require a formal release of information (ROI) request from patients. (Providing patients with other medical records, such as progress notes, would continue to be regulated by current ROI guidelines.)

Three months into the pilot study, the PHJ project was presented to the executive council of the VAPAHCS. Top management supported the PHJ and requested project expansion to include all nine VAPAHCS sites. This meant that the PHJ would be used in six counties in Northern California and would reach approximately 40,000 primary care patients.

test/posttest design to survey patients at the Modesto outpatient clinic, Modesto, CA. First, we administered the Modesto Journal Satisfaction (MJS) questionnaire, a 10-question survey instrument, to a representative sample of 149 ambulatory care patients. Next, we distributed the PHJ, the independent variable, to all patients visiting the clinic. In preparation for its use, staff attended a one-hour training session on customer service, the need for performance improvement, and the ways in which the PHJ could help meet this need. Six months later, the MJS questionnaire was administered to the original cohort of subjects. Ninety patients (60% of the original sample) completed the posttest.

There was improvement in eight of the nine patient education areas addressed by the MJS, with a mean change of +9.3%, a median change of +9%, and change range

Continued on page 45

Continued from page 42

**Table 2. Scores on the Modesto Journal Satisfaction (MJS) questionnaire\* administered at the Modesto outpatient clinic before and after implementation of the Personal Health Journal (PHJ)**

MJS question	% of positive responses pre-PHJ (n = 149)	% of positive responses 6 mo. post-PHJ (n = 90)	Change (%)
1. Does your provider explain the reason why you need tests in a way that you can understand?	77%	73%	-4%
2. Do you know how you will find out results of your tests?	68%	83%	+15%
3. Do you know when you will find out results of your tests?	42%	65%	+23%
4. After tests are done, does your provider explain the results in a way you can understand?	66%	74%	+8%
5. Does someone explain the purpose for any prescribed medicines in a way you can understand?	74%	80%	+6%
6. Does someone tell you about side effects of your medicines in a way you can understand?	61%	71%	+10%
7. Do you get as much information about your condition and/or treatment as you want from your provider?	63%	72%	+9%
8. Does your provider explain what to do if problems or symptoms get worse or come back?	68%	74%	+6%
9. Do you know who to call if you need help or have questions after you leave your appointment?	63%	74%	+11%
10. Does the Personal Health Journal help you better manage your health care?	N/A	73% (neutral = 25%)	N/A

\*Questions 1–9 were adapted for use in the MJS questionnaire from the Picker Institute (National Research Corporation, Lincoln, NE).

of -4% to +23% (Table 2). While 66 (73%) of respondents indicated that the PHJ helped them better manage their care, 22 (25%) of them were neutral. The level of patient

satisfaction with care remained high, with more than 80% of respondents rating their care as very good or excellent in both the pretest and the posttest.

By June 2002, six of nine primary care sites were using the PHJ for all of their patients (Table 3). Patients at the other three sites began sending written requests for

**Table 3. Timeline for implementation of the Personal Health Journal (PHJ)**

Prior to September 2000	<ul style="list-style-type: none"> <li>• Reviewed patient satisfaction results and suggestions</li> <li>• VA Palo Alto Health Care System (VAPAHCS) participated in Patients' Evaluation of Performance in California project</li> </ul>
September 2000	<ul style="list-style-type: none"> <li>• Talked with Colorado hospital</li> <li>• Customized concept of PHJ for use at VAPAHCS</li> <li>• Discovered barriers: Release of Information (ROI) interpretation</li> </ul>
October 2000	<ul style="list-style-type: none"> <li>• Sought legal opinion: No ROI issues</li> </ul>
October 2000–January 2001	<ul style="list-style-type: none"> <li>• Worked with clinical applications department and programmer to develop the patient health summary</li> <li>• Wrote core contents for PHJ</li> <li>• Worked with graphic design artist to develop cover</li> <li>• Found printing source for binders (Government Printing Office); ordered 1,000 binders and tabs</li> <li>• Sought and obtained patient input (patient education committee)</li> <li>• Worked with one provider at pilot site</li> </ul>
April 2001	<ul style="list-style-type: none"> <li>• Assembled core contents of PHJ</li> <li>• Distributed PHJ to pilot site (at this time only one provider participated at pilot site)</li> <li>• Educated and developed staff</li> <li>• Sought and obtained provider and patient feedback</li> </ul>
April 2001–September 2001	<ul style="list-style-type: none"> <li>• All providers at pilot site began using PHJs</li> </ul>
July 2001	<ul style="list-style-type: none"> <li>• Formally presented PHJ to executive council of the VAPAHCS</li> <li>• Project endorsed/supported by top leadership of the VAPAHCS</li> </ul>
October 2001	<ul style="list-style-type: none"> <li>• Additional site chosen for PHJ distribution</li> </ul>
January 2002	<ul style="list-style-type: none"> <li>• Created timeline for introduction of PHJ at all VAPAHCS sites</li> </ul>
April 2002	<ul style="list-style-type: none"> <li>• "Prejournal" distribution study</li> </ul>
April 2002–June 2002	<ul style="list-style-type: none"> <li>• Coordinated volunteer manpower for journal assembly</li> <li>• Continued expansion of the PHJ core contents based on patient and provider feedback</li> <li>• Six of nine sites brought on board</li> </ul>
October 2002	<ul style="list-style-type: none"> <li>• "Postjournal" survey/study completed</li> <li>• Director increased resource allocation</li> </ul>
October 2002–December 2002	<ul style="list-style-type: none"> <li>• All nine sites distributed PHJ</li> </ul>

PHJs to facility administrators, but we had to postpone plans to add the last sites because of an inability to keep up with journal assembly. Voluntary service enabled us to bring the remaining clinics on board by January 2003, almost two years after the start of the pilot.

**ADJUSTING TO THE CONCEPT**

To make the journal concept a success, we needed a change in culture. First, we had to dispel the myth that VA regulations prohibit the sharing of written clinical information with patients without a formal ROI request. To alleviate this

staff concern, it was necessary to seek legal council before beginning the project.

**Provider adjustment**

Initially, there was some resistance on the part of a few providers to the idea of giving patients their



own test results and problem lists. These providers expressed concern about the amount of time that would be involved in explaining numerous test results and the terminology used in the problem lists. Fortunately, this resistance was offset by strong administrative support for the simple logic of giving patients information they had a right to have.

Developing a partnership with the patients was critical. By promising to provide each patient with a health journal and to contribute to the journal at each primary care encounter, the health care provider began to build this partnership with trust and accountability. In exchange, patients were asked to maintain their journals, refer to them often, and bring them along each time they sought care. The value of the PHJ also was reflected in its durability; its attractive, professionally designed cover; the easy-to-read and standardized fonts used for core contents; and its overall ease of use. By using the highest quality materials within budget and by referring to the PHJ at every visit, the health care providers demonstrated the value of the PHJ and how it promoted patient-provider "partnerships in care."

### Patient adjustment

Overcoming patient reservations to keeping a health journal was equally crucial to the PHJ project's success. Many veterans had come of age in an era when medical decisions were not always participatory. Older, sicker, less educated patients have shown a preference for the more paternalistic doctor-patient relationship.<sup>6</sup> To help patients adjust to the concept of the journal, the PHJ begins with a let-

ter to patients explaining that keeping them informed is a cornerstone of good health care and an important component in their satisfaction with that care. The journal is described as part of a partnership of care and a commitment to care quality. Nurses were given "talking points" to help them explain to patients receiving the PHJ for the first time its purpose and use. As an additional means of explanation and publicity, an article on the PHJ was published in the quarterly patient education newsletter and the PHJ was highlighted as a bulletin board topic in all primary care clinics.

### POST PHJ CARE

Before we incorporated the PHJ into our primary care model, the VAPAHCS lacked a defined mechanism by which to share test results with patients. Although this was accomplished on an individual provider level, the lack of protocol by which it occurred left patients with unclear expectations. Different providers had different styles and, ultimately, patients were left with the notion that "no news is good news."

Now, each patient is given a copy of their most recent test results when they present to the clinic for a primary care appointment. The provider verbally reviews the test results with the patient during the encounter and, after review, test results are kept in the laboratory section of the PHJ and can be accessed by the patient at any time. Providers continue to act upon abnormal laboratory studies or values requiring intervention by contacting the patient by phone.

The PHJ gives patients current information about services that are offered and how to access those services. Most important, each time

patients visit their primary care providers, they are given a personalized patient health summary, which lists their most recent test results, current medications, upcoming appointments, and health maintenance status. Patients, therefore, have access to their health information to review or share with family members at any time.

From the initial pilot distribution to the present (two and a half years later), the PHJ has received scores of compliments from patients who find their journals to be an important part of the health care they receive. Local feedback, collected continuously through our program, shows an upward trend in patient satisfaction in those areas of care aspects we intended to affect most with the PHJ.

Patients, providers, and administrators have adopted the journal concept readily. The PHJ has been distributed to nearly all of the 40,000 patients enrolled in the primary care clinics at the VAPAHCS. New patient education materials have been developed to be used as basic components of the PHJ. The PHJ project has been shared with other VA medical centers nationwide. In fact, VISN 21 leaders have incorporated the PHJ project into their strategic plan, making it a VISN standard of care. The PHJ appears to have the potential to help us meet VA performance measures related to patient satisfaction, but more important, it has been shown to be effective in helping us form partnerships with our patients. These partnerships, we believe, are fundamental to the quality of care we provide. ●

*The authors wish to acknowledge Marilyn K. Douglas, DNSc, RN, FAAN and John B. Pollard, MD for*

Continued from page 47

*their assistance in preparing the manuscript for submission, and the nurses, clerks, and primary care providers who sustain this project.*

*The opinions expressed herein are those of the authors and do not necessarily reflect those of Federal Practitioner, Quadrant HealthCom Inc., the U.S. government, or any of its agencies. This article may discuss unlabeled or investigational use of certain drugs. Please review complete prescribing information for specific drugs or drug combinations—including indications, contraindications, warnings, and adverse effects—before administering pharmacologic therapy to patients.*

## REFERENCES

- Coulter A. Patients' views of the good doctor. *BMJ*. 2002;325:668-669.
- Laine C, Davidoff F, Lewis CE, et al. Important elements of outpatient care: A comparison of patients' and physicians' opinions. *Ann Intern Med*. 1996;125:640-645.
- Boohaker EA, Ward RE, Uman JE, McCarthy BD. Patient notification and follow-up of abnormal test results: A physician survey. *Arch Intern Med*. 1996;156:327-331.
- Richards T. Patients' priorities. *BMJ*. 1999;318:277.
- Meza JP, Webster DS. Patient preferences for laboratory test results notification. *Am J Manag Care*. 2000;6:1297-1300.
- Benbassat J, Pilpel D, Tidhar M. Patients' preferences for participation in clinical decision making: A review of published surveys. *Behav Med*. 1998;24(2):81-88.
- Little P, Everitt H, Williamson I, et al. Observational study of effect of patient centredness and positive approach on outcomes of general practice consultations. *BMJ*. 2001;323:908-911.
- Streiffer RH, Nagle JP. Patient education in our offices. *J Fam Pract*. 2000;49:327-328.
- Terry PE, Healey ML. The physician's role in educating patients. A comparison of mailed versus physician-delivered patient education. *J Fam Pract*. 2000;49:314-318.
- Epilogue—Customer fit: A paradigm shift. *Nurs Clin North Am*. 1999;34:965-967.
- Bodenheimer T, Wagner EH, Grumbach K. Improving primary care for patients with chronic illness. *JAMA*. 2002;288:1775-1779.
- Holman H, Lorig K. Patients as partners in managing chronic disease. Partnership is a prerequisite for effective and efficient health care. *BMJ*. 2000;320:526-527.
- Kaplan SH, Greenfield S, Gandek B, Rogers WH, Ware JE Jr. Characteristics of physicians with participatory decision-making styles. *Ann Intern Med*. 1996;124:497-504.
- Westberg J, Hilliard J. Fostering healthy behavior. In: Woolf S, Jonas S, Lawrence R, eds. *Health Promotion and Disease Prevention in Clinical Practice*. Baltimore, MD: Williams & Wilkins; 1996:146.
- Flocke SA, Miller WL, Crabtree BF. Relationships between practice style, patient satisfaction, and attributes of primary care. *J Fam Pract*. 2002;51:835-840.
- Agha Z, Lofgren RP, VanRuiswyk JV, Layde PM. Are patients at Veterans Affairs medical centers sicker? A comparative analysis of health status and medical resource use. *Arch Intern Med*. 2000;160:3252-3257.
- Bodenheimer T, Lorig K, Holman H, Grumbach K. Patient self-management of chronic disease in primary care. *JAMA*. 2002;288:2469-2475.
- About the Speak Up Program. Joint Commission on Accreditation of Healthcare Organizations web site. Available at: [www.jcaho.org/accredited+organizations/speak+up/speak+up+initiatives.htm](http://www.jcaho.org/accredited+organizations/speak+up/speak+up+initiatives.htm). Accessed October 19, 2004.
- Roswell, RH. Statement before the Committee on Veterans' Affairs, U.S. House of Representatives, on the State of VA Health Care. January 29, 2003. Available at: [www.va.gov/OCA/testimony/030129RR\\_usa.htm](http://www.va.gov/OCA/testimony/030129RR_usa.htm). Accessed October 8, 2004.
- Jessen B. Excel in patient satisfaction through a culture based on information, education, and communication. *Dimensions—A Newsletter to Improve the Patient Experience*. March 2003;1(3):1-2. Available from: National Research Corporation, Lincoln, NE.
- Grumbach K, Bodenheimer T. A primary care home for Americans: Putting the house in order. *JAMA*. 2002;288:889-893.

E-mail us at:  
[fedprac@qhc.com](mailto:fedprac@qhc.com)