

PACO

Patient Advisory Committee

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Carry-along Passport

RA "Health Passport"

The Patient Advisory Committee (PAC) met on July 25, 2007. The main order of business was a working session on the new PACO "Health Passport" for RA patients, which is modeled after a European version produced by EULAR (European League Against Rheumatism).

The Passport is designed to help patients manage their health information and to support communication with their rheumatologist.

After examining a draft of the Passport, PAC members suggested adding:

- Space on the front to record the **date range** covered in each Passport
- Space to record **general health concerns**, since there are many ailments that might be related (For example: skin cancer may be affected by immunosuppressant therapies)
- A **list of contacts** in the Arthritis Center, including nurses
- A **list of questions** that you can use to jump-start conversations with your rheumatologist
- Space to record **surgeries** and other medical procedures
- Space to record **current medications**

Concerning the Passport's format (a booklet the size of a standard passport about 3"x4.5"):

- Several people mentioned that they liked the size, saying that it would be easy to carry
- The majority thought that it could be somewhat larger to leave more space for comfortable writing

Most people liked the idea of being able to keep each completed Passport as a health chronicle, and thus preferred a replaceable approach. We will accompany these replaceable Passports with a permanent booklet where long-term information, such as medical history, medical contacts, and surgeries, can be stored. We also plan to make an electronic version available on the BRASS website.

We are incorporating PAC suggestions into a revised version of the Passport to be distributed at the next PAC meeting.

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Discussion Questions from Dr. Shadick

PAC members responded to questions from Dr. Shadick.

1. What frustrates you most about your clinic visits?

- Doctors who work on their computers while patients are talking. It feels like they are not listening. An instance that doctors may not realize is at the beginning of the clinic visit. The patient maybe answering the question of how s/he is doing, while the doctor is working on the computer, pulling up the patient's file or writing notes.
- Feeling that the visit is rushed. When patients feel that there is not enough time, or that they are keeping other patients waiting, the pressure makes them forget what they want to talk about.

2. For those of you who email your doctors, what do you use email for?

- Questions about issues that come up between visits
- Dosage changes for medication
- Matters that don't require confidentiality or extensive communication
- Matters that aren't time-sensitive: email response times can vary, as some doctors do not check email daily, or on weekends.

3. What suggestions do you have to improve the clinic visit?

- Have another healthcare professional ask questions before the visit, so that the patient is prompted to think about issues ahead. The doctor can then read the interview and address any concerns during the visit.
- Have a technician take vitals so the doctor can have more time. (Some prefer that the doctor do this.)

4. How far away are you from getting back to where you were before your diagnosis?

- The group discussed using the term "new normal" to describe the changes in their expectations, and what constitutes normal, since RA diagnosis.
- Most have had at least a few "normal" days since diagnosis.
- This "new normal" is different for everyone.
- Some mentioned strategies for managing life in light of this, such as taking advantage of days when you feel better to get things done.

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PACO Project

A collaborative effort between patients and researchers at the Brigham and Women's Hospital, funded by Bristol-Myers Squibb



Education for Newly Diagnosed Patients

Plans are underway to make educational materials available to newly diagnosed patients, based on your comments in the May PAC meeting, and ideas from RA nurse Pat Green and others.

An approach we discussed is to create **information packets based on specific topics and stages of disease**. Each packet would feature a laminated, 2-sided document that would contain the basics about the topic, recommended readings, where to go for more information, whom to contact, clinic resources, and brief success stories. The packets would also contain relevant brochures from AF and other sources.

Suggested topics were: **nutrition, exercise, being active, medications, information for partners/friends, alternative therapies, pain management, and patient success stories** (People liked the idea of developing a portfolio of positive success stories that would help new patients learn how others manage their disease, as those available from other sources are often either unrealistic or overly negative).



Buddy System

We heard from patients in the PACO October 2006 focus groups that they would like the chance to talk to others with RA. Many of the focus group participants said that they had never met another patient with RA. Research has shown that, while patient response to different medications may vary, those with chronic illness universally require social support and human empathy to achieve the best physical and emotional outcomes.^{1,2} Buddy systems matching patients with similar needs or interests have been successful in addiction rehabilitation and oncology treatment, and group sessions have long been used as teaching and support tools in diabetes management. Plans are underway as part of the PACO initiative to establish a buddy program as part of the Brigham and Women's Arthritis Center. The Buddy system would be a way to have one patient connect with another patient - to discuss topics of concern, e.g., what to expect when you're initially diagnosed, ways to deal with fatigue, or side effects of medications or any other topic of concern—or simply to chat!

We asked PAC members for their thoughts on how to shape the buddy system. Points discussed were:

- Buddies could find it helpful to be matched geographically so they could meet face to face
- Mini-support group could be a good approach: a short presentation on a topic, followed by time for members to interact

1 King G, Willoughby C, Specht JA, Brown E. Social support processes and the adaptation of individuals with chronic disabilities. *Qualitative health research* 2006;16(7):902-25.

2. Hurdle DE. Social support: a critical factor in women's health and health promotion. *Health & social work* 2001;26(2):72-9.

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