



# PACO

## Patient Advisory Committee

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*Patient Centered Outcomes Initiative (PACO)*  
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## Overview of Rheumatologists' Interviews

One of the goals of PACO is to identify issues of concern to both physicians and patients, to devise ways to address the concerns through changes to the visit to make it run more smoothly and to implement some of these changes into the clinic. In fall 2006 the research team talked with patients in focus groups to learn about their concerns. Over the past year, the research team has been interviewing rheumatologists and fellows, which has brought many valuable insights and suggestions. Among the most interesting reflections are:

- Doctors' overarching goal is to make the patient well, wanting to make sure that they can handle their life - at work, home, and school. One doctor stated, "My goal is to make the patient better and if s/he is not doing well what we can do to make them better." Also part of that goal is to make sure that patients are taking their medicine correctly and safely.
- Doctors view patients as partners in their care. They emphasize the need for patients to come into the visit with a list of current medications, (the dosage, when they take it and whether refills are needed) concerns, questions, chronology of symptoms, and goals. Having this list would make the visit more efficient and allow more time for patient questions.
- Central to the visit is assessing and tracking patient health over time. Most of the rheumatologists rely largely on concrete measurements, blood tests, joint exams and other indicators of disease severity such as hospitalizations. Most said that a tool for tracking patient progress along dimensions not captured through laboratory tests and joint exams such as daily function, fatigue, sleep, and emotional well-being would be helpful.
- Time is a major constraint in the visit. Several of the doctors felt that the limited time prevents them from discussing more functional and social issues with patients.
- Related to discussions of lifestyle and psychological issues, most said they are aware of the patient's lifestyle and goals but do not directly

## Overview of Rheumatologist Interviews (cont.)

ask questions during the visit. Doctors know their patients well and want to keep them doing what they normally do. They consider the patient who enjoys drinking wine and does not want to go on Methotrexate, or the patient who is in her child bearing years and how that affects medication choices. They consider other diseases such as osteoarthritis, the amount of disease activity and severity, whether medications work for the patient, and whether the patient has other co-morbidities.

When it comes to depression, the doctors do not ask about it at every visit. If a doctor thinks something is wrong, or the patient is depressed he will inquire. Certain signs such as patient distress, a decrease in work schedule, enrollment in disability or if patients' tests look fine but they report that they are not doing all the things they would like to will trigger doctors to ask about patients' mental health status. All doctors want a support group or program - if we had the resources available in clinic they would recommend to their patients.



PAC members and the PACO team discussed aspects of the interviews highlighting 1) the importance of having patients bring their medication list (the Health Log is useful for this). The hospital is in the midst of a medication reconciliation program to insure that it can account for the medications patients are on with the goal of reducing errors.

Additionally, insurance companies scrutinize costly rheumatology medications and are requiring reauthorization more frequently than before. In order to maintain medications doctors may have to submit paper work in advance to obtain a new prescription.

The clinic has begun plans to gather patient self-report data before the appointment on functional status, sleep, pain, fatigue and other quality of life aspects similar to information found in the Health Log. Nurse Pat Green commented that this is good not only because it will give the doctors more information about how you are doing and with which to monitor your health, but it will show that the drugs are helping and drug and insurance companies want to see hard data. It will also provide more information on how you are doing in between visits beyond lab reports and will give a more complete picture of how RA affects your life.

## Overview of Rheumatologist Interviews (cont.)

The interviews were conducted with rheumatologists and fellows. One PAC member asked what the difference is. A fellow is a person who has completed medical school and become a doctor but is now working in the rheumatology department to complete training as a rheumatologist. The fellows in the clinic are selected on the basis of a national competition and are excellent doctors. Fellows also have longer appointments with patients, approximately 35 minutes, and are supervised by one of the senior rheumatologists.

## Upcoming Seminar – May 27, 2009

On Wednesday, May 27<sup>th</sup> at 6 pm  
Dr James Ioli, a podiatrist at Brigham and Women's Hospital, will be presenting the next PACO seminar

**“All about Caring for Your Feet: A Session for Those with Arthritis”**



Dr. Ioli is Board Certified in Foot and Ankle Surgery (ABPS), Foot and Ankle Orthopedics and Primary Podiatric Medicine (ABPOPPM). He is a Fellow in the American College of Foot and Ankle Surgeons and the American College of Foot and Ankle Orthopedics and Medicine. He is Chief, Division of Podiatry, Department of Orthopedics at the Brigham and Women's Hospital. Dr Ioli has provided lectures and has co-authored articles for professional journals. His primary areas of interest are foot surgery, diabetic and arthritic disorders and sports medicine.

PAC members gave suggestions for what types of topics they would like covered and questions that would be helpful to have answered by Dr. Ioli. Members were concerned with general foot care, exercises and foot maintenance. Good shoes were of particular concern and patients were interested in learning what companies provide quality shoes as well as where to purchase them. A few patients even had their own recommendations, including Merrill and Naot. Naot can be purchased online ([www.naot.com](http://www.naot.com)) or at the Walking Company. The patient who suggested this brand has them in sandals, and is unsure if they come in closed toe version but affirms that they are more comfortable than sneakers. In contrast, members were also interested in learning about being barefoot and whether or not that is good for the feet. Several patients commented on how painful being barefoot can be and are interested in more information regarding that matter. A few PAC members would like to learn more about solutions for when feet are in pain or not doing well. They wondered if remedies such as soaking, elevating, massaging or getting a pedicure might be helpful.

## Discussion about clinic wait times

At the end of the meeting Dr. Shadick conducted a discussion on the topic of what the PAC would like the committee to do. Thus far the PAC has been successful in developing the Health log and building awareness with hospital administration to improve the registration process and parking assistance. The Health log will soon be distributed to BRASS patients as well as newly diagnosed patients. The PACO team is hoping to start a program titled "CARE-PAC" that works with patients and their significant others in order to research what partners go through, and how they help patients with their illness. It will include more seminars relating to partners and patients and will be open to all. Currently there is no other program in the country like this.

Several patients commented about the "wait time" to see their rheumatologist. One person noted that the wait was 2.5 hours once. Dr. Shadick and the committee brainstormed strategies that might circumvent a long wait. One idea would be to have someone call the patient and tell them that the doctor was running late and give an estimate of when to come in. If the patient was already in the waiting room, someone could let the patient know so that they could do errands while waiting. Another possible solution would be to have the patient get their blood drawn or X-rays taken if



Next PAC Meeting - May 29, 2009

Time: 12:00 - 2:00pm

Location: Bayles Conference Room  
75 Francis Street