

# The Benefits of Online Communities for Pre-Operative Knee Replacement Patients

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Online patient communities and patient forums have sprouted up all across the web, focusing on diseases and conditions ranging from insomnia, to epilepsy, to cancer, and joint replacement surgery. For the most part, these forums serve as a reliable source of medical information and the benefits of them are becoming well documented.

One community in particular, patients planning for knee replacement surgery, is showing dramatic growth and popularity. Pre-operative knee replacement patients create a social network in the online forums where members can discuss their concerns about upcoming surgeries and ask specific questions from moderators and experienced e-patients.

Tom Ferguson and Dan Hoch's article, "What I've learned from E-Patients," breaks down the benefits of e-patient forums into three useful categories: source of support, source of information, and source of collective knowledge and experience. In terms of support, the authors write, "The constant outpouring of sympathy and support that we observed in interactions among community members surpassed anything a patient might conceivably expect to receive at a doctor's office."

Pre-operative knee replacement patients benefit enormously from the support they receive in forums like the one at BoneSmart.org. Josephine Fox, chief moderator at the BoneSmart.org knee replacement forums and nurse of over fifty years, says that encouragement and reassurance from the peer group increases confidence and provides a sense of stability. Moreover, she and another moderator, who have both undergone knee replacement surgeries themselves, act as specialized sources of support and information. A sticky note posted at the top of the forums tells patients not to be discouraged by the "number of problems that seem to be represented" by user posts.

The goal of these forums is to foster communication between persons who may need knee replacement surgery and those who have had one or more of their own joints replaced. Experienced users are encouraged to help "mentor" new patients, and provide a nurturing environment of support and knowledge.

Online forums are also useful as sources of information. Pre-operative knee replacement patients ask specific questions like, "Is it better for me to wait before getting a surgery?" and "How active will I be after the surgery?" Patients receive advice on choosing a surgeon, and are properly informed about

surgical procedures, rehab and recovery. To someone who is just beginning to investigate knee replacement surgery, the various approaches and procedures can be overwhelming. This is where the moderator's specialized knowledge and the community's general knowledge assist the pre-operative patient.

The authors of "What I've learned from E-Patients" write: "About 10% of the members' posts spontaneously mentioned that they had been unable to get the medical information that they needed from their own clinicians. When we surveyed members directly, more than 30% said that they had been unable to obtain all the medical information they would have liked from their physicians." From these findings, the authors reason that online patient forums are serving a real need for medical information.

But collective knowledge and experience in patient communities serve as perhaps the greatest benefit. Josephine Fox writes that worries about longevity of implants and incidence of complications and failures are assuaged in the knee replacement forums. By sharing their experiences, patients can provide more assistance to each other than even a physician might be able to. Tom Ferguson notes, "I have also learned that an online group . . . is not only much smarter than any single patient, but is also smarter, or at least more comprehensive, than many physicians-even many medical specialists."

#### About BoneSmart.org

BoneSmart.org is a National Public-Awareness Campaign for Candidates of Hip Replacement Surgery and Knee Replacement Surgery. The BoneSmart® National Consumer Awareness Campaign's mission is to raise patient awareness of the options available to persons diagnosed as a hip replacement or knee replacement candidates by providing an Internet portal for awareness of the latest advances in joint replacement materials, their longevity and suitability for various applications. With this information the potential patient may be better informed when discussing options with his or her surgeon.