Development of a Patient-and-Family-Centered Guide for Patients with Serious Illness

The Problem
It is important for seriously ill patients to understand the full range of treatment options available to them. In addition, a law recently passed in Massachusetts and associated Department of Public Health (DPH) regulations require that health care systems and providers identify patients at increased risk of death, and then ensure that they are offered information and counseling about their end-of-life care options. BIDMC incorporated these regulatory requirements into a policy (PR-02 Informed Consent and Decision Making), and tasked a work group with crafting an informational pamphlet to be distributed to appropriate patients.

Aim/Goal
To produce a patient-and-family-centered guide for BIDMC patients with serious illness that is accessible, respectful and compassionate, and that fulfills the DPH regulation.

The Team
- Sarah Bates, BA, Center for Bioethics
- Lachlan Forrow, MD, Ethics; Palliative Care
- Jennie Greene, MS, Department of Medicine
- Caroline Moore, MPH, Patient & Family Engagement
- Barbara Samoff Lee, LICSW, Social Work
- Lauge Sokol-Hessner, MD, Health Care Quality
- Jacqueline St. Onge, BA, Department of Medicine
- Jane Wandel, RN, Department of Nursing
- 44 Patient and Family Advisors

The Interventions
1. Team modified MA Department of Public Health's (DPH) "Guide for Patients with Serious Advancing Illness" to incorporate BIDMC's culture principles, and resources.
2. New version was sent to 25 Patient and Family Advisors, who reviewed the guide and completed a survey eliciting reactions and suggestions.
3. Team further revised the guide based on survey data.
4. 8 Patient and Family Advisors participated in a focus group to review the original DPH version alongside BIDMC's version.
5. Team made considerable revisions based on focus group findings (e.g., preference for "nuts-and-bolts" information, Q&A format, and photo).
6. 15 Advisors, 4 of them new to the process, reviewed the revised draft and offered additional comments, suggestions and edits.
7. Team incorporated feedback into final draft for printing and distribution.

The Results/Progress to Date

Lessons Learned
Throughout the year-long process, the Patient and Family Advisors supported the idea of a guide for patients with serious illness. However, Advisors stressed that complex care decisions call for face-to-face discourse, supplemented with but not replaced by written materials. Advisors’ feedback taught the team that assumptions about what patients want and need in this guide may be flawed. Involving Advisors early in the process of developing patient-facing communications results in a savings of time and money, and helps ensure the dissemination of patient-and-family-centered materials.

Next Steps/What Should Happen Next
- The materials will be integrated into inpatient settings via the BIDMC Welcome Packet after outreach is done to key stakeholders.
- The team continues to collaboratively develop distribution processes for ambulatory practices.
- The materials will be shared with DPH and other medical centers.
- Feedback on the packet will be solicited from patients, family members, and providers, and revisions will be made as needed for future printings.
- A system will be developed to measure dissemination of the materials and the process of distributing them will be modified as needed.
- Translated versions will be developed.

For more information, contact: Lauge Sokol-Hessner, MD, Associate Director of Inpatient Quality, lhessner@bidmc.harvard.edu