Published in final edited form as:

JAMA Surg. 2016 October 1; 151(10): 938–945. doi:10.1001/jamasurg.2016.1308.

Engaging Patients, Providers and Community Members to Develop a Tool to Improve Preoperative Decision Making for Older Adults Facing High-Risk Surgery

Nicole M. Steffens, MPH^{1,2}, Jennifer L. Tucholka, BS¹, Michael J. Nabozny, MD¹, Andrea E. Schmick, BA^{3,4}, Karen J. Brasel, MD, MPH⁵, and Margaret L. Schwarze, MD, MPP^{1,6}

¹Department of Surgery, University of Wisconsin. Madison, Wisconsin

²Denver Public Health, Denver Health and Hospital Authority. Denver, Colorado

³Department of Family Medicine and Community Health, University of Wisconsin. Madison, Wisconsin

⁴Department of Pediatrics, University of Wisconsin. Madison, Wisconsin

⁵Department of Surgery, Oregon Health & Science University. Portland, Oregon

⁶Department of Medical History and Bioethics, University of Wisconsin. Madison, Wisconsin

Abstract

Importance—Older patients are at greater risk for postoperative complications yet they are less likely than younger patients to ask questions about surgery.

Objective—To design an intervention to improve preoperative decision making and manage postoperative expectations.

Design—We created a Patient and Family Advisory Council (PFAC) to help identify preoperative decisional needs. We met monthly for one year to examine findings from a prior qualitative study and to integrate themes with PFAC members' lived experience. PFAC members and other stakeholders evaluated 118 publically available questions and selected 12 corresponding to identified needs to generate a question prompt list. To refine this intervention, we conducted focus groups and a clinical pilot.

Setting—The local library and one outpatient surgical clinic in Madison and three community centers in Madison and Milwaukee, Wisconsin.

Participants—Four men and women who had previous experience with high-risk surgery as either older patients or family members participated in our PFAC. Three focus groups included 31

Correspondence: Margaret L. Schwarze, MD, MPP, G5/315 CSC, 600 Highland Ave, Madison, WI 53792, Phone: (608) 265-4420, Fax: (608) 265-1148, schwarze@surgery.wisc.edu.

Data Access: Dr. Schwarze had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Conflicts of Interest: The authors have no conflicts of interest—including relevant financial interests, activities, relationships, and affiliations—to report.

community members from diverse backgrounds. We pilot tested the intervention with 42 patients considering surgery.

Exposure(s)—None

Main Outcome and Measure(s)—Generation of an intervention to address patients' preoperative informational and decisional needs.

Results—Through exploration of qualitative data the PFAC noted three critical problems; patients and family members believed surgery “had to be done,” were surprised that postoperative recovery was difficult and lacked knowledge about the use of advance directives perioperatively. The PFAC identified a need for more information and decisional support during preoperative conversations including clarification of treatment options, setting postoperative expectations and advance care planning. Three question prompt categories arose: “Should I have surgery?”, “What should I expect if everything goes well?”, and “What happens if things go wrong?” The final list includes 11 questions within these domains, was understandable in English and Spanish, and was acceptable to patients in clinic.

Conclusions and Relevance—Through direct engagement of stakeholders, we created a question prompt list to address core decisional and informational needs of surgical patients. Future testing will evaluate whether this list can be used to improve patient engagement and reduce postoperative regret and conflict about postoperative treatments.

Introduction

Each year, approximately 500,000 Americans age 65 and older will have a high-risk operation, such as heart bypass or major cancer surgery.^{1–3} Although many patients benefit from high-risk surgery, it carries real potential for mortality and serious complications, particularly for older patients with multiple comorbidities. High-risk surgery can have other unintended consequences including postoperative suffering, conflict about additional aggressive treatments and receipt of unwanted interventions.^{4,5} Thus, much is at stake for patients in the decision to proceed.

Surgeons play an important role helping patients make preference-sensitive decisions. Yet, they often miss opportunities for these discussions.^{6–11} Patients report that “explanations are rushed, issues are not explained, and choices are not understood.”¹² While patients generally prefer involvement in the decision-making process, they frequently do not know how to engage.^{13,14} Patients who are activated receive more patient-focused care and are more likely to take part in collaborative decision making.^{15,16} This is especially critical for older patients, who are less likely to ask questions and less effective in ensuring that physicians attend to their concerns than younger patients.¹⁷

In other settings, question prompt lists (QPLs) can effectively improve patient engagement.^{18–22} Questions “to ask your surgeon” exist, but patients who have experience with surgery rarely participate in their development. To improve patient engagement in surgical decision making, we need to bridge the gap between patients' need to make the consequences of surgery relevant to their lives and the surgeon's goal of setting realistic expectations. The objective of this study was to design an intervention to improve

preoperative decision making. By formalizing a partnership between patients, family members and researchers, our Patient and Family Advisory Council (PFAC) developed a QPL to help older adults with high-stakes surgical decisions.

Methods

Development of a PFAC

We engaged with our PFAC as consultants to provide feedback and reflection on our research, specifically to clarify concepts from previously generated qualitative data and integrate the PFAC's lived experiences with identified priorities. We enlisted PFAC members through clinic nurses, surgeons and hospital patient relations. We invited patients and family members of older patients who had experience with high-risk surgery and purposely selected a small group with strong literacy skills who could critically interpret abstracted data. Two members previously had major surgery (cardiac, neurologic) and two members were primary care givers for patients who had surgery (vascular, oncologic). This group of two men and two women met monthly at a public library and received \$1000 for attendance at twelve 90-minute meetings, reviewing materials independently, and travel.

Origins of Qualitative Data

Before conception of our PFAC, we conducted an observational qualitative study over a three-year period that included 91 audio recorded preoperative conversations between patients and 11 surgeons described in-depth elsewhere.^{10,23,24} We also interviewed patients before (n=34) and after (n=27) surgery. We used an inductive coding strategy and deliberative adjudication process among researchers to support higher-level analysis whereby codes were expanded and refined to capture phenomena present in the data.

PFAC Process

Meeting agendas included an opening question, a statement of the meeting objectives, and a wrap-up forecasting next steps. (Table 1) Our first meetings established project goals, timeline, and expectations. Members also shared their experience with surgery. Next, we presented themes from our qualitative analysis and linked each theme with a deidentified patient story. Members discussed their reactions and connected study data with their personal experience with high-risk surgery. This member-checking process²⁵ enriched data integration with the lived experience of members of our PFAC (Figure 1).

QPL Development

Discussions from the first three PFAC meetings generated key informational and decisional deficits to guide development of the QPL. We then collected 271 "questions to ask your doctor" from publically available websites^{26–29} and published literature.^{21,30–32} and excluded duplicate questions and concerns irrelevant to our targets (e.g. "Is there anything specific I need to bring to the hospital?") We asked PFAC members, two surgeons who routinely perform high-risk operations on older patients, a patient advocate and a hospital administrator to score the remaining 118 questions on a 5-point Likert scale.

We brought the 20 highest-rated questions to the PFAC. Members deliberated about the meaning of each question, whether they could ask each question, and whether the surgeon's answer would be valuable. Using these criteria, they generated a 12-question prototype.

Community Focus Groups

We presented the prototype QPL to focus groups and iteratively revised it in response to feedback. We engaged a well-established panel of people (6 participants) specifically trained to provide feedback to researchers and hailing from difficult-to-reach populations recruited from service programs such as food pantries and parenting groups.³³ A facilitator presented each question and asked: "Does this question make sense?" "Would you feel comfortable asking this question?" and, "If you ask this question, what information are you hoping to get?" We brought the revised prototype to a second group (6 participants) and a Spanish version to 19 Spanish-speaking seniors who reflected on the appearance, comprehensibility, and whether they could ask the questions to a surgeon.

Because QPLs are effective only when physicians endorse their use,²⁰ we employed this same iterative process with our stakeholders: the PFAC, two surgeons and community groups, to generate a letter from the surgeon to accompany the QPL.

QPL Pilot

To evaluate the acceptability of our QPL, we tested pre-visit mail delivery of the QPL and surgeon letter at a local vascular surgery clinic. We then informally interviewed patients who had received the intervention about its use and ascertained their comfort asking the questions. We also solicited feedback from surgeons.

Human Subjects Considerations

Collection of qualitative data was approved by the Institutional Review Boards (IRB) of the University of Wisconsin and Partners Health Care System and the Research Ethics Board (REB) of University of Toronto. We did not pursue IRB approval for the work described by the PFAC or community groups as they did not have access to protected health information and are considered research advisors. All PFAC members were apprised of the extent of this project in advance, their compensation and participated voluntarily. The QPL clinical pilot was exempted from IRB review.

Results

PFAC members identified informational and decision support failures in the qualitative data including misunderstandings about treatment options and postoperative expectations. They then integrated this with their lived experience to generate a QPL to address these deficiencies. After examining the qualitative data, PFAC members felt patients and family members were unprepared for surgery. They were concerned that patients believed surgery "had to be done," were surprised that postoperative recovery was difficult and lacked knowledge about the use of advance directives. (Table 2)

Choices

PFAC members examined qualitative data that exposed a lack of choice about whether to have surgery. Patients in the qualitative study reported their surgeon had not presented alternatives or that the alternatives presented were unacceptable. This notion was linked to belief that the surgeon felt strongly surgery should be done or a personal understanding that their illness required surgery. These data showed patients and families had developed an understanding that the disease itself compelled the need for surgery, thereby determining the absence of alternatives.

Furthermore, in the setting of an unwanted outcome this inextricable link between surgery and disease provided reassurance about the choice to proceed with surgery. For example, the wife of a patient whose cognitive impairment progressed markedly with surgery sought comfort with their decision: "... *because we asked the doctor... because he said about the confusion [dementia], it could have been worse with the surgery. I said, well, what's my option? Does he really need the surgery...and he goes, no, he did need it.*" Another patient who spent months in the hospital after resection of a benign pancreatic mass reported, "*I wouldn't have had surgery if I didn't have to have the tumor removed.*" Belief that there was "*no choice*" or surgery "*had to be done*" appeared comforting to patients with serious illness and generated concern from the research team that this conviction should not be disrupted by efforts to improve decision making.

PFAC members were distressed that our qualitative study patients appeared uninformed about alternatives. Simultaneously they empathized with the notion that surgery had to be done. One member told us "[patients] *already have one foot into the surgery room*" before meeting a surgeon, as the referral process promotes a message that surgery is essential. Still, they were clear that informed decision making was crucial for all patients even if they ultimately concluded surgery "*had to be done.*" They stressed that patients need to be "*told all the ramifications and possibilities of both having [surgery] and not having it*" which requires a clear explanation about what could be gained and what would happen without surgery.

These discussions generated the first decision support target for our QPL: "Should I have surgery?" Our PFAC wanted patients to deliberate about having surgery and receive explicit information about how surgery might improve symptoms or longevity. To address this need, our stakeholders selected the question prompts: "What are my options?" "What is likely to happen if I do have surgery? If I don't have surgery?" "Will surgery make me feel better?" and "Will surgery help me live longer? If so, how much longer?"

Expectations

The PFAC explored qualitative data suggesting patients were unprepared for what occurred postoperatively. For example, one patient noted she had been apprised of specific risks, but did not recognize this information could be used to prepare for complications or prolonged recuperation. She described how frightened she was by her slow recovery and postoperative weakness:

No, no I wasn't expecting anything. They didn't tell me there could be [complications]. They did say you could develop A-fib and they did say that after the operation you could have a stroke or heart attack... So I didn't really, I did ask questions, but I guess I didn't ask if it would be a long recovery or what could happen...I mean you're not expecting, and I don't think you know all the questions you should ask...

Although surgeons named risks and described operations under consideration as “*big surgery*” patients struggled to translate this information. Patients assumed they would return to normal postoperatively: “*If I can't come back normal, I don't want to come back.*”

The PFAC expressed concern that patients underestimated the impact and had a naive outlook about the seriousness of surgery, leading to surprise or distress when recovery was arduous. This notion was familiar to PFAC members who reported feeling “*blindsided*” postoperatively. They worried that what was “normal” after surgery for the surgeon was not “normal” for the patient and this might cause distress when the surgeon's expected outcome was unexpected by the patient.

This discussion generated the target, “What should I expect if everything goes well?” The PFAC chose question prompts to prepare for recovery and long-term physical changes including: “How do you think my daily life will look after surgery? Right after surgery, three months later, one year later?” “Will I have any tubes or drains put in during or after surgery? Will I need them at home?” “How will this surgery affect my other health problems?” and “After I leave the hospital, what type of care do you think I will need?”

Complications

The PFAC reviewed qualitative data that exposed wide variation in treatment preferences for serious postoperative complications. Patients believed the surgeon knew their wishes despite lack of explicit discussion. For example, one study patient stated, “*The only thing I don't want, if I do die, I don't want to be revived...*” This type of *information* was not discussed with surgeons. A few patients mentioned their advance directive, but the surgeon did not explore their preferences further. Thus it was unclear how to proceed in the event of a postoperative complication. Some believed family members were familiar with their preferences and could make decisions if needed.

PFAC members were concerned that patients needed more advance care planning. They expressed dismay that patients' treatment preferences were not communicated: “*There is a disconnect between what the patients want and who is the right person to tell these wishes.*” The PFAC struggled to understand how specific directives might need to be tailored to the surgical setting, and were shocked by the lack of standard procedures for notifying all providers about existing directives. They identified a critical need for patients to clarify their preferences with the surgeon and discuss how directives might be interpreted during the perioperative period.

The PFAC sought questions to promote conversation about “What happens if things go wrong?” They chose question prompts to encourage this type of discussion: “Can you describe serious complications and explain what those might mean for me?” “If I'm too sick

to speak for myself, how can I make sure you know my wishes?” and “If I decide to appoint someone to make medical decisions for me, what do I need to do to make those arrangements official?”

Acceptability of the QPL

English and Spanish-speaking community members endorsed the questions on the QPL and felt they could ask all questions on the list. Surgeon stakeholders agreed they could answer the questions.

We iteratively revised words that community members felt were difficult to understand or use in conversation. Community members worried that “Will surgery help me live longer?” was difficult to answer because it suggested surgeons can guarantee specific outcomes. They did not want patients to “*hold doctor[s] accountable*” for unreasonable information and suggested we add “In your opinion” to three questions. Community members praised the brochure’s clarity and understood they did not need to ask every question. They were not frightened by questions about advance care planning. Our final QPL intervention is a brochure with 11 questions (Figure 2) and a letter from the surgeon endorsing its use.

Pilot testing

In clinic, patients used the QPL to assist communication and felt confident they were well informed. They noted “*it puts questions in your mind*,” “*...questions you never would have thought to ask*.” They felt they were able to explore how surgery might impact their quality of life and to secure formal designation of a health care proxy – “*just in case*.” One patient reported nervousness upon receiving the QPL because he did not know “*surgery was on the table*” and had inferred his problem was serious. Still, this patient understood surgical consultation was an opportunity to get his questions answered. During consultations surgeons noted patients would pull the list out to ensure their questions were answered.

Discussion

Through engagement of patients, family members and other stakeholders we created a QPL to address core decisional and informational needs of patients considering high-risk surgery. The intervention, which includes both the list of questions and a supportive letter from the surgeon (available at <http://www.hipxchange.org/SurgicalQPL>), targets elements of primary importance for informed decision making, including discussion of treatment options, clarification of goals and preparation for both expected and unexpected outcomes. Although these elements seem to be covered during traditional informed consent, this intervention is designed to rectify gaps in communication identified by patients and family members that current practices fail to address. These results have important implications for surgeons, patients and their family members.

For surgeons, this intervention will require translating professionally defined notions of risk and benefit into patient-centered outcomes, specifically goals and expectations. We have previously documented that surgeons skillfully describe the gravity of high-risk surgery and routinely disclose risk,²⁴ yet we find it remarkable that this process inadequately supports patients as they decide about surgery or prepare for expected outcomes. Although surgeons

work hard to provide critical information, the meaning of “big surgery” and “risk of heart attack” is unfamiliar to patients and families who struggle to imagine how such events may be experienced. Rather than more information, they need more interpretation of the information surgeons currently provide.³⁴ QPL questions are framed to help patients access surgeons’ knowledge in a way they can understand.

For patients, the QPL aims to promote informed decision making by supporting inquiry with questions they would not have thought to ask. Traditional models of clinical decision making theorize that patient preferences for decisional control are unique and decision dependent: some prefer complete physician control whereas others want equally shared decisions or complete control.^{35,36} Newer theoretical models propose most patients want to be involved; they simply do not know how.¹⁴ This problem can be mediated by pre-visit education or coaching with interventions like the QPL. Because the patient experience is transactional, i.e., it is determined by the actions of both surgeons and patients,³⁷ patients who are motivated to be involved are more likely to participate in collaborative decision making.

Although many lists of “questions to ask your surgeon” exist, they contain questions that patients ask spontaneously. In our observation, surgeons regularly inquire whether patients have questions and patients respond with logistic or technical concerns: “Can my wife sleep in my room?” and “Will you use stitches or staples?”²⁴ While these concerns are important to patients, these questions do little to engage patients in a discussion about trade-offs, or set realistic expectations for what life might be like after surgery. The QPL addresses specific needs that aren’t routinely queried by patients and families.

For family members, the QPL provides an opportunity to discuss unwanted outcomes at a time when the patient, surgeon and family are together and able. Postoperative conflict about life supporting treatment is distressing³⁸ as patients aren’t always clear about their preferences preoperatively²³ and surgeons are surprised when patients have not bought in to the use of prolonged life support.⁸ While some patients may be too anxious to have such conversations before major surgery, we found many patients who desired this type of discussion.²³ Furthermore, respondents in our focus groups and patients in the pilot understood they did not need to ask every question.

Our study has strengths and limitations. Our qualitative data was collected in multiple sites in order to capture geographic variation and demonstrated robust patterns of preoperative conversation.¹⁰ However, there may be regional differences in how surgery is presented and understood by patients not captured by our sample. Although we have piloted the QPL and others have demonstrated the efficacy of such interventions, the effectiveness of this QPL is unknown. We need evidence about how the QPL might improve these high-stakes conversations, support value-directed deliberation, set realistic postoperative expectations and avoid conflict in the setting of an unwanted outcome. We have recently received funding from the Patient-Centered Outcomes Research Institute to test these effects in a randomized controlled trial.

Conclusion

We integrated the experiences of patients and family members through observational study and direct stakeholder engagement to create a QPL for older adults considering high-risk surgery. This intervention aims to overcome gaps in current practice by activating patients and family members before surgical consultation in order to promote deliberation about treatment choices and prepare patients for both expected and unexpected outcomes.

Acknowledgments

The authors would like to thank Betty Kaiser, PhD, RN, and Gay Thomas, MA, from the Wisconsin Network for Research Support for their guidance in creating our Patient and Family Advisory Council and support with meeting planning and evaluation. We would also like to thank the Qualitative Research Group supported by the Institute for Clinical and Translational Research (ICTR) at the University of Wisconsin and Nora Jacobson, PhD, for assistance with the study research design and analysis.

Financial Support: Dr. Schwarze is supported by 1) Training Award KL2TR000428 from the Clinical and Translational Science Award program, in part by grant UL1TR000427 to UW ICTR from NIH/NCATS; 2) through the University of Wisconsin-Madison School of Medicine and Public Health's Wisconsin Partnership Program, WPP-ICTR grant #3086; and 3) the Greenwall Foundation (Kornfeld). The project described was also supported by the National Institute for Minority Health and Health Disparities Center of Excellence program through University of Wisconsin Collaborative Center for Health Equity Grant 5P60MD003428. Research reported in this article was partially funded through a Patient-Centered Outcomes Research Institute (PCORI) Award (CDR-1502-27462). The statements in this article are solely the responsibility of the authors and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute (PCORI), its Board of Governors or Methodology Committee. These funding sources had no role in the design and conduct of the study; collection, management, analysis, and interpretation of the data; preparation, review, or approval of the manuscript; and decision to submit the manuscript for publication.

References

1. Goodney PP, Stukel TA, Lucas FL, Finlayson EV, Birkmeyer JD. Hospital volume, length of stay, and readmission rates in high-risk surgery. *Ann Surg.* 2003; 238(2):161–167. [PubMed: 12894006]
2. Finks JF, Osborne NH, Birkmeyer JD. Trends in hospital volume and operative mortality for high-risk surgery. *N Engl J Med.* 2011; 364(22):2128–2137. [PubMed: 21631325]
3. Schwarze ML, Barnato AE, Rathouz PJ, Zhao Q, Neuman HB, Winslow ER, Kennedy GD, et al. Development of a List of High-Risk Operations for Patients 65 Years and Older. *JAMA Surg.* 2015
4. Scarborough JE, Pappas TN, Bennett KM, Lagoo-Deenadayalan S. Failure-to-pursue rescue: explaining excess mortality in elderly emergency general surgical patients with preexisting "do-not-resuscitate" orders. *Ann Surg.* 2012; 256(3):453–461. [PubMed: 22868360]
5. Paul Olson TJ, Pinkerton C, Brasel KJ, Schwarze ML. Palliative Surgery for Malignant Bowel Obstruction From Carcinomatosis: A Systematic Review. *JAMA Surg.* 2014
6. Braddock C 3rd, Hudak PL, Feldman JJ, Bereksnyi S, Frankel RM, Levinson W. "Surgery is certainly one good option": quality and time-efficiency of informed decision-making in surgery. *J Bone Joint Surg Am.* 2008; 90(9):1830–1838. [PubMed: 18762641]
7. Fagerlin A, Sepucha KR, Couper MP, Levin CA, Singer E, Zikmund-Fisher BJ. Patients' knowledge about 9 common health conditions: the DECISIONS survey. *Med Decis Making.* 2010; 30(5 Suppl): 35s–52s. [PubMed: 20881153]
8. Schwarze ML, Bradley CT, Brasel KJ. Surgical "buy-in": the contractual relationship between surgeons and patients that influences decisions regarding life-supporting therapy. *Crit Care Med.* 2010; 38(3):843–848. [PubMed: 20048678]
9. Schwarze ML, Redmann AJ, Alexander GC, Brasel KJ. Surgeons expect patients to buy-in to postoperative life support preoperatively: results of a national survey. *Crit Care Med.* 2013; 41(1):1–8. [PubMed: 23222269]

10. Kruser JM, Pecanac KE, Brasel KJ, Cooper Z, Steffens NM, McKneally MF, Schwarze ML. "And I Think That We Can Fix It": Mental Models Used in High-risk Surgical Decision Making. *Ann Surg.* 2015; 261(4):678–684. [PubMed: 25749396]
11. Nabozny MJ, Kruser JM, Pecanac KE, Chittenden EH, Cooper Z, Steffens NM, McKneally MF, et al. Do Patients Buy-In to the Use of Postoperative Life Supporting Treatments? A Qualitative Study. *Academic Surgical Congress Abstracts.* 2015
12. Institute of Medicine. Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life. 978-0-309-31174-8.
13. Couet N, Desroches S, Robitaille H, Vaillancourt H, Leblanc A, Turcotte S, Elwyn G, et al. Assessments of the extent to which health-care providers involve patients in decision making: a systematic review of studies using the OPTION instrument. *Health Expect.* 2013
14. Joseph-Williams N, Elwyn G, Edwards A. Knowledge is not power for patients: a systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. *Patient Educ Couns.* 2014; 94(3):291–309. [PubMed: 24305642]
15. Butow PN, Dunn SM, Tattersall MH, Jones QJ. Patient participation in the cancer consultation: evaluation of a question prompt sheet. *Ann Oncol.* 1994; 5(3):199–204. [PubMed: 8186168]
16. Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. *Health Serv Res.* 2004; 39(4 Pt 1):1005–1026. [PubMed: 15230939]
17. Maly RC, Frank JC, Marshall GN, DiMatteo MR, Reuben DB. Perceived efficacy in patient-physician interactions (PEPPI): validation of an instrument in older persons. *J Am Geriatr Soc.* 1998; 46(7):889–894. [PubMed: 9670878]
18. Walczak A, Butow PN, Clayton JM, Tattersall MH, Davidson PM, Young J, Epstein RM. Discussing prognosis and end-of-life care in the final year of life: a randomised controlled trial of a nurse-led communication support programme for patients and caregivers. *BMJ Open.* 2014; 4(6):e005745.
19. Brandes K, Linn AJ, Butow PN, van Weert JC. The characteristics and effectiveness of Question Prompt List interventions in oncology: a systematic review of the literature. *Psychooncology.* 2014
20. Brown R, Butow PN, Boyer MJ, Tattersall MH. Promoting patient participation in the cancer consultation: evaluation of a prompt sheet and coaching in question-asking. *Br J Cancer.* 1999; 80(1–2):242–248. [PubMed: 10390003]
21. Smets EM, van Heijl M, van Wijngaarden AK, Henselmans I, van Berge Henegouwen MI. Addressing patients' information needs: a first evaluation of a question prompt sheet in the pretreatment consultation for patients with esophageal cancer. *Dis Esophagus.* 2012; 25(6):512–519. [PubMed: 22054056]
22. Clayton JM, Butow PN, Tattersall MH, Devine RJ, Simpson JM, Aggarwal G, Clark KJ, et al. Randomized controlled trial of a prompt list to help advanced cancer patients and their caregivers to ask questions about prognosis and end-of-life care. *J Clin Oncol.* 2007; 25(6):715–723. [PubMed: 17308275]
23. Nabozny MJ, Kruser JM, Steffens NM, Pecanac KE, Brasel KJ, Chittenden EH, Cooper Z, et al. Patient Reported Limitations to Surgical Buy-in: A Qualitative Study of Patients Facing High-Risk Surgery. *Annals of Surgery.* 2015 In press.
24. Pecanac KE, Kehler JM, Brasel KJ, Cooper Z, Steffens NM, McKneally MF, Schwarze ML. It's Big Surgery: Preoperative Expressions of Risk, Responsibility, and Commitment to Treatment After High-Risk Operations. *Ann Surg.* 2014; 259(3):458–463. [PubMed: 24253139]
25. Patton, MQ. Qualitative evaluation and research methods. Fourth. SAGE Publications, inc; 2001.
26. [Accessed November 26, 2014] Questions To Ask Your Doctor. Agency for Healthcare Research and Quality. <http://www.ahrq.gov/patients-consumers/patient-involvement/ask-your-doctor/index.html>
27. Questions to Ask the Doctor. American Association of Retired Persons. [Accessed November 26, 2014] http://www.aarp.org/relationships/caregiving-resource-center/info-08-2010/pc_questions_to_ask_the_doctor.html.

28. [Accessed November 26, 2014] Having Surgery? What You Need to Know: Questions to Ask Your Doctor and Your Surgeon. Agency for Healthcare Research and Quality, Rockville MD. <http://archive.ahrq.gov/patients-consumers/diagnosis-treatment/surgery/questions/index.html>
29. Doctella. [Accessed November 26, 2014] <https://www.doctella.com/>.
30. Clayton J, Butow P, Tattersall M, Chye R, Noel M, Davis JM, Glare P. Asking questions can help: development and preliminary evaluation of a question prompt list for palliative care patients. *Br J Cancer*. 2003; 89(11):2069–2077. [PubMed: 14647140]
31. Brandes K, Butow PN, Tattersall MH, Clayton JM, Davidson PM, Young J, Epstein RM, et al. Advanced cancer patients' and caregivers' use of a Question Prompt List. *Patient Educ Couns*. 2014; 97(1):30–37. [PubMed: 25023487]
32. Questions to Ask Before Surgery. John Hopkins Medicine. [Accessed November 26, 2014] http://www.hopkinsmedicine.org/healthlibrary/conditions/surgical_care/questions_to_ask_before_surgery_85.P01409/.
33. Wisconsin Network for Research Support. Community Advisors on Research Design and Strategies. [Accessed February 16, 2015] <http://winrs.son.wisc.edu/index.php/services/cards/>.
34. Russ AJ, Kaufman SR. Family perceptions of prognosis, silence, and the "suddenness" of death. *Cult Med Psychiatry*. 2005; 29(1):103–123. [PubMed: 16108205]
35. Singh JA, Sloan JA, Atherton PJ, Smith T, Hack TF, Huschka MM, Rummans TA, et al. Preferred Roles in Treatment Decision Making Among Patients With Cancer: A Pooled Analysis of Studies Using the Control Preferences Scale. *The American journal of managed care*. 2010; 16(9):688–696. [PubMed: 20873956]
36. Degner LF, Sloan JA, Venkatesh P. The Control Preferences Scale. *Can J Nurs Res*. 1997; 29(3): 21–43.
37. Greene J, Hibbard JH, Sacks R, Overton V. When Seeing The Same Physician, Highly Activated Patients Have Better Care Experiences Than Less Activated Patients. *Health Affairs*. 2013; 32(7): 1299–1305. [PubMed: 23836747]
38. Danjoux Meth N, Lawless B, Hawryluck L. Conflicts in the ICU: perspectives of administrators and clinicians. *Intensive Care Med*. 2009; 35(12):2068–2077. [PubMed: 19756499]

Figure 1.
Process and activities for engaging patients, family members and community members in creating a question prompt list.

[illegible]

Figure 2.
Front, middle, and back of question prompt list brochure.

Table 1

Patient and Family Advisory Council (PFAC) Meeting Timeline, Objectives, Activities, and Outcomes.

	Meeting Objectives	Meeting Activities	Meeting Outcomes
Months 1–2	Establish expectations and group harmony	<ul style="list-style-type: none"> • Introduce members • Establish standards for engagement • State project goals, timeline and expectations • Share personal experiences with surgery 	<ul style="list-style-type: none"> • Clear understanding of group conduct, PFAC expectations and researcher roles • Recognition that PFAC member's experience can contribute to the research project
Months 3–5	Integrate preliminary qualitative study results with PFAC experience with high-risk surgery	<ul style="list-style-type: none"> • Learn about qualitative research methods • Reflect on study patients' stories and integrate with personal experience • Identify personally important themes extant in qualitative data 	<ul style="list-style-type: none"> • Identification of core decisional and informational needs • Identification of targets for intervention: choices, expectations and complications
Months 6–8	Create question prompt list	<ul style="list-style-type: none"> • Brainstorm questions to ask a surgeon • Discuss top 20 questions from 118 that PFAC and other stakeholders ranked in pre-meeting online survey • Explore question applicability to preoperative decisional needs • Provide feedback on 12 question prompt list prototype 	<ul style="list-style-type: none"> • Question prompt list prototype
Months 8–12	Gain input on design for future comparative effectiveness study	<ul style="list-style-type: none"> • Assess measures and outcomes that are valuable and meaningful to patients and family members • Provide feedback on grant application • Provide feedback on study recruitment materials 	<ul style="list-style-type: none"> • Research protocol that is acceptable and relevant to stakeholders

Table 2

Informational and decision support failures identified in qualitative data by the PFAC.

Perception	Qualitative Study: Preoperative Interview	Qualitative Study: Postoperative Interview	PFAC Discussion
Surgery “has to be done”	<p><i>I didn't really decide I wanted to have it... after all those tests...sent me to the heart surgeon... he said, well it should be done.</i></p> <p><i>I don't know. Just get it done and go on with your life, I guess.</i></p>	<p><i>... there wasn't really any other options, and then so, you know, there wasn't uh, nothing to think about really.</i></p> <p><i>But, you know, what, what's the option? Um, do you not have the surgery and wait for a heart attack and then your recovery is going to be a whole lot more complicated and probably protracted...So, to me it was like a no brainer, you know.</i></p>	<ul style="list-style-type: none"> • Patients need more information about alternatives. • Patients “already have one foot into the surgery room” because the surgical referral process implies that surgery is the only option. • Patients may still conclude surgery “has to be done” but need to have more information about what would happen if they did not have surgery.
Surprise: recovery is arduous	<p><i>Just to fix the problem which I am having... That is my expectation.</i></p> <p><i>[Surgery is] going to be the easiest, best opportunity for me to live a couple more years...It's just a little treatment here and there afterward.</i></p>	<p><i>Hey if I'm gonna feel like I got hit by a truck, tell me before. So it was more, it was more intensive... than I realized it would be.</i></p> <p><i>I thought it was going to be an in and out thing.</i></p>	<ul style="list-style-type: none"> • Patients are not fully prepared for the intensity of surgery and the recovery process. • Patients should know what to expect postoperatively. • Patients who are surprised postoperatively may be upset with the surgeon.
Unclear advance directive	<p><i>They just know what they got to do. I don't want to be laying around being a vegetable.</i></p> <p><i>Yeah I think [the surgeon] knows [what to do in an event of a complication]... Whatever he thinks is best.</i></p>	<p><i>Should I let him go ahead and do the CPR? ...I didn't want to put him through that... It's the hardest decision I've ever made.</i></p> <p><i>...if you were going to get good results, it's one thing, but if you're going to come home and do nothing... stick your finger in a light socket.</i></p>	<ul style="list-style-type: none"> • Patients do not have the opportunity to clearly express their preferences for postoperative life supporting treatments. • PFAC member: “There is a disconnect between what the patients want and who is the right person to tell these wishes” to.