

Washington University School of Medicine

Digital Commons@Becker

Open Access Publications

11-1-2021

Development of a resource guide to help patients receive appropriate care

Erin D Solomon

Heidi Walsh

Meredith Parsons

Tristan McIntosh

Jessica Mozersky

See next page for additional authors

Follow this and additional works at: https://digitalcommons.wustl.edu/open_access_pubs

Authors

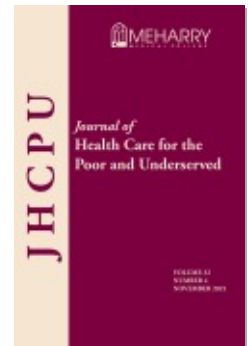
Erin D Solomon, Heidi Walsh, Meredith Parsons, Tristan McIntosh, Jessica Mozersky, and James M DuBois



PROJECT MUSE®

Development of a Resource Guide to Help Patients Receive Appropriate Care

Erin D. Solomon, Heidi Walsh, Meredith Parsons, Tristan McIntosh, Jessica
Mozersky, James M. DuBois



Journal of Health Care for the Poor and Underserved, Volume 32, Number
4, November 2021, pp. 2249-2257 (Article)

Published by Johns Hopkins University Press

DOI: <https://doi.org/10.1353/hpu.2021.0197>

➔ *For additional information about this article*

<https://muse.jhu.edu/article/837351>

Development of a Resource Guide to Help Patients Receive Appropriate Care

Erin D. Solomon, PHD
Heidi Walsh, MPH, CHES
Meredith Parsons, BS, CHES
Tristan McIntosh, PHD
Jessica Mozersky, PHD
James M. DuBois, DSC, PHD

Summary: After 10 years researching physician wrongdoing (i.e., sexual violations, improper prescribing, and unnecessary procedures), we developed a resource guide to help patients receive appropriate care and respond to inappropriate care. We gathered evaluative patient feedback, engaged physicians, and disseminated the guide. It is available at beforeyourvisit.org.

Key words: Delivery of health care, focus groups, health equity, justice, patient advocacy, patient education, physicians.

Egregious wrongdoing by physicians causes direct physical, emotional, and financial harm to patients and undermines the public's trust in medicine.¹⁻⁵ We define *egregious* wrongdoing as behavior that directly harms patients and could be prosecuted as a felony. In 2018, roughly 4.2 out of every 1,000 physicians in the U.S. were disciplined by a state medical board, with 40% of those resulting in severe disciplinary actions involving probation, revocation, or suspension of the physician's medical license.⁶ This rate of severe disciplinary actions is similar to the U.S. annual incidence of breast cancer (1.3 per 1,000), and much higher than the annual incidence of HIV cases (.14 per 1,000). Both are considered major public health concerns.⁷ Thus, educating patients regarding appropriate care from their physicians should be a similarly important concern.

Our research team spent 10 years researching egregious physician wrongdoing.⁸⁻¹⁰ We examined 280 cases of wrongdoing involving improper prescribing of controlled substances, unnecessary invasive procedures, and sexual abuse of patients by physicians, drawing from more than 6,000 court documents, press releases, and news

All the authors are affiliated with the Division of General Medical Sciences, Department of Medicine, Washington University School of Medicine in St. Louis. Please address all correspondence to: Erin Solomon, Division of General Medical Sciences, Department of Medicine Washington, University School of Medicine in St. Louis, Campus Box 8005, 4523 Clayton Avenue, St. Louis, MO, 63110; Email: erin.solomon@wustl.edu.

reports.⁵ Wrongdoing was largely intentional, selfishly motivated, and involved repeated instances.⁵ Perpetrators were typically male physicians in non-academic environments with little oversight or oversight problems.⁵ The full 6,000-document dataset has been deposited with the Inter-university Consortium for Political and Social Research (ICPSR) data repository. Additionally, we researched 100 cases of wrongdoing in medical practice and research involving less egregious behaviors such as conflict of interest violations.^{9,10} However, these were not the focus of our patient education activities because predictors of less egregious behaviors are different and do not cause the same level of harm to patients.¹¹

We convened a 13-member multidisciplinary working group meeting with experts in health law, leadership, patient advocacy, state medical boards, and physician education and remediation.¹² The group was diverse in terms of gender, age, and discipline. Most of the recommendations crafted by the working group focused on changes that must be made to the field of medicine and oversight systems. However, one recommendation was to provide patients with educational materials to inform expectations and choices.¹²

Based on our research and the consensus of the working group, we developed a resource guide, *Before Your Visit: Tips for Patients Seeking Medical Care*. The guide provides resources aimed to help patients advocate for themselves and receive appropriate health care. To refine the guide, we conducted patient focus groups. We aimed to produce a guide that was brief, clear, useful to diverse patients, and struck a balance between providing patients with the information they need to receive appropriate care while avoiding fostering mistrust in physicians, which can contribute to health problems for patients.¹

Resource Guide Content

We organized the resource guide into three patient-oriented sections: Research Your Options, Establish Open Communication, and Advocate for Yourself and Others. The guide's Lexile score is 1210L-1400L, indicating approximately an 8th-grade reading level.^{9,13} See sample information from the guide in Figure 1.

Patients are often unaware of the resources available to gather information on physicians. The "Research Your Options" section educates patients on factors to consider when selecting a doctor. This section includes information on board certification and web links to search for physicians' information (e.g., HealthGrades.com) and details the state medical board's role. The information about state medical boards informs patients that boards post records of disciplinary cases online.

The "Establish Open Communication" section educates patients on how their relationship with their physician can affect their health and encourages them to ask questions during their appointments. This section informs readers that patients who trust their physicians are more likely to follow their physician's recommendations and see their physicians sooner when they have a health concern, leading to better health.¹ The guide provides a web link to the Agency for Healthcare and Research Quality website, which provides templates for questions patients can ask their physician before, during, and after appointments. Having a list of questions prepared can empower patients to learn more about their health and build stronger relationships with their physicians.¹⁴

Informing Expectations & Choices

Research
your options

Establish

Advocate

For some procedures or treatments...

Educational websites can tell you when and why doctors recommend them. Here are some resources that can provide you with trustworthy health information.

But be careful!

There are countless websites offering health advice online, many of which contain information that is outdated, inaccurate, or unproven. Online resources are not appropriate for diagnosing illness, and they should never replace a visit with a doctor.

Choosing Wisely

Created by the American Board of Internal Medicine Foundation, the [Choosing Wisely website](#) has many patient resources to guide choices on a variety of medical procedures, treatments, and exams—including pelvic exams and opioid use after surgery.

Mayo Clinic

Mayo Clinic is a nonprofit organization dedicated to clinical practice, research, and education in healthcare. The [Mayo Clinic website](#) provides detailed information about many diseases, procedures, and treatments that can help inform your expectations before an appointment.

Centers for Disease Control and Prevention

The CDC is a federal agency committed to health promotion, prevention, and preparedness in the U.S. The [CDC website](#) provides guidelines and recommendations for many drugs and procedures that can help you make educated choices about your care.

Figure 1. Sample image from the “Research Your Options” section of the resource guide.

The “Advocate for Yourself and Others” section addresses physician misconduct and how patients can respond. This section indicates that patients can request chaperones or serve as chaperones for others, which may deter physician misconduct.^{15,16} Additionally, patients who have experienced potential abuse, assault, or fraud by their physicians are provided with information about how to report misconduct to their state medical board and web links to the Patient Advocate Foundation.

Physician Engagement

The working group included six physicians (all White, two women, from the Association of American Medical Colleges (AAMC), Accreditation Council for Graduate Medical Education, American Medical Association Council on Ethical and Judicial Affairs, Federation of State Medical Boards (FSMB) Journal of Medical Regulation, Academy for Professionalism in Health Care, and Physicians Assessment and Clinical Education Program). They reviewed the initial case study data and provided recommendations used for guide development. A physician consultant provided expert feedback throughout the project.

Additionally, we gathered feedback from three physicians—an obstetrician/gynecologist, internist, and a pediatrician (all White, two women, two medical fellows, one full professor)—on whether the guide’s information was accurate and helpful, and if any of the content could promote distrust between patients and physicians or be offensive to physicians. We made minor wording edits as a result of their minimal and positive feedback.

Focus Groups

To refine the resource guide, we conducted four focus groups (N=20; Table 1) to gather patient perspectives. The structure of the focus groups and questions asked appear in Appendix 1 (available from the authors upon request). After each focus group, we made minor refinements to the resource guide, such as clarifying technical language and removing confusing information or graphics, before conducting the next focus group. Once all focus groups were conducted, we made final improvements based on aggregated feedback.

From the focus groups, we identified four important themes about the guide. Themes were identified through an iterative process. We identified key ideas from each focus group and then developed a list of themes that represented the consensus of focus groups.¹⁷ These themes were: the resources provided are useful and novel, the guide is

Table 1.
FOCUS GROUP PARTICIPANT DEMOGRAPHICS^a (N = 20)

Demographic Variable	Frequency	Percentage
Sex		
Female	10	50%
Male	10	50%
Race		
Black	8	40%
White	12	60%
Age		
20–29	4	20%
30–39	5	25%
40–49	3	15%
50–59	2	10%
60 +	6	30%
Education		
Less than High School	0	0%
High School	1	5%
Some College	5	25%
Associate’s Degree	2	10%
Bachelor’s Degree	6	30%
Master’s Degree	4	20%
Doctoral Degree	1	5%
Other	1	5%

Note

^aFocus group participants were recruited from a volunteer research participant registry, Volunteer for Health, at Washington University in St. Louis. Participants from racial groups other than Black and White did not volunteer to participate.

helpful for a variety of people, the guide is not helpful for everyone, and the revised guide does not promote mistrust.

The resources provided are useful and novel. Participants indicated that the resource guide provides new and useful information. They thought that the guide would be helpful for educating patients:

- I had known of HealthGrades.org but I never would've thought to go on that website and look up any doctor.
- I didn't know I could see what money has been given to my physician by different organizations.

Participants reported that the most important piece of information in the guide was learning that patients can request a chaperone for medical appointments:

- For me, it was just new information that I didn't really know about. Like the chaperoning, I didn't know you could request an additional medical professional.

The guide is helpful for a variety of people. Participants listed a wide variety of people, groups, and situations in which people might benefit from having access to the guide:

- It would be useful for people that were turning 18 and getting on their own [health insurance] plan and picking doctors.
- I could see it being given out at a health fair, just when you're trying to learn more about the health system and things available in your area.

The guide is not helpful for everyone. A criticism of the guide was that it assumes patients have a choice in their health care provider. Participants pointed out that individuals from some groups, notably those that are poor or underserved, will not be able to make use of some of the resources because they are not able to choose their health care provider:

- Your insurance is telling you . . . who you can and can't go see. So, it's like, what's the point? It's either going to be this [doctor] or nobody.

Not having a choice of health care provider also played a role in whether participants thought information on how to respond if a patient is the victim of abuse, assault, or fraud should be included in the guide. Some participants thought these behaviors do not occur with enough frequency and severity to include them in the guide. Other participants pointed out that these behaviors may not be rare for some groups:

- The part about Responding to Mistreatment, [it says it's only] "in extremely rare cases"—that might not be that rare to some communities . . . Mistreatment might not be rare to people who only have one option for a doctor, and that's just the kind of jerk he is. [They] have to deal with it.

The revised guide does not promote mistrust. The first two focus groups reviewed a version of the guide that included brief information about our research on physicians accused of misconduct. Participants found this information problematic. Once this

section was removed (after the second focus group), participants indicated the guide did not promote mistrust of physicians or the health care system.

Dissemination

We disseminated the guide to many organizations and individuals, asking them to share it with their members, personal contacts, and on their websites. We sent the guide to patient advocacy organizations (e.g., National Patient Advocate Foundation, Alliance of Professional Health Advocates), social work organizations (e.g., National Association of Social Workers, Immigrant & Refugee Service Provider Network), and leaders in health care, social work, and public health. In particular, we sent it to the FSMB leadership, and 41 members of state medical boards who were personal contacts. The President of the FSMB plans to host the guide on their website and send it to all state medical board members. Finally, we promoted the guide via Twitter.

Discussion

Resource guide development was informed by 10 years of empirical research and the consensus of a multidisciplinary working group. Feedback from patients suggests that the guide was well-received. Patients indicated that the guide contained useful resources and would empower many people. After information about our past research on wrongdoing was removed, patients indicated the guide did not promote mistrust of physicians, which was a primary concern.

The guide was designed to serve a wide variety of patients. It is available as a printable document and a webpage, and is suitable for distribution to patients, patient advocates, social workers, and others who work with vulnerable and underserved groups in health care. Our focus group participants indicated that individuals new to the United States health care system (e.g., refugees and immigrants) may particularly benefit from the guide.

We have disseminated the guide widely. Dissemination efforts focused on individuals who work with patients, such as patient advocates, and those involved in physician remediation, such as members of state medical boards.

Limitations and Next Steps

The guide does not address structural problems in health care. Patients noted those who lack choice in their health care provider or are victims of other forms of structural injustices might find the guide less useful. While empowering patients to advocate for themselves helps, it cannot solve structural problems that cause some groups to receive poorer care than others.^{18,19}

The representativeness of our focus groups limited the development of the guide. Namely, while Black and White patients were well represented in our focus groups, Hispanic, Latinx, Asian, and other groups were not represented. We aim to create a Spanish language version of the guide and gather evaluative feedback in Spanish-language focus groups.

We are continuing this work through a project funded by the Greenwall Foundation.²⁰ We are working with members of state medical boards to identify practices and essential resources that could curtail egregious wrongdoing, including several patient-facing tools for state medical board websites.

Finally, we include mechanisms in the guide for professionals to share how they have used the guide, and for patients to provide feedback on the guide or ask questions. We plan to update the guide in response to feedback, and as new patient resources become available.

Access the Guide

View the guide free of charge as a website or downloadable .pdf at <http://www.beforeyourvisit.org>.

Acknowledgments

The authors thank the focus group participants and physicians who provided us with valuable feedback. We would also like to thank Ruby Varghese for her help with typing up select quotes from the focus group audio recordings.

Funding

NIA, R01AG043527
UL1, TR002345

References

1. Khullar D. Do you trust the medical profession? A growing distrust could be dangerous to public health and safety. *New York, NY: New York Times*, 2018 Jan 23.
2. Krause JH. Skilling and the pursuit of healthcare fraud. *U Miami L Rev*. 2012 Jan 1;66(2):363–90.
3. DuBois JM, Walsh HA, Chibnall JT, et al. Sexual violation of patients by physicians: A mixed-methods, exploratory analysis of 101 cases. *Sex Abuse*. 2019 Aug; 31(5):503–23. <https://doi.org/10.1177/1079063217712217>
PMid:28627296 PMCID:PMC6031470
4. Carr G. Professional sexual misconduct—an overview. *J Miss State Med Assoc*. 2003 Sep;44(9):283–300.
5. DuBois JM, Anderson EE, Chibnall JT, et al. Serious ethical violations in medicine: A statistical and ethical analysis of 280 cases in the United States from 2008–2016. *Am J Bioeth*. 2019 Jan;19(1):16–34. <https://doi.org/10.1080/15265161.2018.1544305>
PMid:30676904 PMCID:PMC6460481
6. Federation of State Medical Boards of the United States. *U.S. medical regulatory trends and actions 2018*. Washington, DC: Federation of State Medical Boards of the United States, 2018.
7. National Center for Health Statistics. *Health, United States, 2016: with chartbook*

- on long-term trends in health. (Report No.: 2017-1232.) Hyattsville, MD: National Center for Health Statistics, 2017 May.
8. DuBois JM, Kraus EM, Vasher M. The development of a taxonomy of wrongdoing in medical practice and research. *Am J Prev Med.* 2012 Jan;42(1):89–98.
<https://doi.org/10.1016/j.amepre.2011.08.027>
PMid:22176853 PMCID:PMC3244684
 9. DuBois JM. Understanding the severity of wrongdoing in healthcare delivery and research: lessons learned from a historiometric study of 100 cases. *AJOB Prim Res.* 2013 July 22;4(3):39–48.
<https://doi.org/10.1080/21507716.2013.807892>
PMid:26523237 PMCID:PMC4626637
 10. Dubois JM, Carroll K, Gibb T, et al. Environmental factors contributing to wrongdoing in medicine: a criterion-based review of studies and cases. *Ethics Behav.* 2012 May 9;22(3):163–88.
<https://doi.org/10.1080/10508422.2011.641832>
PMid:23226933 PMCID:PMC3515073
 11. DuBois JM, Chibnall JT, Tait RC, et al. Lessons from researcher rehab. *Nature.* 2016 June 8;534:173–5.
<https://doi.org/10.1038/534173a>
PMid:27279195
 12. DuBois JM, Anderson EA, Chibnall JT, et al. Preventing egregious ethical violations in medical practice: evidence-informed recommendations from a multidisciplinary working group. *J Med Regul.* 2018 Dec;104(4):21–31.
<https://doi.org/10.30770/2572-1852-104.4.23>
PMid:30984914 PMCID:PMC6461379
 13. MetaMetrics. Lexile framework for reading: compare Lexile measures with grade levels. Durham, NC: MetaMetrics, 2021. Available at: <https://lexile.com/educators/measuring-growth-with-lexile/lexile-measures-grade-equivalents/>.
 14. Greenfield S, Kaplan S, Ware JE Jr. Expanding patient involvement in care. Effects on patient outcomes. *Ann Intern Med.* 1985 Apr;102(4):520–8.
<https://doi.org/10.7326/0003-4819-102-4-520>
PMid:3977198
 15. Rogstad KE. Chaperones: Protecting the patient or protecting the doctor? *Sex Health.* 2007 Jun;4(2):85–7.
<https://doi.org/10.1071/SH07022>
PMid:17524284
 16. Feldman KW, Jenkins C, Laney T, et al. Toward instituting a chaperone policy in outpatient pediatric clinics. *Child Abuse Negl.* 2009 Oct;33(10):709–16.
<https://doi.org/10.1016/j.chiabu.2009.04.005>
PMid:19818498
 17. Thomas DR. A general inductive approach for analyzing qualitative evaluation data. *Am J Eval.* 2006 June 1;27(2):237–46.
<https://doi.org/10.1177/1098214005283748>
 18. Kawachi I, Daniels N, Robinson DE. Health disparities by race and class: why both matter. *Health Aff (Millwood).* 2005 Mar–Apr;24(2):343–52.
<https://doi.org/10.1377/hlthaff.24.2.343>
PMid:15757918

19. Edin KJ, Schaeffer HL. *\$2.00 A Day: living on almost nothing in America*. New York: Houghton Mifflin Harcourt Publishing Company, 2015.
20. McIntosh T. Helping state medical boards effectively protect patients by identifying and promulgating promising practices and essential resources. New York, NY: The Greenwall Foundation, 2019. Available at: <https://greenwall.org/making-a-difference-grants/helping-state-medical-boards-effectively-protect-patients-by-identifying-and-promulgating-promising-practices-and-essential-resources>