

## BACKGROUND

The National Marrow Donor Program® (NMDP)/Be The Match® supports patients undergoing blood and marrow transplant (BMT) and their caregivers by providing support programs and educational resources.

BMT is a complex treatment used for malignant and non-malignant blood disorders, such as leukemia and sickle cell disease. To make informed decisions about BMT, patients and their caregivers require effective communication of risk, survival and outcomes information.

Plain language and numeracy experts offer best practices for communicating complex numbers and statistics to non-expert audiences. The effectiveness of these practices has not been evaluated in BMT. Past studies involved healthy participants, which limited the generalizability.

## OBJECTIVES

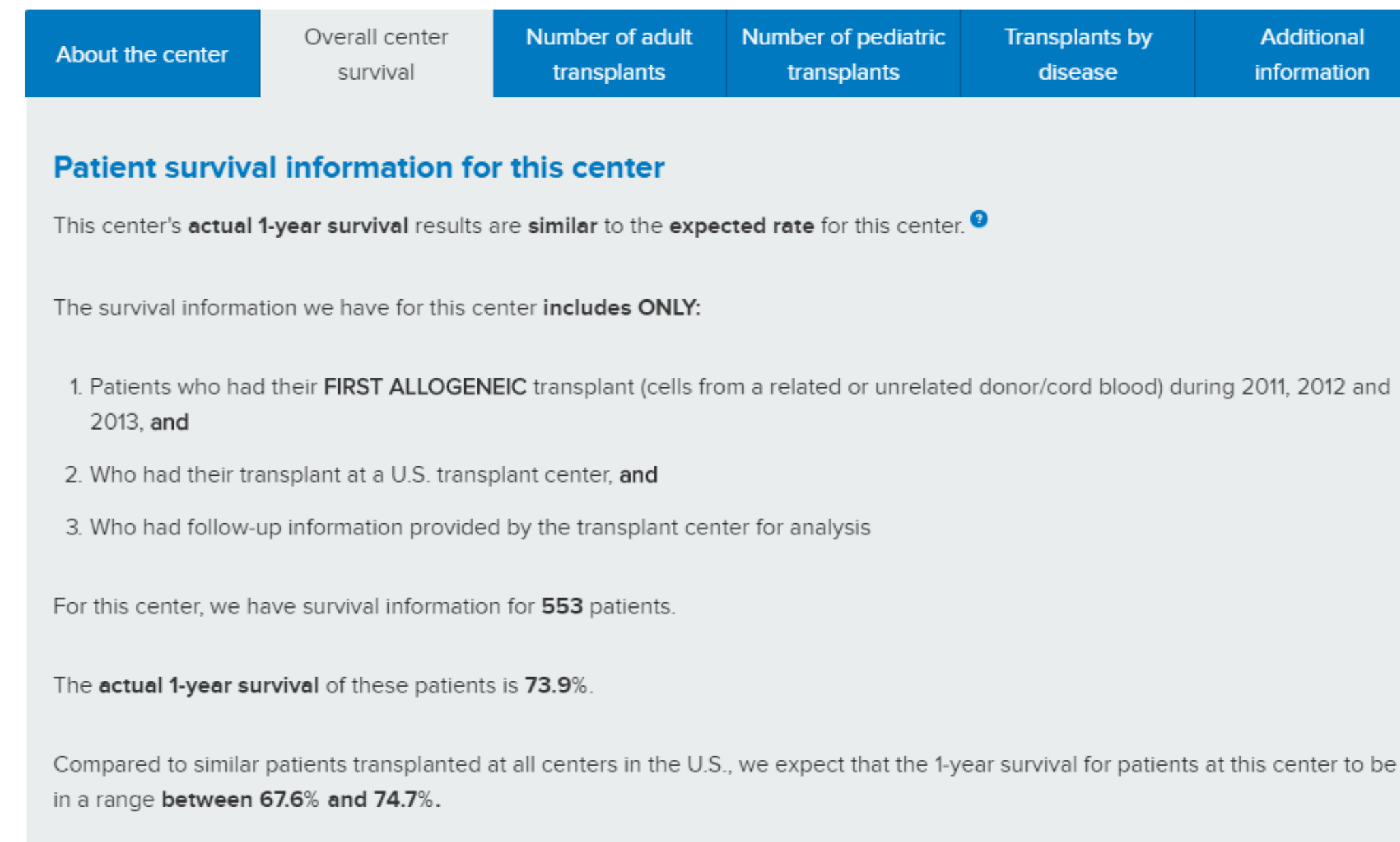
- 1) To identify best practices communicating treatment risk, survival and outcomes.
- 2) To design a study to determine whether plain language and numeracy best practices enhance patients' understanding.

## METHODS

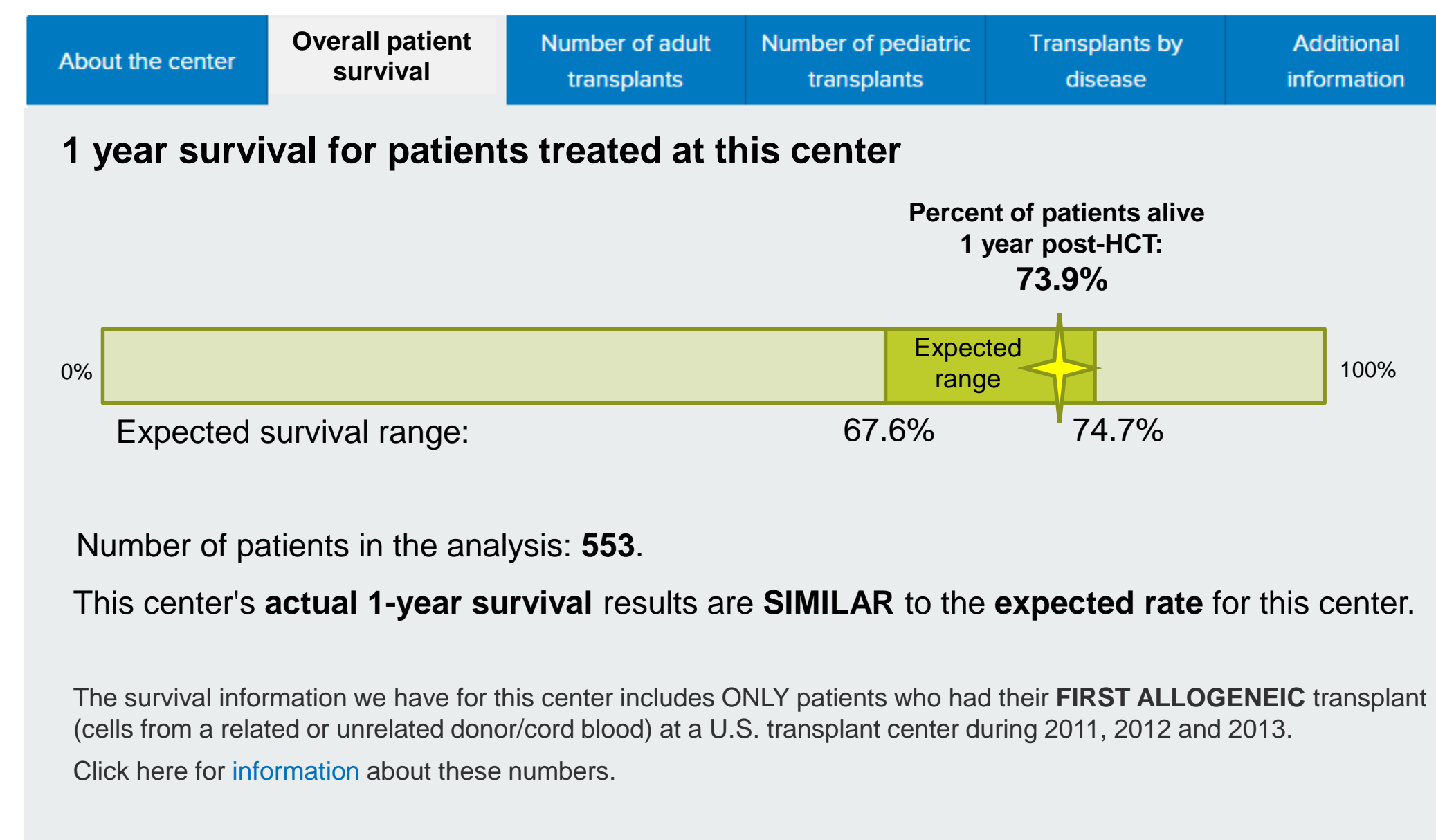
- Conducted search of PubMed for articles published 2007-2016 with these terms:
  - Evidence-based numeracy and health literacy
  - Risk, survival and outcomes communication
  - Best practices communication
- Reviewed existing patient education resources to identify essential information for informed treatment decision making.
- Applied best practices to the current transplant center survival outcomes (Figure 1A).

**FIGURE 1. EXAMPLE OF CURRENT AND BEST PRACTICE DISPLAYS OF TRANSPLANT CENTER SURVIVAL OUTCOMES**

### 1A: CURRENT



### 1B: BEST PRACTICE



## RESULTS

Themes from 3 of 8 key articles include:<sup>1-8</sup>

- Careful consideration of visual display, data presented and textual framing is essential.<sup>1-3</sup>
- Limit information to only the necessary details required for decision making.<sup>1,2,4</sup>
- A degree of miscommunication is expected so testing prior to implementation is crucial.<sup>5</sup>

Federal guidelines support these findings.<sup>9,10</sup>

The best-practices display incorporates these themes and guidelines (Figure 1B).

## DISCUSSION AND NEXT STEPS

To help facilitate informed decisions about health care, patient educators and advocates can use plain language and numeracy best practices to improve understanding of risk, survival and outcomes information.

A research protocol is in development to test strategies for communicating risk and survival statistics with BMT patients and caregivers.

## FOR MORE INFORMATION

- Patients and caregivers: [BeTheMatch.org/patient](http://BeTheMatch.org/patient) or (888) 999-6743
- Clinicians: [BeTheMatchClinical.org](http://BeTheMatchClinical.org)

## REFERENCES

1. Reyna, V., Nelson, W., Han, P., & Dieckmann, N. (2009). How Numeracy Influences Risk Comprehension and Medical Decision Making. *Psychology Bulletin*, 135(6) 943-973.
2. Trevena, L. J., Zikmund-Fisher, B. J., Edwards, A., Gaissmaier, W., Galesic, M., Han, P. K., ... Woloshin, S. (2013). Presenting Quantitative Information About Decision Outcomes: A Risk Communication Primer for Patient Decision Aid Developers. *BMC Medical Informatics and Decision Making*, 13(Suppl 2), S7. <http://doi.org/10.1186/1472-6947-13-S2-S7>
3. Fagerlin, A., Zikmund-Fisher, B., Ubel, P. (2011). Helping Patients Decide: Ten Steps to Better Risk Communication. *Journal of the National Cancer Institute*, 103(19) 1436-1443.
4. Peters, E., Dieckmann, N.F., Dixon, A., Hibbard, J.H., Mertz, C.K., Slovic, P. (2007). Less is More in Presenting Quality Information to Consumers. *Medical Care Research and Review*, 64, 169-190.
5. Tait, A. R., Voepel-lewis, T., Zikmund-Fisher, B. J., & Fagerlin, A. (2010). The Effect of Format on Parents' Understanding of the Risks and Benefits of Clinical Research: A Comparison between Text, Tables, and Graphics. *Journal of Health Communication*, 15(5), 487-501. <http://doi.org/10.1080/10810730.2010.492560>
6. Garcia-Retamero, R. & Dhani, M. K. (2011). Pictures Speak Louder Than Numbers: On Communicating Medical Risks to Immigrants with Limited Non-native Language Proficiency. *Health Expectations*, 14 (Suppl. 1), 46-57.
7. Hofman, S., Vetter, J., Wachter, C., Henne-Bruns, D., Porzolt, F., Kornmann, M. (2012). Visual Aids for Multimodal Treatment Options to Support Decision Making of Patients with Colorectal Cancer. *BMC Medical Informatics and Decision Making*, 112(18)1-9.
8. Cohen, M., Jenkins, D., Holston, E., & Carlson, E. (2013). Understanding Health Literacy in Patients Receiving Hematopoietic Stem Cell Transplantation. *Oncology Nursing Forum*, 40(5) 508-515.
9. Fischhoff, B., Brewer, N. T., & Downs J. S. (Eds.). (2011). *Communicating risks and benefits: An evidence-based user's guide*. Silver Spring, MD: Food and Drug Administration.
10. National Cancer Institute (U.S.). (2011). *Making data talk: A workbook*. Bethesda, Md.: National Cancer Institute.