



Building Bridges: Developing a Health Literate Digital Oncology Patient Education Library

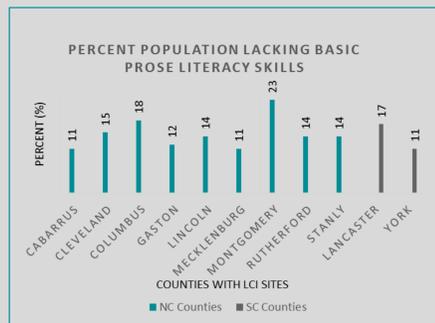
Melynda Ozan, MLIS¹, Pavani Gingrich, BS¹, Sanjana Prabhu, MS²

¹Levine Cancer Institute, Atrium Health, Charlotte, NC

²Brody School of Medicine, East Carolina University, Greenville, NC

Introduction

The Levine Cancer Institute (LCI) has 25 regional cancer clinics in North and South Carolina, serving diverse rural and urban populations. Literacy levels within these populations vary widely, with significant portions on the lower end of the literacy spectrum.



U.S. Department of Education, Institute of Education Services. National Center for Education Services. (2003). National assessment of adult literacy: State & county estimates of low literacy. Retrieved from <https://nces.ed.gov/naal/estimates/index.aspx>

LCI's sites largely use their own collections of patient education materials (PEMs) with few shared, system-wide materials. The selection of oncology PEMs from LCI's patient education vendor is limited, leaving clinicians to create their own or pull them from multiple sources.

A 2016 analysis revealed lack of consistency and wide variation in the health literacy of the materials being used. Many were written at 11th-12th grade reading level and failed to follow health literacy guidelines.

To address these health literacy and standardization issues, a Consumer Health Librarian was hired to create and manage a digital library of original, health-literate oncology patient education materials.

Objectives

- Make standardized PEMs available to LCI's regional network through a digital platform
- Write original, health-literate oncology PEMs for LCI
- Promote health literacy awareness throughout LCI
- Eventually offer a public-facing website with health-literate oncology consumer health information

Methods

Phase 1: Planning

- ✓ Form a core team: Librarian, Physician Advisor, Interns (long and short term)
- ✓ Lay the foundation for organizational support. If possible, establish as an organizational goal.
 - LCI's 2017 Commission on Cancer Programmatic Goal
- ✓ Present the project as a crowdsourced, team effort
 - Recruit writers, reviewers, champions
 - Potential writers: RNs on clinical ladder, MPH or MSN students, highly engaged staff
- ✓ Select a platform, ideally one that is already in place to keep costs low
 - We use SharePoint- no new cost, easy to access and maintain
- ✓ Consult with clinicians to build a list of topics needed
- ✓ Collect and evaluate existing PEMs for perspective and scope
 - Bonus: helps demonstrate need for better quality materials

Phase 2: Build a framework

- ✓ Create a site in your platform, based on topics list
- ✓ Design a workflow and process for writing, editing, and reviewing
- ✓ Create a timeline for periodic reviews and updates
- ✓ Ask clinicians what PEMs they need
 - Bonus: spreads awareness and broadens grassroots support

Phase 3: Fill in the framework

- ✓ Start writing- adjust writing strategy and priorities as needed
- ✓ Offer plain language training and document review for volunteer writers
- ✓ Incorporate patient feedback into the review process
- ✓ Take PEMs to Oncology Patient Education Committee for review and approval
- ✓ Meet regularly to evaluate and adjust workflow and priorities

Final Phase: Open for business

- ✓ Fully populated digital library available to entire LCI network
- ✓ Promote library through presentations, networking, and health literacy education
- ✓ Add topics by request from clinicians
- ✓ Review and update PEMs as needed or by schedule

Discussion

This is an evolving project. Response has been positive with many clinics and departments writing and contributing materials. One challenge has been teaching clinicians how to write health literate materials. The good news is that they are willing to learn.

Crowdsourcing the writing and review process allows our core team to remain lean and efficient. This combined with the work of enterprising and highly engaged interns helps keep costs low.

Gaining the buy-in and culture shift required to ensure clinicians use the library is a slow but steady process. We promote the library through presentations at meetings, leader advocates, and word-of-mouth.

Continuing Goals

- Integrate PEMs into the EHR for easier documentation
- Integrate PEMs into patient portals
- Work with clinical leadership to promote health literacy and consistent use of the library
- Improve processes and expand methods for collecting patient feedback
- **Long-term goal: offer a public-facing consumer health website with *health-literate* cancer information**

Acknowledgements

Thank you to the following advocates, mentors, and helpers:

Michael Richardson, MD
 Mellisa Wheeler, BSW, MHA
 Janice Scotton, RN, BS, CPXP
 LCI Oncology Patient Education Committee

Contact

Melynda Ozan: Melynda.Ozan@AtriumHealth.org

A Word About Patient Feedback

How?

- Participants read a PEM, circle difficult or confusing words, and write comments on the sheet. They also fill out a short, multiple choice survey.
- Interns are a great help with this.

Where?

- We visit rural and urban sites to ensure diversity.

