

The Patient First: Honing Health Literacy for Cancer Patients

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BACKGROUND

Communicating health information is a challenge, no matter the patient. In stressful situations such as a cancer diagnosis, educating patients about their disease, treatment, symptom management, and available resources adds responsibility.

In 2007, Huntsman Cancer Institute (HCI) created an interdisciplinary team with two patient advocates to improve the process. Two hundred providers responded to an electronic survey, identifying these deficiencies:

- Lack of foundational, evidence-based research
- Generic materials from vendors or non-vetted websites
- Language not patient-friendly
- Unprofessional appearance
- Inappropriate branding
- No unified repository for materials

METHOD

HCI formed a multidisciplinary Patient Education Committee (PEC) to address the issues. Members agreed on these necessities:

- “One true source” to house and access materials
- Consistent look and feel for all materials
- Reviews and updates on a specific timeline

HCI’s in-house communications team created a factsheet template. Working with HCI’s service lines and departments, team writers and editors reviewed and customized materials using health content best practices and plain language principles as well as facilitated PEC review board approval.

In 2010, the PEC added a formal health literacy review. Using a multi-domain health literacy tool adapted from the Suitability Assessment of Materials¹, the PEC scores each factsheet for these features:

- Content
- Literacy demand
- Graphics
- Layout and typography
- Learning stimulation and motivation
- Cultural appropriateness
- Numeracy

RESULTS

- In 2015, HCI built a public-facing web platform—the HCI Patient Education Resources portal. The comprehensive, searchable document library groups materials in these categories:
 - Cancer type
 - Care providers and staff
 - Treatments and services
 - Well-being
- Each category contains several subgroupings. All materials are ready to print on demand and updated on a 3-year cycle.
- As of February 2017, the web portal holds 243 custom factsheets in English. The most frequently used factsheets and those about blood and marrow transplant are available in Spanish currently.
- University of Utah Health cited our process as a best practice for effective patient education aligned with health literacy principles.



All factsheets meet a target HEALTH literacy SCORE: 90% OR GREATER

DISCUSSION

Our patient education production, approval, maintenance, and review process took more than a decade of effort, culminating in the current web platform for document management and distribution.

The result of gathering a multidisciplinary committee demonstrates effective and positive institutional change. We succeeded in these efforts:

- Identifying patient education deficiencies or gaps
- Collaborating on a review process
- Creating a web portal that efficiently and effectively serves as the “one true source” for custom material

We continue to face challenges:

- Communicating with physicians and staff about the resource
- Incorporating factsheets into patient electronic medical records
- Managing significant, ongoing workflow needs, including increasing requests

FUTURE GOALS

- Surveying patients to ensure material is accessible and applicable
- Verifying factsheets meet care provider needs
- Assessing effects on clinical outcomes, patient compliance, and patient satisfaction
- Translating the entire custom library into Spanish and identifying other language needs

ACKNOWLEDGMENTS AND REFERENCES

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¹Doak CC, Doak LG, Root JH. 1996. Teaching Patients with Low Literacy Skills, 2nd Ed. Lippincott, Philadelphia.

