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# A Patient's Guide to Smart Research

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# A Patient's Guide to Smart Research

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# The Problem

- ▶ Two decades of research show that almost 9 out of 10 adults have difficulty using, locating, and evaluating the credibility and quality of health information that is routinely available (13).
- ▶ According to the U.S. Department of Education, 53% of adults have intermediate health literacy, 22% have basic literacy, and 14% have below basic literacy; 89% of adults with lower health literacy were more likely to obtain information about health issues from radio and television rather than books, brochures, or the internet (11).
- ▶ For those using the internet, top searches consist of patient education materials that require comprehension levels higher than the reading level of the general public (8). Most popular internet searches also direct patients to top-level domains such as “.com,” which may be less credible than “.org” or “.gov” counterparts.
- ▶ Distributing patient resources is provider-specific and there is no standardized method to provide patients with easy-to-read, yet reliable resources.
- ▶ A health care system with a preventative focus needs to have an effective method for delivering patient education (12). Knowledge of how resources affect patient understanding may help providers better create and distribute patient education materials.

# Public Health Cost

- ▶ Studies have linked low health literacy to misunderstanding instructions about prescription medication, medication errors, poor comprehension of nutrition labels, and mortality (13).
- ▶ Due to the complexity and multifactorial nature of health literacy, there are limited studies that assess the full impact of low health literacy with costs for health care services (13). However, some studies indicate that people with limited health literacy have higher medical costs. It is estimated that low health literacy costs between 106 and 236 billion dollars annually and is associated with chronic illness, poor quality of life, and disability (9).
- ▶ According to the National Assessment of Adult Literacy (NAAL), 22% of adults had basic health literacy and 14% had below basic health literacy. Of Vermont residents, 7% of adults lack basic literacy skill. In Washington county, 6% of residents lack basic literacy skills (12). This number may be higher in the context of medical information.
- ▶ Health literacy is important because it may help predict mortality and morbidity. For example, in a rural setting like Vermont, low literacy adults hospitalized with heart failure were 1.94 times more likely to be readmitted (7).

# Community Perspective

- ▶ “It can be dangerous for patients if they don’t know where to look. For example, they may stop their statins because they’ve read about an association with Alzheimer’s Disease somewhere.” –Dr. Kowalski
- ▶ “Debunking ideas patients come in with can take time out of a visit that could be used in a more effective way.” –Dr. Rodriguez
- ▶ “Education level may be a barrier for patients.” –Laura from the Community Health Team

What I’ve learned in interviews: Patients may not know where to look when researching a health issue. This may lead them to resources that are not supported by research and may become an issue for their own health. Some websites may be filled with medical jargon, which can potentially exacerbate anxiety about a particular condition or cause concern for unrelated health issues. A handout compiling a list of resources would be helpful to providers and beneficial to patients.

# Intervention and Methodology

The Goal: To create a handout that contains reliable and user-friendly websites to distribute to patients. A “dot-phrase” containing this list was also created to include in patient’s discharge instructions.

- ▶ Interviews were conducted to obtain provider insight of the problem and their perspectives on which resources would be most helpful to include.
- ▶ A 10 question Likert scale survey was completed by 30 patients visiting UVMHC-Berlin. Survey contained non-identifiable questions pertaining to current resources used, knowledge gained, office experience, and utility of an educational handout.

Have you ever...	1 (Never)	2 (Rarely)	3 (Sometimes)	4 (Often)	5 (Always)
a. Independently researched about your reason for visit?					
If yes, what type of resource(s) did you use? (blogs, government websites, pamphlets, handouts, other websites, etc.)					
b. Found it difficult to find or read this particular resource(s)?					
c. Felt that your questions were addressed before your visit?					
d. Felt more anxious or concerned after your own research?					
e. Ever taken action after your research and before your visit? (i.e. stopped a medication or began a treatment)					
If yes, what action did you take?					
f. Addressed your independent investigations with your doctor?					
h. Would you utilize a handout equipped with reliable and credible medical patient education resources?					

# The Handout

The handout consists primarily of government and non-profit organization websites.

Resources include information on common medical conditions, diet, exercise, travel, immunizations, wellness, sexual health, and mental health.

It also includes resources one should generally avoid when researching.

## A Patient's Guide to Smart Research

### Educational Websites for Common Diseases

- American Heart Association: For information on healthy living, medical conditions, and support
- American Diabetes Association: Diabetes medical information, living with diabetes, food, and fitness
- Familydoctor.org: Symptom checker, prevention, wellness, and family health
- mayoclinic.org/symptoms: Symptom driven resource

### For Vermonters

- Myhealthvt.org: Support programs for health topics like smoking cessation, diabetes management, and emotional wellness
- UVMhealth.org: The UVM network's guide to doctors, locations, research, and education

### Websites for Travel

- CDC.gov: For general information on diseases, traveler's health, notices, and recommended immunizations
- who.int: World Health Organization for international health, news, immunizations, and emergencies

### Sexual Health

- plannedparenthood.org: Information on sex, relationships, pregnancy, birth control, and STDs
- CDC.gov/std: General information about STDs/STIs

### Diet and Activity

- CDC.gov/physicalactivity: Physical activity, activity with disabilities, resources, and community support
- choosemyplate.gov: Dietary health from the US Department of Agriculture

### What Resources to Avoid

- Websites ending in ".com" are commercial organizations and may be less credible than websites ending in ".gov" or ".org." When researching on the internet, focus more on these latter websites
- Avoid blogs, online forums, and online questionnaires. In general, they are opinionated and not scientifically accurate or reliable

# Results and Responses

- ▶ 22 out of 30 patients (73%) indicated that they would utilize a handout often or always.
- ▶ 14 out of 30 patients (47%) independently researched their medical condition sometimes, often, or always. Common resources used included websites, blogs, forums, magazines, and television.
- ▶ Of the total patients who researched their condition or reason for visit, 32% indicated it raised concerns or they found it difficult to read.



# Effectiveness and Limitations

## Effectiveness

- ▶ Providers at UVMMC-Berlin found the handout useful, especially when included in patient discharge instructions.
- ▶ Providers also said that future follow-up encounter time could be saved with patients who utilized the handout and resources pertaining to their disease.

## Limitations

- ▶ Websites included in the handout have some degree of subjectivity. I chose websites that I thought would be readable and comprehensible by someone with a basic reading level. There is currently no research done that evaluates the effectiveness of one website compared to others.
- ▶ Surveys were distributed to all patients visiting UVMMC-Berlin and not necessarily those who reside only in Washington County. Survey results may reflect a larger geographical community perspective.
- ▶ The utility of a handout with websites is limited to those without internet access.

# Future Directions

- ▶ Update handout and dot-phrase to reflect changing guidelines and website information.
- ▶ Include a tab with updated resources for patient under Health and Wellness on the [uvmhealth.org](http://uvmhealth.org) homepage.
- ▶ Assess effectiveness of handout with patients in the future.
- ▶ “Much more research needs to be conducted to make a definitive statement about the costs of limited health literacy” (9).

Of note, current research projects conducted by the U.S. Department of Education include:

- ▶ Testing Impact of Health Literacy and Integrated Family Approach Programs
- ▶ Improving Literacy Instruction for Adults
- ▶ Research on Reading Instructions for Low Literate Adults

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