eMERGE Infobutton Project Template

Background

The eMERGE Network is exploring use of infobuttons[1-3] as a decision support tool to provide context-specific links within the electronic health record (EHR) to relevant genomic medicine content.

Among organizations implementing the HL7 Infobutton standard, it was a common requirement for knowledge publishers to fine tune their products in order to support clinical decision-making more effectively.[4] These included improving content indexing and tagging to match a standard context information model. Another study showed providing infobuttons that link to specific content topics were more effective than links that point to general overview content.[5]

Toward establishing such an information model among information resources developed by eMERGE institutions, we have prepared this template that contains important content topics for genomic medicine.

The initial list of content topics was from the quality assessment tool, DISCERN-Genetics[6,7]. The DISCERN criteria were developed for assessing information on treatment[8,9], and are widely used for both appraisal[10-13] and to guide the production of health information on treatment for the public[14,15].

Nineteen DISCERN-Genetics question themes (including question hints) were translated into thirteen content topics that comprise the eMERGE Infobutton Project Template:

1. Clinical scenario/Overview
2. Background and effects of the condition
3. Treatment and management choices for the condition
4. Risk of developing, carrying or passing on the condition
5. Types of tests available or being offered
6. Testing procedure
7. Test accuracy and reliability
8. Shared decision making
9. Potential risks (psychosocial consequences, implications of discrimination, potential consequences for others)
10. Local information
11. Additional sources of support and information
12. Content contributors
13. Date of the information

To date, we have assessed the coverage of content topics among information resources developed by eMERGE institutions. Results from that assessment can be found in Ref 16.

Content Topics

Section 1: Clinical scenario/Overview

- What is it about
- What it is meant to cover (and what topics are excluded)

Section 2: Background and effects of the condition

- The problems it can cause
- Who it affects
- The symptoms
- How common it is
- How often it occurs in different populations
- An explanation of how the condition runs in a family
- A description of the difference between being a carrier and having the condition
- A description of the predicted course of the condition
- Details of any complications of the condition

Section 3: Treatment and management choices for the condition

- How the condition is treated
- Any procedure for referral to a specialist
- How symptoms can be reduced
- How well the treatment works
- A description of possible complications of treatment
- Other interventions available e.g. prophylactic surgery, reproductive decision making, medication changes

Section 4: Risk of developing, carrying or passing on the condition

- A reason why patient might be at specific risk
- Any implications for having children
- A description of the risk of having the faulty gene compared with the risk of not having the faulty gene
- An explanation of the chance that the condition will not develop
- A comparison of the risk of developing the condition with the risk of getting other diseases or of other events occurring
- An explanation of risk in alternative formats e.g., 1 in 2 or 50%

Section 5: Types of tests available or being offered

- To confirm a diagnosis where symptoms already exist (diagnostic test)
- To predict whether someone with a family history of a condition will develop the condition (pre-symptomatic test e.g., Huntington's disease) or is likely to develop the condition (predictive test e.g., familial breast cancer)
- To check whether someone is a carrier for a recessive disorder (screening test)
- To screen for genetic disorders during pregnancy (i.e., a test of the fetus)
- To screen for genetic disorders in the newborn
- To inform medication management (pharmacogenomics test)

Section 6: Testing procedure

- How the test is performed
- Where you go to have the test
- If it hurts when you have the test
- The safety/risk of the procedure
- The waiting time for results
- Whether the test is a standard test, part of a research program, and if you have to pay for the test

Section 7: Test accuracy and reliability

- A description of the meaning of false negative and false positive test results
- Any evidence of local variations in laboratory results
- An explanation if a repeat test may be needed, and why
- An acknowledgment of any limitations of testing

Section 8: Shared decision making

- Suggestions of things to discuss with family, friends, doctors, or other health professionals concerning testing and screening

Section 9: Potential risks (psychosocial consequences, implications of discrimination, potential risks for others)

- Any emotional consequences
- Any social consequences
- Possible increase in anxiety
- Statement that a range of reactions are possible and normal
- Implications of discrimination arising from the test result, especially on insurance and employment issues
- What being at increased risk might mean to the person being tested and their family
- The emotional consequences for the family
- The implication for relationship e.g., embarrassment, shame, anger, and strained relationships may all be normal outcomes
- Statement that different people have different reactions
- Statement that misattributed paternity may be discovered

Section 10: Local information

- Any geographical differences in service provision outlined e.g., test availability
- Does it have to be paid for privately or is it free

Section 11: Additional sources of support and information

- e.g., references, websites, other literature, phone numbers, postal addresses, helplines, support groups, other health professionals

Section 12: Content contributors

- Original source of content
- Name, degree and institution affiliation of contributors

Section 13: Date of the information

- Date of publication and any revisions
- An updating policy

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People

Name	Institution	Role
Casey L. Overby, PhD	Univ of Maryland/Geisinger Health System	Leadership team
Luke V. Rasmussen	Northwestern University	Leadership team
John J. Connolly, PhD	Children's Hospital of Philadelphia	Leadership team
Andrea Hartzler, PhD	Univ of Washington/Group Health	Contributor
James D. Ralston	Group Health	Contributor
Eric B. Larson, MD	Group Health	Contributor
Gail P. Jarvik, MD, PhD	Univ of Washington/Group Health	Contributor
Josh F. Peterson, MD, MPH	Vanderbilt University	Contributor
Joshua C. Denny, MD, MS	Vanderbilt University	Contributor
Iftikhar J. Kullo, MD	Mayo Clinic	Contributor
Christopher G. Chute, MD, DrPH	Mayo Clinic	Contributor
Robert R. Freimuth, PhD	Mayo Clinic	Contributor
RoseMary E. Hedberg, MA	Northwestern University	Contributor
Vivian Pan, MS, CGC	Northwestern University	Contributor
Justin Starren, MD, PhD	Northwestern University	Contributor
Marc S. Williams, MD	Geisinger Health System	Contributor
Alan Shuldiner, MD	Univ of Maryland/Geisinger Health System	Contributor
Brian H. Shirts, MD, PhD	Univ of Washington	External collaborator
Peter Tarczy-Hornoch, MD	Univ of Washington	External collaborator
Guilherme Del Fiol, MD, PhD	University of Utah	External collaborator
James Cimino, MD	National Institutes for Health	External collaborator