



# Trust It or Trash It?

## **Who said it? When did they say it? How did they know?**

Use this tool to judge the quality of materials about genetic conditions (such as booklets, websites, and handouts). Also, use it to help create new materials. Click through the three scales to learn how to think about and evaluate the content, quality, and usability of a resource.

### **1. CONTENT SCALE**

Is the information complete or are there topics not covered?

### **2. QUALITY SCALE**

Is the information right?

### **3. USABILITY SCALE**

Is the information presented in a way that is understandable and accessible?

## **The CONTENT SCALE**

### **What is the CONTENT SCALE?**

The Content Scale is a list of topic areas that a group of families, providers, and others thought were important to help people make informed decisions about genetic conditions.

### **Why do I need the CONTENT SCALE?**

While there is generally a large amount of information available on medical conditions, there may or may not be for more rare conditions. Health professionals and families with a new diagnosis may not know where to look for help or what type of information is available. We have created the Content Scale to assist with the development of written materials that families and health professionals can refer to when making informed decisions.

### **How do I use the CONTENT SCALE?**

The Content Scale organizes the topic areas into four main categories, with key questions listed beneath. Clicking on each broad topic area will link to suggestions for other, more detailed, topic areas that may be relevant to the condition in question. To assess materials, the questions can serve as a checklist to identify information that is covered and other information that might be available. Click on each question for more detailed topic areas.

## Basic Information

### What is this condition? What are its features?

- Description of the condition
  - Major physical, developmental, and behavioral features
  - Affected body systems and common health concerns (What usually requires regular treatment and visits to doctors? Do people with this condition die early? If so, what causes their death?)
  - Changes in the condition as your child gets older (Do symptoms appear, disappear, or change over time?)
  - Likelihood of having specific symptoms at different ages
- Differences among people who are affected
  - Variable expressivity
    - People with the same condition have different features, even within the same family. Different organs can be affected and some people may have mild symptoms while other people are severely affected. These differences can happen because of other genes or something in the environment.
  - Reduced penetrance
    - In some conditions, a person can carry the gene change that causes the condition but have NO symptoms.
- Other conditions with similar symptoms (differential diagnosis)
  - Diagnostic criteria or characteristic symptoms of similar conditions
  - Tests and/or evaluations that can differentiate between different conditions
  - Clinical diagnosis: Diagnosis of a condition based on the presence of a number of specific findings (symptoms).
  - Molecular diagnosis: Diagnosis of a condition based on finding a change in a gene known to be associated with the condition.
  - Diagnosis of exclusion: Diagnosis of a condition that does not have a definitive test based on excluding other similar conditions.
- Clinical trials
  - Finding: [www.clinicaltrials.gov](http://www.clinicaltrials.gov)
  - Defining: <http://clinicaltrials.gov/ct2/info/understand>
  - Decision to participate: <http://www.gene.com/gene/pipeline/trial-education/faqs.html>
    - [http://cancer.emory.edu/userdocs/Pros\\_and\\_Cons\\_of\\_Clinical\\_Trials-32354.pdf](http://cancer.emory.edu/userdocs/Pros_and_Cons_of_Clinical_Trials-32354.pdf)

### What causes this condition?

- Molecular Basis for the Condition
  - Name of gene and its function
  - Reason the gene change causes the specific symptoms
  - Percentage of people with the condition who have a change in the known gene
  - Other conditions that are caused by different changes in the same gene
- Cause of Condition

## Content Scale Details

- Reasons the condition is believed to be caused by a gene change and not environmental factors
- Accepted theories that explain the connection between features--why is this thought to be a syndrome rather than a random collection of medical problems?
- Inheritance
  - Patterns of Inheritance (e.g., What is my chance of having another child with the condition? How is the condition passed on in the family? Are my relatives at risk for having this condition or having children with the condition?)
    - Inheritance patterns:  
<http://ghr.nlm.nih.gov/handbook/inheritance/inheritancepatterns>
- Clinical trials
  - Finding: [www.clinicaltrials.gov](http://www.clinicaltrials.gov)
  - Defining: <http://clinicaltrials.gov/ct2/info/understand>
  - Decision to participate: <http://www.gene.com/gene/pipeline/trial-education/faqs.html>
    - [http://cancer.emory.edu/userdocs/Pros\\_and\\_Cons\\_of\\_Clinical\\_Trials-32354.pdf](http://cancer.emory.edu/userdocs/Pros_and_Cons_of_Clinical_Trials-32354.pdf)

### Who is affected by this condition? How common is it?

- Number of people affected
  - How are the number of affected people counted?
  - How were the affected people found? (e.g., were they counted from a group of people with medical problems or from a random group of people, some who had medical problems and some who did not?)
  - How easy is it to diagnose? Could people with the condition be missed or diagnosed with something else?
- Distribution of affected people
  - Is one sex affected more than the other?
  - Is the condition more common in some populations or areas of the world? Should people with certain ethnic backgrounds have specific tests for certain conditions?
- Clinical trials
  - Finding: [www.clinicaltrials.gov](http://www.clinicaltrials.gov)
  - Defining: <http://clinicaltrials.gov/ct2/info/understand>
  - Decision to participate: <http://www.gene.com/gene/pipeline/trial-education/faqs.html>
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### What is the research on this condition?

- Current Focus of Research
  - Aspects of the condition researchers are studying (e.g., progression, diagnostic testing, treatment, etc.)
  - Names and locations of researchers studying the condition
  - Highlights of specific studies that have published results or that are ongoing

## Content Scale Details

- How and where to find out about studies that are recruiting patients
- Ways to facilitate further research (advocacy)
  - <http://wikiadvocacy.org/index.php/Research>
- Participation in Clinical Trials
  - Definition and explanation of clinical trials
    - Finding: [www.clinicaltrials.gov](http://www.clinicaltrials.gov)
    - Defining: <http://clinicaltrials.gov/ct2/info/understand>
  - Pros and cons of participating in a clinical trial
    - <http://www.gene.com/gene/pipeline/trial-education/faqs.html>
    - [http://cancer.emory.edu/userdocs/Pros\\_and\\_Cons\\_of\\_Clinical\\_Trials-32354.pdf](http://cancer.emory.edu/userdocs/Pros_and_Cons_of_Clinical_Trials-32354.pdf)
  - Expectations for clinical trials (for the participant and the researcher)
  - Questions to ask about clinical trials
  - Adults with disabilities and consent to participate in trials
- Clinical trials
  - Finding: [www.clinicaltrials.gov](http://www.clinicaltrials.gov)
  - Defining: <http://clinicaltrials.gov/ct2/info/understand>
  - Decision to participate: <http://www.gene.com/gene/pipeline/trial-education/faqs.html>
    - [http://cancer.emory.edu/userdocs/Pros\\_and\\_Cons\\_of\\_Clinical\\_Trials-32354.pdf](http://cancer.emory.edu/userdocs/Pros_and_Cons_of_Clinical_Trials-32354.pdf)

## Resources and Examples

- Patterns of inheritance
  - <http://ghr.nlm.nih.gov/handbook/inheritance/inheritancepatterns>
- Encouraging scientists to do research
  - <http://wikiadvocacy.org/index.php/Research>
- Clinical trials
  - Finding: [www.clinicaltrials.gov](http://www.clinicaltrials.gov)
  - Defining: <http://clinicaltrials.gov/ct2/info/understand>
  - Decision to participate: <http://www.gene.com/gene/pipeline/trial-education/faqs.html>
    - [http://cancer.emory.edu/userdocs/Pros\\_and\\_Cons\\_of\\_Clinical\\_Trials-32354.pdf](http://cancer.emory.edu/userdocs/Pros_and_Cons_of_Clinical_Trials-32354.pdf)

## Medical Care

### How do we pick a good doctor or other health professional?

- Identify key resources or experts
  - Educational and informational materials: Organizations that create materials should have information about clinical experts. Contributing authors are often experts on the conditions and may have additional resources and contacts.
  - Use of support groups: Members of these groups may be able to identify local providers and/or national experts and provide information about their experiences with different doctors.
  - Clinics and hospitals that specialize in the condition
- Determining appropriate first health professional contact
  - Primary care
  - Acute health concerns: Can the primary care doctor deal with the concerns related to the condition or should an expert be involved?
  - Health professional who can coordinate care: What type of health professional can help make sure all potential health concerns are being considered?
- Other considerations
  - Confirming or finding a diagnosis
  - Managing and treating a condition
  - Patient-provider communication
  - Assessing conflicting information and opinions: Consider the quality of the information (Who said it? When did they say it? How do they know?)

### What is involved in getting a diagnosis?

- Clinical Diagnosis
  - Identify the important features of the condition. Provide information about the frequency of features within the affected population.
  - Testing needed to confirm or rule out the condition.
- Genetic Testing
  - Different types of genetic testing that are available for the condition
  - National Coalition for Health Professional Education in Genetics ([www.nchpeg.org](http://www.nchpeg.org))
  - Genetics Home Reference (<http://ghr.nlm.nih.gov/>)
  - Benefits and limitations of genetic testing
  - Genetics Home Reference (<http://ghr.nlm.nih.gov/handbook/testing/riskslimitations>)
  - Mayo Clinic (<http://www.mayoclinic.com/health/genetic-testing/MY00370>)
  - Maternal and Child Health Bureau (<http://mchb.hrsa.gov/programs/>)
  - CETT materials (<http://rarediseases.info.nih.gov/cettprogram/resources.aspx>)
  
  - Practical information about testing (e.g., type of sample and procedure, cost, CPT codes, insurance coverage, turnaround time)
  - Approach to testing if multiple methods are available (e.g., biochemical and genetic testing) or changes in multiple genes have been associated with the condition.

## Content Scale Details

- Information about sensitivity (How often is the test positive, meaning a mutation is present, when the condition is present?) and specificity (How often is the test negative when the condition is not present?)
- Interpretation of test results for diagnosis, management, and family members—positive, negative, and variant of unknown significance.
- Determining the need for genetic counseling

### **What major body systems are affected?**

- Potential and frequency of condition-associated symptoms
- Change in symptoms over time
  - How does the condition appear in older versus younger individuals?
  - What problems or changes happen over time that patients, families, and doctors should look for?

### **How is the condition treated?**

- Types and purpose of specific treatments
- Effectiveness of different treatment options
- Deciding among multiple treatment options
  - Role of parents/families as care coordinators and partners in decision-making
  - Role of second opinions
  - Lack of consensus statements for management
- Translation of research findings into clinical treatment
- Conditions related to the condition that may require medical care/treatment, such as anxiety, depression, and OCD behaviors.

### **Will the symptoms change over time?**

- Effects on the condition by normal developments in the body (for example, a greater production of hormones).
- Transition from pediatric to adult care
  - Institute for Community Inclusion (<http://www.communityinclusion.org/index.php>)

### **How will we pay for treatment and therapy?**

- Insurance coverage
  - What types of treatments and condition-associated necessities (wheelchairs, assistive devices, alternative treatments) are typically covered?
  - Process to determine what is covered
  - Availability of Medicaid and Social Security benefits
- Other available resources
  - Local disability organizations, support groups, charity organizations, local organizations
- Research protocol vs. clinical treatment
  - Cost
  - Effectiveness of treatment

## Content Scale Details

- Balancing potential risks and benefits
- Expectations (e.g., just because it is research does not mean it is better or more likely to work)

### Resources and examples

- Types of genetic testing
  - National Coalition for Health Professional Education in Genetics ([www.nchpeg.org](http://www.nchpeg.org))
  - Genetics Home Reference (<http://ghr.nlm.nih.gov/>)
- Genetic Testing
  - Collaboration, Education, and Test Translation (CETT) program guidelines for educational materials development (<http://www.cettprogram.org/resources.aspx>)
- Benefits and limitations of genetic testing
  - Genetics Home Reference (<http://ghr.nlm.nih.gov/handbook/testing/riskslimitations>)
  - Mayo Clinic (<http://www.mayoclinic.com/health/genetic-testing/MY00370>)
  - Maternal and Child Health Bureau (<http://mchb.hrsa.gov/programs/>)
- Interpretation of test results
  - GeneTests  
(<http://www.genetests.org/servlet/access?id=8888891&key=VKPfSd70NPSum&fcn=y&fw=tTue&filename=/concepts/primer/primerordertest.html#testresult>)
  - CETT materials (<http://rarediseases.info.nih.gov/cettprogram/resources.aspx>)
- Transition from pediatric to adult care
  - Institute for Community Inclusion (<http://www.communityinclusion.org/index.php>)



## Developmental Issues

### Characteristics of Development

- Developmental issues related to the condition
- Type and frequency of motor, cognitive, and language development delays
  - Range of severity and variation among individuals
  - Telling the difference between normal variation in development and delays in development
  - Resources for evaluation and therapy (e.g., local and state sponsored programs)
  - Types of tests and what different tests evaluate
- Available management and treatment for behavioral and developmental concerns (e.g. sensory integration and ADHD)
- Choices of management approaches
- Current, applicable research

### Are there behavioral issues associated with this condition? Are they treatable?

- Type and frequency of behavioral issues
  - Range of severity and variation among individuals
  - Timing of behavioral issues; changes over time
  - Telling the difference between normal variation in development and delays in development with regards to behavioral issues
- Available management and treatment
  - Choices of management approaches
  - Current, applicable research

### How can I best help my child learn?

- Specific deficits and strengths associated with the condition that might affect learning
- Working with the education system
- Available educational resources to help with learning
- Transitional education needs

### How will we pay for behavioral and developmental therapies?

- Insurance coverage for developmental therapies and behavioral treatment
- Other resources available to cover management costs
  - Local resources (e.g. NY State Department of Health)
    - [www.health.state.ny.us/publications/0548.pdf](http://www.health.state.ny.us/publications/0548.pdf)
  - How parents should plan financially
    - National Endowment for Financial Education ([www.nefe.org](http://www.nefe.org))

### Resources and Examples

- Local resources

## Content Scale Details

- NY State Department of Health
  - [www.health.state.ny.us/publications/0548.pdf](http://www.health.state.ny.us/publications/0548.pdf)
- How parents should plan financially
  - National Endowment for Financial Education ([www.nefe.org](http://www.nefe.org))

## Family Issues

### How will our family be affected?

- Positive and negative impact
- Family stories
- Balancing needs of family members
  - Give attention and support to family as a whole, not just affected individual
- Parent role as advocate and coordinator of care
  - Communicating with your doctor, therapists, teachers, case managers, etc.
  - How to Communicate Effectively with Your Doctor: Working Toward Informed and Shared Decision Making
    - <http://www.pinestreetfoundation.org/avenues/avenues5/advocate5.html>
  - How to Evaluate a Clinical Study: Guidelines to Help Understand Published Research
    - <http://www.pinestreetfoundation.org/avenues/avenues4/byoa4.html>
- Meeting caregivers' needs
  - National Family Caregivers Association
    - <http://www.thefamilycaregiver.org/>
  - How to Define Your Needs: Getting Support from Family and Friends
    - <http://www.pinestreetfoundation.org/avenues/avenues8/advocate8.html>
- Emotional impact
  - Possibility of caregiver becoming isolated
  - Emotional as well as medical journey
  - Support group availability
  - Feelings of guilt and responsibility

### How will things change in the future?

- Expectations during lifespan
  - Maintaining hope but being realistic
  - Natural history of the condition
  - Differences in the condition among affected individuals
- Family planning
  - Chances of having another child with the same genetic condition
  - Discussion with siblings about the condition and care giving expectations
  - Siblings who are carriers of the condition but are not affected
- Long-term care planning
  - Process and timing: when should we start thinking about planning and what is involved?
  - Financial considerations –private pay vs. state funded; waitlists; partial vs. comprehensive services
  - Living situation options
  - Independent living
  - Assisted living

## Content Scale Details

- Residential homes

### **How do we talk to relatives about their risk?**

- Ideas for communicating with relatives about condition
- Testing options
  - Who should be tested
  - When they should be tested
  - How they can get tested
- Feelings of guilt and responsibility
  - Chance aspects of genetics
- Respecting relatives' decisions about testing

### **What will this condition cost us, financially? Are there resources available to help?**

- Costs associated with the condition—obvious and hidden (e.g., insurance coverage for different services, transportation costs).
- Local and national resources that can help with specific expenses
- Use of support groups as source of ideas

### **Resources and Examples**

- Communicating with the doctor
  - How to Communicate Effectively with Your Doctor: Working Toward Informed and Shared Decision Making
    - <http://www.pinestreetfoundation.org/avenues/avenues5/advocate5.html>
  - How to Evaluate a Clinical Study: Guidelines to Help Understand Published Research
    - <http://www.pinestreetfoundation.org/avenues/avenues4/byoa4.html>
- Meeting caregivers' needs
  - National Family Caregivers Association
    - <http://www.thefamilycaregiver.org/>
  - How to Define Your Needs: Getting Support from Family and Friends
    - <http://www.pinestreetfoundation.org/avenues/avenues8/advocate8.html>

## **THE QUALITY SCALE**

### **What is the QUALITY SCALE?**

The Quality Scale is one way to assess the quality of information in educational material. This scale is made up of six elements, and these elements can be used individually or collectively to judge the quality of the information.

### **Why do I need the QUALITY SCALE?**

There are some genetic conditions that are so rare (in contrast to common conditions like heart disease or diabetes) that there are relatively few people that can be studied to learn scientific facts about these conditions. Therefore, information about these genetic conditions can vary in quality. Some may be of high quality if they are based on studies that looked very carefully at the group of affected people, while some may be of lower quality because the information is based on only a few findings. Of course, information about common conditions can vary in quality as well. The quality scale will help you think critically about the information that you are reading, and will help you determine whether the information is reliable.

### **How do I use the QUALITY SCALE?**

The Quality Scale has six elements. Each element is followed by definitions and examples to help you 'score' the information. The purpose is not to come up with an overall score, but, rather, to help you think about how you should use the information in decision making. Please use your own good judgment.

### **Source of the Information**

#### **DESCRIPTION:**

Assess the quantity and ease of locating the source(s) of the information. To answer this question, one should know who is responsible for the content (i.e., who provided the content). For example, the material might mention a journal article or an expert in the field, or there might be a reference list at the end with a list of journal articles or books.

#### **SCORING:**

- **LOW:** Information about the source of the information is not provided.
- **MID:** The material does not have many references, or it is difficult to determine where the information came from.
- **HIGH:** There are numerous references cited in the material that are easy to find or a reference list.

#### **EXAMPLES:**

## Quality Scale Details

- **LOW:** A webpage with information about treatments for Fragile X that does not include a reference list.
- **MID:** A webpage with information about treatments for Fragile X that has many sub-topics, but only one reference list at the end (making it difficult to know which information came from which source).
- **HIGH:** A webpage with information about treatments for Fragile X that has citations within the webpage and a reference list at the end.

### POINTS TO CONSIDER:

- **Government agencies:** Government agencies have many people who help review materials before they are shared with the public. The information **may** not be the most current because of the time it takes for the many rounds of review.
- **Parent-sponsored groups:** Parent-sponsored groups may provide a wide range of information that is targeted mainly for parents. These groups may differ in how they assess the quality of the information they include in materials.
- **University or academic groups:** Universities try to include peer-reviewed research (meaning it has been reviewed by noted experts) using well-accepted scientific methods. The quality of a study depends on the methods used by researchers. Therefore, study results can be difficult to interpret if one does not know the strengths and weaknesses of the study methods.

## Quality Scale Details

### Depth or Nature of Expertise

#### DESCRIPTION:

Assess whether the individual or group that wrote or supports the material has experience with the condition and is well connected with the community of people who have the condition. Depending on the content and purpose of the material, it can be written or supported by a parent or professional familiar with the condition.

#### SCORING:

- **LOW:** There are no credentials listed and no background information included; or the author has no experience with the condition.
- **MID:** The authors have little experience with the condition.
- **HIGH:** The authors have a lot of experience with the condition, are well respected in the community, and are well respected by peers.

#### EXAMPLES:

- **LOW:** Material explaining how Duchenne Muscular Dystrophy (DMD) is passed on in families is written by a scientist who studies earthquakes and has no experience with DMD.
- **MID:** Material explaining how DMD is passed on in families is written by a parent who has a basic understanding of genetics.
- **HIGH:** Material explaining how DMD is passed on in families written by a research team that has been studying DMD for 20 years.

#### POINTS TO CONSIDER:

An individual with expertise may be a parent or a professional. However, one should not automatically dismiss an individual or group who has little experience because they may be motivated to learn quickly and become “experts” for the patients with whom they work.

## Quality Scale Details

### Consistency among materials

#### DESCRIPTION:

Assess whether the information discusses generally accepted facts about the condition, which could be scientific, psychosocial, or management related. If there is new information, the source and date should be provided.

NOTE: If you can find only one source of information about a particular topic, it cannot be scored for consistency, because there is nothing to compare it to.

#### SCORING:

- **LOW:** The information presented is clearly wrong given the current state of the science and expert consensus.
- **MID:** The information is different from that in other resources and does not provide details about the source of the conflicting information.
- **HIGH:** The information is supported by multiple organizations, publications, and experts. Information that is new/different than other sources contains study information.

**No other materials:** No other materials are known to exist, so a comparison is not possible.

#### EXAMPLE:

- **LOW:** Material explaining the history of Fragile X does not include information about the use of medications.
- **MID:** Material explaining the history of Fragile X includes information about a pharmacologic treatment that has not yet been reported in journal articles.
- **HIGH:** Material explaining the history of Fragile X includes information about treatments that are supported by several research studies.

#### POINTS TO CONSIDER:

If you are unfamiliar with the subject, you may not be able to judge this element. If you are familiar with the subject and the information is unique to this educational material, you may wish to check on its accuracy with an expert in the field.



## Quality Scale Details

### Basis for information

#### DESCRIPTION:

The basis for information can be evaluated in the following 3 ways:

- (1) The type of data -- whether authors used anecdotal data (meaning something was observed in a few patients) or expert-reviewed data,
- (2) The type of research design, and
- (3) The relevance of the population studied by researchers to the audience for the material.

NOTE: if you can find only one source of information about a particular topic, it cannot be scored for consistency, because there is nothing to compare it to.

#### SCORING:

- **LOW:** The material provides no information about the basis of the data, type of research design, or is not relevant to the audience.
- **MID:** The basis of the material is good, but the information provided is not relevant to me or my child.
- **HIGH:** The information comes from a strong basis, e.g., a peer-reviewed, published study that is relevant to me or my child.

#### EXAMPLES:

- **LOW:** Material about the prevalence of Fragile X includes only an estimate from one genetic clinic's patient population.
- **MID:** Material about the prevalence of Fragile X includes only information about boys (and I am seeking information about the prevalence in girls).
- **HIGH:** Material about the prevalence of Fragile X includes information about treatments that are supported by several research studies.

#### POINTS TO CONSIDER:

If no traditional research has been published, personal experience or anecdotal evidence can serve as quality information. An example would be a parent writing about ways to deal emotionally with a child's diagnosis, and that is stated in the article.

## Type of sponsoring or funding group

### DESCRIPTION:

Assess whether the group that endorses or provides financial support for the creation of the material has an obvious conflict of interest, financial interest, or bias with the information provided. Advertisements should be labeled as such.

NOTE: This element will be more or less relevant depending on the information included in the material. For example, treatment information may be suspect if it is produced by a company selling that treatment. Information about the basic science of the condition, provided by the same company, may be less questionable.

### SCORING:

- **LOW:** No information about the funding or sponsoring group is provided.
- **MID:** The information reflects the group's bias, or the group does not have much experience with the condition.
- **HIGH:** The sponsor has a lot of experience with the condition and may be biased, but the material does not reflect that bias. The information does not try to sell a product or point of view.

### EXAMPLES:

- **LOW:** Material about treatment of DMD supports one type of treatment, but does not list who makes that treatment or whether it is the same company that wrote the material.
- **MID:** Material about the treatment of DMD supports one type of treatment, but the company that makes the treatment sponsored the material and does not list other treatments.
- **HIGH:** Material about the treatment of DMD supports one type of treatment, but the company that makes the treatment has done clinical trials comparing the treatment to other treatments, and the supported treatment has been shown to be better than the others.

### POINTS TO CONSIDER:

The importance of this element will depend on the type of information available. For example, a company that is providing a treatment may publish slanted or incomplete information about the types of treatment available, but they may publish unbiased information about the basic science of the condition. Some examples of types of sponsors or funding groups are:

## Quality Scale Details

- Government: Government agencies make careful decisions about which groups to work with, so the majority of government sponsored information has been carefully reviewed and is reliable.
- Private business: Businesses make decisions about whom they will work with and why. Businesses usually offer money to develop a project with a partner, but it may be difficult to assess the true nature of the partnership.
- Non-profit organization: A non-profit organization may be very invested in producing educational materials, but it may not be clear why.

## Quality Scale Details

### Date

#### DESCRIPTION:

Review the date when the material was created or when the content was last updated. You may need to look at other sources to see if important, new information about the condition has been published since the material you are reviewing was last updated.

#### SCORING:

- **LOW:** The information is clearly out of date.
- **MID:** The information is not clearly out of date, but certain parts of it do not reflect updated information.
- **HIGH:** The information is the most currently available.

#### EXAMPLES:

- **LOW:** Material explaining Fragile X premutation carriers that does not include information about Fragile X-associated tremor/ataxia syndrome (FXTAS).
- **MID:** Material explaining Fragile X premutation carriers that includes information about FXTAS, but does not mention Fragile X-associated primary ovarian insufficiency (FXPOI).
- **HIGH:** Material explaining Fragile X premutation carriers that includes information about both FXTAS and FXPOI.

#### POINTS TO CONSIDER:

- If no date is provided, the material may be general and provide background information only. It is also possible that newer information about the condition is known but is not included. Therefore, material without a date should be used only with caution.
- It can take a long time before new information about rare disorders is available, so it may not be a problem if the material was created more than five years ago. However, there could also be newer information available that is not included.

## **THE USABILITY SCALE**

### **What is the USABILITY SCALE?**

The Usability Scale is a tool to assess whether the information in an educational product is understandable and accessible to the audience. There are four elements of the Usability Scale, with the underlying theme of asking the target audience for feedback about the material at every step of the development process (not just at the end).

### **Why do I need the USABILITY SCALE?**

Some conditions are so complicated that they can be difficult to understand. To make informed decisions, families and health professionals must both have a good understanding of the condition. When the condition is genetic, the entire family and extended family may be affected. Therefore, it is very important for individuals and families to have access to information they can easily understand and to be given tools that help them evaluate the information they read about a condition. The presentation of informational materials can influence the way it is understood and used.

### **How do I use the USABILITY SCALE?**

The Usability Scale consists of four elements, and the audience of the material should be asked for feedback at every step of the development process (not just at the end).

## Know your audience

### **\*Work with your audience to develop the material.**

Get to know members of your audience (the people who will be reading the material). Ask them for their input and suggestions.

### **Example**

With today's technology it is easy to include your audience in the development of your material. Contact condition-specific organizations. For example:

- If you are working on material related to muscular dystrophy, contact Parent Project Muscular Dystrophy (PPMD) at [www.parentprojectmd.org](http://www.parentprojectmd.org).
- If you are working on material related to Fragile X, contact the FRAXA Research Foundation at [www.fraxa.org](http://www.fraxa.org) or the National Fragile X Foundation at [www.fragilex.org](http://www.fragilex.org).
- For other genetic conditions, visit [www.geneticalliance.org](http://www.geneticalliance.org) to see if advocacy organizations for the specific condition exist.

Many organizations have active online support communities or medical advisory councils who are experts in the field. Use the experts, professionals, individuals with the condition, and/or caregivers to ensure your material will meet your audience's needs.

### **\*Present information that is useful to your audience.**

Ask your audience to identify information that would be most useful for them. For example, do they want to know about the natural history of the condition or do they want to know about resources for treatment of the condition?

### **Example**

You've created a pamphlet for Fragile X and your audience is individuals who are new to the diagnosis. They need information in laymen's terms. If you want to define the gene, you need to keep it simple and brief (see \*Work with your audience to develop the material.)

Before:

FMR1, located at Xq27.3, consists of 17 exons and is approximately 38kb in size 1;2. The mRNA is approximately 4.4kb and contains 1.9kb of coding sequence. Within the 5' untranslated region (UTR) of FMR1 is a polymorphic CGG repeat coincident with a rare fragile site on the X chromosome known as FRAXA. FRAXA was a cytogenetic marker instrumental in the identification of patients and, ultimately, the gene itself.

After:

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Fragile X is a family of genetic conditions, which can impact individuals and families in various ways. These genetic conditions are related in that they are all caused by gene changes in the same gene, called the FMR1 gene.

### **\*Use terms preferred by the group you want to reach.**

Many terms are archaic and may induce negative images, creating pity, fear, unjustly stereotyping individuals and may be offensive to the audience, whether it be individuals who are caregivers or those who have the diagnosis. Respect the individual and the caregivers. Recognize the person first, then the diagnosis. Don't use labels or archaic terms.

### **Example**

Before:

Fragile X syndrome is the most common cause of mental retardation. This impairment can range from mild to severe retardation.

After:

Fragile X syndrome is the most common cause of inherited mental impairment. This impairment can range from learning disabilities to more severe cognitive or intellectual disabilities.

### **\*Use pictures and examples that represent your audience.**

For example, if your audience is mainly African American, use pictures that show African American individuals. If your audience uses wheelchairs, use pictures that show people in wheelchairs. If you are writing general material that is applicable to a broad audience, include pictures that capture the range of people affected. For example, a brochure discussing cystic fibrosis should include picture of ethnicities other than Northern European because other ethnicities are affected or a pamphlet on Fragile X should include pictures of girls as well as boys.

### **\*Use a professional translator to translate your material into other languages.**

Use a professional who knows the condition you are writing about (or knows medical terminology) to translate your material. Each language has fine points that would be known to a professional translator but not known to a computer program or to a lay person who speaks the language.

Materials should also be back translated, which means once they are translated from English into another language they should be translated back to English. This provides a way to check the translation, especially when you are not familiar with the language. Translated materials should ideally undergo testing in the target population to assess cultural sensitivity issues.

## **Consider the Reading Level**

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### **\*Determine the reading level of your audience and write to that level or lower.**

The average reading level of U.S. adults is 8<sup>th</sup>-9<sup>th</sup> grade. One in five adults read at the 5<sup>th</sup> grade level and below. Research suggests that printed materials for parents should aim for the 6<sup>th</sup> grade reading level. Materials written for professionals should aim for a reading level at the 12<sup>th</sup> grade level or lower. ["Adult Literacy in America (NALS)" National Center for Education Statistics, U.S. Dept of Education, Office of Educational Research and Improvement (NCES 1993-275), April 2002.]

- You can check the reading level of your material using a number of different tools including the Fry, SMOG, or Flesch-Kincaid readability formulas. The FRY and SMOG formulas involve counting words and syllables in a selection of text. The Flesch-Kincaid method also estimates the reading level by counting words and sentences, but is considered less accurate than the FRY and SMOG. Microsoft Word will calculate reading level using the Flesch-Kincaid method.
- Follow these links for more information about...
  - Fry
    - <http://school.discoveryeducation.com/schrockguide/fry/fry.html>
  - SMOG (Simplified Measure of Gobbledygook)
    - <http://en.wikipedia.org/wiki/SMOG>
  - Flesch-Kincaid and Microsoft Word
    - <http://www.techlearning.com/article/3796>

### **\*Make information easy to read. One way to do this is to use a question-and-answer format.**

Organizing information into a question and answer format makes the information easier to remember. It also helps people find specific information quickly. The best headers are those that express a complete thought or idea. (Doak and Doak, 1996).

Example:

#### Paragraph Format

Duchenne muscular dystrophy (DMD) is caused by a mutation in a specific gene within the X chromosome that provides instructions for the formation of the dystrophin protein. Females can be carriers but generally do not experience the symptoms of the condition. Duchenne muscular dystrophy occurs in approximately 2 out of 10,000 people and can either be inherited or occur spontaneously. A family history of Duchenne muscular dystrophy is a significant risk factor.

#### Question-and-Answer Format

##### **How common is Duchenne and Becker Muscular Dystrophy?**

Duchenne and Becker Muscular Dystrophies together affect 1 in 3,500 to 5,000 male births. Between 400 and 600 boys in the United States are born with these conditions each year. Females are rarely affected by these forms of muscular dystrophy.



**What genes are related to Duchenne and Becker Muscular Dystrophy?**

Mutations in the DMD gene cause Duchenne and Becker types of muscular dystrophy. The DMD gene is found on the X chromosome.

**\*Cover only a few key ideas in each section of material.**

Try to limit each piece of material to 3-4 key concepts. Including too much information in written material makes it difficult to understand. People who are unfamiliar with the condition may find it overwhelming to have too much information included in one piece of material. Covering too much information will make your key points difficult to find. Remember that you can create a number of different materials to cover all the important topics.

Example:

- What is the condition?
  - How common is the condition?
- What genes are related to the condition?
  - How is the condition inherited?
- Where can I find more information about:
  - The condition?
  - Treatment?

Each of these topics could make up a separate unit of information. Think about the right level of detail to include for your audience. You might look at well-established support groups (e.g., [www.parentprojectmd.org](http://www.parentprojectmd.org)) to get an idea for ways to separate the information.

## Write your material

### **\*Use common words and avoid or define medical terms.**

In general, short words tend to be more common and are better to use (doctor vs. physician). There are some common words that are hard to understand because they are vague or have multiple meanings. For example, the phrase “test results in the normal range” does not describe what is 'normal', and 'range' has a number of different meanings, depending on the reader's personal experience. Be as specific as possible and test the materials with the end users to make sure they understand the information by creating a survey or talking with a group of them and avoid terms that parents might find offensive (e.g., mentally retarded). Use current terms such as intellectual disability.

Helpful Hints:

- Use the Google “define:” function to find alternative words and synonyms. Go to [www.google.com](http://www.google.com), type *define: your word* (replace “your word” with whatever word you are looking up). For example, *define: subcutaneous* gives *under the skin* and *beneath the skin* as alternatives.

Example:

Medical Term	Common Word(s)
Cardiovascular	heart and blood vessels
Categories	groups
Cautiously	with care
Chronic	does not end or constant
Cognitive	learning or thinking

### **\*Use the active voice.**

The active voice shows the subject of the sentence performing the action. The active voice is more clear and engaging for the reader. The passive voice is signaled by the verb 'to be'.

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Example:

<b>Passive Voice</b>	<b>Active Voice</b>
Treatment must <b>be</b> done every day.	You must do treatment every day.
Your lungs will <b>be</b> tested by a doctor.	A doctor will test your lungs.

**\*Use short sentences and paragraphs that cover only one point.**

Short sentences are easier to understand than long sentences. "Short" means 15 words or fewer. Sometimes longer sentences sound better and, in that case, it is better to use more words. Try to take out extra words and use specific language. Each paragraph should discuss only one topic and have a clear opening sentence.

Example:

**BEFORE:** The Dietary Guidelines for Americans recommend a half hour or more of moderate physical activity on most days, preferably every day. The activity can include brisk walking, calisthenics, home care, gardening, moderate sports exercise, and dancing.

**AFTER:** Do at least 30 minutes of exercise, such as brisk walking, most days of the week.

**\*Use practical examples to make the information clearer.**

Concrete examples are easier to understand than abstract ones. Including examples can also help to form a mental image of the concept and make it easier to remember.

Example:

Abstract

Alzheimer's has its share of safety hazards and everyday activities can be dangerous and difficult.

Concrete

When a person has Alzheimer's, everyday activities such as driving a car, chopping vegetables, getting the right water temperature, or turning a stove on or off can be dangerous.

## Present Your Material

### **\*Organize the information in a logical way.**

- Start with a clear title. Be sure to include the purpose of the material.
- Organize ideas in the order that the audience will use them. The organization may be different for different audiences. For example, 1) description of the condition, 2) diagnosis of the condition, 3) treatment of the condition, and 4) inheritance and recurrence risk.
- Use major headings to "chunk" text. The headings should express a complete idea, rather than just a word or two, to tell the reader the type of information that will follow. Leave more space above headings than below them to make a stronger connection to the text.
- Place the most important information at the beginning and end of the document.

### **Sentence format:**

Many readers frequently move back and forth between text and pictures. Having pictures can help readers better understand the words, clarifies the words' meaning, enables them to construct or elaborate a model of the situation, and aids in building a mental model of the unfamiliar.

### **\*Use simple graphics (visual images), but only if they help to present information.**

- Use graphics to help communicate your messages, not for decoration.
- Choose the best type of graphic for your materials: photographs (real life events, emotions), line drawings (procedures, sensitive issues), or cartoons (set casual tone or convey humor). Each can be useful for different purposes.
- Make graphics culturally relevant and sensitive.
- Make graphics easy for your readers to follow and understand by including captions and emphasizing key information.
- When illustrating internal body parts or small objects, use realistic images and place them in context.
- Avoid poor quality graphics.

[Adapted from "Scientific and Technical Information: Simply Put" produced by CDC & ATSDR, 2nd edition, 1999, [www.cdc.gov/healthmarketing/pdf/Simply\\_Put\\_082010.pdf](http://www.cdc.gov/healthmarketing/pdf/Simply_Put_082010.pdf)]

Example:

### BEFORE

This is a multipurpose passenger vehicle that will handle and maneuver differently from an ordinary passenger car, in driving conditions that may occur on streets and highways and off road. As with other vehicles of this type, if you make sharp turns or abrupt maneuvers, the

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vehicle may roll over or may go out of control and crash. You should read driving guidelines and instructions in the Owner's manual, and WEAR YOUR SEATBELT AT ALL TIMES.

### AFTER



[http://www.plainlanguage.gov/examples/before\\_after/carsafety.cfm](http://www.plainlanguage.gov/examples/before_after/carsafety.cfm)

#### **\*Don't crowd the page.**

- Use white space, bullets, and headings to organize your material and keep it from being over crowded.
- Limit the amount of text on each page.
- Leave white space around the margins of the page and between columns.

#### **\*Make the text easy to read. Use large enough print and don't use all capitals or italics.**

- Use a font size of at least 12 point. Headings should be larger than the size of the rest of the text.
- Do not use fancy lettering.
- Do not use all capital letters.
- Use **bold** or underlining to emphasize text. Limit the use of italics because they are harder to read.

#### **\*Emphasize key points by using headings and bullets.**

Headings and bullets divide up text and give "sign posts" to help the reader know where they are in the document.

Example:

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### No Headings

Duchenne muscular dystrophy (DMD) is caused by a mutation in a specific gene within the X chromosome that provides instructions for the formation of the dystrophin protein. Females can be carriers but generally do not experience the symptoms of the condition. Duchenne muscular dystrophy occurs in approximately 2 out of 10,000 people and can either be inherited or occur spontaneously. A family history of Duchenne muscular dystrophy is a significant risk factor.

### With Headings

#### **How common is Duchenne and Becker Muscular Dystrophy?**

- Duchenne and Becker Muscular Dystrophies together affect 1 in 3,500 to 5,000 male births.
- Between 400 and 600 boys in the United States are born with these conditions each year.
- Females are rarely affected by these forms of muscular dystrophy.

#### **What genes are related to Duchenne and Becker Muscular Dystrophy?**

Mutations in the DMD gene cause the Duchenne and Becker types of muscular dystrophy. This gene is found on the X chromosome.