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Literacy Assessment of Family Health History Tools for Public Health Prevention

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Key Words
Document complexity · Family health history · Genetic literacy · Health literacy · Readability

Abstract
Objectives: This study aimed to systematically identify and evaluate the readability and document complexity of currently available family history tools for the general public. ***Methods:*** Three steps were undertaken to identify family history tools for evaluation: (a) Internet searches, (b) expert consultation, and (c) literature searches. Tools identified were assessed for readability using the Simple Measure of Gobbledygook (SMOG) readability formula. The complexity of documents (i.e., forms collecting family history information) was assessed using the PMOSE/IKIRSCH document readability formula. ***Results:*** A total of 78 tools were identified, 47 of which met the criteria for inclusion. SMOG reading grade levels for multimedia-based tools ranged from 10.1 to 18.3, with an average score of 13.6. For print-based tools, SMOG ranged from 8.7 to 14.1, with an average score of 12.0. Document complexity ranged from very low complexity (level 1 proficiency) to high complexity (level 4 proficiency). ***Conclusion:*** The majority of tools are written at a reading grade level that is beyond the 8th grade average reading level in the United States. The lack of family history tools that are easy to read or use may compromise their potential effectiveness in identifying individuals at increased risk for chronic diseases in the general population.

Health literacy has been defined as 'the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions' [1]. Health literacy consists of a constellation of skills, which include the ability to perform basic reading tasks and comprehend text, such as written instructions (prose literacy) as well as the ability to locate information and use documents such as medical forms, charts, and tables (document literacy) [2, 3]. Approximately 90 million adults in the United States have limited literacy skills, or difficulty understanding health information [1].

Evidence for the negative impact of poor health literacy is accumulating. Adults with limited health literacy have less knowledge of disease management and of health-promoting behaviors, are less likely to use preventive services, and report poorer health status [1, 2]. Not surprising, health literacy levels are lower among minority populations, those with limited English proficiency, the elderly, poor, and less educated [4, 5].

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Related to health literacy, the issue of genetic literacy has received much attention in recent years. Genetic literacy pertains to one's capacity to understand and apply genetic information to make appropriate health and lifestyle decisions. Advances in genomics have led to exciting possibilities for the future of medicine, health care, and public health initiatives. The growing understanding of how genetics play a role in chronic diseases has spurred an ambitious vision of genomics for medical science emphasizing the potential health benefits for all [6]. Preliminary studies, however, have found that the general public has limited knowledge of basic concepts related to genetics [7, 8]. As such, genomic advances have prompted concerns about the general public's readiness to process and utilize the knowledge gained to make informed decisions about their health [8].

To facilitate the use of genomic information for health promotion and disease prevention, several government agencies, including the Office of the Surgeon General and the Centers for Disease Control and Prevention (CDC), have advocated for the use of family history assessment as a tool to increase genetic literacy [9–11]. Family history offers an ideal proxy to assess genomic risk and is the simplest applied 'genomic tool' available [9]. An individual's family history is more than genetics alone, but rather reflects the consequences of genetic susceptibilities, shared environmental and cultural factors, and common behaviors [10]. All of these factors are important when estimating disease risk.

In spite of public health communication efforts that have been undertaken to promote increased awareness of family history, several factors may severely limit the impact of these endeavors. Complex health information that is traditionally conveyed on family history tools (e.g., genetic predisposition, heredity, blood relative, index patient, pedigree) are inherently difficult to understand and may not lend themselves to easy simplification. Moreover, little is known about how the public responds to family history tools. For example, it is unclear whether the public is able to access available tools, understand how to use them, and apply that information in terms of taking health protective actions [10, 11], which may compromise their potential effectiveness. Readability, comprehension and cultural/linguistic appropriateness of available family history tools are rarely, if ever, assessed. Underserved populations, in particular, may face distinctive literacy-related barriers for the effective use of such tools because of less access to culturally and linguistically appropriate health information. By not addressing literacy-related barriers, public health efforts to encourage the use of family history as a tool for prevention may inadvertently serve to magnify health disparities [12].

To better delineate the barriers to the effective use of family health history tools, the present study was designed to systematically identify and evaluate the readability and document complexity of currently available family history tools for the general public.

Materials and Methods

Identification of Family History Tools

We undertook 3 steps to systematically identify existing family history tools to be included in the present study. First, we conducted general Internet searches using search terms such as 'family history tool', 'family health history', 'family history risk assessment' as well as targeted searches on government websites focused on disseminating family history information: CDC (www.cdc.gov/genomics/public/famhix/links.htm) and National Human Genome Research Institute (www.genome.gov/11510372). Second, upon generating an initial list of print and multimedia-based tools, we contacted a total of 9 experts in family history or genetics for feedback and to identify tools that were not included on our original list. These were identified by the study team because of their prior work either in promoting the importance of family history or developing family history tools. Experts identified were from various backgrounds including public health professionals, genetic counselors, nurses, and physicians. Third, we examined the published literature using similar search terms as noted earlier for other family history tools to be included. The reference section of published articles was also examined for additional tools.

Our definition of what constituted a 'tool' per se was broad in scope. Criteria were established by the research team to determine what constituted an appropriate tool for literacy assessment, including (a) availability and appropriateness for general public (vs. targeting provider), (b) focus on family history assessment and not behavior risk factor assessment (e.g., traditional health risk appraisals), and (c) availability of an English language version. Tools that did not meet these criteria were not included in the literacy assessment (see complete list of tools identified in table 1). For example, questionnaires or single-page forms used to collect family history information were included in our literacy assessment(s). We also included web sites that provided information on the importance of knowing one's family health history and detailed how to collect the information (e.g., instructions for which family members to include, information to include). However, we limited these web sites that provided family history guidelines to those representing national organizations (e.g., National Society of Genetic Counselors) or that were referenced by other government websites such as the CDC (e.g., Mayo Clinic).

In contrast, we did not include family history tools that were embedded in existing electronic medical record systems of a particular medical or hospital establishment even though several exist (e.g., Hughes riskApps [13], Centricity™ EMR) or are in development (e.g., Fox Chase Cancer Center [14], Intermountain Healthcare [15]). Other tools that were identified but no longer accessible either online or through the developer were also not

included. In addition, we did not include medical research surveys that included a family history component (e.g., National Health Interview Survey – NHIS; National Health and Nutrition Examination Survey – NHANES). Publications that discussed a family history tool but either (a) did not present the actual tool (i.e., in appendix) or (b) pertained to family history questionnaires administered via face-to-face or telephone interviewers, were also not included. Family history tools provided through commercial companies that required a fee to access were also not included in our assessment.

All tools were identified and assessed over the period of January 2008 to June 2009.

Literacy Assessment

Family history tools exist in many different formats and as such, we undertook different literacy assessment approaches to accommodate the various formats. We assessed reading grade level for all family history tools that contained sentence-type text. For all print-based tools that contained questionnaires, charts, or family history tree diagrams to be 'filled in', we assessed document complexity. As a result, tools were assessed for either readability or document complexity, although some tools (N = 16) were assessed for both.

To assess readability, we used the Simple Measure of Gobbledygook (SMOG) readability formula [16] calculated through 2 methods: (1) 'Readability Plus' (a computer software program designed by Micro Power & Light Co. to assess the reading level of materials) and (2) by hand – as a quality check to confirm results from the software program. The SMOG formula calculates for the reading grade level based on the number of polysyllabic words, or words with 3 or more syllables, for every 30 sentences. The SMOG reading grade level assumes 100% comprehension and is a more stringent criterion for comprehension compared to other readability formulas available [17]. We chose this formula because of its robustness and accuracy, strict criterion for comprehension, and widespread use in prior published literature assessing health education materials [17–19].

To prepare materials for readability assessments, we omitted numbered and bulleted lists, removed any punctuation including periods, colons, semi-colons, exclamation and question marks not indicating the end of a sentence, and omitted headings and sub-headings. Using 'Readability Plus' we took samples of approximately 300 words from each document (100 from 3 different sections). Text samples were taken from the beginning, middle and end of each family history tool. For tools that contained 300 words or less, we assessed all the available text. For hand calculations of SMOG, 10 sentences were taken from the beginning, middle, and end of every tool for a total of 30 sentences. For tools with less than 30 sentences, all of the material was used.

Some of the interactive family history tools calculated risk assessments based on family history and provided detailed summary reports based on risk level. For these tools, we separately assessed and reported the readability assessments for the instructions (i.e., front matter including description of tool, purpose, and instructions on how to complete) and actual tool for collecting family history information versus the summary report generated based on the information provided by an individual. This was undertaken to allow for more consistent comparison across tools and to capture any differences in language used between the 2 sections.

Document complexity was assessed by hand on all print-based family history tools that included 'fill in' sections, including questionnaires, charts, or family tree diagrams. Often, print-based family history tools contained insufficient text for traditional readability assessments (N = 9). Document complexity was particularly useful for assessing the tools that did not have sufficient text to perform SMOG readability assessments and allowed for another form of literacy comparisons across available tools. To assess document complexity, we used the PMOSE/IKIRSCH document readability formula [20]. Assessment of document complexity entails identifying and scoring documents based on the complexity of their structure (e.g., simple list, nested lists, etc) and their density (e.g., number of labels and items on the list). The majority of tools assessed for document complexity were print-based questionnaires or family history tree forms that are used to collect family history information (with the exception of one multimedia tool that consisted of a single screen or 'page' to complete family history information). Scoring on the PMOSE/IKIRSCH ranges from Level 1 proficiency – very low complexity (range including grade 4 equivalent to less than 8 years of schooling) to Level 5 proficiency – very high complexity (range including 16 years of schooling to more advanced postgraduate degree).

Results

A total of 78 tools were identified, 47 of which met the criteria for inclusion (table 1). Overall, 13 of the family history tools were multimedia-based, 5 were websites that detailed how to collect family history information, and 29 were print-based. A total of 8 of the multimedia-based tools were capable of generating summary assessment reports (e.g., risk assessments and/or preventive messages) and, as such, SMOG was assessed separately for the instructions/tool versus the summary report.

Several tools included in our assessment were developed for specific disease conditions, especially cancer (N = 13, tool #1, 2, 10, 11, 12, 16, 50, 57, 60, 63, 64, 67, 77). Five tools focused on metabolic conditions including coronary heart disease, stroke, and diabetes (#28, 29, 30, 55, 69). Some tools were developed for specific target populations such as African Americans (N = 3, #24, 47, 55). Seven tools were available in Spanish (#18, 28, 35, 40, 52, 66, 76), whereas only two tools have been translated into multiple languages for use (#40, 66). Only 3 of the tools included in our assessment collected family history information and generated risk estimates for multiple diseases (#3, 15, 21).

A list of the tools assessed for readability is included in table 2, organized by type of tool (i.e., multimedia, website, print). Overall, SMOG reading grade levels for the multimedia-based tools ranged from 10.1 to 18.3, with an average score of 13.6 that is equivalent to a college level

Table 1. Complete list of family history tools identified

Tool	Name of tool	Available at/from:	Description	Included in assessment (Y/N)
Multimedia				
1	Aurora Health Care: Hereditary Cancer Risk Assessment Tool	http://www.aurorahealthcare.org/services/cancer/geneticcounseling/screening-tool.asp, accessed December 2008	Web tool assessing family history risk for hereditary cancers.	Y – tables 2 and 3
2	Case Western University: Genetic Risk Easy Assessment Tool (GREAT)	https://family.case.edu/, accessed August 4, 2008. See also Acheson et al. (2006) [31]	Computer tool that collects and displays family history of cancer.	Y – table 2
3	Centers for Disease Control and Prevention: Family Healthware™	Available from developer, accessed September 2008	Computer tool assessing family history risk for 6 diseases: coronary heart disease, stroke, diabetes, and colon, breast and ovarian cancer.	Y – table 2
4	Dana-Farber Cancer Institute: Lynch Syndrome (Hereditary Nonpolyposis Colorectal Cancer)	http://www.dana-farber.org/pat/cancer/gastrointestinal/crc-calculator/default.asp, accessed December 2008	Web tool assessing risk for Lynch syndrome.	N – risk assessment for Lynch syndrome, not focused on family history.
5	Duke University Medical Center: The Cancer Risk Intake System (CRIS)	See Skinner et al. (2005) [32]	Touchscreen, tablet computer to assess risk for breast, ovarian, and colorectal cancers.	N – risk assessment for cancer, not focused on family history.
6	Families for Depression Awareness: Mental Health Family Tree Program	http://www.familyaware.org/familytree/, accessed December 2008	Web tool to collect family health history information. Targets mental health.	Y – table 2
7	Harvard School of Public Health: Disease Risk Index	http://www.diseaseriskindex.harvard.edu/update/, accessed December 2008	Web tool assessing risk for developing 5 diseases: cancer, diabetes, heart disease, osteoporosis, and stroke.	N – health risk appraisal tool, not focused on family history.
8	Hearst Women's Network: Real Age	http://www.realage.com/health_guides/Breast Cancer/introduction.asp, accessed December 2008	Web tool assessing risk for breast cancer.	N – general risk assessment for breast cancer, not focused on family history.
9	Massachusetts General Hospital: HughesRiskApps	See Ozanne et al. (2009) [13]	Computerized system to identify women at risk for hereditary breast/ovarian cancer.	N – developed for use in primary care offices and risk assessment clinics. Targets physicians/health care providers.
10	Munroe-Meyer Institute for Genetics and Rehabilitation and the Eppley Cancer Center University of Nebraska Medical Center: Medical Family Tree	http://app1.unmc.edu/gencancer/, accessed August 28, 2008	Web tool assessing family history risk for cancer.	Y – table 2
11	Myriad Genetic Laboratories, Inc.: Cancer History Guide	http://www.myriadtests.com/cancerhistory.htm, accessed August 4, 2008	Web tool to collect information on family history of cancer.	Y – table 2
12	NorthShore University HealthSystem (Formerly Evanston Northwestern Healthcare): My Generations	https://mygenerations.enh.org/enhweb/newuser.asp, accessed August 28, 2008	Web tool assessing family history risk for cancer.	Y – table 2
13	Norwich Union: Health Tree	http://www.norwichunion.com/healthtree/index.htm, accessed August 4, 2008	Web tool to collect family health history information.	Y – table 2
14	Ohio State University Comprehensive Cancer Center: Family Cancer History Questionnaire – Touchscreen Kiosk	See Westman et al. (2000) [33]	Computer touchscreen kiosk tool to collect family history of cancer.	N – developed for use in hospital system.
15	Ohio State University Comprehensive Cancer Center: Family HealthLink (formerly JamesLink)	http://www.jamesline.com/patientsandvisitors/prevention/cancergenetics/, accessed August 28, 2008. See also Kelly et al. (2008) [34]	Web tool assessing family history risk for cancer and coronary heart disease (CHD).	Y – table 2

Table 1 (continued)

Tool	Name of tool	Available at/from:	Description	Included in assessment (Y/N)
16	Penn State Cancer Institute: Cancer Risk Assessment	http://www.hmc.psu.edu/cancer/outreach_education/community/cancer_risk_assessments/cancer_risk_assessment.htm, accessed December 2008	Web tool assessing risk for colon cancer.	Y – table 2
17	SGgenomics Inc.: ItRunsInMyFamily.com: Family Health History Tool	http://www.itrunsinmyfamily.com/, accessed June 2009	Web family pedigree tool to collect family history information.	Y – table 2
18	U.S. Surgeon General's Family History Tool: My Family Health Portrait (Web version – updated version January 2009)	https://familyhistory.hhs.gov/, accessed May 26, 2009	Web tool that collects family history for 6 diseases: coronary heart disease, stroke, diabetes, and colon, breast and ovarian cancer.	Y – table 2
19	University College London/University of Cambridge: Genetic Risk Evaluation Assessment in the Clinical Environment (GRACE)	See Braithwaite et al. (2005) [35]	Prototype computerized hereditary breast cancer risk assessment tool.	N – developed for use in clinical setting.
20	University of Pennsylvania Abramson Cancer Center: The Penn II *BRCA1* and *BRCA2* Mutation Risk Evaluation Model Official Web Site	https://www.afcri.upenn.edu:8022/itacc/penn2/index.asp, accessed December 2008	Web tool assessing risk for *BRCA1* or *BRCA2* mutations.	N – risk assessment for *BRCA* mutation status, not focused on family history.
21	University of Virginia: Health Heritage	http://www.healthsystem.virginia.edu/internet/phs/HealthHeritage/home.cfm, accessed August 4, 2008. See also Kinze et al. (2002) [36]	(Demo) Web tool assessing family history risk for 89 health conditions.	Y – table 2
Websites				
22	ADHD Support: Apples on the Family Tree	http://www.adhdsupport.com/adhd-evaluation-tool.aspx, accessed December 2008	Web page detailing how to collect family history of symptoms or diagnoses related to ADHD. Includes a family history tree for collecting information.	Y – tables 2 and 3
23	Centre for Genetics Education of the NSW Genetics Service: Family Health History Can Matter (My Family Health Record)	http://www.genetics.com.au/fhh/fhhhome.htm, accessed June 2009	Web site detailing the importance of family history and how to collect family history information. Includes a form (My Family Health Record) for collecting family history.	Y – tables 2 and 3
24	Howard University - National Human Genome Center: Collect Your Family Health History	http://www.genomecenter.howard.edu/community/CollectYourFamilyHealthHistory.htm, accessed December 2008	Web page detailing how to collect family health history information.	Y – table 2
25	March of Dimes: Genetics and Your Practice	http://www.marchofdimes.com/gyponline/index.bm2, accessed December 2008	Web site providing information and resources on integrating genetics into patient care. Includes information on how to collect a family health history.	N – targets physicians/health care providers.
26	Mayo Clinic: Medical history: How to Compile Your Medical Family Tree	http://www.mayoclinic.com/health/medical-history/HQ01707, accessed August 4, 2008	Web page detailing how to collect family health history information.	Y – table 2
27	National Society for Genetic Counselors: Your Family History: Your Future	http://www.nsgc.org/consumer/familytree/index.cfm, accessed August 4, 2008	Web page detailing how to collect family health history information.	Y – table 2
Print				
28	American Heart Association: Go Red for Women Family Tree	http://www.americanheart.org/presenter.jhtml?identifier=3059464, accessed December 2008	Family history tree for mapping out family health history. Targets heart disease among women.	Y – tables 2 and 3

Tool	Name of tool	Available at/from:	Description	Included in assessment (Y/N)
29	American Heart Association: The Heart of Diabetes	http://www.americanheart.org/presenter.jhtml?identifier=3044888, accessed December 2008	Family history tree for mapping out family health history. Targets diabetes and related conditions.	Y – table 3
30	American Heart Association-Wisconsin Stroke Committee: Reproducible Family Health History Tree	http://www.americanheart.org/presenter.jhtml?identifier=3056055, accessed December 2008	Family history tree for mapping out family health history. Targets stroke and high blood pressure.	Y – table 3
31	American Medical Association: Adult Family History Form	http://www.ama-assn.org/ama/pub/category/2380.html, accessed August 25, 2008	Questionnaire to collect family history information.	Y – table 3
32	American Medical Association: Family Medical History in Disease Prevention	http://www.ama-assn.org/ama/pub/category/2380.html, accessed August 4, 2008	Booklet detailing the importance of family history and the 'red flags' for inherited conditions. Includes information on how to collect a family health history.	N – targets physicians/health care providers.
33	American Society of Human Genetics & Genetic Alliance: Family History Fact Sheet	http://www.ashg.org/press/consumers.shtml#4, accessed August 4, 2008	Fact sheet describing how to collect a family health history and draw a family tree.	Y – table 2
34	Brigham and Women's Hospital, Division of General Medicine: Family History Form	See Murff et al. (2007) [37]	Form to collect family history of cancer and other diseases.	N – not available in article.
35	Centers for Disease Control and Prevention: Family History Is Important for Health	http://www.cdc.gov/genomics/public/famhix/fs.htm, accessed August 28, 2008	Fact sheet detailing the importance of family history and how to learn about own family history.	Y – table 2
36	Children's Hospital of Eastern Ontario Eastern Ontario Regional Genetics Program: Family History Assessment Tool	See Gilpin et al. (2000) [38]	Tool to record family history of cancer.	N – risk assessment tool targeting physicians/health care providers.
37	Cincinnati Children's Hospital Medical Center: Collecting Your Family's Medical History	http://www.cincinnatichildrens.org/svc/alpha/h/hereditary-cancer/visit/before.htm, accessed August 28, 2008	Brochure describing how to collect family health history.	Y – table 2
38	Comenius University	See Hlavaty et al. (2005) [39]	Questionnaire to collect family history of colorectal cancer.	N – not available in article.
39	Dana-Farber Cancer Institute and Massachusetts General Hospital: Family History Questionnaire	See Grover et al. (2004) [40]	Questionnaire to collect family history of cancer.	N – not available in article.
40	Genetic Alliance: Does It Run in the Family? A Guide to Family Health History	http://www.geneticalliance.org/ws_display.asp?filter=ccfhh, accessed August 28, 2008	Customizable booklet detailing how to collect family health history information.	Y – table 2
41	Genetic Alliance: Family Health History Questionnaire	http://geneticalliance.org/ws_display.asp?filter=ccfhh, accessed August 4, 2008	Questionnaire to collect family history information.	Y – tables 2 and 3
42	Genetic Alliance: Healthcare Provider Card	http://geneticalliance.org/ws_display.asp?filter=ccfhh, accessed August 4, 2008	Questionnaire to collect family history information. Information available for healthcare provider on how to use family history to determine risk.	N – targets physicians/health care providers.
43	Genetics in Primary Care (GPC) project, Family History Working Group: Genetic Tools Family Disease Checklist	http://www.genetests.org/servlet/access?id=8888892&key=Cdbs0RTAjlynd&fcn=y&fw=AO5o&filename=/tools/concepts/checklist.html, accessed September 25, 2008	Checklist to track diseases in the family.	Y – table 3

Table 1 (continued)

Tool	Name of tool	Available at/from:	Description	Included in assessment (Y/N)
44	Genetics in Primary Care (GPC) project, Family History Working Group: Your Family Medical History	http://www.genetests.org/servlet/access?id=8888892&key=CFY3dMa06Ml4r&fcn=y&fw=7x1-&filename=/tools/concepts/medHist.html, accessed September 25, 2008	Questionnaire to collect family history information.	Y – table 3
45	Heartland Regional Coordinating Center University of Oklahoma Health Sciences Center: Family Health History Toolkit	http://www.heartlandfamilyhistory.org/familyhistorytools.htm, accessed September, 2008	Toolkit detailing how to collect family health history.	Y – table 2
46	Helsinki University Central Hospital, Department of Oncology: Family History Questionnaire	See Eerola et al. (2000) [41]	Questionnaire to collect family history of breast and ovarian cancer.	N – not available in article.
47	Howard University – National Human Genome Center: Planning for a Healthy Future: The Importance of Family Health History	National Human Genome Center, Howard University	Booklet developed for African Americans detailing how to collect, use and share family history information. Includes a family history tree for collecting information.	Y – tables 2 and 3
48	Indiana University School of Medicine Department of Medical Genetics: Family History Questionnaire	See Cole et al. (1978) [42]	Questionnaire to collect family history information.	Y – table 3
49	Institute for Cultural Partnerships: Does It Run in the Family? A Guide to Family Health History	www.culturalpartnerships.org/documents/DoesItRun.pdf, accessed December 2008	Booklet detailing how to collect family history information.	N – similar to Genetic Alliance Tool that was included.
50	Lahey Clinic Foundation Familial Cancer Risk Assessment Center: Cancer Risk Evaluation Packet	http://www.lahey.org/Medical/FCRAC/FCRAC_FI_FHT.asp, accessed December 2008	Packet including questionnaires for collecting family history of cancer.	Y – tables 2 and 3
51	Leiden University Medical Centre	See de Jong et al. (2006) [43]	Questionnaire to collect family history of colorectal cancer.	N – not available in article.
52	March of Dimes: Family Health Questionnaire (Prenatal)	http://www.marchofdimes.com/pnhec/4439_1109.asp, accessed August 4, 2008	Preconception/prenatal questionnaire to collect family history information.	Y – tables 2 and 3
53	Massachusetts General Hospital and Lahey Clinic: Family History Questionnaire	See Hughes et al. (2003) [44]	Questionnaire to collect family history of breast and ovarian cancer.	N – not available in article.
54	Memorial University of Newfoundland and the University of Toronto: Family History Questionnaire	See Green et al. (2007) [45]	Questionnaire to collect family history of colorectal cancer.	N – not available in article.
55	Michigan Department of Community Health: Family History and High Blood Pressure	http://www.cdc.gov/pcd/issues/2005/apr/pdf/04_0134_01.pdf, accessed August 25, 2008. See also Theisen (2005) [22]	Handout that includes a worksheet to collect family history information on high blood pressure, heart disease, and stroke.	Y – tables 2 and 3
56	Michigan Department of Community Health: Family History and Your Health	http://www.migeneticsconnection.org/factcards.shtml, accessed December 2008	Fact sheet detailing how to collect family history information.	Y – table 2
57	National Breast Cancer Centre: Family History Questionnaire	See Fisher et al. (2003) [46]	Questionnaire to collect family history of breast cancer.	Y – tables 2 and 3
58	National Coalition for Health Professional Education in Genetics: Family History Questionnaire	http://pa.nchpeg.org/, accessed August 4, 2008	Questionnaire to collect family history information.	Y – table 3
59	New York Hospital-Cornell Medical Center, Strang Cancer Prevention Center	See Breuer et al. (1993) [47]	Form to collect family history of cancer.	N – not available in article.

Tool	Name of tool	Available at/from:	Description	Included in assessment (Y/N)
60	New York State Department of Health: Sample Cancer Family History Questionnaire	http://www.health.state.ny.us/nysdoh/cancer/obcancer/append11.htm, accessed December 2008	Questionnaire to collect family history of cancer.	Y – table 3
61	Northwestern University	See Frezzo et al. (2003) [48]	Questionnaire to collect family history information.	N – not available in article.
62	Ontario Cancer Institute	See Theis et al. (1994) [49]	Questionnaire to collect family history information.	N – not available in article.
63	Prevent Cancer Foundation: Guide to Preventable Cancer	http://orders.asapmail.com/sqlimages/crpf/preventable%20cancer%20guide%209-07.pdf, accessed December 18, 2008	Booklet that includes a family history medical chart/tree to collect family history information.	Y – tables 2 and 3
64	Princess Margaret Hospital: Family History Questionnaire	See Armel et al. (2009) [50]	Questionnaire to collect family history of cancer.	Y – tables 2 and 3
65	Royal Melbourne Hospital, Familial Cancer Centre	See Gaff et al. (2004) [51]	Questionnaire to collect family history of prostate cancer.	N – not available in article.
66	U.S. Surgeon General's Family History Tool: My Family Health Portrait (Paper version)	http://www.hhs.gov/familyhistory/order.html, accessed August 28, 2008	Questionnaire to collect family history information.	Y – tables 2 and 3
67	University of Bristol: The Questionnaire	See House et al. (1999) [52]	Questionnaire to collect family history of colorectal cancer.	Y – table 3
68	University of Cambridge: Questionnaire on Cancer Family History	See Leggatt et al. (1999, 2000) [53, 54]	Questionnaire to collect family history of cancer.	N - not available in article.
69	University of Chicago: Cardiology Family History Questionnaire	See MacLeod et al. (2008) [55]	Questionnaire to collect family history of cardiovascular disease.	Y – tables 2 and 3
70	University of Cincinnati Family History Working Group: Family Health History	http://www.cahs.uc.edu/gc/FamilyHistoryProject.htm, accessed September 2008	Fact sheet describing how to collect a family health history.	Y – table 2
71	University of Hawaii	See Glanz et al. (1999) [56]	Questionnaire to collect family history of cancer focusing on colorectal cancer.	N – not available in article.
72	University of Liverpool: Familial Cancer Assessment Tool	See Benjamin et al. (2003) [57]	Questionnaire to collect family history of cancer.	N – targets physicians/health care providers.
73	University of Nottingham: Family History Questionnaire	See Qureshi et al. (2005) [58]	Questionnaire to collect family history information.	N – not available in article.
74	University of Queensland Medical School	See Aitken et al. (1995) [59]	Questionnaire to collect personal and family medical history of colorectal cancer.	N – not available in article.
75	University of Virginia Health Systems: Are You at Risk for Hereditary Breast Cancer?	See Cohn et al. (2008) [60]	Brochure to facilitate the collection and recognition of hereditary breast and ovarian cancer syndrome.	Y – tables 2 and 3
76	Utah Department of Health: Family Health History Toolkit	http://health.utah.gov/genomics/familyhistory/toolkit.html, accessed August 28, 2008	Toolkit detailing how to collect family health history. Includes a family history tree for collecting information.	Y – tables 2 and 3
77	Virginia Commonwealth University: Family History Questionnaire	See Quillin et al. (2006) [61]	Questionnaire to collect family history of cancer.	N – not available in article.
78	Wake Forest University: Family History Form	See Hurt et al. (2001) [62]	Form to collect family history of cancer.	N – not available in article.

Note: This table does not include tools that are known to be in development, unavailable from the developer, or part of electronic hospital record systems.

Table 2. Reading grade level of family history tools

Name of tool	Available in Spanish	Reading level SMOG
Multimedia		
Aurora Health Care:		
Hereditary Cancer Risk Assessment Tool – Instructions/Tool	No	15.9
Hereditary Cancer Risk Assessment Tool – Report		16.4
Case Western University:		
Genetic Risk Easy Assessment Tool (GREAT) – Instructions/Tool	No	13.7
Genetic Risk Easy Assessment Tool (GREAT) – Report		13.8
Centers for Disease Control and Prevention:		
Family Healthware™ – Instructions/Tool	No	10.1
Family Healthware™ – Report		11.8
Families for Depression Awareness:		
Mental Health Family Tree Program	No	13.5
Munroe-Meyer Institute for Genetics and Rehabilitation and the Eppley Cancer Center University of Nebraska Medical Center:		
Medical Family Tree – Instructions/Tool	No	12.6
Medical Family Tree – Report		13.4
Myriad Genetic Laboratories, Inc.:		
Cancer History Guide	No	14.3
NorthShore University HealthSystem (Formerly Evanston Northwestern Healthcare):		
My Generations – Instructions/Tool	No	12.6
My Generations – Report		12.8
Norwich Union:		
Health Tree	No	18.3
Ohio State University Comprehensive Cancer Center Family History Cancer Risk Assessment:		
Family HealthLink (formerly JamesLink) – Instructions/Tool	No	11.7
Family HealthLink (formerly JamesLink) – Report		13.2
Penn State Cancer Institute:		
Cancer Risk Assessment – Instructions/Tool	No	11.5
Cancer Risk Assessment – Report		14.8
SGgenomics Inc., ItRunsInMyFamily.com:		
Family Health History Tool	No	13.7
U.S. Surgeon General's Family History Tool:		
My Family Health Portrait – updated version January 2009	Yes	10.7
University of Virginia:		
Health Heritage – Instructions/Tool	No	11.1
Health Heritage – Report (Limited Sample)		16.1
Websites		
ADHD Support:		
Apples on the Family Tree	No	11.1
Centre for Genetics Education of the NSW Genetics Service:		
Family Health History Can Matter (My Family Health Record)	No	12.6
Howard University – National Human Genome Center:		
Collect Your Family Health History	No	11.9
Mayo Clinic:		
Medical History: How to Compile Your Medical Family Tree	No	16.1
National Society for Genetic Counselors:		
Your Family History: Your Future	No	12.6

Table 2 (continued)

Name of tool	Available in Spanish	Reading level SMOG
Print		
American Heart Association: Go Red for Women Family Tree	Yes	11.2
American Society of Human Genetics & Genetic Alliance: Family History Fact Sheet	No	13.5
Centers for Disease Control and Prevention: Family History Is Important for Health	Yes	12.7
Cincinnati Children's Hospital Medical Center: Collecting Your Family's Medical History	No	13.5
Genetic Alliance: Does It Run in the Family? A Guide to Family Health History	Yes (also available in Chinese)	12.8
Genetic Alliance: Family Health History Questionnaire	No	10.9
Heartland Regional Coordinating Center University of Oklahoma Health Sciences Center: Family Health History Toolkit	No	12.2
Howard University – National Human Genome Center: Planning for a Healthy Future: The Importance of Family Health History	No	13.5
Lahey Clinic Foundation Familial Cancer Risk Assessment Center: Cancer Risk Evaluation Packet	No	13.7
March of Dimes: Family Health Questionnaire (Prenatal)	Yes	14.1
Michigan Department of Community Health: Family History and High Blood Pressure	No	11.5
Michigan Department of Community Health: Family History and Your Health	No	11.9
National Breast Cancer Centre: Family History Questionnaire	No	10.3
Prevent Cancer Foundation: Guide to Preventable Cancer	No	12.5
Princess Margaret Hospital: Family History Questionnaire	No	8.7
U.S. Surgeon General's Family History Tool: My Family Health Portrait (paper version)	Yes (also available in Chinese, French, Polish, and Portuguese)	11.9
University of Chicago: Cardiology Family History Questionnaire	No	11.1
University of Cincinnati Family History Working Group: Family Health History	No	11.3
University of Virginia Health Systems: Are You at Risk for Hereditary Breast Cancer?	No	10.3
Utah Department of Health: Family Health History Toolkit	Yes	11.5

reading ability. Differences in SMOG reading grade level between the instructions/tool and summary reports ranged from 1 to 5 (i.e., less than 1 grade level to 5 grade levels). Websites that contained information on how to collect family history information contained text written at grade levels ranging from 11.1 to 16.1, with an average score of 12.9. For the print-based family history tools, we were able to conduct a SMOG assessment on 20 of them. Reading grade levels for these tools ranged from 8.7 to 14.1. The average score was 12.0, which is equivalent to a 12th grade or high school level reading ability.

A total of 25 family history tools included fill-in sections or questions that could be assessed for document complexity (table 3). Overall, document complexity for the tools ranged from level 1 proficiency to level 4 proficiency. Level 1 is equivalent to a range of 4th grade to less than 8th grade reading ability. Level 4 is equivalent to a range of 15 years of schooling to college degree reading ability. Almost half of the tools (48%) scored at level 2 proficiency, which is equivalent to a range of 8th grade to high school diploma reading ability. Over a quarter (28%) of the tools scored at level 4 proficiency and are considered to be highly complex.

Discussion

The overarching goal of this study was to systematically identify and evaluate family history tools available to the general public for readability and document complexity. Although readability assessments on either a single family history tool [21, 22] or a group of familial cancer risk assessment tools [23] have previously been conducted, this is the first study to our knowledge that systematically conducts literacy assessments of available family history tools for the general public focused on all diseases to allow for comparison across tools. A better understanding of the readability and document complexity across family history tools may help health practitioners and public health educators to better chose a tool that is appropriate for the audience they are working with.

Overall, our findings suggest that most tools are written on average at a 12-13 grade level that is beyond the 8th grade average reading level in the United States. This is consistent with evaluations of patient education materials in general which are often written at a 10th grade reading level or higher [1, 4, 24], and raises concerns about whether patients and individuals in the general public understand the materials they are provided with. Developers of patient materials and education products are often faced with the challenge of producing materials at a low reading grade level despite the fact that the majority of individuals, including those who are highly educated, prefer simple materials [25]. However, the design and evaluation of simple and easy to use materials is an increasing necessity given the prevalence of limited health literacy in the U.S. population [1, 26, 27].

The family history tools assessed for document complexity varied widely in their scores, with tools ranging from very low to high complexity. These results highlight the need for the developers of family history questionnaires to take into consideration how information is structured and organized. Highly complex forms that have multiple subheadings and nested columns have a greater likelihood of confusing the respondent and may result in inaccurate reporting of important family history information (fig. 1 illustrating the difference between low versus high complexity forms). Although it is desirable for family history questionnaires to collect the most detailed and accurate information, developers should also take into consideration how the forms will be used. For example, if the goal of the family history questionnaire is to obtain a quick 'screen' of a patient's family history that can be taken to a provider who can then prompt for more detailed information (e.g., age of diagnosis, other family members), then a simple tool may be all that is necessary to serve that purpose.

There were several limitations to the present study. First, the rapid proliferation of family history tools posed a challenge to this study as tools are constantly being developed, adapted, and modified on a regular basis. As such, the findings reported in this study are only accurate to the extent that the tools listed have not been modified since the time of submission (June 2009). Second, all the experts included in the study were based in American academic, non-profit, or government settings. Although efforts were made to identify family history tools from other countries including the United Kingdom (tool #19, 67, 68, 72, 73), Canada (#36, 54, 62), and Australia (#23, 57, 65, 74), the study likely has an American bias.

All the literacy assessments were performed by a single coder (R.E.G.), which serves as a limitation to this study. However, SMOG calculations conducted by hand were compared to the computer derived SMOG and were highly correlated ($r = 0.95$, $p < 0.001$). Moreover, extensive discussions occurred between the coder and the lead author when there were ambiguities to be resolved while coding family history tools using PMOSE/IKIRSCH.

Table 3. Document complexity of fill-in family history forms

Fill-in family history forms	Available in Spanish	Disease focus	Document complexity level
ADHD Support: Apples on the Family Tree (Family Tree)	No	ADHD	Level 2 proficiency – low complexity
American Heart Association: Go Red for Women Family Tree	Yes	Heart disease	Level 2 proficiency – low complexity
American Heart Association: The Heart of Diabetes	No	Diabetes	Level 2 proficiency – low complexity
American Heart Association – Wisconsin Stroke Committee: Reproducible Family Health History Tree	No	Stroke and high blood pressure	Level 2 proficiency – low complexity
American Medical Association: Adult Family History Form	No	Multiple	Level 3 proficiency – moderate complexity
Aurora Health Care: Hereditary Cancer Risk Assessment Tool	No	Cancer	Level 2 proficiency – low complexity
Centre for Genetics Education of the NSW Genetics Service: Family Health History Can Matter (My Family Health Record)	No	Multiple	Level 1 proficiency – very low complexity
Genetic Alliance: Family Health History Questionnaire	No	Multiple	Level 2 proficiency – low complexity
Genetics in Primary Care (GPC) project, Family History Working Group: Genetic Tools Family Disease Checklist	No	Multiple	Level 4 proficiency – high complexity
Genetics in Primary Care (GPC) project, Family History Working Group: Your Family Medical History	No	Multiple	Level 3 proficiency – moderate complexity
Howard University – National Human Genome Center: Planning for a Healthy Future: The Importance of Family Health History (Family Health History Tree)	No	Multiple	Level 3 proficiency – moderate complexity
Indiana University School of Medicine Department of Medical Genetics: Family History Questionnaire	No	Multiple	Level 4 proficiency – high complexity
Lahey Clinic Foundation Familial Cancer Risk Assessment Center: Cancer Risk Evaluation Packet	No	Cancer	Level 4 proficiency – high complexity
March of Dimes: Family Health Questionnaire (Prenatal)	Yes	Prenatal syndromes	Level 4 proficiency – high complexity
Michigan Department of Community Health: Family History and High Blood Pressure	No	Blood pressure	Level 2 proficiency – low complexity
National Breast Cancer Centre: Family History Questionnaire	No	Breast cancer	Level 2 proficiency – low complexity
National Coalition for Health Professional Education in Genetics: Family History Questionnaire	No	Multiple	Level 4 proficiency – high complexity
New York State Department of Health: Sample Cancer Family History Questionnaire	No	Cancer	Level 2 proficiency – low complexity
Prevent Cancer Foundation: Guide to Preventable Cancer (Family Medical History Chart)	No	Cancer	Level 2 proficiency – low complexity
Princess Margaret Hospital: Family History Questionnaire	No	Cancer	Level 4 proficiency – high complexity
U.S. Surgeon General's Family History Tool: My Family Health Portrait (paper version)	Yes	Multiple	Level 3 proficiency – moderate complexity
University of Bristol: The Questionnaire	No	Colorectal cancer	Level 1 proficiency – very low complexity

Table 3 (continued)

Fill-in family history forms	Available in Spanish	Disease focus	Document complexity level
University of Chicago: Cardiology Family History Questionnaire	No	Cardiovascular disease	Level 4 proficiency – high complexity
University of Virginia Health Systems: Are You at Risk for Hereditary Breast Cancer?	No	Breast and ovarian cancer	Level 2 proficiency – low complexity
Utah Department of Health: Health Family Tree Tool	Yes	Multiple	Level 2 proficiency – low complexity

Note: Grade level equivalent range for proficiency levels. Level 1: grade 4 equivalent to less than 8 years of schooling; Level 2: grade 8 equivalent to high school diploma; Level 3: grade 12 equivalent to some education after high school; Level 4: 15 years of schooling to college degree equivalent; Level 5: 16 years of schooling to more advanced postgraduate degree.

Our study used the SMOG to assess readability and may have provided grade reading level estimates that are higher than estimates provided by other readability formulas (e.g., Fry, Fog, Flesch). We calculated readability using the Fry formula [28] on a subset of family history tools and noted that scores on average were one grade level lower than the SMOG results. Although researchers have noted that readability estimates using different formulas can vary widely for the same material [17], others have shown strong positive correlations between commonly used readability formulas [19]. In spite of potential discrepancies across readability formulas, our use of a single approach, nonetheless, enables us to compare across family history tools using the same criteria. Developers of family history tools may want to assess materials using multiple readability formulas to ensure a more reliable readability score and help to guide text revision until readability is at a suitable level [17].

All family history tools were assessed without any prior editing for jargon. For example, 'family history' was counted as 2 polysyllabic words each time it was presented. Because the words 'family history' would be used repeatedly in family history tools, this may inflate the SMOG estimates calculated. To account for the potential impact of jargon, we performed an additional set of SMOG assessments on a subset of 6 tools where the words 'family history' was counted only once. The results of our assessment demonstrated that SMOG levels were reduced by an average of 0.8 (range 0.1–1.4). Nonetheless, SMOG reading grade levels for these tools remained high, ranging from 9.7 to 12.8, suggesting that family history tools would benefit from additional efforts to reduce reading grade levels.

Although we used the PMOSE/IKIRSCH document readability formula to assess print-based family history tools, we were unable to apply the same approach to assess the complexity of interactive multimedia-based family history tools. This approach was developed specifically to assess the readability of static print-based documents. Hence, it was not possible to capture the unique features and dynamic nature of electronic media, given its interactivity capabilities (e.g., prompts to correct for entry errors) and the extent to which the reader helps to determine the text (Irwin Kirsch, personal communication). As such, we were unable to provide comparative data on document complexity between print and multimedia-based family history tools.

In a related vein, this study did not address the usability and navigation challenges of multimedia-based family history tools. Although SMOG assessments can provide researchers with a sense of prose literacy (i.e., knowledge and skills needed to search, comprehend, and use information from continuous texts), the dynamic nature of multimedia-based programs may facilitate the process of collecting family history information and overcome some of the challenges of using more complicated text (e.g., glossary pop up for complex words). On the other hand, multimedia-based family history tools may usher in a new set of challenges that will need to be addressed, such as unfamiliarity and lack of skills in using computers, especially among older target audiences.

This study does not address issues related to the use of plain language among the family history tools. Plain language (also called plain English) is communication an audience can understand the first time they read or hear it

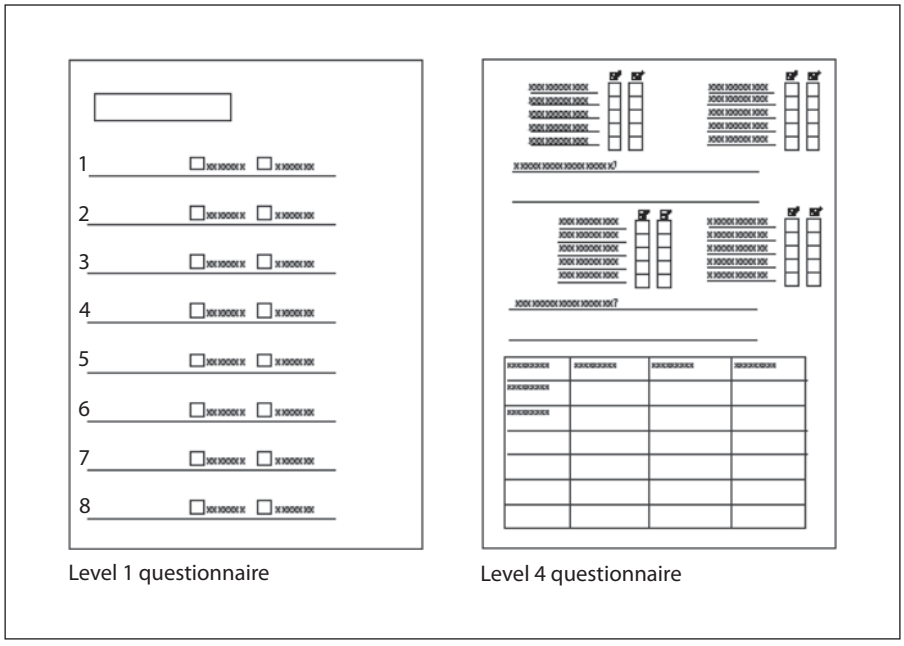

Fig. 1. Example of documents with differing complexity levels.

(www.plainlanguage.gov). Materials are considered to be written in plain language if audience members can find what they need, understand what they find, and use what they find to meet their needs. Elements of plain language include appearance/appeal (i.e., text layout, illustrations), organization (i.e., headings, short paragraphs), and writing style (i.e., active voice). Although approaches to assessing plain language are currently available (e.g., Suitability Assessment of Materials – SAM [29]), we chose not to use this approach in this study. Rating materials using SAM is a subjective process and therefore not as objective of a measurement compared to either SMOG or PMOSE/IKIRSCH. Further, the categories for rating on the SAM are more applicable to health education type materials and are less appropriate for evaluating forms that collect (family history) information from a respondent. For example, SAM requires scoring for categories including graphics and learning stimulation. Although this would be useful for some of the family history tools included in our list (in particular, some print-based tools that are structured like health education materials and contain personal stories), it would be less useful for tools that simply ask respondents to complete information about their family members. The lack of comparative information across family history tools on the elements of plain language is a limitation in this study.

Finally, we should note that the assessment of readability and document literacy, while important, does not address issues related to the accuracy or value of a family history tool. Future work is needed to examine the clinical validity and utility of these tools on identifying individuals at increased disease risk and improving health outcomes. We refer readers to other references for further discussion on this issue [10, 30].

In sum, the findings from this study suggest the need to consider ways to simplify family history tools. We recommend some of the following strategies, based on the findings from the study, and that are commonly used by plain language experts (www.plainlanguage.gov) when developing education materials for the general public: (a) use simpler language (e.g., 'use' instead of 'utilize', 'doctor' instead of 'physician'), (b) use shorter sentences, (c) use active voice, (d) avoid unnecessary words, (e) avoid technical jargon, (f) write short sections to break up material, using clear headings and sub-headings, (g) use an easy-to-read layout by including lists, illustrations or tables to simplify information, (h) identify and write for a specific target audience, and (i) pretest the tools with individuals in target audience. To reduce document complexity, developers of family history tools may want to consider using a simpler structure for fill-in forms (e.g. avoid using a nested list structure) and reducing the density or the total number of headings/labels in tables. In addition, shortening the length of a form and reducing the number of items in general that people are asked to fill in would also reduce the complexity of documents.

Conclusion

The proliferation of tools in recent years to facilitate the collection of family history information may serve to enhance genetic literacy among the general public and thereby assist in the translation of discoveries stemming from the Human Genome Project. Disparities in health literacy, however, may serve as a critical barrier to the effective use of family history tools, particularly among underserved populations. The lack of family history tools that are easy to read or use may compromise their potential effectiveness in identifying individuals at increased risk for chronic diseases in the general population. Future efforts are needed to examine strategies for overcoming barriers to the effective use of family history tools, in particular, by those in the general population who may face the greatest challenges to benefiting from genomic advances.

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