Family Health History Project Report

Farzin Ahmed, BDS, MPH
Mufaddal Mamawala, MBBS, MPH

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School of Public Health

3500 Camp Bowie Blvd.
Fort Worth, TX 76107

Sharon Homan, PhD
Professor and Chair, Department of Biostatistics and Epidemiology
Director, Biostatistics and Evaluation Services and Training (BEST) Center
817-735-5162
314-583-2825 (cell)
1sharon.homan@unthsc.edu

Summary: This report provides background information about family health history tools, as well as specific details regarding existing tools, and a discussion of considerations in the implementation of FHH tools in health practices. The report aims are to provide: (1) basic information about family health history (consumer perspective), (2) description of methods and tools for obtaining family health history; (3) review of existing FHH tools; (4) the Surgeon General's "My Family Health Portrait" and considerations for adopting and customizing this tool in practice settings; and (5) opportunities and challenges for developing and implementing a FHH tool in the region.

Part 1: Basic Family Health History Information (Consumer Perspective)

Family health history is a written document of the diseases and health conditions from past and present family members. A useful family health history shows at least three generations of a person's biological relatives, and would include family member name, relationship in the family clan, what illness or disease they have, at what age was the diagnosis made, and age and cause of death for family member. [1] Family health history is a practical tool for discovering illness and disease in a family. In a clinical setting, providers may use patient history tools to educate patients about possible present and future health risks, and to recommend screening and preventive measures, including lifestyle choices for lowering risk of developing illness/disease.[1]

Family history tools typically gather key information including:[1]
- health problems of family members
- age when the problem started or was diagnosed
- age and cause of death
- lifestyle habits (smokers/nonsmoker, diet, weight and exercise habits)
- ethnic background
- work or occupational Health History

Health problems that can run in families include:
- alzheimer's disease or dementia.
- arthritis
- asthma
- birth defects
- cancers (breast, colon, lung, prostate, ovarian and other cancers)
- diabetes
- depression
- heart disease or sudden heart attack
- other heart problems
- high blood pressure and high cholesterol
- pregnancy losses, stillbirths and miscarriages
- stroke or blood clots.
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Genetic, environmental and behavioral factors potentially contribute to a person inheriting or developing an illness/disease.[2] A person may have an increased risk of developing a health condition if his or her family has:
- health problems that occur at an earlier age than expected (10 to 20 years before most people get the problem);
- the same health problem in more than one close family member;
- health problem that does not usually affect a certain gender (e.g., breast cancer in a male family member); and/or
- certain combinations of health problems within a family (breast and ovarian cancer or heart disease and diabetes).

Sharing one's family health history enables a person to work together with his or her family to make good health decisions. If a person is adopted it can be harder to learn about the family health history; however, health information from birth parents can be obtained through the National Adoption Clearinghouse (http:www.childwelfare.com; accessed 08/20/2014).

A family health history is treated like other confidential patient information gathered during a healthcare visit. The HIPAA law protects private health information, including the family health history. The U.S. Surgeon General's office recommends that family members actively share health information. [3] Guidance is found at http://www.hhs.gov/familyhistory/start/startenglish.pdf, accessed 08/20/2014.

The Surgeon General, in cooperation with other agencies of the U.S. Department of Health and Human Services,[4] launched a national public health campaign, called the *Surgeon General's Family History Initiative*, to encourage all American families to learn more about their family health history. Each year since 2004, the Surgeon General has declared Thanksgiving to be National Family History Day. Over the holiday or at other times when families gather, the Surgeon General encourages Americans to talk about, and to write down, the health problems that seem to run in their family. Learning about one's family's health history may help ensure a longer, healthier future together.

Part 2: Family Health History Methods and Tools

Methods for Collecting Family History

> *Method 1*: **Family History Questionnaire or Checklist**
> - is a common tool used in general practice;
> - uses a self-administered questionnaire, completed at home to allow time to contact family members and provide more accurate information; and
> - clarifies medical terminology that may be unclear to patients.
>
> Examples of family history questionnaires or checklists include:
> - March of Dimes: *Your Family Health History;* and
> - Family History Tools - Prenatal Genetic Screening Questionnaire, Pediatric Clinical Genetics Questionnaire, Adult Family History Form by AMA (American Medical Association).
>
> *Method 2*: **The Pedigree / Family Tree**
> - Is a commonly used tool by genetics professionals;
> - ideally depicts at least three generations;
> - uses standardized symbols, which clearly mark individuals affected with a specific diagnosis to allow for easy identification;
> - visibly assists in determining the size of the family and the mode of inheritance of a specific condition; and
> - may facilitate identification of members at increased risk of developing the condition.

Examples include:
- *Family Healthware* (Centers for Disease Control and Prvention);
- *The Heart of Diabetes Family History Tree* (American Heart Association); and
- *My Family Health Portrait* (US Surgeon General's Office).

➤ Some family history tools both consist of questionnaires/checklists and the pedigree.

Readily Available Family History Tools

1. ***Tool: Surgeon General's Family History Initiative***
   Title: My Family Health Portrait
   Developers: Surgeon General; US Department of Health and Human Services (HHS.gov).
   Format: Web based tool can be completed online with data stored on individual's computer. Printable report includes table of family health history and drawing of family tree. A print family history tool is also available.
   Target population: General population.
   Diseases: Heart disease, stroke, diabetes, colon cancer, breast cancer, and ovarian cancer, and open ended fields to include diseases of concern to the individual.
   Language: English/Spanish/Italian. (Also available in many other languages.)
   Confidentiality: Limited to person completing personal family health history.
   Risk assessment: None.
   Behavioral or environmental factors: None.
   Limitations: too general to detect rare genetic disorders.
   Website: http://www.hhs.gov/familyhistory/, accessed 08/20/2014.

2. ***Tool: Family Health History*** (CDC)
   Title: Family Healthware
   Developer: Centers for Disease Control and Prevention (CDC).
   Format: Web based tool. Data are saved and stored in database. Information can be updated as needed. Printable record includes drawing of family tree, familial risk assessment and personalized prevention recommendations.
   Target population: General population.
   Availability: Currently being evaluated in a clinical trial. Also available for licensure and research studies. Contact www.familyhealthware.com, accessed 08/20/2014.
   Diseases: Heart disease, stroke, diabetes, colon cancer, breast cancer, and ovarian cancer.
   Language: English.
   Confidentiality: Limited to person completing personal family health history.
   Data: For each person the tool collects data about:
   - health behavior factors (e.g. smoking, exercise, diet, alcohol, aspirin);
   - screening tests (e.g. blood cholesterol, blood glucose, colonoscopy, sigmoidoscopy, clinical breast exam, mammography); and
   - health history among first and second degree relatives.

   Risk assessment: Algorithms assess familial risks for each disease. User classified as strong, moderate or weak familial risk.
   Family-history based interventions: Algorithms assess familial risk and generate prevention recommendations.
   Website: http://www.cdc.gov/genomics/famhistory/famhx, accessed 08/20/2014.

3. **Tool: Family Medical History (AMA)**
   Titles: Prenatal Genetic Screening Questionnaire, Pediatric Clinical Genetics Questionnaire, and ***Adult Family History Form***
   Developer: American Medical Association (AMA).
   Type: Can be completed online and printed. Data are not saved.
   Target Population: Physician and patients.
   Diseases: Numerous diseases and conditions across all life stages.
   Language: English/Spanish/Italian.
   Behavioral and environmental factors: Pregnancy exposures.
   Website: http://www.ama-assn.org, accessed 08/20/2014.

4. **Tool**: ***The Heart of Diabetes Family History Tree* (AHA)**
   Developer: The American Heart Association (AHA).
   Format: An online tool that draws a family tree and allows a person to make a record of heart disease and stroke risk factors including diabetes for blood relatives. Requires free registration. Data are encrypted and not accessible to the AHA.
   Diseases/conditions: Diabetes, heart attack, high blood pressure, high total cholesterol or LDL cholesterol, Low HDL cholesterol, obesity, stroke.
   Behavioral and environmental factors: Physical activity, smoke and second-hand smoke.
   Risk assessment: None.
   Website: www.heart.org/idc/groups/heart-public/@wcm/@hcm, accessed 08/20/2014.

5. **Tool** : ***Your Family Health History* (MOD)**
   Developer: March of Dimes (MOD).
   Type: online form available to download and populate.
   Limitations: Prenatal/preconception focused. Lengthy and time consuming to complete.
   Website: www.organizedwisdom.com/your-family-history, accessed 08/20/2014.

6. **Tool: Medical Family Tree**
   Developers: The Munroe-Meyer Institute for Genetics and Rehabilitation.
   The Eppley Cancer Center of the University of Nebraska Medical Center.
   Diseases: Different types of cancers and tumors.
   Format: Online tool to build a three generation family tree. Can print family history in table-form and as a family tree. Macromedia Authorware web player needs to be installed to draw family tree.
   Risk assessment: Algorithms assess family history and determine if there are features suggestive of hereditary cancer.
   Website: http://app1.unmc.edu/gencancer/, accessed 08/20/2014.

7. **Tool** : ***My Generations***
   Developer: NorthShore University Health System.
   Disease: Cancer.
   Format: An interactive web-based tool that collects personal and family history of cancer; draws an annotated family tree.
   Risk assessment: Produces a cancer risk assessment.
   Family-history based interventions: Provides personalized risk based screening, behavioral and referral information.
   Website: Actual tool currently under development.

8. **Tool**: *JamesLink : Personalized Cancer Risk Assessment*
   Developers: The Ohio State University Comprehensive Cancer Center, and Multi Media Design, Center for Knowledge Development, College of Medicine Public Health.
   Diseases: Different types of cancers.
   Format: An interactive web-based tool that asks a series of questions regarding personal and family history of cancer. Data are not saved. Report can be printed.
   Risk assessment: Algorithms estimate cancer risk based on patterns of cancer in the family. User classified as being at high, moderate or average risk.
   Family-history based intervention: A printable summary includes risk assessment, cancer screening and prevention recommendations. Counseling and assessment by genetics professional recommended for ''high risk''.
   Contact info: Call the James Line with and question and concern at 1-800-293-5066.
   Website: www.familyhealthlink.osumc.edu/Notice.aspx, accessed 08/20/2014.

9. **Tool: Family Health History Tool Kit**
   Title: Health Family Tree Tool
   Sponsoring entity: UTAH Dept. of Health.
   Diseases: multiple.
   Format: An interactive web-based tool with 10 questions about family health history, how to get started, genealogy resources, when to see a genetic counselor, fun ideas to help you break the ice and get started, and "turkey talk" health discussion.
   Risk assessment: Online and secure tool to collect and analyze family health history.
   Family-History Based Intervention: Users receive free personalized report detailing what their family health history means for them and their family.
   Website: www.health.utah.gov/genomics/familyhistory/documents/, accessed 08/20/2014.

10. **Tool**: *Does it run in the family? Toolkit*
    Developer: Genetic Alliance partnered with a diverse group of communities.
    Format: This printable booklet from the Genetic Alliance is a paper-based tool that helps gather, explain and record family health history. Captures heredity, diet and environmental information.
    Language: English / Spanish.
    Risk assessment: Booklets have many parts that might not be useful for all people; however, the tool can be customized for individual families. Booklets can be printed.
    Websites: http://www.talkhealthhistory.org/, accessed 08/20/2014;
    http://www.genesinlife.org/, accessed 08/20/2014;
    http://www.geneticalliance.org/publications/fhhtoolkit, accessed 08/20/2014; and
    http://www.doesitruninthefamily.com/, accessed 08/20/2014.

11. **Tool : National Society of Genetic Counselors: Your Family History**
    Developer: National Society of Genetic Counselors.
    Family tree link: http://nsgc.org/p/cm/ld/fid=143, accessed 08/20/2014.
    Website: http://nsgc.org/p/cm/ld/fid=52, accessed 08/20/2014.

My Family Health Portrait. Good Option in General Practice Setting

The key features as detailed in the Surgeon General's *My Family Health Portrait* (https:familyhistory.hhs.gov/fhh-web/home.action, accessed 08/20/2014) include the following:

➢ *Among all the above-mentioned tools, which one is the best option for gathering family health history in general practice settings?*
There are many tools in a variety of formats with different degrees of detail and emphasis of disease selection available to help get families started on the journey to discover, document and share their family health history. Family risk assessment and disease prevention are the primary purpose in family health histories. The *My Family Health Portrait* developed by the Surgeon General in collaboration with the Department of Health and Human Services is a user friendly tool and widely utilized.

➢ *What are some of the features that make "My Family Health Portrait" a better option for adopting in a health care settings for gathering family health history?*
- User friendly.
- Open access to anyone (general people) who wants to create his or her family health history.
- Online instruction is available to help people filling out their family health history.
- Available in multiple languages. (English/ Spanish/ French/ Portuguese/ Polish / Chinese).
- Web based interactive tool which can be completed online with data stored on individual's computer.
- Print version of family history tool is also available.
- Covers a wide variety of diseases.
- Can be customized according to the user's needs.
- Maintain confidentiality.
- Offers interoperability with electronic health records (EHRs).

➢ *What are some of the drawbacks of "My Family Health Portrait" tool?*
- Too general to detect rare genetic disorders.
- Does not assess familial risk for each disease.
- Does not generate family health history based interventions.

➢ *What are the key features of the Surgeon General's family health history tool?*
The Surgeon General's *My Family Health Portrait* is an internet-based tool that makes it easy for a person to record his or her family health history. The tool is easy to access on the web and simple to complete. It assembles information and makes a pedigree family tree that can be downloaded. It is private--it does not keep anyone's information. It gives a person a health history that can be shared with family members or sent to health care practitioner.

➢ *How long does it take to fill out the form? What does a person do with it then?*
It should only take about 15 to 20 minutes to build a basic family health history. Individuals with larger families will spend more time entering in their information. Individual has the option of sharing history with other family members. The relatives may help provide information the person did not know. Relatives can start with his information and create their own history.

➢ *What about privacy? Does the government (or others, employer) have access to an individual's information?*
The Surgeon General's *My Family Health Portrait* tool does NOT keep a government record of any individual's information nor makes health information available. The tool is only software for organizing the person's information. By accessing the tool on the web, the person makes use of that software, and the individual's information is never available to anyone else, unless the individual chooses to share or disclose it.

➢ *What will be done to keep an individual's information private and confidential on the Microsoft Health Vault website?*
The Microsoft Health account privacy statement is located at http://www.healthvault.com/privacy-policy.html, accessed 08/20/2014. Additional information about the terms of service can be reviewed at http://www.healthvault.com/terms-of-use.html, accessed 08/20/2014.

➢ *What if an individual needs help in filling out the tool?*
The tool should be easy to complete. If a person needs help with this website, it is available from the Application Support Desk at the National Cancer Institute's Center for Biomedical Informatics and Information Technology (CBIIT). A person can contact the CBIIT help desk by email at ncicb@pop.nci.nih.gov, accessed 08/20/2014, and by telephone at 888.478.4423 (toll free) or 301-451-4384. The CBIIT help desk is open from 8:00 AM to 8:00 PM Eastern time, but they take recorded messages from 8:00 PM to 8:00 AM Eastern time. The help desk can assist a person with problems with the tool, but questions about an individual's health history or medical conditions should be referred to a qualified health professional.
If a person needs assistance saving or copying personal information to and from Microsoft HealthVault, s/he *should direct questions to HealthVault* support at http://support.microsoft.com/healthvault, accessed 08/20/2014.

➢ *Why is it important that the tool "re-indexes" as different family members use it?*
If an individual shares his or her family health history with relatives, they can use this information as a starting point to create their own family health history. This is made even easier by re-indexing. "Re-indexing" means the person's relative becomes the center of the information, with own family health history, and the original individual's information is automatically readjusted to show the correct relationship to the relative.

➢ *How can a person encourage other family members to share their health information?*
Privacy is important, and no one should be forced to share personal health information if they don't wish to. But knowledge of family health histories may be spread over different family members, so sharing can help create the best product. Maybe the best way to encourage sharing is to help make it clear how this information can help health care practitioners provide better care and make more informed decisions.

➢ *What security precautions should a person take when he shares information with relatives?*
Since the information that is aggregated by the tool is personal health information, a person should take reasonable precautions when sending this information to relatives. Precautions might include encrypting the information before sending it via email or transfering the information on a CD or memory stick.

➢ *What if an individual's knowledge about his family health history is incomplete or imprecise?*
Very few people are likely to have detailed and precise information about their family members' health histories; however, any information can be helpful. Once an individual has completed her/his history, it is important to talk about it with one'shealth care practitioner. He or she may be able to help provide perspective, or even increase understanding.

➢ *Why is it important that the tool is "EHR- and PHR-ready"?*
Electronic health records (EHRs) can help improve quality of care and improve cost-effectiveness of care at the same time. With interoperable EHRs, a person's health information can be available when and where it is needed--whether in an emergency, or merely when seeing a new physician. For EHRs to be useful, products like *My Family Health Portrait* need to be compatible and "EHR-ready." This will allow the history to be embedded in the EHR, or in the electronic "personal health record" (PHR) maintained by the consumer. The Surgeon General's *My Family Health Portrait* tool is ready for use in EHRs.

➢ *What is "clinical decision support"? How does it apply to family health history?*
"Clinical decision support" refers to software tools that help health care practitioners deliver the best quality care. These tools usually operate as a feature of EHRs. For example, these tools can alert a practitioner to potentially dangerous drug interactions by automatically matching a new prescription with medications a patient is already taking. Likewise the tools can remind a physician or consumer when certain procedures may be due. Such tools can interact with health history information and help in forming personalized health recommendations.

➢ *Can doctors use information from the tool even if they don't have EHRs?*
Yes. The most important goal is simply to record an individual's information. The Surgeon General's *My Family Health Portrait* tool can help a person to do that easily. The information will be useful to that person and his/her health care practitioner, whether or not the practitioner currently uses electronic records.

➢ *Will the family health history tool give a person advice on actions he or she should take?*
No. The Surgeon General's tool helps gather information that will be useful for a person and health care practitioner, but does not provide medical advice. A person should consult with a health professional about advice based on the family health history information.

➢ *What does "adoption" mean?*
Organizations can adopt the tool under their own names and even customize it, while preserving its standards-based features. The computer code that supports the Surgeon General's *My Family Health Portrait* is openly available, without charge or royalty. The code can be downloaded by organizations and customized to their needs and purposes. This includes offering the tool under an organization's own brand, without attribution to the Surgeon General tool. In this way, it is hoped that many organizations will promote the gathering of family health history and the use of the new family health history tool.

➢ *What kinds of organizations might be likely "adopters" of the tool and its code?*
Many health plans already provide web-based portals for their customers, and many of them make their customers' electronic personal health records securely available on-line. They could offer their own version of the family health history tool to their customers as part of their suite

of electronic information services. Many health care payers also provide portals or websites where the tool could be included under their own brand. Vendors who produce EHR and PHR products could build the tool into their products, possibly adding custom features. Disease advocacy and patient-support groups could offer their own versions of the tool, customized to focus on areas of particular concern. Others including health professional and pharmacy organizations, physician practices or other providers might wish to adopt and customize the tool. Adopters may be commercial or non-commercial.

➢ *Why might an organization want to become an adopter?*
Family health history is part of the foundation of good primary care. The new tool makes the information easy to gather, easy to share, and ready for enhanced use in an EHR environment. Further, family health history is especially important for identifying disease risk and supporting steps to reduce that risk or look for early disease signs. All of these represent steps that improve quality of care and potentially reduce disease and its costs. Finally, as the tool can be customized, different organizations can offer features that may be especially helpful to a given population, or that may represent a quality or competitive edge.

➢ *In what ways can adopters customize the tool and its code to better serve their particular purposes?*
Aside from re-branding the tool under their own names, adopters might want to add enhanced information-gathering regarding particular diseases, links to other web-based services like risk-assessment tools or patient support, and features making the tool more compatible with the operations of the adopting entity. However, adopters should avoid suggesting that this tool provides medical advice: it is an information vehicle to help consumers and health professionals make health care decisions, not a source of advice.

➢ *What obligations does an adopter agree to?*
While the tool can be customized, the core standards used in the tool and the resulting interoperability of the information it generates must be preserved. This interoperability is at the heart of the value of the new tool. As part of the code downloading process, adopters must accept an End User Agreement to the effect that the core program architecture and data structure must be preserved such that the data generated by the software remains compatible with the original software. In addition, customized products may not claim endorsement by HHS or the Surgeon General.

➢ *How should an organization proceed if it is interested in adopting, or learning more about adoption?*
Those interested in adopting should proceed for help at: ncicb@pop.nci.nih.gov, accessed 08/20/2014.

➢ *Is help available for those who wish to adopt the tool and its code?*
The downloading process is designed to be as easy as possible. In addition, the NCI Center for Biomedical Informatics and Information Technology (CBIIT) maintains a help desk:
CBIIT Application Support
Email: ncicb@pop.nci.nih.gov, accessed 08/20/2014.
Local: 301.451.4384
Toll-Free: 888.478.4423
Support: http://ncicb.nci.nih.gov/support, accessed 08/20/2014.

> *Is the family health history information collected with this tool protected under HIPAA Privacy Rule?*
> Yes. If you are a covered entity under the Health Insurance Portability and Accountability Act of 1996 (HIPAA), the family health information that you collect via this tool should be protected as individually identifiable health information as required by the HIPAA Privacy Rule. You may use and disclose this information as the Privacy Rule allows for any other protected health information about the individual. Information is available at http://www.hhs.gov/ocr/privacy/familyhealthhistoryfaqs.pdf, accessed 08/20/2014.

> *What existing standards have been adopted to make the tool interoperable and EHR-ready?*
> In order to make the products of the *My Family Health Portrait* tool interoperable in an EHR environment, developers of the tool have used existing standards including the HL7 Family History Model, LOINC, SNOMED-CT and HL7 Vocabulary. In addition, the tool includes an applicable subset of information from the minimum core dataset for family health history as developed pursuant to recommendations by the American Health Information Community.

Part 3: Family History Tool Adoption: Consumer and Provider Concerns

> In designing a family history tool, "there will be a trade-off between keeping it simple and collecting enough information to make prediction possible. A simple tool may not be able to distinguish between high and moderate risk. Issues that will need to be considered and evaluated include the collection of information on more than first-degree relatives, the list of diseases included in the tool, and the use of a classification system or algorithm for defining level of risk."[7]

> "When a person is adopted or has few relatives, the possibility of a family history rich in disease-specific information is obviously much reduced. The collection of family history information will also have to be evaluated in the context of additional screening information."[7]

> "In addition to assessing the effect that knowledge of disease risk may have on people, there are ethical considerations that must be evaluated as well. Labeling a person as high- or moderate-risk for disease may have important psychological, social, and economic costs. The use of a family history tool could only be successful if people perceived greater benefit than risk associated with revealing family medical information, if there was no stigma associated with being at above average risk, and if there were interventions and options for behavior change that could make a difference in reducing morbidity and mortality. These characteristics of family history of disease will need to be evaluated for each disease that may be included in a family history tool and for different population and cultural groups."[7]

> Currently many providers find it too time consuming to gather and document and review relevant information. To facilitate the process without interrupting the regular workflow is extremely important in clinical practice.

> Integrating Family Health history with EHRs. [5]

Part 4: Integrating Family Health History with Electronic Health Records (EHRs)

Research studies have been conducted for effective integration of family health history tool with electronic health records (EHRs) data. *My Family Health Portrait* (MFHP) tool developed by the Surgeon General offers interoperability with EHRs. MFHP are ready to use with both EHRs and PHRs (Personal Health Records).[5.]

➢ Integrating family health history tools with EHRs is a challenge because:
- Integration requires high technology-driven solutions to be effective;
- Integration creates more time demands on health care providers;
- there is often limited capacity in EHRs to accept family health history data;
- there are barriers to the systematic collection of family health history data in clinical practice; and
- there may be poor access and/or lack of knowledge to use electronic tools effectively. [5]

➢ In order to capture patient-generated family history data across diverse patient populations, EHR's may need to offer patients a variety of data entry options, customizing for preference, convenience, computer literacy, and computer availability. [5]

➢ In a research trial conducted by Brigham and Women's Hospital, researchers developed and implemented three innovative portals to transfer and integrate patient-generated family history data with an EHR.[5.] The three portals included:
- computer tablets in waiting rooms to complete the MFHP;
- a secure internet portal to transfer data collected by patients at home using MFHP; and
- an interactive voice response (IVR) system to collect necessary data elements by phone.

Note: Here are some current information systems that have been developed to integrate clinical (EHR) and genomic data.

Partner's Health Care (www.hpcgg.org, accessed 08/20/2014).
Inforsense (www.inforsense.com, accessed 08/20/2014).
Xenobase (www.xbtransmed.com, accessed 08/20/2014).
Cerner (www.cerner.com, accessed 08/20/2014).
Indivo (indivohealth.org, accessed 08/20/2014).

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