



National Human Genome
Research Institute

GENOMIC HEALTHCARE BRANCH (GHB)

Long Tool Descriptions (Optional)

ZibdyHealth- Family Medical History

ZibdyHealth allows individuals to create a private family network, in which information on disease, treatments, and responses to treatment can easily be shared. The application creates a map of a **family's medical history** for to aid in predicting risks of disease and responses to treatment. A core tenet of ZibdyHealth's approach is that good health care requires accurate data. ZibdyHealth has been designed to record data in a structured manner, from barcode scanning of medications, to import of data directly from electronic health records. The application is unique in its ability to aggregate and compile high quality data.

Specific to family history, ZibdyHealth's network based approach allows family members to each share their personal medical history to compile a more accurate family history than any one person could "remember" on their own. This approach allows ZibdyHealth to create highly accurate health profiles which can be then run through predictive and suggestive analytics tools. ZibdyHealth allows family members from healthcare systems across the world to simply and easily connect, to share valuable information, and use the health and wellness knowledge available within their network. By helping users build detailed and expansive family medical histories, ZibdyHealth helps physicians tailor prevention and treatment strategies based on this history and not general population data. Until genomic data is widely available, this "**Virtual Pharmacogenomics**" approach can be used to personalize medicine.

ZibdyHealth retains its records in perpetuity – so when a family member passes, their record remains, and the family medical history with it. ZibdyHealth is aware that not all individuals are willing to share their entire medical history with even their closest relatives. The application has been designed with multiple of layers of privacy control, allowing users to share as much or as little as they want. Sharing medical data is always wrought with ethical and legal issues. By putting the information in the hands of the user, ZibdyHealth empowers the user to share their data as they see fit.

By facilitating collection and control of data by the consumer, ZibdyHealth creates a Personal Health Record that works synergistically with other EMRs to share data. It can also function on its own as a health record when an EMR is not present. This functionality allows users to **easily consolidate and share** their own medical data between providers. In addition, ZibdyHealth has a full suite of tools for personal health management including features to facilitate **transitions of care, chronic disease management, monitor lab results** or **medications adherence** to encourage use of our application.

Reach: Global

Security: 256-bit AES Encryption at rest and transit

Privacy: HIPAA and CMIA compliant; Section and Item level privacy

Use Case: Full suite for patient care

HIE: Smart Health Information Exchange (“Smart HIE”)

Platform Supported: Web, iOS, Android, Blackberry, Windows, Amazon Fire

Interoperability: Ability to import and export data from any EHR

HL7: Fully compliant with version 3

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Open Source: No but willing to share and collaborate

Platform: Independent Application

Health Heritage

Health Heritage (HH) is a consumer facing web-based application that enables patients and their family members to easily extract and update detailed and accurate clinical data from EMRs. Data are extracted using custom built queries and a natural language processing engine and include exact diagnoses and dates of onset, the number and type of colonic polyps, as well as many other risk factors. HH maintains a standards-based data model independent of any original data source. Patients are asked branching logic questions about gaps in their EMR data and are guided through manually entry of other personal and family information. HH also provides secure methods for family members to automatically share and maintain data, creating evolving and up-to-date family histories. This information enables personalized wellness, prevention, and treatment decisions as well as establishes a “living legacy” that can be passed down to future generations. HH’s ability to collect complete and accurate family histories consistently outperformed usual care by primary care practitioners (analytic validity). [Public Health Genomics 2010; 13:477–491, DOI: 10.1159/000294415]

HH’s family histories are then evaluated by a sophisticated risk engine that identifies risk and provides detailed, individualized evidence-based recommendations, ranging from changes in lifestyle, to referrals for genetic evaluation, to increased disease surveillance. These are provided to the HH user and their clinician(s). HH currently identifies risk and provides recommendations for seven common cancers (and soon other common diseases). This is possible because we have transformed detailed and complex clinical guidelines into hundreds of algorithms and have combined these with established quantitative risk models. The clinical validation of HH’s current risk engine demonstrated very strong agreement (97%) between HH’s referral and eligibility for genetic evaluation versus an expert genetics team relying on guidelines and professional expertise. [Familial Cancer 2015; 15:331-339, DOI 10.1007/s10689-015-9863-3]

HH uses HL7 standards to export its risk reports and data to primary care providers, genetic counselors, and others for decision support, without impacting existing workflows. HH was also designed to be an essential component of research consortiums and biobanks since the contribution of family history data is complimentary to genomic and other clinical data.

HH went live in May 2014 within the NorthShore University HealthSystem in Evanston, IL. At NorthShore, HH automatically extracts data directly from the Epic® EMR, including all reports originating from an anatomic pathology laboratory information system. One goal at NorthShore is to identify and increase appropriate referrals for genetic evaluation without the need for specialized training of primary care and non-genetic specialists. We now have experience that previously unrecognized high-risk patients will independently pursue genetic evaluation after receiving a recommendation from HH with a decrease in such encounters for lower risk individuals. Insurance providers have also accepted HH high-risk reports as justification for genetic testing.

In September 2015, HH became a key patient-facing technology for NantHealth, a precision medicine company founded and led by Dr. Patrick Soon-Shiong. HH will become part of NantHealth's Moonshot 2020 and other research and biobanking endeavors. Further information can be found at www.HealthHeritage.org, www.NantHealth.com and www.cancermoonshot2020.org.

Family Healthware™ Risk Assessment

Family Healthware™ from Sanitas, Inc. is an FDA 510(k)-cleared web-based software application that assesses familial risk for six diseases (coronary heart disease, stroke, diabetes, breast cancer, ovarian cancer, and colorectal cancer) and provides a prevention plan with personalized recommendations for lifestyle changes and screening.

When it comes to your health, family health history may be the most accurate predictor of health risks. It's no secret that most common diseases tend to run in families. But heredity is not destiny. Knowing your family health history can lead to early detection and even prevention. According to the World Health Organization, at least 80% of all heart disease, stroke and type 2 diabetes, and over 40% of cancer could be prevented by eliminating risk factors.

Family Healthware empowers consumers to uncover what's in their family tree that may increase their risk for disease. It supports proactive, personalized health goals by:

- Identifying likelihood of acquiring six specific diseases
- Learning what to do next if at risk for disease
- Receiving a tailored prevention plan based on risk factors
- Getting educated on how a healthy lifestyle can reduce risks

Family Healthware makes it easy and affordable for consumers to understand their risks—and take appropriate action toward prevention. The Family Healthware solution is:

- Trusted: CDC-developed, patented and FDA-cleared solution.
- Reliable: Published clinical impact and research studies.
- Effective: Personalized risk score, screening, and prevention plan.

Value for Physicians/Health Systems

Today's clinical workflows don't allow enough time to collect detailed patient profiles, which include family history, lifestyle and behavioral attributes. Pointing patients to Family Healthware first can result in a more complete health risk assessment that helps identify risks, and supports an effective migration to value-based care delivery. Clinician benefits include:

- Saving precious in-office time
- Better understanding of the patient's health history
- Empowering patients with a trusted, reliable, online health risk assessment
- Supporting patient education and engagement strategies for improved health
- Helping patients manage their risks before they become acute care requirements

Value for Employers and Health Plans

Consumers are acutely aware of their share of rising costs for employer-sponsored health plans. Enabling employees to identify their risks for chronic diseases can help foster a culture of health and promote prevention. It can also help employers and health plans keep a lid on rising healthcare costs. Employers benefit from:

- Lower health care and disability costs
- Enhance employee productivity
- Reduce employee absenteeism
- Decrease rates of illness
- Enhance corporate image
- Improve employee morale
- Improve employee recruitment and retention

Population health managers need innovative ways to address their members' diverse needs. Enabling members to identify their personal risk is a low-cost, low-impact way to build awareness, engagement and self-management. Health plans benefit by:

- Keeping low-risk members healthy with a personal prevention plan.
- Avoiding unnecessary spending for rising-risk members while keeping them from becoming high risk members
- Building member loyalty to your plan
- Improving member satisfaction ratings
- Engaging members in programs to delay onset or disease progression

More info at www.FamilyHealthware.com.

CancerGene Connect

CancerGene Connect (CGC) is among the original family history and risk assessment tools to exist in the cancer genetics space. Originally developed by breast surgeon and Director of the Cancer Genetics Program at UT Southwestern Medical Center, David Euhus MD in 2009, CGC uses a patient-facing questionnaire to collect family structure and personal and family health history. The original impetus for developing CGC was to expand the use of technology within the genetic counseling process beyond the collection of family history to include streamlining cancer risk assessment, clinical documentation, management of patient follow-up, and incorporation of database functionality and integration of data from multiple sources within one system. To date, 14,097 patients have been entered into the CGC program at UT Southwestern alone.

The questionnaire currently utilized within CGC underwent rigorous evaluation to ensure accuracy and reliability of patient-reporting; the efforts of which were published in a time-study in the Journal of Genetic Counseling in 2014¹. Completion rates of each question were assessed to determine those questions that were not being answered by participants and to explore and minimize barriers to answer completion. UT Southwestern's Clinical Sciences team performed cognitive interviews with patients (both English- and Spanish-speaking) to ensure that questions were understandable and responses valid in both languages. Patients were also administered a separate Likert-style questionnaire during the validation process of CGC to assess their reaction to the program. Seventy two percent of users strongly agreed that the program was easy to use and 100% agreed or strongly agreed that the questions were easy to understand. Workflow analysis showed that the program reduced time spent per case by

clinician from 14 to 46% compared to previously reported genetic counseling times. Implementation of CGC provides a reduction in redundancy in clinic workflows as medical and family history information only needs to be entered once in order to be documented and generate risk estimates and pedigrees.

The CGC platform was built to allow flexible integration with a variety of systems. Family health history such as cancer diagnoses and other clinical findings are collected in a patient-centered lexicon that is mappable to SNOMED and ICD-10 codes. The questionnaire consists primarily of structured data which can be easily queried by the provider through the internal database, but is flexible enough to also allow for collection of unstructured data. Personal and family health history is completely customizable and can be customized for clinical uses outside of cancer. End to end, the CGC program was designed to increase clinical accuracy and efficiency while minimizing clinician time and effort. For more information, please view the CancerGene Connect Website at cagene.com.

- 1) Pritzlaff, M., et al. An Internal Performance Assessment of CancerGene Connect: An Electronic Tool to Streamline and Improve the Genetic Counseling Process. *J Genet Counsel* (2014) 23:1034-1044

VICKY (VIRtual Counselor for Knowing Your Family History)

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Approximately one-third of U.S. adults have limited health literacy, which disproportionately affects those who are less educated, elderly, poor, or have limited English proficiency. Because of literacy-related challenges in family history collection, our team developed VICKY, a “virtual counselor” to collect family health history for common health conditions. VICKY is a Relational Agent (RA), a computer-animated character that simulates face-to-face conversation with patients. An early prototype was tested with an underserved patient population in a pilot study, demonstrating greater usability compared to My Family Health Portrait (Wang et al., 2015; <http://www.nature.com/gim/journal/v17/n10/full/gim2014198a.html>). Results of the pilot have led to a refinement of the tool to further increase its usability and accuracy in family history collection. VICKY is a web-based, patient-facing tool that collects family history on first- and second-degree relatives for 20 conditions. The tool generates a pedigree chart that users may print and share with others. VICKY also counsels users to share family history information with health providers. A Spanish language version of VICKY will be finalized later this year. VICKY does not perform risk assessments or provide clinical decision support to clinicians. VICKY can be deployed in waiting rooms or used at home, and can export HL7 FHIR data to EHR systems and other risk assessment and clinical decision support tools. A large randomized trial to test the efficacy of VICKY is in progress.

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