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iLibrary Project Medical Genealogy Tool Kit

Heartland Genetics and Newborn Screening Collaborative

Overview



Background

Collaboration

- Family Historians
- Genealogists
- Staff Midwest Genealogy Center
- Medical Geneticists

Methods & Observations

Participatory Process
Sense Making

Presentations with Activities

- Pedigree Format & Red Flags
- Cancer & Genetics
- Birth Defects & Pediatrics
- Genetic Testing

Family Reunion Kit

Medical Genealogy Tool
Kits for Libraries

MID-CONTINENT PUBLIC LIBRARY

Books, Movies, Music Catalog Online Resources | Events Genealogy | Kids Teens | Locations About Us

Home > Midwest Genealogy Center > Resources for Genealogy & Family History

Midwest Genealogy Center

Midwest Genealogy Center
Roots of a Nation
About MGC
Directions and Hours
Getting Started
Resources for Genealogy & Family History

Resources for Genealogy & Family History

NEW! Books added to the MGC collection in the last 14 days

Partnerships

The [Family History Archive](#) is a collection of published genealogy and family history books. The Midwest Genealogy Center is collaborating with the Family History Library program to add scanned images of many books within the MGC collection to this valuable online archive.

The [Ancestry.com Yearbook Program](#) is scanning school annuals owned by the Midwest Genealogy Center.

Databases

- Genealogy Databases
- Geographic Databases

<http://www.mymcpl.org/genealogy/resources-genealogy-family-history>

PART ONE: BACKGROUND

Participatory Process and Presentations



Genealogy is the
fastest-growing
hobby in
North America

[Kpowell](#)

60% of Americans
are interested
in their family history

[2000 Maritz Marketing Research poll](#)



Family History / Three Generation Pedigree

“Best genetics test”

[The Clinical Content of Preconception Care](#), OSU High Risk Clinic

“Gold Standard”

[American Society of Human Genetics](#)

“Cheapest genetics test”

[University Hospitals Authority & Trust](#)



The importance of family history

U.S. Surgeon General
– Thanksgiving, Family History Day
U.S. Senate
- October, Family History Month



Understanding

What **DO** we know?

Our discussions with family historians, genealogists and genealogy librarians revealed that

they were *not* familiar with

National Library of Medicine resources or Surgeon General's "My Family Health Portrait" tool.

- Increasing awareness of these resources would enhance the personal research of genealogists
- These resources could assist genealogists identify family history "red flags"
- Genealogists could share valuable resources with family members and other family historians

Project Objectives

1. Determine relevant health/genetic resources for genealogists and family historians
2. Provide resources to librarians and patrons
3. Develop a participatory model to engage genealogists in every phase of the website development

Our To Do List

Enhance **OUR UNDERSTANDING**

DISCOVER how genealogists conceptualize genetics information

Understand **WHY** genealogists want health information

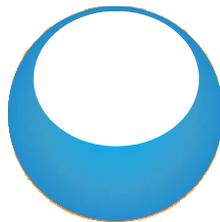
Understand **WHEN, WHERE** and **HOW** they want to use health information

INVOLVE genealogists in every stage of development

What Happened?

We discovered the barriers genealogists identified to using the U.S. Surgeon General's "My Family Health Portrait"

We developed tools designed to enhance genealogists ability to use "My Family Health Portrait"



**PART TWO:
METHODS & OBSERVATIONS**

Presentations & Activities



**Tool Kit Overview
How was it developed?**

Overview of the Medical Genealogy Participatory Model

The Model was designed to be:

- Interdisciplinary
- Iterative
- User Centered
- Diverse

Multiple interactions with:

- Professional genealogists
- Family historians
- Genealogy librarians

Numerous opportunities for:

- Meaningful and ongoing interactions
- Rich discussions
- Deeper, more complete understanding of the tasks, goals, concerns of family historians



How can family health history affect my health?

Please Join Us
Thursday, May 27
10:00 a.m.

Please join us for a round table discussion about your questions and concerns about how your family health history can affect your health.

Who should attend?
librarians, family historians, anyone interested in learning about health history.

Light refreshments will be provided

Discussions will be facilitated by:
Debra Collins, M.S., CGC
Director of the Genetic Education Center at KU Medical Center

Julie Brodz, MEd
Consumer Health Project Manager, JIR Dybas
Medical Library, KU Medical Center

Please RSVP by calling 913-588-6022 option 6 or sign up at the reference desk.

**Medical Genealogy:
Birth Defects & Pediatric Conditions**

Many disorders of childhood have an inherited or genetic cause. Holly Walsh, MS, CGC, a certified Genetic Counselor with Children's Mercy Hospital, will help family historians and genealogists learn the connections between their family's health history and genetic disorders. Light refreshments will be available.

Friday, January 7, 2011
11:00 a.m. - 1:00 p.m.
Midwest Genealogy Center
3440 S. Lee's Summit Road
Independence, MO 64055

Contact the Midwest Genealogy Center by phone (816) 255-8743 to sign up. For more information, contact Julie Brodz, jbrodz@ku.edu

Your Family Health History

Ask Questions and Get Involved!

Midwest Genealogy Center
February 18
1:00 to 3:00 pm

Ask Questions
Are you questioning your family history?
Do you have questions about sharing your family health history with your physician?
Debra Collins, M.S., CGC Genetic Counselor from KU Medical Center will be on hand to answer your questions.

Get Involved
Have you heard of us? We are in development on how to better help historians. We want to hear from you. Share your thoughts about our new Medical Genealogy website and recruitment lists and other resources.
Friday, February 18th, 1PM-3PM
Midwest Genealogy Center
3440 S. Lee's Summit Road, Independence, MO

Light refreshments will be provided.
Please RSVP at Midwest Genealogy Center or contact Julie Brodz, jbrodz@ku.edu

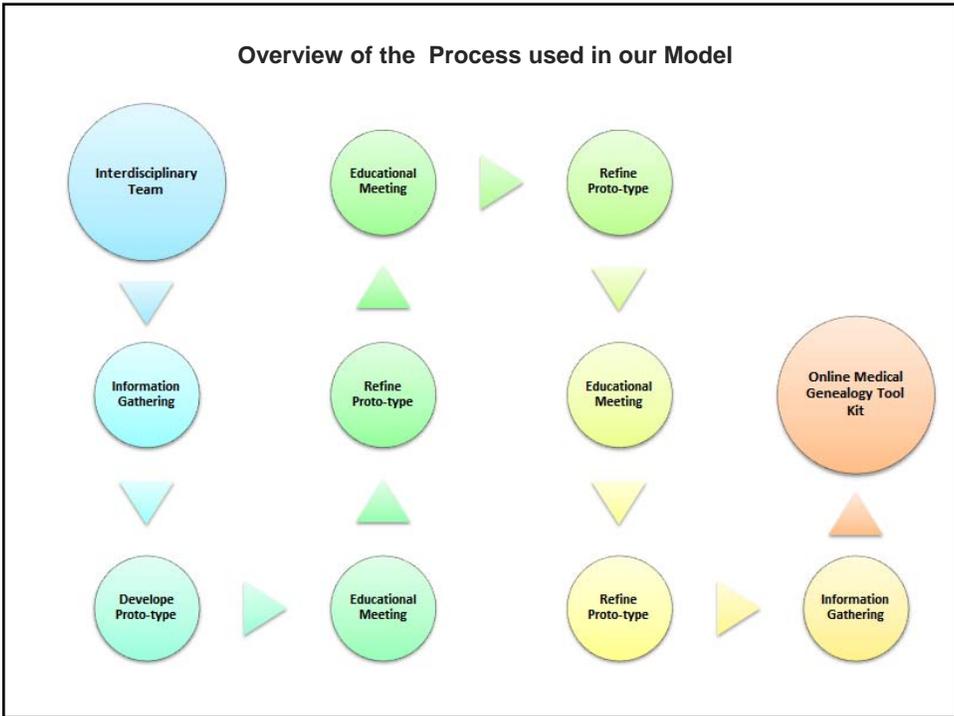
Communication Research and Sense-making

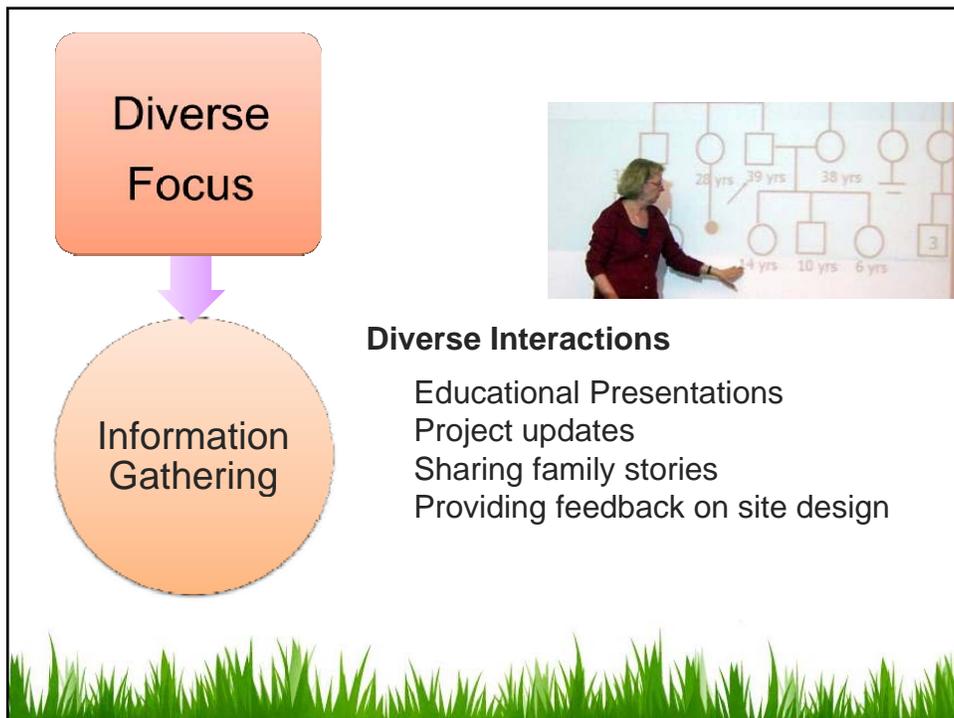
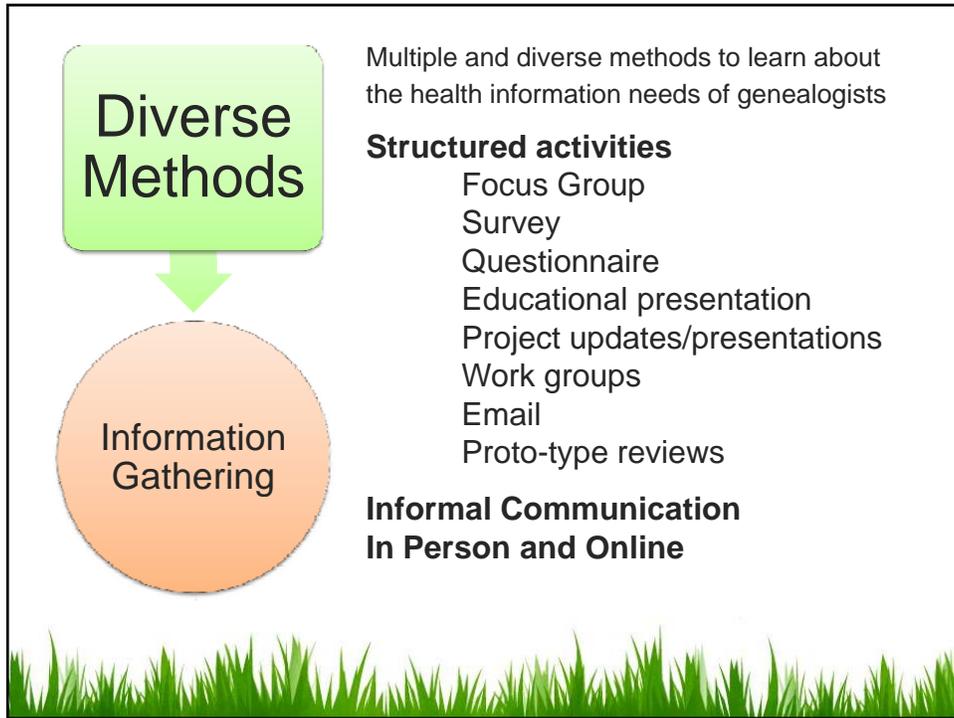
**Tool Kit Overview
How was it developed?**

Sense-Making is an approach to thinking about and implementing communication research.

It is also an approach to the practice and the design of communication-based systems and activities .

The goal of Sense-Making Methodology is this is to “find out what users –”really” think, feel, want, dream.”



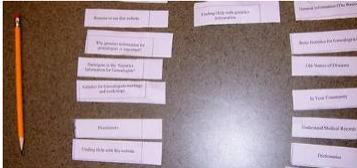
**Develop
Prototype**

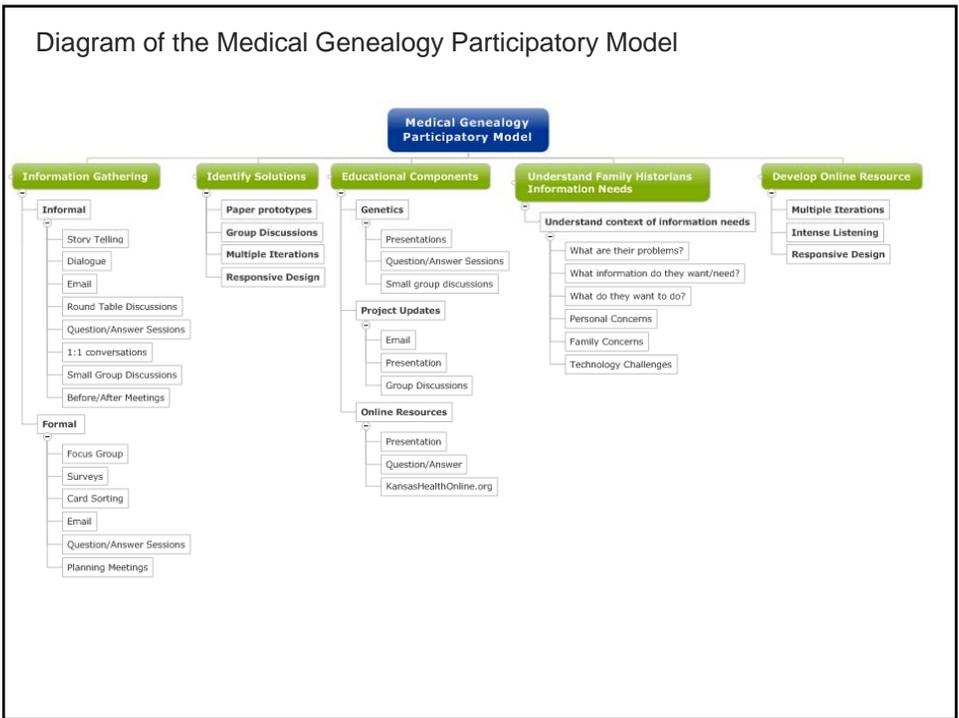
Iterative Process

Paper proto-types
Online proto-types

Iterative process supports information gathering

Proto-type development contributes to information gathering and the creation of shared knowledge





What
worked

Setting for Presentations

Most meetings were conducted at Mid West Genealogy Center.

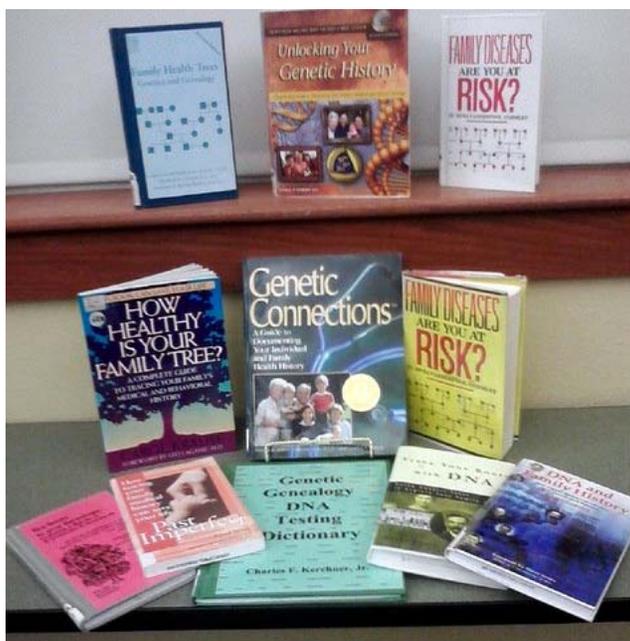
Participants appeared to be particularly comfortable and at home at the library.

Meetings were primarily conducted during weekdays.

Facilitators gained knowledge about genealogy resources, staff displayed genetics books.

One participant has a blog, wrote about meetings

Resources at the Midwest Genealogy Center on Display



THURSDAY, NOVEMBER 18, 2010

Medical Genealogy

Staying Abreast of Trends

Staying abreast of the trends in genealogy can be daunting, but is definitely necessary for the serious family historian or professional genealogist. I attended a wonderful informative seminar "Red Flags in Your Medical Family History," hosted at the Midwest Genealogy Center in Independence, MO. The presenters, Debra Collins, MS, CGC and Julie Broski were from the University of Kansas Medical Center, in Kansas City.

Although I have a rudimentary understanding of the topic, I walked away with a few vital pointers.

Why Now?
The Surgeon General, in cooperation with other agencies, has launched the *Surgeon General's Family History Initiative* to encourage all American families to learn more about their family health history. Thanksgiving has been declared National Family History Day, allowing for updates and information to be shared at an annual family gathering.

What is Medical Genealogy?
Medical Genealogy, Genetics for Genealogists, and Family Health History are all names we hear when referencing tracing and documenting one's family medical patterns. It is **not** just the application of genetics applied to traditional genealogy; therefore, I prefer the term "Medical Genealogy" as I believe this keeps the family historian focused. (How many geneticists do you know who are genealogists or family historians?)

"Medical Genealogy is the practice of tracing and recording family health patterns that are unique to your family (hopefully to include three generations) in order for the family practitioner to analyze."
Defined by Kathleen Brandt - a3Genealogy, Not an official definition.

Although genealogists and family historians are quite talented, we don't want to cross the lines of diagnosing based on family history, or predicting life spans or early deaths based on information and patterns. No excuses...even if the evidence points to this, doesn't mean you will be memorializing Uncle Charlie on his 58th birthday. Our job is to recognize patterns and document them.

As a community, we can begin by gathering family data and creating a helpful family health pattern.

Your Medical Tree
Your Medical Family Tree

NEW 8 100% Yes

• This is a space for each side with a link to web home.
• If a couple has children, show a vertical bar connecting the horizontal side with the vertical bar of the other to be horizontal but not connected to it. This is a horizontal bar.
• Connect the person, showing connected bar.
• To make your family's pedigree more clear, list or use initials or initials and names.
• For reference, assign each person on the site their family name and requesting details.
• Now, add markings to highlight persons.
• For more, visit the site of the site.
• For a link through the page or site to the site and site of the site.
• Finally, use a coding system to help identify people and their family names and a code name.
• Use the site to make all other people.

a3Genealogy
Accurate Accessible Answers

"Those who do not look upon themselves as a link, connecting the past with the future, do not perform their duty to the world." Daniel Webster

Your ancestors have never been so close. [The Ancestry Store](#)

Tools of Interest: Remember to Research African American Military/NARA Europe Native and Africa American

Who Do You Think You Are?

User Centered Process

User Centered Design incorporates user-centered activities throughout the entire development process

- Maloney-Krichmar

End-users influence how a design takes shape in order to increase ultimate usability

-Lee

"User Centered Design is widely accepted best practice for developing usable products. It involves iterative design based on a deep understanding of the users, their tasks, and the context in which they work"

Gould





PART THREE: MEDICAL GENEALOGY TOOL KIT



The Medical Genealogy Tool Kit

Tool Kit Overview

- **The Medical Genealogy Tool Kit helps genealogist plan and gather their family health history before, during and after a family reunion**

Navigating the Tool Kit

- **Step by step instructions**
- **A planning guide to**
- **Checklists**
- **Forms to customize and print**
- **Other resources you might need include, pens and paper, USB drives, etc.**

Additional Resources

- **The FAQ provides links to genetics resources for genealogists**
- **Share your thoughts with us on our website in the Discus Section**

**Tool Kit Overview
Purpose****The purpose of the Medical Genealogy Tool Kit**

Provide an online resource to assist genealogists and family historians:

1. Gather family health histories at family reunions
2. Input information into the US Surgeon General's "My Family Portrait"
3. Share information with their health care providers and family members

**Navigation
What's Included****The Tool Kit provides:**

- A timeline and reunion planning guide
- Documents to customize and print
 - Family Letter
 - Health Questionnaire
 - Information about privacy and security
- Links to genetics resources
- Guidelines on sharing health information
- Frequently Asked Questions and more



Kansas Health Online

Health Topics
Health Policy and Reform
Using Health Information
Wellness and Prevention

Home » Medical Genealogy Tool Kit » Medical Genealogy Tool Kit for Librarians

Medical Genealogy Tool Kit for Librarians

The Medical Genealogy Tool Kit for Librarians provides an overview of the project and provides information about the purpose and use of the Tool Kit. If you would like to replicate this model in your community you're welcome to use or revise any of the tools developed for the Medical Genealogy Project including posters, questionnaires or the focus group moderator guide. A brief summary documenting the development of the Medical Genealogy Participatory Model provides an overview of the process and additional background information.

Share your feedback

Optional: Login below.

Attachment	Size
FOCUS GROUP participant questionnaire.doc	41 KB
FOCUS GROUP Moderator Guide.doc	54.5 KB
POSTER Family Health History workshop.doc	274 KB
POSTER Birth Defects and Pediatric Conditions workshop.doc	834 KB
Medical Genealogy Model.ppt	995.5 KB
Medical Genealogy Tool Kit for Librarians.ppt	2.5 MB

<http://www.kansashealthonline.org/topic/medical-genealogy-tool-kit-librarians>

During the Family Reunion

- ➔ Distribute the [Medical Genealogy Questionnaire](#) to each person at the reunion
- ➔ Distribute the [Quick Info Card](#) to answer questions about the usefulness of a medical genealogy
- ➔ Collect your family's Medical Genealogy Questionnaires

After the Family Reunion

- ➔ Enter information from your Medical Genealogy Questionnaires online at the Surgeon General's ["My Family Portrait"](#)
- ➔ Share copies with your family
- ➔ Share copies with your health care providers
- ➔ [Share your experience with us on Discu](#)

Medical Genealogy Resources

- [About the Medical Genealogy Project](#)
- [Conditions/Disorders/Diseases](#)
- [Find Help When you Need More Information](#)
- [Frequently Asked Questions](#)
- [Genetic Testing and Genetic Counseling](#)
- [Medical Genealogy Tool Kit for Librarians](#)
- [Pediatric and Pregnancy Genetics](#)
- [Regional Genetic Resources](#)
- [Symptom Navigators](#)

My Family Health Portrait

A tool from the Surgeon General

Using *My Family Health Portrait* you can:

- Enter your family health history.
- Print your family health history to share with family or your health care worker.
- Save your family health history so you can update it over time.

Talking with your health care worker about your family health history can help you stay healthy!

[Learn more about My Family Health Portrait](#)

Create a Family Health History

En Español

Use a Saved History

Em Português

In Italiano



<https://familyhistory.hhs.gov/fhh-web/home.action>

Additional Resources

More Information

The Medical Genealogy Tool Kit additional resources genetics resources:

- Genetics Home Reference Resource
- Genetic Alliance Guide to Family Health History
- Surgeon General’s “My Family Portrait”
- Frequently Asked Questions

