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Goal 1

Assess current understanding of the influence of genetics and chronic disease in the public sector and among primary care providers.

Objective 1

Determine how well the public is informed regarding chronic disease and genetics.

Objective 2

Determine how knowledgeable primary care providers are regarding chronic disease and genetics.

Activities:

1. Identify or develop questions for inclusion in the Behavioral Risk Factor Surveillance System (BRFSS) questionnaire to assess public knowledge, attitude, and behaviors.
2. Initiate process of adding questions to the Youth Risk Behavior Survey (YRBS).
3. Identify and implement tools for assessing primary care provider knowledge and practices.
4. Assess primary care providers through focus groups or key informant interviews.
5. Assess use of the American Medical Association family history booklet.
6. Summarize literature regarding provider practices.

Desired Outcomes

- Increased understanding of how the public views genomics.
- Increased understanding of the barriers for collecting family history in primary care settings.
- Identification of strategies for overcoming barriers in primary care.

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2 Goal 2

Improve understanding of genetics influence on chronic disease in the public sector and among primary care providers.

Objective 1

Develop, implement, and evaluate a comprehensive and coordinated social marketing campaign designed to educate and increase utilization of family health history by the public and primary care providers.

Objective 2

Assure all activities are culturally appropriate and meet the needs of underserved populations.

Activities:

1. Define the target populations for the social marketing campaign.
2. Develop appropriate messages for the chosen target audiences.
3. Conduct formative research to determine best communication channels and messages.
4. Develop an evaluation plan for all activities.
5. Gather personal stories of Utah families to use in messages, media activities, etc.
6. Identify available resources, tools, and materials and adapt to meet the needs of the target audience(s).
7. Identify appropriate funding sources for the social marketing campaign (United Way, Eccles, Comcast, Pharmaceutical companies, etc).
8. Identify and engage “champions” and appropriate partners for the social marketing campaign and to push messages.
9. Partner with agencies to develop, test, and distribute materials (such as the Genetic Science Learning Center, Cancer Learning Center, etc).
10. Identify appropriate avenues for distribution. Distribution should encompass the following community education settings:
 - a. Schools
 - b. Youth activities (scouting, FGS Youth Initiative, national youth websites)
 - c. Mass media (newspaper, radio, TV, magazine, PSAs)
 - d. Community organizations and events (Healthy Communities, civic/volunteer organizations)
 - e. Genealogists
 - f. Libraries (Eccles Health Sciences Library, book clubs)
 - g. Health departments
 - h. Museum exhibits
 - i. Faith based groups/churches

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Goal 2

(continued)

Objective 1

Develop, implement, and evaluate a comprehensive and coordinated social marketing campaign designed to educate and increase utilization of family health history by the public and primary care providers.

Objective 2

Assure all activities are culturally appropriate and meet the needs of underserved populations.

- j. Senior centers, housing, senior expo
- k. Oral histories/interviews
- l. Hospitals or clinic settings/offices
- 11. Address various age groups with activities (aging, adult, school age).
- 12. Partner with the Public Broadcasting System to develop a documentary program.
- 13. Partner with policy makers (i.e. legislators, city/community councils) to integrate messages into initiatives, proclamations, legislative resolutions, etc.
- 14. Integrate family health history into genealogical software programs.
- 15. Partner with genealogy organizations to develop specific messages and distribution methods to reach this target population.
 - a. National Genealogical Society
 - b. Federation of Genealogical Societies
 - c. Ancestry broadcasts and radio segments
- 16. Explore ways to utilize technology to promote messages.
 - a. Internet
 - b. Blogs
 - c. Podcasting
 - d. Web-based materials
- 17. Review core curriculum for opportunities to collaborate with public schools.
- 18. Explore use of continuing medical education for primary care providers.
 - a. Partner with Utah Medical Association, Academy of Family Physicians, etc. for educational efforts
- 19. Incorporate messages into current and future professional development trainings. Trainings may include:
 - a. Teacher development workshops
 - b. Booths or presentations at professional conferences

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Goal 2

(continued)

Objective 1

Develop, implement, and evaluate a comprehensive and coordinated social marketing campaign designed to educate and increase utilization of family health history by the public and primary care providers.

Objective 2

Assure all activities are culturally appropriate and meet the needs of underserved populations.

- c. Professional listservs or newsletters
- d. Public health and health education programs
- e. Provider trainings/medical symposiums

20. Identify key decision makers/gatekeepers of underserved and ethnic populations and engage them in this process
21. Explore integration of family health history into Utah Department of Health programs targeted to the public (such as the Women, Infants, and Children nutrition consultation visits).
22. Work with the Clinical Applications Committee to develop patient resources (hospitals, doctor offices, etc) promoting messages.

Desired Outcomes

- 60% of Utahns will recognize and appreciate the importance of their family health history.
- Increased collection of family health history by individuals, families, and health care providers.
- Creation of culturally appropriate materials and messages.

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Goal 3

Improve the method and subsequent use of family history collection in primary care and community settings.

Objective 1

Evaluate the current standard of care among primary care providers.

Objective 2

Explore currently available family history tools.

Objective 3

Develop test, and evaluate a model plan to increase use of family history data collection tools in primary care and community settings.

Activities:

1. Review medical school curriculums for family history collection.
 - a. Identify and utilize opportunities to enhance curriculum.
2. Identify role of staff in primary care provider offices/clinics.
 - a. Intake evaluations
 - b. Nurses collecting family history
3. Develop a plan to address the use of family history and education by allied health professionals.
4. Utilize the electronic Utah Health Family Tree in clinical, school, and other community settings.
5. Conduct a comparison study of CDC family history tool and the electronic Utah Health Family Tree.
6. Conduct a pilot project in a clinical setting.
7. Utilize or adapt currently available protocols and identify the family health history tool(s) for use in the pilot project.
8. Involve genetic counselors in the project development.
9. Identify, develop, or adapt standard guidance messages for providers.
10. Conduct pre-assessment with providers to determine knowledge, attitudes, and beliefs or use of family health history information.
11. Develop clinical outcomes desired and integrate into pilot test.
12. Identify case and control populations or clinic that will participate in pilot test and obtain necessary IRB approvals.
13. Develop resources for primary care providers.
14. Develop provider training such as risk messages, referral guidelines, etc.
15. Develop patient materials.
16. Evaluate the tool's effectiveness, provider and patient knowledge, and clinical and behavioral

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Goal 3

(continued)

Objective 1

Evaluate the current standard of care among primary care providers.

Objective 2

Explore currently available family history tools.

Objective 3

Develop test, and evaluate a model plan to increase use of family history data collection tools in primary care and community settings.

outcomes.

17. Assess public response to use of family history tools and quality of data collected.
 - a. In various applications (self-administered, staff assisted)

Desired Outcomes

- 50% of Utah health care providers will appropriately utilize family health history in their clinical practice.
- Development of risk messages and clinical guidelines based on family history.
- Implementation of the electronic Utah Health Family Tree in various settings.

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Goal 4

Identify interventions and guidelines based on family history or genetic information that might reduce the burden of chronic disease in Utah.

Objective 1

Conduct a review to identify all known interventions (evidence-based) for clinical, public health, and other groups (industries, etc).

Objective 2

Disseminate findings.

Objective 3

Identify how primary and secondary prevention efforts that utilize family history change provider practices.

Activities:

1. Create a database of known interventions.
 - a. Rank interventions by whether they are proven/unproven and strength of evidence.
 - b. Convene a subcommittee and recruit graduate students to develop the project scope.
 - c. Distribute results of findings through appropriate channels to the public and primary care providers.
2. Assess how primary and secondary prevention efforts change in the presence of positive family history.
 - a. Among those with positive family history.
 - b. Among primary care providers who diagnose and treat those with a positive family history.

Desired Outcomes

- Implementation of evidence-based family history interventions in public health and clinical practice.
- Increased understanding of how family history information changes provider practice.

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5 Goal 5

Educate the public and providers regarding genetic screening and testing.

Objective 1

Identify current issues among the public and/or health care providers.

Objective 2

Determine how health care providers are using genetic screening and/or testing.

Activities:

1. Develop a database of information on genetics tests that includes information such as:
 - a. Available tests
 - b. Web sources that offer tests
 - c. Other resources
2. Develop guidelines for how to assess genetic tests.
 - a. Utility
 - b. Costs
 - c. Identify other appropriate criteria
3. Invite interested partners to participate in discussions and development of the guidelines.
4. Identify appropriate resources for educational efforts.
 - a. Consumer awareness
 - b. Provider guidance
5. Explore relevant policy issues, such as:
 - a. How genetic information and/or test results are used by the health insurance industry
 - b. Gaps in current state and federal laws

Desired Outcomes

- Increased understanding of the appropriate use of genetic screening/testing among the public and health care providers.
- Development and dissemination of guidelines for using genetic screening/testing.

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Goal 6

Gain a clearer understanding of the clustering of chronic diseases and the degree of genetic impact on these clusters in Utah.

Objective 1

Use epidemiologic methods to identify family and regional clustering of disease.

Objective 2

Compile informational listings of identified clusters with impact on suffering.

Activities:

1. Continue project with Lisa Cannon-Albright and medical informatics students to utilize the Utah Population Database.
2. Use familial clustering methods to rank all disease endpoints in the Utah Population Database by strength of clustering.
 - a. Starting with disease with greatest burden in population
 - b. Population attributable risk
3. Apply findings to public health through population strategies.

Desired Outcomes

- Application of the Utah Population Database to public health practice.
- Increased understanding of the impact genetics has on chronic diseases in Utah families.

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Goal 7

Utilize all available resources to develop a statewide family health history database.

Objective 1

Assure appropriate methodology so that as datasets are developed they can work together.

Objective 2

Identify and engage appropriate stakeholders to discuss solutions for the following issues:

- Funding
- Maintenance of the database
- Sources of data
- Commitments from stakeholders
- Appropriate model(s) to manage the database
- Privacy and confidentiality concerns

Activities:

1. Identify the tools that currently exist for family health history collection which are available to the public and used by health care providers and researchers.
2. Identify existing sources of data.
3. Determine the best model for the database to be developed.
4. Determine what Internet tools are required to provide education to the public and health care providers.
5. Involve all Family Health History Taskforce committees in the planning and development process.

Desired Outcomes

- Identification of barriers impeding the development of a family health history database.
- Stakeholders have agreed to work together to overcome barriers
- Development of a non-research family health history database for public health and clinical practice.

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Goal 8

All efforts in the Utah Genomics Plan will address appropriate policy and ethical issues.

Objective 1

Understand and identify gaps of current national and state legislation concerning genetic discrimination.

Objective 2

Assure that privacy and confidentiality are included in all methods and protocols developed.

Activities:

1. Review the current Utah Genetic Testing Privacy Act and other applicable state laws.
2. Review current national laws, such as HIPAA.
3. Identify specific issues of concern for the public and underserved populations.
4. Identify genetic policy and ethics experts to serve on appropriate Family Health History Taskforce committees during the development of protocols and activities.

Desired Outcomes

- Appropriate components of legislation to protect against genetic discrimination are identified.
- Increased understanding of the potential harms genomics may have on the population.
- Ethical and policy issues are addressed in all state genomics activities.