

Genomics Toolkit Workgroup
Grand Summit Resort and Conference Center, Park City, UT
August 21-22, 2002

Summary

Attendees: Janice Bach (CSGC), Chris Chalkley (ASTDHPPE), Jeff Goldhagen (NACCHO), Alissa Johnson (NCSL), Sarah Patrick (CSTE), David Schor (AMCHP), and Ann Willey (APHL) **Federal Attendees:** Tim Baker (CDC), Marie Mann (HRSA), Melanie Myers (CDC), and Kristen Peterson (CDC) **ASTHO Attendees:** Amy Klein, Alana Knudson-Buresh, and Laura Sternesky
Absent: Jean Chabut (CDD) and Heidi Keller (ASTDHPPE)

Welcome and Introductions

The Toolkit Workgroup meeting began with participants introducing themselves to one another. Since the Workgroup's last meeting in March, the membership of the group changed. Jeff Lobas is no longer able to serve on the committee due to time constraints. David Schor has replaced Dr. Lobas as the Association of Maternal and Child Health Program's (AMCHP's) representative. Also, attending for Heidi Keller, Association of State and Territorial Directors of Health Promotion and Public Health Education (ASTDHPPE) representative not able to attend this meeting, was Chris Chalkley.

Toolkit Review and Direction Setting

The meeting began with a discussion of the Genetics Advisory Committee's requests to the Toolkit Workgroup regarding the breadth of the Toolkit. Ms. Klein noted that the Advisory Committee did discuss the Toolkit, but a consensus was not reached regarding exactly how the Toolkit should be shaped. The Committee stated that it would like the Workgroup to move forward with bringing the Toolkit into a final form and to cover certain topics. Specifically, the Advisory Committee would like to see a marketing plan for the Toolkit, and the inclusion of affiliate activities regarding genomics, materials targeting the primary health care system, and case studies on state/local and private sector partnerships. An indexing system that would allow individuals in a specific specialty to find materials that are especially relevant to them also should be included.

The next topic of discussion was outline and contents of the Toolkit. Ms. Klein noted as a sidebar that in addition to a hardcopy version, the Toolkit will be made available in Web based format. The Workgroup must decide whether the Toolkit will be a compilation of tools or a "how-to" guide for integrating genomics into public health. Ms. Klein handed out a mock-up of the Toolkit that was based on the framework the Workgroup decided on during its July conference call. Mr. Baker added that the Workgroup also should consider whether the Toolkit is static or dynamic. Dr. Willey noted that the Toolkit will probably contain tools that already exist and that need to be created. The Toolkit is not an index of everything that exists; it should explain how to use genomics in public health. Dr. Willey also noted that the Advisory Committee

indicated that after the Toolkit is completed and disseminated, it will decide what future activities are appropriate for the Toolkit.

Dr. Schor stated that he thought a Web-based toolkit is rather novel, and to include a mechanisms for toolkit users to provide input, including relevant, newly, developed documents, would enrich the contents of the Toolkit. Mr. Baker suggested that the Toolkit be a combination of instruction sets and existing tools. Dr. Willey added that affiliates should be invited to add tools; although, many affiliate representatives have indicated that their organizations are not involved with genomics or are just becoming involved with genomics.

Dr. Goldhagen declared that his vision of the Toolkit is something similar to the Healthy People 2010 Toolkit. The toolkit should assist the user with getting started by providing guidance and the corresponding tools necessary to accomplishing a task. Ideally, this type of toolkit for genomics would be something would be updated every 2 years.

Dr. Knudson-Buresh asked the group to clarify whether the Workgroup was essentially discussing two different concepts—one being a toolkit the other being a clearinghouse. Dr. Goldhagen noted that the Advisory Committee did ask for an availability of tools, but separate from the toolkit. He expressed that when one begins a project a clear set of instructions, like a manual, is needed.

Ms. Bach emphasized that Genetics Advisory Committee's request to provide a mechanism for individuals to find tools related to their specialties is very important. An example of this index could be used is if a health agency staff member was going to meet with the laboratory staff, s/he could easily identify activities laboratory staff could participate in and corresponding resources. Dr. Patrick expressed concern over whether individuals in a particular specialty will only look at what they want and not other pieces. Dr. Willey noted that organizing the toolkit by specialty will create great redundancy, but indexing would be useful and might lead others to notice others involved in this work that they may not previously had thought would be involved.

Toolkit Framework

Wednesday night, participants also focused their energies on creating a flowchart that would serve as the general outline for the Toolkit. On Thursday morning, the Workgroup began filling in details of the Toolkit. Borrowing a quote from Maxine Hayes, "Genomics is a marathon, not a sprint," the Workgroup decided to use the image of running a marathon as the Toolkit's theme. Adages like "don't miss the starting gun," "catching up," "water stations," "training phase," "hitting the wall," "setting the course," "recovering from injury," and "running downhill" will be used to weave together sections of the Toolkit. It also was decided that the Toolkit needed an executive summary that briefly summarizes the following questions which are addressed in greater in the Toolkit. The questions are: Why integrate genomics into public health? What is genomics and public health? How do I start? The executive summary as well as the introduction to the Toolkit will contain other information specific to the creation of the Toolkit. The Workgroup drafted the following outline for the toolkit:

- Executive Summary—briefly summarizes the contents of the Toolkit
- Introduction—contains answers to: Why the toolkit was developed (Intent)? How to use it? Who developed it? What is the history of making the Toolkit? What is the breadth of the Toolkit? What is happening in genomics now? What are affiliates doing? What are some resources?
- Why Genomics?—explains how genomics is impacting public health and why it is important for public health to integrate genomics into practices and policies.
- What is Genomics?—provides relevant definitions.
- How Do I Start?—guides the user step by step through the beginning stages of integrating genomics into public health.
- Tools Section—provides tools that correspond and that assist with the work to be accomplished through using the Toolkit.

Each section of the Toolkit is explained in more detail below.

Executive Summary

This section will be a very brief overview of the entire Toolkit. It also will contain some introductory wording that is meant to entice the reader into taking action to integrate genomics into public health using the Toolkit to assist with that task.

Introduction

The purpose of the introduction is to inform readers of the intent for developing the Toolkit and familiarize them with its contents. Each of the questions mentioned above will be answered in an easy to read format. The Workgroup specifically stated that this section and the next two sections should be formatted in a fashion similar to ASTHO's Adolescent and School Health starter kit.

Why is Genomics Important to Public Health?

This section will address the benefits of integrating genomics into public health. Some of this information can be taken from the Framework document and other existing sources. However, the Workgroup expressed that this section should be brief and easy to read. For example, one paragraph and bullet points would probably suffice.

What is Genomics?

A section with the same title was drafted for the mock-up presentation of the Toolkit. The Workgroup thought this section was done well and thought that it should be used as is.

How Does Genomics Impact Public Health?

Again, this section was drafted as part of the mock-up presentation of the Toolkit. The Workgroup members felt that the existing section should remain.

During the meeting, a copy of the Adolescent and School Health Starter Kit was disseminated. The Workgroup members thought that that kit was well done and some section could serve as a model for the Genomics and Public Health Toolkit. Specifically,

they noted that the sections of the Toolkit noted above could be formatted similarly to beginning section of the Starter Kit.

How do I Start?

This section represents the bulk of the material in the Toolkit, and is the “how-to” section. The Workgroup believed that the pieces outlined below would essentially walk an individual through the steps necessary to begin the process of integrating genomics into public health. The following is an outline of steps that should be included in this section and some corresponding tools:

- Assess your internal resources and existing programs—include a checklist
- Identify outcomes you hope to achieve and cross tab with information garnered above—include a worksheet to help with this process.
- Identify key stakeholders to serve on an internal and external committee—include an example list of organizations that would be appropriate to have represented on the committee(s).
- Convene the committee(s)—include example letters, approaches for achieving interest, and example agendas for at least the first three meetings.
- Integrate into a meeting a session addressing Genomics in Public Health 101—include, when available the course the Genomics and Public Health Centers are creating and one page case studies.
- Perform a needs assessment—include sections addressing all areas that the stakeholders’ represent.
- Identify gaps and set priorities, goals, objectives, evaluation, and timelines.

In keeping with the marathon theme, the Workgroup thought that a motto like, “Don’t miss the starting gun or you will have to catch up,” would be appropriate.

Assess your internal resources and existing programs

The Workgroup felt that it was appropriate to include more than one person to carry out this internal inventory accounting. Involving individuals from other areas of the health agency permits a more accurate collection of resources and programs associated with genomics, and helps to build collaboration early on. Staff responsible for the internal assessment should carefully review the state’s public health plan and the program area plan (e.g., the diabetes plan), and note whether and how genomics is incorporated into these plans. This activity is in essence a preliminary program review or needs assessment. To assist staff carry out this task a checklist that specifies area that should be reviewed, for instance policies and specific programs, and examples of things to look for will be included in the Toolkit. The checklist will be formatted in such way that it will line up with the five strategic areas the Genetics Advisory Committee (GAC) identified. Another possible tool for this section is a form to help users identify how genetics relates to and can be used to achieve the Healthy People 2010 objectives.

Identify key stakeholders to serve on an internal and external committee

An internal and an external committee may be necessary to address the needs associated with integrating genomics into existing programs and to address the larger needs of the public’s health which involve individuals and organizations outside the

walls of state agencies. There were a number of tools Workgroup members felt would be appropriate for this section. A checklist of possible key representatives and information on how to identify key stakeholders holders will be included. When considering who to involve on the committees it is important to collect information on what each organization has done in they are of genomics or why it is interested in becoming involved in genomics. For the internal committee participants in state agencies outside of the health agency, such as environmental health and Medicaid, should be considered. Some examples of who should be included on these committees includes marginalized populations (external), ethicists (external), members of the faith community (external), purchasers of services (external), bio/industry (external), health information systems (internal), payors (internal and external), federal health agency representatives (internal), and legislators (internal or external). The Workgroup pointed out that is important to create an institutional memory of the work performed by these committees.

The value and possible role of each committee should be clearly explained in the Toolkit. The Workgroup also realizes that some individuals or organizations that ideally should be represented on either committee may need some convincing. Therefore, they suggested that the Toolkit include materials that explain the value of participating on these committees. Other suggested tools were suggestions for the size of the committee, details on possible committee and subcommittee structures, information on how to work with existing groups, and ideas to help maintain participants' interest. One member of the Workgroup noted that some states have regulations regarding the formation of committees and these regulations should be reviewed before the committee is formed. The key to these groups may be to start small and build.

Convening the Group

Once the committee(s) has been assembled, the Workgroup acknowledged that several tools will be needed to get the group started. One of the first items the person(s) convening the meeting might want is information on how to run effective meetings. There were several other tools the Workgroup stated it would to have included in this section, namely:

- Example invitation letters;
- Information on how much staff support is needed to support the internal and external committee and how to provide resources.
- Estimated costs for convening the committees. Note, travel costs will need to be factored into the costs of the external committee.
- Group naming exercises. It was thought this could be bonding activity for the group.
- Example agendas for the first 1-3 meetings.
- Necessary background materials, such as genomics and public health, and information on ASTHO's affiliates. The conveners may also want to collect relevant materials from committee participants.
- A worksheet to assist with drafting meeting expectations.

- Example tools for conducting periodic self-evaluations for the committee, i.e., ask members what they like about the meetings and what do not like. (Kris has a good example of this from Minnesota.)
- Information on how to select committee leadership, by-laws, and other structuring details.
- Checklist of other things to consider, such as the frequency of meetings.

Genomics in Public Health 101

The Workgroup felt strongly that an educational component be included in the Toolkit. They felt equally as strong that this tool does not need to be created; rather the tool being created by CDC's Centers for Genomics and Public Health could be included in the Toolkit. They also had some suggestions for the Centers. They would like for the principles of public health to be a component of the educational instruction. Also a CD-ROM with case studies such as genomics and asthma, environmental health (PON-1), and others including sickle cell (this should include lessons learned from the introduction of sickle cell testing) should be included to allow for individual learning. There also should be a self-assessment component. The genomics competencies that CDC developed should be integrated into the course. Also the group thought it would be helpful to include educational components for specific areas of expertise.

Needs Assessment

The Workgroup noted that an internal and external assessment is needed. The internal assessment is described more fully above (Assessing internal resources), and is more of an accounting of genomics activities and existing resources. There are several needs assessment tools currently available. However, the Workgroup wanted to be sure some key components were included in the needs assessment. Ms. Klein and Ms. Sternesky will assess the existing tools to be sure those pieces are included. Specifically, the needs assessment should address:

- Community needs and education—possible tools the Washington tool and focus groups and community asset mapping.
- Policies
- Programs
- Knowledge/expertise and available training opportunities
- Surveillance
- Technology capacity and data infrastructure including registries
- EPI-analysis plans
- Clinical services (availability of services/providers and referrals)
- Funding sources
- Information sharing resources
- Staff capacity
- Leadership involvement and commitment

Identifying Gaps and Setting Priorities

Keeping with the marathon theme, this section could be called setting the course. The Workgroup recommended that the GAC's five goals (policy, infrastructure, training/workforce development, information dissemination, and leadership and

education) to identify areas for which priorities may need to be set. This section of the Toolkit is the appropriate time to focus on the mission and vision, goals, objectives, work plan, evaluation, and timeline for the committee(s). Periodic review and revision of the gaps and priorities will need to be conducted. The Workgroup emphasized that not only should the committee(s) have a plan but the areas participants represent should also have one.

Other Tools

The Toolkit also will include presentation on genomics and its relevance to public health, and other relevant topics. A list of key Web links will be included on the Toolkit's Web page and possible on the CD-ROM. Also, an annotated list of resources, including affiliates, will be included.

Toolkit Rollout Plan

With the time remaining, the Workgroup decided to focus on the marketing and rollout plan for the Toolkit. It was acknowledge that marketing the toolkit will be a multi-step process that includes a through review of the draft from internal and external sources, focus groups, revisions, final review and release. These steps are more fully discussed below. It was noted that the Coalition of State Genetic Coordinators should be involved early in this process.

Review and Focus Groups

The Workgroup expressed that they would like the Toolkit to be reviewed by the following groups, GAC, selected individuals, and affiliates. At first it was thought that it would be pilot tested, but given the timeframe for completing the Toolkit focus groups will be used to assess the usability and fine tune the Toolkit before it is released nationally. Individuals that participated in the initial set of Toolkit focus groups will be included in these focus group, plus individuals that are not familiar with genomics and public health. Particular effort will be made to include local health agency representatives. After the review process has been completed, the GAC will have a final review.

Release

The Workgroup suggested that there be several components to the release of the toolkit including, pre-conference workshops, booth displays, posting on other organizations Websites, postcard notices, Webcasts or satellite broadcasts, and conference receptions have demonstration modules of the Toolkit to get users familiar with it. Other opportunities to keep in mind are the regional HHS meetings and the CDC broadcasts. The Workgroup also recommended that an expert in social marketing be brought on to assist with the development of a marketing plan.

Adjournment

The Toolkit Workgroup meeting was adjourned at approximately 2:30 p.m., August 22, 2002.