Input on Genomics
In Minnesota:
Focus Groups with Key People

Report prepared for the
Minnesota Department of Health

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Genomics Focus Groups

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Executive Summary

The Minnesota Department of Health (MDH) received a $1 million grant from the Center for Disease Control and Prevention to integrate genomics into public health activities in the state. This five-year project will focus on chronic diseases. The project is just getting underway and MDH staff wanted to get input from key people to help shape the direction of the project. Five telephone focus groups were held with 23 people including researchers, educators, public health practitioners, healthcare providers, and healthcare advocates. The following is a summary of the questions asked and input offered. Questions included:

- What issues are important related to genomics? What are your concerns related to genomics?
- What role should MDH play related to genomics?
- Do you have a particular gathering or meeting format that you find useful?

What is important?

When thinking of genomics, participants said the issues of greatest importance and of greatest concerns to them are:

1. The ethical, legal, and social issues related to genomics, including but not limited to:
   - How genomics will influence health disparities
   - How resources will be allocated to genomics versus other health issues
   - How individual privacy will be weighed against the collective good
   - Whether adequate rules, regulations, policies, and procedures are in place to address ethical, legal, and social issues

2. Public policy issues related to genomics, including the preceding and following points
3. Concerns about education
   - Concerns that decision-makers (including the public and legislators) do not have the information needed to make enlightened decisions
   - Concerns that those who counsel people on health (including public health practitioners and healthcare providers) do not adequately understand or know how to use genetic/genomic information
   - Concerns that educating people about genomics will be difficult because:
     o It is a complex science
     o People have different, and conflicting, belief systems that will influence their perceptions of the value of genomics. As a result, discussions could get emotional and heated.

What role should MDH play related to genomics?

Participants said MDH should:

- Educate a variety of audiences including:
  - The public
  - Public health practitioners
  - Healthcare providers
  - Legislators

- Provide support to public health practitioners so they can incorporate genomics into existing programs. This includes providing:
  - Education/information
  - Coaching
  - Materials to share with various audiences

- Maintain a safe repository for genetic/genomic data
  - Explain to the public why MDH is collecting genetic/genomic data and how it will improve public health
  - Anticipate ethical, legal, and social issues associated with keeping and using genomic data
  - Have systems in place to protect individual privacy, yet allow researchers to study the data to improve public health
  - Seek experts to help design safeguards and guide legislators in passing laws that safeguard data

- Advocate for things MDH believes are important. A few people suggested that MDH advocate for things it believes important, such as certain tests and/or funding for tests and counseling
Clearly, participants believed that the Minnesota Department of Health’s primary role is to educate people about genomics. They suggested that MDH collaborate with other organizations (e.g., University of Minnesota, medical associations, local public health associations, health plans) to connect with audiences. Participants also suggested that MDH “stay true to the science,” respect different belief systems, and educate in a way that limits fear.

Participants suggested that education focus on the following items:

The Basics
- What is genomics?
- What can we do with genomics?
- What can’t we do with genomics?
- What are the benefits and risks of genomics?
- What is the difference between gene determinism versus influence?
- What are modifiable risk factors? What role does environment play?

Genomics and Public Health
- Why is genomics important to public health?
- How will MDH’s efforts in genomics improve the health of Minnesotans?
- Why should the state put money into genomics when budgets are tight?
- How can chronic diseases be improved with genomics?

Ethical, Legal, and Social Issues
- What are the ethical, legal, and social implications of genomics?
- What processes, procedures, rules, and/or regulations have been developed to address these concerns?
- Are these processes, procedures, rules, and regulations adequate?
- If they aren’t adequate, what more is needed?
- Who provides funds for screening and testing if people do not have insurance that covers it?

Updates
- Advances in genomics and their implications
MDH is considering convening a group of people interested in genomics. Do you have a particular gathering or meeting format that you find useful?

Participants advised MDH staff to consider the following items before deciding on the format for a gathering:

- The purpose of the gathering
- The intended audience
- The location (metro versus regional/local locations)
- What it will take to get the intended audience to attend

It may be easier to attract public health workers to a meeting/offering than people outside of public health. Public health workers seemed to be familiar with and positive about the various meeting formats used within public health circles.

People who are not employees of MDH or local public health departments may be more difficult to reach. They must clearly understand the purpose of a meeting and how they will benefit. Participants said they are invited to many conferences and meetings and they can only allocate their time to those that seem particularly worthwhile.
Background/Methods

The Minnesota Department of Health (MDH) received a $1 million grant from the Center for Disease Control and Prevention to integrate genomics into public health activities in the state. This five-year project will focus on chronic diseases. The project is in the planning stages and MDH staff wanted to get input from key people to help shape the plan. They wanted to listen to people within and outside of MDH. They wanted to listen to community leaders, healthcare providers, researchers, educators, counselors, and healthcare advocates. They wanted to listen to people who operate at a local level as well as people who operate at the state level.

Because these key people have busy schedules and are geographically dispersed, we knew it would be difficult to convene focus groups. Instead, we decided to use telephone focus groups to gather information. Telephone focus groups typically have four to six participants and last one hour. Participants were sent the focus group questions and background information on genomics a week before the discussions.

MDH staff scheduled the groups, invited participants, arranged the conference calls, and sent out all background materials. Richard Krueger moderated the five telephone focus groups the last week of May 2004. Twenty-seven people agreed to participate in one of the one-hour groups. Twenty-three people actually participated.

Each group was audiotaped and transcribed. Mary Anne Casey and Richard Krueger analyzed the discussions and prepared this report.
Findings

Here are the questions that were asked in the focus groups, and responses. Quotes from the participants are in italics.

Please rate each of the following issues from 1 to 5 with 1 being “not at all important” and 5 being “extremely important.” (Participants were given a list of the following 10 issues and asked to quickly rate each item.)

<table>
<thead>
<tr>
<th>Genomics Issue List</th>
<th>N (some participants did not rate items)</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethical, Legal, and Social Issues</td>
<td>21</td>
<td>4.8</td>
</tr>
<tr>
<td>Public Policy Issues</td>
<td>21</td>
<td>4.3</td>
</tr>
<tr>
<td>Genomics in Health Education, Health Promotion and Disease Prevention</td>
<td>21</td>
<td>4.0</td>
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<tr>
<td>Genomics Education / Capacity Building</td>
<td>21</td>
<td>3.8</td>
</tr>
<tr>
<td>Genomics and Health Disparities</td>
<td>21</td>
<td>3.7</td>
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<td>Genomics and Public Health Research</td>
<td>21</td>
<td>3.7</td>
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<tr>
<td>Genomics in Public Health Sciences and Data Collection</td>
<td>20</td>
<td>3.6</td>
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<tr>
<td>Public Health Systems Role in Assuring Genomics Capacity and Delivering Services</td>
<td>21</td>
<td>3.6</td>
</tr>
<tr>
<td>Genetic Testing in Public Health</td>
<td>20</td>
<td>3.2</td>
</tr>
<tr>
<td>Emerging and Established Genomics Technologies in Practice</td>
<td>20</td>
<td>3.1</td>
</tr>
</tbody>
</table>
Participants said it was difficult to rate the items because the issues were not discrete and it was difficult to tell what each item might encompass. Some participants asked for clarification of the issues.

The purpose of this exercise was to quickly identify the items that participants viewed as most important. Participants shared their ratings. The participants then discussed the two or three items that appeared to get the highest ratings.

Two issues rose to the top in most groups: 1) Ethical, Legal, and Social Issues, and 2) Public Policy Issues.

**What makes these items so important?**

**Ethical, Legal, and Social Issues**

Across groups, “Ethical, Legal, and Social Issues” was rated the most important of the 10 genomics issues. People said this issue is important because:

- Genomics is complex and the related ethical, legal, and social issues may be difficult to anticipate or understand.
- The ethical, legal, and social stakes are so high. There is potential for great benefit; there is potential for great harm.
- People can easily point to examples in history when ethical issues have not been addressed.
- The use of genomics could increase health disparities.
- Technology is being created so quickly that it may be difficult for ethical, legal, and social implications to be addressed.
- People hold different, and conflicting, values and beliefs around genomics.
- Decision-makers will have to weigh individual rights against the collective good.
- Ethical, legal, and social issues underlie all other genomics issues.

Participants said:

> You can’t do good public policy construction without dealing with the fundamental ethical dilemmas and they have to be resolved through appropriate laws or regulations.... It seems to me that the denominator in all of this around genomics will be the individual / society differentiator. How do we address the rights and interests of individuals and at the same time do
what is appropriate to improve society and contribute to the common good in some way?

One of the problems is that it could be easily abused. This kind of information is important for health insurance, social issues, classification of people, seeing it as a way to suppress people, to make higher classes of other folks. I also think that it is important because of the high level of probability for abuse—judging from past issues.

Just look at history. Ethnic populations have suffered from people not being ethical in their approaches. From the public health perspective, the good of many over the good of one has not served those populations well.

I think that this [Ethical, Legal, and Social Issues] is important because a lot of times, especially with the populations of color, it is not something that is seen as a positive. Monkeying with things that don’t need to be monkeyed with. I think it is a hard sell in certain populations. For people who are science-based it is very believable but I think that when you come to your general population it does get to be a point where it is like, it becomes dangerous and taboo and maybe going too far.

This is uncharted territory that we are looking into. I think we need to make sure we have some real good procedures in place and look at all the ethics behind it before we progress.

Contrary to other participants, one researcher said she felt the ethical, legal, and social issues have been adequately addressed and were less important than many of the other issues. She said there are enough policies, procedures, and legislation in place to protect people. Yet if this is true, the vast majority of people doesn’t know what is in place or don’t believe these policies and procedures are adequate.

This researcher suggested that the real problem is not further exploration of ethical, legal, and social issues, but rather how to communicate that those issues have been adequately considered and addressed. This researcher offered the following views:

I think the genome project was a good example of incorporating ethical, legal and social issues throughout a project. I am the one who ranked ‘Ethical, Legal, and Social Issues’ the lowest because I have been so immersed in the field. I feel that a lot of ethical, legal, and social issues have been articulated already. There has been quite a volume of work that has been done on this from a research perspective and from an application perspective to the point that I feel that the communication about it has been almost alarmist. It has
almost inhibited the application of genomics to better the human condition. I think the field is approaching saturation in terms of vetting out all the possible issues. To me the big issue is really communicating it properly.... There are good ethics established around the field of genetics. If we can translate some of that same information and research into genomics. The most important part of communicating concerns over ethical, legal, and social issues is not that there is a problem with those issues—it is that people need to understand that those are being considered and weighed heavily.

Public Policy

Participants believe public policy is extremely important. Public policy will determine how genomics proceeds. Many people felt that ethical, legal, and social issues will become public policy issues—they are intertwined. Participants were concerned that advances in genomics would require legislators to address issues they have not encountered before and about which they are probably not well informed.

Public policy is my top-ranked because we are going to be facing a whole host of issues that we have not faced before. Our very concept of insurance may be challenged as we get better with genomic information. Insurance is built around risk pooling and as we develop a greater and greater knowledge of people’s risk, the idea of pooling is going to be challenged. So that will be a question of public policy, how will we do risk pooling? How do we deal with the issues of access to care and access to health benefits? There are a whole variety of questions like that, that will be a sense of individual rights and the collective social responsibility. Those issues will very much become public policy issues as the genomics frontier is pushed back.

Genomics Education

Across the five groups, “Genomics in Health Education, Health Promotion, and Disease Prevention” and “Genomics Education and Capacity Building” were rated highly. Education is a theme that came up throughout the focus groups. It will be addressed later in this report.
Genomics and Health Disparities

"Genomics and Health Disparities” was among the top-rated issues in several of the groups. While a few people thought genomics might play a role in decreasing health disparities, others thought genomics could add to health disparities. People were concerned about the potential for increased racism, potential to stigmatize groups, and decreased access to care.

This is why I rated ‘Genomics and Health Disparities’ high and this is coming from a March of Dimes perspective. When we are looking at infant mortality rates and the huge disparities that we see, just in those rates alone, we want to look further into the cause of why there is such a discrepancy. I think genomics could add a lot to that discussion.

Genetics may be a part of it, but it is the interaction with social policy that creates health disparities. When I was thinking of disparities I was thinking about the difference in accessibility of healthcare if you are poor or a minority person or so forth. I wouldn’t want to emphasize genomics when we really want to look at the social policies and the economy that may have as much or more of an influence as the genetics.

Health disparities resonated with me the most because we don’t want to get into the trap of trying to create the perfect child and really disenfranchising and stigmatizing different groups. I think that is particularly important with the mental health piece. At the same time, sometimes genomics can reveal very preventable things. Like when I was sitting in the dental taskforce I didn’t realize that dental disease is often a predisposer to premature birth. Well, that is kind of preventable. Some very exciting things could happen if we dug into those subtle causes.

I do feel that it is one more place where it is real easy for racism to plug in and where racism can operate without being called that.
What are your concerns related to genomics in Minnesota?

People voiced these concerns/questions:

Education concerns
- That the public, public health practitioners, healthcare providers, and decision-makers don’t know enough about genetics/genomics.
- That misunderstandings/misinformation will guide decision-making.
- That it may be challenging to educate/communicate about genomics in a balanced way that encourages inquisitiveness but not fear.

Resource questions
- How will/should resources be allocated?
- How will the uninsured or underinsured access services?

Privacy questions
- How will privacy issues be managed?

Education concerns
A number of participants said they are concerned that people who work in health, and people who make decisions about health, don’t know enough about genomics. Misinformation or a misunderstanding of the science could lead legislators to pass legislation that is too restrictive or not restrictive enough. And health educators and providers may not have enough information/understanding of genetics/genomics to provide the best guidance to individuals.

While participants believe education is crucial, they see several challenges:
- How to communicate about/discuss genomics while being respectful of different values.
- How to explain genetics/genomics in ways that non-scientists understand.
- How to communicate about/discuss potential ethical, legal, or social issues without being alarmist.

A concern of mine is education and capacity building. [It is important] to get a baseline knowledge in the public and within public health professionals so there is inquisitiveness but not knee-jerk suspicion/paranoia that you see sometimes.

Issues of morality, religious context, spiritual beliefs would be incorporated into [discussions of genomics]. People having a problem with that [genomics] .... Like monkeying around with something that doesn’t need to be
monkeyed with. I hear that comment quite a bit in reference to this issue.... People whose belief pattern would conflict with this process.

My concern would be about the ethical and legal underpinnings behind public policy issues. I’m concerned that we will have a politicized discussion that is uninformed. So connect the education to having an informed legislature where the discussions are based on something other than a very shallow understanding or lack of understanding of what the true issues are.

I think it is going to be a problem of education of the public and the people who set policy. I think the health department is already doing things in genomics and genetics and there is a lot of research going on. But being able to get it to the general public, being able to get it to people who practice public health to accept it will be a difficult process I think. My concern is, can we educate them well enough to assure people—can we be assured—that we are not going to be making Frankenstein's and so on. Misusing genomics.

Resource Concerns
How will/should resources be allocated?
Several people said they want resources to go to address our greatest needs. Some wondered how resources should be allocated to genomics versus other health issues. Some wondered how resources should be allocated within genomics. How many resources should be committed to genomics when other needs, like mental health, are not being adequately addressed? Within genomics, should more resources be allocated for high incidence conditions versus low incidence conditions? Should resources be committed to the generation of information in genomics if it can’t be used to improve public health?

At this stage in history I feel that genomics is an option and there is not a lot that we can do with the information. We can’t cure a lot of things.... So how do we really use genomics to raise the level of health of a population? Is this the best bang for our buck when resources are so scarce and we have so many problems that we aren’t meeting well right now? For example, mental health needs. So for me it is a question of resources—allocation. Where should we be putting our resources at this time?

From a local public health perspective a concern is how the resources for the whole healthcare delivery system are allocated. My concern is about putting a lot of resources into the identification and implementation of programs around conditions that are relatively low incidence when we already have a
number of high incidence conditions that we do know about and that we are really not addressing.

The Department of Health has to prioritize. If we go in these directions, then what we are prioritizing that we are going to be improving? This is a policy question. Why are we going here? What is it that we think is most important to improve in Minnesota? Is it health disparities? That would be a good place to start, but is there any genomic entry point to that?

The one huge success story of genomics in public health is in fact, the newborn screening programs that are out there that are publicly funded. I think the reason those are successful is because the science proves that it was a worthwhile thing to do, there were clear-cut interpretations, and the interventions were potentially there and feasible to start. When we start moving into all the other diseases that are out there I start to have questions because it is not necessarily cost effective. We should not definitely be testing the population. To me it is opening a can of worms at this point. You really need to have a lot more evidence base to get involved in actual practice of genetic screening or genetic testing.

How will the uninsured and underinsured access services?
Several people wondered how people without good health insurance could access screening or testing. What insurance plans cover screening or testing? How can people without coverage be linked with services or funds for services?

I have been thinking about the populations that we see. I don’t know that Medical Assistance would pay for screening for families that might have a risk factor or an issue. So I am having a hard time wrapping my thoughts around this because for the populations that we work with, there would be such a barrier related to money.

I was just making an assumption when I was thinking about linking people to payers that this would start with an appointment for the family history, along with genetics testing. Now maybe that is not what this is, but I do believe MA pays for that.

There is no way that people without funding are going to pay for this or people who are underinsured—the old Wal-Mart insurance which is $5000 deductible per person per year.
How can the Minnesota Department of Health step on the insurance companies to cover these tests that are needed?

I think we need to address some of the concerns about reimbursement. I think the regulations and the laws around reimbursement are based in ignorance.

Privacy Concerns
How will privacy issues be managed?
Several people mentioned that they are concerned about how individual privacy will be weighed against the good for society. How will these decisions be made? By whom?

I have a great concern of how we would manage the issue of privacy as we proceed in the direction of genomics in public health.

Related to privacy issues. I think there is more we could do with this information in our work. I am thinking about the families that have clustering of chronic diseases. Utilizing the information that could come from genomics, providing preventative information for people. That could be a positive, versus a concern.
What role should the Minnesota Department of Health play related to genomics?

Participants suggested that MDH play these roles related to genomics:

- Educate a variety of audiences
- Support public health practitioners
- Maintain a safe repository for genetic/genomic information
- Advocate for things MDH believes are important (e.g., certain tests, funding)

Educate a variety of audiences

Clearly, participants believed that education is the primary role MDH should play related to genomics. People suggested answers to:

- Who needs to know more about genomics?
- What approach should MDH take in educating audiences?
- What do people need to know?

Who needs to know more about genomics?

- The public
- Public health practitioners
- Healthcare providers
- Legislators

Participants believe there are several audiences that could benefit from a better understanding of genomics: those who influence or make policy decisions (e.g., the public, legislators), and those who counsel individuals (e.g., public health practitioners and healthcare providers).

*Education should really be the number one priority of the Minnesota Department of Health. By having an educated populace, as well as educated lawmakers, [they] can make appropriate policies. A lot of times they are operating in a knowledge vacuum. So our task in this time of tremendously limited financial resources and the need to prioritize, the most effective way we can get to out there is for MDH to take a lead in educating the professionals as well as the public about what genomics is and what it is capable of doing.*
There is a need to educate the general public, public health providers, and medical providers. There is also a need for a pretty high-level and sophisticated educational effort with policy makers so that laws that are passed and rules that are written are based on good information, good training, a solid knowledgebase.

In terms of the legislature, I think it is a long-term, if not a continuous process. I presume the knowledge is going to keep developing all the time. And the legislature turns over periodically.

We have found that over the whole history of genetic screening, even with single gene dominant conditions, doctors and nurses get it wrong. There is education in a number of medical schools now. Almost none in nursing schools. So the misinterpretation of what is simple now, compared to what comes in genomics is just rampant. I think the Department of Health could have a role in creating or encouraging practitioner education.

What approach should MDH take in educating audiences?
Participants gave advice about how to educate audiences:

- Stay true to the science
- Collaborate with other organizations/associations

Stay true to the science
During the focus groups, a question kept arising: How can an organization educate and communicate about genomics without creating undue public concern? Genomics could be an emotional, political, hotly-debated topic. Participants advised MDH to focus on the science, play the role of mediator, and be respectful of differing values.

We need to stay true to the science because there has been a lot of mixing politics and science. So staying true to the science. What we don’t know, we say we don’t know. As the new information comes out, we share it.

I think [the role of MDH] is mediator .... Where there can be very polarized perspectives. I think there is a mediation role through education.

I view our role as being pretty much down the middle between the people who will only see the good and great things that could come of this...and the people who think it is morally wrong and evil.... Educate, but don’t engage in the moral, emotional discussions. Our role is to stay at the factual/informational level.
Collaborate
People suggested reaching public health practitioners and healthcare providers through collaborative efforts with their current affiliations:

- University of Minnesota undergraduate and graduate schools (e.g., School of Public Health, Medical School, School of Nursing)
- Local public health associations
- Medical associations
- Health plans

*I think physicians need to be educated about this but the way to do that is to have meetings or continuing education credits. Go to their society and try to get them. (Second person)* You may wish to go through their health plans.

*I see it as a collaborative role between the educational establishments here and the Minnesota Department of Health to sort of get the word out.*

*The school of public health and the medical school should really work together with the Minnesota Department of Health.*

**What do people need to know about genomics?**
**Potential topics:**

The Basics
- What is genomics?
- What can we do with genomics?
- What can’t we do with genomics?
- What are the benefits and risks of genomics?
- What is the difference between gene determinism versus influence?
- What are modifiable risk factors? What role does environment play?

Genomics and Public Health
- Why is genomics important to public health?
- How will MDH’s efforts in genomics improve the health of Minnesotans?
- Why should the state put money into genomics when budgets are tight?
- How can chronic diseases be improved with genomics?

Ethical, Legal, and Social Issues
- What are the ethical, legal, and social implications of genomics?
- What processes, procedures, rules, and/or regulations have been developed to address these concerns?
- Are these processes, procedures, rules, and regulations adequate?
If they aren’t adequate, what more is needed?

Who provides funds for screening and testing if people do not have insurance that covers it?

Updates

• Advances in genomics and their implications

[The role of MDH is to provide] public education about what genomics is, what it means, the benefits as well as the risks, and anticipating the public angst, as I put it, in helping all of us to address both the potentials and the protections. Addressing people’s concerns.

Related to education, the Department of Health, in some clear way, must define how genomics pertains to the goal of improving the public health. Looking at the documents you sent, Genomics in Public Health, how does the public understand that these goals really matter?... How is genomics a public health issue?... Can that be really well articulated in a way that the public can understand it?... Not just championing something that could, in the wider scheme of things, be relatively a waste of money. Even though we would agree that if we had all the money in the world it would be very important to do this kind of thing.

I think one major issue is that obtaining genetic information can lead to a sense of predestination as to what an individual is going to be, especially from a psychological standpoint or from an intellectual standpoint. And I think those sort of issues are ones that could be helpful but also misused.

I fear that there is a great deal of misunderstanding in terms of how genetics influences health. Some gene influence things are just that, influence. There is no causal determination. I am afraid that it is very difficult to educate the public so that they get that. There aren’t single genetic markers for everything and if someone has something, a genetic marker, it may just mean a disposition. So how far do we take this from a public health perspective and how does the public interpret it? Which is the educational issue. This is very complex material to convey to the public and not create alarm, not create difficulties that we can’t manage.
Provide support to public health practitioners so they can incorporate genomics into existing programs

Types of support to provide:

- Education/information
- Coaching
- Materials

Provide high quality education/information, coaching, and materials to practitioners across the state. Several practitioners suggested that the genomics staff study the support provided by MDH’s HIV/AIDS project because it is an example of exemplar support. They said that practitioners received consistent training and materials that they could easily use. They appreciated this approach and it appears to be a well-known example of top-notch state-level support.

Many of the education topics listed in the previous section of this report would be appropriate for public health practitioners. In addition, they would like specific guidance on, or examples of, how to incorporate genomics into their current programs. What can/should public health practitioners DO with genomics?

Coach public health practitioners in how they might respond to different types of comments in different types of settings (e.g., public meeting, education session, individual counseling). Practitioners want to know how to focus on the information, be respectful of different beliefs, and avoid religious or value debates. Coach public health practitioners on how to convey this complex information in a way that is useful.

Provide practitioners with materials that they can easily use with their audiences. Local practitioners do not want to recreate materials. Keep in mind that materials may need to be adapted for different cultures.

It wouldn’t be so much of an issue to tie some of these things in at a local level health department if the Minnesota Department of Health provided us with that information or it was coming from a reliable source. [We could] include that in the programs that already exist—if those materials are given to us.

On MDH’s role, how do we as staff respond to comments about, ‘It is the will of God’ and ‘What will be will be.’ To be respectful of the people who believe that, but knowing there may be other people present who want to know more.

I was reading your fact sheet about Genomics and Public Health and it says which diseases are associated with genomic susceptibilities or resistance factors. We [MDH] have strategies in place for every one of these areas:
tobacco, obesity, etc. These are huge focuses for public health right now. I had never thought about combining them with genomics.

I also see us [MDH] taking a leadership role in working with local public health agencies to try to figure out what their role is in terms of genomics. Maybe developing some guidelines or some plans to help them figure out how they can incorporate this into the work they do in education or home visiting.

We work at the local level.... I can honestly say that my counterparts in health education and most of my counterparts in our local health department would not know what genomics is to begin with. They would not necessarily know how to define it.... Without educating them properly there is going to be a lot of fear and skepticism. For us to properly do our jobs, the state would therefore educate us at our local level and we would therefore educate our employees and our employees would be able to educate the public.... [It helps if] everyone is on the same page, they all have consistent information, they are all using the same thing around the state, so we are all saying the same things.

[There is a] need for culturally specific and appropriate educational materials for a whole variety of cultures in Minnesota, particularly as it becomes increasingly diverse. There may be the need for translated materials, but in many cases it is a need for understandable and appropriate materials. And also education.... on how to carry out that kind of adult education in a way that is useful.
Maintain A Repository for Data
Participants said MDH should:

- Maintain a safe place where genomic data can be kept.
- Explain why MDH is collecting genetic/genomic data and how this will improve public health.
- Have systems in place that insure individual privacy, yet allow researchers to study the data to improve public health.
- Anticipate ethical, legal, and social issues associated with keeping and using genomic data.
- Seek experts to help design safeguards.
- Guide legislators in passing legislation to safeguard data.

You [MDH] are the depository for the information on individuals.... You are creating biochemical fingerprints on people through the mass spec work. As we start getting into chip technology we are going to start looking at 10,000 or maybe 100,000 snips, which would certainly be possible. And this information is going to be kept and it is going to accumulate.

One of the guiding factors for public health is the assurance factor. MDH should, and hopefully does, have safeguards built into these processes that will keep this information from being misused by not only the professionals within the area but also from others obtaining the material and utilizing it in a harmful way.

You have two competing interests here. You have one interest that you keep the information private, so very personal information that could be harmful is not released. The second is that this information provides a phenomenal resource. It will probably increase in its importance in being able to uncover the genetic basis of disease. So on one hand you want to keep it safe, on the other you want it to be available to researchers to try to find the underlying genetic component to certain complex disorders. It is a tightrope.

Certainly a role that could be played is data collection. What will be the role of MDH in collecting genetic information? Then there are all the associated issues around privacy and protection of individual rights.

The Department of Health is going to have to explain why it is its job to collect genetic information. So somehow it has to help make the connection between getting this kind of information and improving the public health.
I think this should be ahead of the legislation. They should have consultants on ethics and legal issues before regulations come about. It should be anticipatory of the needs and the problems. I think they [MDH] get this by being in contact with a lot of groups that are involved with the issue.

Advocate for Tests/Funds
A few people suggested that MDH advocate for things they believe are important, such as certain tests and/or funding for tests and counseling.

I think the Department of Health has a role in advocating for the lab tests that they think are important, like the newborn screening tests. Educating people about why they are important. Then there are policy implications out of those, especially if this gets more in the public and people don’t want them. The issue of voluntary and mandatory newborn screening will probably come up.
MDH is considering convening a group of interested people. Do you have a particular gathering or meeting format that you find useful?

People advised MDH staff to consider the following items before deciding on the format for a gathering:
- The purpose of the gathering
- The intended audience
- The location (metro versus regional/local locations)
- What it will take to get the intended audience to attend

What is the purpose of the gathering?
People said the meeting format should be based on the purpose of the gathering. Participants said it would be difficult to convene people without a specific purpose, task, or desired outcome. People need to clearly see the reason for a meeting and how they will benefit. Three purposes mentioned included education (MDH gives information), advisory (MDH gets information), and work (people gather to complete a task—e.g., draft a document).

*It would be the particular purpose of the meeting that would make a difference…. If it is for education about genomics, it might be more user friendly if it was in a setting...where the participants know each other or have a common interest. Then if they could break into smaller groups to discuss it. So the purpose of the gathering or meeting would determine [the format].*

*My question would be, what is the importance of the group? Are they just trying to come up with ideas or are they trying to come up with something substantive that will be utilized in public policy. If it is going to be substantive I think you need to spend the time to bring people together and bring people up from an educational standpoint so that everyone is on the same page in understanding some of the major issues and take the time to have the face to face. Then maybe supplement that with videoconferencing.*

Some wondered how this gathering of people would be different than advisory groups or interest groups currently meeting.

*What about this group would be different from the other groups that have already been convened around genomics, just so I am clear. Is this more a grassroots community type of group?*
Who is the audience?
Participants who worked in local or state public health organizations were quick to suggest methods that would be to help them learn more about genomics and how it might related to their work.

People outside public health had many more questions about the purpose of a gathering, how it would be distinguished from other gatherings currently being held, what types of people might be invited, and what it might take to get people to attend a gathering.

Some people said that the format might depend on the types of people invited: community groups prefer small face-to-face meetings rather than the use of technology. Local public health people might not be able to attend a training in the Twin Cities.

Where will the gathering be held?
People outside the metro area said it is difficult to travel to meetings in the Twin Cities. They suggested regional face-to-face meetings, or the use of some kind of technology (e.g., WebX, interactive video, satellite, conference calls). People discussed the advantages and disadvantages of various methods; face-to-face meetings are difficult to attend but provide the best opportunity to develop relationships and share ideas. Some of the new technology saves travel time but when not used well can frustrate and bore the audience.

What will it take to get people to attend?
People outside the public health system seemed most sensitive to this challenge—what would get them to go to a meeting? Several people said there are so many meetings, workshops, conferences to attend that a new meeting would have to include something special.

Other quotes related to the format for a meeting or gatherings are listed in the appendix.
Added Question:

How does one do needs assessment on a topic that few people, even in public health, are aware of? People know so little that they have difficulty answering questions about what they need.

A few people suggested methods for collecting information—online surveys, conference calls, or getting a little time on the agendas of pre-established meetings. Others suggested contacting groups of people through their organizations: the MCH coordinators, public health directors, community health coordinators, nursing groups, physician groups, the graduate medical, nurse practitioner, and public health graduate schools.

The local public health association is good if you want to connect with public health directors and community health services administrators because generally there is really good representation. There are a lot of members throughout the state and so getting on the agenda for that meeting, which you could do through Laurel La Croix. That is helpful as far as a starting point.

When thinking of captive audiences, I am also thinking of physicians and their different specialties, like family practice doctors and pediatricians. They must have statewide meetings. I wonder if that is a way to get to a captive group of them and give them a FAQ fact sheet and a two-question thing to respond to.

You might be able to link to an online survey for them as well, from their Minnesota Medical Association website. And the nurses association.

However, these methods don’t address the issue—people not having enough information about genomics to know what information would be helpful to them. It may be helpful to try to approach the topic from their perspective. They may have questions like:

• Why do I need to know about genomics? I am doing my job just fine without it.
• How does genomics apply to what I do?
• What can I do with genomics to better help the people I serve?
Appendices

Focus Group Questions

These are the questions that will be asked in your focus group. You may find it helpful to review them and think about your answers ahead of time.

1. Take one minute to introduce yourself. Tell us what organization you are with and what you do for that organization.

2. Before you is a list of issues related to genomics.
   a. Quickly, is there an issue that you feel is really important that is missing?
   b. Please rate each of these issues from 1 to 5 with 1 being “not at all important” and 5 being “extremely important.”
   c. ______ seems to be rated the highest. What makes that so important?

3. What are your concerns related to genomics here in Minnesota? (Or related to your job?)

4. What role do you think MDH should play related to genomics? What should MDH be doing?

5. MDH is considering convening a group of interested people. Do you have a particular gathering or meeting format you find useful? What do you like about it?
Genomics Issues List

May 17, 2004

1. Ethical, Legal, and Social Issues
2. Public Policy Issues
3. Genetic Testing in Public Health
4. Genomics in Public Health Sciences and Data Collection
5. Genomics Education / Capacity Building
6. Emerging and Established Genomics Technologies in Practice
7. Public Health Systems Role in Assuring Genomics Capacity and Delivering Services
8. Genomics in Health Education, Health Promotion and Disease Prevention
9. Genomics and Health Disparities
10. Genomics and Public Health Research
Additional quotes related to meeting formats

I would just say either interactive video or there are some new technologies that are coming out where people can sit at their computer and interact too. So if you are looking for input, doing it that way. If you are looking at trainings, either going around and doing them in person or interactive video with someone in the local site that knows about it, especially in an area like this where people know so little about it, it would almost be better to have people go out to talk to people.

Conference calls are nice, especially when you are trying to convene a group of people from around the state. We use WebX quite a bit in our national organization. If you were looking at convening a group of people and possibly doing some kind of presentation, maybe combining it with an education component, those have worked very well for us. I prefer face to face because I think you get more interaction but I also know that in budget times and more roles with less time to do things in, conference calls or WebX trainings are really quite doable.

Most of us who live outside the metro area get used to going to that area for meetings but it is still an impediment for participation from all over the state. So, electronic connectivity. I think ITV is more powerful than teleconferencing. I also think there is a lot to be said for being in the same place at the same time in terms of what can develop as relationships because regardless of the structure or concepts or other values that we have around all these topics, the relationship between the people working on them turns out to be a very important variable and sometimes a make or break variable.

I do know that the videoconference works great unless you have some kind of training where you want input from the audience. Questions, answers back and forth. It wastes way too much time to go around all the sites, Bemidji are you still there? Do you have any questions? Rochester? That eats up way too much time. I think coming out and doing regional workshops if you want a lot of audience participation really has to be in person.

MDH recently did a project with Linda Olson Keller where they were trying to link schools of nursing with public health agencies to build workforce. They did it with a kickoff session for a couple of days here in the cities.... It was education and brainstorming time. People decided whether they wanted to
sign on or not. And from there they broke out in regional groups where there was not so much travel. It has been very effective. There have some partnerships that we never thought possible that came out of it.... MDH gave us the tools but they didn’t say, this is how you are going to do it. Each region came up with a little different approach but we accomplished the same thing.

I agree with the concept of a town hall meeting in various regions of the state where you can get people who are close by so people from the Minnesota Department of Health could travel. In that kind of a live format it does have the advantages of face to face which you don’t get over the television screen and it is the personal contact that makes it important. Then if you can be in a situation that is less formal in the sense that you are there and it is a town hall meeting. People who would not ordinarily speak up on a web cast might have their opinions put forth in a less threatening, less technical kind of situation.

I am not a big proponent or fan of videoconferencing or teleconferencing. For me face-to-face is important, especially when you are first meeting. I think it is really important to have that personal interaction and be able to really see people. In my experience of convening people, it is definitely bringing people to a place where they feel comfortable and safe and specific to the Latino population it is definitely doing outreach and making those connections.

I would suggest that in some cases you might want to look at a hybrid where you might start with a brief program or you might have a speaker or panel of speakers, perhaps people who have experience with the things being discussed, people who have done it in other settings or whatever the case may be, and you breakout groups, much like focus groups and have the breakout groups go and if there are specific issues to be discussed and have the breakout groups report back. So combining the ideas of expert information and focus groups or breakout groups.

You were asking what kind of format might be useful if you were pulling together a lot of different people from different perspectives. I have always found that having short talks by people where you assign them a topic is very useful. You have to decide the purpose is to educate people and then to stimulate the discussion. I think a point/counterpoint or a debate format where you assign people to take a position on something, so that everyone in the room can hear all the points of view.

I think you have to give them a carrot to make it worthwhile to be there. You have to reinforce the behavior. You have to pay expenses. You have to make it attractive.
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