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Abstract

This paper describes the development of an audio visual genomics glossary that was designed as an education tool for American Indian communities. This “Talking Glossary of Genomics Terminology” is a multimedia DVD that was modeled on the “Talking Glossary of Genetics,” which was developed by the National Human Genome Research Institute (NHGRI). The NHGRI Glossary was modified and expanded with content designed to increase awareness among American Indians about cancer, genomics, and personalized medicine. Partners on the project include the Inter Tribal Council of Arizona, Inc., Phoenix Indian Medical Center, Arizona Cancer Center at the University of Arizona, the Translational Genomics Research Institute, as well as Arizona State University and University of Arizona graduate students.

Keywords

American Indians; Cancer; Genetics; Genomics; Indians of North America; Medical care; Personalized medicine; Terms and phrases

Cover Page Footnote

This project was supported by a grant awarded by the National Cancer Institute, Community Network Program (Grant Number 1U01 CA114696). The contents are solely the responsibility of the National Cancer Institute - National Institutes of Health.

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ABSTRACT

This paper describes the development of an audio visual genomics glossary that was designed as an education tool for American Indian communities. This "Talking Glossary of Genomics Terminology" is a multimedia DVD that was modeled on the "Talking Glossary of Genetics," which was developed by the National Human Genome Research Institute (NHGRI). The NHGRI Glossary was modified and expanded with content designed to increase awareness among American Indians about cancer, genomics, and personalized medicine. Partners on the project include the Inter Tribal Council of Arizona, Inc., Phoenix Indian Medical Center, Arizona Cancer Center at the University of Arizona, the Translational Genomics Research Institute, as well as Arizona State University and University of Arizona graduate students.

Keywords: personalized medicine, genomics, American Indians

INTRODUCTION

Personalized medicine is a rapidly growing, multi-disciplinary area of research and clinical practice that tailors health care to patients by taking into account their individual genetic makeup to improve detection, treatment and prevention of disease. As greater emphasis is placed on integrating genomics, or the study of all the genes and their interactions, in mainstream medical care, it becomes increasingly important to support broader genetic/genomic science education, both for health care professionals and for the general public (Lanie et al., 2004). Personalized

medicine holds considerable promise for society in general but, paradoxically, the disadvantaged populations most in need may be the last to benefit from these advances in medicine, leading to ever increasing health disparities between rich and poor and between different ethnic groups. The reasons that disadvantaged populations rarely participate in clinical studies are multi-faceted, but include distrust, barriers to health care access, unwillingness/inability to participate in genetic studies and lack of understanding regarding the significance of genetic information for individual patients and their family members.

One sector of the population that experiences some of the greatest health disparities, including higher mortality rates, when compared to the general population in the United States, is that of American Indians (Espie et al., 2007). Given a long history of under-funding and under-provisioning of health care for American Indians, it is likely that information about emerging treatments and new insights into the molecular mechanisms of disease are not commonly available or known, nor are they impacting the American Indian health care system. An additional problem that further exacerbates the situation is the fact that for social and historical reasons, these communities may face particular barriers – historical, cultural, and trust – that make individuals less willing to participate in clinical studies or to access personalized medicine.

American Indian communities are often reluctant to participate in biomedical and genetic research, citing mistrust of the research process and/or researchers (Warne, 2006). Genetic research is of particular concern as a result of past abuses and deception by researchers, and lack of cultural sensitivity regarding the use of biospecimens for research purposes (Arizona Biomedical Research Commission Report [ABRC], 2006). American Indian tribes may be less inclined to participate in research studies if the perceived benefit is not specifically directed toward the tribal community or if there is little to no involvement by the community in the research design and process (Warne, 2006). Participation in research may not be regarded as a priority when a lack of resources and access to basic health services present more pressing issues (Warne, 2006). Another possible barrier may be the general lack of understanding of, and education about, advances in rapidly developing fields of genomic and clinical research.

To introduce the American Indian population to the rapidly developing field of genomics and personalized medicine, the Southwest American Indian Collaborative Network (SAICN, Grant Number 1U01 CA114696), a multi-institutional cancer network serving the regions of Arizona, Utah and Nevada, has developed an educational tool that aims to increase the understanding of genetics, genomics, cancer and personalized medicine. An additional motivational factor underlying the development of this educational tool is the fact that the state of Arizona is strategically developing a biomedical base that attracts cutting-edge genomic and clinical research. Various academic, research and non-profit institutions in the state are now proposing partnerships with underserved populations in a collaborative approach that allows more effective participation in emerging translational research that moves findings from the lab into clinical practice (see ABRC Report, 2006).

The educational tool that the SAICN has developed is a “Talking Glossary of Genomics Terminology,” a multimedia DVD modeled after the “Talking Glossary of Genetic Terms” developed by the National Human Genome Research Institute (NHGRI). Partners on the project include the Inter Tribal Council of Arizona, Inc. (ITCA), Phoenix Indian Medical Center (PIMC), Arizona Cancer Center (AZCC), the Translational Genomics Research Institute (TGen), as well as Arizona State University (ASU) and University of Arizona (UA) graduate students. While the educational materials explain genetic terms and the link between genes and cancer, they are for explanatory purposes only and not intended as advocating or promoting genetic or biomedical research. In this paper we describe the development and content of this SAICN Genomics Glossary.

METHODS

The SAICN Training and Education Core (SAICN T&E) evaluated the existing “Talking Glossary of Genetic Terms,” which was created by the NHGRI to serve as a public resource on terms and concepts in genetic research. This glossary is a web-based tool that includes the written definition of scientific terms, recorded phonetic pronunciations by National Institutes of Health (NIH) scientists, illustrations, and links to related terms. Both English and Spanish language versions are available on the web link (www.genome.gov).

The NHGRI glossary, launched in January 1999, helps people without scientific backgrounds understand key terms and concepts used in genetic research. The project was the first online genetic glossary to combine text, audio, and visuals in a highly accessible, easy to understand and user-friendly format. Students, teachers, librarians, medical professionals, journalists, and the general public are the intended audience. Featuring nearly 200 entries, the glossary offers handy pronunciation guides, brief text definitions, and dozens of illustrated diagrams of selected terms. The illustrations can be downloaded and printed without copyright restrictions. Beyond its standard dictionary-style definitions, the glossary also includes in-depth audio clips provided by more than two-dozen researchers in the fields of genetics, molecular biology, and medicine. Offered as a public service, the glossary is now linked to over 100 outside institutions, universities and other publicly available web pages.

The SAICN T&E Core members first reviewed existing terms of the NHGRI glossary, and of the genetic and scientific terms included, selected 145. With the assistance of the biomedical research institute TGen, AZCC and PIMC, the T&E Core members identified additional recent genomic and clinical terms to be included in the glossary. These added terms, which were specifically related to genomic and translational research, included such terms as “gene expression profiling,” “human genome,” “pharmacogenetics,” “single nucleotide polymorphism” as well as additional clinical terms not included in the NHGRI version. In addition, Core members added terms for the cancers most commonly diagnosed in American Indians living in the Southwestern U.S. A science writer from TGen was designated to provide written scientific definitions with review and comment by the SAICN T&E Core members.

After an updated glossary list was completed, the ITCA hired three American Indian graduate students, one from Arizona State University (ASU) and two from the University of Arizona (UA), as junior investigators. Their job was to provide lay audio interpretations for the written scientific definitions and voice recordings of the lay definitions. Under the guidance of Pauline Davies, a former BBC science broadcaster, now Professor of Practice at the Hugh Downs School of Human Communication at ASU, the students simplified the genetic terms to render them more suitable for the target audience. Once these definitions were approved, the students completed a voice recording of all the terms.

In compiling the Talking Glossary, the students took into account several requirements. Accuracy is of primary importance, since the Talking Glossary of Genomics Terminology aims to be regarded as a trusted source of information. The definitions are intended to be as accessible as possible to the lay population, so unnecessary jargon and complicated language need to be avoided. To ensure comprehensibility, students were asked to write at a level suitable for an American Indian close relative, from a cousin to a grandparent. Relevance to American Indians was maintained by providing extra information of particular significance to American Indian populations, such as the prevalence of lung cancer amongst certain tribes or screenings for certain cancers that are available at Indian Health Service medical centers and clinics. Since the glossary could become an important resource for people wanting information about their personal medical status, when discussing diseases or

hereditary conditions, a brief overview of symptoms and testing options was frequently included. The aim is to give the user enough information to lead to a better understanding of their personal risk and to describe options for testing for treatable conditions. When appropriate, for example in the definition of colon cancer, a more expansive overview of testing options was provided. Such information may allow people to discuss alternative approaches with their health care providers. Finally, the voice recording by the American Indian students had to be clear and friendly, and accurately convey the meaning of the words.

Satisfying the above criteria posed challenges for the students. The process began when the students were each allocated a share of the 165 glossary words. The students researched the meaning and wrote a first draft of a lay definition of each term. Before the recording session, the drafted definitions were checked by researchers for accuracy, comprehensibility, and ease of reading aloud. More obscure entries were, if necessary, carefully re-written, in consultation with appropriate researchers working with SAICN. After recording and editing, the terms were again checked for factual accuracy and ease of understanding.

RESULTS

The completed voice recorded terms are compiled onto a user-friendly and interactive DVD learning tool to provide a customized glossary of scientific based terms related to genomics, genetics and cancer for the American Indian community. In addition, the DVD includes other features that provide information about cancer and related issues. Both written and audio versions of glossary terms are included, accompanied by a link to a visual illustration of the term if appropriate. Auditory commentaries on genomics by American Indian Tribal leaders in Arizona, scientists and medical doctors are now being added to the Glossary. These interviews address different viewpoints about issues, ranging from research, the collection of biological material and genetics, to the impact of cancer and other diseases within American Indian communities. To help conceptualize the terms in application, a genomics workbook is being developed to be included on the ITCA Website. This workbook is focused on family trees and inheritance of disease.

Once the Talking Glossary of Genomic Terminology project is completed, DVD copies will be mailed to the American Indian tribes in the SAICN network and the glossary will also be made available on the ITCA and affiliated SAICN partner websites. The T&E Core members are now working on an evaluation for the Glossary and a Junior Investigator affiliated with SAICN is preparing a workbook to compliment the Glossary.

DISCUSSION

The SAICN is dedicated to reducing cancer health disparities between American Indians and the broader population by providing collaborative education, training and research based on the communities' expressed needs and by encouraging utilization of cancer control interventions by tribal members. The SAICN identified this project as an educational tool that can help reach these objectives.

Prior to the onset of the Genomics Glossary project, members of the SAICN T&E Core spent a significant amount of time discussing potential audiences. At the end of these discussions the decision was made that the glossary would be targeted at students, tribal leaders, and communities members as well as health care providers such as physicians, nurses, case managers, health educators, and Community Health Representatives (CHRs). The rapidly progressing field of genomics

and personalized medicine will also necessitate future changes to keep the information and terminology updated.

Members of the T&E Core, since the inception of the project, planned that the American Indian graduate students who participated in the development of the Glossary would gain direct benefit from this learning experience. Graduate student feedback indicates that involvement in the project was meaningful both personally and academically. Students reported that the project, first of all, provided them with the opportunity to learn from a wide spectrum of health professionals, all of whom are working directly with tribal community members and patients. This was especially significant to those students who previously had minimal experience working with community-based programs. "As a trained scientist and as a student pursuing a PhD, I realize that it is important to maintain contact with the community," one student stated. Another student indicated that she could see how an emerging recognition of the knowledge to be gained by collecting family medical histories could be linked to a better understanding of disease susceptibility as related to genetic factors and lifestyle behaviors.

The effort to reframe the scientific terminology into more general lay descriptions often led the students into discussions with other American Indians, including family members. These informal discussions were learning experiences as they allowed the students to identify perceptions and levels of knowledge about genetics and associated issues held by different individuals. From these discussions, students were able to discern general misunderstandings or fear of genetic research. Concerns were also shared as to ownership of the biological material and data and possible misuse of genetic and family information. One student described a personal conflict in continuing participation in the Genomics Glossary project as a result of such concerns. In the end however the student not only continued with the project but subsequently decided to develop a culturally-appropriate genomics education workbook to compliment the genomics glossary. The development of this added component will also fulfill one of the student's graduate study requirements.

At the conclusion of the recording portion of the project, students were asked to provide information based on their experience working on the Glossary, about how, in their opinion, the Genomics Glossary might best be used. One student commented that the Glossary could be most useful in improving health literacy on genomics and related research. This student particularly valued learning about the impact of cancer in American Indian communities and the high mortality rate as a result of late screening and detection. The student emphasized the importance of promoting better literacy concerning the potential benefits of genomics research, which may in turn lead to more informed decision-making about health and treatment options. This student felt that the Glossary may also encourage more proactive tribal participation in developing policies to address clear tribal concerns surrounding genetic research. Another student stated that the glossary could prove to be valuable for the patients receiving care from the Indian Health Service, the federal health service provider for American Indians. Oftentimes, families faced with a diagnosis want to know as much as possible about the disease and to understand the terminology used by physicians and other medical specialists. This glossary gives the patients and families the opportunity to be better informed about cancer and treatment options.

In addition, students reported that the project provided them with valuable experience in communicating complex ideas in a clear and concise manner to American Indian community members. The writing skills that the students developed in crafting terms will be of use in many different fields of public health communication and bioscience. The recording experience itself enabled the students to practice reading aloud from a carefully prepared script and to maximize meaning and impact, essential elements of good public speaking and broadcasting.

To this project, the students brought and contributed an intimate knowledge of American Indian culture, which will greatly enhance the significance of the Genomics Glossary for the target audience. For instance, when talking about the effect of tobacco on health, deliberate care was taken to distinguish between the effects of commercial tobacco use and ceremonial smoking. The students' awareness of health disparities between the American Indian population and the U.S. general population made it possible to include information of particular relevance to American Indians, such as the significance of breast cancer screening to survival outcome. 'Cancer' is often an unmentionable word to American Indians and coupled with cultural considerations, such as a sense of modesty about their bodies, people may not seek cancer screenings, even when facilities are available. Therefore, specific information was added to the Genomics Glossary to stress the benefits of early cancer detection and screening as part of routine healthcare practice.

The SAICN T&E Core also intended that the project include the voices of tribal leaders to speak on related subjects important to their communities. This addition provides a broader context to the issues of genetics-based and community-based participatory research, cultural values, health access issues and future direction for potential projects. By including the participation of both students and tribal leaders, the project is directly contributing to an increase in the community knowledge of genetics, genomics and advances in biomedical research.

The Talking Glossary project also fulfills an important need identified by American Indian tribes. Initiatives to build knowledge and continuing education are viewed as important steps in establishing collaborative partnerships between American Indian communities and academic/clinical/research institutions (ABRC Report, 2006). Education is valued as a capacity-building tool that may lead to more long-term intervention strategies to improve health outcomes.

This education module was supported on a premise that the emerging areas of genomics and personalized medicine will have significant impacts on the future of medicine, especially in view of the expansive efforts in genomics, bioscience and personalized medicine in Arizona. Benefits may be more widespread if the population has a greater understanding of the basic concepts and terminology (Lanie et al., 2004).

Members of the SAICN and the T&E Core recognize that the language and concepts of genomics and cancer are difficult for any lay person to understand and that a comprehensive understanding of the issues cannot be achieved simply through a phonetic glossary and workbook. However, the SAICN actively supports providing this tool to students and tribal communities as a first step towards encouraging interest and promoting cancer-related scientific and educational literacy. T&E Core members also recognized that scientific research and discoveries are discussed in the local media and newspapers and the specially tailored glossary may be a tool by which people from local tribes can enhance their awareness of these matters. An improved understanding of basic terminology can lead to a desire for a more in-depth knowledge of genetics and genomics among students. SAICN also has other education projects that can work in conjunction with the glossary to provide a more comprehensive approach toward understanding cancer risk and care.

In conclusion, the SAICN views the genomics education module as an innovative tool that can raise interest about genomics and personalized medicine among the American Indian community. This tool is only one step in a much larger and needed strategy to improve health outcomes.

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