



## WHEC UPDATE

Briefings of worldwide activity of Women's Health and Education Center (WHEC)  
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### ***Achieving Global Health***

*Genetic information* includes information about a person's genetic tests; genetic tests of his and her family members (up to and including fourth-degree relatives); any manifestation of a disease or disorder in a family member; and participation of a person or family member in research that includes genetic testing, counseling or education. *Genetic tests* means tests that assess genotypes, mutations or chromosomal changes. Examples of protected tests are *BRCA1 / BRCA2* (breast cancer) or *HNPCC* (colon cancer) mutations.

A wealth of research has shown that the “fear factor” is a major obstacle to patients’ participation in research studies that involve the collection of genetic information. Research at the National Institutes of Health (NIH) has demonstrated that fear of losing health insurance is the top concern expressed by individuals from at-risks who are contemplating genetic testing for a familial disorder, and that a third of these individuals refuse potentially life-saving genetic testing because of this fear. Sadly, even health care providers are not immune to these fears, and a survey of genetic counselors specializing in cancer showed that most (68%) would not bill their insurance companies for genetic testing because of fear of discrimination and that 26% would use an alias when being tested. The specter of misuse of genetic information has long been a dark cloud over the field of personalized medicine. Even before the human genome was sequenced and there were relatively few genetic tests available to the public, many policymakers and health professionals were concerned that the lack of protection for genetic information would discourage patient participation in genomic research, and ultimately prevent meaningful application of genomic medicine to public health.

The first piece of federal legislation addressing misuse of genetic information was introduced in 1995, but few would have predicted that this forward-thinking remedy would take more than 13 years to be realized – longer than it took for the entire human genome to be mapped. The slow, frustrating slog through the legislative process was not for lack of trying on the part of advocacy groups, health policy experts and genetics researchers. On the contrary, many individuals believed that reform was needed and made the case for federal protection of genetic information as a crucial part of advancing the science of genetics. Still, employers and health insurers waged a tough campaign against the legislation they viewed as cumbersome and potentially opening the proverbial “floodgates of litigation”. The opposition was so staunch and well connected, that while several versions of the Genetic Information Nondiscrimination Act (GINA) passed the Senate unanimously, not one ever got a vote in the House, and multiple bills died in committee between 1995 and 2006. The tide ultimately turned in GINA’s favor, when President Bush signed GINA of 2008 into law. The health insurance regulation took effect in May 2009 and the employment regulations took effect on November 21, 2009.

GINA is the first major new civil rights bill of the new century. Discrimination in health insurance and the fear of potential discrimination threaten both society’s ability to use new genetic technologies to improve human health and ability to conduct the very research we need to understand, treat and prevent genetic disease. There were dramatic changes in the field of genomic changes in the field of genomic medicine during the 13 years it took for GINA to become law. The number of genetic tests has skyrocketed to encompass more than 1,500 conditions, fueled by rapid expansion in the era of common diseases. With many of these tests becoming available in clinic and some even being offered directly to consumers over the Internet, the public’s concern about genetic discrimination increased, and GINA’s protections became essential for personalized medicine to become a reality.

Keeping Pace with the Times

**Rita Luthra, MD**

## Your Questions, Our Reply

What are the scope and limitations of The Genetic Information Nondiscrimination Act (GINA) of 2008?

**Scope and Limitations of GINA:** It is essential for health care providers and researchers to understand both the scope and the limitations of GINA to provide accurate information to patients. The following summary explains what GINA does and does not do, and provides details on some of the key definitions within the bill.

What GINA does?

- Prohibits group and individual health insurers from using a person's genetic information in determining eligibility or premiums (including their family history);
- Prohibits an insurer from requesting or requiring that a person undergo a genetic test;
- Prohibits employers from using a person's genetic information in making employment decisions such as hiring, firing, job assignments or any other terms of employment;
- Prohibits employers from requesting, requiring or purchasing genetic information about a person or their family members.

What GINA does NOT do?

- Does not prevent health providers from recommending genetic tests to their patients;
- Does not mandate coverage for any particular test or treatment;
- Does not prohibit medical underwriting based on current health status;
- Does not cover life, disability or long-term care insurance;
- Does not apply to members of the military.

Nothing in GINA limits the ability of health care professionals to decide whether to recommend genetic testing to patients under their care. Insurers are permitted to require evidence of genetic tests for coverage determinations; they can require evidence of *BRCA* status before covering prophylactic mastectomy, but they cannot use the information for eligibility, rating or setting premiums.

## United Nations At A Glance

### Australian Permanent Mission to the UN

Australia has a demonstrated commitment to the UN spanning more than 65 years. As a founding member, we fought for the inclusion of the economic, social and development provisions of the UN Charter, and for all states – no matter their size – to be treated equally. We stand by these principles today.



Australia is an active participant in UN institutions and the 12th largest contributor to the UN regular and peacekeeping budgets. We have contributed 65,000 personnel to more than 50 UN and other multilateral peace and security operations worldwide, including in Timor-Leste, Solomon Islands, Lebanon, Sudan, Cyprus, Korea, Somalia, and Rwanda.

Australia is deeply committed to accelerating progress towards achievement of the [MDGs](#) and the ongoing discussions on the post-2015 agenda.

The Australian Mission to the United Nations in New York is one of four posts representing Australia's interests in the United Nations system. The other posts are in Geneva, Vienna and Nairobi.

The Mission serves as the nucleus of the Australian delegation to the regular sessions of the General Assembly and represents Australia at a range of UN meetings that take place when the Assembly is not in session.

Australia is firmly committed to the United Nations. Engaging with the multilateral system, including through the UN, is a key pillar of Australia's foreign policy. This is because we live in a complex, interconnected world where countries cannot address on their own some of the major challenges we face today. Australia is determined to work through the UN to enhance security, improve economic and social well-being, and strengthen environmental protection, worldwide.

The Mission is led by the Permanent Representative, [Gary Quinlan](#), and the Deputy Permanent Representative, [Philippa King](#).

Details: <http://australia-unsc.gov.au/australian-permanent-mission-to-the-united-nations/>

## Collaboration with World Health Organization (WHO)

### WHO | Australia

In 2010, Australia had a population of 22 342 398: 11 124 254 males and 11 218 144 females. Most of the population is concentrated along the eastern seaboard and the south-eastern corner of the continent. It is one of the world's most urbanized countries, with around 89% of Australians living in urban areas. Australia's population density of 2.9 people per square kilometer varies greatly across the country, being very low in remote areas and very high in inner-city areas.



Australia's population grew by 1.7% between June 2009 and June 2010, with 57% of that increase due to net overseas migration and 43% due to natural increase (302 200 births and 140 600 deaths). Between 1961 and 2001, Australia's total fertility rate declined from 3.6 babies per woman to 1.7. The fertility rate for Australian women in 2009 was 1.9 babies per woman. Australia's population is ageing, with the number of people aged 65 years or more projected to increase from 3 million in 2010 to 8.1 million in 2050; an increase from 13.5% to 22.7% of the total population.

Life expectancy at birth is 81.6 years (79.3 for men and 83.9 for women), one of the highest in the world. Gains in Australia have been primarily due to reduced child and maternal mortality in the early decades of the last century, and improved longevity for other ages, particularly for older people with chronic diseases.

Details: <http://www.who.int/countries/aus/en/>

## WHO Reproductive Health Update

### Global causes of maternal death



A new WHO study, published today in *The Lancet Global Health*, adds new knowledge about the global causes of maternal death. A WHO systematic analysis, finds that more than 1 in 4 maternal deaths are caused by medical conditions such as diabetes, HIV, malaria and obesity, which can all be aggravated by pregnancy. This is similar to the proportion of deaths during pregnancy and childbirth from severe bleeding—previously cited as the main cause of maternal deaths.

[Lancet article](#) | [More on maternal and perinatal health](#)

**Bulletin of the World Health Organization; Complete list of [contents](#) for Volume 92, Number 6, June, 385-464**

**Collaboration with UN University (UNU)**

UNU-WIDER (World Institute for Development Economics Research) *Expert Series on Health Economics:*

**Asylum-seekers as Pariahs in the Australian State - Security Against the Few**

During the last decade measures of overt and covert surveillance, information sharing and deterrence of the illegal movement of people has increased within and between states. Border security has come to dominate international relations, and increasingly to deflect the needs of asylum-seekers who search for a state that will offer them substantive protection under the Refugee Convention. Measures of internal and external deterrence diminish the reality of protection to genuine refugees as some of the most vulnerable individuals in the world today. Australia, as a country of relative geographic isolation, has not experienced the large-scale influxes of asylum-seekers seen in many parts of the world. Notwithstanding this, the Australian Government has in recent years implemented harsh policy and administrative measures directed at asylum-seekers with a substantial measure of public support.

In August 2001, an incident involving 433 asylum-seekers was branded in popular discourse an 'asylum crisis'. This incident involved a Norwegian freighter, the Tampa, which picked up survivors from a sinking boat who were making their way to Australian waters in order seek protection under the Refugee Convention. The Tampa was repelled by Australian security forces from disembarking the people they had picked up in distress on Australian soil. In this article, I explore the Tampa incident against the backdrop of refugee policy development from 1999. I argue that rather than responding to a crisis, the Australian government has generated the perception of a crisis in the Australian community. Implications of the Australian response to asylum-seekers are significant not only in the Asia/Pacific region, but further afield, as policy responses toward asylum-seekers by receiving states have converged in the recent past.

Concerns over security are by no means new phenomenon in the logic which drives state responses to those seeking protection. However, heavy-handed responses to asylum-seekers, or to those who have been 'ethnically profiled' as a terrorist risk, engender a degree of unease alongside the moral conviction of those who argue for a sanctity of territorial borders to the entry of people, while encouraging deregulation in global trade and the movement of money.

The continuation of a system which extends political, social and economic rights only to members of a particular territory, is a system which can be maintained only through increasingly defensive measures, including communicative modes which constantly reinforce a fear of strangers. As this article has argued through an analysis of the developments in the Australian case, Western states face a dilemma in relation to how best to respond to 'irregular' immigrants: setting in place legal and administrative measures to restrict the entry and the duration of stay of such arrivals, while at the same time being seen to be maintaining a 'fair' and open system in relation to obligations at the national and international level. Certainly, Australia may not prove to be the yardstick for how Western states respond to those who arrive without authorization and subsequently seek protection. However, the response of a state such as Australia which has benefited from earlier waves of immigration and which until recent years, was regularly invoked as a model of successful multicultural integration of newcomers, cannot be overlooked. Moreover, the treatment of asylum-seekers cannot easily be distanced from the treatment from other marginalized and voiceless groups.

Publisher: UNU-WIDER; Author: Claudia Tazreiter; Sponsors: UNU/WIDER gratefully acknowledges the financial contributions to its 2002-2003 research programme by the governments of Denmark, Finland, Norway and Sweden.

(*Details of the paper can be accessed from the link of UNU-WIDER on CME Page*  
<http://www.womenshealthsection.com/content/cme/>)

## **United Nations Girls' Education Initiative (UNGEI)**

*The Effort to Advance the Global Strategy (Continued)*

### SCHOOL-RELATED GENDER-BASED VIOLENCE IN THE ASIA-PACIFIC REGION

The purpose of this review is to examine existing approaches in policy, programming and implementation responses to school-related gender-based violence (SRGBV) in the Asia-Pacific region. It seeks to advance our knowledge and learning in this field, both in terms of what we know about the phenomenon and its impact on individuals, as well as how best to address it, including through education. In many parts of the world, gender-based violence is tolerated and sustained by social institutions, including the school – the very place where children are expected to be safe, protected and empowered.

UNESCO's Asia-Pacific Regional Bureau for Education and the East Asia Pacific Regional UN Girls' Education Initiative partnered to review the evidence on the nature, manifestations, scale and consequences of school-related gender-based violence, and policy, programming and implementation approaches in the Asia-Pacific region. It seeks to advance our knowledge and learning in this field, both in terms of what we know about the phenomenon and its impact on individuals, as well as how best to address it, including through education.

Gender-based violence (GBV) is a fundamental violation of human rights. It is one of the worst manifestations of gender-based discrimination, disproportionately affecting girls and women. GBV is a global phenomenon that knows no geographical, cultural, social, economic, ethnic, or other boundaries. It occurs across all societies, and is a major obstacle to the achievement of gender equality.

Governments have signed onto international frameworks to protect children from all forms of violence. Despite these frameworks, recent reviews and initiatives have highlighted the extent to which children are exposed to school-related gender-based violence (SRGBV) and the significance of education to prevent and eliminate this form of violence.

In the region, GBV is often tolerated and sustained by social institutions, including the school – the very place where children are expected to be safe, protected and empowered. SRGBV remains not fully examined in the region, and is perhaps even overlooked in many educational environments.

SRGBV continues to affect children in the Asia-Pacific region each year, and boys, girls, transgender and intersex children can be targets. In Asia and the Pacific – as elsewhere – SRGBV is a critical barrier to the right to education, not only because of its serious physical and psychological health implications, but also because it may lead to the deterioration of the learning environment as a whole. The experience or even the threat of SRGBV often results in irregular attendance, dropout, truancy, poor school performance, and low self-esteem, which may follow into their adult lives. Importantly, SRGBV is often aggravated in conflict-affected countries and during emergencies. Witnessing or experiencing violence in schools may have irreversible consequences for students in perpetrating or further experiencing violence in adult lives.

Teachers, schools and education systems are fundamental in transforming practices, attitudes and values, including instilling in learners the understanding and practice of gender equality, non-violent behavior and acceptance of difference. To do so, though, and to fulfil children's right to education, learners need safe and supportive environments.

Details: [http://www.ungei.org/files/SRGBV\\_EAP.pdf](http://www.ungei.org/files/SRGBV_EAP.pdf)

*To be Continued.....*

## Top Two-Articles Accessed in May 2014

1. Stillbirth: Evaluation and Management;

<http://www.womenshealthsection.com/content/obs/obs032.php3>

WHEC Publications. Gratitude is expressed to [Dr. Robert M. Silver](#), Professor of Obstetrics and Gynecology, Chief, Division of Maternal-Fetal Medicine, University of Utah Health Sciences Center, Salt Lake City, UT (USA) for contributions and helpful suggestions in preparing the manuscript. Special thanks to the Board of Directors for providing the funding for research and development.

2. The Ethical Concept of the Fetus as a Patient;

<http://www.womenshealthsection.com/content/obs/obs019.php3>

Authors: [Frank A. Chervenak, M.D.](#); Given Foundation Professor and Chairman; Department of Obstetrics and Gynecology; Weill Medical College of Cornell University, New York, New York (USA) and [Laurence B. McCullough, Ph.D.](#); Professor of Medicine and Medical Ethics, Associate Director for Education; Center for Medical Ethics and Health Policy; Baylor College of Medicine, Houston, Texas (USA)

## From Editor's Desk

### Human Genetics Programme

The World Health Organization (WHO) advocates enjoyment of the highest attainable standard of health as one of the fundamental rights of every human being. To this end, WHO is concerned with providing international expertise and technical advice to countries in their efforts to initiate and manage national programmes of major health importance.

As early as 1963 an Expert Committee of WHO observed the importance of genetics in health considerations: "genetic considerations add a new dimension to public health work: a concern not only for the health and well-being of persons now living, but also for... generations yet to come".



WHO's Human Genetics programme aims to provide information and raises awareness within health sector, government and the public on the health challenges and opportunities within the new and rapidly developing science of human genetics.

This website overviews the issues and concerns around human genetics and public health, and, in particular, addresses the ethical, legal and social implications (ELSI) of genetics

### About Human Genetics programme (HGN)

The **goal** of the Human Genetics programme (HGN) is to encourage the optimal utilization of genetics and genomics to contribute to WHO's goal of achieving the best attainable health for all people. In catering for the needs of major stakeholders; namely, the general public, patients, health care professionals, and policy makers, the HGN aims to:

- Build public understanding of the science of human genetics and genomics, related technologies and health services; and their ethical legal and social implications (ELSI).

- Provide up-to-date information on the role of genetic research, genomic technologies and services in the prevention, treatment and management of human disease.
- Provide the necessary tools to health care professionals and policy makers, enabling better genetic service management and delivery.
- Enhance the transfer of genomics information and foster informed dialogue, collaboration and assistance among health services and research institutions, patients and support groups.
- Improve genetic health services by facilitating transfer of knowledge especially between the high- & low to middle-income countries.
- Promote community education and build capacity in low- & middle-income countries.
- Improve gender and diversity mainstreaming in genetic service delivery and ELSI analysis.

The **design and content** of the HGN are especially sensitive to the informational needs and technological capabilities of low- & middle- income countries. The HGN is instrumental in understanding the work of the Human Genetics Programme, its contribution towards the prevention and control of chronic disease, and promote health through effective partnerships, especially in low- & middle-income countries.

### **Know more about the HGN**

- [About WHO's Human Genetics](#)
- [WHO definition of genetics and genomics](#)
- [Genomics and the global health divide](#)

### **Words of Wisdom**

Life must be understood backwards. But it must be lived forwards.

– Søren Kierkegaard; Danish philosopher (1813-1855)

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*Monthly newsletter of WHEC designed to keep you informed on  
the latest UN and NGO activities*

<http://www.womenshealthsection.com/>

