Ethical issues in genetics and public health in Latin America with a focus on Argentina

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Abstract This paper reviews the health situation and developments in medical genetics and bioethics in Latin America, with a focus on Argentina. The region is the most inequitable in the world, with an average Gini Index of 52.5 and 25 % of the population living in poverty. Health expenditures are low and health systems are fragmented and privatised, with curtailed governmental responsibility and regulation. Health-care decision making is mostly in the hands of private insurance corporations and the medical-industrial complex, so that what is (or is not) covered by health plans is arbitrary and determined by the market and not by population health needs. This inequity and the lack of meaningful governmental intervention in the provision of health care, including genetic services, are at the heart of the bioethical dilemmas in Latin America. It is not surprising, therefore, that bioethics in the region has developed an approach grounded in social justice, equity and human rights as guiding principles, in contrast to the individualism espoused by Anglo-Saxon bioethics. The main ethical issues identified in genetics in Latin America are (1) inequity in access to genetic services, particularly in prenatal diagnosis, (2) genetic discrimination and (3) the lack of adherence to internationally accepted requisites of clinical validity and utility for diagnostic and predictive genetic testing. In this context, there is a risk that the impressive advances in genetics/genomics occurring in developed countries may fail to improve the public's health and deepen inequity, with the implementation of expensive genetic technologies of unproven validity.

Keywords Bioethics and genetics · Public health · Genetic services · Equity · Latin America · Argentina

Latin America: background

What is now Latin America was originally inhabited by millions of native Amerindians, 90 % of whom were decimated by centuries of war, oppression, inhumane forced labour conditions and disease associated with the process of conquest and colonisation, which began in the 16th century. Conquistadors came primarily from Spain and Portugal, with a smaller participation from the French, British and Dutch. The slave trade burgeoned in the 17th and 18th centuries, bringing to this region millions of Africans, especially in Brazil and the Caribbean. The current population of Latin America numbers about 625 million people, with different degrees of admixture of the original indigenous population with the Spanish and Portuguese colonialists and African slaves and then extensive immigration from Europe and, to a lesser degree, from Asia in the 19th and 20th centuries. Common cultural and historical features that characterise modern Latin Americans include common roots, similar (Spanish and Portuguese) languages, common revolutionary wars against colonial powers and, more recently, a growing political and commercial integration. Amerindians are about 10 % of the population, in varying proportions in different sub-regions and countries.

Most Latin American countries have medium-low gross national incomes, with a regional average of US \$5000 per capita (World Bank 2014). Industrialisation and urbanisation are occurring at a fast pace, albeit with marked disparities among and within countries. Socioeconomic inequalities are high and persistent, with some of the highest country Gini indices (a measure of income inequality) in the world (Monteiro de Andrade et al. 2014). In 2004, the average

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income Gini index was 52.5, i.e. 8 points higher than in Asia, 18 points higher than in Eastern Europe and Central Asia and 20 points higher than in high-income countries (Gasparini and Lustig 2011). Close to half of the Latin American population lives in poverty and 27.6 % earns less than \$2 per day (World Bank 2014). In Argentina and Brazil, the 2012 income ratios of the superior 10 % over the inferior 10 % were 11.3 and 20.6, respectively. In these two countries, the income of the highest and the lower 10 % were, respectively, 31.8 % and 1.5 % in Argentina and 41.7 % and 1.0 % in Brazil (PAHO 2014).

Regional average birth rate is 17.6 per 1000 (11 million births per year) and fertility rate (number of children per woman) is 2.1. Average life expectancy is 75 years and infant mortality rate is 15.7 per 1000; mortality <5 years of age is 19.4 per thousand and maternal mortality reaches 85 per 100,000, with wide variations according to country, income and social class (PAHO 2014). Due to epidemiological transition, congenital anomalies rank high among the causes of infant mortality, while the main burden of disease is from non-communicable diseases with a genetic contribution, particularly cardiovascular disease, cancer, hypertension, diabetes and mental illness, as well as traffic accidents, violence and increasing illicit drug use (PAHO 2012). Prevalence of genetic diseases and congenital defects in Latin America is similar to other regions of the world, with haemoglobinopathies posing a significant public health burden in countries with a high proportion of African ancestry (such as Brazil and the Caribbean) (Penchaszadeh 2004).

In summary, the high degree of socioeconomic inequalities leads to wide differences in both health indices and access to health services among socioeconomic groups (PAHO 2014).

Health care in Latin America

Most Latin American countries organised their health services in the mid-20th century, under the responsibility of the state, with three main coexisting health subsystems. (1) The public system, run directly by the state and funded from general revenues, comprises national, provincial and municipal networks of health-care services (at primary, secondary and tertiary levels), with largely free access (albeit a number of deficiencies that require out-of-pocket expenses by patients). Although in theory, any citizen can access this; in practice, it covers only 50–60 % of the population. (2) The social security system, funded by employer-employee contributions, provides health services to personnel and retirees, either directly or through contracts with the private or the public sector, covering about 35 % of the population. (3) The private sector, in turn, caters to the 10 % of the population with the highest income and is based on private-for-profit insurance. While there are non-governmental not-for-profit health-care providers, their share in health care is minimal. The average

annual health expenditure per capita, in 2010, was only US \$262 (PAHO 2012), with wide variations by social class and marked inequities in distribution, favouring high technology medicine in tertiary centres, rather than primary care-centred health services. The number of hospital beds in the region is 2.0 per 1000 inhabitants, with a very unequal distribution.

Latin America has a sizeable workforce of skilled, well-trained physicians (17.2 per 10,000), while nurses are in short supply (13.8 per 10,000) (PAHO 2014). The distribution of health professionals, however, is very unequal among and within countries, privileging larger cities and high-income population groups, to the detriment of rural areas and the poor.

Clinical genetics in Latin America

Medical genetics services have had a fragmentary and uneven development in Latin America, being mostly concentrated in wealthy, urban areas. The number of clinical geneticists is close to one per million (Penchaszadeh 2004), and virtually all countries have a national professional society of human or medical genetics. Most clinical geneticists work part-time in the public sector and run private practices as well, similarly to other specialties. The specialty has been recognised in several countries. Genetic counselling is largely performed by clinical geneticists since training programmes in genetic counselling for non-physicians are only beginning in some countries and very scarce. The only country that developed genetic counselling as a separate field is Cuba, albeit through a 6-month training programme actually targeting general physicians (Penchaszadeh 2004; Lantigua-Cruz 2013).

The public sector is the largest provider of genetic services in the region, but under-financing, poor planning and coordination and deficient regulations and quality assurance have hindered their quality and their responsiveness to population needs. The social security system is in general better resourced than the public sector but serves only former or current employees that contributed taxes and with many conditions not covered, while the private sector cares for about 10 % of the population and its main goal is profit. Quality of care is very variable in the three sectors. Departments of health in the public sector at the city, provincial and national levels have not risen to the challenge of formulating and implementing policies and programmes in genetic services, except for newborn screening, which is mandated by national law (Penchaszadeh 2004), and has better coverage than other programmes. Notable exceptions are Cuba and Brazil, which have national health-care systems with genetic services as an integral component (Lantigua-Cruz 2013; Marques-de-Faria et al. 2004).

Abortion in Latin America

Access to family planning services and contraception in Latin America is limited and induced abortion is largely illegal, in

almost all countries of the region, with exceptions allowed to save the life or health of the mother or in case of rape, but not for reasons of foetal health. Illegality, however, has not prevented abortion, which is practised extensively, mostly in an unsafe manner, leading to complications that account for one third of the maternal mortality rate. Recently, national or local legislation in some countries (Argentina, Brazil and Colombia) has begun to allow pregnancy termination for anencephaly. A few jurisdictions have enacted legislation that allow elective abortion (without consideration of reason), such as Mexico City in 2007 and Uruguay in 2012 (Center for Reproductive Rights 2014).

Several considerations are of note regarding the ethics of abortion in Latin America. Firstly, it is practised extensively, certainly in the millions annually. Secondly, the socioeconomic gap in access to safe abortion is huge, with the immense majority of victims of the legal restrictions and unsafe abortion being poor women. Thirdly, the criminalisation of abortion has led to the lack of prenatal genetic diagnostic services in the public health system, whereas this is easily accessible in the private sector to those who can pay or have private insurance (5–10 % of the population). The case of Cuba is unique, as induced abortion has been legal since the triumph of the revolution in 1959 (Penchaszadeh 2004).

Argentina: an overview

Argentina is situated in the southern tip of South America, with a surface of 2,791,810 km² and a length of 3694 km from north to south, bordering to the west with Chile and to the north and northeast with Bolivia, Paraguay, Brazil and Uruguay. To the east, Argentina faces the Atlantic ocean, with a 4725-km long coast. The estimated total population is 40 million, 90 % of whom live in urban areas.

In the 16th century, the territory of today's Argentina was inhabited by hundreds of thousands of Amerindians of at least 30 different ethnicities. In spite of decimation, genocide and admixture during the following three centuries, a native population of about 400,000 (1 % of the population) remain in the region, concentrated in the northwest, northeast and the south of the country, and living in very precarious conditions. West Africans brought as slaves numbered in the tens of thousands, at the beginning of the 19th century, but they virtually disappeared in the second half of the century, probably through admixture and migration to neighbouring countries. In the second half of the 19th and first half of the 20th century, Argentina received a large influx of immigrants from virtually all countries of Europe, including large contingents of European Jews and, to a lesser extent, Middle Eastern peoples. In more recent times, immigration has come primarily from neighbouring countries (Paraguay and Bolivia) with strong Amerindian ancestry. Finally, immigration from South Korea

and China has been the latest wave in the 1980s. It is estimated that about 50 % of the population descend from Italian immigrants and 25–30 % from Spaniards. In the 1960s, Jews numbered close to half a million people, comprising the third largest concentration in the world (after Israel and the USA).

Reproductive patterns among Argentines have been largely open, with a resulting extensive admixture. In Buenos Aires, the relative European, Amerindian and West African genetic contribution to the gene pool has been estimated in 67.5, 25.9 and 6.5 %, respectively (Martínez-Marignac et al. 2004). Average consanguinity is less than 0.5 %, except for some remote, isolated areas. The official language is Spanish and the majority of the population is (nominally) of the Catholic faith.

Argentina: political, social and economical characteristics

Argentina is a federal republic with a presidential system, where each province has its own constitution and elects its governing officials. In the 20th century, Argentina declined from being the 8th world economy and passed through recurrent political and economic crises. These included a succession of military dictatorships, the last of which engaged in the most brutal repression the country had ever seen: between 1976 and 1983, 30,000 persons were 'disappeared' by the military, while their small children were appropriated by people with links to the military (CONADEP 1984; Penchaszadeh 1997, 2011), and hundreds of thousands fled the country to escape repression.

During the dictatorship, the country incurred a huge foreign debt, much of the national industry was dismantled, and most strategic state enterprises and public services, including health services, were privatised. Shortly after the restoration of democracy at the end of 1983, the top generals that ran the country were brought to trial and convicted of crimes against humanity. Civilian governments, however, did not reverse the wave of privatisations and the concentration of the economy in few hands, resulting eventually in huge unemployment and poverty and an economic meltdown in 2001, with a 300 % depreciation of the currency and a default on repayment of the foreign debt. The economic crisis was eventually brought under control by 2004, although poverty and socioeconomic inequality persisted: in 2003, the poorest 10 % had an average monthly income, per person, of US \$16, compared with US \$590 among the wealthiest 10 %. Furthermore, the poorest quintile's share of national income decreased from 4.8 to 3.1 %, between 1992 and 2005, while that of the wealthiest quintile increased from 50.6 to 54.7 % (Gasparini and Lustig 2011).

Argentina: health conditions and services

Morbidity and mortality figures are similar to higher-income countries, with the burden of disease being contributed largely by non-communicable diseases (such as cancer, cardiovascular disease, diabetes, road accidents, violence and mental

illness), although diseases of poverty (infections and malnutrition) are still a major problem, particularly among the disadvantaged (PAHO 2012). Maternal mortality is unacceptably high (62 per 100,000), with 31 % of this resulting from complications of unsafe, illegal abortion. Infant mortality is 11.1 per 1000, and its main causes are perinatal conditions (52 %) and congenital anomalies (27 %) (PAHO 2012). Genetic and congenital disorders have a prevalence similar to that in developed countries (Penchaszadeh and Beiguelman 1998), with variations due to founder effects and consanguineous isolates, including clusters of rare single-gene disorders, such as Sandhoff disease (Dodelson de Kremer et al. 1987) and oculocutaneous albinism (Castilla and Adams 1996).

The modern health system of Argentina dates from 1945–1955, a period of economic bonanza, characterised by industrialisation, rapid urbanisation and active unionism. The national Ministry of Health is responsible for the development of general objectives, policies and regulations, executing national programmes (such as vaccinations, campaigns against tobacco, cancer, obesity and diabetes), overseeing the general operation of health services and negotiating the coverage and fees of health insurance plans, all in coordination with provincial health authorities; however, its leverage to influence decisions at the provincial level is weak, leading to a wide variation in health coverage and quality of care between provinces.

Annual total expenditure in health is approximately 8.5 % of GNP, about US \$450 per capita (Penchaszadeh and Rovere 2010; PAHO 2012). As in most Latin American countries, health-care delivery is fragmented in three sectors: (1) the public system maintains public hospitals and ambulatory health centres throughout the country, with free health care, spending 22 % of total health expenditure to serve 48 % of the population, mostly the poor and those without insurance. (2) The social security system spends 29 % of total health expenditure to serve 47 % of the population, largely blue-collar workers, employees and retired workers, contracting mostly with the private sector. (3) The private sector accounts for 49 % of total health expenditure and serves 7.5 % of the population (upper-middle classes).

While the Argentine health system has good human and structural resources, it suffers from significant fragmentation and inefficiency and inequity in allocation of resources, access to services and quality of care (Penchaszadeh and Rovere 2010; PAHO 2012).

Argentina: genetic services and care of congenital anomalies

Clinical genetic services developed in Argentina in the late 1960s, in a small number of public hospitals, led by a few clinical geneticists trained abroad. In 1970, the Ministry of Health created a National Centre of Medical Genetics, which conducts epidemiological research on genetic conditions and trains medical geneticists. In the mid-70s, most of the few

existing medical geneticists left the country, because of the military dictatorship. Currently, about 100 clinical geneticists are certified by the Argentine Society of Genetics and are recognised by the Ministry of Health and staff about 40 clinical genetics units in major cities throughout the country, mainly in paediatric and maternity public hospitals, providing genetic diagnosis and genetic counselling, mostly for single gene disorders and congenital defects. While about 20 % of paediatric patients in tertiary care centres present with a monogenic disorder or chromosomal anomaly, understaffing and long waiting lists explain why many patients remain undiagnosed (Liascovich et al. 2006; Penchaszadeh 2013).

Cytogenetic laboratories perform standard chromosome analysis in some major hospitals; few use molecular cytogenetics. DNA testing for diagnostic purposes is provided in a few public hospitals and academic centres, for cystic fibrosis, fragile X, congenital adrenal hyperplasia, muscular dystrophy, beta-thalassemia, haemophilia, breast cancer (BRCA1 and BRCA2), thyroid cancer, MEN1 and 2, familial adenomatous polyposis, Huntington disease and spinocerebellar ataxias. Testing for other conditions is usually sent to labs abroad. Predictive genetic testing is performed in very few instances (Penchaszadeh 2013).

Public hospital-based genetic services have little connection with primary and secondary level health services. Indeed, there are no easy referral channels from primary and secondary level health facilities to specialised centres, leading to deficiencies in diagnostic and remedial capability of the system as a whole. Thus, many patients are not diagnosed nor are they properly cared for and followed, and their families are not counselled appropriately.

In order to address part of this problem, the Ministry of Health has implemented a special programme for surgical repair of congenital heart defects, neural tube defects and cleft lip/palate. This programme has been in operation since 2008 and includes better detection at birth and prompt referral to specialised centres. Between 2010 and 2013, over 6000 patients have had surgery for one of those defects in 17 medical centres (Ministerio de Salud 2014a). Furthermore, there have been recent initiatives to improve staffing in, and networking among, the clinical genetic units (Bidondo et al. 2014). In addition, training of primary care professionals in basic clinical genetics is being improved in different provinces, under the aegis of the Ministry of Health and the Argentine Society of Paediatrics (Barreiro et al. 2013). It is expected that these initiatives will improve the reach of medical genetics and provide better services to the groups that have been underserved.

Prenatal genetic diagnosis is virtually non-existent within the public health system, except for prenatal ultrasound to rule out foetal anomalies. Although induced abortion is largely illegal, it is estimated that 600,000 voluntary abortions occur annually in the country (Mario and Pantelides 2007), which is close to the number of annual live-born deliveries (750,000).

Newborn screening

Newborn screening has been mandated by law for phenylketonuria (PKU), congenital hypothyroidism (CH) and cystic fibrosis (CF) since the 1990s. In 2007, a new law extended it, in the whole country, for galactosemia, congenital adrenal hyperplasia, biotinidase deficiency, retinopathy of prematurity, congenital deafness, Chagas disease and syphilis (Penchaszadeh 2013; Ministerio de Salud 2014b). The law states that the public sector and social security insurance must cover the expenses of screening and treatment for these disorders; however, only 22 of 28 provinces test for PKU and CH. Of those 22, 40 % are also screening for CF and 10 % for galactosemia. Average population coverage is estimated at 60 % and is related to resources, political will and the degree of development and organisation of health services, with the wealthiest cities and provinces and the private sector having better coverage and follow-up than poorer areas and the public system. The tests are performed in various laboratories, either in public hospitals or outsourced to the private sector. While there is neither a national system of laboratories for newborn screening nor a unified quality control system, the Laboratorio de Errores Congénitos del Metabolismo of the Fundación Bioquímica Argentina, based in La Plata, runs a quality control programme with which many provincial programmes, as well as some from other Latin American countries, are affiliated (Fundación Bioquímica Argentina 2014; SLEIMPN 2014). There are no data on follow-up or long-term management of affected infants (Penchaszadeh 2013).

Surveillance of congenital anomalies

The Estudio Colaborativo Latinoamericano de Malformaciones Congénitas (ECLAMC), a voluntary study of congenital malformations in newborns, started in Argentina in 1969 and later expanded to most South American countries. ECLAMC is still operating after 45 years, with millions of births analysed and is the major source for the prevalence at birth of congenital defects, as well as the source of hundreds of research publications (Castilla and Orioli 2004; Campaña et al. 2010). In 2009, the Ministry of Health began a hospital-based National Registry of Congenital Anomalies in livebirths and stillbirths over 500 g, which currently includes 141 maternity hospitals throughout the country, with a total of 280,000 births per year (38 % of the country) (Groisman et al. 2013; Bidondo et al. 2014; RENAC 2013).

Forensic genetics

Fueled by the need to identify hundreds of remains found in mass graves of possible disappeared persons during the military dictatorship of 1976–1983 and to solve conflicts of identity of several hundred children of the disappeared, who were

abducted and appropriated illegally by the military during the dictatorship of 1976–1983, forensic genetics applied to solve cases of human rights violations has had a speedy development in Argentina after the restoration of democracy in 1984, under the auspices of the government (EAAF 2014; Penchaszadeh 2015).

Prevention of congenital and genetic conditions

Screening of carriers of recessive conditions with high prevalence is not an established policy. While beta-thalassemia is relatively prevalent in the country because of Italian descent (Feliu-Torres et al. 2002), there are no systematic carrier detection programmes. Similarly, and in spite of the sizeable Ashkenazi Jewish community in Argentina, carrier testing for genetic diseases common in this group is not part of medical practice. One reason may be the lack of legal reproductive options for carrier couples.

Folic acid fortification (2.2 mg/kg of wheat flour and derivatives) is mandatory by law since 2002, and evidence already indicates a significant reduction of prevalence at birth of neural tube defects (Lopez-Camelo et al. 2010). Rubella immunisation is mandatory and the congenital rubella syndrome was eradicated many years ago.

Bioethics in Argentina

Bioethics developed as a discipline in Latin America, from the 1990s. The ideological underpinnings of bioethics are complex as there are different orientations according to institutional, political and religious origins and persuasions (Casado and Luna 2012). A strong bioethics school of thought in the region has been secular, politically progressive and based in human rights and social justice. This eventually led to the creation of the Latin American and Caribbean Network of Bioethics in 2003, an autonomous academic organisation sponsored by UNESCO, that has active members in most countries of the region (Redbioética 2014). While acknowledging the relevance of ethical dilemmas that gave birth to bioethics in industrialised countries (such as conflicts in the exercise of personal autonomy in the face of the power of new technologies), this line of thought maintains that the most relevant issues confronting bioethics in Latin America are the disempowerment and poverty of large segments of the population, their poor access to health services, the exploitation to which poor patients are subjected in clinical trials by the pharmaceutical industry, the discrimination against persons with disabilities and genetic conditions in health plans and the lack of access to safe abortion (Garrafa et al. 2005; Casado and Luna 2012).

Bioethics with a human rights approach, espoused by UNESCO in its Universal Declaration of 2005 (UNESCO, 2005), has been the basis for the academic work of Latin

American bioethicists distancing themselves from more conservative schools of thought, influenced either by Anglo-Saxon principlist bioethics or by the Catholic Church. The result has been a fertile ground for debate and controversy (Tealdi 2008).

In Argentina, in the past decade, the state has taken multiple initiatives with progressive legislation addressing bioethical issues (Ministerio de Salud 2014c). These established a number of patients' rights, including the right to proper medical care with dignity, autonomy, privacy, confidentiality, informed consent and the access of patients to their medical records (National Law 26529); the right to decline treatment, including that which would be lifesaving, without having to give a reason (National Law 26742); privacy of medical information (National Law 25326); the right not to suffer discrimination because of genetic conditions and the right of patients with rare diseases or with mental illness to access health care (National Law 26689; National Law 26657).

Bioethics and genetics

The following are some of the ethical issues in research, prevention, diagnosis and care of genetic conditions in Argentina that are currently being debated in various forums (Penchaszadeh 2012):

- (a) Inequity of access: This is a persistent and deep-rooted issue which will require a comprehensive reform of health care that puts the needs of the people above the economic interests of the medical-industrial complex.
- (b) Diagnostic genetic testing: Traditional medical paternalism, lack of knowledge by physicians about the complexities of genetic testing and economic interests together conspire to promote the overuse of genetic tests by the wealthy in the absence of sound medical indications and their underuse by the poor, even when medically indicated.
- (c) Predictive genetic testing: This issue is not addressed frequently in Argentina, except for breast cancer in women with a positive family history. Direct-to-consumer genetic testing via internet, bypassing health professionals, is available and anecdotal information indicates that it is used although its magnitude is unknown.
- (d) Genetic discrimination: Current legislation prohibits health insurance discrimination against people with disabilities or genetic disorders. In spite of this, loopholes, misconceptions and the economic interests of insurers continue to constitute barriers for decent health coverage for affected people.
- (e) Prenatal diagnosis: The practice of prenatal genetic diagnosis where abortion for foetal reasons is illegal poses many ethical dilemmas, not the least of which is the

inequity that the wealthy can resort to both, as if the law did not apply to them, while the poor are left without the service and are penalised if they interrupt an affected pregnancy.

- (f) Overselling and overuse of genomics: This issue (i.e. the ethical and methodological nuances of next generation sequencing) has not yet fully impacted on bioethics and genetics circles in Argentina, compared to other industrialised countries. Among the reasons for this lag may be that entrepreneurs may have not yet seen the market niche for genomics in health, or the technology remains too expensive for the country's economy, or the makers of health policy are not yet sufficiently educated or a combination of these and other factors. In the near future, however, Argentina may confront the bioethical and technical conundrums of non-validated genetic/genomic testing with no proper medical indication. Were this to become a reality, two complementary ethical dilemmas could occur: on the one hand, their use may increase genetic reductionism, without improving the public's health, and drive valuable resources away from addressing the social determinants of disease that explain most differences in population health. On the other hand, those genetic technologies that turn out to be safe and effective might exacerbate inequity.

Conclusions

The debate on bioethics and genetics in Latin America in general, and in Argentina in particular, is uncovering a number of dilemmas in the prevention, diagnosis and treatment of diseases influenced by genetic factors, at the heart of which are poverty and social inequality.

The main barriers for the rational and equitable application of genetics to public health in Latin America are (a) lack of universal access to health care, with fragmented, inefficient and inequitable health systems; (b) the heavy burden of unmet needs in infectious diseases, malnutrition and basic primary health care, particularly in prenatal, newborn and infant care; (c) deficient understanding of genetics by health professionals and health officials; (d) discriminatory practices by for-profit health insurance leading to poor coverage for genetic conditions; and (e) weak governmental regulation of genetic testing.

The following are some key points to consider in the ethical implementation of genetic/genomic technologies in health care in Latin America:

1. States must commit to develop well-funded, powerful and efficient systems for the evaluation and regulation of the application of genetic/genomic technologies to health care, based on criteria for the determination of their

clinical validity and utility and their cost and comparing their efficacy with alternative technologies and interventions and ethical issues.

2. Application of genetics/genomics should not drive attention away from social determinants of health and disease (such as living and working conditions, socioeconomic conditions, preventable inequalities, nutrition and exposure to infectious and toxic agents), which influence most health differences at the population level and must be addressed to ensure the best possible level of health for all.
3. Development of networks of genetic health services as part of the public system, with adequate funding and proper training of health professionals in genetics to face needs and demand, based in primary health care and with proper channels of referral to secondary and tertiary care.
4. Education of health professionals to assess potential benefits and risks (including ethical issues) of the adequate utilisation of genetic/genomic technologies in health care.
5. Education of policymakers in the nuances of the scientific, technical and ethical aspects of genetics/genomics in health care.
6. Address the ethics of interruption of pregnancy for foetal reasons, respecting the autonomous decision of each couple according to their culture and world vision, as well as personal beliefs, values and attitudes.
7. Encourage the democratic and pluralistic debate on ethical and scientific application of genetics/genomics in health care, including all stakeholders (such as parent-patient organisations, health professionals, social movements, ethicists, policy makers and industry).

Compliance with ethical guidelines This article does not contain any studies with human or animal subjects performed by the author.

Conflict of interest Victor Penchaszadeh declares that he has no conflicts of interest.

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