Instituto Nacional de Medicina Genómica

México

Fostering global responsible research with CRISPR-Cas9

INSERM-Sponsored Workshop
Buenos Aires, Nov. 2016
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Instituto Nacional de Medicina Genómica
MÉXICO

Main focus of the National Institute of Genomic Medicine

Genomics of Metabolic Diseases

Population Genomics

Genomics of Cancer

Pharmacogenomics

Genomics of Infectious Diseases

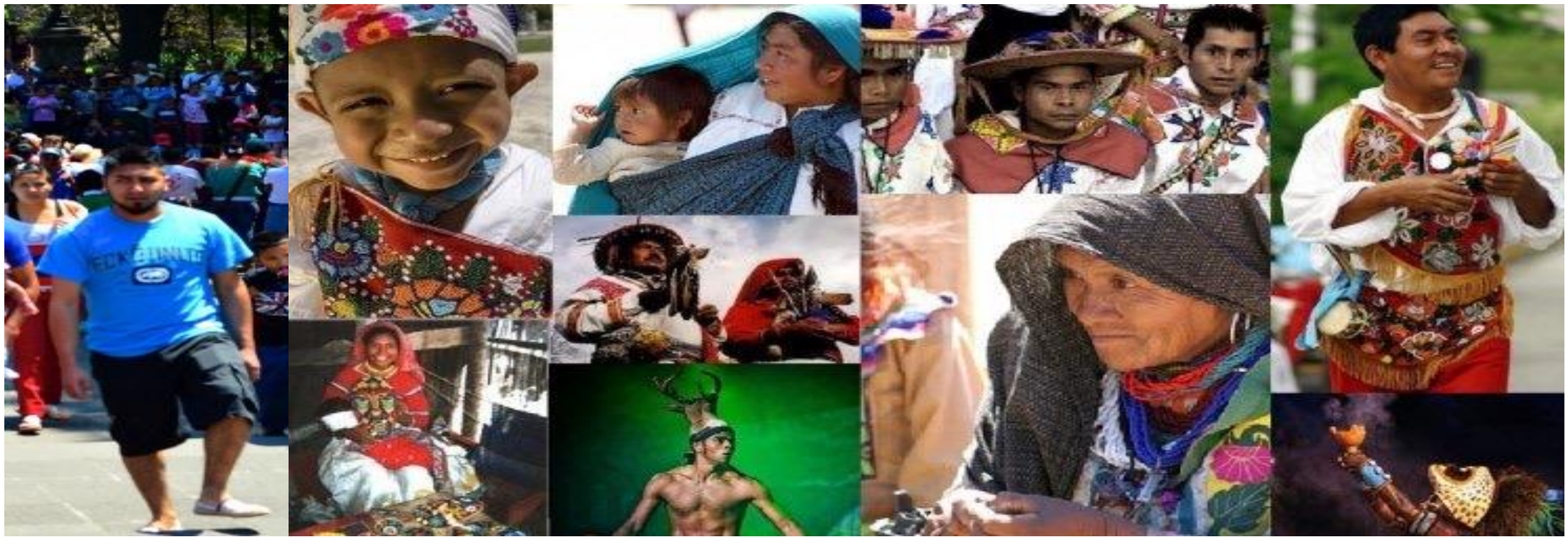
Systems Biology / Bioinformatics

Genomics of Psychiatric Diseases

Epigenomics

INMEGEN

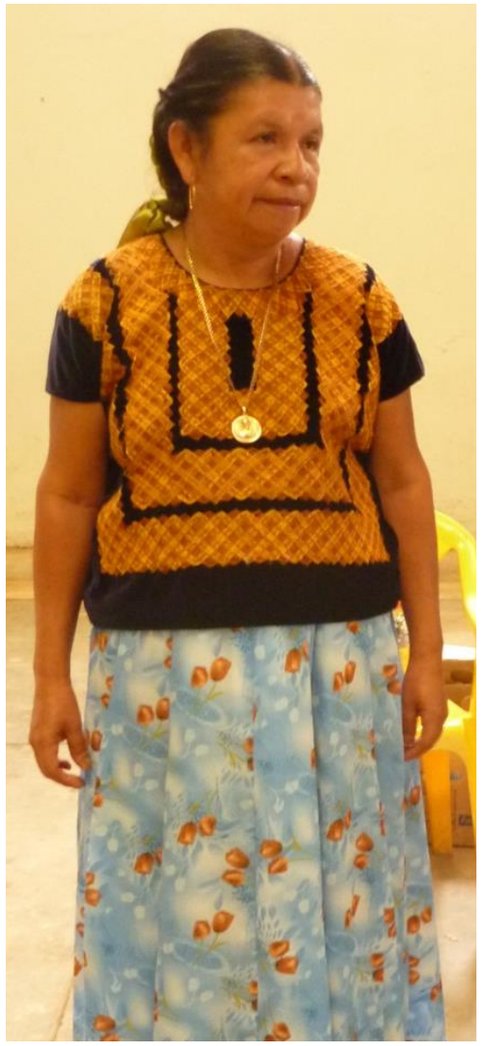
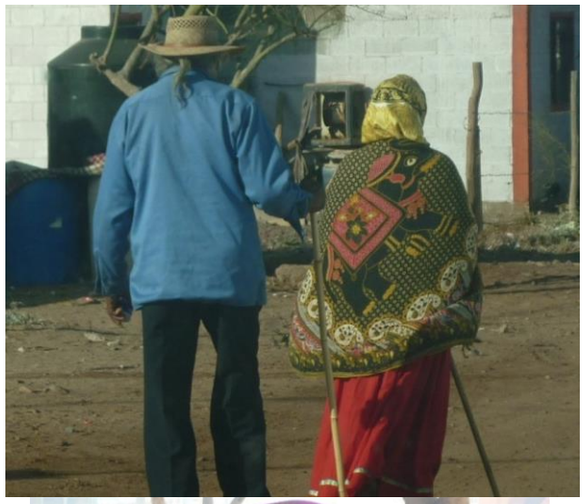
A central role of INMEGEN is to characterize the genomic diversity of our different populations

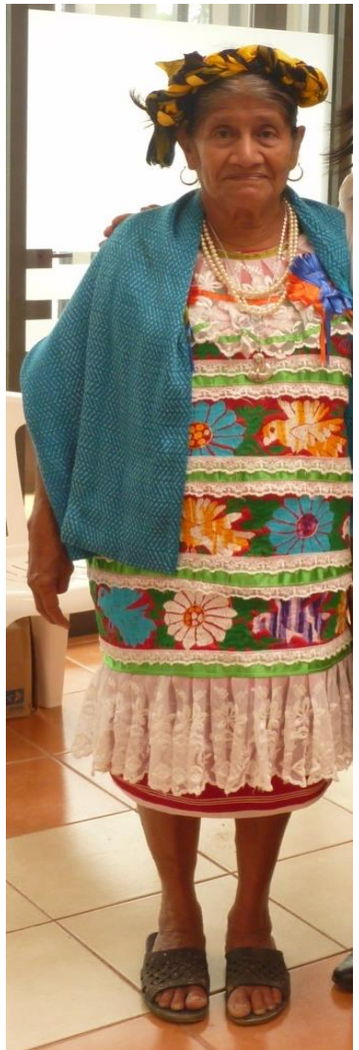
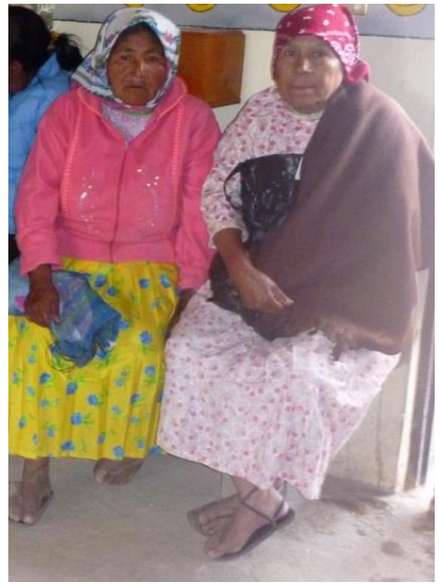
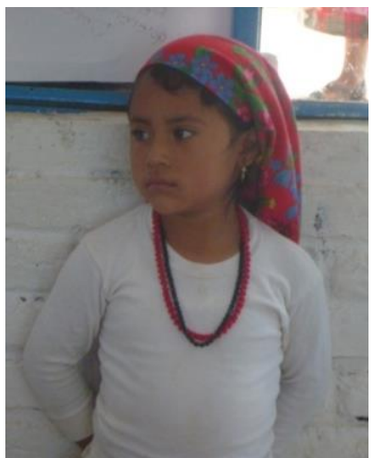
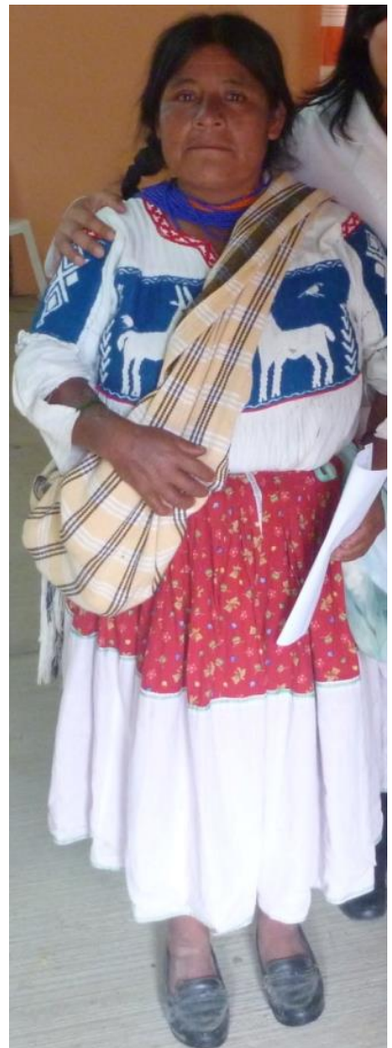


México is a mosaic of a large number of original American peoples, Europeans and, to a lesser extent, west Africans with diverse degree of admixture between them.

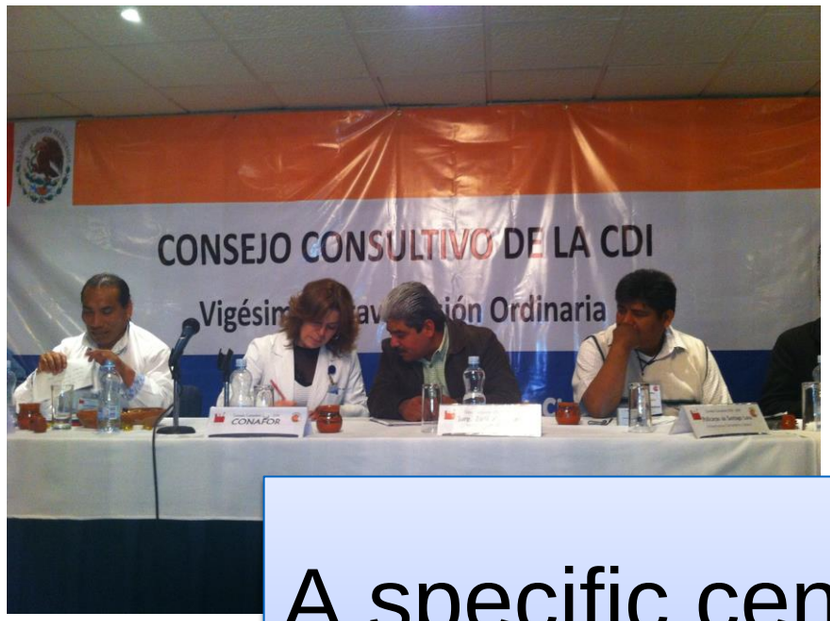
100G-MX Project

National Project to generate a catalog of the human genetic diversity in Mexico.

Bioethics policies at INMEGEN



A specific center devoted to the Ethical, Legal and Social implications of human genomics Centro EJES

It is crucial to be meticulous about human rights respect. Thus, the informed consent was carried out jointly with indigenous lawyers of the Comisión para el Desarrollo de los Pueblos Indígenas (CDI).

Decalog:

Decálogo sobre los derechos de la persona respecto a su muestra biológica y su información genética

En un esfuerzo por generar una cultura genómica en México y considerando que los avances en el conocimiento sobre el genoma humano y su constante diversificación deben aplicarse con apego a los derechos humanos, se presenta este decálogo para garantizar el respeto a la libertad y dignidad de todas las personas que participen en procesos de obtención de muestras biológicas e información genética. Al existir un consenso internacional en cuanto a los principios éticos que deben regir la generación de conocimiento genómico y sus aplicaciones, se reconocen los siguientes derechos respecto a las muestras biológicas y la información genética de la persona:

participar en procesos

que deberá respetarse

ión, tanto verbal como
po de estudios que se
el uso que se les dará.

ención de su muestra biológica y su información genética, así como sobre la comunicación de resultados, la donación, el almacenamiento, el uso presente y futuro, y el destino final de éstas.

6. Tener acceso a la información derivada del proyecto de investigación en el que participó, cuando se considere que ésta tenga una consecuencia directa en su salud o la de su familia.

7. Decidir si desea o no conocer total o parcialmente los resultados de los estudios diagnósticos o de investigación obtenidos de su muestra biológica y su información genética.

8. Recibir asesoramiento especializado con carácter confidencial acerca de los resultados del análisis y la interpretación de su información genética.

9. Poder revocar el consentimiento otorgado en cualquier momento y poder solicitar la destrucción de su muestra biológica y de la información derivada de ésta, siempre y cuando sea posible.

10. No se lucrará con la muestra biológica ni con la información genética de la persona, estás sólo se utilizarán con los fines para los que otorgue el consentimiento.

Bioethics discussion from the outset (Year 2004)

- INMEGEN was created to conduct research around the human genome to improve health, **including gene therapy (Law of the National Institutes of Health)**

- **On the other hand, the Organic Statute was required by the same “Diputados” that passed the previous law, creating the Institute, to specifically forbid: “In no case will it conduct research on human stem cells from live embryos, or those obtained by nuclear transplant”**

Is there research involving gene editing in your country? If so provide details

So far, virtually non existent with human tissues and probably also with human cell lines.

- Quite a few groups have worked for years with transgenic mice and flies without any problem or opposition.

- All this has started to change with CRISPR-Cas. E.g. new work with Zebra Fish and *C. elegans*, human cancer cell lines, at least.

- No work with human embryos, to my knowledge

- Notable: recent mitochondrial replacement procedure (not technically gene editing)

How has been the implementation of genomics technologies in general in your country, have you faced any reject from the civil society?

- No significant reject as long as it is not manipulating, just studying and understanding the genome.

- Main concern has been with risk of revamping racism and discrimination.

Are you dealing with anti-technology movements and how do you cope with them?

Again, relatively low scale in Mexico.

- The most visible would be animal rights (moderate activity)

- And anti-GMO. More significant and with larger popular suport. Main concern has been with risk of revamping racism and discrimination.

If you are having discussions about these technologies? Who is engaged in them - i.e. the church?

- Discussions (more a deaf dialogue) have occurred with anti-transgenic crop lobby. Some scientists participate in the opposition. The larger scientific community is in favor.

- The church has continued to be an opposition force, not to technology itself, but to any intervention with the human reproductive process (from artificial insemination on)

Are you aware of regulation in your country that covers gene editing technologies

- **Nothing directly covering editing per se**. Just the use of “genetically modified organisms” in agriculture. Also some precautions (approval by scientific and ethics committees) for all recombinant DNA work.

- An initiative to regulate assisted reproduction has been looming for over 12 years now. I believe the “three parent baby” will force discussion and the final passage of the law.

- I anticipate that there will be a lot of pressure to ban any possible manipulation on human embryos (from the conservative sector of society). The current initiative is in that vein.

If there is no legislation, should there be and who should be leading these discussions?

- It is becoming urgent to have specific legislation pertaining to gene editing of human tissues. In my view it is imperative to distinguish between germline and somatic gene therapy.

- The development of gene therapy protocols is becoming a real possibility for the Mexican clinical and biomedical communities (already there are several human clinical trials of gene therapies, using older editing techniques).

How do you see the debate/ or how is the current debate on gene editing in the Latin American context/ or your country different to other regions/countries?

It will be different from the developed world for two main reasons:

1) It is totally new endeavor. Almost no activity has been present previously (I am talking about human gene editing).

2) The conservatives will be very active, specially trying to stop any form of manipulation of the embryo.

I also believe the scientific/medical/liberal community will be actively pursuing the freedom to use embryonic derivatives for experimentation with no reproductive goal. Also the authorization of gene editing for disease correction in somatic gene therapy. I doubt there will be any pressure to do germline gene editing.

SALUD
SECRETARÍA DE SALUD

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