Human germline genome editing: ethics, science and future modes of governance

ANSC691 Seminar / GEFSES-Create
July 2, 2020
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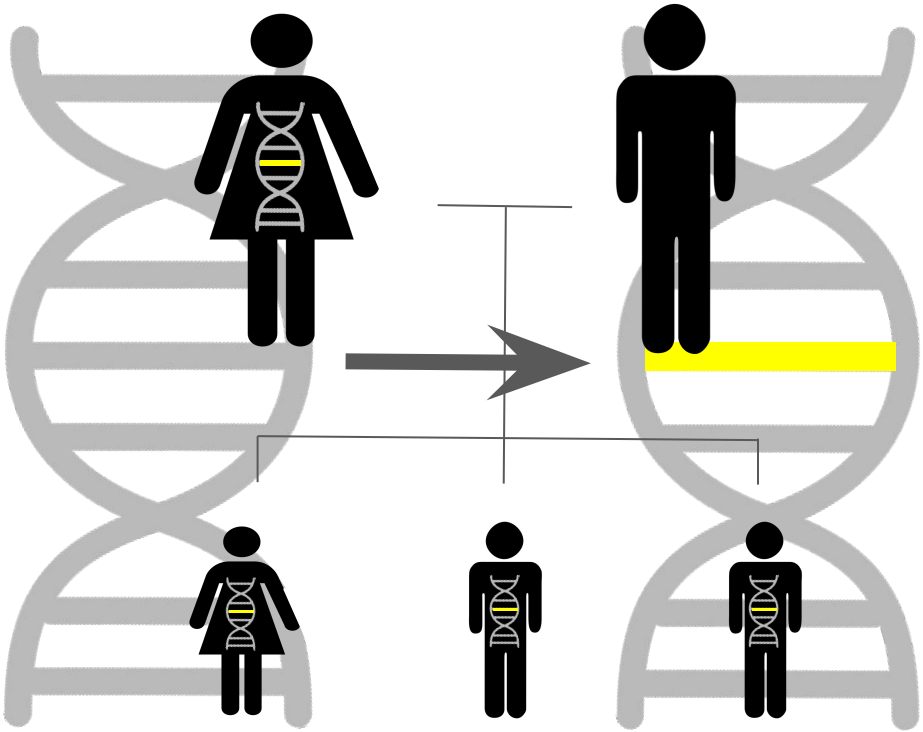
Overview of the seminar

- The “CRISPR babies” scandal and why it matters
- The multidimensional debates surrounding germline editing
- Proposed governance models to chart a path forward

Image source: https://oncologynews.com.au/

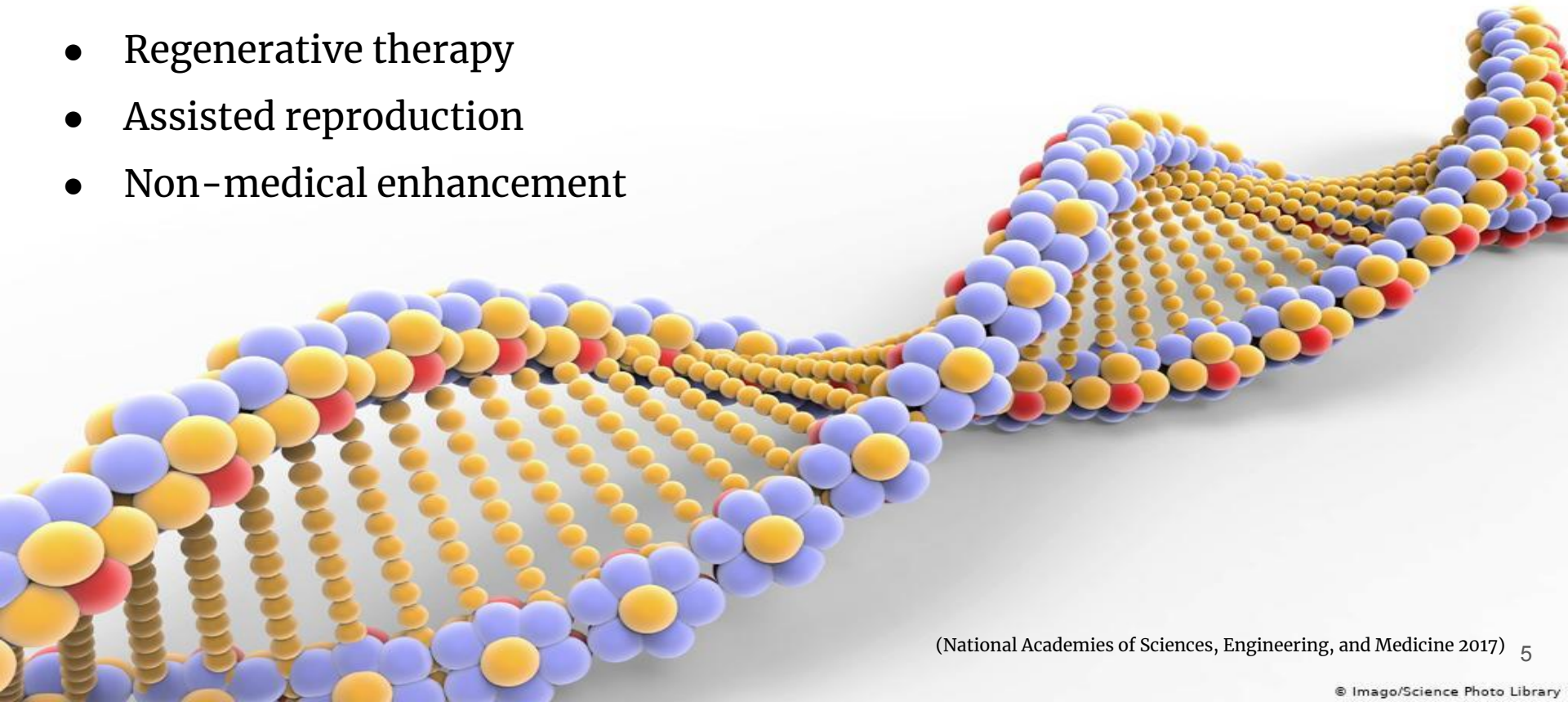
‘Gene surgery’: human germline genome editing (HGGE)

- Scientists make changes to an individual’s DNA
- These changes can be passed on to the individual’s children
- CRISPR has made HGGE possible



CRISPR could have many germline editing applications

- Regenerative therapy
- Assisted reproduction
- Non-medical enhancement



(National Academies of Sciences, Engineering, and Medicine 2017)

Governance

“how we collectively to steer the ship make decisions about problems or issues”

(Hurlbut 2020; Image Source: bustle.com)

The multidimensional debates surrounding HGGE

Ethical

Social

Scientific

Regulatory

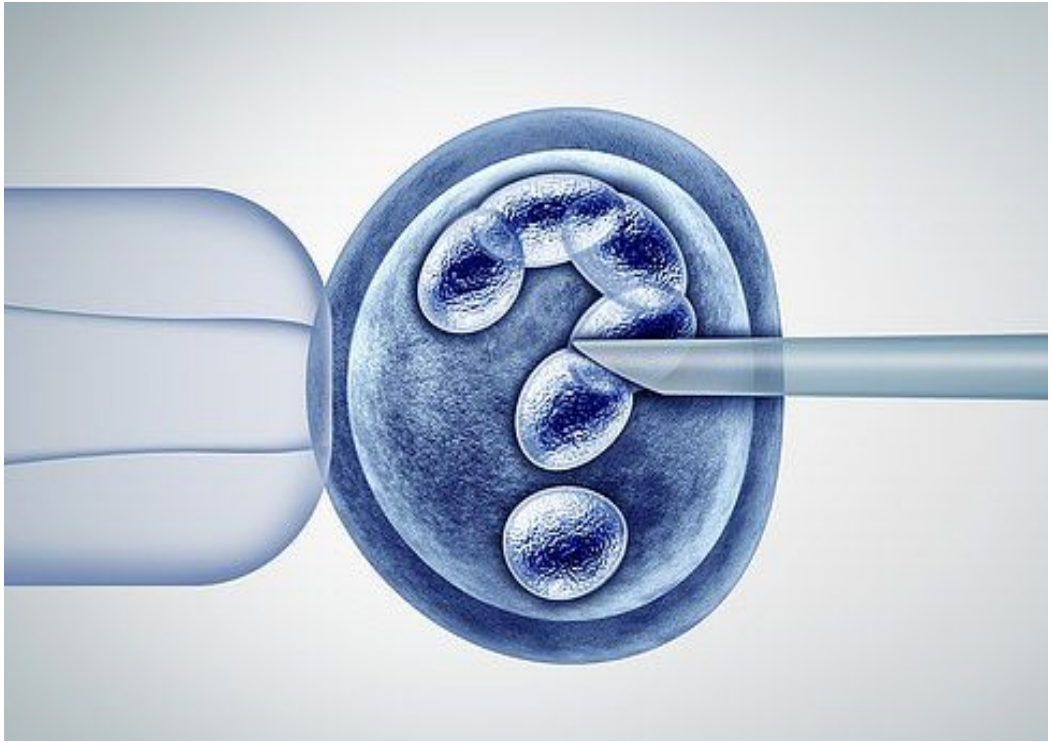
Image source: https://oncologynews.com.au/

Finding the balance between procreative and embryonic autonomy

(Image source: statnews.com)

Do we have a moral obligation to cure embryos?

- Curing with CRISPR vs conventional selection



(Image source:livescience.com)

(Cavaliere *et al* 2018)

Drawing lines is not straightforward

Therapy Prevention Enhancement

(National Academies of Sciences, Engineering, and Medicine 2017)

The road to enhancement could be a slippery slope

- Negatively influence parent-child relational dynamics

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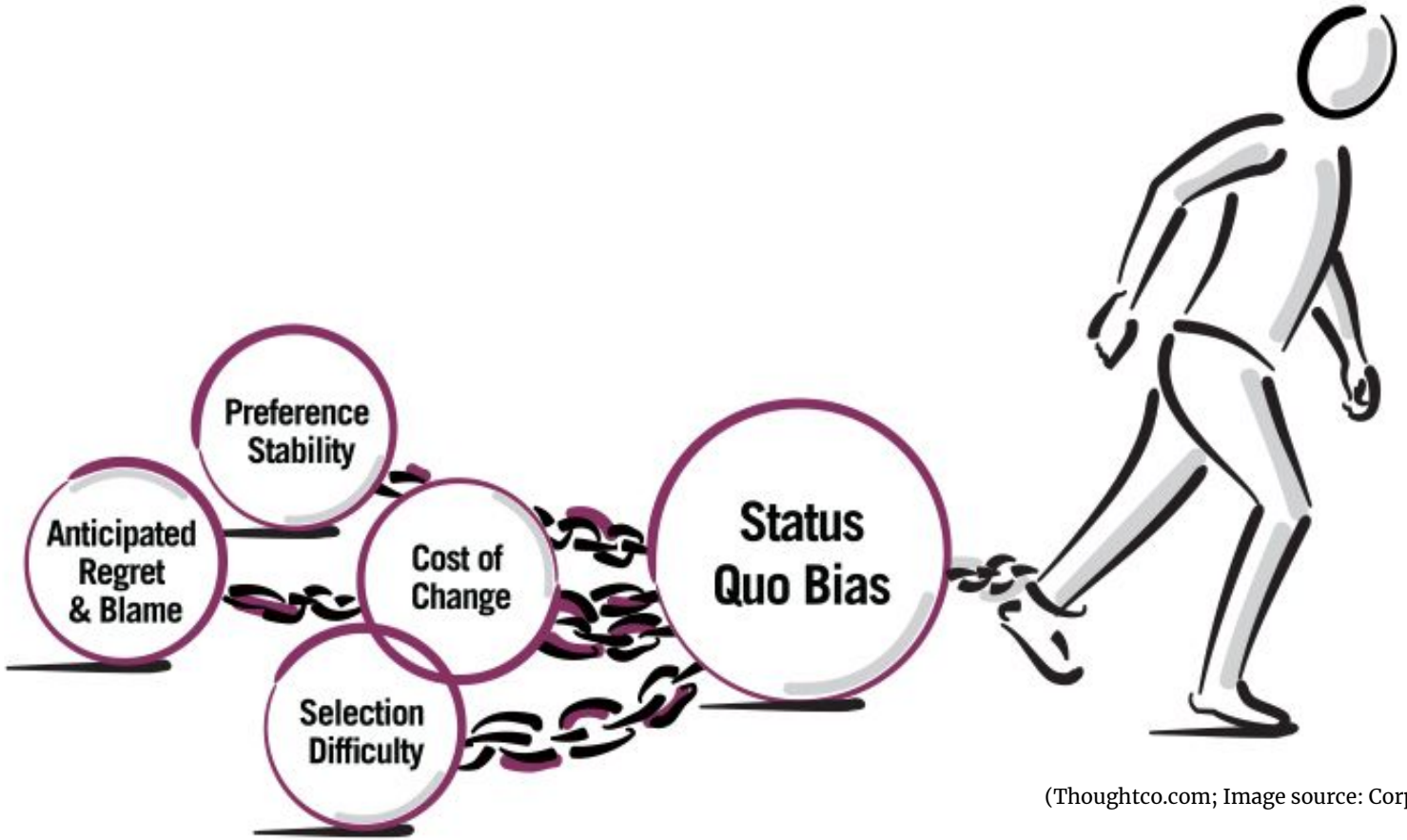
Leveling the playing field to promote “**genetic equality**”

The treatment of heritable diseases

(Image Source: genengnews.com)

Individuals may prefer their current environment or situation



(Thoughtco.com; Image source: Corporatevisions.com)

Uneven resource allocation can lead to social injustice

(Image Source: Sevenpillarsinstitute.org)

Rethinking disability: a burden or a benefit?

- Screening of genetic diseases can have negative impacts

(Image Source:the hoya.com)

The possible return of “eugenics”

- Promoting “**good**” genes and excluding “**bad**” ones

(Image source: Kenanmailk.com)

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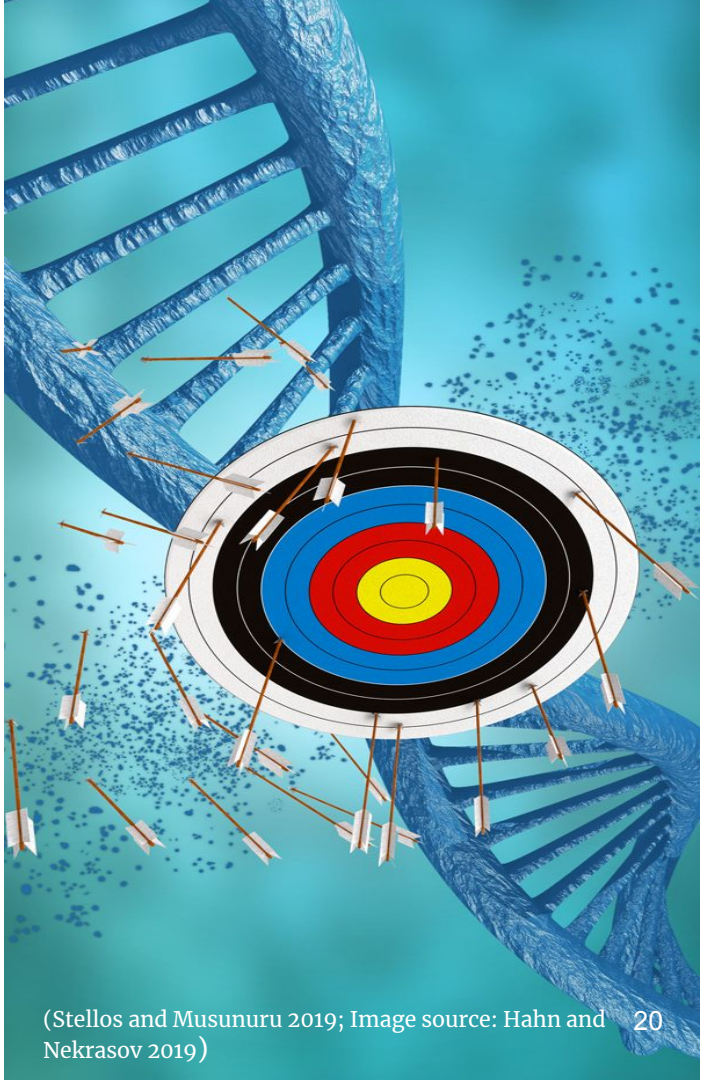
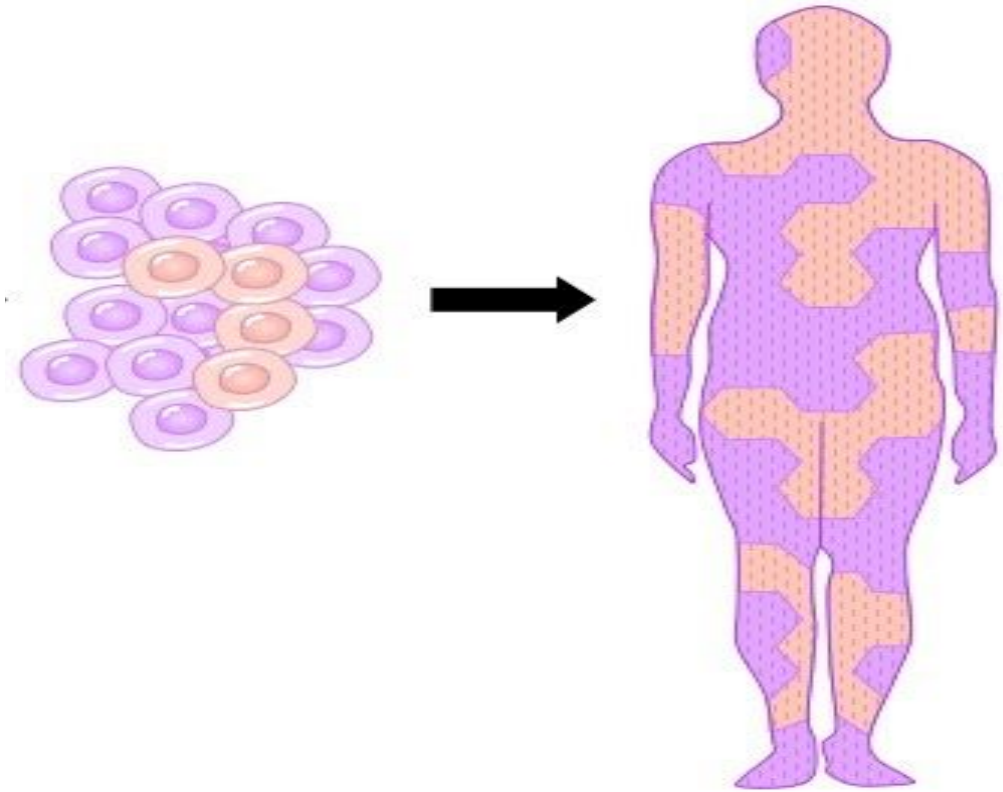
Even the best tools are not perfect

- Off-target mutations are unwanted additional non targeted alterations



(Stellos and Musunuru 2019; Image source: Hahn and Nekrasov 2019)

Mosaicism



(Image source: Mitchell 2011)

Is there a need to **rethink** and **reform** regulations over HGGE ?

(Image source: Lagomarsino and Wilson 2019)

The multidimensional debates surrounding HGGE

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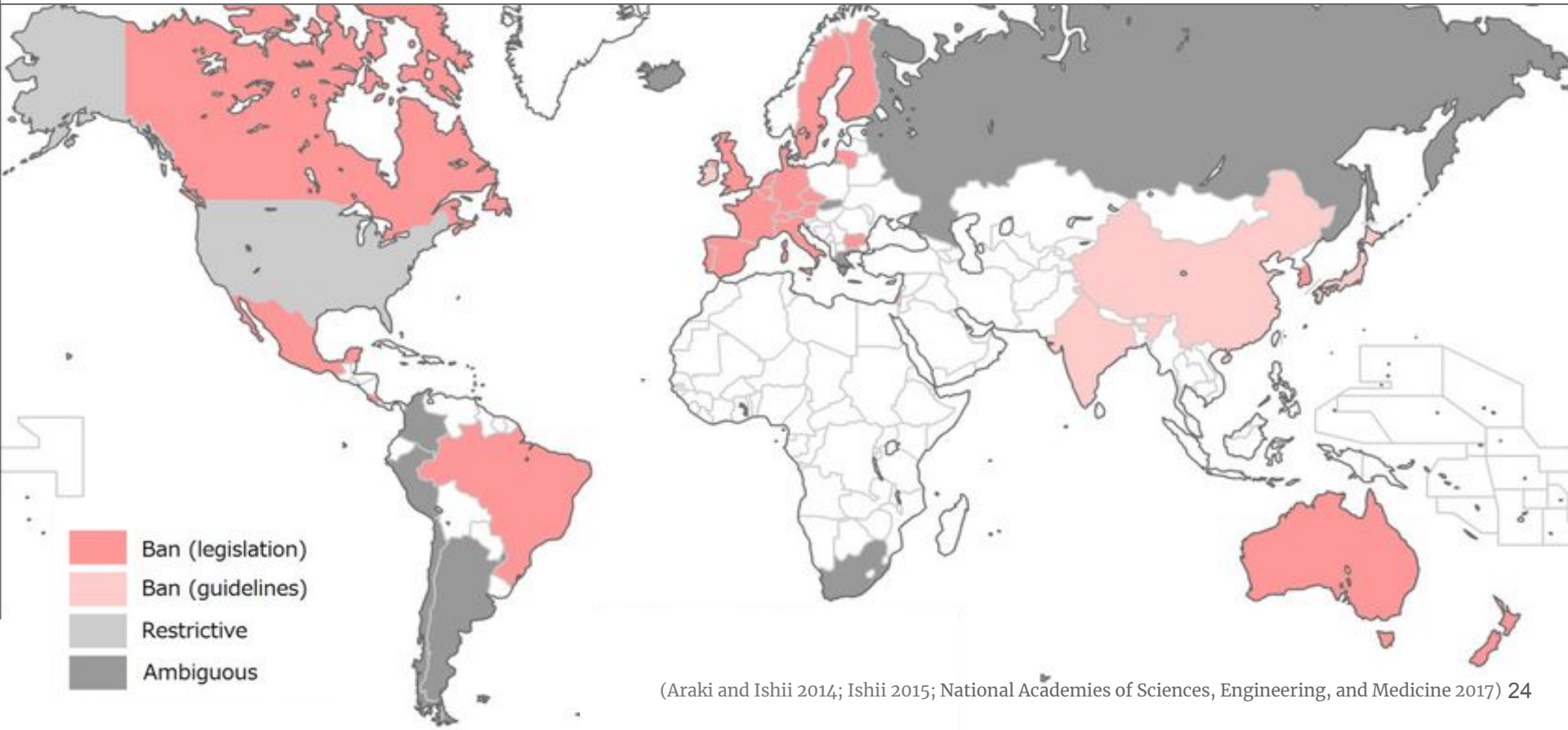
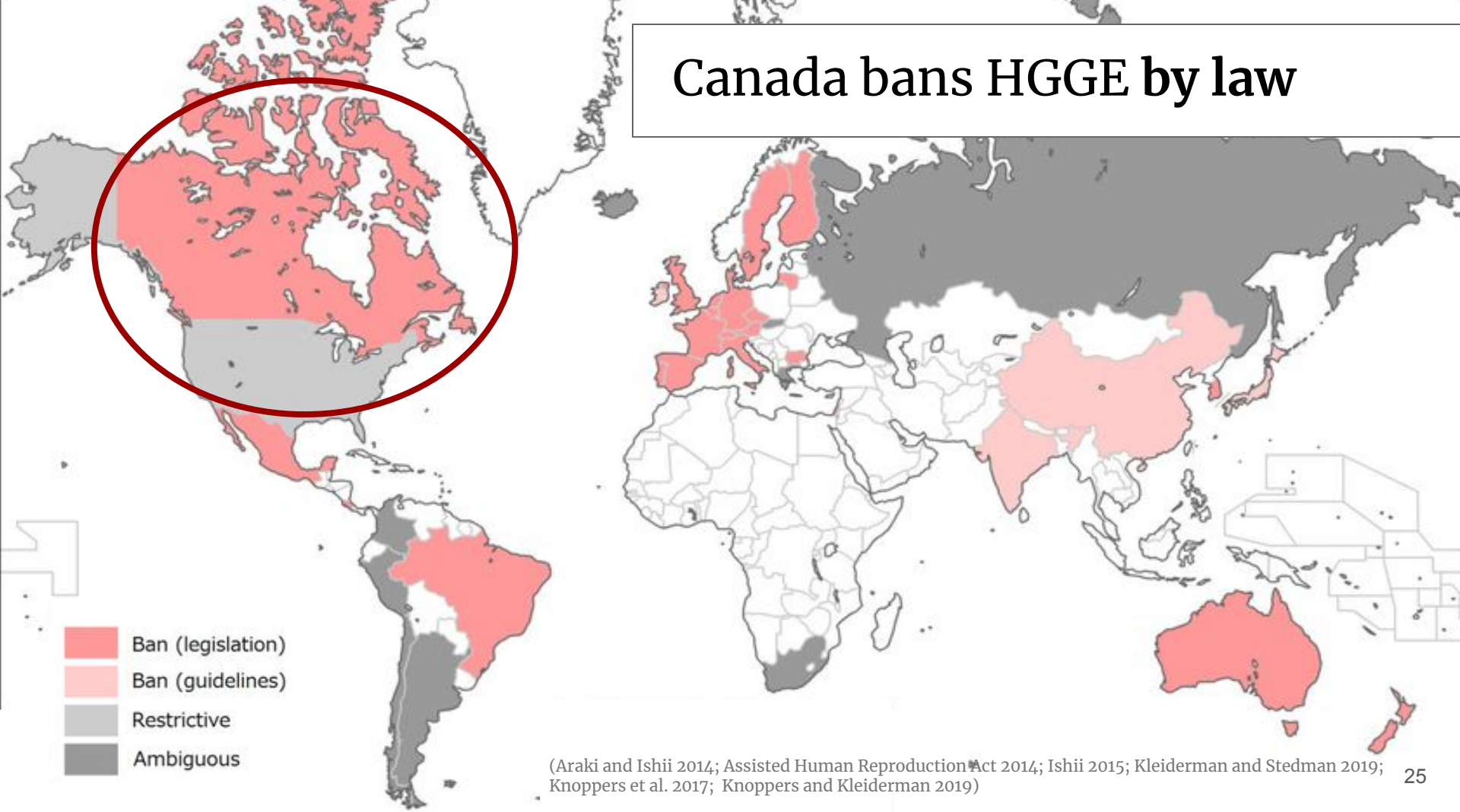
Image source: https://oncologynews.com.au/

There is international mosaicism in the regulation of HGGE



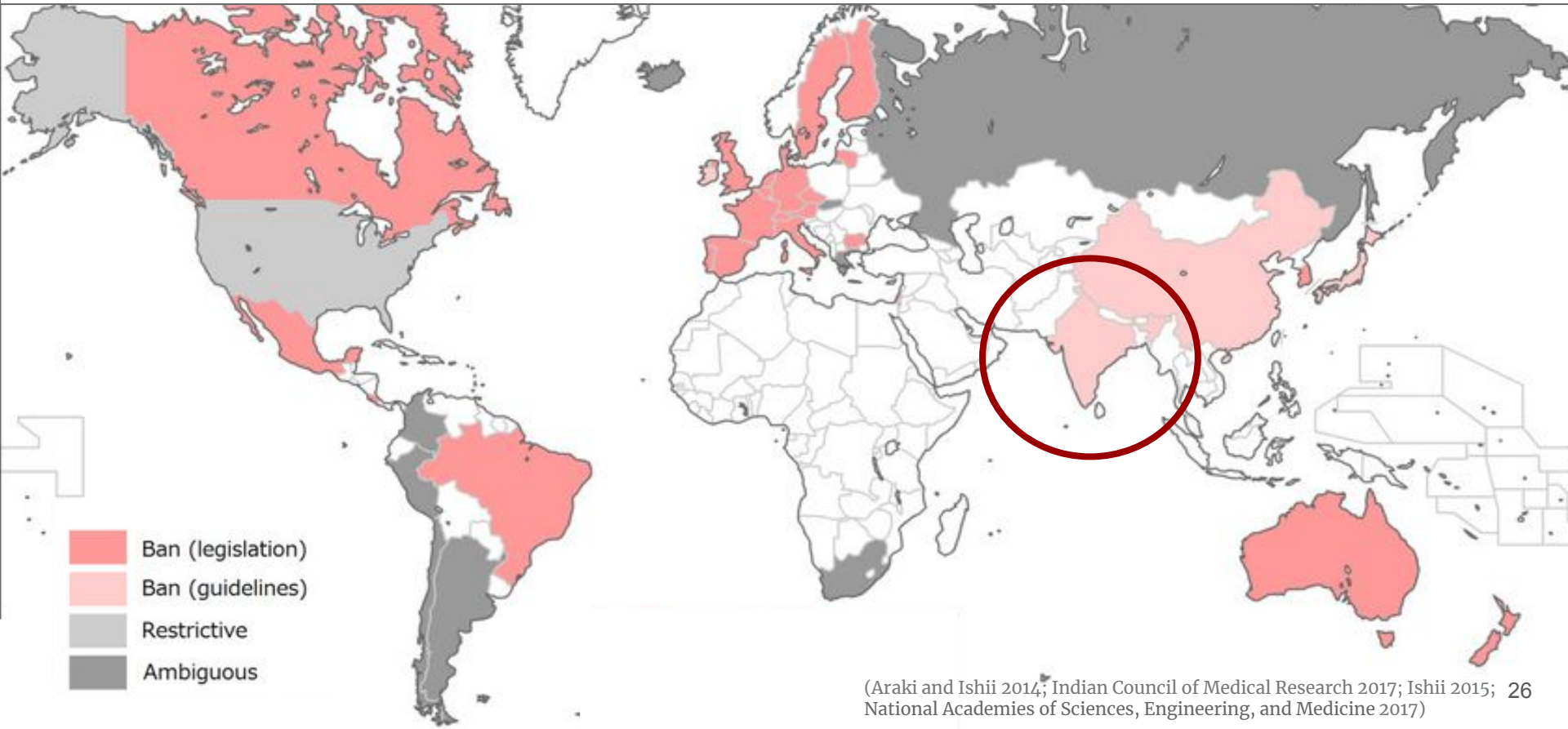
(Araki and Ishii 2014; Ishii 2015; National Academies of Sciences, Engineering, and Medicine 2017)

Canada bans HGGE **by law**



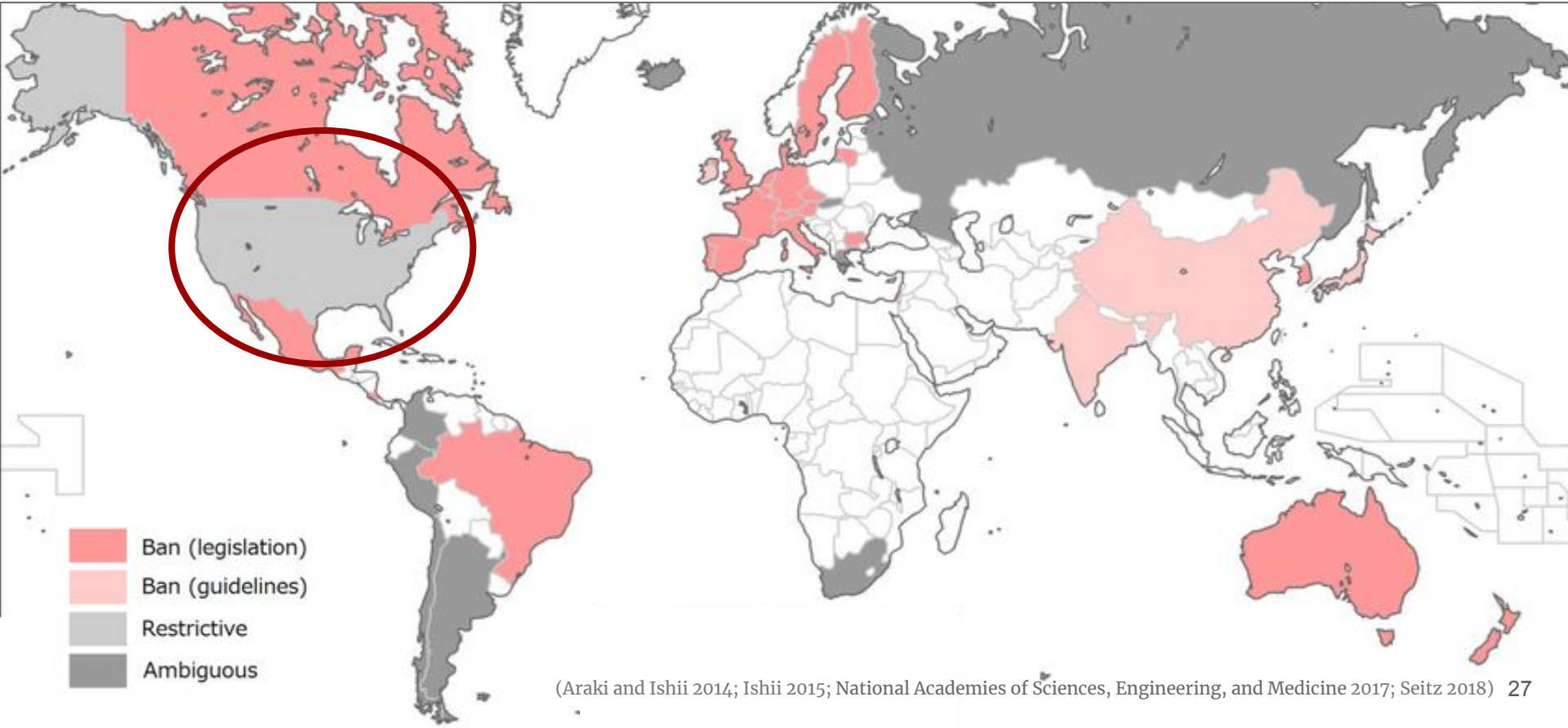
(Araki and Ishii 2014; Assisted Human Reproduction Act 2014; Ishii 2015; Kleiderman and Stedman 2019; Knoppers et al. 2017; Knoppers and Kleiderman 2019)

National **guidelines** state HGGE is not allowed in India



(Araki and Ishii 2014; Indian Council of Medical Research 2017; Ishii 2015; National Academies of Sciences, Engineering, and Medicine 2017)

The US **restricts** HGGE through federal funding measures



(Araki and Ishii 2014; Ishii 2015; National Academies of Sciences, Engineering, and Medicine 2017; Seitz 2018)

Nations regulate HGGE in different ways

	Canada	India	United States
Regulatory approach	**Legal Prohibition**	**Prohibition by guideline**	**Restrictive (funding measures)**
Governing act/body	Assisted Human Reproduction Act (2004)	Indian Council of Medical Research (2017)	Food and Drug Administration (2018)
Criticisms	Lacks flexibility Stifles debate “chilling effect”	Not enforceable by law	Federal/regulatory loopholes

(Hurlbut 2020; Image Source: bustle.com)

Charting a path forward: proposed modes of governance

Two (of many) proposed modes of governance

	Science Driven (Schweikart 2019)	Society Driven
Model	Summit at Asilomar	Global Observatory
Decision making	Experts decide	Democratic Deliberation
What matters?	Immediate safety and containment risks	Mediate safety and social risks
Cost	Efficient	Intensive

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Image source: https://oncologynews.com.au/

To summarize

- “CRISPR babies” scandal and why it matters
- The current debates surrounding HGGE
- Charting a collective path forward

(Image source: https://oncologynews.com.au/; Hurlbut 2020)

How *best* to proceed is unclear

- Just because we can, does it mean that we should?
- In what circumstances, with what limitations?
- Who decides?

Questions?

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Genome Editing for Food Security
and Environmental Sustainability