

## OPPORTUNITY #9

WHAT IF THE WORLD AGREED TO A GENETIC CHARTER?

# INTERNATIONAL AGREEMENTS IN OUR DNA


A global agreement on gene editing ensures access to advances while safeguarding against discrimination and abuse

### WHY IT MATTERS TODAY

The public's perception of gene-based editing and therapy has fluctuated over recent decades. Deaths and damage have occurred among patients in gene therapy trials,<sup>77</sup> weakening public support, and the technology remains far from perfect. In one research study in London, researchers found that approximately 16% of the human embryo cells analysed had 'accidental mutations'<sup>78</sup> after gene editing had been done.

However, following the use of CRISPR (clustered regular interspaced palindromic repeats) editing to provide accurate diagnosis of Covid-19 and associated variants,<sup>79</sup> there has been an uplift in public sentiment. Although perceptions of gene editing improve more generally in the medical sphere, together with an increase in public acceptability of such treatments,<sup>80</sup> ethical concerns grow about its potential to be a source of discrimination when used for physical, aesthetic, cognitive, physical or moral enhancement.<sup>81</sup>

Meanwhile, the technology has expanded. The US Food & Drug Administration (FDAP) approved the first cell and gene therapy in 2017.<sup>82</sup> As of November 2021, there are 22 FDA-approved cell- and gene-based therapy products available to minimise genetic diseases.<sup>83</sup> However, despite expansion, underlying genetic data used in genomics research do not always include underrepresented groups.<sup>84</sup> This is particularly relevant for the Arab population as most of the research comes from the US where the Arab population is only a minority. Some projects are being developed in Kuwait, Qatar and Saudi Arabia but more regional efforts are needed.<sup>85</sup>



In an effort to improve the ethical standing of genomics programmes, the Global Alliance for Genomics and Health (GA4GH) has developed a number of frameworks that countries follow when implementing genomics in their healthcare systems. One such framework is the Ethics Review Recognition Policy that takes into account the difficulties with current cross-border genomics programmes.<sup>86</sup> The Oviedo Convention – opened for signature in 1997 and ratified by 29 countries in Europe<sup>87</sup> – is the only international legally binding instrument covering biomedical research, genetics and organ and tissue transplantation.<sup>88</sup> It addresses concerns about genetic enhancement by limiting the purposes of any intervention on the human genome to prevention, diagnosis or therapy.<sup>89</sup>

### THE OPPORTUNITY TOMORROW

A combination of expert scientific and ethical debate and political willingness to align regulations across nations can lead to the adoption of a global charter setting out principles relating to genetic manipulation. Such a charter would promote the role of gene editing as a tool to treat diseases while setting out processes for managing risks and, if necessary, responding to situations where indirect mutations arise and harm those who have had their genes edited.

#### BENEFITS

A gene charter for editing, including provisions on enhancement, would provide clear regulatory guidelines for tackling genetic diseases, providing countries with a framework to use for gene editing services. It would enforce equal access for all people looking to receive this service and protect the rights of those whose genes have or have not been edited. It would support gene editing as a means of preventing suffering and help prevent gene editing from becoming a source of abuse.

#### RISKS

Risks of unintended harm arise through discrimination against groups rejecting genetic editing for value-based reasons and lack of participation and adoption by nations.