

JANUARY 2016

**GENOME
EDITING**

**ANWAR
ODURO-KWARTENG**



DEBATING MATTERS
**TOPIC
GUIDES**

MOTION:

**“WE SHOULD
WELCOME THE
ADVENT OF HUMAN
GENOME EDITING”**

ABOUT DEBATING MATTERS

Debating Matters because ideas matter. This is the premise of the Institute of Ideas Debating Matters Competition for sixth form students which emphasises substance, not just style, and the importance of taking ideas seriously. Debating Matters presents schools with an innovative and engaging approach to debating, where the real-world debates and a challenging format, including panel judges who engage with the students, appeal to students from a wide range of backgrounds, including schools with a long tradition of debating and those with none.

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KEY TERMS

[Genome editing](#)

[Germline](#)

[Somatic](#)

INTRODUCTION

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In late 2015 doctors at Great Ormond Street children’s hospital in London performed successful ground breaking treatment on 17 month old Layla Richards, who at the time was gravely ill with an incurable form of leukaemia. In the first human use of a new technology [Ref: [BBC News](#)], the doctors effectively ‘edited out’ the disease with the use of ‘molecular scissors’, named TALENS, which “edit out genes to create specialised killer cells which could hunt out and eradicate her leukaemia.” [Ref: [Telegraph](#)] The case made headlines around the world in what appeared to be another example of the power of genome editing in the field of medicine and science. The scientific breakthrough which caused most excitement in the process was the Crispr-Cas9 tool, which has the ability to alter DNA and potentially replace faulty human genes with healthy ones [Ref: [BBC News](#)]. Supporters of genome editing emphasise the potential impact the new technology could have on genetically carried diseases, such as Huntingtons or Sickle Cell Anaemia but, despite the potential benefits, there are critics who question both the infancy of the technology, as well as the ethical implications which surround the ability to modify human beings. Crucially, critics are concerned with germline editing [Ref: [Genetherapy.net](#)] which some suggest is the next logical stage in genome modification – and genetically modified humans - with experiments already taking place on non-viable embryos in China [Ref: [Telegraph](#)]. This debate takes place at the intersection between ethics and medicine, forcing society to consider the shifting boundaries of scientific experimentation and ethics; and weighing this against the impact such a breakthrough technology could have on mankind in the future. Given the complexity of the issue, are we right to welcome the advent of human genetic editing?



THE GENOME EDITING DEBATE IN CONTEXT

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What Is Human Genome editing?

Genetic therapies aimed at curing illness are not new, and since the 1990's scientists have had the ability to insert new DNA into patients with genetic conditions, with varying results [Ref: [BBC News](#)]. However, the new technology potentially takes us beyond this capacity, because: "With conventional gene therapy, it is only possible to add genes. With gene editing, though, genes can also be disabled" [Ref: [New Scientist](#)] In this respect, we can view genome editing as the process of editing 'in' or editing 'out' specific genes, by identifying faulty or irregular strands of DNA, and correcting them – "Crispr can be thought of as a pair of molecular scissors guided by satnav" [Ref: [Guardian](#)]. Potentially, this means that diseases involving faulty genes such as Beta Thalassaemia, Haemophilia, Cystic Fibrosis and Muscular Dystrophy could be treated by locating the faulty gene, cutting it out of the DNA sequence, and replacing it with a functioning version of the same gene. There are two types of therapy that genome editing encompasses – germline therapy and somatic therapy. Germline editing is undoubtedly the more controversial of the two, and would involve editing DNA during embryonic development – resulting in permanent changes which are passed on to subsequent generations - which may in theory mean that hereditary diseases such as Huntingtons could be eradicated [Ref: [BBC News](#)]. Somatic editing on the other hand, only concentrates on specific cells, and changes are not passed on to subsequent generations [Ref: [Genetherapy.net](#)].

Changing what it means to be human?

In December, many of the world's foremost geneticists attended a conference in Washington to discuss the ethics of genome editing [Ref: [Guardian](#)]. Considering the profound impact that the new techniques may have on humanity, author and philosopher Francis Fukuyama observes that: "The moment when we will be able to alter characteristics that will be handed down to all future generations of human beings is upon us". He warns that rather than becoming over excited about the possibilities, we as a society need to think very carefully before we proceed, because, "this type of activity potentially strikes at the core of what it means to be human." [Ref: [New York Daily News](#)] Likewise, bioethicist Dr Calum MacKellar is similarly cautious about the ethics of genome editing. He notes that whilst we may be some way from being able to genetically engineer humans in the way that Aldous Huxley depicts in his dystopian classic 'Brave New World', he worries that the research is moving at such a pace that, "technologies like Crispr have brought (that) future a whole lot closer." [Ref: [Scotsman](#)] For other critics, the possibilities that gene editing presents means it can be used for both good and bad, which is ethically problematic because: "This could mean eliminating harmful genetic conditions, or enhancing traits deemed advantageous, such as resistance to diseases", and it "may also open up the door to eugenics" [Ref: [The Conversation](#)]. Aside from the ethics, there are also practical concerns about the safety and efficacy of current gene editing procedures. The results of the recent Chinese experiment to genetically edit non-viable embryos were poor – with just 4 of the 86 eggs tested being successfully modified [Ref: [New Scientist](#)]. Moreover, some worry that our understanding of DNA is not advanced



THE GENOME EDITING DEBATE IN CONTEXT CONTINUED

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enough for scientists to accurately predict the full consequences of editing genes with any confidence. One writer argues that this uncertainty might result in a scenario where a cure for a condition through gene editing, could end up causing other severe genetic defects [Ref: [Huffington Post](#)].

A Brave New World?

Advocates of gene editing focus on the potential applications for treating debilitating illnesses, with trials into finding a “functional cure” for HIV and Sickle Cell disease for example, currently underway [Ref: [New Scientist](#)]. Moreover, genome editing could “allow physicians to fix...some types of blindness, the blood disorder Beta Thalassaemia and the neurodegenerative disorder Tay-Sachs disease. It could also mean new approaches to treating cancers and viral infections”, according to scientist Professor George Church [Ref: [New Scientist](#)]. Supporters dismiss claims that the technology could pave the way for a slippery slope towards designer babies, with columnist Matt Ridley suggesting that moral panics about scientific discoveries in the recent past have proved to be wrong. He cites examples such as IVF and sequencing the human genome, which were at the time seen by some as the beginning of a dangerous slippery slope, but concludes that ultimately: “People want to use these techniques to cure diseases, not to do eugenics. Genetic knowledge has not undermined morality or respect for human life.” [Ref: [The Times](#)] And even if there were a desire to create ‘designer babies’ with the new technology, some argue this is not within the possibilities of genome editing anyway [Ref: [H-Plus Magazine](#)]. Although we are not yet at the stage where embryos can be successfully edited – thus potentially eradicating certain genetic

illnesses, Professor John Harris is bullish about the ethics of genome editing in this controversial sphere, arguing that: “If there is a discernible duty here it is surely to create the best possible child.” [Ref: [Guardian](#)] He concludes that we should, “keep open the possibility of using gene editing to protect embryos from susceptibility to major diseases, and prevent other debilitating genetic conditions from being passed on through them to future generations.” [Ref: [Guardian](#)] In support of this, Huntingtons disease carrier Charles Sabine, claims that we should welcome genome editing in embryos when it is safe to do so, because it, “offers a glimmer of light for families suffering from genetic diseases. For generations to come this could be priceless.” [Ref: [BBC News](#)] With all of the arguments considered, should we welcome a much heralded scientific breakthrough with the potential to change many lives? Or instead, should we be asking if it is right that “society should use technologies like CRISPR, just because it can” [Ref: [Scotsman](#)]?



ESSENTIAL READING

[The gene hackers](#)

Michael Specter *New Yorker* 16 November 2015

FOR

[Why human gene editing must not be stopped](#)

John Harris *Guardian* 2 December 2015

[Gene editing: Bring it on](#)

Jessica Griggs *New Scientist* 26 September 2015

[Smile! Genetic engineering is here to help](#)

Matt Ridley *The Times* 7 September 2015

[Genome editing raises complex issues – banning it is not the answer](#)

Sarah Norcross *Guardian* 6 September 2015

AGAINST

[Human genetic editing is a social and political matter, not just a scientific one](#)

Marcy Darnovsky *Guardian* 4 December 2015

[Concerns over the ability to edit a human life](#)

Callum MacKeller *Scotsman* 11 November 2015

[Once we start editing our genes, where do we stop?](#)

Michael Hanlon *Telegraph* 2 September 2015

[Genome editing poses ethical problems that we cannot ignore](#)

Anthony Wrigley & Ainsley Newson *The Conversation* 31 March 2015

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IN DEPTH

[The Crispr quandary](#)

Jennifer Kahn *New York Times* 9 November 2015

[Easy DNA editing will remake the world. Buckle up](#)

Amy Maxmen *Wired* August 2015



BACKGROUNDEERS

[Don't worry about designer babies – gene editing won't work on complex traits like intelligence](#)

A Cecile JW Janssens *H-Plus Magazine* 14 December 2015

[Why treat gene editing differently in two types of human cells?](#)

G Owen Schaefer *The Conversation* 7 December 2015

[Excitement rises over gene editing tool, but ethical doubts remain](#)

Clive Cookson *Financial Times* 6 December 2015

[Regulate gene editing now: this technology strikes at the heart of what it is to be human](#)

Francis Fukuyama *New York Daily News* 4 December 2015

[Gene editing: is the era of designer humans getting closer?](#)

Fergus Walsh *BBC News* 3 December 2015

[What can you actually do with your fancy gene editing technology?](#)

Ed Yong *Atlantic* 2 December 2015

[The promise of gene editing](#)

Fergus Walsh *BBC News* 1 December 2015

[Can Crispr avoid the Monsanto problem?](#)

Michael Specter *New Yorker* 12 November 2015

[Gene editing beat a baby's leukaemia. Are other cancers next?](#)

Michael Le Page *New Scientist* 11 November 2015

[Why there is an urgent need for a moratorium on gene editing](#)

Vivek Wadha *Huffington Post* 9 September 2015

[The Guardian View on human genome editing: find, replace – and cure](#)

Guardian 2 September 2015

[The age of the red pen](#)

Economist 22 August 2015

[CRISPR: is it a good idea to upgrade our DNA](#)

Zoe Corbyn *Guardian* 10 May 2015

[Human gene editing has arrived – here's why it matters](#)

Penny Sarchet *New Scientist* 29 April 2015

[Chinese scientists genetically modify human embryos](#)

David Cyranoski & Sara Reardon *Nature* 22 April 2015

[Don't edit the human germline](#)

Edward Lanphier et al *Nature* 12 March 2015

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NOTES

ORGANISATIONS

[Centre for Genetics and Society](#)

[Progress International Trust](#)



IN THE NEWS

[UK scientists ask permission to genetically modify human embryos](#)

Guardian 18 December 2015

[Scientists urge caution on human gene editing](#)

Al Jazeera 4 December 2015

[Safer way to do gene editing](#)

BBC News 1 December 2015

[Humans will be 'irrevocably altered' by genetic editing, warn scientists ahead of summit](#)

Telegraph 30 November 2015

[Time has come to engineer DNA to block transmission of inherited disorders, say scientists](#)

Independent 30 November 2015

[Future of human gene editing to be decided at landmark summit](#)

Guardian 28 November 2015

['Almost a miracle': 1 year old girl saved by genome editing therapy](#)

Russia Today 7 November 2015

[Dawn of gene editing medicine?](#)

BBC News 6 November 2015

['Designer cells' reverse one year old's cancer](#)

BBC News 5 November 2015

[British Baby given genetically edited immune cells to beat cancer in world first](#)

Telegraph 5 November 2015

[UK scientists seek permission to genetically modify human embryo's](#)

Guardian 18 September 2015

[What is genome editing and how does it work?](#)

Wellcome Trust 10 September 2015

[Embryo engineering a moral duty, says top scientist](#)

BBC News 13 May 2015

[China shocks world by genetically engineering human embryos](#)

Telegraph 23 April 2015

[Gene advance heralds new breeds](#)

The Times 16 November 2013

[Precise genome editing could transform therapy](#)

The Times 8 November 2013

[UNESCO panel of experts call for a ban on editing human DNA](#)

UNESCO

AUDIO/VISUAL

[Editing the human genome](#)

BBC 28 November 2015

[Science and morality](#)

Moral Maze BBC Radio 4 22 February 2014

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NOTES



ADVICE FOR DEBATING MATTERS



FOR STUDENTS

READ EVERYTHING

In the Topic Guide and in the news - not just your side of the argument either.

STATISTICS ARE GOOD BUT.....

Your opponents will have their own too. They'll support your points but they aren't a substitute for them.

BE BOLD

Get straight to the point but don't rush into things: make sure you aren't falling back on earlier assertions because interpreting a debate too narrowly might show a lack of understanding or confidence.

DON'T BACK DOWN

Try to take your case to its logical conclusion before trying to seem 'balanced' - your ability to challenge fundamental principles will be rewarded - even if you personally disagree with your arguments.

DON'T PANIC

Never assume you've lost because every question is an opportunity to explain what you know. Don't try to answer every question but don't avoid the tough ones either.

FOR TEACHERS

Hoping to start a debating club? Looking for ways to give your debaters more experience? Debating Matters have a wide range of resources to help develop a culture of debate in your school and many more Topic Guides like this one to bring out the best in your students. For these and details of how to enter a team for the Debating Matters Competition visit our website, www.debatingmatters.com

FOR JUDGES

Judges are asked to consider whether students have been brave enough to address the difficult questions asked of them. Clever semantics might demonstrate an acrobatic mind but are also likely to hinder a serious discussion by changing the terms and parameters of the debate itself.

Whilst a team might demonstrate considerable knowledge and familiarity with the topic, evading difficult issues and failing to address the main substance of the debate misses the point of the competition. Judges are therefore encouraged to consider how far students have gone in defending their side of the motion, to what extent students have taken up the more challenging parts of the debate and how far the teams were able to respond to and challenge their opponents.

As one judge remarked *'These are not debates won simply by the rather technical rules of schools competitive debating. The challenge is to dig in to the real issues.'* This assessment seems to grasp the point and is worth bearing in mind when sitting on a judging panel.



**“WORLD REQUIRES
THE CAPACITY
TO MARSHALL
CHALLENGING IDEAS
AND ARGUMENTS”**

**LORD BOATENG, FORMER BRITISH HIGH
COMMISSIONER TO SOUTH AFRICA**