This response was submitted to the Call for Evidence held by the Nuffield Council on Bioethics on genome editing and human reproduction between 15 May 2017 to 14 July 2017. The views expressed are solely those of the respondent(s) and not those of the Council.

## Nuffield Council CfE Human Reproduction – Amarpreet Kaur

- In my study conducted between December 2016 and March 2017 with 17
  participants who have various genetic conditions, it was found that genome
  editing was considered a greater good in comparison to PGD. This view was
  largely held because participants felt that genome editing was more respectful to
  life, and the process the woman/couple has to go through to conceive a child, in
  light of having a inheritable genetic condition.
- 2. Participants in my study believed that genome editing should be restricted to medical conditions that they considered to be highly debilitating, i.e. conditions which result in high levels of dependency, and/or high levels of pain and suffering. Participants felt that legislation and regulation should ensure restrictions pertaining to medical need alone are kept in place, and genome editing for non-medical purposes should never be made legal.
- 3. In my opinion, considering the views of participant in my study and other individuals I have spoken to, scientists should restrict their curiosity to genetic markers relating to medical characteristics alone. Scientists should focus on the effects CRISPR-Cas9 has on DNA once the edit has been implemented and how cells develop/react to the change. I think scientists owe greater understanding of current capacities of CRISPR in relation to human reproduction to society. Genome scientists should feel obligated to not run before they can walk, and to envisage the catastrophic effects their experiments could have, in addition to the good they could bring. In distinction from other scientists, genome scientists are potentially editing a whole life and human being, as opposed to just part of a body or cell.
- 4. Genome editing could be a valuable research tool, but I think society is currently divided and undecided on the necessity of developing such technologies. I think genome editing has the potential to transform reproductive decisions if the platforms that will enable it, i.e. IVF and PGD are first perfected to have greater success rates. At present, PGD is relatively unsuccessful in terms of how many live births result from cycles initiated, and this is unlikely to change with the addition of genome editing.
- Governments should have obligations to keep scientific research and development within moral interests of society rather than creating false needs for society. I think regulation is key, but the extent of regulation should be done in consultation with wider society.