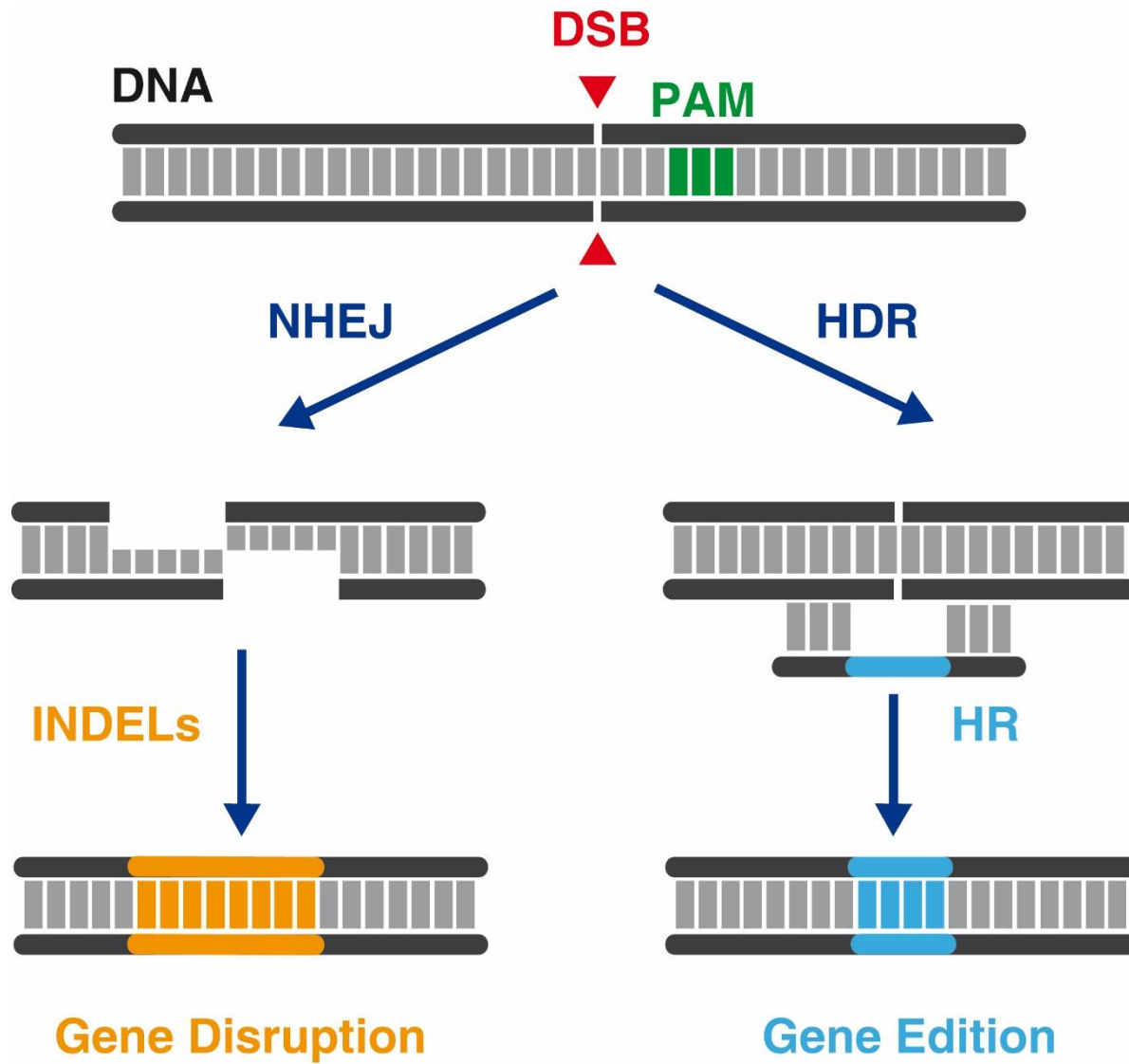


Association for Responsible Research and Innovation in Genome Editing

Next Steps



ARRIGE: Kick-Off Meeting - Paris - 23 March 2018



- INSERM
- Paris, March 2016
- Africa
- South America
- India
- Publication, July 2017
- Paris, November 2017

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LETTER TO THE EDITOR

Fostering responsible research with genome editing technologies: a European perspective

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European Steering Committee

1. To Foster research that will assess the feasibility, the efficacy and the safety of genome editing techniques
2. To evaluate the potential adverse effects of gene drive applications
3. To reassess the ban on all modifications of the germ line nuclear genome for clinical application in human reproduction
4. To be pro-active to prevent this technology from being hijacked by those with extremist views and to avoid misleading public expectation with overinflated promises
5. To raise awareness about the distinction between the care/treatment of human diseases and human enhancement

Paris, 13 November 2017

1. Thinking ahead when enacting new legislation, anticipating rather than reacting
2. To foster a governance risk-management approach, taking into account the many uncertainties
3. Inclusive debate on “acceptability and desirability” extended to civil Society, and not only limited to safety issues, potential health risks and benefits
4. Transparency to expose what science is doing, what science could do and what science should not do
5. Need to deal with race towards the market of some applications, the constraint of some patent fights or the development of the “do it yourself” movement.

Paris, 23 March 2018

1. Many reports and documents dealing on Ethics issues and responsible use of genome editing (GE) techniques
2. Time to join efforts, to team up: scientists, research institutions, ethicists, regulators, representatives of economic sectors impacted by GE (health, agricultura, environment,...), general public, patient associations and NGOs
3. To create the ARRIGE (Association for Responsible Research and Innovation in Genome Editing) initiative with the goal to promote a global governance of GE.

Two Options

1. Maintain a **discussion group**, associated with a web page and an email discussion list, but without a structure and without legal existence or representation. **Easier, probably less effective.**
2. Founding a non-for-profit **association**, obtaining a legal status, legal representation, implies defining goals, objectives, activities, also commitment and co-responsability, requires officially registering it in an EU country (i.e. France), bylaws, electing a board and executive delegates, liability, membership fees, assets, committees, internal structure, different areas, a **lot of work, probably more effective.**

ARRIGE Association

- **What should be steer?**
 - Defining the field of questions that need to be tackled.
- **How can be steer?**
 - Defining realistic goals to assist the process of governance.
 - To provide researchers with framework and guidance when assessed.
- **Whom should be steer?**
 - Agencies, public bodies
 - Public, patients, everyone
- **Creating guidance, toolboxes**
 - Interesting for researchers and regulators
 - Interesting for public engagement too

ARRIGE Association

- **Human issues**
- **Environmental issues**
- **Animal issues**
- **Intellectual properties & economic issues**

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