Annex Ethics self-assessment

**Ethics self-assessment**

Questions on ethics (obligatory information)

The networking event is limited to discussing research results. This section on ethics is obligatory to fill in within the European Rare Disease Research Alliance (ERDERA).

For more information, please read the Call text, section 5.3.3 (Ethics self-assessment).

A pre-filled Horizon Europe self-assessment ethics template is used. Red rows are considered not applicable (NA) for your proposal since no activity will be carried out during the networking event as specified in the Call text that could lead to the mentioned ethics issues, while green rows may be applicable or not. Please check the information in the green rows and complete the blank rows:

* *Humans: “YES”- although humans will not be SUBJECTS of the activity, since human participants will participate in the event and personal data from them is to be collected. Please include a reference to the information in the application on this section.*
* *Personal data: “YES” since personal data (e.g.,* *name, address, occupation, e-mail, photo, videos) from participants is to be collected for logistical and dissemination purposes. If sensitive (e.g., health and genetic data) is processed during the event (e.g., collected, analysed, disclosed), please reply “Yes” to the specific questions. Moreover, please specify if a data transfer from EU to non-EU countries or vice versa is foreseen (e.g., if participants come from a non-EU country). Please include a reference to the information in the application on this section.*
* *Third countries:* *“YES” only if some* *of the activities will be carried out in non-EU countries. Please include a reference to the information in the application on this section.*
* *Reference: provide a reference to the subsection in the application where the specific information is written*

Identifying ethics issues

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| --- | --- | --- | --- | --- | --- |
| **Section 1: HUMAN EMBRYONIC STEM CELLS AND HUMAN EMBRYOS** | | | | **NA** |  |
| **Section 2: HUMANS** | | | | **YES** | **Reference** |
| Are they children/minors? | | | |  |  |
| **Section 3: HUMAN CELLS / TISSUES** | | | | **NA** |  |
| **Section 4: PERSONAL DATA** | | | | **YES** | **Reference** |
| Does this activity involve processing of personal data? | | | |  |  |
| If YES: | Does it involve the processing of special categories of personal data *(e.g. sexual lifestyle, ethnicity, genetic, biometric and health data, political opinion, religious or philosophical beliefs)*? | | |  |  |
| If YES: | | Does it involve processing of genetic, biometric or health data?  *Explanations on this point are provided in the  Frequently Asked Questions (FAQ) on the* [*ERDERA website*](https://erdera.org/nss/) |  |  |
| Does it involve profiling, systematic monitoring of individuals, or processing of large scale of special categories of data or intrusive methods of data processing (such as, surveillance, geolocation tracking etc.)? | | |  |  |
| Does your activity involve further processing of previously collected personal data *(including use of pre-existing data sets or sources, merging existing data sets)*? | | | |  |  |
| Is it planned to export personal data (data transfer) from the EU to non-EU countries? | | | |  |  |
| If YES: | | *Specify the type of personal data and countries involved:* | |  |  |
| Is it planned to import personal data (data transfer) from non-EU countries into the EU or from a non-EU country to another non-EU country? | | | |  |  |
| If YES: | | *Specify the type of personal data and countries involved:* | |  |  |
| **Section 5: ANIMALS** | | | | **NA** |  |
| **Section 6: THIRD COUNTRIES** | | | | **YES/NO** | **Reference** |
| Will some of the activities be carried out in non-EU countries? | | | |  |  |
| If YES: | | *Specify the countries:* | |  |  |
| In case non-EU countries are involved, do the activities undertaken in these countries raise potential ethics issues? | | | |  |  |
| If YES: | | *Specify the countries:* | |  |  |
| Could the situation in the country put the individuals taking part in the activity at risk? | | | |  |  |
| **Section 7: ENVIRONMENT, HEALTH AND SAFETY** | | | | **NA** |  |
| **Section 8: ARTIFICIAL INTELLIGENCE** | | | | **YES/NO** | **Reference** |
| Does this activity involve the development, deployment and/or use of Artificial Intelligence-based systems? | | | |  |  |
| Could the AI based system/technique potentially stigmatise or discriminate against people *(e.g. based on sex, race, ethnic or social origin, age, genetic features, disability, sexual orientation, language, religion or belief, membership to a political group, or membership to a national minority)*? | | | |  |  |
| Does the AI system/technique interact, replace or influence human decision-making processes *(e.g. issues affecting human life, health, well-being or human rights, or economic, social or political decisions)*? | | | |  |  |
| Does the AI system/technique have the potential to lead to negative social *(e.g. on democracy, media, labour market, freedoms, educational choices, mass surveillance)* and/or environmental impacts either through intended applications or plausible alternative uses? | | | |  |  |
| Does the AI to be developed/used in the project raise any other ethical issues not covered by the questions above *(e.g., subliminal, covert or deceptive AI, AI that is used to stimulate addictive behaviours, life-like humanoid robots, etc.)?* | | | |  |  |
| **Section 9: OTHER ETHICS ISSUES** | | | | **YES/NO** | **Reference** |
| Are there any other ethics issues that should be taken into consideration?  *Please specify:* | | | |  |  |

If you wish to explain your answer to item 9 (Questions on ethics) you may use 1 additional page (DIN-A4, Inter 10 or Arial 11, single-spaced, and margins of 2.54 cm). This is not mandatory to fill in.