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DIVERSIunity recommendations for the European Commission's consultation on GDPR

As the European Commission has opened a consultation on potential revisions to existing GDPR legislation, different actors in the field of research and innovation are expected to provide feedback for the 2025 report. Reading Science Europe's feedback (published on 8 Feb 2024), DIVERSIunity would like to raise some concerns regarding diversity.

It is our viewpoint that some of the suggestions put forward would directly disincentivise minorities from providing data to research projects, putting individuals at risk, whether they be research subjects, colleagues or collaborators.

DIVERSIunity's concerns are focused around three themes:

Combining Data in the Age of AI

No matter the specific issue during the previous year, the solution put forward has predominantly been "AI". This dialogue has also been present within the research and innovation community. The use of AI poses challenges to GDPR, as this multiplies the possibilities, speed and scale of combining data. Despite the risks, data collection and analysis increasingly happen in an AI 'black box', which very few can understand and even fewer access. The risks associated with decoding metadata, unintended data leaks and the potential exposure of minority persons to these situations, appears to be at a scale that very few imagined in recent years. The pending EU AI Act and national legislation cover some of these challenges, but as the scientific community pushes for increased opportunities for combining data and for a looser iteration of the GDPR legislation, any revision has a special responsibility to protect the most vulnerable groups in our society. Their identities and data risk being used for



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training AI models, analysing data and advancing science without any concern for the security of these minority groups. While intentions may be well-meaning, proper and nuanced data is increasingly needed for the development of more inclusive AI. The price should not be paid by minorities, as has too often previously been the case.

Recommendations:

- ✦ The 2025 report should suggest clear legislative improvements that protect data on personal characteristics to be analysed in public AI models even when anonymised due to the unknown content of the AI “black box”.
- ✦ The 2025 report should make it clear that the research data protected by GDPR should not be used to train AI at the risk of revealing the identities (or other personal or protected information) of minority individuals, which could compromise the security of minority groups or individuals.
- ✦ The 2025 report should outline penalties for using AI to decode GDPR-protected identities intentionally or unintentionally fx when combining research data with fx real-life data.
- ✦ The 2025 report should describe a system for redress should a significant negative legal, social or political outcome to an individual or organisation occur due to bias from AI in processing data through GDPR.
- ✦ The 2025 report should outline clear and commensurate penalties for researchers who neglect the security concerns of minority groups, preferably suspending researchers and research institutions from collecting, hosting and accessing data. Otherwise, minority groups carry the entire burden and the consequences of a conscious or unconscious negligent scientific community.
- ✦ The 2025 report should outline penalties when AI models in research circumvent the GDPR protection. An enforcing measure should be when this is used in IP and spinouts that make money while risking the security of minority groups and building on societal inequalities by making money off them.



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Politicisation

Several protected characteristics (particularly LGBTQ+ identities) have in recent years been politically contested in many countries both within and outside Europe. At the same time, we see autocratic movements, often in the same countries. While this does not present an immediate risk, it does, however, provide a window into potential future problems if research data on minorities is decoded and then used for political persecution.

Recommendations:

- ✦ The 2025 report should insist on aligning interpretations as suggested by Science Europe. Regarding personal characteristics, this interpretation should be as strict as necessary to protect minorities from political persecution.
- ✦ The 2025 report should reaffirm the political independence of GDPR compliance and define personal characteristics protected by the European Declaration of Human Rights that form the basis of the “European Values” that play an increasingly important role in EU guidelines for international collaboration, including for research and innovation.

International collaborations

While GDPR is a challenge to international research collaborations, as described by Science Europe, for minority groups, these ‘challenges’ are crucial. For LGBTQ+ persons, the consequences of data sharing can be imprisonment or even capital punishment in certain countries if something goes wrong for technical or political reasons, as described in the previous two themes of this submission. Whether individuals belong to a minority group based on their race, ethnicity, sexual orientation, religion, ability, etc., they become at risk of detainment or imprisonment, social, cultural, financial or political exclusion in their home countries or when going abroad, or death,



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these real-life consequences must be considered the first priority when adjusting the GDPR legislation for smoother international research collaboration and data sharing. It is important to note that the populist and autocratic movements, described in theme two of this submission, can also be seen in countries with which Europe usually has strong research collaborations.

Recommendations:

- ✦ The 2025 report should strengthen data protection relating to personal characteristics when research collaborations cross borders due to the increasingly insecure political environment globally with minimum standards for protection. Due to the overlap of concerns, these standards could be reinforced when collaborating with countries mentioned in the EU's list of countries with concerning standards of academic freedom or the latest list from the European Union Agency for Fundamental Rights.
- ✦ The 2025 report should set out procedures for retracting data collaboration in research on a national level if minority groups are persecuted and political interference with research data puts groups at risk.
- ✦ The 2025 report should describe sanctions for researchers and research institutions, banning them from accessing data relating to personal characteristics if data has been shared with researchers or research institutions internationally, putting minority persons at risk.

Conclusion

Considering these recommendations in the report and future updates on the GDPR legislation will improve transparency for minority groups and ensure continued trust in science in all parts of society. It is important to remember that, unlike for the research community, for minorities, it isn't about protecting data but about protecting identity and, ultimately, about protecting life.



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Further information

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