

Revision of the European Data Protection legislation Potential harmful consequences for public health monitoring and research

What is the current situation?

The current EU Data Protection legislation is under revision and will be replaced by a new General Data Protection Regulation. In 2012 the European Commission published a first [proposal](#). In October 2013 the European Parliament passed several [amendments](#), which could have serious negative effects for public health monitoring and research.

What will the further process be?

- The Council aims to adopt its amendments in 2015;
- After that, the Commission will draft a new compromise proposal, which will be discussed again in the European Parliament and the Council.

The process may be delayed due to the European elections next year, as the new Commissioner and rapporteur can decide to draft completely new proposals.

What can you, as a public health expert, do?

- Inform your MEPs and counterparts at the Ministries of Justice about the potential devastating effects of the current EP proposal on public health monitoring and research, and hence on the health of European citizens.
- Stress that it is necessary and possible to strike the right balance between public and private interests. Citizens want protection of their privacy but they want good health research as well. Good techniques and methods exist that ensure the protection of data subjects in public health monitoring and research.

Why do we need personal health data for public health? → [EUPHActs](#)

Which amendments potentially have the most serious consequences?

- Using personal health data for public health monitoring and research (M&R) without informed, explicit consent will only be possible in cases of “high public interest”. What constitutes high public interest may be defined in such a way that using data for public health purposes may be severely restricted.
 - The definition of informed, explicit consent is not clear. It is therefore questionable whether broad consent, which currently is commonly applied in research, will still be possible.
 - The definition of pseudonymized data is not clear. It might mean that all pseudonymized data will be considered to be personal data. If this is the case, this will complicate M&R in countries in which currently pseudonymized data are considered anonymous data if specific safeguards are met.
 - If the right to be forgotten applied to M&R contexts, statistical information about public health threats would become unreliable.
- These amendments will seriously hamper the possibilities for doing population based research, especially research using register based data and research linking different data sources. Magnitude and quality of M&R will diminish, while costs and time scales for doing M&R will significantly increase.

What will EUPHA do? → Inform the decision makers, in liaison with fellow public health and research organizations.
→ Support its members in their advocacy actions through making an impact assessment for the current EP proposal.