



PARTICIPATORY APPROACHES TO A NEW ETHICAL AND LEGAL FRAMEWORK FOR ICT

PANELFIT Project is funded by the EU Commission, H2020 SWAFS Programme, research grant number 788039



Using data in pandemics

Iñigo de Miguel Beriain

FUNDAMENTALS - KEY POINTS

- Journalists have to report about pandemics
- This might involve using personal data
- These data can only be processed if a legal basis allows it
- If there are special categories of personal data involved, there is a general veto to their processing
- The availability of data does not involve the lawfulness of processing

Fundamentals: health data. The veto

- Processing of personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, or trade union membership, and the processing of genetic data, biometric data for the purpose of uniquely identifying a natural person, data concerning health or data concerning a natural person's sex life or sexual orientation shall be prohibited.
- General veto. Exceptions (article 9.2)

Exceptions applicable

- The data subject has given explicit consent to the processing of those personal data for one or more specified purposes
- Processing relates to personal data which are manifestly made public by the data subject
- processing is necessary for reasons of substantial public interest, on the basis of Union or Member State law which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject

Further on...

- Member States may maintain or introduce further conditions, including limitations, with regard to the processing of genetic data, biometric data or data concerning health (article 9.4)

Legal basis data processing

- the data subject has given consent to the processing of his or her personal data for one or more specific purposes;
- processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller;
- processing is necessary for the purposes of the legitimate interests pursued by the controller or by a third party, except where such interests are overridden by the interests or fundamental rights and freedoms of the data subject which require protection of personal data, in particular where the data subject is a child.

Some essential tips

- Most probably, the Journalist exception (article 85 GDPR) will provide for exemptions or derogations from Chapter II (principles), Chapter III (rights of the data subject), Chapter IV (controller and processor)
- You must check your national legal framework

Takeaway points

- Publishing sensitive information might cause considerable harm to private life of the data subject. You must be sure that benefits to public interest justifies this harm. To this purpose, you should balance the interest at stake, considering different levels of intrusion into their private life of the data subject. Only when public interest considerations clearly prevail against their privacy you are allowed to publish this information.
- The intervention of senior editorial or the use of expert input might be of great help to ensure that this requirement applies. Never forget that usually the interested journalists are not so objective while balancing the interests involved.
- Always remember that you should only gather data that are relevant to your investigation and might of public interest. If, for instance, you are investigating a politician on the basis of a possible corruption practice and you discover sensitive information about his or her sexual orientation, you should not process it, provided that it is not relevant for the issue at stake. This is an essential requirement of the minimization principle, a key concept in the GDPR.
- In particularly contentious cases, where it is not entirely clear if or to what extent the “journalistic exemption” applies to data processing, an audit trail should be kept in order to explain the data protection considerations, as well as the consultation from the lead supervisory authority, should be sought.

Takeaway points

- Special precautions must be adopted where personal data are processed which reveal racial or ethnic origin, political opinions, religion or philosophical beliefs, trade union membership, and the processing of genetic data, data concerning health or data concerning sex life or criminal convictions and offences or related security measures.
- Data concerning vulnerable population and specially minors should only be processed if strong reasons justify it. You must be absolutely sure that they apply to the concrete processing before proceeding with it.

And a hot issue

- Quite often, journalists take data from social networks (Facebook, Twitter, etc). This is problematic.
- Read the terms of use provided by the social media site (e.g. [Twitter rules](#)).
- You may be able to access a profile or other kinds of social media data on a site because you are registered user. This is **not** the same as that information being publicly available.
- You can only use the data available to you as registered user of a site in accordance with the policy of that site (which users consent to when they join). For example, Facebook allows the collection of information by third parties from its site, but users' consent must be obtained.
- **The use of social media data is not automatically ethical just because it is accessible.**