

## Heidi Beate Bentzen

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Heidi Bentzen researches the legal and ethical aspects of emerging technologies and large-scale data sharing and secondary use of health and genetic data, within and across contexts and jurisdictions. Bentzen conducts research or provides supervision and training in five EU funded projects and two Research Council of Norway financed projects. Additionally, she is Ethics Advisor for five EU financed projects, and on the external advisory board of another EU funded project, all in the medical field.

Bentzen was a member of the United Nations Special Rapporteur on the Right to Privacy's health data task force, part of drafting the global *Recommendation on the protection and use of health-related data*. She co-chairs the legal working group of the Nordic Society of Human Genetics and Precision Medicine, is a member of the Norwegian Directorate of Health's User Board for Health Data and the Bio Reference Group, an expert advisory group for the Norwegian authorities in biotechnology related matters.

She has published in some of the world's foremost scientific journals, is frequently invited to present at international conferences, teaches data protection law and research ethics, and provides legal advice on international data transfers to the Cancer Registry of Norway. Bentzen evaluates scientific proposals for the European Commission and conducts ethics reviews for the European Commission and a Norwegian Regional Ethics Committee.

Some of Bentzen's scientific publications relevant to her presentation at the 14<sup>th</sup> International Workshop on Advanced Genomics include:

- **Bentzen HB**, Olav HK, Ursin G. *Maximizing the GDPR potential for data transfers: first in Europe*. The Lancet Regional Health – Europe (2023), doi: <https://doi.org/10.1016/j.lanepe.2023.100600>
- **Bentzen HB**. *Exchange of human data across international boundaries*. Annual Review of Biomedical Data Science (2022), doi: [10.1146/annurev-biodatasci-122220-110811](https://doi.org/10.1146/annurev-biodatasci-122220-110811)
- Ursin G & **Bentzen HB**. *Open science and sharing personal data widely – legally impossible for Europeans?* Acta Oncologica (2022), doi: [10.1080/0284186X.2021.1995894](https://doi.org/10.1080/0284186X.2021.1995894)
- **Bentzen HB**, Castro R, Fears R, Griffin G, ter Meulen V, Ursin G. *Remove obstacles to sharing health data with researchers outside of the European Union*. Nature Medicine (2021), doi: <https://doi.org/10.1038/s41591-021-01460-0>
- O'Doherty K, Shabani M, Dove ES, **Bentzen HB**, Borry P, Burgess MM et al. *Better governance of human genomic data: clarifying the issues and balancing competing values*. Nature Genetics (2021), doi: <http://dx.doi.org/10.1038/s41588-020-00742-6>
- Griffin G, ter Meulen V, Albert A, **Bentzen HB**, Boiten J-W, Danesh J et al. (2021). *International Sharing of Personal Health Data for Research. The ALLEA, EASAC and FEAM joint initiative on resolving the barriers of transferring public sector data outside the EU/EEA*. ALLEA, EASAC and FEAM (2021), doi: [www.doi.org/10.26356/IHDT](http://www.doi.org/10.26356/IHDT)
- Nicol D, Eckstein L, **Bentzen HB**, Borry P, Burgess M, Burke W et al. *Consent insufficient for data release*. Science (2019), doi: [10.1126/science.aax0892](https://doi.org/10.1126/science.aax0892)
- **Bentzen HB** & Høstmælingen N. *Balancing protection and free movement of personal data: The new European Union General Data Protection Regulation*. Annals of Internal Medicine (2019) doi: [10.7326/M18-2782](https://doi.org/10.7326/M18-2782)
- **Bentzen HB** & Mascialzoni D, Ljøsne IB, Bygrave LA, Bell J, Dove ES et al. *Are requirements to deposit data in research repositories compatible with the European Union's General Data Protection Regulation?* Annals of Internal Medicine (2019), doi: [10.7326/M18-2854](https://doi.org/10.7326/M18-2854)