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Leiden
The Netherlands

A fair balance: health data protection and the promotion of health data use for clinical and research purposes

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Citation

Kist, I. R. (2024, June 5). *A fair balance: health data protection and the promotion of health data use for clinical and research purposes*. Retrieved from <https://hdl.handle.net/1887/3759726>

Version: Publisher's Version

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Note: To cite this publication please use the final published version (if applicable).

11. List of professional activities and affiliations

Professional activities⁵⁴³

2018 - present:

- Data protection officer at the Netherlands Cancer Institute. The advices to both clinicians and researchers have served as a foundation for identifying and defining the scope of this thesis. Furthermore, I am the first point of contact for patients as regards privacy-related questions. I give workshops to colleagues and I participate in meetings of moral deliberations.

2019:

- 25 – 26 March 2019: Cancer Core Europe Annual Meeting in Barcelona. Member of the Data Access Committee (DAC).
- July: submission of a conference paper for the sixth International Workshop on Genome Privacy and Security (GenoPri'19) on 20 and 21 October 2019 in Boston, Massachusetts. Title of the paper: "GDPR consent requirements and other legal bases for processing."⁵⁴⁴
- 25 November 2019: Data Access Committee (DAC) of Cancer Core Europe at the Netherlands Cancer Institute, Amsterdam.
- 2 September 2019: panelist at the Work forum about Artificial Intelligence at the Netherlands Cancer Institute, Amsterdam.
- 6 November 2019: moderator at the Congress on Internet Accountability in the Digital Age at the Peace Palace in The Hague.

2020:

- 4 and 5 February 2020: guest speaker at the Data Protection World Forum in London. Topic: international data transfers in health research.
- 24 February 2020: guest speaker at the ELSI (Ethical, Legal and Social Issues) workshop on the GDPR and observational health research, organized by the ELSI Servicedesk of Health-RI (Research Infrastructure).⁵⁴⁵
- 11 March 2020: participant at the round table, organized by the Dutch Data Protection Authority.
- 1 June 2020: publication of my GDPR brief for the Global Alliance for Genomics and Health (GA4GH) on "The interplay between the Clinical Trials Regulation and the GDPR."⁵⁴⁶

⁵⁴³ The list includes professional activities from 2018 until January 2024.

⁵⁴⁴ For the full program, see <https://broadinstitute.swoogo.com/ga4gh7thplenary/388434>. Accessed 30 October 2023.

⁵⁴⁵ <https://elsi.health-ri.nl/nieuws/meld-u-nu-aan-voor-workshops-over-verantwoord-nader-gebruik-van-lichaamsmateriaal-en-data>. Accessed 30 October 2023.

⁵⁴⁶ https://www.ga4gh.org/news_item/ga4gh-gdpr-brief-the-interplay-between-the-clinical-trials-regulation-and-the-gdpr-june-2020/. Accessed 30 October 2023.

- 10 June 2020: guest speaker at the virtual AI Symposium, organized by the Elisabeth Twee Steden hospital.⁵⁴⁷
- 16 June 2020: member of the advisory group on the Revision of the Code of Conduct in Health Research (*Herziening Gedragscode Gezondheidsonderzoek*)
- February – July 2020: member of the task group on the digitalization of consent, organized by the Cooperation Organization for digital services in higher education and research (*Samenwerkingsorganisatie voor Computerdienstverlening in Hoger Onderwijs en Onderzoek (SURF)*)
- 25 August 2020: participant at the Roundtable of data protection officers, organized by the Dutch Data Protection Authority on the topic of “De-regulate science” (*Ontregel de wetenschap*).

2021:

- From 2020 – 2021: member of the expert group of the model authorization of the Dutch Basic Registration of Persons (*Basis Registratie Personen*). Result: revision of the Dutch Authorization Decree (*Autorisatiebesluit*).
- 26 May 2021: completion of the course Scientific Conduct for PhD candidates in Law.
- Fall: Completion of the Course Philosophy of Science for PhD candidates by Leiden University (5 ECTS).
- Fall: co-author of a case study, a dilemma with legal, ethical and medical components. This case study was published in the Dutch Journal of Health care and Ethics (*Tijdschrift voor Gezondheidszorg en Ethiek*).⁵⁴⁸
- 17 – 19 November 2021: IAPP Conference in Brussels.

2022:

- 19 May 2022: presentation at the General Membership meeting of the Dutch Association of data protection officers (*Nederlands Genootschap voor Functionarissen Gegevensbescherming, NGFG*).
- 8 and 9 June 2022: guest speaker at the IAPP Dutch Intensive.
- August 2022: interview as ‘Captain of Privacy’, organized by the Dutch Center for Information Security and Privacy (*Centrum voor Informatiebeveiling en privacybescherming, CIP*).⁵⁴⁹
- August 2022 – present: member of the Data Protection Advisory Committee at the Municipality of Amsterdam (*Commissie Persoonsgegevens Amsterdam*).

⁵⁴⁷ <https://www.etz.nl/Over-ETZ/Nieuws/2020/06/Veel-belangstelling-online-Ai-symposium>. Accessed 30 October 2023.

⁵⁴⁸ T. Smorenburg et al., Casus: altijd transparant over medische informatie? *Tijdschrift voor Gezondheidszorg en Ethiek*, 3(2021)31. https://www.tijdschriftge.nl/art/50-6663_Casus-Altijd-transparant-over-medische-informatie. Accessed 30 October 2023.

⁵⁴⁹ <https://www.it-academieoverheid.nl/actueel/nieuws/2022/10/27/captains-of-privacy>. Accessed 30 October 2023.

- 24 November 2022: guest lecture at the Free University of Amsterdam (*Vrije Universiteit Amsterdam*).

2023:

- 2022 – 2023: member of the Health-RI expert group on legislative developments in the Obstacles Removal Trajectory (*Obstakel Verwijder Traject, OVT*).
- 15 – 16 March 2023: Guest speaker at the Dutch Hospital Association (*Nederlandse Vereniging van Ziekenhuizen, NVZ*).
- 16 May 2023: guest lecture for clinicians and researchers at the Academic Medical Center in Leiden on data sharing in health care and research.
- 23 May 2023: master class on data protection in health care and research, hosted at Erasmus University, together with the data protection officer at the Erasmus Academic Medical Center in Rotterdam.
- 6 June 2023: guest lecture at the Center of expertise for standardization and Ehealth (*Nederlandse kennisorganisatie voor digitale informatievoorziening in de zorg, Nic-tiz*).
- 1 June – present: chair of the privacy committee at the Netherlands Institute for Health Services Research (*Nivel, Nederlands Instituut voor Onderzoek van de Gezondheidszorg*).
- 15 June 2023: guest speaker at the International Association of Privacy Professionals (IAPP) Dutch Intensive.
- 4 September 2023: guest speaker at the International Litigation Forum in Amsterdam. Topic: international data sharing in health & legal foundations.
- 21 – 22 September 2023: guest speaker based on a conference paper at the symposium on Privacy in Context in Toronto, with author and organizer prof. Helen Nissenbaum.⁵⁵⁰
- 27 September 2023: guest speaker at the World Litigation Forum in Amsterdam. Topic: preventive actions in international data sharing.
- 12 October 2023: panelist at the Health-RI (Research Infrastructure) conference.
- 9 November 2023: guest speaker at the National Biobanking and Collections Day.
- 14 November 2023: guest speaker at the Center for Post-graduate Legal Education (*Centrum voor Postacademisch Juridisch Onderwijs, CPO*).
- 15 November 2023: guest speaker at the NedMec Congress (the Medical Research Ethics Committee (MREC) NedMec is the medical research ethics committee to which the Antoni van Leeuwenhoek, the Princess Máxima Center for pediatric oncology and the UMC Utrecht are affiliated).

⁵⁵⁰ Based on her conceptual framework of privacy. See, inter alia: Nissenbaum, H. (2020). *Privacy in context: Technology, policy, and the integrity of social life*. Stanford University Press.

2024:

- 22 and 23 January 2024: guest speaker at the World Litigation Forum in Dubai. Topic: emerging trends in data privacy and litigation.

Professional affiliations and memberships

- Member of CIP; member of the group of legal experts for CIP.
- Member of Collaborating Intramural Health Institutions in the Amsterdam Region (*Samenwerkende Intramurale Gezondheidszorgvoorzieningen Regio Amsterdam, SIGRA*).
- Member of the Regulatory Ethics Working Group of the Global Alliance for Genomics and Health (GA4GH).
- Member of the expert group of data protection officers at the Dutch Hospital Association (*Nederlandse Vereniging van Ziekenhuizen, NVZ*).
- Member of the Dutch Association of data protection officers (*Nederlands Genootschap voor Functionarissen Gegevensbescherming, NGFG*).
- Member of the International Association of Privacy Professionals (IAPP).
- Member of two expert groups at Health-RI (Research Infrastructure).
- Member of the Data Protection Advisory Committee at the Municipality of Amsterdam (*Commissie Persoonsgegevens Amsterdam*).
- Chair of the privacy committee at the Netherlands Institute for Health Services Research (*Nivel, Nederlands Instituut voor Onderzoek van de Gezondheidszorg*).