ACHIEVING ANONYMIZATION IN HUMAN - DERIVED RESEARCH DATA

12 - 16 weeks

April - July 2019

BACKGROUND

Anonymization of personal data is broadly defined by the GDPR legislation; this leaves room for interpretation and creates fear of punishment should data be deemed insufficiently anonymized. However, if institutions opt to "play it safe" and treat **all** human-derived research data as personal data, including potentially anonymous data, an enormous administrative burden will be placed on the shoulders of research staff. This, in turn, may hinder the achievement of open science and data sharing.

PLAN OF ACTION

- ✓ Review GDPR definition of anonymization and potential interpretations thereof
- ✓ Discuss balance between open science and privacy rights
- ✓ Assess the re-identification risks of various types of data, starting with data types generally thought to be anonymous: consider likelihood, feasibility and impact of re-identification with such data

WHY IS THIS A CROSS-INSTITUTION ISSUE?

In a world with big data, online profiles and machine learning algorithms, it is impossible 100% anonymity. Efforts to do so result in data that is worthless for reuse. So what level of risk is sufficiently low? Can certain types of human-derived research data be considered sufficiently anonymous, allowing them to be more readily shared? Opinions on these issues vary across institutions, and it is unknown how strictly anonymity will be enforced by the Dutch Data Protection Authority. Bringing together stakeholders from several institutions and backgrounds will allow for discussion about when we can consider certain types of human-derived research data as anonymous and, thus, no longer subject to the GDPR.

OUTPUT

- ✓ A clear definition of anonymized, human-derived research data

- ✓ Report presenting the re-identification risks for various types of data

TASK GROUP COMPOSITION

- ✓ Researchers who work with human-derived data
- ✓ Data scientists
- ✓ Anonymization experts
- ✓ Privacy lawyers

WANT TO KNOW MORE?

Jessica Hrudey
e.j.hrudey@vu.nl

Henk van den Hoogen
h.vandenhoogen@maastrichtuniversity.nl

WANT TO APPLY?

Ingeborg.Verheul@surfsara.nl

National **Coordination Point**
Research Data Management