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IP in Health Data Sharing

Essentials of Medical Data Sharing and Privacy –
Maximize the use of data

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Background

- Health data sharing is strongly supported in principle, not only for (non-economic) research purposes but also involving industry partners.
- Health data sharing can be challenging to implement in practice.

Question

- What are the actual bottlenecks to health data sharing in Switzerland?

Approach

- transactional perspective

Legal uncertainty in data deals

- Interview study: What are the bottlenecks to health data sharing in Switzerland?*
- identified legal uncertainties in the following areas
 - privacy laws in international data sharing settings
 - “who owns the data”
 - Swiss general consent being implemented differently across different institutions
 - definitions and operationalisations of anonymization
- “[...] *participating parties struggled with missing legal clarifications and uncertainties of governance-related aspects and their **associated intellectual property regulations** to share health data with third parties.*”

* ORMOND et al., What are the bottlenecks to health data sharing in Switzerland? An interview study, published 22 January 2024

Intangible asset as contract subject matter

- no data ownership right
 - no comprehensive right of domination;
 - data ownership does neither fit into existing categories of property rights nor liability provisions
- legal monopoly position on IP rights
 - patents: invention, novelty, inventive step
 - copyrights: intellectual creation with an individual character
- factual monopoly position on know-how
 - Art. 5 lit. c and Art. 6 of the Unfair Competition Act
 - Art. 162 of the Criminal Code
 - EU Trade Secret Directive 2016/943
- contractual rights and obligations on data
 - effects limited on contracting parties

Reliance on contractual terms

- no data ownership right



Protection by law

IP rights:
legal monopoly

know-how:
factual monopoly

data:
contractual rights
and obligations

Agreement terms

What is stopping us from sharing health data from a transactional perspective?

Undetermined Secondary Use at Time of Negotiation

Informational value of data develops in context and over time

Data are several things simultaneously

Data serves multiple purposes



Deal Value?

lack of
enforce
ment
right

competitive
edge

incremental
value of
data



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Thank you for your attention!

Follow-up questions to
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