

INCISIVE data sharing scheme

Benefits of data sharing through INCISIVE

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Plan of the workshop

Barriers and
benefits to
data sharing

INCISIVE
proposal for
data sharing

Q&A and
feedback from
the participants

This project has received funding from the European's Horizon 2020 research and innovation programme under Grant Agreement number: 952179



Benefits and barriers to data sharing

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Benefits of data sharing*

Transparency

Maximising the utility and impact of the data collected

Making collaboration easier

Research acceleration

Reproducibility

Data citation & credit

Long-term data preservation

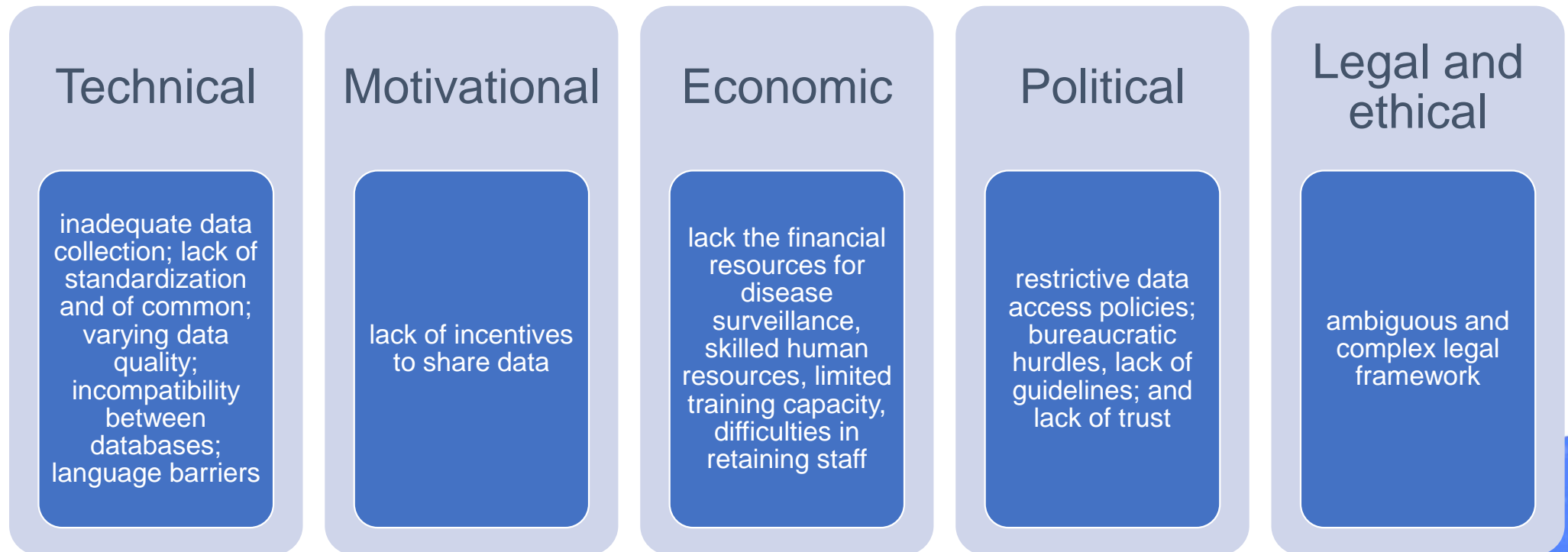
Meeting requirements of funding and publications

*based on ODAP The Open Data Assistance Program at Harvard (<https://projects.iq.harvard.edu/odap/benefits-sharing-data>), <https://www.ccdc.cam.ac.uk/Community/depositastructure/cif-deposition-guidelines/benefits-of-data-sharing/>

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Barriers of data sharing*



*based on Sane, J. and Edelstein, M. (2015). [Overcoming Barriers to Data Sharing in Public Health: A Global Perspective](#).

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Complex legal requirements (EU)

Overview of most relevant obligations

GDPR	IP (copyright, database rights)	Data Governance Act	EU proposals
<ul style="list-style-type: none"> • Roles of the data providers, data users and platform administrator • Agreements required by law • Security measures • Restriction on data transfers outside of EEA 	<ul style="list-style-type: none"> • IP rights to data and AI models • License terms to use the data & models • Acknowledgement and citation rights 	<ul style="list-style-type: none"> • Rules on re-use of data by public sector • Rules for data intermediaries 	<p><u>EHDS</u></p> <ul style="list-style-type: none"> • Data holders' obligations to allow data re-use • Secure processing environments • Quality and utility labels <p><u>AI Act</u></p> <ul style="list-style-type: none"> • Requirements for AI training and documentation

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Incisive model of data sharing

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Different models for health data repositories

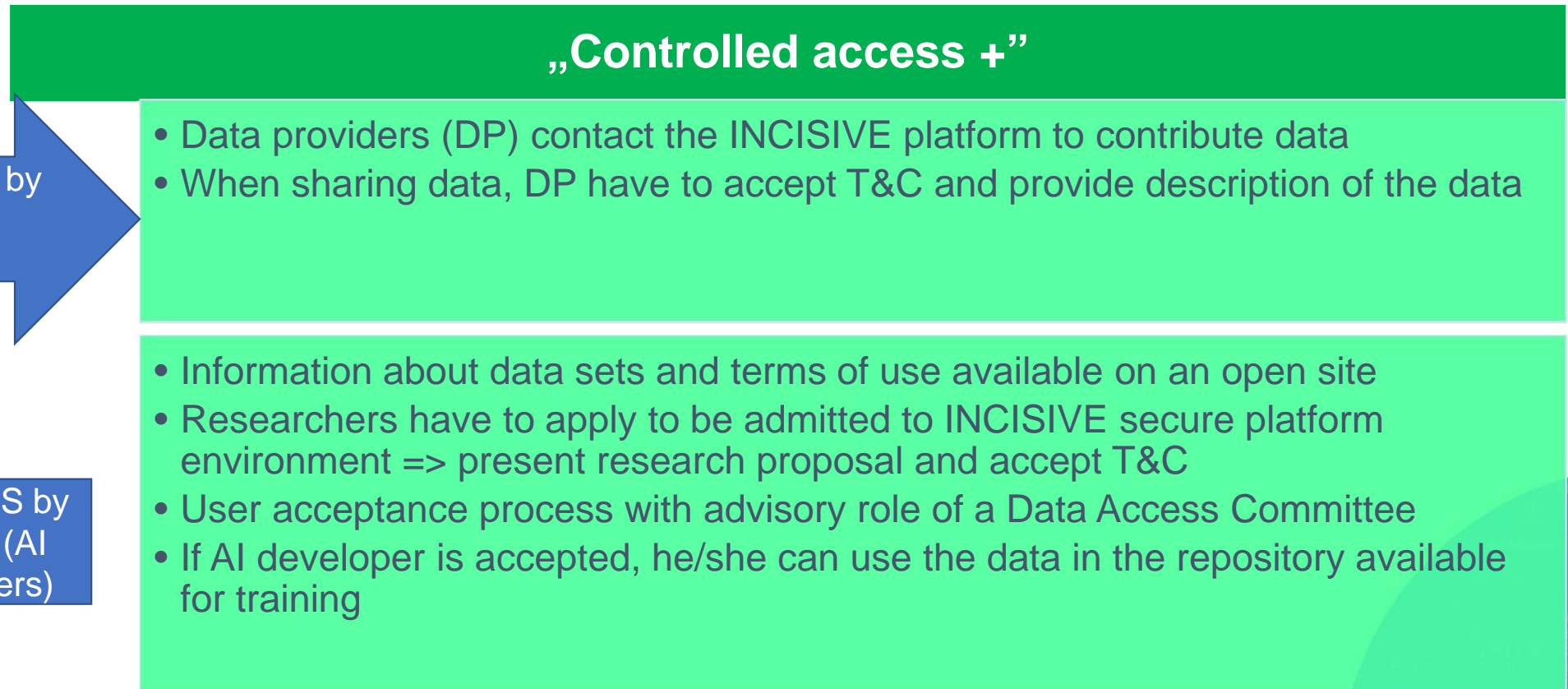
PRO

CON

	Repository is fully open	Controlled access: researcher applies for access to the repository content	Researcher must apply to use <u>specific</u> data set
PRO	<ul style="list-style-type: none"> • Simpler to use by the AI developers • No governance required 	<ul style="list-style-type: none"> • Acceptance of the terms of use is tracked • Possibility to record transactions made by the user • Approach followed by many health repositories 	<ul style="list-style-type: none"> • More control over data for the data provider • Easier to obtain ethical approval to contribute data • More aligned with the (<i>potential</i>) requirements of EHDS secure processing environments • Approach followed by many health repositories
CON	<ul style="list-style-type: none"> • No means of control over data use • Higher security risk • May raise objections of ethics committees 	<ul style="list-style-type: none"> • Longer time to obtain access • Requires to determine process for admission of the users based on set criteria • Requires to put in place a governance structure 	<ul style="list-style-type: none"> • Additional layer of technical complexity • Difficult to use data - even longer time to obtain access



INCISIVE model for data sharing & access



How can Data Provider control use of data in INCISIVE?

Transparent terms of data contribution

Participating in admitting users to shared repository (with DAC)

Information about data use through blockchain records

Possibility to opt out (remove dataset)

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From the AI developers' perspective

Data in the INCISIVE repository is stored in controlled environment

- Description of datasets is available openly

Users apply for access to the repository

- When accepted, they must log in (trusted access)

Must accept terms of use - AI developer prohibited from

- Copying data
- Circumventing security measures
- Modifying data
- Limitations to use specific models



License terms for the Data Providers

No transfer of ownership => license to use

Unlimited in time

No right to sublicense

No exclusivity

Citation requirement

No IP claims on results derived from the data



Comments? Questions?

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THANKS FOR YOUR
ATTENTION

A
INCISIVE