



VIRTUAL WORKSHOPS ON COMMON GOVERNANCE PRINCIPLES FOR THE RE-USE OF HEALTH DATA

DAY 1. Technology and Interoperability

Tuesday, 23 June 2020

DAY 2. Public Health and Research

Wednesday, 24 June 2020

DAY 3. Policy and Regulation

Thursday, 25 June 2020

Morning sessions: CEST 10:00-12:00

Afternoon sessions: CEST 14:00-16:00

WP 5 – Innovative Use of Health data

Thank you for joining
MORNING AND AFTERNOON SESSIONS (CEST 10:00-12:00 AM and 14:00-16:00 PM)
of the Focus Group Meetings of
VIRTUAL WORKSHOPS ON COMMON GOVERNANCE PRINCIPLES FOR THE RE-USE OF HEALTH DATA

Day1, 23th June -Technology and Interoperability

Moderator: Arto Vuori (THL, FI)

Breakout Room Facilitators: Arto Vuori (THL, FI) and Cátia Pinto (SPMS, PT)

Day2, 24th June - Public Health and Research

Moderator: Claudia Habl (GOEG, AT)

Breakout Room Facilitators: Claudia Habl (GOEG, AT) and Kathrin Trunner (GOEG, AT)

Day3, 25th June – Policy and Regulation

Moderator: Márton Kis (SU, HU)

Breakout Room Facilitators: Cátia Pinto (SPMS, PT) and László Bencze (SU, HU)

1. Intro - 30' total

2. Pitches - 25' total

3. Principles, part A – 15' total

4. Principles, part B – 45' total

5. Wrap-up and Closing

- Welcome to the session
- Introduce Agenda
- Introduction of the online platform of the meeting (Zoom meetings) and explaining the tool and working methods (raise hand, etc.)
- *“Kindly note that we plan to record the session – please inform us in case you wish not to be recorded.”*
- Setting the frame (eHAction, WP5)
 - background and objectives
 - dimensions

Please ensure that you have named yourself correctly

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WP 5 – Innovative Use of Health data

eHAction
Joint Action supporting
the eHealth Network
JA-05-2017

Participants (4)

- Istvan Csizmadia (Me) **Mute** **More >**
- Kis Márton (Host)
- felleranna
- Anna feller

Raise Hand yes no go slower go faster more

Invite Mute Me

Rename
Edit Profile Picture

Co-funded by the European Union's Health Programme (2014-2020)

ning the meeting
nptly at **10:00 am**

that you have
elf correctly:

Your full name (your country and institution)
E.g. István Csizmadia (HU, NHSC)

To do this, click on the 'Participants' icon, hover over your name until the 'More' box appears, then click on 'Rename'

Meeting etiquette



Include the code of the country and organisation after your name with the “rename” function

Example: Full Name (MS, Institution)
E.g.: István Csizmadia (HU, NHSC)



Use the “hand-raising function” or type in „chat” window to indicate you would like to comment / ask a question when invited by the chair



Please remain muted

throughout the meeting, unless you’re invited to speak by the Chair



Cameras off

Cameras will be used by the Chair and presenters, so please camera on when you receive the floor during the meeting

Please be advised that video and audio recordings will be taken by recording pictures, notes, chats and speeches appearing at the online platform used for organising the events, for use in eHAction’s reports, and communication and dissemination materials on the eHAction's website and in other online media such as LinkedIn, Facebook, and twitter.

- During the meeting, please use the chat or email dissemination.emk@emk.sote.hu if you have questions or need support.
- Please feel free to add/amend comments
- We will organise breakout-sessions in the 2nd part of each session.
- Participants will be invited during the session to join the breakout rooms.

Plan for today

1. Intro - 30' total

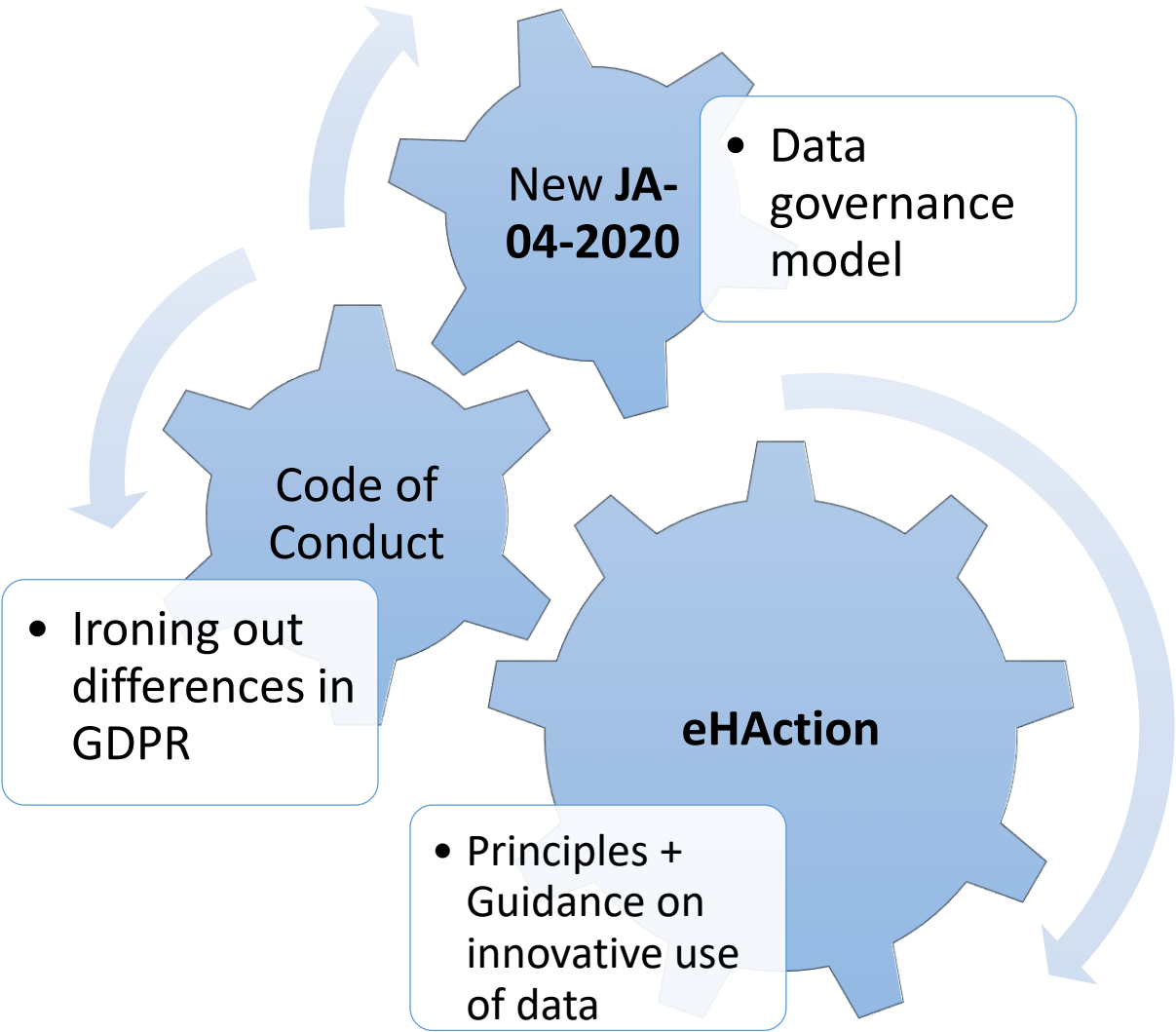
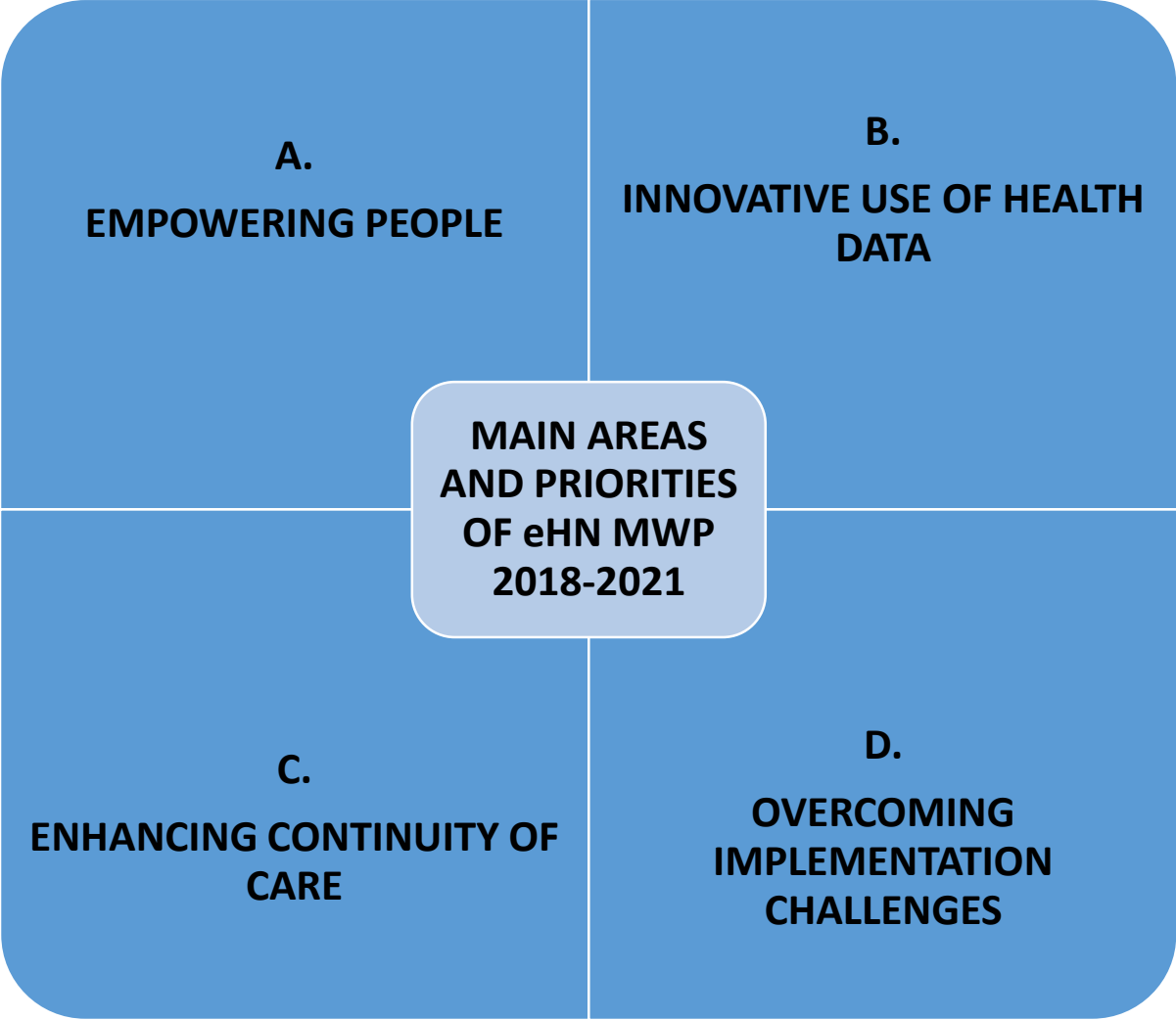
2. Pitches - 25' total

3. Principles, part A – 15' total

4. Principles, part B – 45' total

5. Wrap-up and Closing

- Welcome to the session
- Introduce Agenda
- Introduction of the online platform of the meeting (Zoom meetings) and explaining the tool and working methods (raise hand, etc.)
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 - dimensions



Background - The aim of work package 5 (Innovative Use of Health data)

- How to support application of good practices and available propositions for innovative use of health data / big data in Member States?
- How to handle big data in health within the existing EU regulatory framework to ease the uptake of innovative usage of data across the healthcare sector for the benefits of society, individuals and performance of Member States health systems?
- Final deliverable of WP5 (eHN 19th meeting - Spring 2021)

VISION - Where do we want to get? – What do we imagine?

- *Public health, research and quality assurance in healthcare take advantage of the benefits of using health data (primary and secondary use / innovative use)*

AIM - What do we wish to achieve to realise the vision?

- *Best practices and ideas how to overcome obstacles and challenges in taking advantage of benefits of using health data will be shared among policy makers and other key stakeholder groups*

OBJECTIVE - How do we wish to achieve the aim?

- *WP5 will deliver common principles for*
 - *practical governance of big data / innovative use of health data*
 - *implanting available relevant recommendations and use cases*
- *Guidance for the implementation of the principles*

Aims of preparing common principles for practical governance of big data

The result of mapping challenges showed that three general obstacles appeared as reasons slowing down or hampering translation of policy-level recommendations into actions:

1. lack of trust,
2. legal uncertainties, and
3. lack of funding and financial resources.

Looking for common policy level principles and guidance which can assist MS/C to overcome obstacles (National + Xborder)

Learn stakeholders' view and expectations regarding policy level unmet needs for

- ✓ common principals and practical guidance why and how to foster innovative use of health data, big data and AI,
- ✓ as well as how to implement available relevant recommendations.

Plan for today

1. Intro - 30' total

2. Pitches - 25' total

3. Principles, part A – 15' total

4. Principles, part B – 45' total

5. Wrap-up and Closing

- Introduction of panel:
 - Briefly introduce each pitcher (name, affiliation, organisation)
- Presentations (4 pitches)

Pitches

DAY	SESSION	SPEAKER	ORGANIZATION	TITLE OF THE PITCH
day1	morning	Luc Niciolas	EHTEL	Governance principles for semantic interoperability
day1	morning	Paul Coebergh van den Braak	MedTech Europe	Interoperability: The role of Member States
day1	afternoon	Nicholas Nicholson	EC JRC, Italy	Lack of trust – "the good, the bad, and the ugly"
day2	morning	Lars Münter	DCHE, Denmark	Health Literacy at the Speed of Trust
day2	morning	Luís Velez Lapão	UNL, Portugal	Building up Trust by Co-Designing Digital Tools with Health Prof...
day2	morning	Markus Kalliola	SITRA, Finland	Trust is a Must
day2	morning	Petronille Bogaert	Sciensano, Belgium	InfAct: Distributed Infrastructure on Population Health (DIPoH)
day2	morning	Vesa Jormanainen	THL, Finland	Rapid Set Up of Novel National COVID 19 Symptom Checker for...
day2	afternoon	Claudia Habl	GÖG, Austria	Data and Public Health Research - A story of legal challenges
day2	afternoon	István Csizmadia	NHSC, Hungary	Who is the customer in data re use?
day2	afternoon	Nicholas Nicholson	EC JRC, Italy	Lack of trust – "the good, the bad, and the ugly"
day3	morning	Angel Martin	MedTech Europe	Data governance: building trust and enabling digital health
day3	morning	Christine Lee	MedTech Europe	Legal uncertainties and the re-use of health data: Clarify and ...
day3	morning	Gözde Susuzlu Briggs	EPF	Data Saves Lives
day3	morning	Isabella Weber	MoH, Austria	Interoperable digital health eco-system as pre-requisite for ...
day3	morning	Martha De Cunha Maluf-Burgman	MedTech Europe	Cybersecurity: It is a shared responsibility
day3	morning	Stephan Schug	EHTEL	Towards a European Trust Architecture - Re use enablers and ...
day3	afternoon	Catia Pinto	SPMS, Portugal	FROM big DATA TO smart HEALTH ... Data strategy for ...
day3	afternoon	Louisa Stüwe	HDH, France	Health Data Hub - Overview, strategy and lessons learned

1. Intro - 30' total

2. Pitches - 25' total

3. Principles, part A – 15' total

4. Principles, part B – 45' total

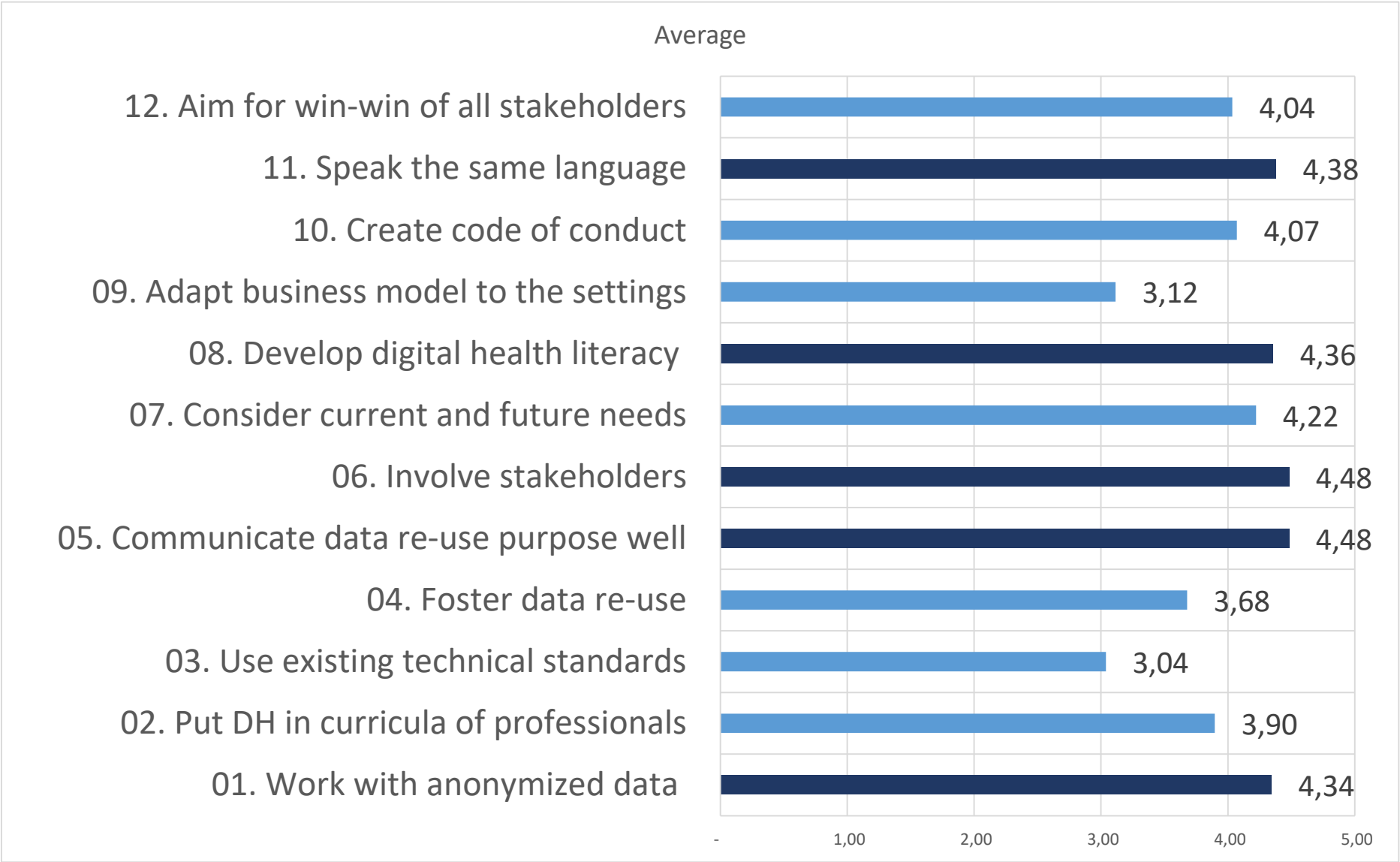
5. Wrap-up and Closing

Short presentation of draft common principles (for practical governance of big data / innovative use of health data & implementing available relevant recommendations and use cases)

- Participants could rate 12 optional principles during registration
- Participants could offer addition ideas for principles during registration

Average values of the replies to our short survey

Rating values:
From 1 to 5,
where 5 means the
best option.
30 participants
(33%) took part in
the rating so far.



Proposed principles 1-6

1. Work with anonymized data as far as possible for the purpose of secondary use of data and big data.
2. Curricula of health professionals should be adapted to include digital health literacy + big data in all EU countries.
3. Avoid evolution of new technical standards, but use already existing ones and maintain "zero trust".
4. Choose the right customers, users and beneficiaries of the business model for open data and data sharing to foster data reuse.
5. Communicate socially acceptable purpose to reuse data.
6. Involve stakeholders in the reuse of data and creating value.

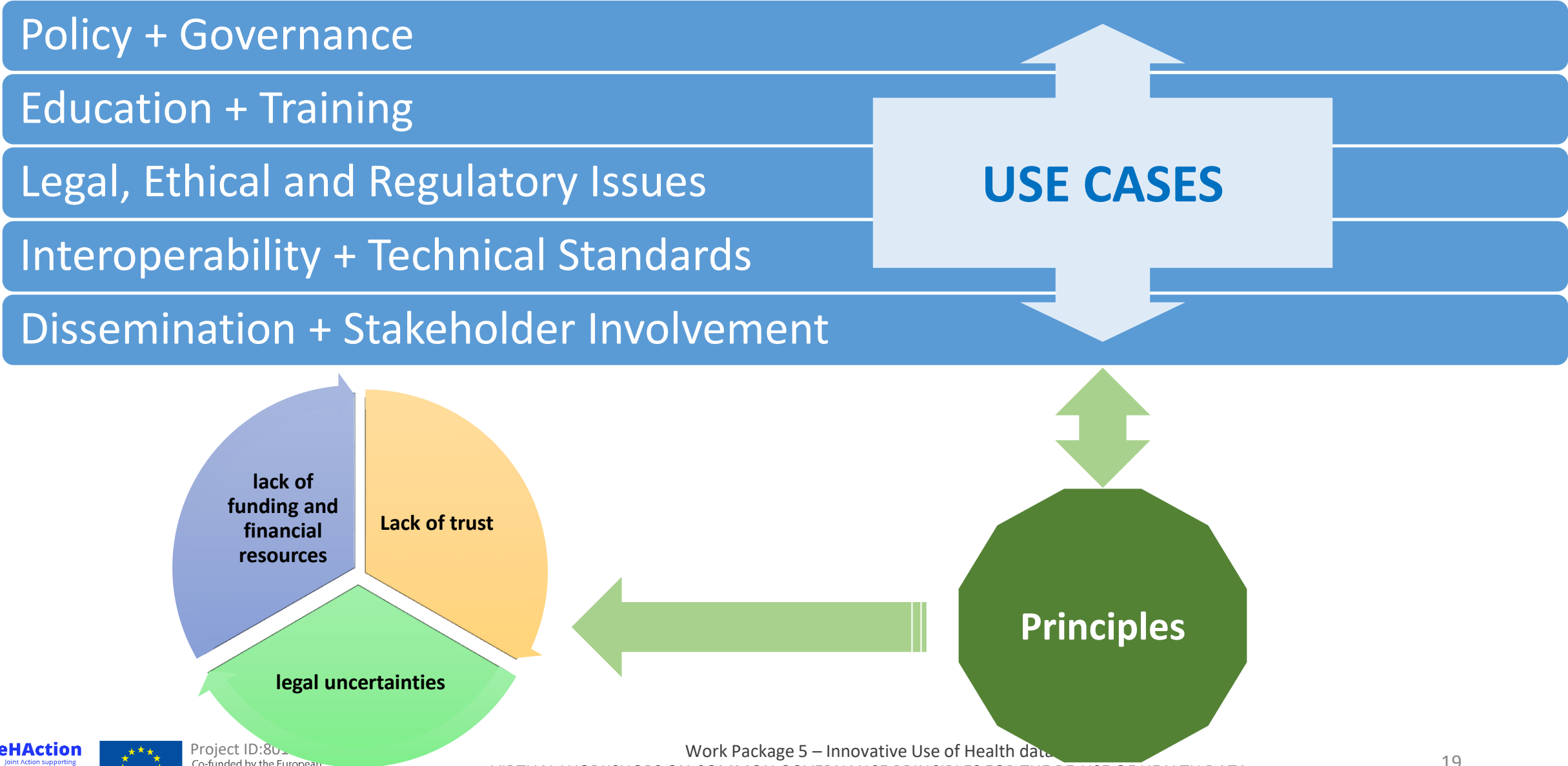
Proposed principles 7-12

7. Learn current and future stakeholder needs (incl. non-negotiables, differentiators and dissatisfiers)
8. Develop digital health literacy of stakeholders to strengthen empowerment and adherence to data sharing and re-use.
9. Treat health challenges in the urban environment with a special business model for data management & data governance.
10. Create international terms of data ownership, sharing, exchange and access to mitigate risks regarding sensibility and privacy.
11. Share common vocabulary to avoid misunderstandings and led to exploit the value of data.
12. Measure, manage, engineer and communicate worth of the customers, users and beneficiaries of data sharing and access.

Comments by Attendees

- Keep data owners informed about the real life impact of their data. This may fall under the ownership and/or management of your data but not very clear.
- One important issue is the basics for health information, which includes IT Governance and user rules.
- To clarify in better ways the needs of epidemiology to access sensitive data solely for the purpose of obtaining the correct cohort of patients and the ability thereafter to work with that data anonymously. On the basis of this fundamental aspect, to find improved data-sharing processes, models, and solutions.
- Establish a common data model and facilitate the tools to deploy federated (distributed) networks of analysis where data stays where it is generated in the custody of their owners and knowledge and analysis are provided in a rigorous, auditable and reproducible way enabling data owners to contribute to the research effort by deploying the study's design and analytic scripts within their systems and sharing results and insights generated by those analyses.
- Less techno-babble - use simple cases for storytelling. Stronger (public) regulation of Big IT - stronger (public) oversight of big governmental data (as this is not big brother).
- Take big data model on European scale by taking simple available data and concentrate on data access across several countries

Domains and uses cases, principles, root causes



1. Intro - 30' total

2. Pitches - 25' total

3. Principles, part A – 15' total

4. Principles, part B – 45' total

5. Wrap-up and Closing

- Participants will be invited to enter 2 “breakout rooms”
- Each principle shall be discussed in “breakout rooms” by
 - Showing initial comments (rating) from registration
 - Modify text of existing principles, if necessary
 - Prioritize principles using poll (Putting principles in order of importance, so that you can deal with the most important first) – Did something change?
 - Proposal to add/eliminate principle(s) - optional
- Selecting “Presenter” for Wrap-up and Closing of the Session
- Fixing mandate for the “Presenter”

Principle 1 - Work with anonymized data

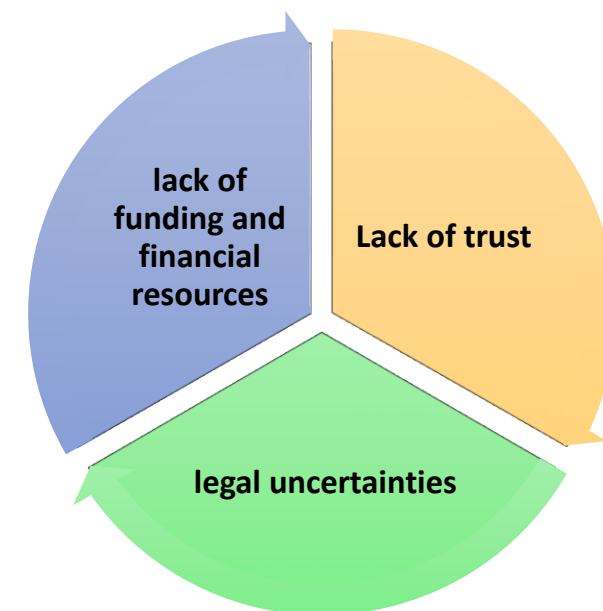
Work with anonymized data as far as possible for the purpose of secondary use of data and big data.

- Domains concerned:

Policy + Governance

Legal Issues

Interoperability + Technical Standards



Principle 2 - Put DH in curricula of professionals

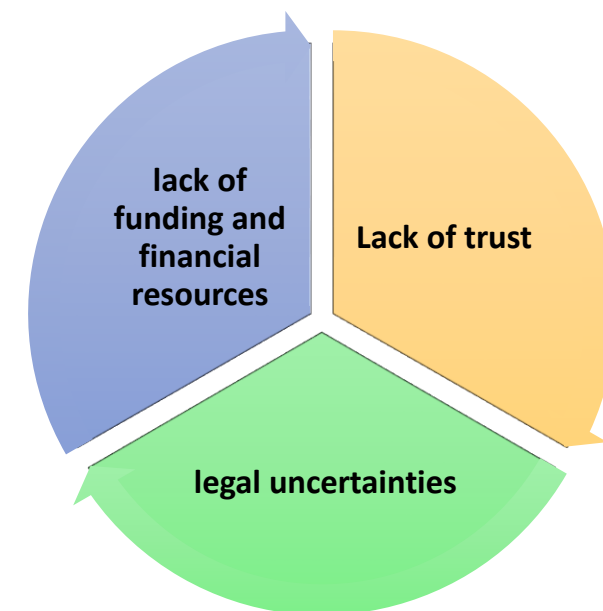
Curricula of health professionals should be adapted to include digital health literacy + big data in all EU countries.

- Domains concerned:

Policy + Governance

Education + Training

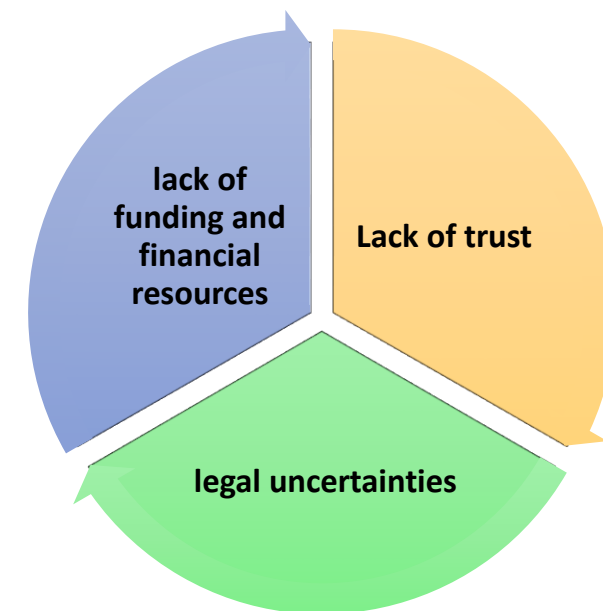
Legal Issues



Principle 3 - Use existing technical standards

Avoid evolution of new technical standards, but use already existing ones and maintain "zero trust".

- Domain concerned: Interoperability + Technical Standards



Principle 4 - Foster data re-use

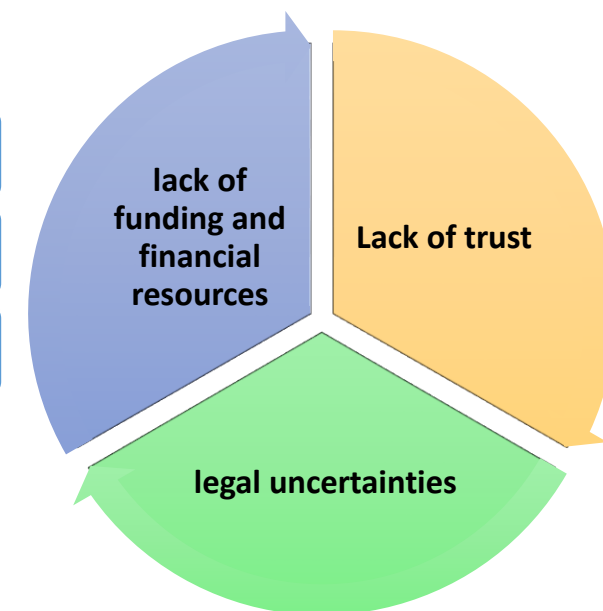
Choose the right customers, users and beneficiaries of the business model for open data and data sharing to foster data reuse.

- Domains concerned:

Policy + Governance

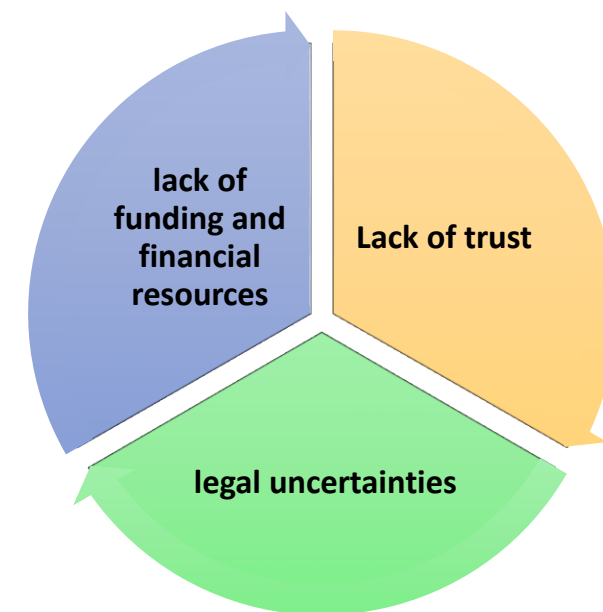
Interoperability + Technical Standards

Dissemination + Stakeholder Involvement



Communicate socially acceptable purpose to reuse data.

- Domains concerned: **Dissemination + Stakeholder Involvement**

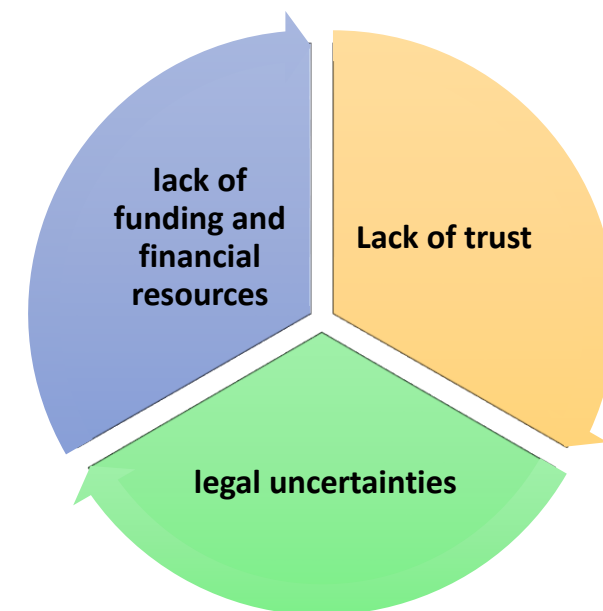


Principle 6 - Involve stakeholders

Involve stakeholders in the reuse of data and creating value.

- Domains concerned:

Dissemination + Stakeholder Involvement



Principle 7 - Consider current and future needs

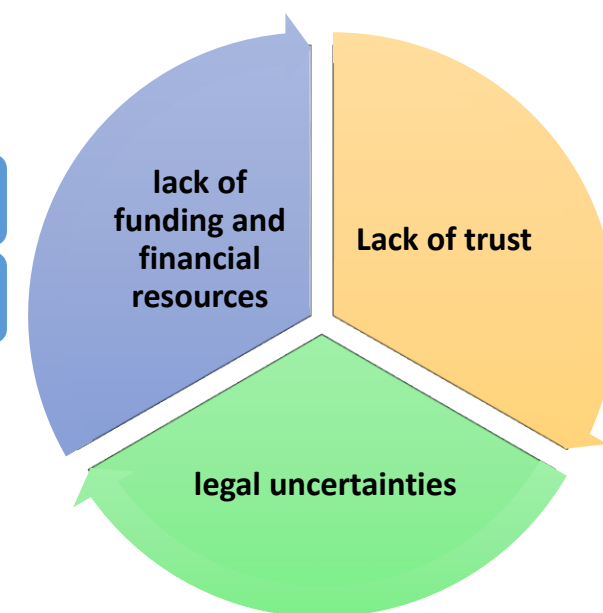
Learn current and future stakeholder needs (incl. non-negotiables, differentiators and dissatisfiers)

'How to Get Ecosystem Buy-In' by Martin Ihrig and Ian MacMillan, HBR, March–April 2017 Issue

- Domains concerned:

Policy + Governance

Dissemination + Stakeholder Involvement



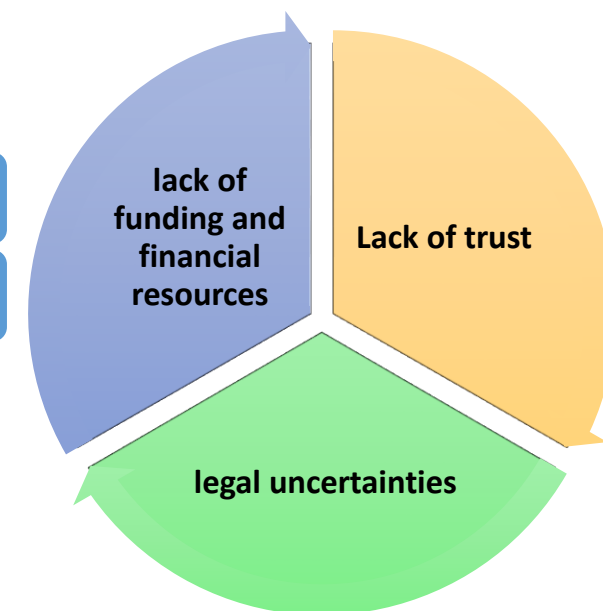
Principle 8 - Develop digital health literacy

Develop digital health literacy of stakeholders to strengthen empowerment and adherence to data sharing and re-use.

- Domains concerned:

Education + Training

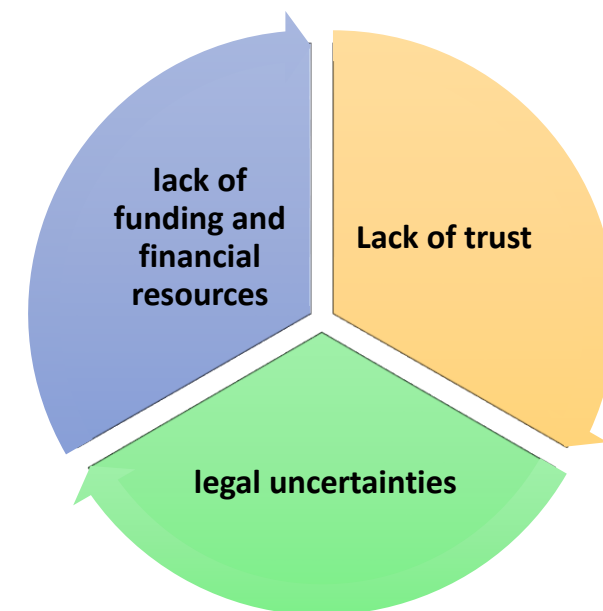
Dissemination + Stakeholder Involvement



Principle 9 - Adapt business model to the settings

Treat health challenges in the urban environment with a special business model for data management & data governance.

- Domains concerned: **Policy + Governance**



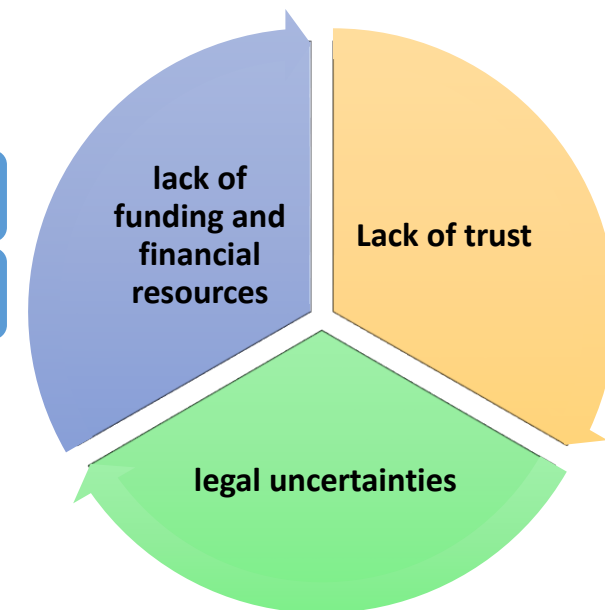
Principle 10 - Create Code of Conduct

Create international terms of data ownership, sharing, exchange and access to mitigate risks regarding sensitivity and privacy.

- Domains concerned:

Legal Issues

Interoperability + Technical Standards



Principle 11 - Speak the same language

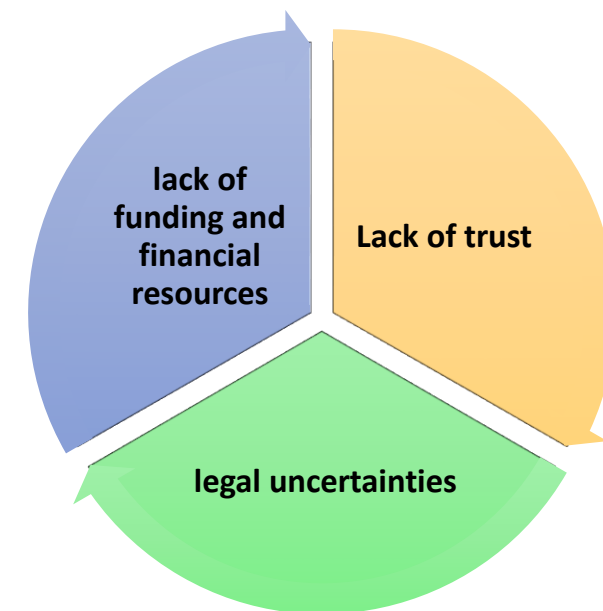
Share common vocabulary to avoid misunderstandings and lead to exploit the value of data.

- Domains concerned:

Policy + Governance

Education + Training

Dissemination + Stakeholder Involvement



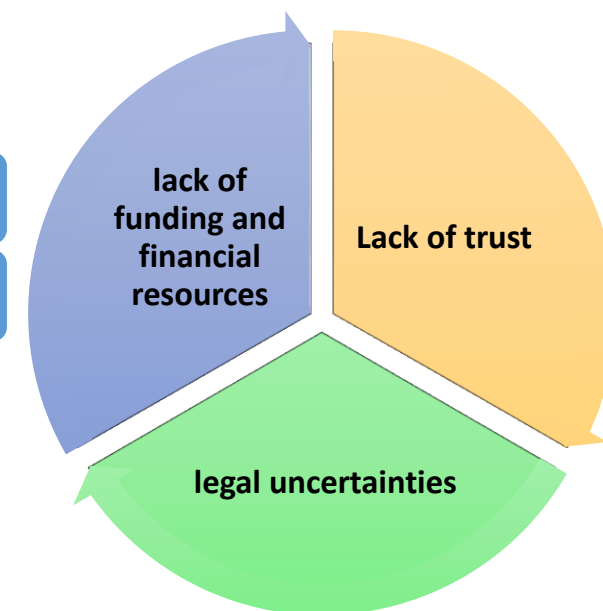
Principle 12 - Aim for win-win of all stakeholders

Measure, manage, engineer and communicate worth of the customers, users and beneficiaries of data sharing and access.

- Domains concerned:

Policy + Governance

Dissemination + Stakeholder Involvement



Average values of the replies to our short survey

Please find vote link in the chat:

<https://directpoll.com/v?XDVhEtdVO8bR7oD9uH4QxPaAS1nN1Tt>

Pick your 5 preferred principles please!

- Prioritize principles using poll (Putting principles in order of importance, so that you can deal with the most important first)
- Did something change?
- Proposal to add/eliminate principle(s) - optional

DirectPoll 

Pick your 5 preferred principles pls!

- ☐ 01. Work with anonymized data
- ☐ 02. Put DH in curricula of professionals
- ☐ 03. Use existing technical standards
- ☐ 04. Foster data re-use
- ☐ 05. Communicate data re-use purpose well
- ☐ 06. Involve stakeholders
- ☐ 07. Consider current and future needs
- ☐ 08. Develop digital health literacy
- ☐ 09. Adapt business model to the settings
- ☐ 10. Create code of conduct
- ☐ 11. Speak the same language
- ☐ 12. Aim for win-win of all stakeholders

VOTE

Plan for today

1. Intro - 30' total

2. Pitches - 25' total

3. Principles, part A – 15' total

4. Principles, part B – 45' total

5. Wrap-up and Closing

- Sharing findings of the breakout rooms
- Closing