Feedback from use cases

Chair: Serena Scollen

05

Slido: **SF2022**

Feedback

Breakout session - WG8 Rare Diseases

Chair: Katrin Õunap

Co-chair: Ruben Kok

ELSI & Data Governance: Which challenges to the scale up (within this Use Case) could be addressed by industry?

- Implementation of an electronic and dynamic consent system
- Sharing knowledge from multinational studies
- Their collaboration on machine readability of consent and use condition of collected data (different from electronic consent)
- Transparency on how patient data benefits the company. It could for instance help to train algorithms, or help as proof of function to boost sales.

ELSI & Data Governance: Which challenges to the scale up (within this Use Case) could be addressed by other stakeholders (please specify stakeholder)?

- Gap between clinical actors and the FAIR principles (understanding, mindset, solutions, and implementation). Funders and academic organisations could help!
- Allow for secondary use of genomic data (data sharing) outside of research studies (EU and government) and share with other nations (such as US)
- We should know who is addressing what issue for example GA4GH is addressing many of the ethical and legal issues surrounding genomic data.
- National DPBs should come up with suggestions on how data can be used responsibly, and allowing collaboration between industry and health care institutes.

Data & Quality Standards: Which challenges to the scale up (within this Use Case) could be addressed by industry?

- Automated extraction of minimal dataset
  - Have plug-ins from all local hospital systems and facilitate those conversions through tools and software we use
  - Enable the capture of data from clinical systems to feed into research and vice versa
- Tools to facilitate data entry with HPO, ORDO within EHRs
- Translation of ontologies
- Standards, tools, and requirements developed and adopted by industry
  - https://github.com/ejp-rd-vp

Data & Quality Standards: Which challenges to the scale up (within this Use Case) could be addressed by other stakeholders (please specify stakeholder)?

- HTA and regulators (EMA and EUnetHTA)
  - They are developing their own processes and data spaces and guiding on the type of data
  - EMA through the DARWIN initiative and have provided a lot of guidelines and data
- Usage of tools already implementing standards (eg. EJPRD virtual platform)
- Quality control, accredited lab/centres
- Strong guidelines on data standardisation on EU level, forcing national implementations to follow the EU guidelines.

Technical Infrastructure: Which challenges to the scale up (within this Use Case) could be addressed by industry?

- Support to find “right” fit for integration/ “make whatever we need” adaptable to personal local situation
- On what level are we sharing data with industry
  - Much easier to share data with industry that you aren’t going to return results to an individual person.
  - There are different local regulations if the data is being returned for the benefit of specific individuals
- Industry infrastructures made interoperable with 1+MG Infrastructure
- (Financial/ technical) Support to find “right” fit for integration/ “make whatever we need” adaptable to personal/local situation.

Technical Infrastructure: Which challenges to the scale up (within this Use Case) could be addressed by other stakeholders (please specify stakeholder)?

- Heterogenous maturity levels among MS in digital data storage and HCP infrastructure
  - Belongs to people who are investigated and the national governing body should decide how to keep that data
- Cloud-based tools and software can be provided locally - no internet access - it requires HPC platforms to engage with providers
- GA4GH toolkits for responsible data sharing (e.g file formats, APIs, standards, recommendations, etc.)
- Critical Path Institute, Data processing/Analysis Platform: https://portal.rdca.c-path.org/

General Comments:

- Workshops (technical hands-on and dissemination/sustainability planning): EJP RD and next phase RD Partnership
- Already mentioned, but many examples have already been piloted, and proven successful (such as EJP-RD and SOLVE-RD)
- Patient initiatives to donate data
- National requirements and resources to build up Germ Line data at clinical level.
- A guidebook containing the relevance resources and tools for researchers just starting or Member States looking to start implementing genomics into healthcare systems.

Feedback

Breakout session - WG9 Cancer

Chair: Giovanni Tonon

Co-chair: Astrid Vicente


Popular ideas
7
ELSI & Data Governance: Which challenges to the scale up (within this Use Case) could be addressed by industry?
Anonymous
5
Harmonisation
Anonymous
4
after data harmonization we will need data quality control - an expensive chapter
Anonymous
3
Data ownership
Anonymous
1
Confidentialy
Anonymous
1
ELSI terminology/contracts only open to 1 interpretation

ELSI & Data Governance: Which challenges to the scale up (within this Use Case) could be addressed by other stakeholders (please specify stakeholder)?

Anonymous — 8

Patient organisations

Anonymous — 7

Policy-makers

Anonymous — 3

Citizens

Anonymous — 3

Creating trust ↔ all relevant stakeholders

Anonymous — 0

Data & Quality Standards: Which challenges to the scale up (within this Use Case) could be addressed by industry?

Anonymous — 10

incorporate standards into their products (e.g. EHR, equipment) and provide easy means of use

Anonymous — 7

Transparent adoption of FAIR data standards

Anonymous — 4

Limited return on engagement for effort required

Anonymous — 1

Capacity

Data & Quality Standards: Which challenges to the scale up (within this Use Case) could be addressed by other stakeholders (please specify stakeholder)?

Anonymous — 10

Data curators - working in semantic interoperability

Anonymous — 9

Hospital IT personnel

Anonymous — 6

Patients having access to their own data is a good leverage to data stndards

Anonymous — 4

make text mining / natural language processing a reality (not all is structured data)

Technical Infrastructure: Which challenges to the scale up (within this Use Case) could be addressed by industry?

Anonymous — 11

Develop Doctor-friendly user interfaces for tools in federated infrastructure

Anonymous — 8

pseudonimisation/key management/persistent identifiers

Anonymous — 8

trusted working/research environments

Anonymous — 3

Linguistic technologies

Technical Infrastructure: Which challenges to the scale up (within this Use Case) could be addressed by other stakeholders (please specify stakeholder)?

Anonymous — 10

connecting hospitals with the European HPC environment - connectivity and security issues.

Anonymous — 5

IT storage

Anonymous — 3

Hospitals

Anonymous — 3

Academia + research

General recommendations

Anonymous — 3

Engage citizens especially Patients

G Giovanni — 3

Engage Doctors

Anonymous — 2

Agree on a date that all stakeholders stick to/execute made agreements/standards/etc

Anonymous — 1

Return on engagement for clinicians who enter data

Anonymous — 0

Feedback

WG10 Common and Complex Disease

WG12 - Genome of Europe

Chair: Andres Metspalu

Co-chair: Serena Scollen

What is needed from policy for responsible implementation - WG10 perspective - some overlaps, some specifics…

A) Public and professional trust: ensuring that the general public, researchers, clinical professionals and policy makers are well informed about genomics and feel empowered to make decisions, in order to ensure its uptake by (public) healthcare systems and integration into personalised healthcare

B) Focus on inclusion and equity: avoiding an increase in unequal access to health services

C) Sequencing facilities and personnel: ensuring that facilities and workforce are facilitated for sequencing, but also counselling and support

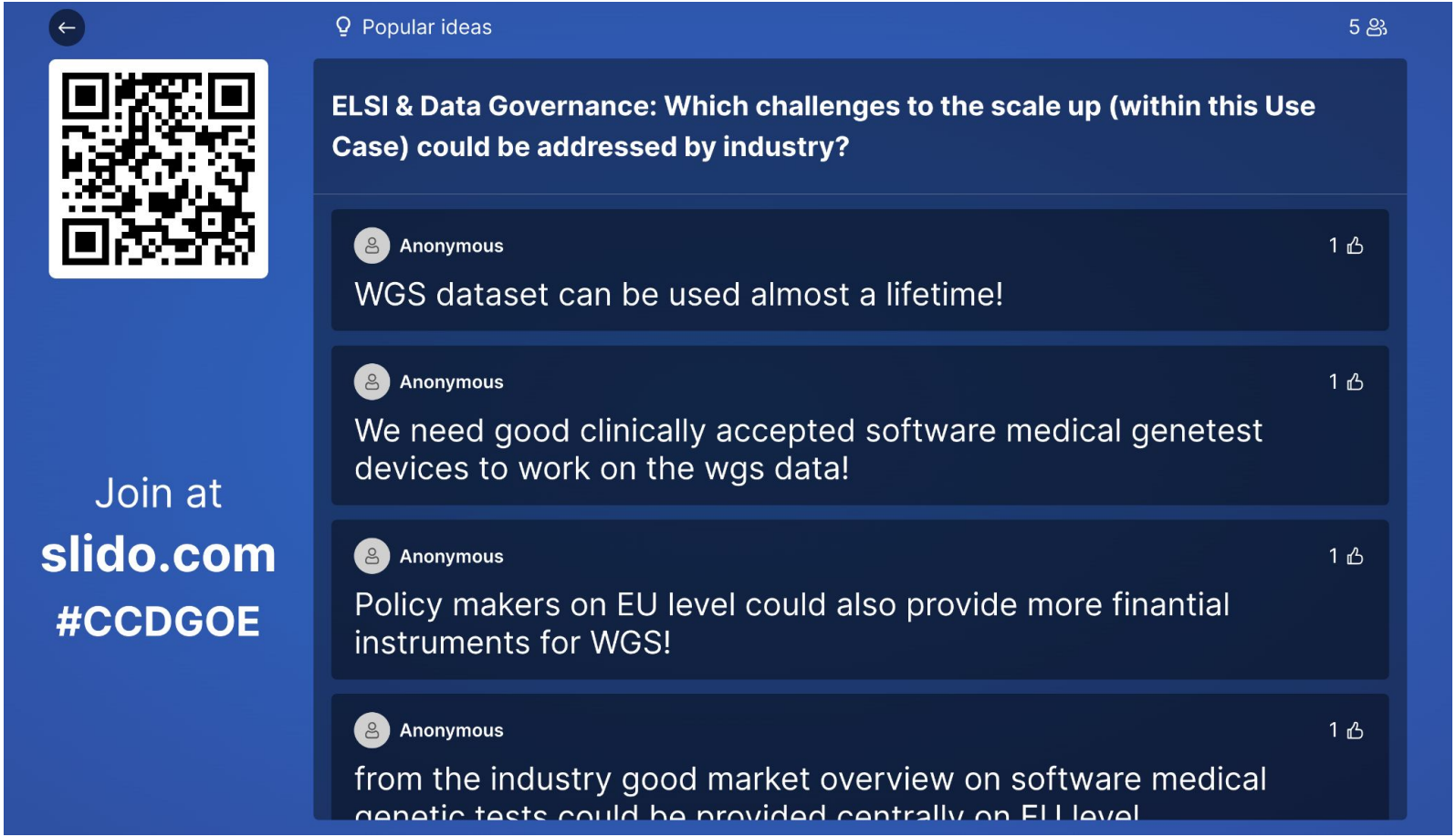
D) IT-infrastructure: a) ensuring that appropriate technical infrastructure is available, allowing for secure, federated access to genomic data, b) implementing interoperability guidelines to achieve data of internationally agreed standards

E) Legal framework allowing safe data-exchange and informed choice:safeguarding privacy and personal control

F) Financial arrangements/reimbursement of testing: ensuring access to testing for citizens

G) Piloting implementation: assessing evidence and identifying and overcoming practical and remaining ethical, legal and societal issues

Slido: **CCDGOE**


Popular ideas
5
ELSI & Data Governance: Which challenges to the scale up (within this Use Case) could be addressed by industry?
Anonymous
1
WGS dataset can be used almost a lifetime!
Anonymous
1
We need good clinically accepted software medical genetest devices to work on the wgs data!
Anonymous
1
Policy makers on EU level could also provide more finantial instruments for WGS!
Anonymous
1
from the industry good market overview on software medical
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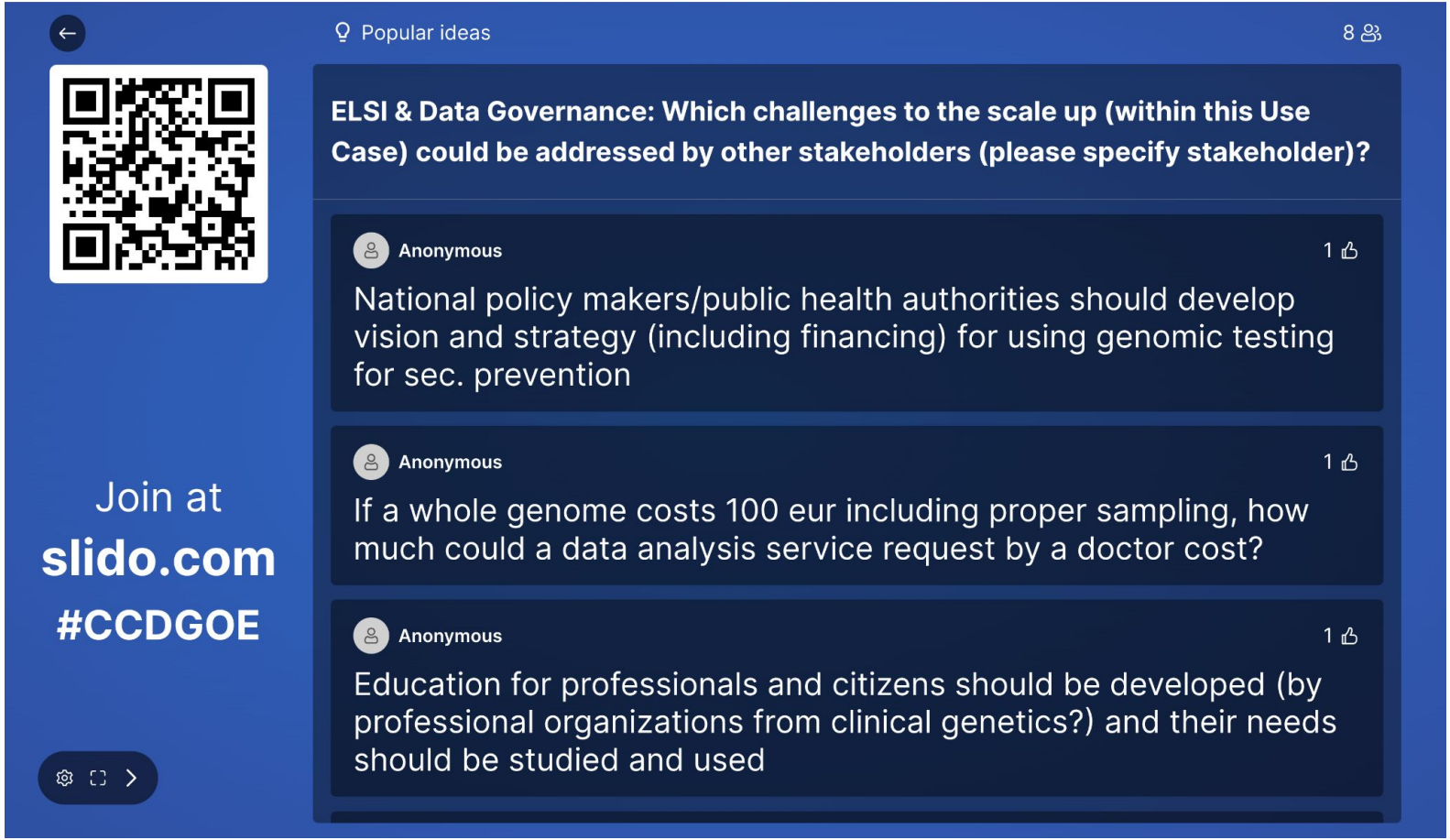
#CCDGOE


Popular ideas
8
ELSI & Data Governance: Which challenges to the scale up (within this Use Case) could be addressed by other stakeholders (please specify stakeholder)?
Anonymous
1
National policy makers/public health authorities should develop vision and strategy (including financing) for using genomic testing for sec. prevention
Anonymous
1
If a whole genome costs 100 eur including proper sampling, how much could a data analysis service request by a doctor cost?
Anonymous
1
Education for professionals and citizens should be developed (by professional organizations from clinical genetics?) and their needs should be studied and used
Join at
slido.com
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Popular ideas 3

Data & Quality Standards: Which challenges to the scale up (within this Use Case) could be addressed by industry?

Anonymous 1

Healthcare - need to set the quality etc; regulation to be set at a government level

Anonymous 0

inter lab quality assessment - industry can produce chips etc that respond to the quality control set

M Mark 0

I may have missed this example earlier but Screen4Care is EFPIA supported on newborn screening using genomics. Could this be extended

Join at

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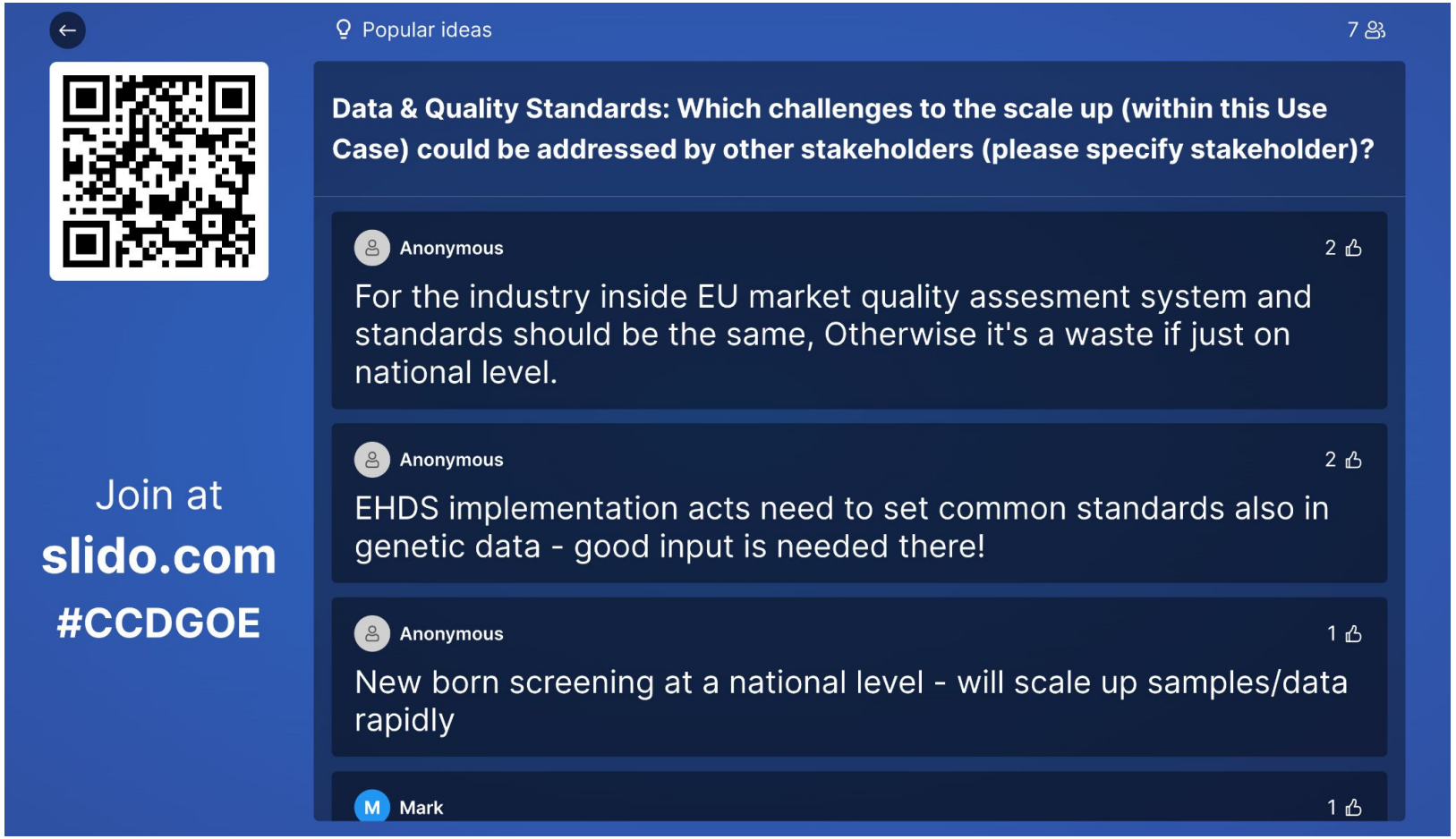
Popular ideas
7
Data & Quality Standards: Which challenges to the scale up (within this Use Case) could be addressed by other stakeholders (please specify stakeholder)?
Anonymous
2
For the industry inside EU market quality assesment system and standards should be the same, Otherwise it's a waste if just on national level.
Anonymous
2
EHDS implementation acts need to set common standards also in genetic data - good input is needed there!
Anonymous
1
New born screening at a national level - will scale up samples/data rapidly
M
Mark
1
Join at
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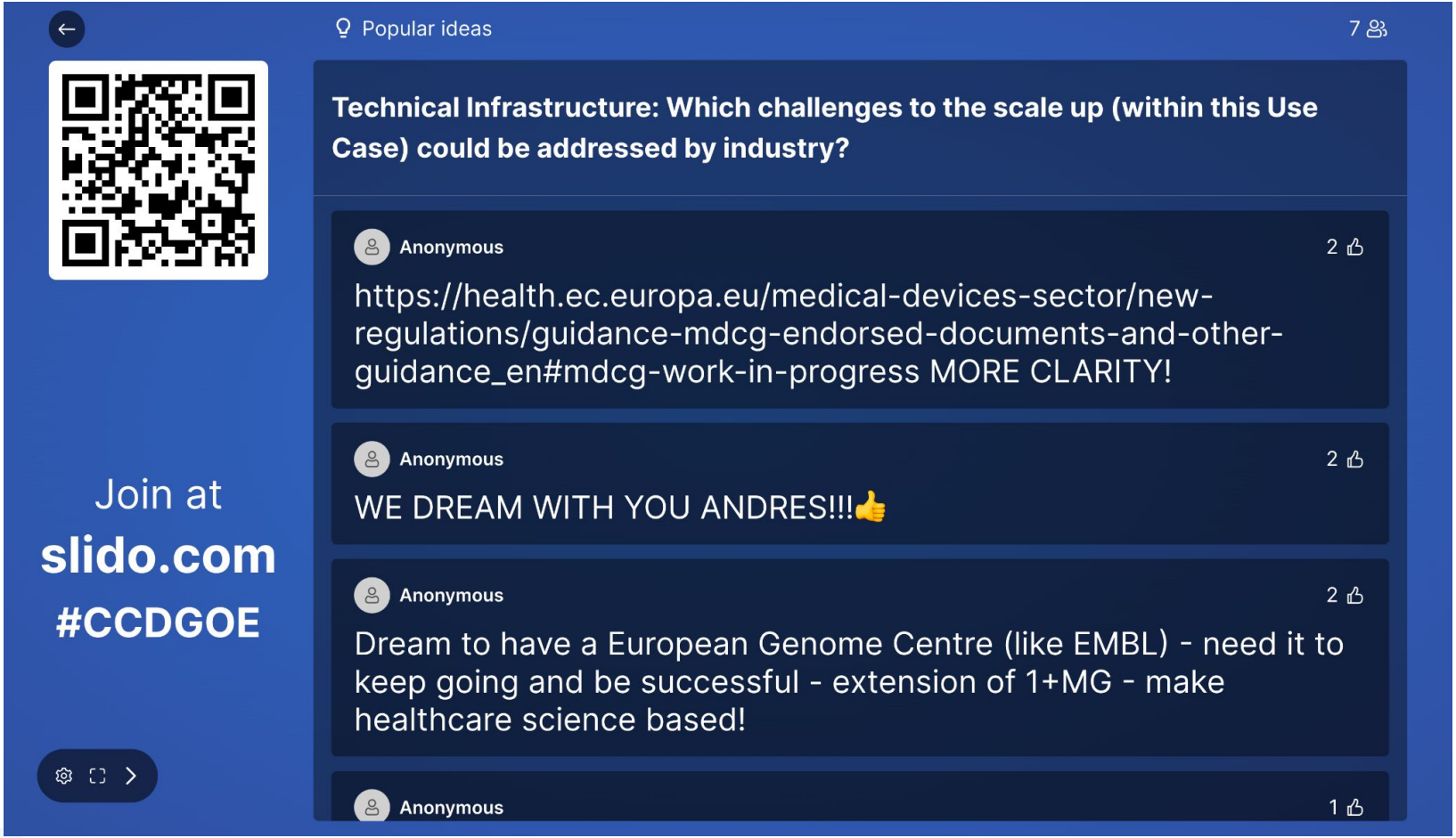
Popular ideas
7
Technical Infrastructure: Which challenges to the scale up (within this Use Case) could be addressed by industry?
Anonymous
2
https://health.ec.europa.eu/medical-devices-sector/new-regulations/guidance-mdcg-endorsed-documents-and-other-guidance_en#mdcg-work-in-progress MORE CLARITY!
Anonymous
2
WE DREAM WITH YOU ANDRES!!!👍
Anonymous
2
Dream to have a European Genome Centre (like EMBL) - need it to keep going and be successful - extension of 1+MG - make healthcare science based!
Anonymous
1
Join at
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#CCDGOE

In summary:

We have a dream …

We will have a European Genome Centre

‘Ideas’ question 7

Feedback

Breakout session - WG11 Infectious Disease

Chair: Katja Kivinen

Co-chair: Juan Arenas Márquez

ELSI & Data Governance: Which challenges to the scale up (within this Use Case) could be addressed by industry?

Anonymous — 4

data privacy

Anonymous — 4

Economically

Anonymous — 3

infrastructure solutions

ELSI & Data Governance: Which challenges to the scale up (within this Use Case) could be addressed by other stakeholders (please specify stakeholder)?

Anonymous — 4

data types, data use, sharing (content of use) (hospitals, patient organization)

Anonymous — 2

National initiatives

Anonymous — 2

Hospitals

Anonymous — 2

know what is the interest of host sequencing in infectious diseases

Back to top

Data & Quality Standards: Which challenges to the scale up (within this Use Case) could be addressed by industry?

Anonymous 2

Collaboration to recommend and use standards

Anonymous 1

data sharing

Anonymous 1

Sequencing capacity

Anonymous 1

Definition of data standards

↑ Back to top

Data & Quality Standards: Which challenges to the scale up (within this Use Case) could be addressed by other stakeholders (please specify stakeholder)?

Anonymous 2

Integration and linking of host and pathogen data (academia, scientific services, & hospitals!)

Anonymous 2

availability of bioinformaticians

Technical Infrastructure: Which challenges to the scale up (within this Use Case) could be addressed by industry?

Anonymous — 4

Solutions for automation

Anonymous — 4

Technical experts

Anonymous — 3

cloud servers

Anonymous — 3

cibersecurity resources

Technical Infrastructure: Which challenges to the scale up (within this Use Case) could be addressed by other stakeholders (please specify stakeholder)?

Anonymous — 3

Sustainability (MS)

Anonymous — 3

metadata organization and interoperability (hospitals)

Anonymous — 1

sequencing devices in public health agencies

General recommendations

Anonymous

2

funding for sequencing and data analysis (hospital, researchers)