

# Advancing Collaboration and Data Sharing Agreements in Biomedical AI Research Workshop

## Filled worksheet photos - Activity 2: Challenge Mapping

**Activity 2 - Challenge Mapping**

**Challenge:** 1 - Data access friction.  
Slow project start + time pressures.

**GROUP:** 5

<b>What does it cause?</b>	<ul style="list-style-type: none"> <li>- Less research happens in complete project.</li> <li>- Research abandoned.</li> <li>- Funding lost.</li> <li>- Reputational damage</li> <li>- Pressure put on other supporting team/friction due to changing priorities</li> </ul>	Worse science, not just less research but also lower quality	Risk aversion / Lack of ambition	Low baseline of understanding → avoidance of sharing
<b>Lifecycle stage where it appears</b>	- on lifecycle sheet.			
<b>Where should it be addressed?</b>	<ul style="list-style-type: none"> <li>- Training researchers / R / centers in legal + data governance.</li> <li>- Right people (data protection / legal) involved in grants / research planning</li> </ul>	Funders to support with resources for data access		data safety governance could aid to expedite trust on certain professional / requesting data (eg. preapprovals)
<b>Who should address it?</b>	<ul style="list-style-type: none"> <li>- Data providers - clear metadata about datasets + data access process.</li> <li>- Senior leadership</li> </ul>			longer funder timelines to build collaborations
<b>What is the program?</b>	<p>plan data access, storage, etc from initial application stage - giving applicants sufficient time - providing necessary capabilities</p> <p>synthesize data to sample datasets + inform applications</p> <p>↓</p> <p>implemented AI research</p> <p>very important for Bennett Institute</p>		d RTP's part of grant reviews and project leadership	Duplication of processes - need national guidelines / minimum standards / Organizational setup
		Writing grants → the consensus shift towards ↓ chances of success		
		challenges to do data access diligence ahead of time		
			Lack of skill at data protection, access + legal side in AI research.	lack of specialized skills and dedicated teams

The Alan Turing Institute EMBL-EBI Advancing coll

## Activity 2 - Challenge Mapping

Challenge: FRAGMENTED DATA & LACK OF INTEGRATED SYSTEMS

GROUP:

What does it cause?

Limitations on breadth and depth of the research work that can be done; difficulties in accessing reproducible and synthesized data to produce outputs  
Frictions in setting up projects

Further fragmentation due to more RDS being created

- Repetition of things like curation / updates / links of data - often done inconsistently.
- Different systems can affect data processing / analysis differently.
- Lack of compatibility / adaptability to collaborate or combine data

Lifecycle stage where it appears

Design stage, when planning on what data to use, platforms, etc.

Deployment stage - fragmented systems make it difficult to train and deploy models, or extract models and outputs

Where should it be addressed?

Design stage

Development - critical to document when identifying / implementing.

Who should address it?

Funders, Data providers

What is blocking progress?

Underkill / lack of suitable skills for all involved parties → Lack to lack of trust in systems

~~The~~ Data ownership - data owners wishing to keep ownership of their data (especially in a research setting)

- Lack of sufficiently common standards for
  - ↳ describing data, provenance, processing / curation / linkage - documentation / data dictionary / synthetic data / user guide (to use / adapt / add to / link)
  - ↳ data sensitivity
  - ↳ systems for working with sensitive data
- Lack of expectations for approaches to derived data & models so they can be downstream inputs / bases for future work (includes ability to "step back" in data pipeline to take diff approaches to data cleaning / identification / linkage etc)





## Activity 2 - Challenge Mapping

Challenge: 3 - Risk Assessment & Governance Misalignment

GROUP: PALAPINS 1/  
AMBASSADORS

①  
What does it cause?

②  
Lifecycle stage where it appears

③  
Where should it be addressed?

④  
Who should address it?

⑤  
What is blocking progress?

① DELAYS IN  
SIGNING OFF  
/ PROGRESS IN

① Legal  
ambiguity

Confusion and lack of  
responsibility  
Delays, rework,  
① Not personal/organisational hassle, potential

① CLINICAL  
RISK/  
RISK OF  
UNETHICAL  
RESEARCH

BADLY SET-UP  
PROJECTS WITH  
NON-COMPLIANCE  
BUILT IN

② AT THE  
END!

② When something  
goes wrong!

② WHEN YOU TRY  
TO GET A DATA  
SHARING  
AGREEMENT  
SIGNED

② WHEN ETHICS  
REVIEW YOUR  
APPLICATION

③ AT THE  
START!  
~~START~~ AT PROJECT DESIGN

③ AT PRODUCT/  
PROJECT  
LAUNCH

④ PROJECT  
MANAGERS  
& PROGRAMME  
MANAGERS  
(to bring stakeholders  
together for  
efficient governance)

④ REGULATORS

FUNDERS

④ IN CONSULTATION WITH  
RESEARCH  
SUBJECTS

Multidisciplinary teams  
that include non-  
academic / legal / privacy

⑤ LACK OF ICO  
ENFORCEMENT  
ACTION

⑤ LACK OF EXPERTISE  
AMONG PEOPLE  
HAVING TO DO THIS  
WORK (e.g. RESEARCHERS)  
[THAT DOESN'T MEAN THEY SHOULD  
BE THE ONES DOING IT!]

Unwilling to  
share / negotiate  
risk appetite.

FORMAT OF  
⑤ FUNDING MEANS  
NO FUNDING DURING  
PLANNING STAGE

⑤ LACK OF  
TRAINING FOR  
RESEARCHERS  
(e.g. REI)

⑤ LACK OF  
COLLAB. BETWEEN  
INDUSTRY, REGULATORS  
RESEARCH SUBJECTS  
ETC

(lack of)  
Support / Engagement  
from the top management  
teams

AND TOP  
MANAGEMENT!

LACK OF RESOURCES  
FOR UPSKILLING  
(IF YOU DON'T HAVE A  
DEDICATED TEAM!)

⑤ NEED MORE  
"FACILITATORS OF  
GOOD PRACTICES"  
(e.g. data standards)

ing collaboration and data sharing as

## Activity 2 - Challenge Mapping

Challenge: 4. Cultural and multidisciplinary barriers

GROUP: 6

What does it cause?

- Lack of common understanding of the project and different teams and roles in the project
- Miscommunication
- Misaligned goals
- Long-term: WE FAIL!
- Team goals not aligned to overall project goal.
- Different approaches across teams / disciplines to how to solve problems / approach things.
- Increase inequalities (e.g. bio data professionals are women for example) → bad culture 44 barriers.

Lifecycle stage where it appears

Any (the most important stage: design)

Where should it be addressed?

- Project planning stage (prior to grant application)

Who should address it?

- Funder - set expectations, collab/support on execution, support/signpost material / good practice.
- Collaborators (senior members of each team collaborating)
  - ↳ embedded "dear" leads need to own this during delivery.
  - ↳ specialised project management specialists could help define good practice / approaches & drive these.

What is blocking progress?

- Incentives to solve this missing / not aligned for co-Is who need to be behind any change
- Imbalance in power / influence across stakeholders
- Lack of clarity on responsibilities
- Lack & expertise on how to do this better.

PLAIN 'SHARED' LANGUAGE

SILLO'D EXPERTISE NOT "LACK"

EMPOWERMENT TRAINING





## Activity 2 - Challenge Mapping

Challenge: 5- AI-specific contractual complexity

Paladins  
GROUP: II

What does it cause?

- complete confusion => delays (unquantifiable) if bespoke or lack of risk coverage (if using standard)
- vacuum of relevant regulatory framework
- what data you are holding will significantly change the contracting
- stalemate in contractual progress
- Contracting only done at the beginning and can hamper agile working because you cannot reopen as you learn more
- Top level "general purpose" clauses that shouldn't change, supplementary that are more flexible [more a solution]
- closes research directions if contract can't be flexible

Lifecycle stage where it appears

Design & Deployment => deployment knowledge to influence contracting  
planning  
 All across, but better design planning needed

Where should it be addressed?

- Pre-design -> implementation right across
- decisions point needed in ~~the~~ deployment (earlier in modular contract) => policy to allow responsible decision making

How to address

- Users of AI forced to address => filling gap of vacuum
- Government (or similar level) needs to set minimum standard [Advisory board to help scrutinize policy/process at organisational level -> But at the right level and not just to mitigate risk]
- Coordinated approach across UKRI -> hopeful with the new coordinated AI plan/strategy
- Bottom up principles from researchers likely quickest, but should be regulator
- X waiting for regulators not possible
- Data owners/platforms will need to proceed first (middle ground btw government/regulator vs primary researchers)

What is blocking

- Unclear where right balance is, or what the minimum standard is (=benchmark)
- Lack of clear regulatory framework to work towards (e.g. GDPR equivalent) to get thing moving
- Lack of common agreed AI design principles (similar to GDPR principles) that can guide design
- No flexibility
- Hard to predict exactly what is needed through full project => can supplementary modules be easier to amend because you don't touch the core contract.
- Need to define everything, rather than accepting iterative design.
- Lack of transparency => everyone trying to do it alone and not sharing knowledge
- Lack of PPIE & clear communication & literacy

Do regulators possess the right skills/know-how/experience to provide guidance and framework?

How to manage expertise with regulation?

## Activity 2 - Challenge Mapping

Challenge: 6. PUBLIC TRUST, ENGAGEMENT, ACCEPTANCE

GROUP: 3

What does it cause?

opt out, especially for  
medical data.  
> potential for  
health inequalities  
(and loss of diversity)

backlash from  
policy maker

Undermine  
research impact  
and implementation

Less cross-sector  
working on  
Knowledge exchange

lack of guideline  
on publishing  
for researcher

different awareness  
of AI.  
Skill gaps between hubs  
& more rural areas

Lifecycle stage where  
it appears

Representativeness  
of sample.  
Importing entire  
life cycle.  
(under-represented)

Private partners  
focusing on rapid  
dev not engaging  
public, but then public  
institutions adopt their  
solutions and struggle to  
engage the public at late stage

Research  
becoming less open  
(people afraid of  
showing data without  
engagement)

Misinformation/  
mistrust for AI.  
→ engagement in  
the long term.

Fear that big companies  
can at some point  
buy NHS patient data

Where should it be  
addressed?

Starting with  
design stage.  
> and even before  
that!

Really crucial to  
start in the design  
stage, but really  
then throughout the  
whole cycle

Train the decision makers/  
leaders / policy makers  
to be aware.

Professionalised PR/E  
vs  
naïve engagement  
heavy diverse voices (not only experts)

Potential resource constraint  
recovery of work to  
accommodate for patient  
withdrawal of consent.  
Not losses, low trust or  
research.

Who should address  
it?

- developers  
- collaborators

Researchers/  
Research teams

Public media

Public funding  
funders

Clinicians,  
hospital staff

Iterative Process  
- engagement needs to  
take into account public  
attitudes change

What is blocking  
progress?

Public-funded  
projects need to  
engage with the  
public, but it's not  
always the case for  
private partners

lack of  
guidance,  
i.e. "how-to"

lack of  
incentives  
for researchers to  
engage with the  
public  
(high pressure system  
doesn't make it a  
priority)

Mis-perception of  
AI?

People's duty to day  
of usage, slightly  
more  
Some public  
is to fearful about  
AI

Different regional  
regulations, blocking  
international engagement.

lack of  
data literacy/  
AI literacy

lack of  
trust for the  
analysis/evaluation process.

Time for AI cycle:  
long development  
process, therefore  
good news stories  
about impact are  
scarce.

Different  
perception of  
stakeholders  
engagement  
across international  
contexts



## Activity 2 - Challenge Mapping

Challenge: ~~7~~ SKILLS, TRAINING AND  
WORKFORCE DEVELOPMENT

GROUP: ~~7~~

What does it cause?

- Slows progress - risks to funded / risks of not delivering
- Lack of confidence leading to frustration
- Problems with staff retention
- Siloed working & lack of collaboration
- Lack of compliance

- Group 2
- lack of competence results in solutions with huge risks, non-ethical compliance
  - lack of credibility

Lifecycle stage where it appears

Design - slow progress  
~~Deployment~~ Development -  
Deployment -

All 3 → Lack of confidence  
→ Staff retention

Where should it be addressed?

- Recognition of roles and career development opportunities for enables
- Training & compliance team → be more proactive in reaching out to researchers → consultancy approach
- Project design phase → clarity of roles & procedures

- Assump. - training & compl. team existing
- organisationally accountability needed, (mentorship, line manager)
  - skills development problem pre employment

Who should address it?

- Training & compliance support teams
- Senior management / Trustees (clear organisational message)
  - ↳ Creating a culture & combined purpose
  - ↳ Culture of respect and equity

- large organisations opening their training
- Research leadership
- organisational and individual accountability
- funders / governmental investment in coordination addressing of skills gap (open-source all skills/training materials, fund multiple orgs. to work together, adopt common skills framework)

What is blocking progress?

- Lack of time
- Organisational set-up
- Lack of autonomy, particularly in large organisations
- People don't always know who is responsible for what
- Buy in
- Training is boring
- Equitable access to training & funding for training
- Equitable access to career opportunities

- changeability of AI
- link competence to JD/CPD / objectives
- lack of framework / best practice that clarifies competence for different roles, and how those competence applies to different stages
- lack of structured / coordinated approach in skills landscape
- Good practice has different roles working together and sharing knowledge → training often doesn't cover this
- The level you look at means contextual difference in competence needs "organisationally", team-based, project-based, it-team  
⇒ what does that mean to you?

