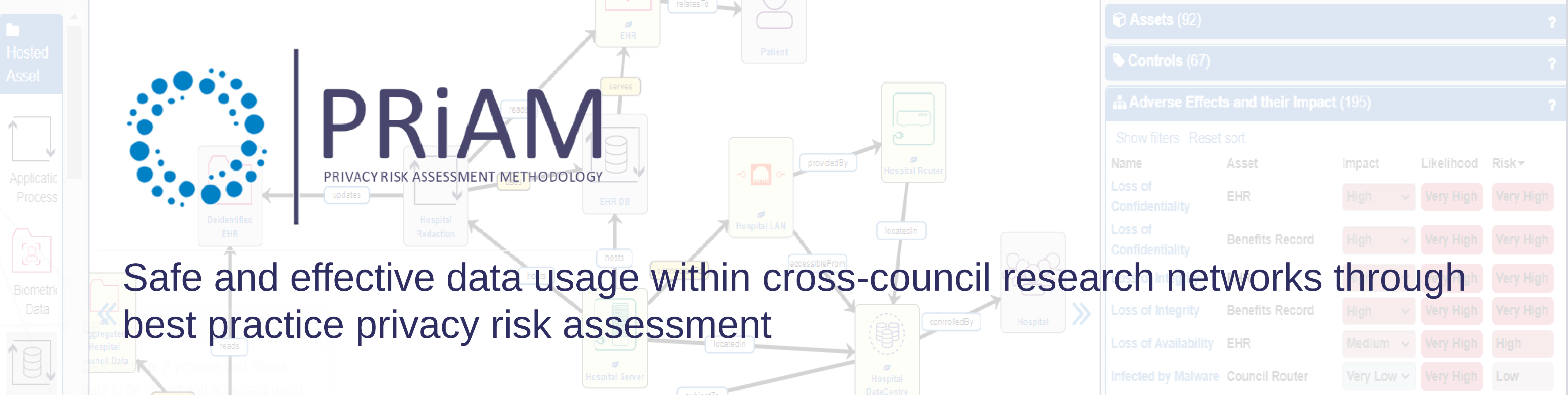
UK Research and Innovation

HDRUK Health Data Research UK

ADRUK Data-driven change



Assets (92)

Controls (67)

Adverse Effects and their Impact (195)

Show filters Reset sort

Name	Asset	Impact	Likelihood	Risk
Loss of Confidentiality	EHR	High	Very High	Very High
Loss of Confidentiality	Benefits Record	High	Very High	Very High
[illegible]	[illegible]	[illegible]	[illegible]	Very High
Loss of Integrity	Benefits Record	High	Very High	Very High
Loss of Availability	EHR	Medium	Very High	High
Infected by Malware	Council Router	Very Low	Very High	Low

PRiAM

PRIVACY RISK ASSESSMENT METHODOLOGY

Safe and effective data usage within cross-council research networks through best practice privacy risk assessment

Presented by Professor Michael Boniface (m.j.boniface@soton.ac.uk)

University of Southampton, IT Innovation Centre

Interim Progress - April 2022

UNIVERSITY OF Southampton

WMG THE UNIVERSITY OF WARWICK

PRIVITAR

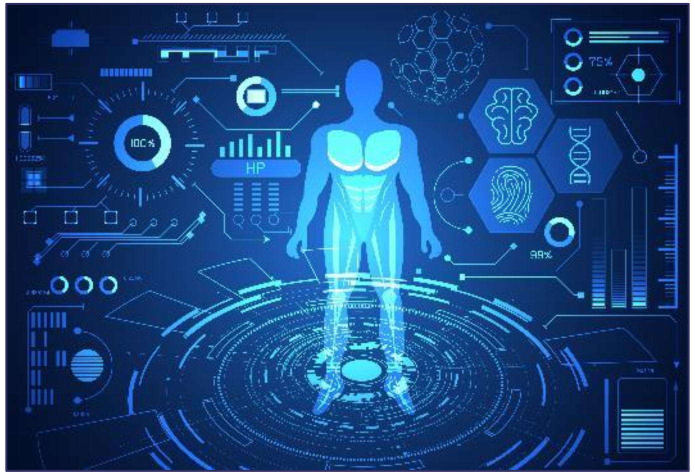
Motivation

- Research to improve health and wellbeing increasingly depends on **combing diverse data from multiple organisations**

- However, "..the **use of data presents risks**; those risks need to be fully understood and taken into account",
  UK's National Data Sharing Strategy, DCMS

- Even with shared principles for safe data usage, **privacy risk management is still vague**
  - no consistent guidance for risk assessment, mitigation and management
  - resulting in different implementations of Trusted Research Environments

- A **common way to assess privacy risk** is needed



Approach

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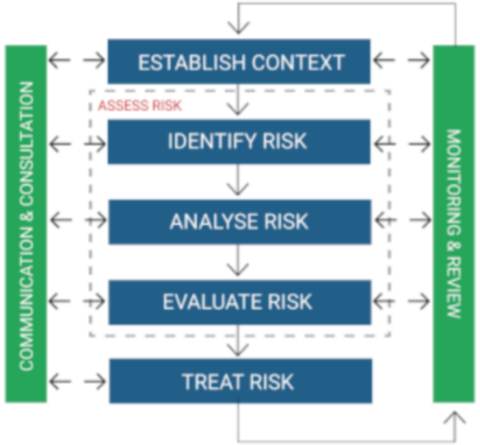
PRIVACY RISK ASSESSMENT METHODOLOGY

- We aim to published a best-practice **privacy risk assessment framework** that can describe and assess privacy risk for **safe data usage** in research networks

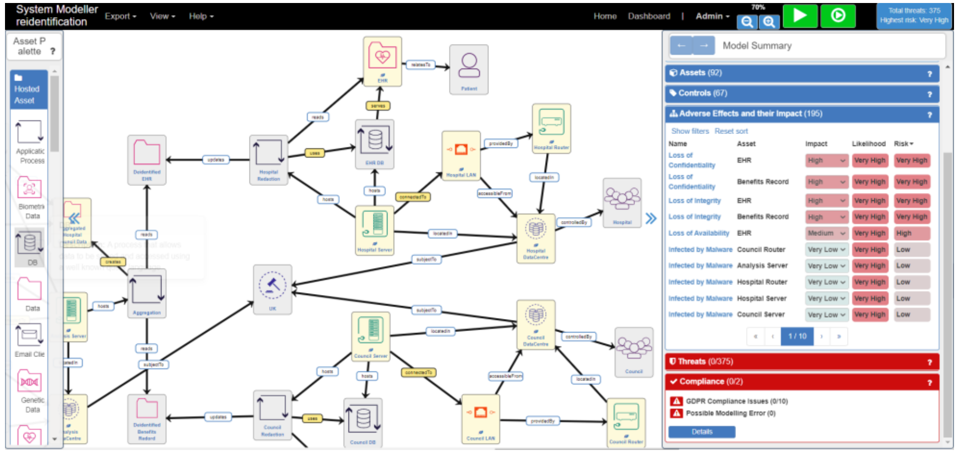
- We will bring together well-known principles for safe research - the **Five Safes** with methodology for information security risk management (**ISO 27005**) to enable consistent, efficient and usable privacy assessment

SAFE DATA
SAFE PROJECTS
SAFE PEOPLE
SAFE SETTINGS
SAFE OUTPUTS

principles



risk assessment and management



Total threats: 375
Highest risk: Very High

Assets (92)

Controls (67)

Adverse Effects and their Impact (195)

Show filters Reset sort

Name	Asset	Impact	Likelihood	Risk
Loss of Confidentiality	EHR	High	Very High	Very High
Loss of Confidentiality	Benefits Record	High	Very High	Very High
Loss of Integrity	EHR	High	Very High	Very High
Loss of Integrity	Benefits Record	High	Very High	Very High
Loss of Availability	EHR	Medium	Very High	High
Infected by Malware	Council Router	Very Low	Very High	Low
Infected by Malware	Analysis Server	Very Low	Very High	Low
Infected by Malware	Hospital Router	Very Low	Very High	Low
Infected by Malware	Hospital Server	Very Low	Very High	Low
Infected by Malware	Council Server	Very Low	Very High	Low

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Threats (0/375)

Compliance (0/2)

GDPR Compliance Issues (0/10)

Possible Modelling Error (0)

Details

risk modelling of systems

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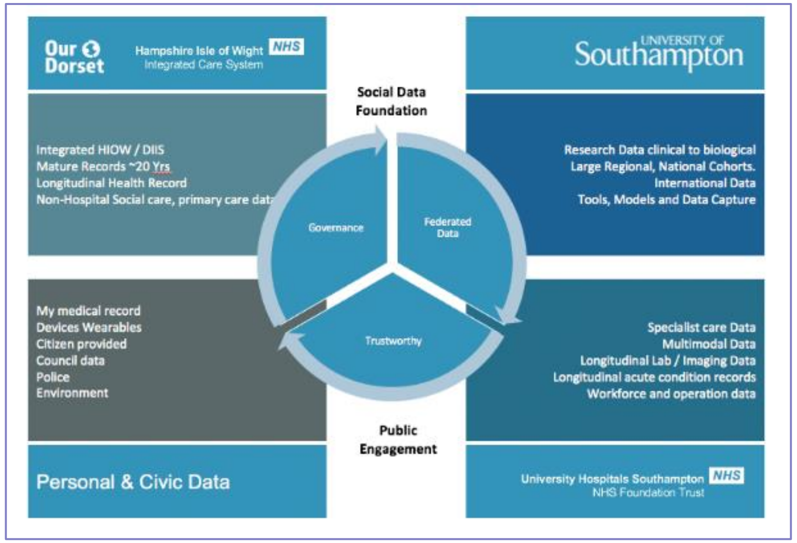
Objectives

- Analyse **driver use cases** in public health prevention and integrated care
- Identify **factors contributing to privacy risks** within the Five Safes
- Define a **framework** to provide a consistent methodology for privacy risk assessment
- Assess privacy risks for use cases using a cyber security **risk modelling and simulation** platform
- Codesign and evaluate the framework, modelling and simulation through **engagement with the public and multidisciplinary stakeholders**



Our Dorset

Hampshire Isle of Wight NHS Integrated Care System

Integrated HIOW / DIIS
Mature Records ~20 Yrs
Longitudinal Health Record
Non-Hospital Social care, primary care data

My medical record
Devices Wearables
Citizen provided
Council data
Police
Environment

Personal & Civic Data

University of Southampton

Research Data clinical to biological
Large Regional, National Cohorts.
International Data
Tools, Models and Data Capture

Specialist care Data
Multimodal Data
Longitudinal Lab / Imaging Data
Longitudinal acute condition records
Workforce and operation data

University Hospitals Southampton NHS Foundation Trust NHS

Source: Wessex Trusted Research Environment (NHSx)

PRiAM
PRIVACY RISK ASSESSMENT METHODOLOGY

Privacy Requirements for Safe Federations

- Explore context of privacy risks for federated research networks
  - address multiple **interpretations** of principles
  - consider multiple **perceptions** of risk
  - elaborate **harms** related to federation
  - focus on **information privacy**
  - define **privacy goals** including CIA, acceptability, intervenability, transparency and unlinkability
  - identify of **privacy controls**

- Introduce the principle of '**safe federation**'
  - Protocols for commitment from parties over goals, standards, success measures, costs, benefits and value creation
  - Benefits -> *local control, risk mitigation, large data, potential reduction in costs, cross border working*
  - Challenges -> *decision making complexity, new risks from infomediaries, new approaches to federated controls (e.g. intervenability)*

- Define of operational/functional privacy requirements for safe federations

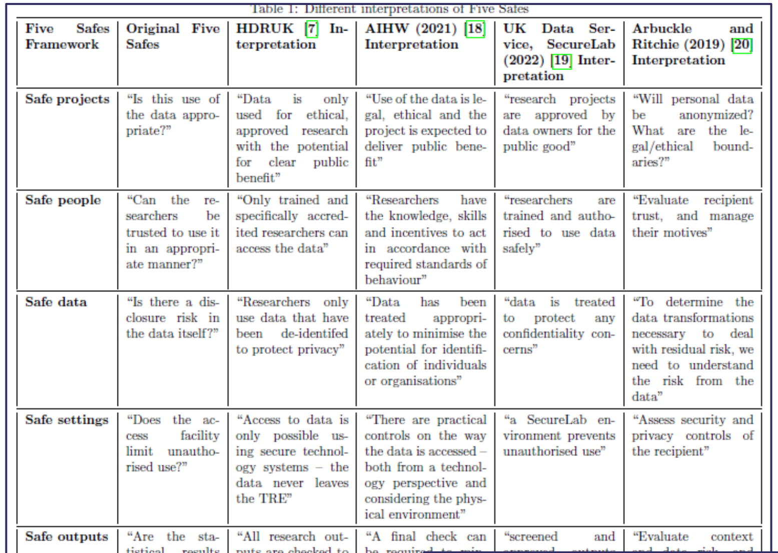


Table 1: Different interpretations of Five Safes

Five Safes Framework	**Original Five Safes**	**HDRUK [7] Interpretation**	**AIHW (2021) [18] Interpretation**	**UK Data Service, SecureLab (2022) [19] Interpretation**	**Arbuckle and Ritchie (2019) [20] Interpretation**
Safe projects	"Is this use of the data appropriate?"	"Data is only used for ethical, approved research with the potential for clear public benefit"	"Use of the data is legal, ethical and the project is expected to deliver public benefit"	"research projects are approved by data owners for the public good"	"Will personal data be anonymized? What are the legal/ethical boundaries?"
Safe people	"Can the researchers be trusted to use it in an appropriate manner?"	"Only trained and specifically accredited researchers can access the data"	"Researchers have the knowledge, skills and incentives to act in accordance with required standards of behaviour"	"researchers are trained and authorised to use data safely"	"Evaluate recipient trust, and manage their motives"
Safe data	"Is there a disclosure risk in the data itself?"	"Researchers only use data that have been de-identifed to protect privacy"	"Data has been treated appropriately to minimise the potential for identification of individuals or organisations"	"data is treated to protect any confidentiality concerns"	"To determine the data transformations necessary to deal with residual risk, we need to understand the risk from the data"
Safe settings	"Does the access facility limit unauthorised use?"	"Access to data is only possible using secure technology systems – the data never leaves the TRE"	"There are practical controls on the way the data is accessed – both from a technology perspective and considering the physical environment"	"a SecureLab environment prevents unauthorised use"	"Assess security and privacy controls of the recipient"
Safe outputs	"Are the statistical results non-disclosive?"	"All research outputs are checked to ensure they cannot be used to identify subjects"	"A final check can be requir imise risk leasing the the projec	"screened and	"Evaluate context
Key purpose	To be used as discussion points about data access	Presented as key principles of TREs	Presented dimension with "pot to be miti		

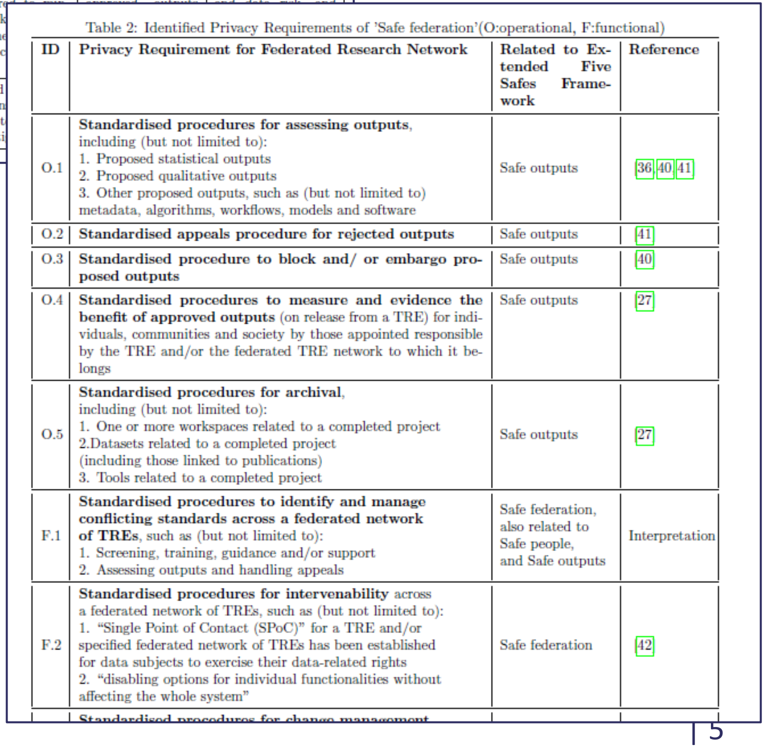
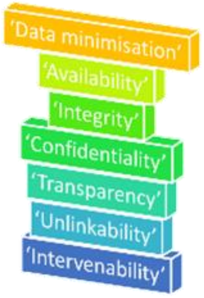


Table 2: Identified Privacy Requirements of 'Safe federation'(O:operational, F:functional)

ID	**Privacy Requirement for Federated Research Network**	**Related to Extended Five Safes Framework**	**Reference**
O.1	**Standardised procedures for assessing outputs**, including (but not limited to): 1. Proposed statistical outputs 2. Proposed qualitative outputs 3. Other proposed outputs, such as (but not limited to) metadata, algorithms, workflows, models and software	Safe outputs	[36,40,41]
O.2	**Standardised appeals procedure for rejected outputs**	Safe outputs	[41]
O.3	**Standardised procedure to block and/ or embargo proposed outputs**	Safe outputs	[40]
O.4	**Standardised procedures to measure and evidence the benefit of approved outputs** (on release from a TRE) for individuals, communities and society by those appointed responsible by the TRE and/or the federated TRE network to which it belongs	Safe outputs	[27]
O.5	**Standardised procedures for archival**, including (but not limited to): 1. One or more workspaces related to a completed project 2.Datasets related to a completed project (including those linked to publications) 3. Tools related to a completed project	Safe outputs	[27]
F.1	**Standardised procedures to identify and manage conflicting standards across a federated network of TREs**, such as (but not limited to): 1. Screening, training, guidance and/or support 2. Assessing outputs and handling appeals	Safe federation, also related to Safe people, and Safe outputs	Interpretation
F.2	**Standardised procedures for intervenability** across a federated network of TREs, such as (but not limited to): 1. "Single Point of Contact (SPoC)" for a TRE and/or specified federated network of TREs has been established for data subjects to exercise their data-related rights 2. "disabling options for individual functionalities without affecting the whole system"	Safe federation	[42]
	Standardised procedures for change management		



+ Acceptability

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Public Involvement and Engagement – Privacy Risk Assessment Forum

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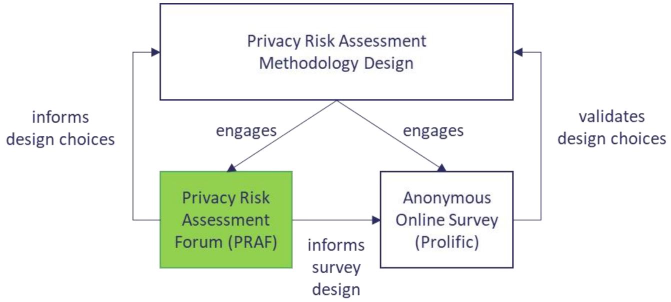
PRIVACY RISK ASSESSMENT METHODOLOGY

- Find ways to involve members of the public in data sharing decisions
- Approach
  - 12 members of the public
  - Participant journey
    - ○ ***1. Privacy attitudes and language (Done)***
    - ○ 2. Privacy and self-efficacy
    - ○ 3. Privacy and responsibilities
    - ○ 4. Check and test findings for online survey
- Emerging themes (1st workshop analysis in progress)
  - Education and support
  - Communication of decisions
  - Polarities in the debate (you signed so your responsibility vs people don't have understanding)
  - Concerns for custodianship incl. data retention beyond business lifecycles
  - Concerns regarding business vs plain language

Public Involvement

James McMahon
J.P.Mcmahon@southampton.ac.uk

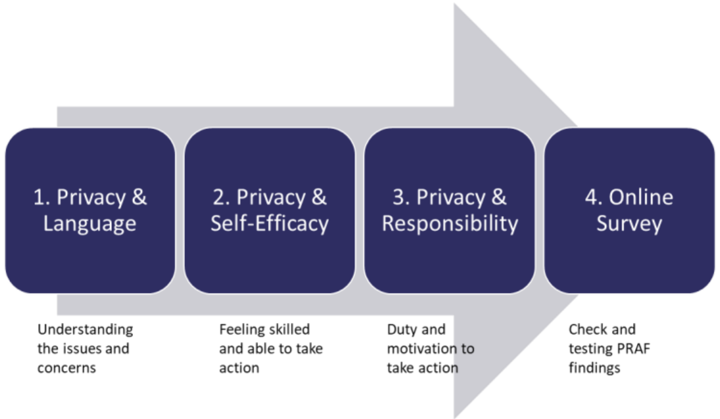

Privacy Risk Assessment Methodology Design
informs design choices
engages
engages
validates design choices
Privacy Risk Assessment Forum (PRAF)
informs survey design
Anonymous Online Survey (Prolific)

Scenario 1 – Online Shopping

Scenario 2 – Activity Tracking

Scenario 3 – COVID Track and Trace

Scenario 4 – Research Project


1. Privacy & Language
2. Privacy & Self-Efficacy
3. Privacy & Responsibility
4. Online Survey
Understanding the issues and concerns
Feeling skilled and able to take action
Duty and motivation to take action
Check and testing PRAF findings

What do you understand by....

- Safety
- Privacy Harm
- Feared Event
- Data Stewardship
- Trusted Research Environment

....would you use different words?

What do you understand by....

- Privacy risk, likelihood and impact
- Asset, threat and vulnerability
- Security and privacy control
- Loss of confidentiality
- Identifier, quasi-identifier, and reidentification

....would you use different words?

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Advisory Group

22 experts including:

- Information governance practitioners
- Practitioners running or developing secure research facilities
- Legal professionals
- Oversight bodies
- Academic experts

Semi-structured interviews to understand the risk factors to consider when research projects request data, the controls available and the decisions tied to privacy risk assessment

SOUTHAMPTON CITY COUNCIL

ico. Information Commissioner's Office

MANCHESTER 1824
The University of Manchester
Centre for Epidemiology Versus Arthritis

National Data Guardian

SAIL DATABANK

Microsoft

The Alan Turing Institute

NHS
University Hospital Southampton
NHS Foundation Trust

UWE Bristol

UNIVERSITY OF CAMBRIDGE

Cambridge Health Informatics Limited

Imperial College London

NHS Digital

University of Southampton

PHIN

Bristows

UKRI Medical Research Council

NHS Hampshire and Isle of Wight

UKRI UK Research and Innovation

HDRUK Health Data Research UK

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Early findings from the Advisory Board

- Decisions by committees to determine ***functional anonymisation*** guarantees can be subjective and lack transparency

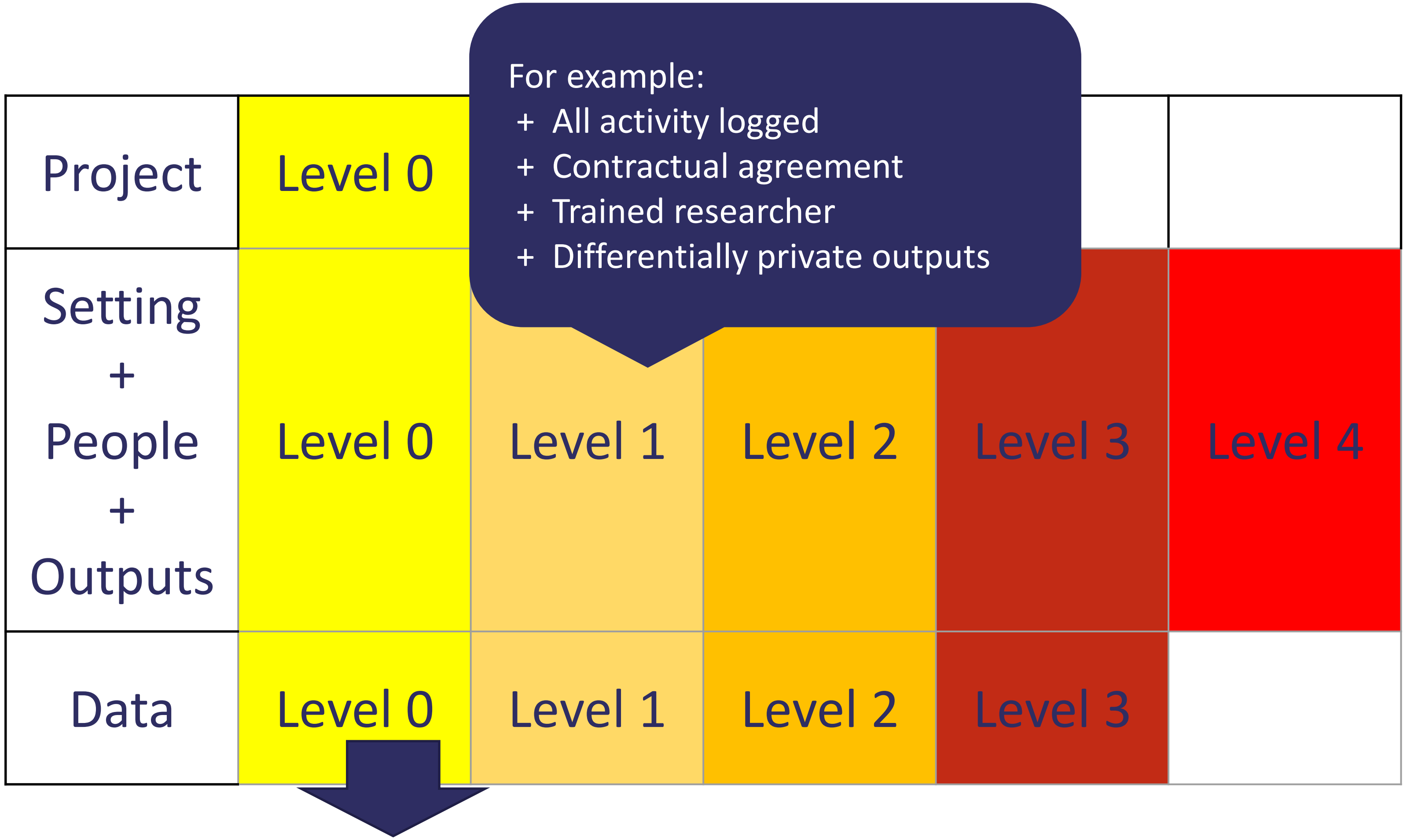
- In data sharing contracts, ***institutions*** that the researcher requesting data is affiliated with matters a lot
  - problems for people who do not have affiliations with a stronger/well established institution
  - bottleneck for researchers to navigate IG inside their own organisation, especially if they are risk averse

- Controls on one safe can ***compensate for risks*** on the other in certain cases (e.g., people and settings) but not in others (e.g., project)

Risk Tiers Framework

Develop a framework to help decision makers:

- **Document** level of risk along each axis of the five safes
- Establish a **shared view** that stakeholders can understand and reason about
- **Evaluate** risk and the actions to reduce risk for each data sharing scenario
- Respond to risk **consistently**



For example:
+ All activity logged
+ Contractual agreement
+ Trained researcher
+ Differentially private outputs

Project	Level 0				
Setting + People + Outputs	Level 0	Level 1	Level 2	Level 3	Level 4
Data	Level 0	Level 1	Level 2	Level 3	

Tier 1	Sum of risk levels = 0 or 1
Tier 2	Sum of risk levels = 2 or 3
Tier 3	Sum of risk levels > 3

Overall risk tier for project mapped to decisions. For example:

- Tier 1 = Fast track approval
- Tier 2 = Increased monitoring of project
- Tier 3 = Rejection

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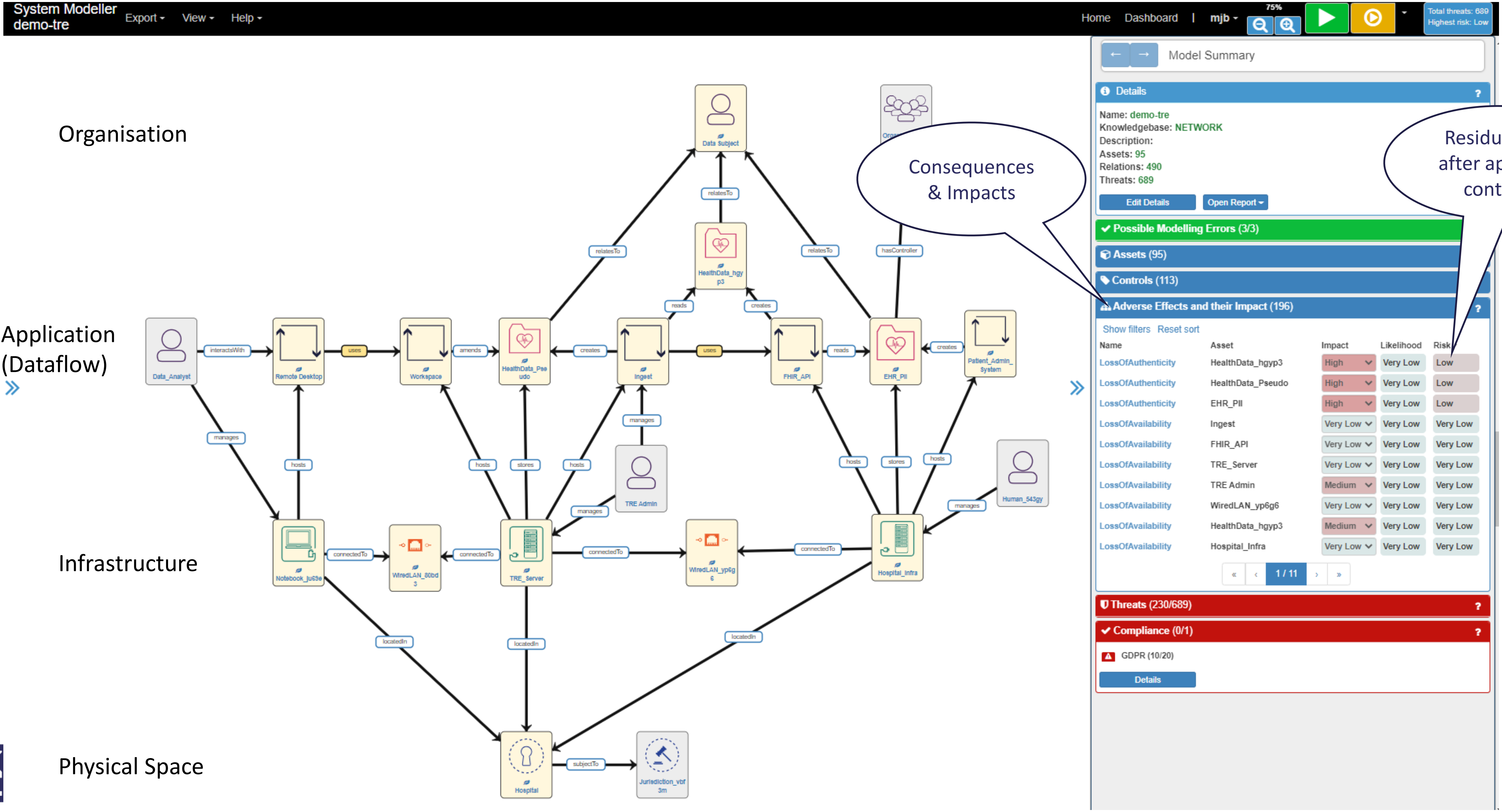
Privacy and Security Risk Modelling – Example TRE system model



Total threats: 689
Highest risk: Low

← → Model Summary

Details

Name: demo-tre
Knowledgebase: NETWORK
Description:
Assets: 95
Relations: 490
Threats: 689

Edit Details | Open Report

✓ Possible Modelling Errors (3/3)

Assets (95)

Controls (113)

Adverse Effects and their Impact (196)

Show filters Reset sort

Name	Asset	Impact	Likelihood	Risk
LossOfAuthenticity	HealthData_hgyp3	High	Very Low	Low
LossOfAuthenticity	HealthData_Pseudo	High	Very Low	Low
LossOfAuthenticity	EHR_PII	High	Very Low	Low
LossOfAvailability	Ingest	Very Low	Very Low	Very Low
LossOfAvailability	FHIR_API	Very Low	Very Low	Very Low
LossOfAvailability	TRE_Server	Very Low	Very Low	Very Low
LossOfAvailability	TRE Admin	Medium	Very Low	Very Low
LossOfAvailability	WiredLAN_yp6g6	Very Low	Very Low	Very Low
LossOfAvailability	HealthData_hgyp3	Medium	Very Low	Very Low
LossOfAvailability	Hospital_Infra	Very Low	Very Low	Very Low

« ‹ 1 / 11 › »

Threats (230/689)

✓ Compliance (0/1)

GDPR (10/20)

Details

Organisation

Application (Dataflow)

Infrastructure

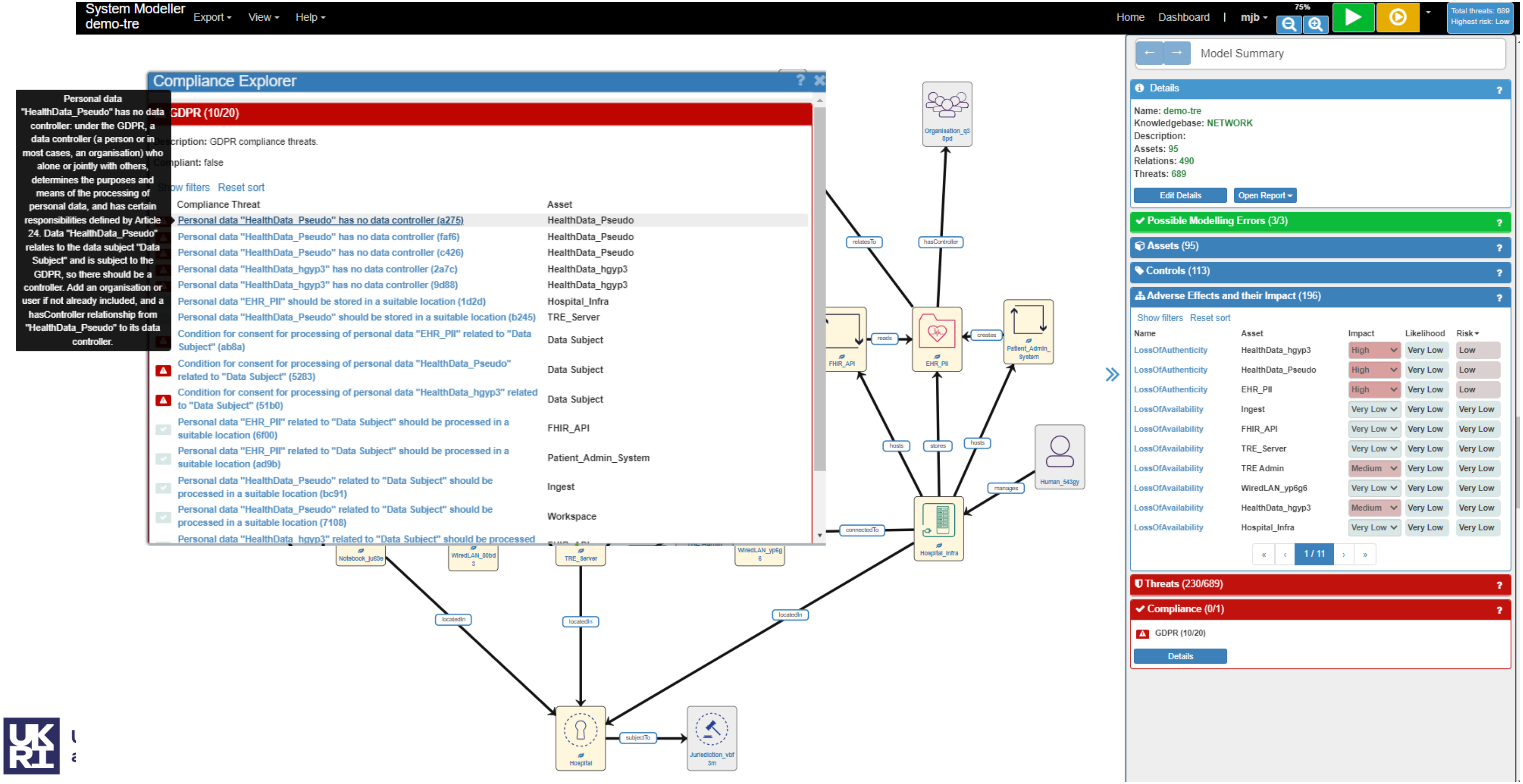
Physical Space

689 Threats

Consequences & Impacts

Residual risk after applying controls

GDPR Compliance Explorer



Personal data "HealthData_Pseudo" has no data controller: under the GDPR, a data controller (a person or in most cases, an organisation) who alone or jointly with others, determines the purposes and means of the processing of personal data, and has certain responsibilities defined by Article 24. Data "HealthData_Pseudo" relates to the data subject "Data Subject" and is subject to the GDPR, so there should be a controller. Add an organisation or user if not already included, and a hasController relationship from "HealthData_Pseudo" to its data controller.

Compliance Explorer

GDPR (10/20)

Description: GDPR compliance threats.

Compliant: false

Show filters   Reset sort

	Compliance Threat	Asset
	Personal data "HealthData_Pseudo" has no data controller (a275)	HealthData_Pseudo
	Personal data "HealthData_Pseudo" has no data controller (faf6)	HealthData_Pseudo
	Personal data "HealthData_Pseudo" has no data controller (c426)	HealthData_Pseudo
	Personal data "HealthData_hgyp3" has no data controller (2a7c)	HealthData_hgyp3
	Personal data "HealthData_hgyp3" has no data controller (9d88)	HealthData_hgyp3
	Personal data "EHR_PII" should be stored in a suitable location (1d2d)	Hospital_Infra
	Personal data "HealthData_Pseudo" should be stored in a suitable location (b245)	TRE_Server
	Condition for consent for processing of personal data "EHR_PII" related to "Data Subject" (ab8a)	Data Subject
⚠	Condition for consent for processing of personal data "HealthData_Pseudo" related to "Data Subject" (5283)	Data Subject
⚠	Condition for consent for processing of personal data "HealthData_hgyp3" related to "Data Subject" (51b0)	Data Subject
✓	Personal data "EHR_PII" related to "Data Subject" should be processed in a suitable location (6f00)	FHIR_API
✓	Personal data "EHR_PII" related to "Data Subject" should be processed in a suitable location (ad9b)	Patient_Admin_System
✓	Personal data "HealthData_Pseudo" related to "Data Subject" should be processed in a suitable location (bc91)	Ingest
✓	Personal data "HealthData_Pseudo" related to "Data Subject" should be processed in a suitable location (7108)	Workspace
	Personal data "HealthData_hgyp3" related to "Data Subject" should be processed	FHIR_API

Model Summary

Details

Name: demo-tre
Knowledgebase: NETWORK
Description:
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Edit Details   Open Report

✓ Possible Modelling Errors (3/3)

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« ‹ 1 / 11 › »

Threats (230/689)

✓ Compliance (0/1)

⚠ GDPR (10/20)

Details

Conclusions

- Privacy requirements for safe federations and use cases analysed
  - D1 report to be published end-May

- Approach codesigned with stakeholder engagement through Advisory Board and the public Privacy Risk Assessment Forum

- Risk Tiers framework outlined and aligned with security and privacy risk modelling tools

- Extensions to privacy domain knowledge for system modelling based on privacy requirements started

- Plans for open community of privacy and security domain experts supported by open methodologies and tools

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Thank you for listening

University of Southampton

WMG The University of Warwick

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