

The Scottish Federated Safe Haven Network

NRS Conference

1st Nov



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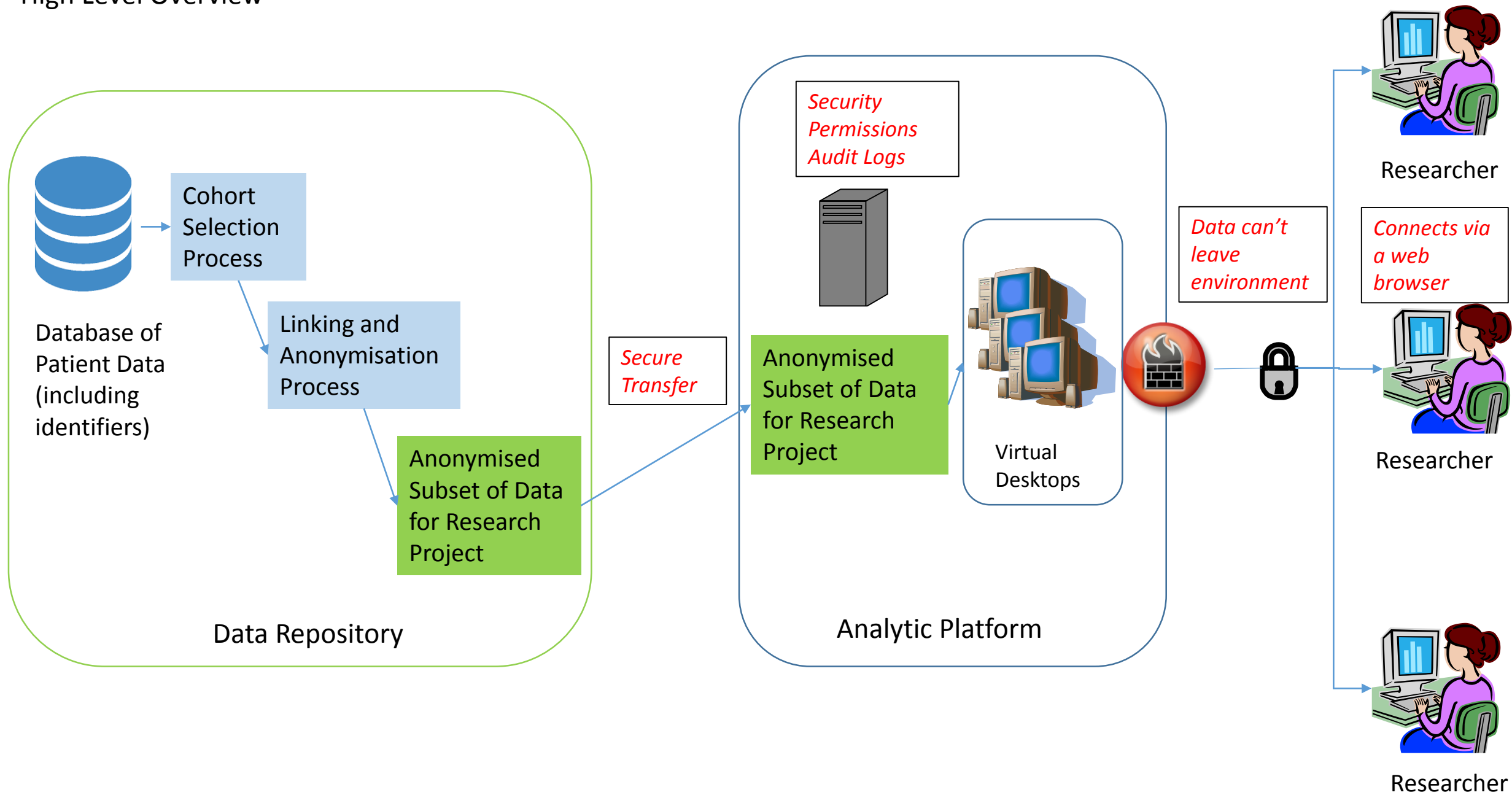
- One National Safe Haven (NSS (eDRIS)/EPCC)
- 4 Regional Safe Havens
 - A collaboration between an R&D Node of NHS Scotland and a University with a Medical School from within that region.



What is a Safe Haven?

- 3 Main Functions
 - **Analytic Platform:** provision of a virtual environment for researchers to securely analyse data without the data leaving the environment
 - **Data Repository:** secure handling and linking of data from multiple sources for research projects
 - **Research Support:** socio-technical environment that serves to bring together teams around health data science. The research coordinators provide support to researchers navigating the data requirements, permissions landscape and provide a mechanism to share the lessons from one project to the next.

High Level Overview



Analytic Platform

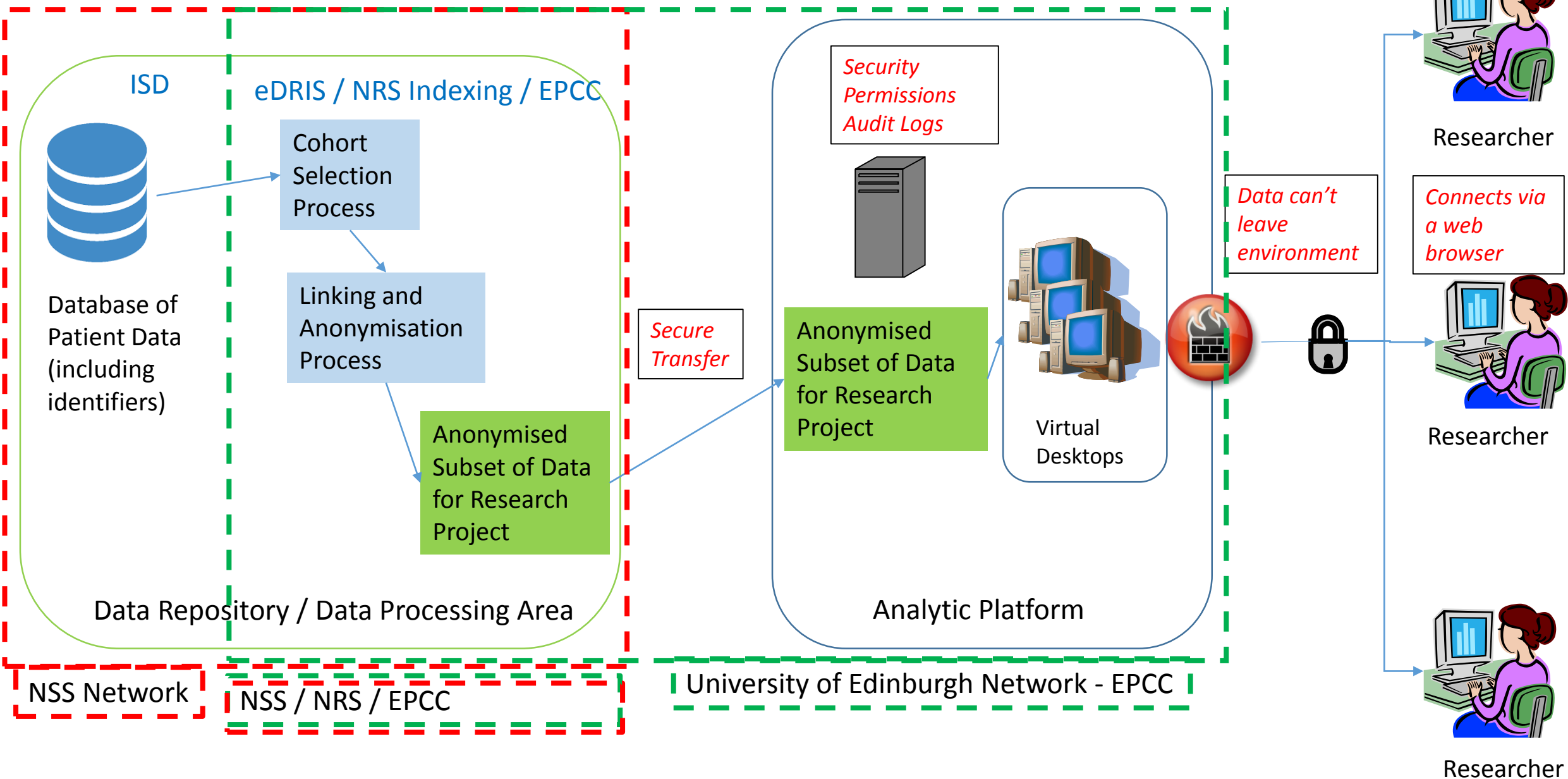
- Researchers provided a remote log on to a Virtual Machine (VM)
- The VM generally has basic statistics packages installed
- Researchers can only see the data for their specific cohort to answer their specific research question
- Researchers can analyse the data in place and can't copy the data out of the environment
- Aggregate level, analysis of the data can be copied out of the environment only once it has been checked by a Safe Haven team member for disclosure control.
- Researchers can't freely access the internet
- Researchers have to sign non-disclosure agreements and have to complete Information Governance Training
- Secure Access Controls:
 - ✓ Firewall
 - ✓ HTTPS Connection
 - ✓ Password Protection

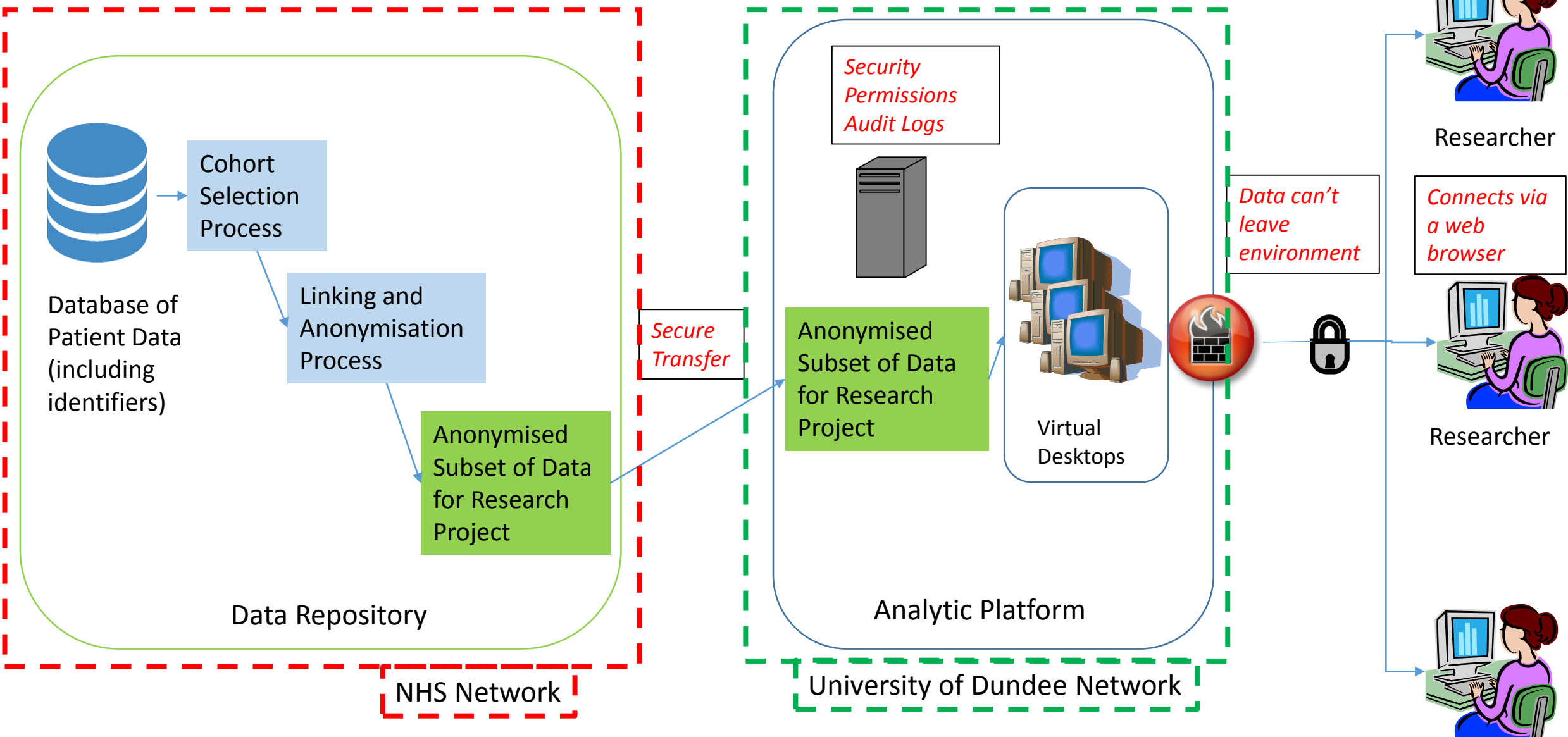
Data Repository Function

- Provision of linked anonymised datasets for research for a specific cohort to answer a specific research question
- The internals of how this works within each Safe Haven is slightly different
- Anyone Safe Haven staff member who has access to identifiable NHS patient data is either an employee of NHS or an Honorary employee



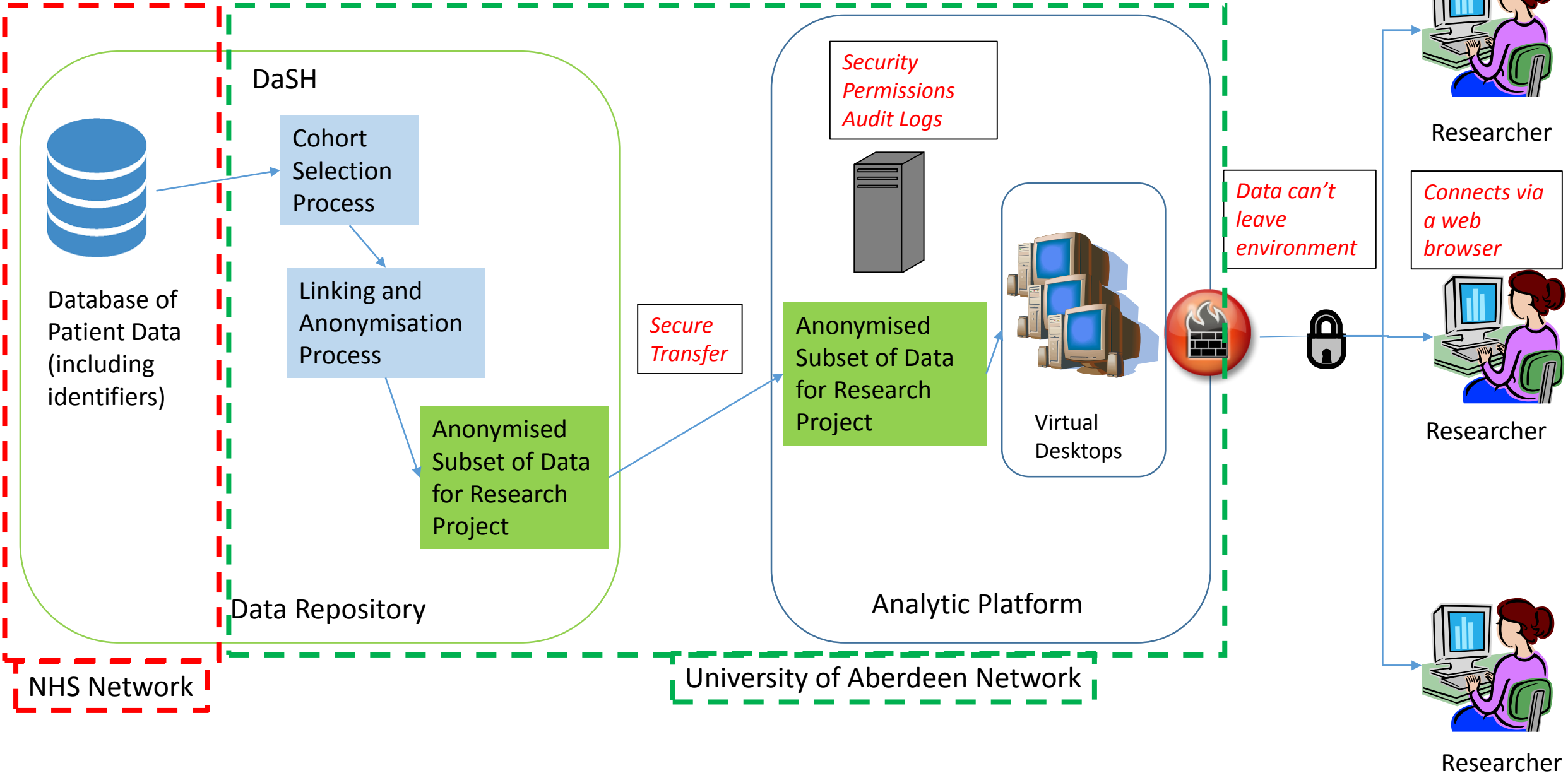
National Safe Haven



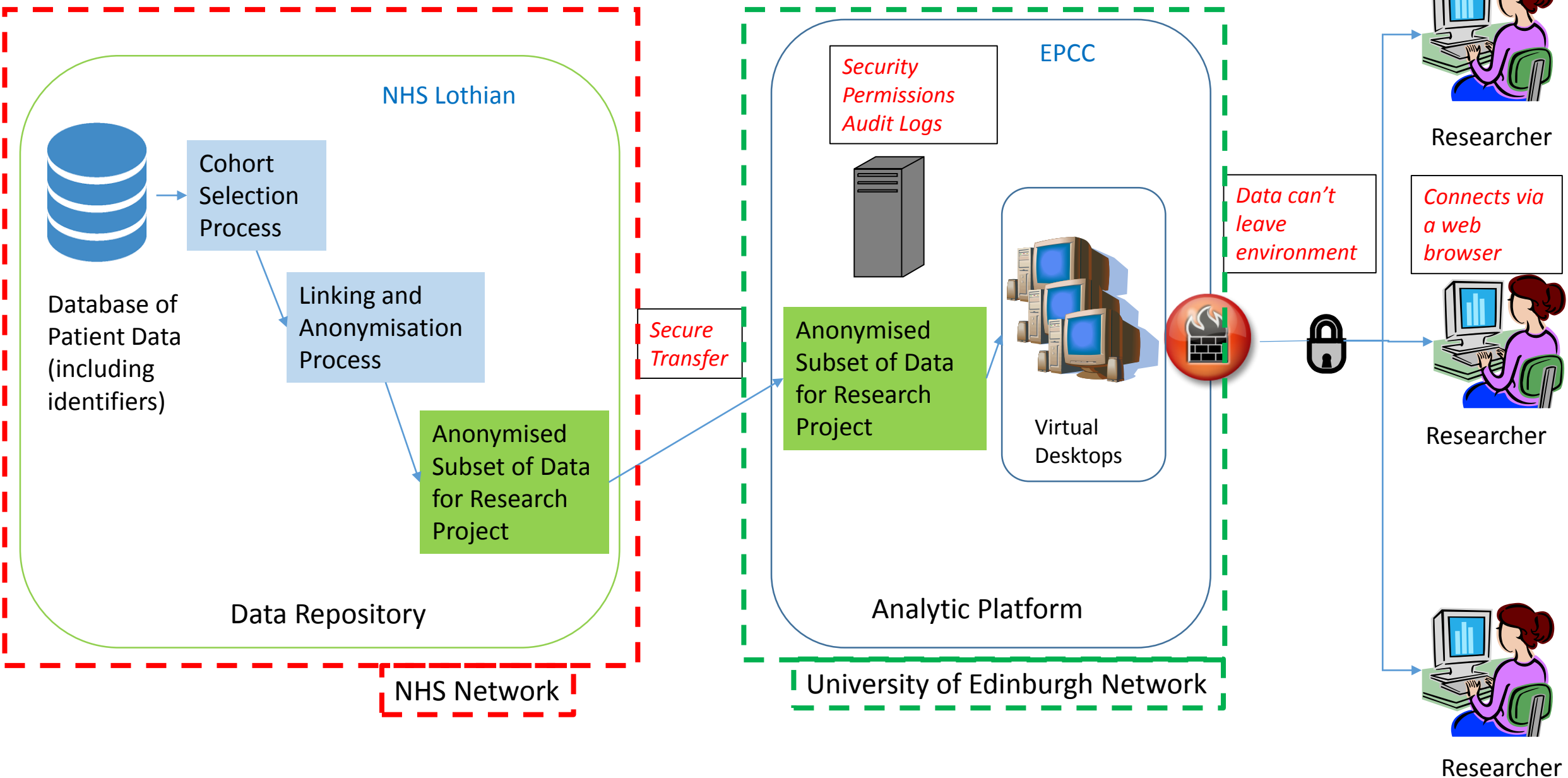




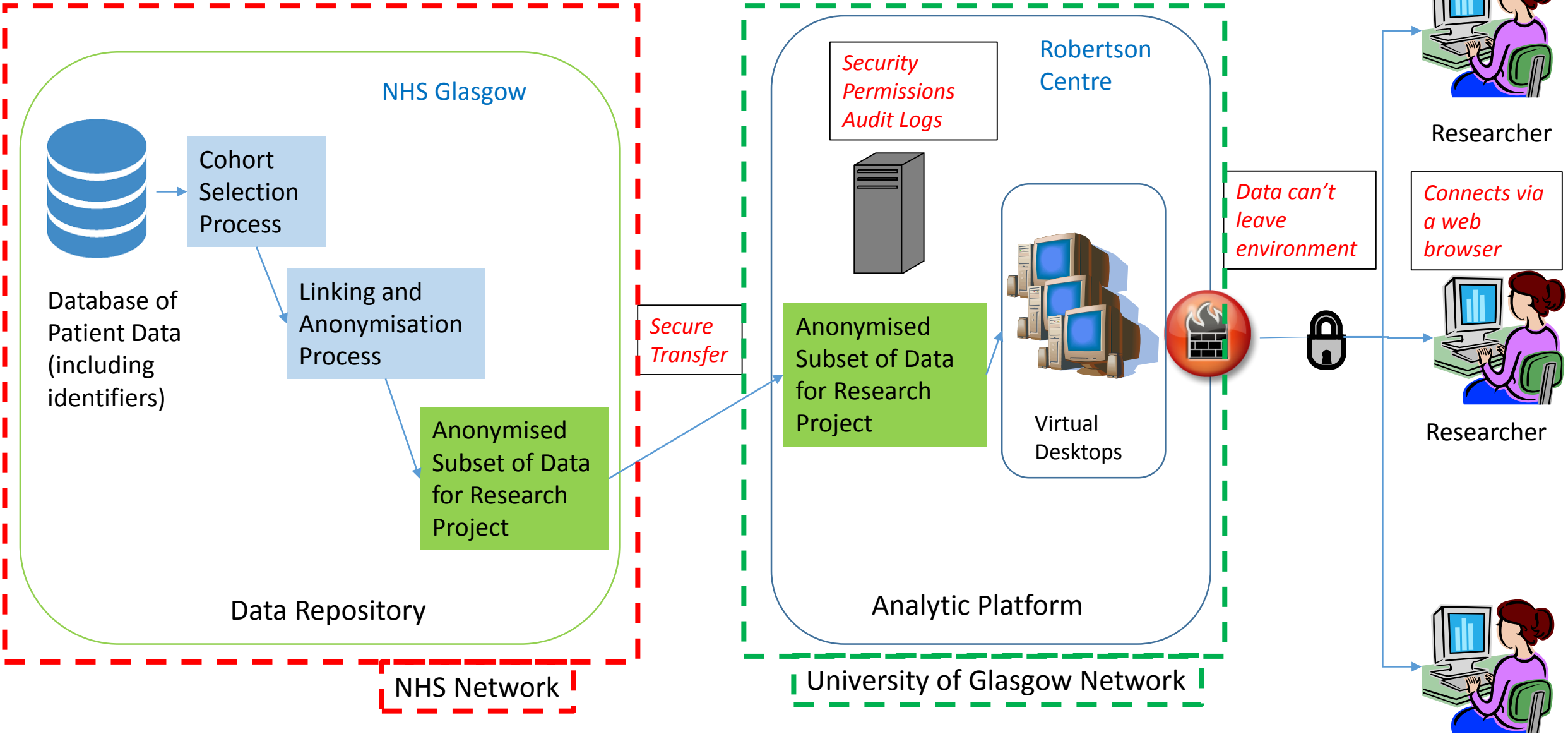
Grampian



Lothian



Glasgow



Data Repository Other Functions

- Safe Havens have many more tasks than provision of linked anonymised extracts
- As they often host identifiable patient records they can also:
 - Support recruitment to clinical trials
 - Running feasibility studies to see if relevant data is available for a specific research project
 - Providing audit data for NHS Boards (once it has been linked and cleaned)
 - Hosting and supporting permanently linked consented cohorts for research
 - Supporting Data Governance applications
 - Hosting disease registries

Historical Context

- Data Protection Act
- 7 Caldicott Principles

Government adoption (Nov 2012)

SHIP Guiding Principles
and Best Practices (Oct
2010)



Guide for Data Controllers (and others) advising on best practices
of linking data for research purposes across different organisations

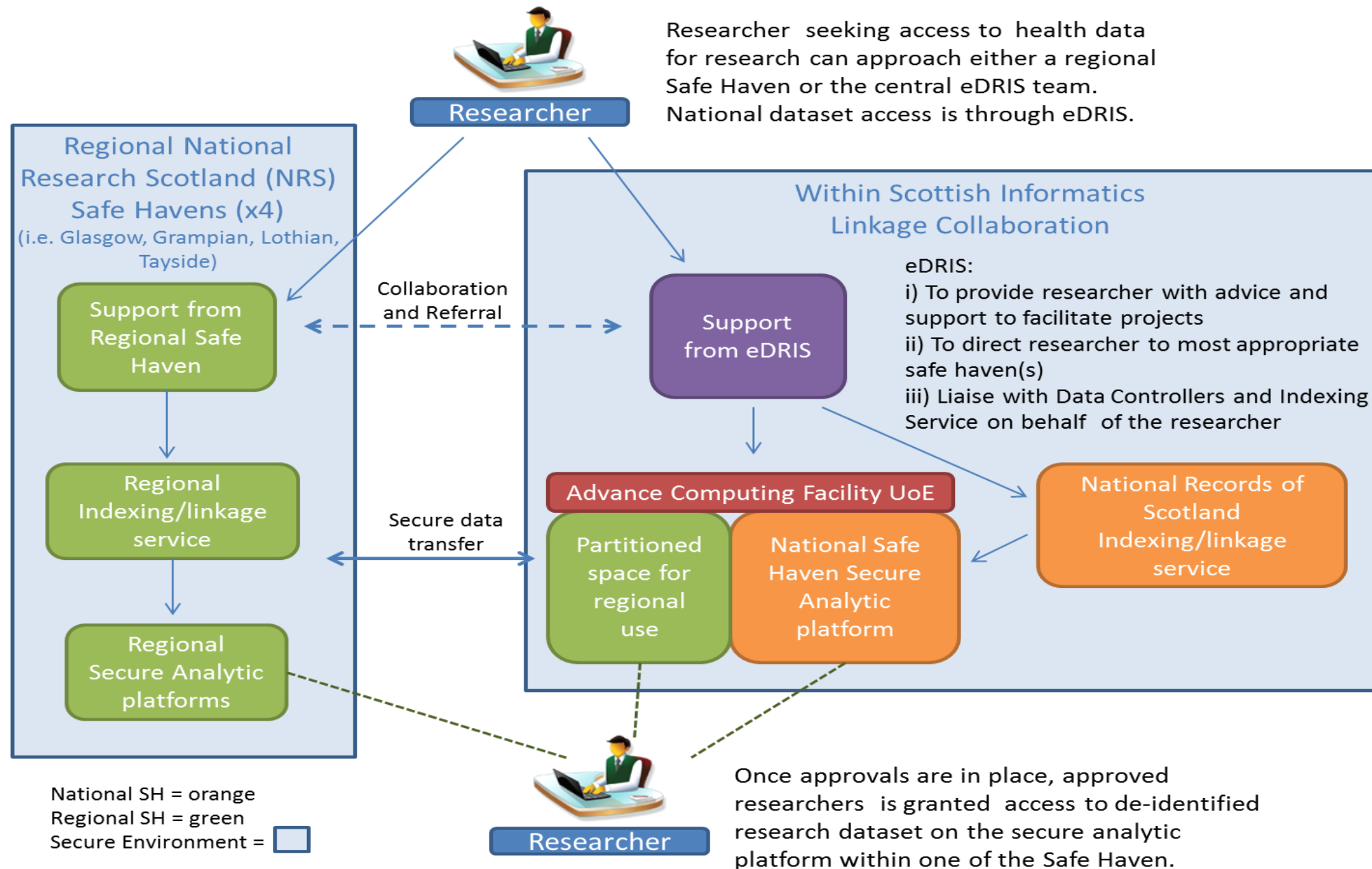
Joined-up data for better decisions

Guiding Principles for Data Linkage



Historical Context

- Scottish Government Safe Haven Charter – 2015
 - Set of standards for all Safe Havens
- Scottish Government Safe Haven Accreditation
 - Aligns with ISO27001 certification
 - Adds some additional controls on top of general ISO27001
 - Independent audit by eHealth (Scottish Government)
- All Safe Havens have signed up to the Safe Haven Charter.
- If a Safe Haven is Scottish Government Accredited they should **work to exactly the same high standards of secure data management and analytic platform provision.**

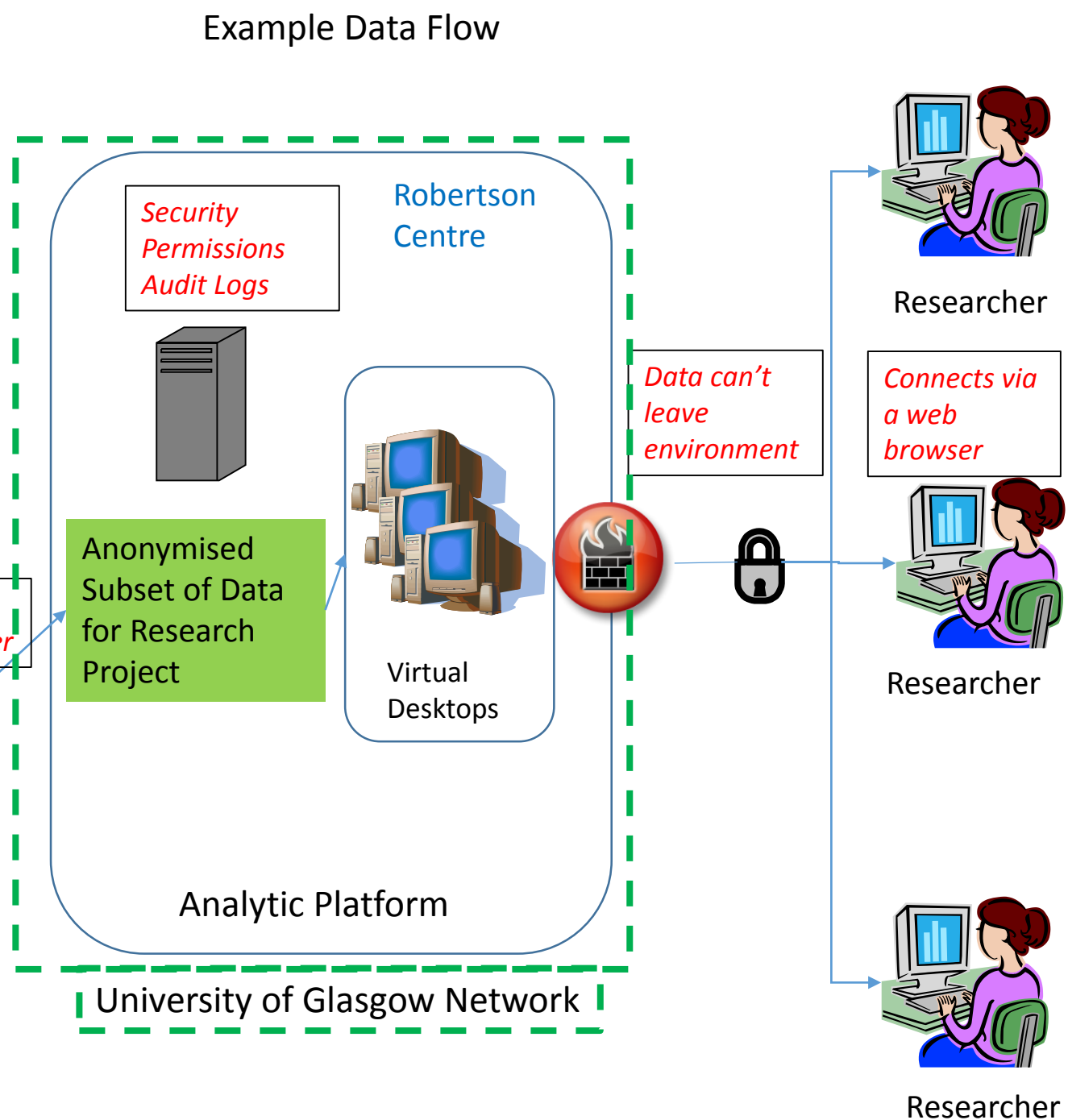
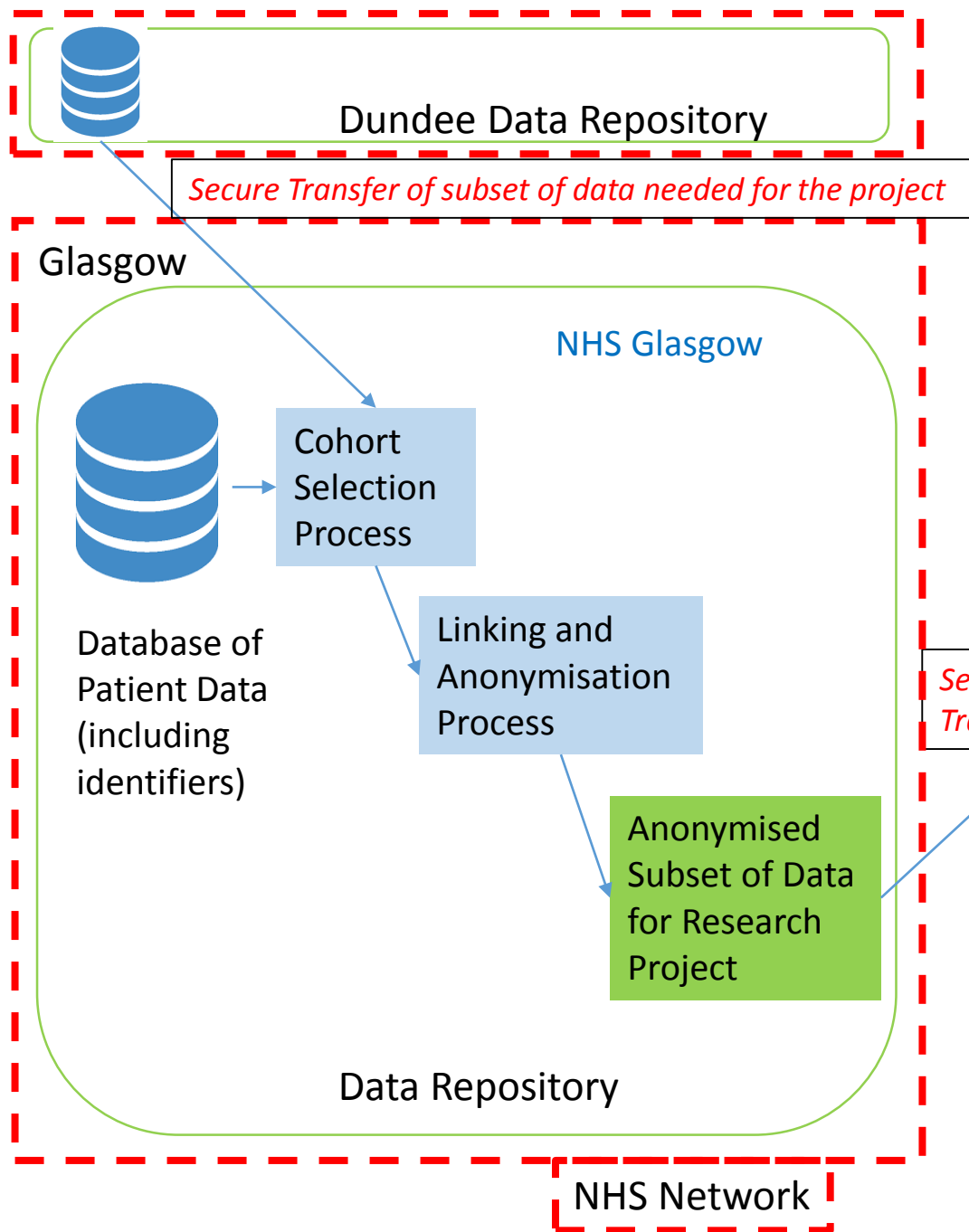


Data Governance

- All Regional Safe Havens have existing Data Governance Approvals processes working with their relevant Health Board(s) and Caldicott Guardians (there are small regional variations)
- Regional Safe Havens generally act as Data Processors rather than Data Controllers
- There are existing data sharing/user agreements and service agreements in place
- The NHS can withdraw support for a project at any time should they wish to do so

Data Flows

- We want to increase the projects which need data from multiple Safe Havens and improve the efficiency of doing this.
- Only a subset of the data held by a Safe Haven needs to be transferred i.e. the data for the specific research project



Example Data Flow

Costing Models

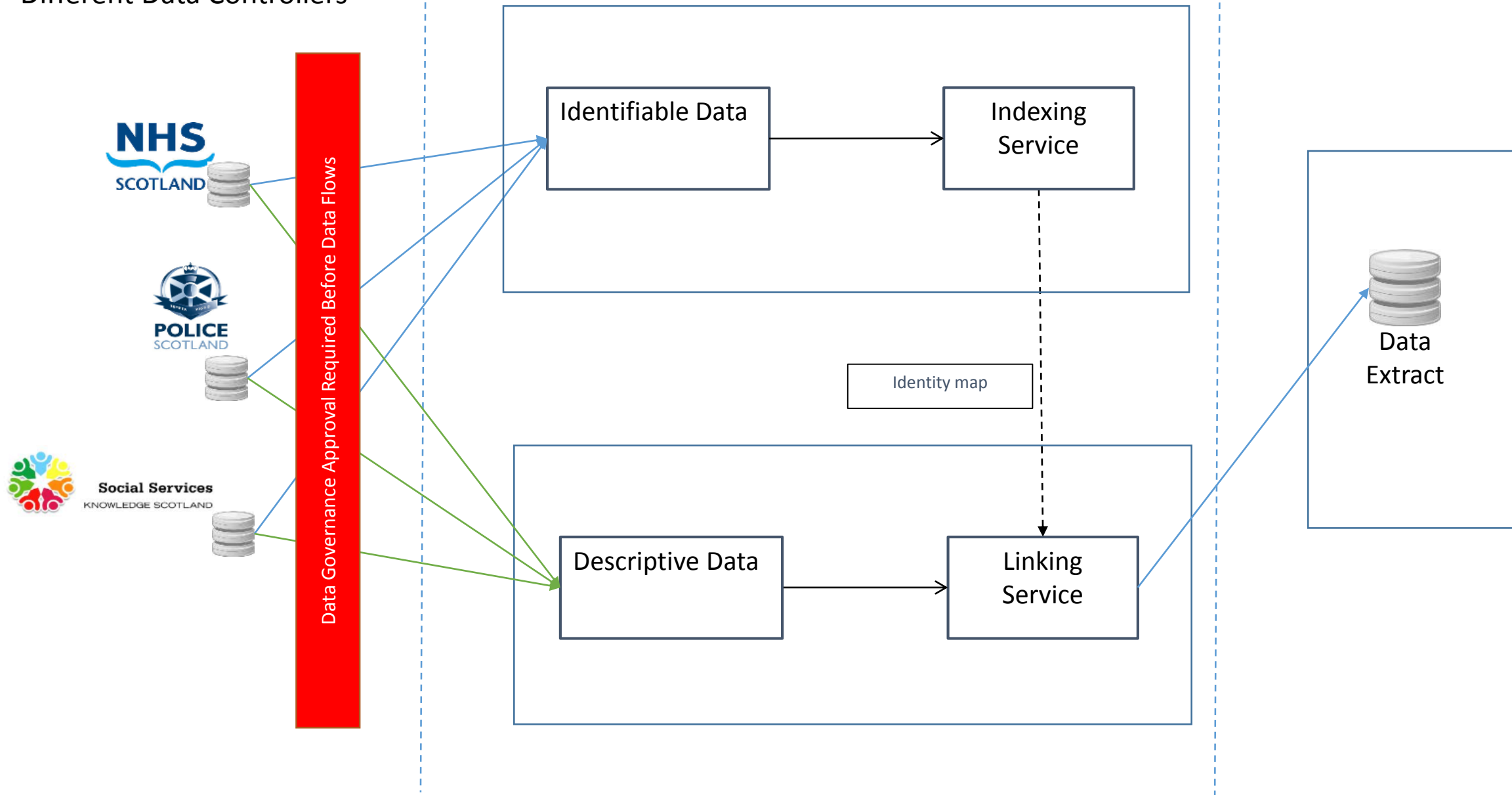
- The Safe Havens are currently meeting to try to standardise their costing model
- This is challenging due to the different way each is structured
- All Safe Havens try to recover their costs from research grant where appropriate.
- Feasibility studies and aggregates are generally done for free.

Thanks for listening!

Separation of Indexer and Linker functions

- Primarily used when linking data from different data controllers if the data is highly sensitive.
- Considered general good practice by Guiding Principles of Data Linkage.
- If there is agreement between Data Controllers to share data without this method then it reduces the coordination requirements of each project

Source Data:
Different Data Controllers



Source Data:
Different Data Controllers

