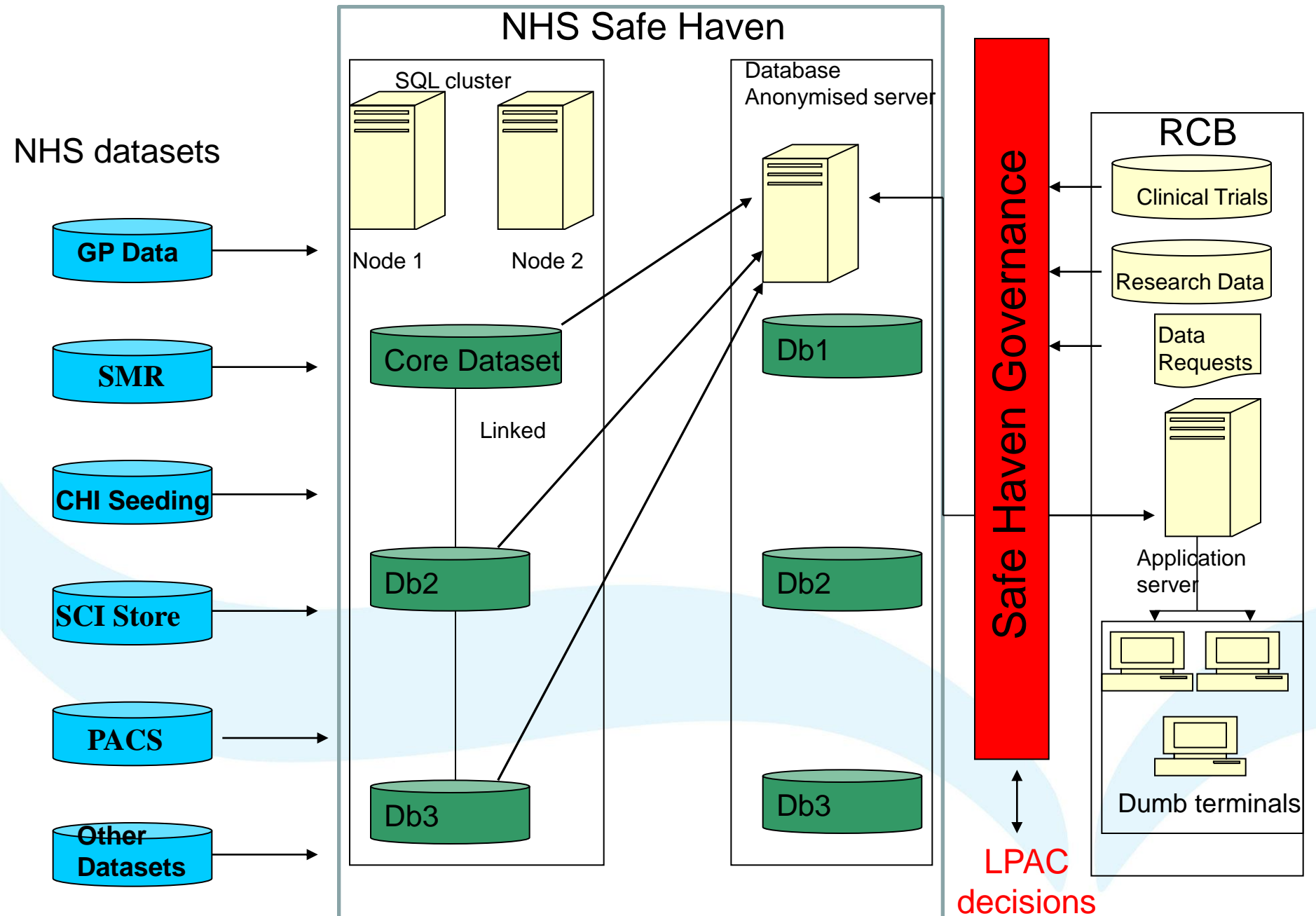# Safe Haven

Marion Flood – NHS GGC

Safe Haven (phase 1)

- NHS Greater Glasgow and Clyde (NHSGG&C) is developing a Safe Haven to support the secondary research uses of clinical data.

- This development is supported by the Scottish Government through the Chief Scientist Office

- It is in partnership with the Robertson Centre for Biostatistics (RCB), University of Glasgow.

- Governance is via a Local Privacy Advisory Committee (LPAC) whose primary function is to protect the privacy and confidentiality of our patients.
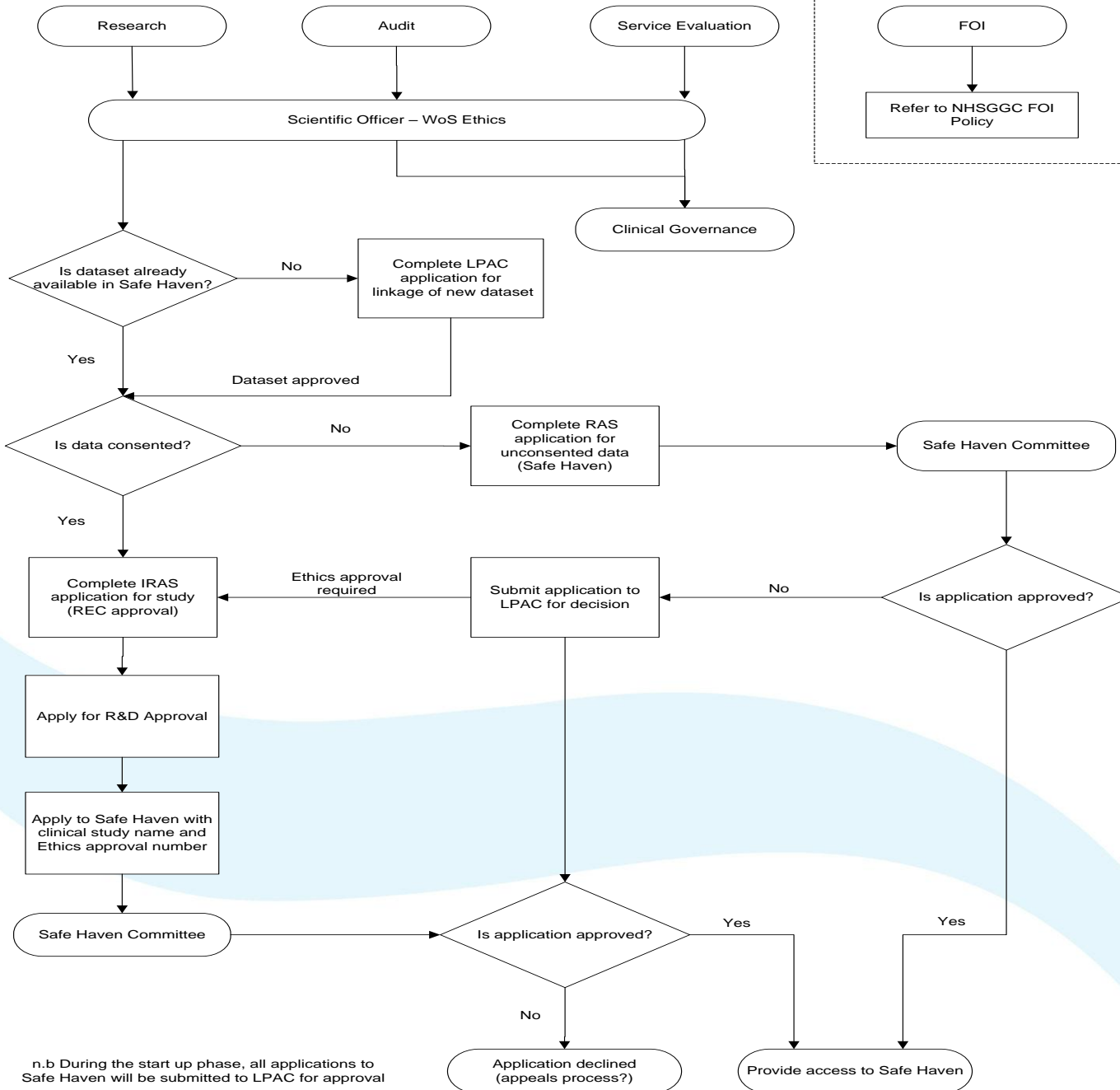
Safe Haven – IT Infrastructure

Local Privacy Advisory Committee

Mary Sweetland   CHAIR

Marian Stewart   GGC Caldicott Guardian

Judith Godden   Ethics Scientific Officer

Isobel Brown   Information Governance Manager

Andy Crawford   Head of Clinical Governance

Richard Groden   Clinical Director, Glasgow City CHP

TBC   Patient Representative

John Ip   LMC Representative

Duncan Porter   Acute Clinician

Frances Paton   Business Intelligence Manager (Information Services)

All unconsented datasets have a finite lifetime determined by the Privacy Advisory Committee and will include statistical disclosure control.

Safe Haven – Data Request Process

NHS Greater Glasgow and Clyde

Research → Scientific Officer – WoS Ethics

Audit → Scientific Officer – WoS Ethics

Service Evaluation → Scientific Officer – WoS Ethics

FOI → Refer to NHSGGC FOI Policy

Clinical Governance

Is dataset already available in Safe Haven?
- No → Complete LPAC application for linkage of new dataset
- Yes

Dataset approved

Is data consented?
- No → Complete RAS application for unconsented data (Safe Haven) → Safe Haven Committee
- Yes

Is application approved?
- No → Submit application to LPAC for decision
- Yes → Provide access to Safe Haven

Ethics approval required → Complete IRAS application for study (REC approval)

Apply for R&D Approval

Apply to Safe Haven with clinical study name and Ethics approval number

Safe Haven Committee

Is application approved?
- Yes → Provide access to Safe Haven
- No → Application declined (appeals process?)

n.b During the start up phase, all applications to Safe Haven will be submitted to LPAC for approval

Going 'Live'

- Use key projects to:

    - write applications

    - test systems

    - understand quality/ limitations of specific NHS data sets involved

    - understand real time availability of data

    - build a core dataset

Core Dataset

- GP data
    - 1000 data items, including lifestyle, diagnosis, co-morbidities, social circumstances, contra-indications, drugs

- E-prescribing data
    - Encashed prescriptions, BNF categorised

- SMR data
    - Hospital admission data

- GRO data
    - Death records for GGC

- Key Clinical datasets
    - Clinical datasets from locally held applications

Key Exemplar Projects

The Safe Haven will provide a service for clinical trials including feasibility, e-Recruitment and follow up using healthcare information:

- SCOT: Standard care versus Celecoxib Outcome Trial in patients with osteo or rheumatoid arthritis. A Large Streamlined Safety Study which can be linked with other clinical data.

- Stratified Medicine: Genetic cancer research project looking at six cancer types; breast, ovarian, lung, prostrate, melanoma and colorectal.

Key Exemplar Projects

- TRUST: An EU funded, multinational study for elderly patients with subclinical hypothyroidism: a randomised placebo controlled trial of Hormone replacement therapy

- FAST: A prospective, randomised, open label, blinded endpoint clinical trial evaluating long term cardiovascular safety of febuxostat in comparison with allopurinol in patients with gout

- EHR4CR: European clinical research project looking at the feasibility of identifying patients electronically

Metadata

- Safe Haven Metadata accessible via website

- Catalogue of datasets held within safe haven:
  - No of records within each dataset
  - Time period
  - Data quality issues

- Data dictionary for each dataset:
  - List of available data items
  - Comprehensive definition for each data item held
  - Data type

The Future

- **Phase 2** – develop system for wider access to datasets

- **Phase 3** – extension across NRS -West

Any Questions?