**P954 ESTABLISHING THE NATIONAL INSTITUTE FOR HEALTH RESEARCH (NIHR) HEALTH INFORMATICS COLLABORATIVE (HIC) MULTIPLE MYELOMA (MM) REGISTRY**

**Topic:** 14. Myeloma and other monoclonal gammopathies - Clinical

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**Background:**

Real world data provides unique insights into the natural history of MM, resource utilisation, adherence to standards and outcomes of treatments outside clinical trials. However, the quality of such initiatives can be poor due to the need for manual data entry, inability to integrate multiple data sources, lack of harmonisation of data across centres and limited generalisability due to centre bias. Exemplar registries collate and transform multidisciplinary routinely collected data from Electronic Health Records (EHRs) to a common data language allowing integration, analysis and expansion.

**Aims:**

To develop a secure national MM registry beginning with a three site pilot.

**Methods:**

Potential registry providers were evaluated against the following criteria: previous experience, infrastructure and technical capability, data governance, compliance with legal standards and cost effectiveness. The platform required ethical and data sharing approvals. A common data model was investigated and a myeloma focused multidisciplinary dataset was designed and mapped to source data. Data extraction, transformation and analysis is planned.

**Results:**

8 providers were assessed for suitability. The NIHR HIC was chosen due to its established data sharing network across 30 UK sites and overarching governance framework. This platform permitted the establishment of harmonised data flow, comparable across sites and retaining clinical interpretability. A minimal myeloma dataset of routinely collected information was agreed by clinicians and data scientists to contain the following fields: baseline and disease characteristics including imaging findings eg: extramedullary/paramedullary disease, skeletal/spinal disease, comorbidities, mode of presentation, cytogenetics, treatments including chemotherapy, stem cell transplants/CAR-T cells, spinal interventions, anti-infectives, bisphosphonates and other supportive care. Each variable was mapped to identify the location of raw data in the EHR, its format and suitability for extraction. For unstructured data, eg: cytogenetics and imaging reports, natural language processing is being developed to extract key fields.

To enable harmonisation of data from different systems, data is transformed into a common data model.
Observational Medical Outcomes Partnership common data model (OMOP CDM) was chosen as it provided a framework for systematic analysis of data from disparate data sources, typical of those held within health care information systems. This model allows for international benchmarking and collaboration for research. OMOP CDM maps commonly used coding systems and vocabularies, eg ICD-10, SNOMED-CT into standard concepts permitting raw data entering the registry to be standardised into a research ready format that is person-centric, disease agnostic and syntactically and semantically defined.

Anonymised data from multiple sites will be electronically transferred to a ISO27001 certified, GDPR compliant UCL data safe haven for analysis. Oversight is provided by the Steering Committee of clinicians, data scientists, myeloma patients and Myeloma UK with patient involvement at every step. Data will be analysed to answer 3 initial themes (Image 1), and extended further to include control data for Health Technology Appraisals. To date we have successfully identified an initial cohort of over 4000 myeloma cases since 2015.

**Image:**

**Summary/Conclusion:** The NIHR HIC Myeloma registry represents a research ready platform to integrate and analyse UK wide real word data. Detailed data analysis and progress in answering the initial 3 themes is ongoing.

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