Scope of Work: Phase I - Apol1 Heat Map Development

Stage 1: Data Gathering for Apol1 Heat Map Development

Project Title: Data Collection for Identifying Geographic Regions with Apol1-Positive Patients in the UK

Objective

To gather, organise, and validate data sources that will provide us with the insights we need to decide on what regions we should focus on with the highest number of Apol1-positive patients, forming the foundation for our geographic heat map development in subsequent phases.

(If you can support with the heatmap phase this would be a separate conversation)

Deliverables

Phase 1: Provide a comprehensive list of data sources

Identify relevant public and online data sources, including:

- Forums, patient advocacy groups, and social media communities.
- Explore public healthcare databases (e.g., NHS resources, PubMed).
- Identify social media groups and niche platforms where patients may congregate.
- Search online for patient communities discussing Apol1-related conditions.
- Public health datasets and government repositories.
- Clinical trial registries and academic publications.
- Raw Data Collection

Phase 2: Consolidation of data into structured formats for analysis in subsequent phases.

- Extract data from identified sources.
- Provide preliminary insights
- Gather and structure data into formats suitable for analysis.
- Assess the relevance and quality of data collected.
- Verify data consistency and reliability.
- Highlight regions or trends observed during the collection process.
- Ensure data is organised and annotated with metadata (e.g., source, relevance, date).
- Document any restrictions or limitations on usage.
- Initial observations on potential high-priority regions based on data trends.

Data Source Index

 A documented index of all data sources used, including access links, permissions, and relevance to the Apol1 project.

Timeline

This phase will be completed on or before COB Friday 7th February 2025

Budget

TBD