

# Epidemiology Information Synthesis for Focal Segmental Glomerulosclerosis (FSGS): An Innovative Approach Using Human-in-the-Loop AI

MSR182



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## INTRODUCTION

- Challenges in Rare Disease Data:** Collecting epidemiological data for rare diseases like Focal Segmental Glomerulosclerosis (FSGS) is hampered by limited and inconsistent sources.
- Data Complexity:** Variability in case reports, studies, and registries complicates the synthesis of reliable epidemiological insights.
- AI-powered Solution:** AI models can streamline and standardize data integration from diverse epidemiological sources.
- Tool Development:** This poster presents the conceptual framework for an AI tool to synthesize epidemiological data for FSGS.
- Future Impact:** The AI solution aims to enhance rare disease data analysis, improving decision-making and patient outcomes.

## METHODS

A semi-automated, AI-powered evidence integration synthesis workflow for FSGS was developed by a multidisciplinary taskforce. This team included AI/ML experts, UI/UX designers, software engineers, senior health economics and outcomes research (HEOR) analysts, and consultant epidemiologists. The proposed roadmap comprises six key steps:

- Design Thinking Workshop:** Conducted to align the team on objectives and strategies.
- Input Data Retrieval:** Gathering relevant data from various sources.
- FSGS-specific Named Entity Recognition (NER) Corpus Development:** Creating a specialized corpus for accurate entity recognition.
- Training Dataset Annotation:** Utilizing Natural Language Processing (NLP) techniques such as entity linking and relationship extraction to annotate the dataset.
- Integration with a Knowledge Graph:** Connecting annotated data with a structured knowledge graph for enhanced insights.
- Product Testing:** Implementing a predefined User Acceptability Testing (UAT) plan, executed by technical and HEOR teams to ensure the product meets user requirements.

This structured approach ensured a comprehensive and efficient workflow for synthesizing evidence in FSGS research.

## Training Dataset Annotation Using NLP Techniques

Training dataset annotation involves tagging and organizing data using NLP techniques to teach our AI models how to understand complex medical texts.

### Techniques Used

#### Entity Linking

- What's this?** Connecting identified entities to established databases or knowledge bases.
- Why?** Ensures that terms like "glomerulosclerosis" are linked to their correct medical definitions and synonyms, enhancing the AI's contextual understanding.

#### Relationship Extraction

- What's this?** Identifying and categorizing the relationships between entities.
- Why?** Helps the AI understand how terms are connected, such as linking "treatment" with "outcome" or "symptoms" with "diagnosis."

### Benefits

- Improved Accuracy:** Trains AI to recognize and correctly interpret complex relationships and entities in FSGS data.
- Enhanced Insights:** Provides clearer, actionable insights from medical texts, leading to better-informed research and clinical decisions.

### Process Highlights

- Annotation Tool Setup:** Deploy NLP tools to assist with tagging and linking.
- Expert Annotations:** Medical professionals review and tag data with high precision.
- Model Training:** Use annotated data to train and refine AI models, ensuring they learn from high-quality examples.

Quality Metrics



High Precision in FSGS Metric Identification



Faster Semantic Query Response with Knowledge Graph



Strong Accuracy in Literature Curation



Significant Time Savings in Report Generation

## Multidisciplinary Team



Multidisciplinary taskforce, including AI/ML experts, UI/UX designers, software engineers, senior HEOR analysts, and consultant epidemiologists.

## Input Data Retrieval

- Scientific Literature Databases:** Extract peer-reviewed articles from PubMed, Google Scholar, and Web of Science focused on FSGS research.
- Health Organization Reports:** Incorporate guidelines and reports from the National Kidney Foundation and KDIGO to reflect best practices and consensus statements.
- Clinical Trial Registries:** Gather data from ClinicalTrials.gov and WHO International Clinical Trials Registry Platform (ICTRP) for insights on ongoing and completed trials related to FSGS.
- Patient Registries:** Leverage real-world data from patient registries to capture disease progression in FSGS.

## FSGS-specific Named Entity Recognition (NER) Corpus Development

The FSGS NER Corpus is a specialized dataset designed to help AI systems accurately identify and understand key entities related to FSGS from vast medical texts.

### Why is it essential?

Developing this corpus allows our AI models to:

- Spot Critical Terms:** From disease names to treatment protocols and patient symptoms, ensuring every relevant entity is recognized.
- Enhance Precision:** Improve the accuracy of data extraction and information retrieval specific to FSGS.
- Facilitate Research:** Accelerate the discovery of patterns and relationships in medical literature, leading to better understanding and potential breakthroughs.

### How does it work?

- Data Collection:** Gather a wide range of medical texts, research papers, and clinical reports on FSGS.
- Entity Annotation:** Experts mark and categorize entities such as disease names, drug names, and patient conditions.
- Corpus Creation:** Compile these annotated entities into a structured dataset for training AI models.

## Integration with Knowledge Graph and User Acceptability Testing (UAT)

**Enhanced Data Connectivity:** Knowledge graph integration allows linking of diverse data points (clinical trials, patient registries, genetic studies) to uncover hidden patterns, improving evidence synthesis accuracy.

**Streamlined Decision Support:** By organizing data hierarchically, the knowledge graph aids users in quickly identifying relevant insights.

**Personalized User Experience:** UAT ensures that the interface is intuitive and tailored to clinicians, researchers, and stakeholders.

**Improved Clinical Relevance:** Testing the tool with real users helps refine features to prioritize actionable FSGS-related evidence.

## CONCLUSION

- Integrated Expertise:** This hybrid workflow synergizes nephrologists, epidemiologists, AI/ML scientists, and HEOR specialists to refine evidence synthesis for rare nephropathies like Focal Segmental Glomerulosclerosis (FSGS). This ensures rigorous, domain-specific insights essential for addressing FSGS's unique pathophysiology and clinical progression.
- Real-world Relevance:** Utilizing robust training datasets informed by glomerular disease registries, patient-reported outcomes, and tailored ontologies pertinent to FSGS phenotypes anchors findings in real-world, patient-centered data reflective of variability in glomerular injury and progression.
- Future Implications:** This methodology informs the advancement of novel epidemiological synthesis tools, optimizing their utility in guiding clinical decision-making and improving health outcomes in FSGS and other rare glomerulopathies.

## CONTACT INFORMATION

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Figure 1.

## Proposed Flow Chart: AI-based Epidemiology Evidence Synthesis PoC

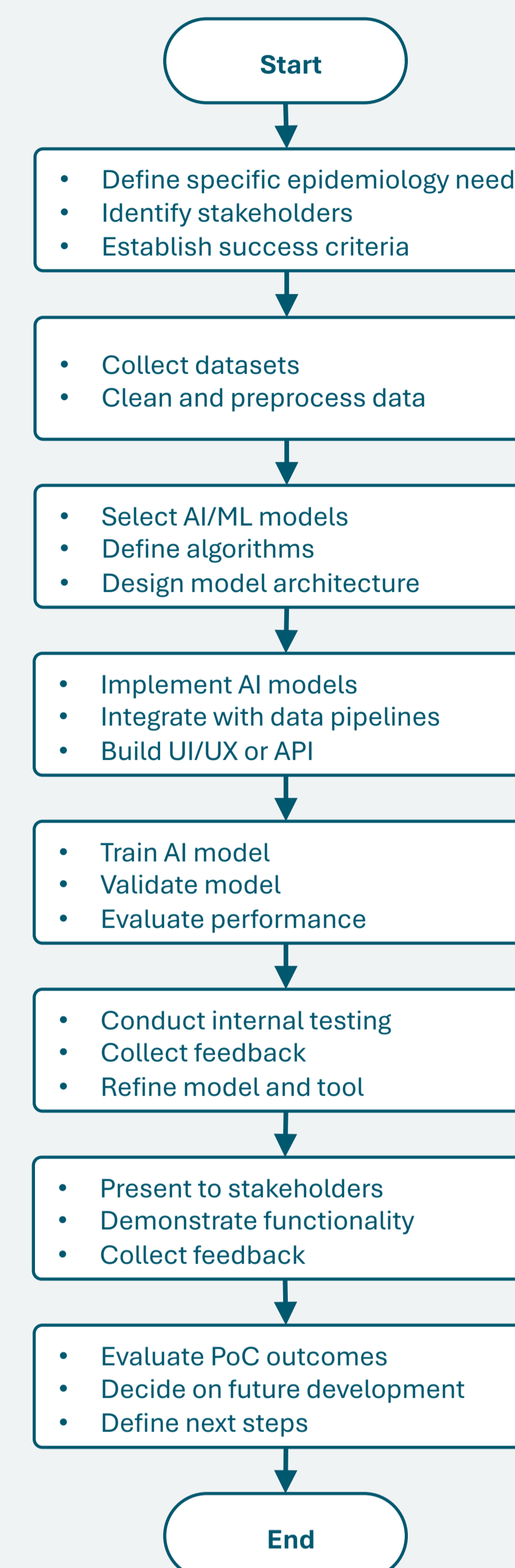
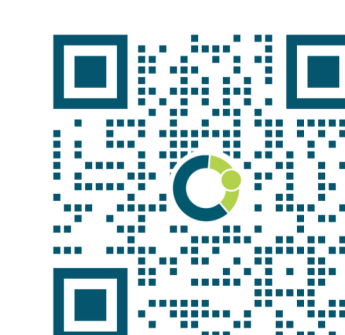


Figure 2.

## FSGS PoC – Design Thinking Workshop Elements

| Design Thinking Stage | Description                     | Application to FSGS Epidemiology Information Synthesis (PoC)   |
|-----------------------|---------------------------------|--|
| 1. Empathize          | Understand user needs           | - Identify challenges in accessing and interpreting FSGS data.<br>- Focus on integration issues and reporting inconsistencies. |
| 2. Define             | Narrow the problem scope        | - Synthesize FSGS data from limited sources.<br>- Assess feasibility using case reports and select registries.                 |
| 3. Ideate             | Generate potential solutions    | - Brainstorm AI solutions for data integration.<br>- Target essential features for standardization.                            |
| 4. Prototype          | Build a low-fidelity version    | - Create a basic AI prototype for data synthesis.<br>- Focus on core data extraction functionalities.                          |
| 5. Test               | Conduct initial user tests      | - Evaluate the tool with a small group of epidemiologists.<br>- Assess data integration effectiveness.                         |
| 6. Refine             | Gather feedback for improvement | - Use feedback to enhance the tool.<br>- Validate its FSGS data synthesis capabilities.  |



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