

# Health registry

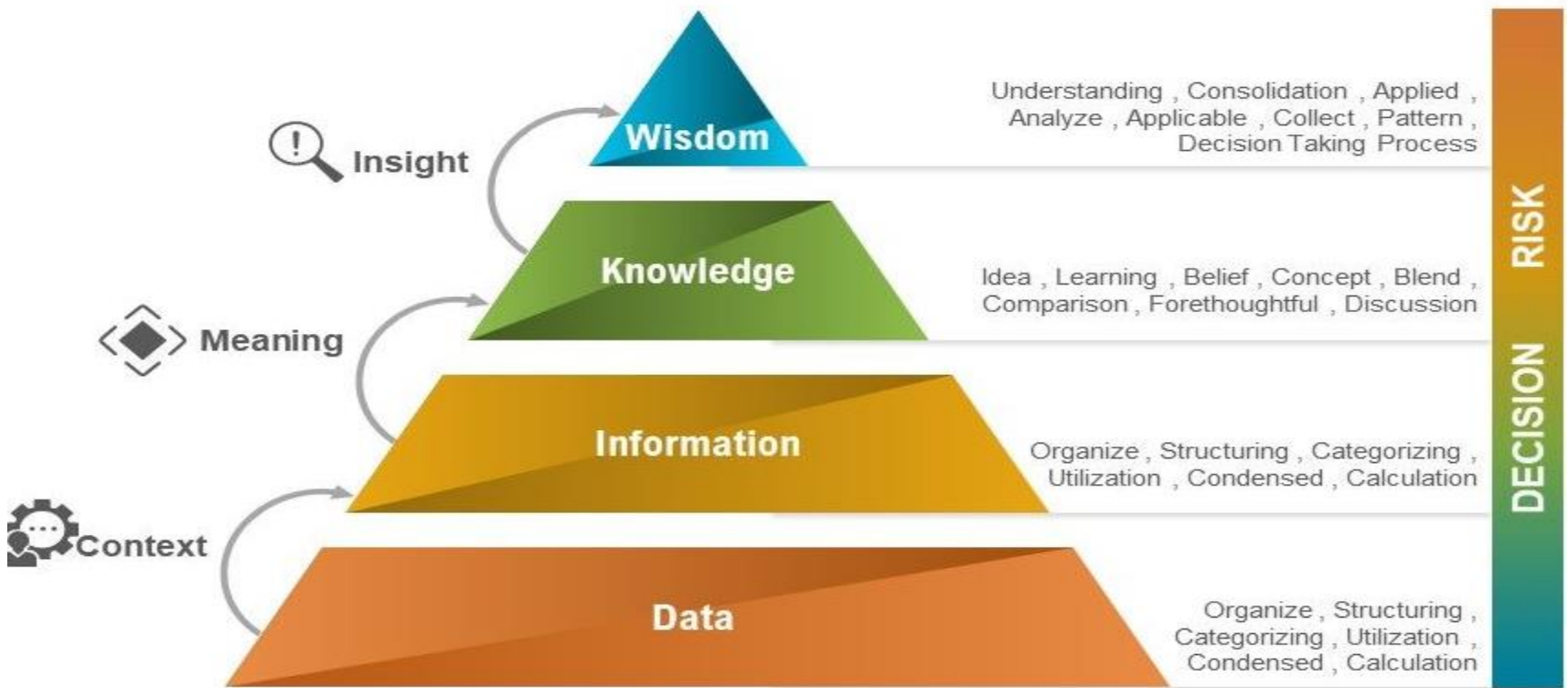
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# Introduction to Health Registry

- Importance of Health Registry
- Definition of a Health Registry
- Types of Health Registry
- Health Registry Implementation

# DIKW Pyramid



**Health Data**

```
graph TD; A[Health Data] --> B[Administrative]; A --> C[Clinical]; B --> D[Health Data Management]; C --> D;
```

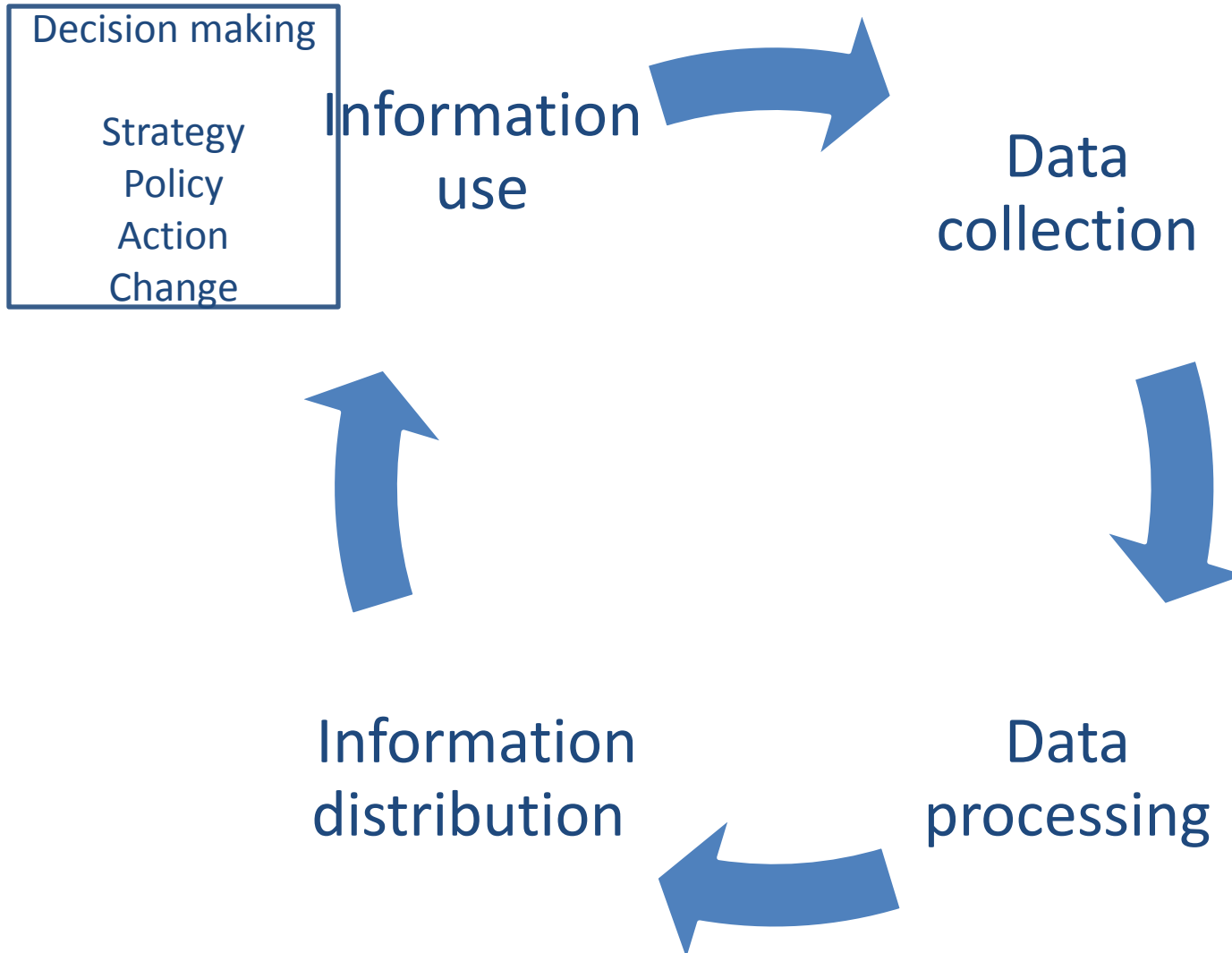
The diagram is a flowchart with three levels. At the top is a box labeled 'Health Data'. Two arrows point downwards from this box to two separate boxes: 'Administrative' on the left and 'Clinical' on the right. From the bottom of both the 'Administrative' and 'Clinical' boxes, arrows point downwards to a single box at the bottom labeled 'Health Data Management'.

**Administrative**

**Clinical**

**Health Data Management**

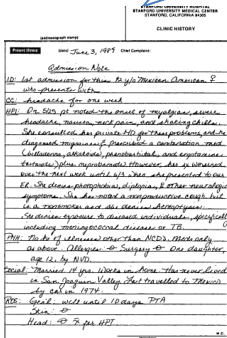
# Health Data Management



# Health Data Sources

Primary

Secondary



Registries

Indices

Statistical reports

Trend analysis

Cost reports

# Registry in Health

- Disease Registry
- Patient Registry
- Medical Registry
- Health Registry
  
- Paper-based/electronic- based

# Health Registry

- An Information System to health data management a population defined by a particular characteristics for specific purposes.

So:

A registry is not only data set

But also it is: data set/Information Technology/  
people/ Process.



# Types of Health Registry

# Types of Health Registry

## Data nature

- Diseases Registry
- Products Registry
- Health Services Registry

## Coverage

- Local
- National
- International
  
- Facility- based
- Population- based

## Purpose

- Describing of Disease
- Effectiveness
- Safety and harm
- Intervention

# Diseases Registry (Data nature)

- Diseases Registry focus on patients having the same diagnosis or the same group of conditions:
  - chronic, acute communicable and rare diseases
  - disabilities
  - exposure to risk factors
  - cause of death

Example: Malta National Cancer Registry

# Products Registry(Data nature)

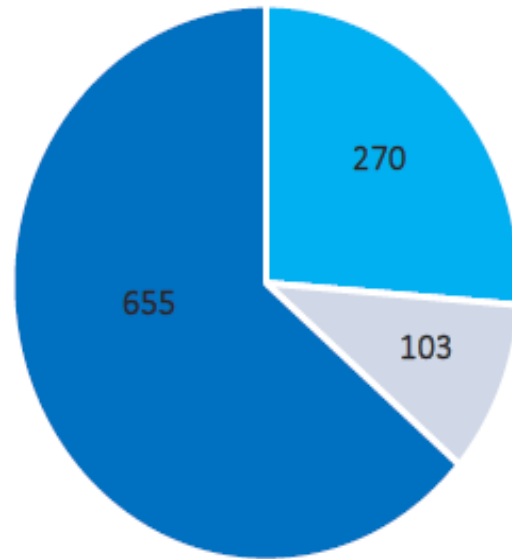
- Products Registry focus on patients who have been exposed to:
  - biopharmaceutical products
  - medical devices
  - diagnostic/therapeutic equipment

Example: Swedish Knee Arthroplasty Registry

# Health Services Registry(Data nature)

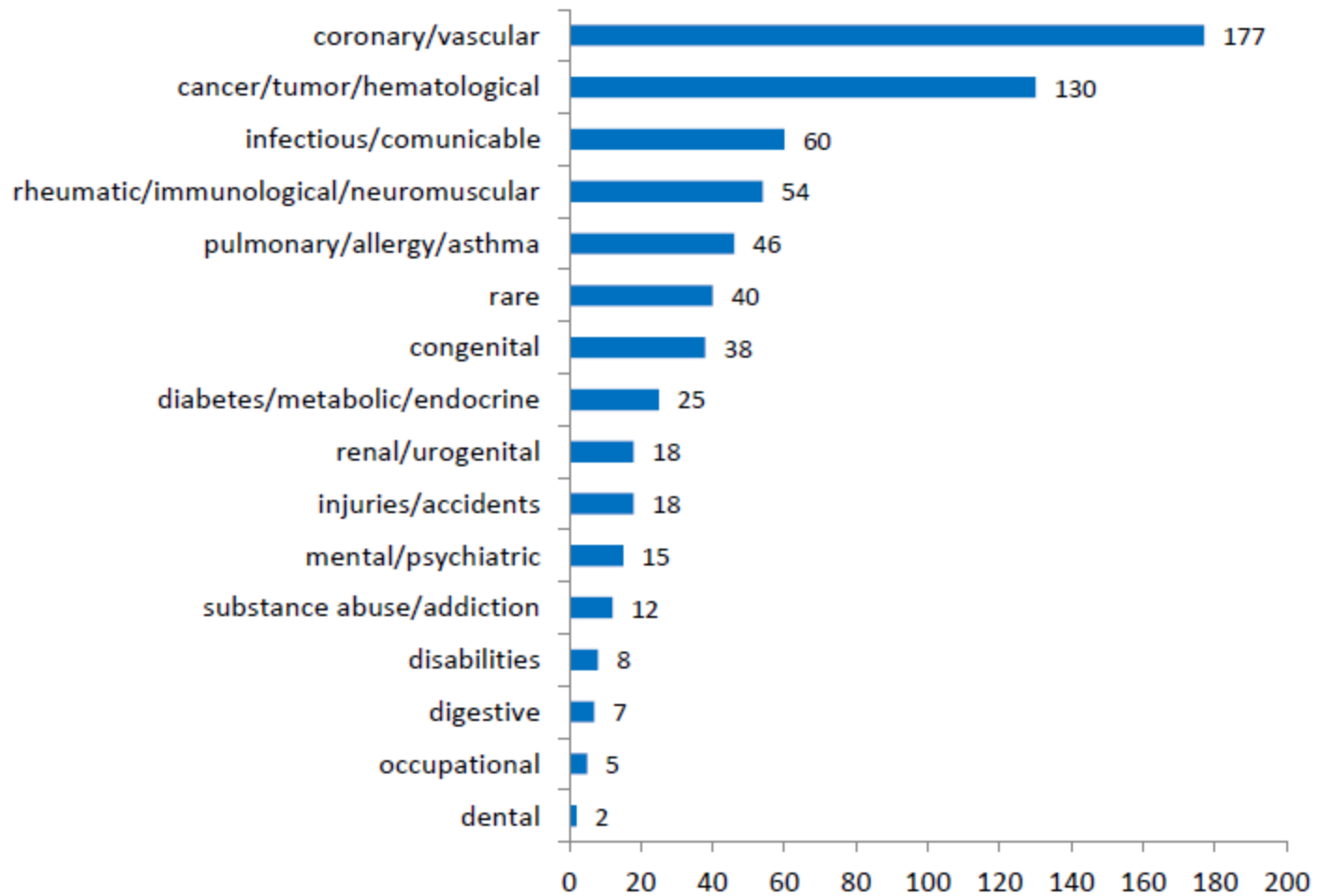
- Health Services Registry focus on patients with same services (a common procedure, clinical encounter, or hospitalization) to improve the quality of care and management of health services:
  - Diagnostic, curative, preventive
  - Discharges, births, abortions

Example: Slovenian Hospital Discharge Registry



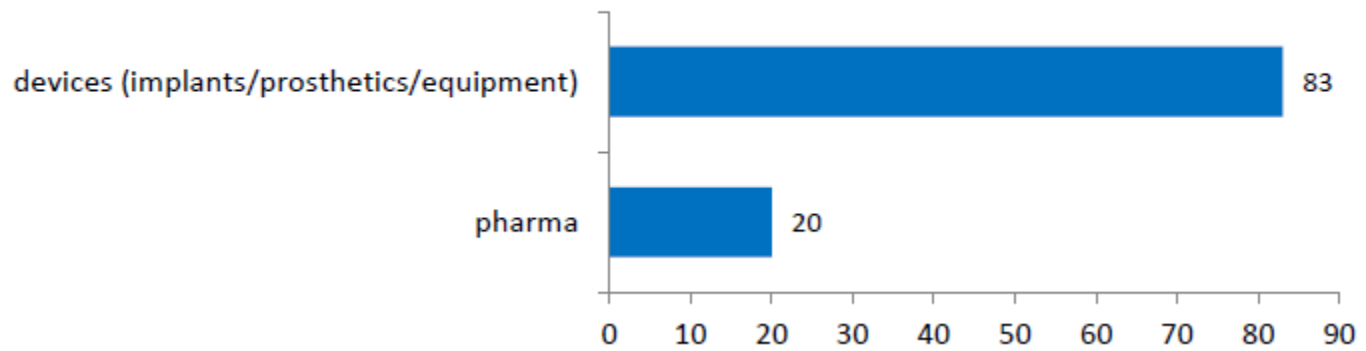
- Service
- Product
- Conditions & diseases

### Disease based registries



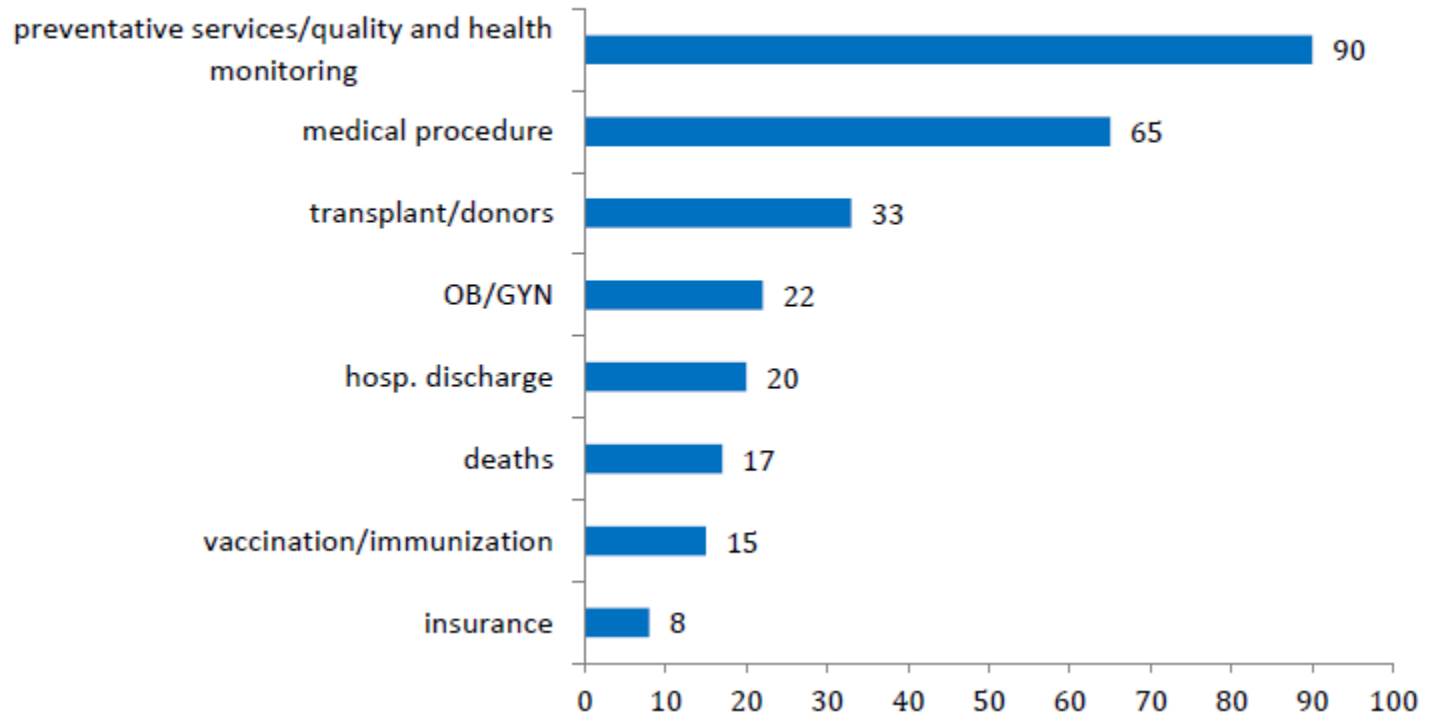
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### Product based registries

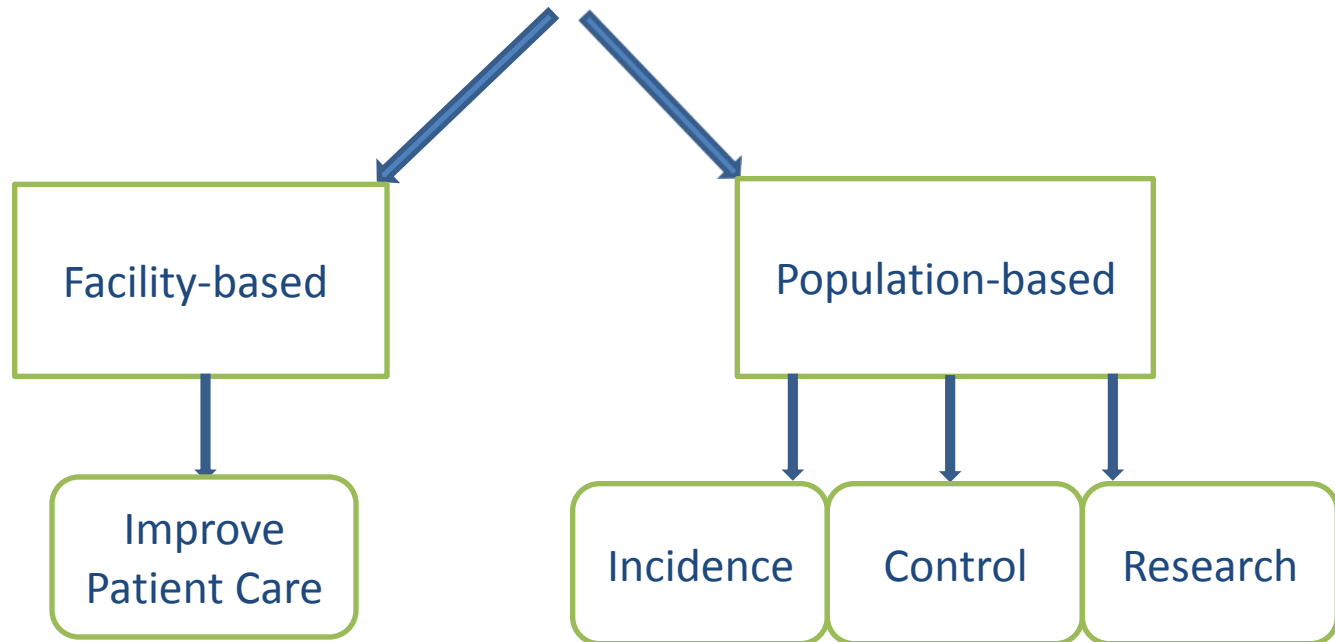




### Service based registries



# Coverage



# Purpose

- to describe the natural history of disease
- to determine clinical and/or cost-effectiveness
- to assess safety or harm
- ...
- Multiple Purposes

So: scientific, clinical or/and public health (policy) purpose.

# Use of Health Registry

```
graph TD; A[Use of Health Registry] --> B[Patient care]; A --> C[Public health]; A --> D[Technology evaluation]; A --> E[Research];
```

Patient  
care

Public  
health

Technology  
evaluation

Research

# Health Registry Implementation

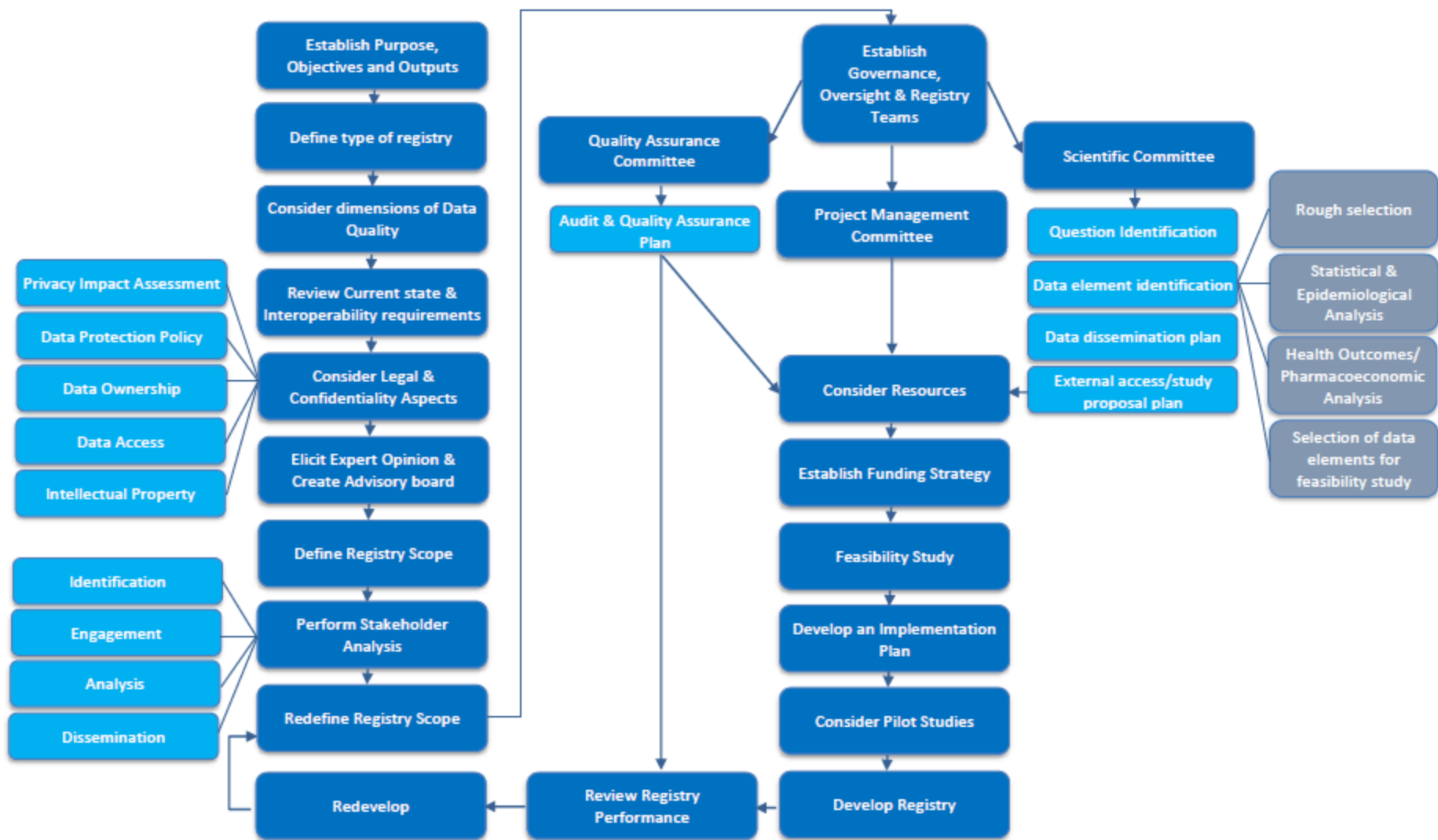
# Creating Registries

## Planning a Registry:

- Defining the Purpose(s)
- Defining the Scope, Target Population, and Size
- Development Team and Identify Potential Experts
- Feasibility study
- Identification of Stakeholders (primary and secondary)
- Data Considerations
- Legal and Ethical Considerations
- ...

## Running Registries:

- Data Collection (data set, data capture, data standards and, data quality)
- Data Analysis(indicators and reporting)
- Information Dissemination and Use
- Registry Evaluation(extend, revision, stop)



# Challenges

- Unstable funding,
- Legal ambiguity,
- Unclear stakeholder roles,
- Predominantly paper-based data collection,
- Lack of awareness of existing standards and standard processes,
- Compromised data quality,
- Lack of registry transparency that support data access for research purposes
- Insufficient information dissemination



# References

- Gliklich, Richard E. Dreyer, Nancy A. Leavy, Michelle B Registries for evaluating patient outcomes: a User's guide. Agency for Healthcare Research and Quality 2014.
- Zaletel, Metka. Kralj, Marcel. Magajne, M. Doupi, P. Methodological guidelines and recommendations for efficient and rational governance of patient registries. National Institute of Public Health 2015.

