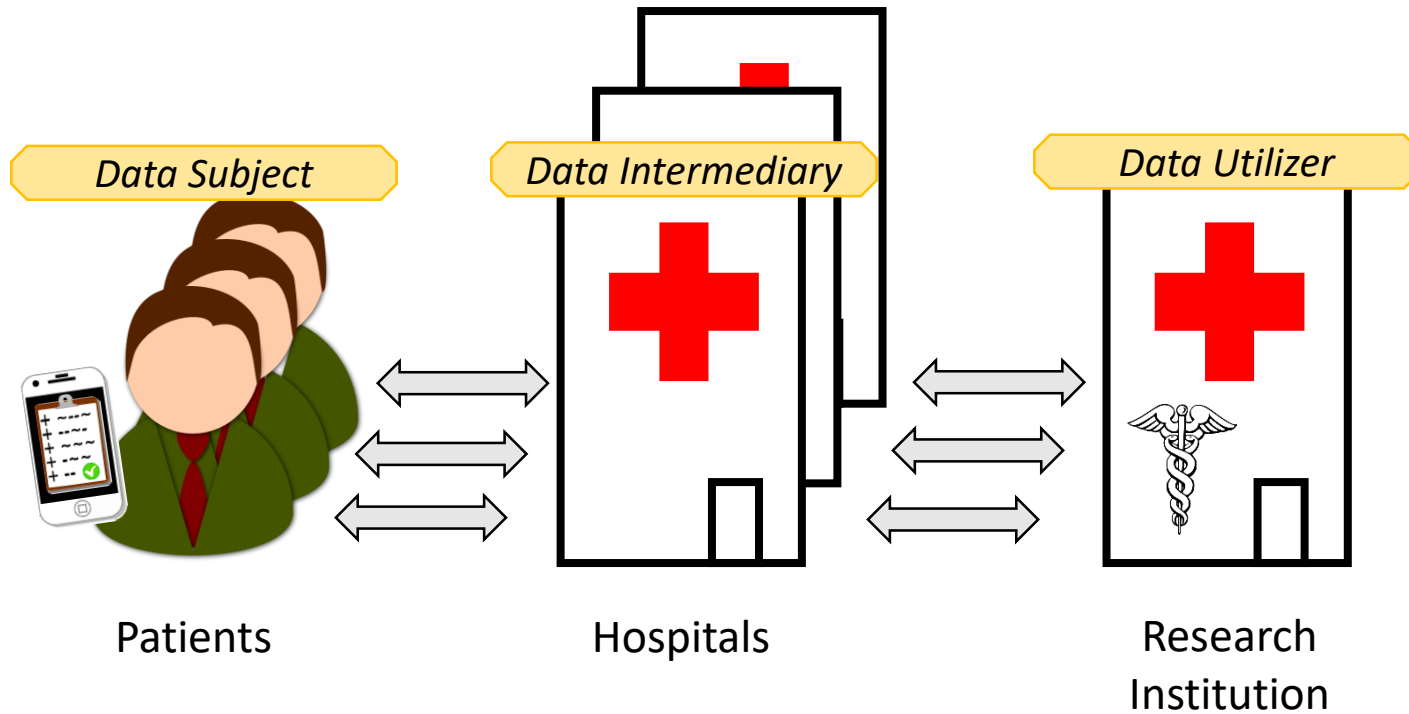


# Data Intermediaries and Data Subject Rights

Considerations on Data Sharing Scenarios

# Roles and Scenarios

Beyond Data (Governance) Acts

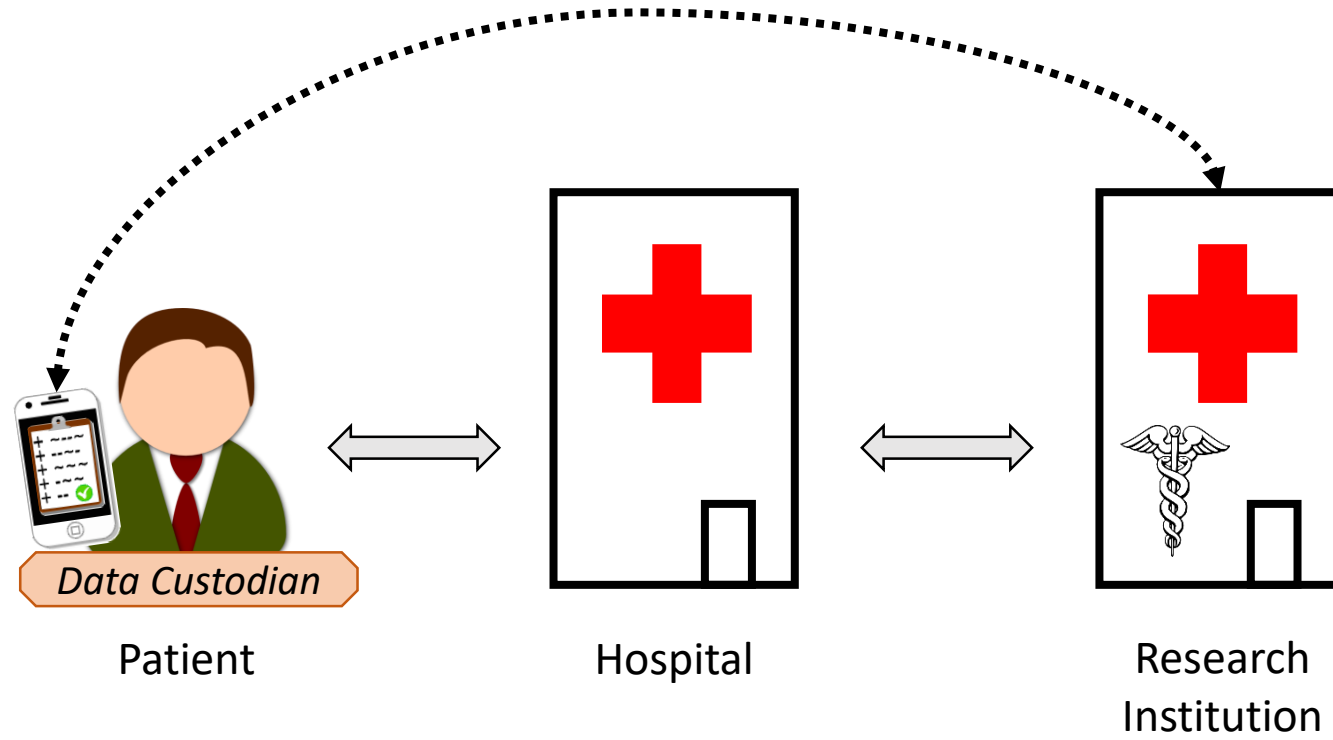


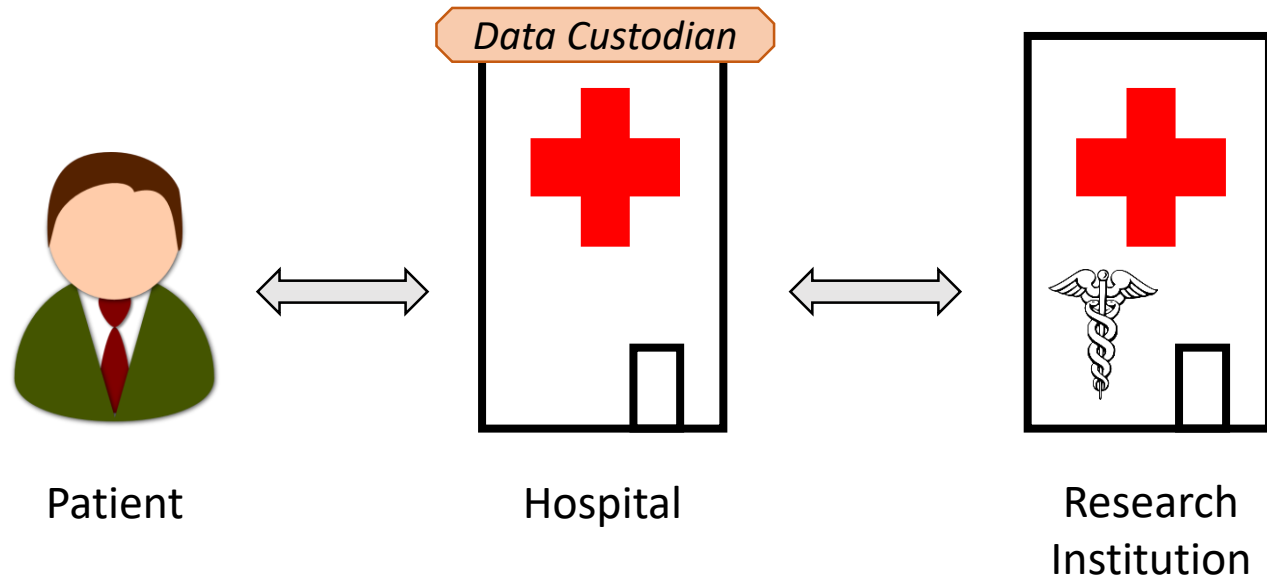
*Data Custodian*

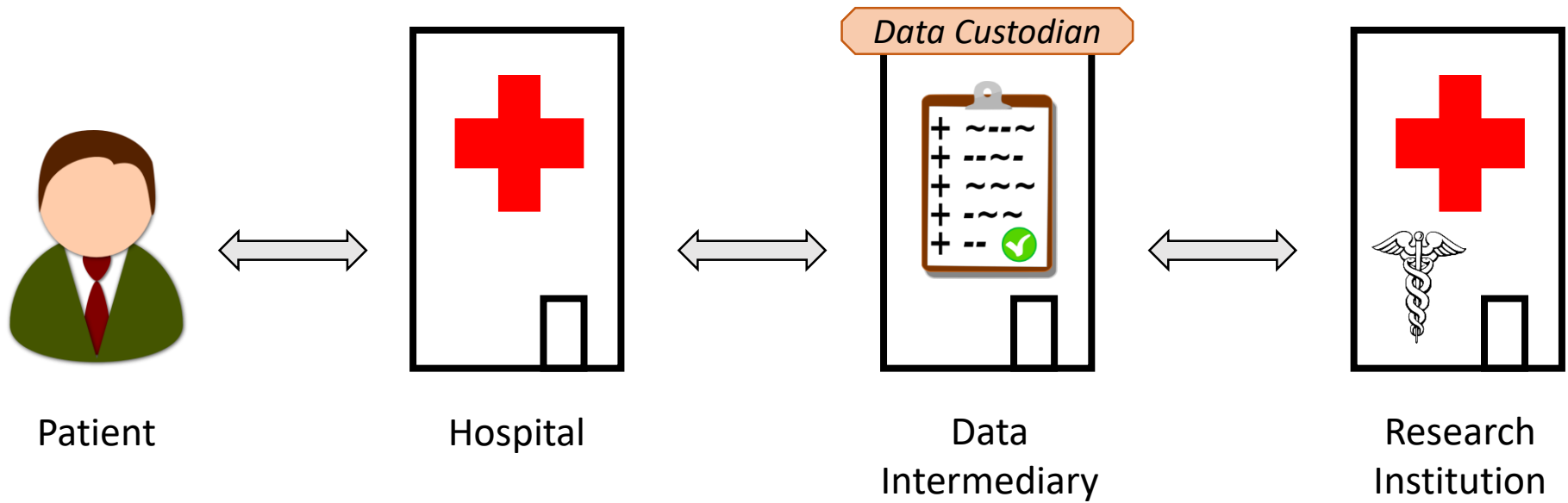
???

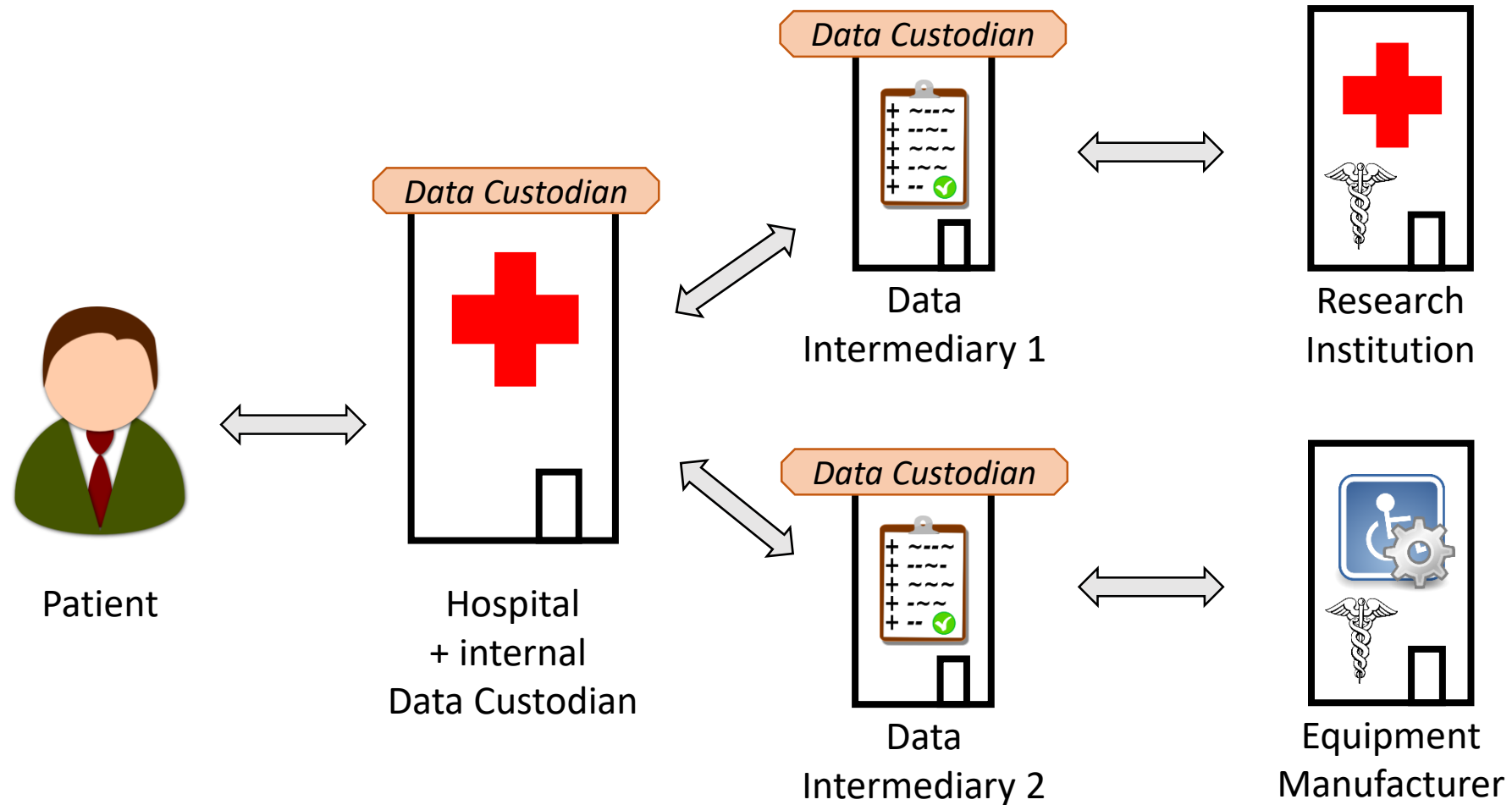
# Data Custodian Duties?

- Help Data Subjects enforce their rights (access, rectification, ...)
- Manage personal data storage
- Manage and enforce personal data sharing and access policies
- Interact with potential data recipients
- Interact with the Data Subject whenever necessary
- Mediate in case of conflicts
- Manage and update consent given (or withdrawn) by Data Subjects („Dynamic Consent“)
- Enable and enforce data sharing consent revocation









Forwarding of (parts of / pseudonymized / encrypted) data to other dedicated data intermediaries (e.g. cloud storage provider of research institution)

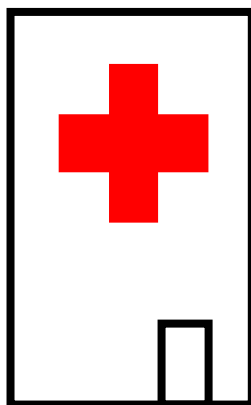


Country A

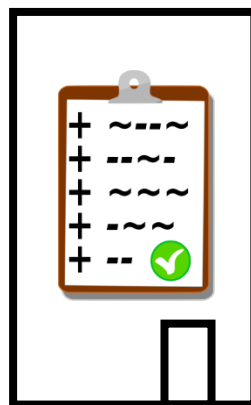
Country B



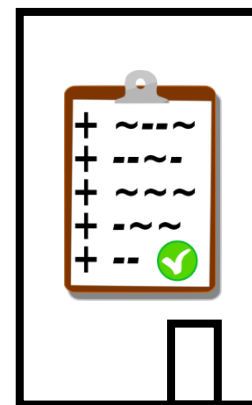
Patient



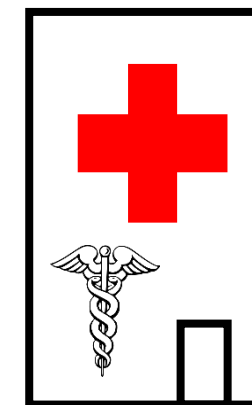
Hospital



Data Intermediary 1

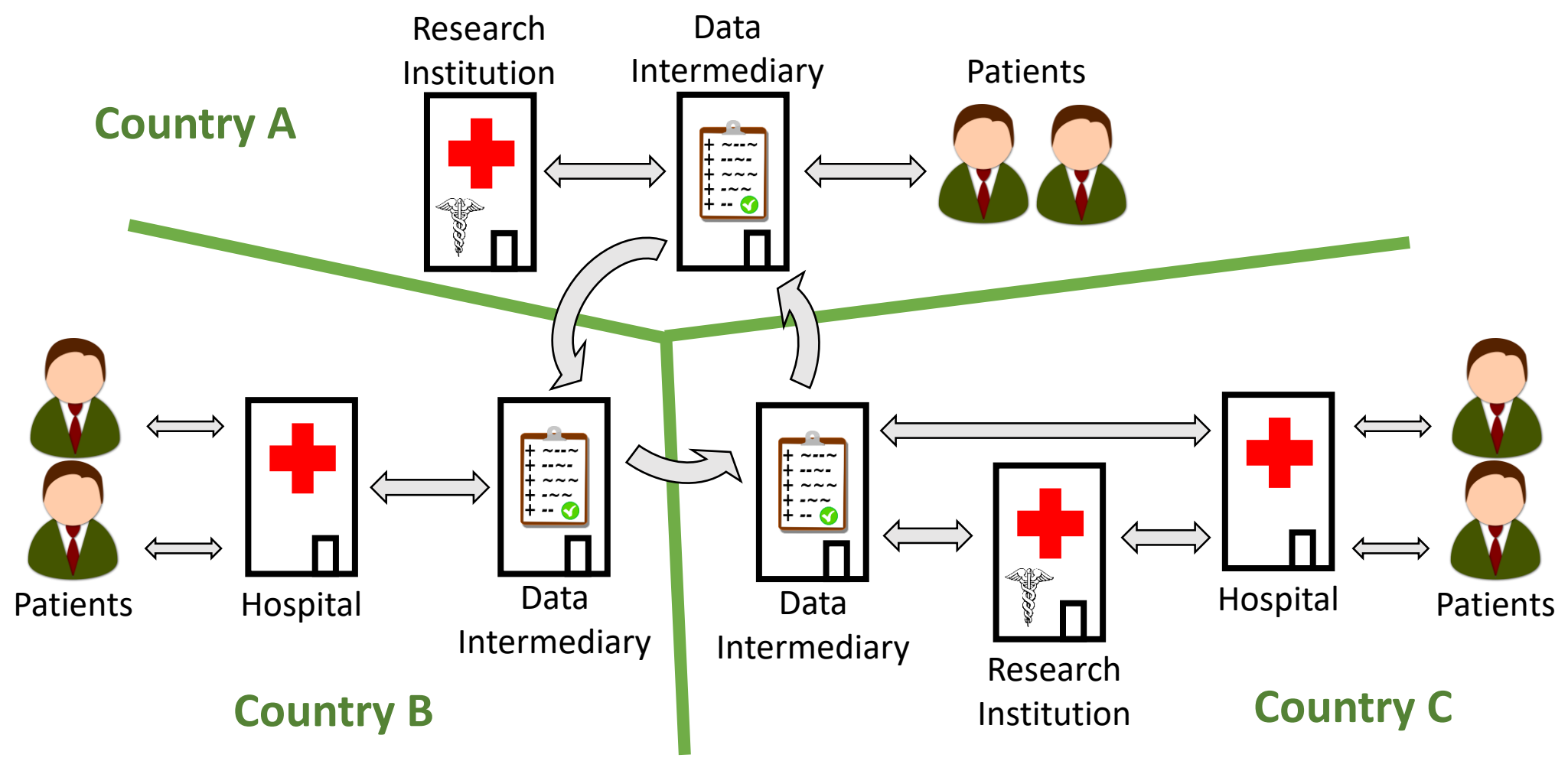


Data Intermediary 2



Research Institution

Federation of data intermediaries, e.g. for cross-border data sharing with different legal systems



Country A

Research Institution

Data Intermediary

Patients

Patients

Hospital

Data Intermediary

Data Intermediary

Research Institution

Hospital

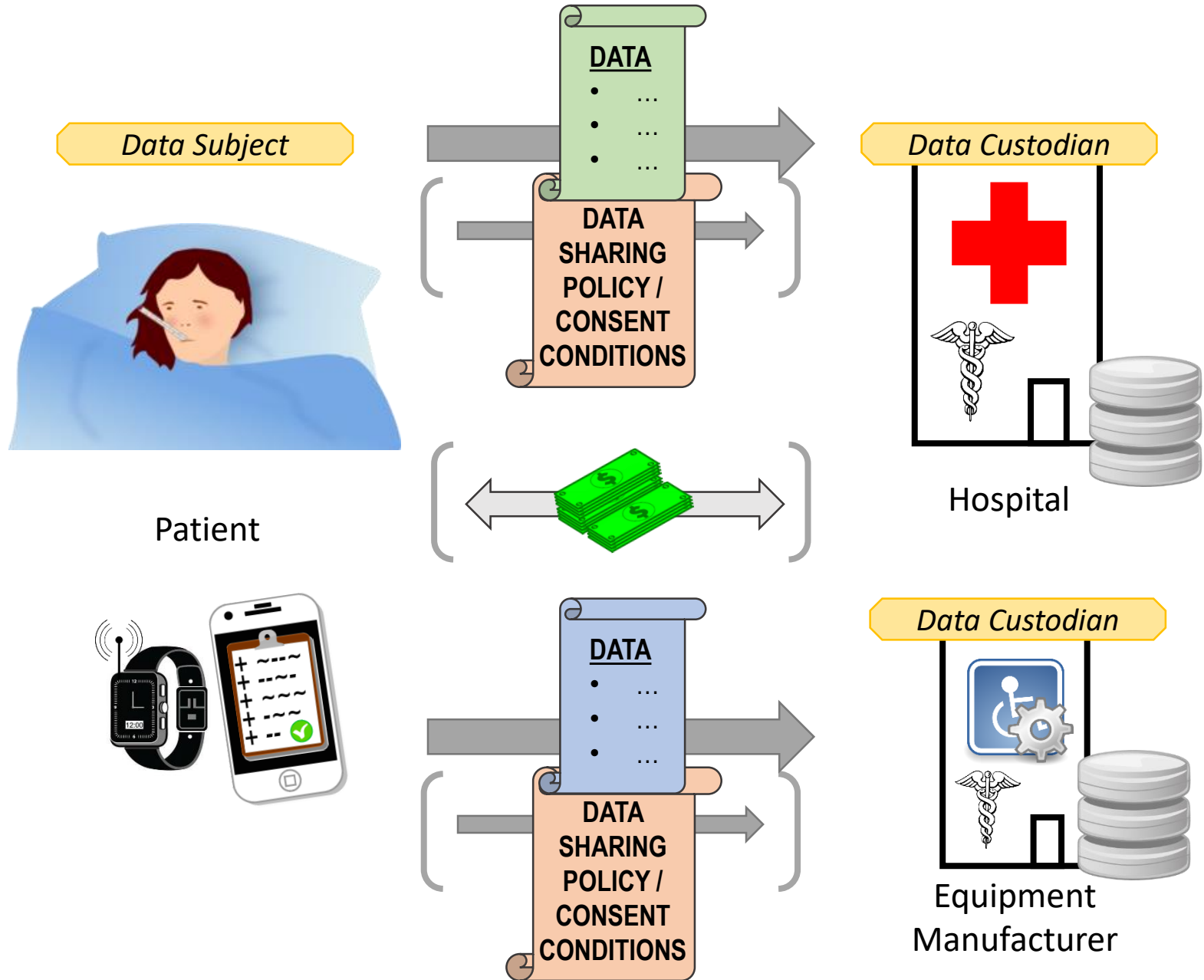
Patients

Country B

Country C

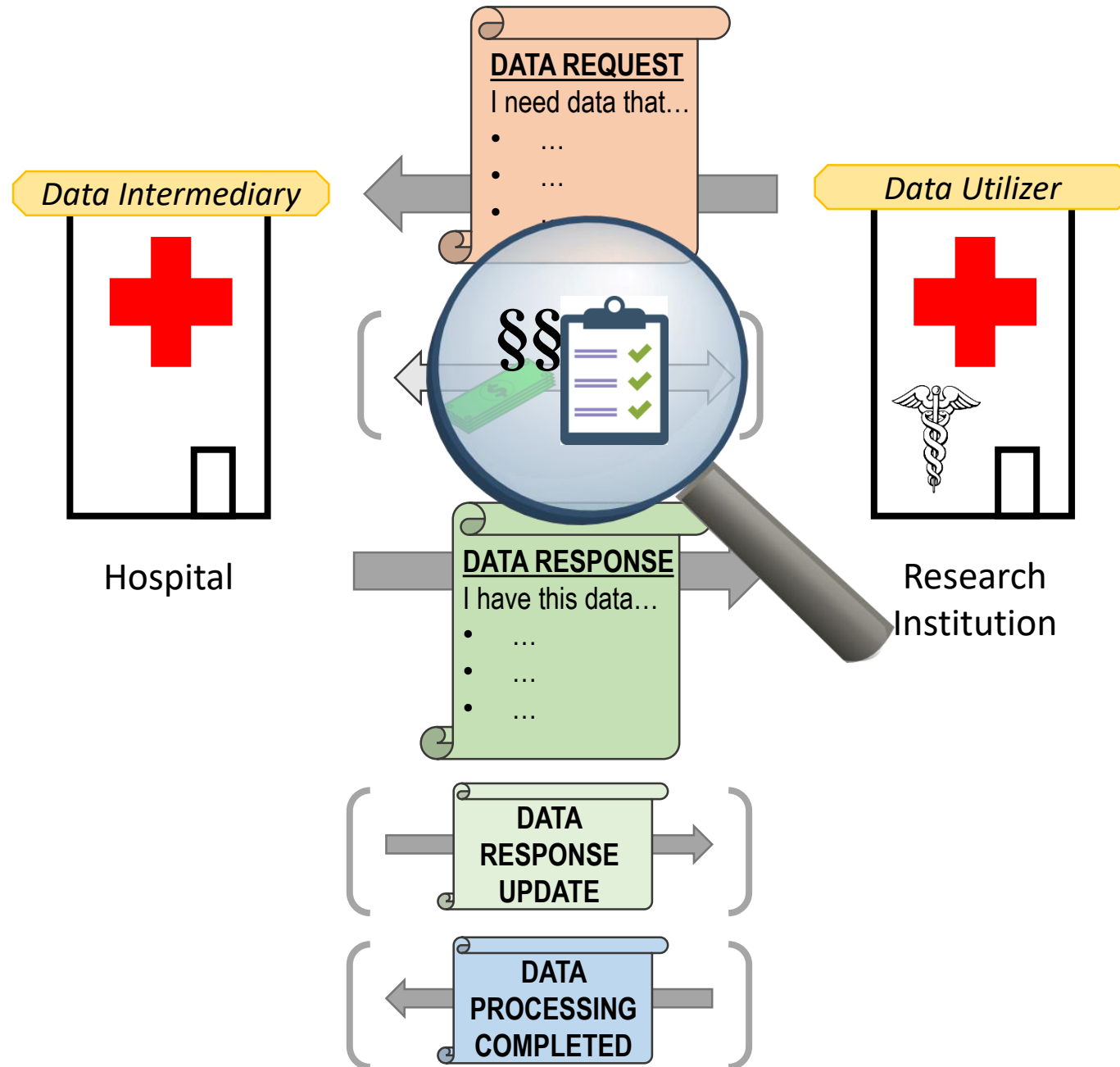
# Interaction Patterns

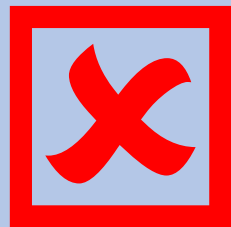
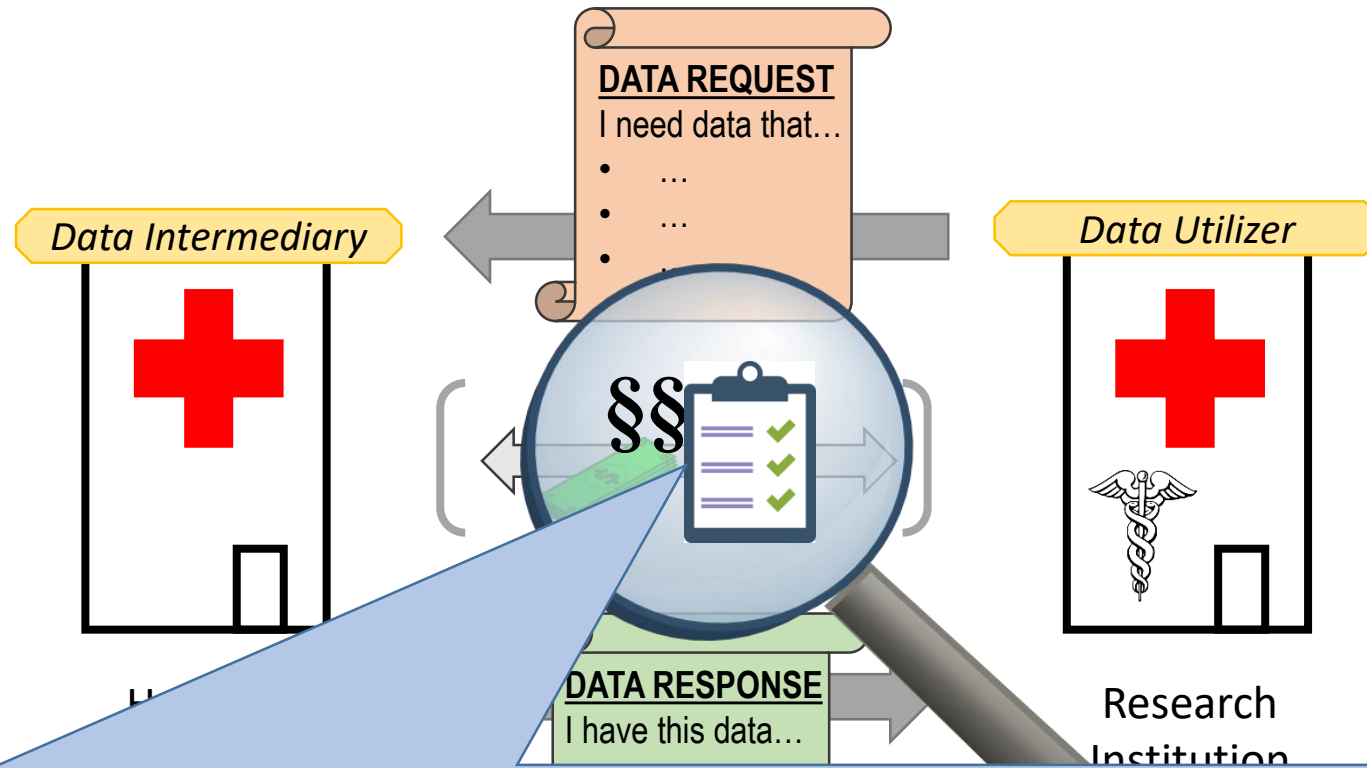
Data Enrollment



# Interaction Patterns

Data Utilization





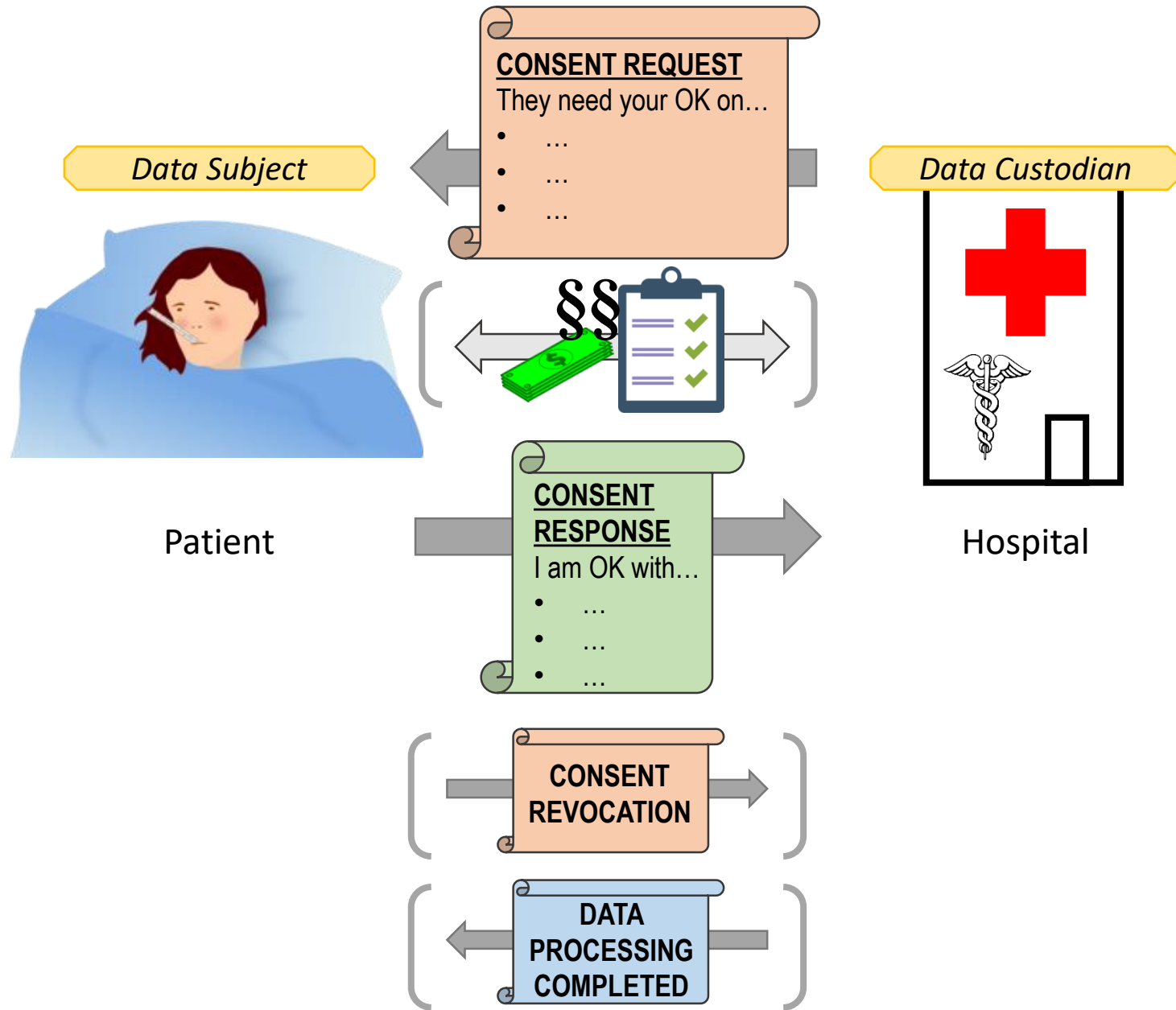
**SHARING NOT OK**



**ASK ME FIRST**



**SHARING OK**





# Conclusions

Data Intermediaries and Data Subject Rights

# Data Sharing Conclusions

- Data Subject Rights must be cared for also in data sharing scenarios
- Data intermediaries have a special role
- Data Custodians must be assigned
  - Manage data subject rights
  - On behalf of the data subject
  - Manage consent policies and consent revocation
- Data Sharing scenarios can get complex and international
  - ➔ European Legislation

➔ Research challenges ahead!