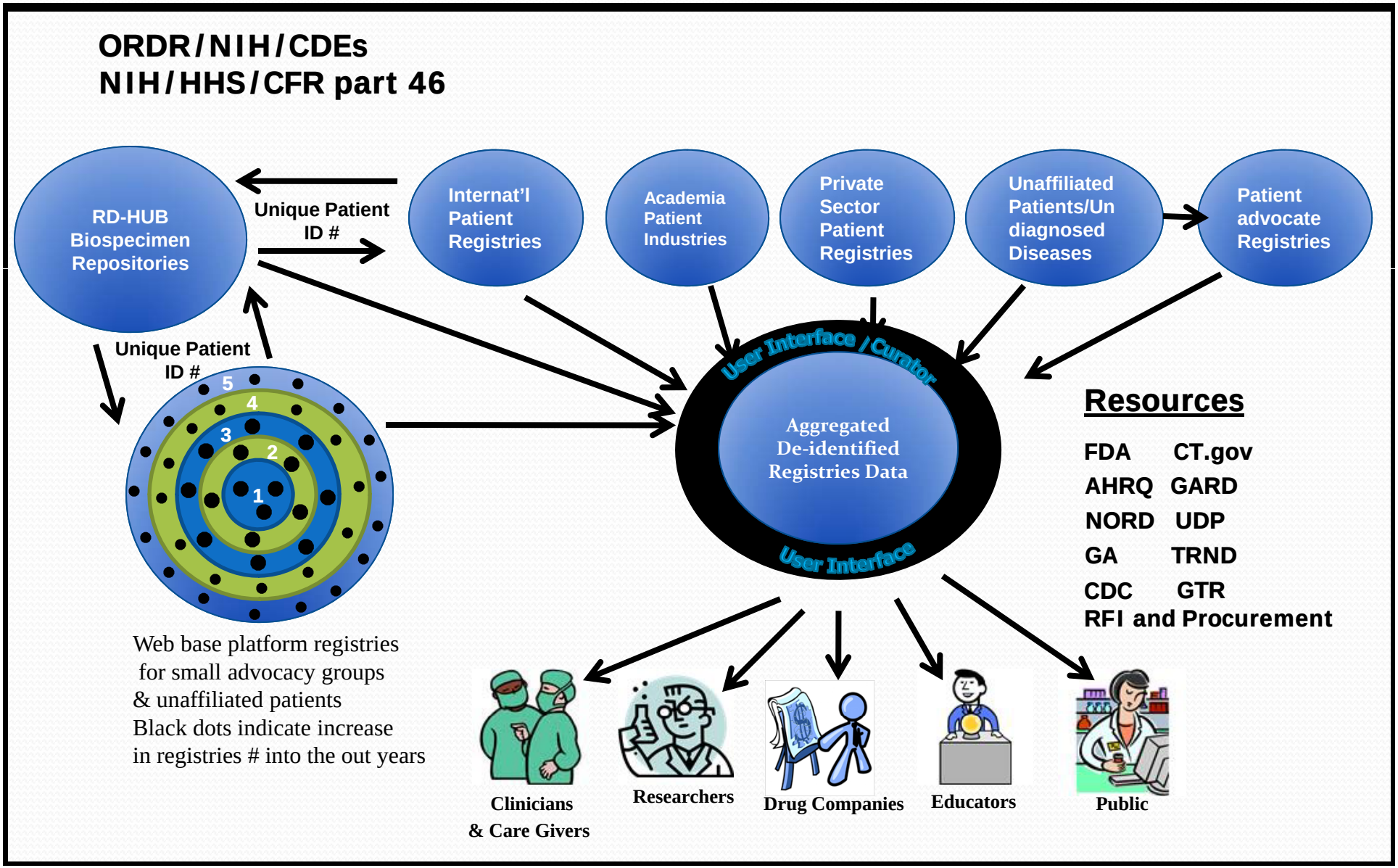
Global Rare Disease (Patient) Registry
GRDR



Considerations

- Informed Consent Issues
- Unique Patient Identifier
- Define Role of Government/Service Providers
- Role of Private Sector/Patient Advocacy Groups
- Completeness and Accuracy of Information in Patient Registries
  - Health Care Provider Data Entry
  - Patient and Family Data Entry
- Common Data Elements – Disease Specific Data Elements
- User Interface
- Identification of Curator/Gatekeeper
  - Identify
  - Roles
- Back-End Receiver of Information
- Who Has Access to De-Identified Information
- Develop and Publish Request for Information (RFI)
- Biospecimen Repositories Samples
  - New samples
  - Re-Consent
- Procurement Activity
  - Pilot Project of Selected Patient Advocacy Groups
  - Full Scale
  - Out Year Expenses