

## Considerations for ERN Software Providers

- **Findability:** This means that your registry data and metadata have unique and persistent identifiers. The registry data should be findable by “search engines” through its metadata. The actual data in the registry may not be accessible via the search engine but the conditions to access the data should be described in its metadata.
  - Define metadata on registry-level for optimizing findability (description, contact person, license, etc)
  - Expose (meta)data in a FAIR data point ([more information on FAIR data points](#))
  - Enable connection to a recommended pseudonymisation service
- **Accessibility:** This does not mean that the data is open, but as open as possible and as closed as necessary respecting the sensitivity of the dataset and that the technical access conditions are clearly stated in the metadata (policy and ethical conditions are related to Reusability).
  - Pick an access mechanism
    - Will the dataset be accessible via resource exchange protocol such as HTTP, FTP, SMTP? If not, have you written a clear set of guidelines for how to request access? (e.g. to whom do I send an email, and what information should I include in that email)
    - Whatever protocol you have selected above, is it able to be used by all stakeholders? E.g. if the protocol is proprietary, then it will not be FAIR.
  - Do you have a policy for maintaining your metadata long-term?
    - Can the metadata be permanently archived, in the event that your resource is de-funded or otherwise disappears?
- **Interoperability**
  - Standardised data entry using international classifications
    - Determine which ontologies should be used (Domain-specific: HPO, ORDO, HUGO, OMIM, etc / more 'generic': NCIT, SNOMED CT, etc)
  - Incorporate the [EJP RD CDE semantic model](#) into the data collection tool
  - Implementation option: [CDE in a box](#)
    - In order to transform collected data to be shared into RDF/JSON-LD format
    - [if possible] + Expansion of semantic model with registry-specific data
- **Reusability**
  - Metadata should have enough information so that data can be evaluated for its fit-for-purpose (contextual metadata and domain-specific metadata)
  - Define data use policy
    - Determine, and declare, who can be given access to the data (public / everyone in participating centres / only specific people) subject to the Accessibility constraints above.
  - Select or Define, and then publish, the data usage license
  - Provide clear citation information