Data Flow Within The I-DSD & I-CAH Registries

1. **Patient encountered by Clinician**
2. **Clinician provides information about Registry to patient**
3. **Clinician has consent from patient to enter data in Registry**
4. **Clinician enters core mandatory data into Registry**
   - Clinician provided registry unique ID for linkage to local records
5. **Clinician enters optional data into Registry**
6. **Patient wants access to the Registry**
7. **Patient provides email to Clinician**
8. **Clinician supplies email to Registry**
9. **Registry provides access to Patient**
   - Patient can view Clinician reported data and select preferences
   - Patient can complete Patient Reported Outcomes
10. **Investigator Submits Data Sharing Agreement & Data Search Form to PMG**
11. **Data Access Committee Review**
12. **Data Access Approved**
13. **PMG obtains approval from Clinician**
14. **Data from Registry supplied to Investigator**
15. **Data For Research**

The I-DSD & I-CAH Registries

Aggregate Reports
- Steering Committee
- Publicly available

Centre specific reports

Patient specific reports