HIGLOBAL REGISTRY

- Project blueprint
- Expert Steering Committee review & recruitment
- Registry provider analysis
- CHI seed funding
- Community engagement
- Registry provider selection & contract

- Secure NHS registry funding
- Patient community engagement & recruitment
- Clinician engagement & promotion
- Researcher engagement & promotion
- Other collaborating parties engagement & promotion
- Multi-country recruitment

- Further research
- Partner developments
- Regulators & funders relationships
- Boards & committees
- Registry outcomes publications
- Registry developments
- Community engagement & retention
- Resource management
- Strategic planning

RESEARCH

2013 - 2015

SET UP

2017 - 2018

POST-LAUNCH

TIMELINE

2017 -

LONG TERM

FUTURE

0

2010 - 2013

CONCEPT DESIGN

Protocol development

NHS registry data set

2015 - 2017

- Data management plan
- Communication plan & deliverables
- Registry design & congifuration
- IRB approval
- Registry testing & training
- Funding analysis
- Partnership development
- Community engagement

LAUNCH

• Multi-country recruitment

- Data management
- Data reports, analysis & dissemnation
- Clinical trial support services
- Research collaboration requests
- Governance board
- Registry committees
- Protocol amendments
- IRB submissions
- Fundraising & securing funding
- Community engagement & retention
- Resource management

- Rare disease patient registry review
- Rare disease registry assessment
- Adoption of natural history study (NHS) model
- Rare disease NHS registry committment

The HI Global Registry has many Global partners and is sponsored by

