We are an alliance of leading health, care and research organisations united to establish best practice around the ethical use of UK health data for research and innovation at scale.
What does the Alliance do?

Our mission is to accelerate improvements in biomedicine, health and care by encouraging widespread and responsible use of structured and unstructured clinical, administrative, imaging, genomic and other molecular data.

- Convene and co-ordinate
- Share knowledge
- Align
- Reduce duplication

- Agree on best practice
- Co-develop standards
- Publish recommendations
- Share resources

- Support organisations
- Facilitate implementation
- Incentivise change
More than 90 members to date

Principles for Participation - summary
1. Demonstrate active and ongoing engagement with patients and the public
2. Encourage the availability and use of health and care data for research and innovation
3. Promote the protection of privacy and data security, including providing access to sensitive data through Secure Data Environments
4. Make data Findable, Accessible, Interoperable and Reusable by adopting the FAIR Guiding principles
5. Use a proportionate approach to the governance of data access based on the five “safes”
6. Maximise the benefits of data for research and innovation through non-preferential access to data
7. Establish mutually beneficial ways of working in partnership
8. Work collaboratively to increase harmonisation and reduce the complexity of data sharing arrangements
9. Contribute to a joined-up and UK-wide offer for researchers
Our approach: building stronger and effective partnerships

- **Alliance Council** convenes all members around key issues and ratify outputs and recommendations

- **Alliance Executive Committee** representative of the main Alliance groups is being established to shape strategy and priorities, join up with other groups and fora

- **Alliance Secretariat** that runs Alliance operations and convenes working groups (as prioritised by members)

- **Alliance workstreams** informed by UK investments and member priorities, international work, HDR UK programmes and regions, to develop standards and best practice, exchange and grow knowledge and promote adoption
Current Alliance workstreams and special interest groups

**TRUST & TRANSPARENCY**
- Pan-UK Data governance steering group and action forces: Data access mapping; Five safes adoption; TRE/SDE legal toolkit; International data access / sharing
- Transparency of data access and use principles and funded improvements
- Alignment with Public Engagement in Data Research Initiative (PEDRI) – health sub-group

**TECH & DATA STANDARDS**
- Data Officer Group
- OMOP Special Interest Group in partnership with OHDSI UK Node
- Diversity in Data (ethnicity coding)
- **Clinical Trials prioritisation forum**
- Data for R&D partnership, including Health Data Gateway development
- Alignment with DARE UK and associated community groups

**CAPACITY BUILDING**
- Health Data Research Futures Learning Platform
- Black internship Programme
- Training Officer group (proposal)
Six use cases

Data for R&D investments are guided by six key, high level use cases

- **AI/algorithm development** (testing, training, and validation)
- **Clinical trial activities** (feasibility, recruitment, efficacy through short- and long-term trial follow up)
- **Real world studies** (safety, effectiveness, cost effectiveness)
- **Translational research** (academic discovery and implementation of discovery into practice)
- **Epidemiological studies** (large cohorts for population health research)
- **Health systems research** (evaluation of systems or processes, including operational and applied research)