LifeArc Accelerating Rare Disease Trials Equality, Diversity and Inclusion Strategy, 2026-2029

1. Background

There is a growing understanding of the inequitable distribution of the benefits and risks of health research, systematically impacting on particular communities and resulting in poor health outcomes(1). This interacts with wider structural forces and exacerbates health inequalities(2). There is a role for research infrastructure to integrate principles of equity, diversity and inclusion within their function in order to generate high quality, impactful, relevant and insightful research outputs that are applicable to the populations they serve and beyond, and direct efforts towards and provide solutions to address systemic inequalities.

Inequalities are deeply embedded in many organisations and our society, impeding progress and achievement of excellence. Stigma, prejudice and discrimination are contributing factors, with structural racism, sexism, ableism and heteronormativity being widespread. Addressing these inequalities requires recognition, acknowledgement and action at multiple levels.

People from diverse backgrounds have historically been under-represented in the health and social care research talent pipeline. In addition to research participants, consistent with the other research leaders, our strategy will involve contribution and leadership relating to the Accelerating Rare Disease Trials (ARDT) professional services, research, and advisory workforce, and public contributors(3). Similarly, the ARDT will impact upon and interface with external partners, including NHS providers, universities, charities, industry and other organisations. As such, the ARDT Equality, Diversity and Inclusion (EDI) strategy must encompass both its diverse functions and broad reach.

This document sets out the strategy for EDI for ARDT, to be executed during the period of funding, until September 2029.

1.1 Aligned strategies and initiatives

This strategy was formulated with consideration for the LifeArc Equality, Diversity and Inclusion (EDI) Strategy as a basis. The National Institute for Health and Care Research West Midlands EDI strategy has also informed its development.

The ARDT programme represents a collaboration between the universities of Birmingham, Newcastle and Queens University Belfast. Each of these structures have their own EDI initiatives. With this strategy, we seek to complement and capitalise on existing and evolving EDI activities. We recognise that ARDT is one of four Translational Centres for Rare Disease and our remit and activities will be shaped and defined by these external actors and others, and will need continual evaluation and re-alignment.

1.2 Aims

Develop an EDI strategy that will facilitate:

1) Generation of high quality, impactful and insightful research that is relevant to and serves the rare disease population and beyond.
2) Integration of EDI principles that promotes inclusion of under-represented groups from diverse backgrounds in the ARDT infrastructure.

1.3 Definitions

Key terms used in this Strategy are provided in Figure 1.

Figure 1 – Key definitions

*Definitions adapted from Calvert et al(4), **Morris et al(5), *** and Enticott et al(6)

2. Research Culture and EDI group

The Work Package (WP) B (EDI) lead developed the draft Strategy in consultation with the those represented in the WPB working group and the ARDT Research Culture and EDI group, for approval by the ARDT Scientific Steering Group. The Group will provide oversight of the Strategy and its delivery, highlight areas of success and identify where efforts are further required, making recommendations for action where appropriate.

The ARDT Research Culture and EDI group endeavours to create a culture where barriers to participation can be raised freely. Reflection periods will be built in for the Group to identify areas for discussion and update, address any concerns raised and develop mitigating structures and processes to ensure adherence to EDI principles irrespective of any personal characteristics.

The Group will meet quarterly to oversee the development and training for postgraduate students, the Centres' staff, public contributors, as well as ensuring the Centres implement best practices and initiatives in support of EDI principles across its activities. Task and finish groups will be established where necessary to complete key points from the action plan. This will be deliberated within the Group and actions will be allocated to Group members with their agreement. Where funds are required, this will be decided in consultation with the programme delivery team in accordance with the pre-defined budget.

Each year a report will be produced of key data and updates to report to the Scientific Steering Committee.

2.1 Membership

The ARDT Research Culture and EDI group is chaired by the Training and EDI Leads (on a rotational basis) and membership will consist of appropriate Centre staff representatives (e.g. at different career stages), two public contributors, and Centre Deputy Operations Managers. Centre Directors will attend rotationally.

2.2 Public Contribution to the ARDT Research Culture and EDI group

The ARDT Patient and Public Involvement and Engagement (PPIE) Lead and Engagement Managers will provide steer regarding alignment with ARDT PPIE activity and strategy. Two members of the Lived Experience Advisory Panel will join the Group and will be recompensated in accordance with ARDT PPIE payment policy.

3. Strategy

The ARDT EDI Strategy covers six areas relevant to ARDT activities, namely Research Community, Research Projects, Research Participants, PPIE, External Stakeholder Engagement, and Monitoring and Reporting. A set of underlying principles and corresponding actions have been developed for each of the six areas.

<u>Research Community</u>

Principles:

- The ARDT research community should reflect the diversity of the four nations of the United Kingdom.
- There should be equitable access to join and be supported within the ARDT research community.

Actions:

- Assess ARDT recruitment practices to expand reach and promote access to a diverse pool of candidates.
- Broker access to local infrastructures (e.g. inclusive staff networks) to support ARDT staff.
- Support the delivery of the WPC activities.

Research Projects

Principles:

- Ask research questions that are representative of public interests, prioritising the research interests of those underserved by rare disease research.
- Employ broader consultation processes that involve a degree of outreach, prior to seeking funding and throughout the research process.
- Adopt inclusive research design.
- Assess and respond to training needs.

Actions:

- Support inclusive PPIE, working with the WPA team.
- Use of ARDT teams site to host methodological/research design resources that uphold EDI principles.
- Undertake audit of ARDT activities annually to assess integration of EDI principles.
- Consult on research training needs via the ARDT Research Culture and EDI group, working with WPC.

Research Participants

Principles:

- Prioritise inclusion of diverse rare disease populations.
- Consider research generalisability, quality, and equity.

Actions:

- Use of ARDT teams site to host methodological/research design resources that uphold EDI principles.
- Undertake audit of ARDT activities to annually to assess integration of EDI principles.
- Consult on research training needs via the ARDT Research Culture and EDI group, working with WPC.
- Co-develop EDI diversity data strategy.

Patient and Public Involvement and Engagement

Principles:

- Support inclusive PPIE
- The cultural competence and/or representativeness of contributors of rare disease populations should be considered.
- Involvement and engagement should be inclusive, with an emphasis on outreach and those underserved by research.

- Dissemination of ARDT activities and research outputs should be accessible and inclusive of those underserved by research.

Actions:
- Work closely in delivery of WPA activities.
- Support involvement and engagement activities with emphasis on underserved rare disease communities.
- Support formulation of accessible communications plan (including generation of plain language summaries, supporting alternative communication methods).

Stakeholder Engagement

Principles:
- ARDT will demonstrate its leadership through its commitment to EDI.
- ARDT will contribute to and encourage the embedding of EDI principles in the local infrastructure and through its engagement with its partners.

Actions:
- Include ARDT EDI activities in communications with stakeholders.
- Engage in relevant EDI activities within international and national rare disease research ecosystems.

Monitoring and Reporting

Principles:
- Examples of excellence in EDI in ARDT should be celebrated.
- Where possible, ARDT EDI reporting will align with LifeArc reporting requirements.
- EDI-related monitoring should be undertaken consultation with ARDT colleagues.

Actions:
- Undertake audit of ARDT activities to annually to assess integration of EDI principles.
- Co-develop EDI data reporting strategy.
- Explore implementation of EDI sections in proposals, protocols, and reporting.

4. References

1. Coleman CH. Equitably Sharing the Benefits and Burdens of Research: Covid-19 Raises the Stakes. Ethics Hum Res. 2020;42(5):38-40.
2. Davey F, McGowan V, Birch J, Kuhn I, Lahiri A, Gkiouleka A, et al. Levelling up health: A practical, evidence-based framework for reducing health inequalities. Public Health in Practice. 2022;4:100322.
3. NIHR. Equality, Diversity and Inclusion Strategy 2022-2027 https://www.nihr.ac.uk/documents/equality-diversity-and-inclusion-strategy-2022-2027/31295: NIHR; 2022 [
4. Calvert MJ, Cruz Rivera S, Retzer A, Hughes SE, Campbell L, Molony-Oates B, et al. Patient reported outcome assessment must be inclusive and equitable. Nature Medicine. 2022;28(6):1120-4.
5. Morris L, Dumville J, Treweek S, Miah N, Curtis F, Bower P. Evaluating a tool to improve engagement and recruitment of underserved groups in trials. 2022.
6. Enticott JC, Shawyer F, Vasi S, Buck K, Cheng IH, Russell G, et al. A systematic review of studies with a representative sample of refugees and asylum seekers living in the community for participation in mental health research. BMC Medical Research Methodology. 2017;17(1):37.