



Connect Immune Research Charter

1. Overarching strategy:

1.1. Vision:

A connected research community generating advances in understanding and in treatments for people living with autoimmune conditions.

1.2. Mission:

To change autoimmunity research into a major biomedical priority that is widely acknowledged, coordinated, and funded to transform knowledge and treatment.

10 Year Ambitions:

- 1.3. By 2030 Connect Immune Research will catalyse the growth of a truly connected autoimmune sector in the UK and raise the profile of autoimmune conditions, along with the challenges and associated multimorbidities faced by people living with them.
- 1.4. People living with autoimmune conditions will be recognised and respected as vital partners in research and campaign activity, playing a decisive role in setting priorities and developing solutions.
- 1.5. To bring about this change Connect Immune Research will provide research funding to enable researchers working on multiple autoimmune conditions to work together and influence other funders to do the same while generating new evidence about the common mechanisms of autoimmune diseases.
- 1.6. We will provide events, publications and campaigns for scientists working in autoimmunity and people living with autoimmune conditions to come together, making new connections and reducing isolation, breaking down walls to tackle new shared challenges and demonstrating the value of working together.

2. Principles

- 2.1. The driving principle of Connect Immune Research is that through collaboration and synergy, together we will rapidly catalyse a connected research community generating advances in understanding and in treatments for people living with autoimmune conditions.

- 2.2. It follows that membership of Connect Immune Research carries advantages for which some conceding of autonomy are considered to be a reasonable price – the global benefits for autoimmune research considerably outweighing the individual restrictions.
- 2.3. Whereas this does not mean that all individual autoimmune research efforts should be subsumed into a single Connect Immune Research effort, we do aspire to a community of ideas, some of which will be best realised via a cooperative approach.
- 2.4. Amongst other advantages, benefits of this cooperative approach are expected to include the strengthening and improving of preliminary ideas via discussion with fellow experts, the possibility of attracting additional resources in support of proposed projects, access to larger sample and data sets, better analytical tools, and sharing of complementary skills.
- 2.5. Members are required to discuss their ideas for Connect Immune Research with the group, following a principle of “no surprises” to foster effective working relationships. This principle holds across all Connect Immune Research activities, from research to communications. Members will be transparent in decision making and clear in communicating news.
- 2.6. Members are further encouraged, but not required, to share relevant ideas and activities that fit with the ambitions of Connect Immune Research, but do not require use of Connect Immune Research shared resources.
- 2.7. Connect Immune Research membership should be balanced and not dominated by one condition or disease area.
- 2.8. Member organisations must be committed to an evidence-based medicine approach, public and patient involvement in research, and AMRC standards of peer review.

3. Structure of Connect Immune Research

Connect Immune Research consists of two membership tiers: the Governance Group and Associate Group. There is no membership fee/cost associated with joining the partnership. All members will be invited to attend at least one annual general meeting (maximum of two per year) to further connection and provide proposals for activity.

Below details the structure of each group:

3.1. *Governance Group*

- 3.1.1. A small, stable group of experienced individuals from at least the four foundation charities who work well together and can be trusted to do what is best for autoimmune research.
- 3.1.2. This group is responsible for setting the long term agenda, tone and principles behind Connect Immune Research. It will lead the review and assessment of Connect Immune Research outputs. It is also charged with settling disputes and ultimately has the final word.
- 3.1.3. Membership will be dependent on equal contribution to achieving the aims of Connect Immune Research, as defined by the Governance

Group, and should include agreed contributions towards funding calls, shared access to communications and campaigns resources.

- 3.1.4. Governance Group members are expected to lead on distinct projects within Connect Immune Research, for example grant management, external affairs (campaigns), Public and Patient Involvement (PPI), research community communications, fundraising etc.
- 3.1.5. Meetings will be scheduled as required to effectively oversee Connect Immune Research, with up to four meetings per year, and will be by video conference or in person.
- 3.1.6. It is expected that Governance Group members will have AMRC membership to ensure shared acceptance of medical research charity gold standards.
- 3.1.7. Governance Group membership may be withdrawn by the member in writing to the rest of the group or withdrawn by the Group after absence at two consecutive meetings. New members must be admitted upon unanimous agreement of existing Governance group members

3.2. *Associate Group*

- 3.2.1. Associate Group members will be important stakeholders for Connect Immune Research's ultimate success but are not expected to directly contribute to activities.
- 3.2.2. Associate Group members will be invited to join Connect Immune Research by any member of the Governance Group. They will be kept up to date with progress and opportunities to participate as appropriate.
- 3.2.3. Associate Group members shall be invited to a dedicated check-in every three years. This process is intended to encourage discussion and feedback on the partnership, its activities and communications.
- 3.2.4. Associate Members can withdraw by written notice to the Governance Group.

4. *Governance*

- 4.1. CIR membership will be confirmed by an email from the Governance Group and is dependent on the new member agreeing to the terms of this CIR Charter and counter signing its Appendix.
- 4.2. Associate Group members will have the opportunity to decide whether or not to participate in funded activities.
- 4.3. All activities requiring a financial contribution from the group's members will be formalised through specific memoranda of understanding (MOU).

5. *Commissioning and decision making*

- 5.1. All Connect Immune Research activities will be developed by the secretariat of the Governance Group with consultation with Associate Group members where appropriate.

- 5.2. Proposals for Connect Immune Research activities from all members will be discussed at Governance Group meetings at least annually and decisions made by unanimous agreement by the Governance Group.
- 5.3. All activity plans (for example campaigns) need to be approved by the Governance Group.
- 5.4. Activity plans should be in-line with this Charter and with the budget agreed by all members providing funding.
- 5.5. A list of all members of Connect Immune Research and the activities will be published on at least the Governance Group member websites to ensure transparency.
- 5.6. The process for commissioned research will be transparent and comply with AMRC guidelines.

6. Communication, Public Engagement and Fundraising

- 6.1. Connect Immune Research members will support wide communication to the public and researchers as a key goal of the project. The logo will be used in all relevant communications to build awareness.
- 6.2. All members should endeavour to share communications regarding CIR with the Governance Group. Communication about the CIR principles and vision is encouraged to build connections and brand.
- 6.3. External communication and public engagement regarding Connect Immune Research will be agreed by the Governance Group. Members will be informed via their relevant staff.
- 6.4. Fundraising teams from members contributing to funding will work together to avoid competing for donations to Connect Immune Research and where possible submit joint bids for support, to be divided based on contribution.