

Terms of Reference for the Diabetes Research Steering Groups

1. Aims and objectives of the Diabetes Research Steering Group (DRSG) initiative

The DRSG initiative aims to improve the lives of people with or at risk of diabetes through research. Bringing together researchers, healthcare professionals and people living with or at risk of diabetes to collaboratively identify research priorities that are important to people with diabetes, its outputs will shape the UK diabetes research landscape, stimulate more diabetes research and strengthen the diabetes research environment.

2. Purpose of the Diabetes Research Steering Groups

- Work collaboratively to identify areas where advances in research could improve the lives
 of those with or at risk of diabetes and establish these as research priority areas.
- Ensure research topic identification and prioritisation is informed by insight that represents the full diversity of lived experience and healthcare provision.
- Recommend innovative solutions to stimulate research in priority areas, with a focus on partnership.

3. Relationship with Diabetes UK

Diabetes UK uses insights from the groups to inform its own research strategy, however this initiative is intended as a resource for the wider diabetes research community and funding organisations. As such it is expected that the DRSGs will discuss priorities beyond the Charity's own funding capacity.

For Diabetes UK to invest financially in DRSG priorities, they must also align with the <u>Charity's strategic outcomes</u> and this is subject to its internal governance pathways, including review by the Science and Research Advisory Group and the Board of Trustees.

3. Frequency of meetings and operational and funding support

Each DRSG will be provided with financial support for two face to face meetings, and facilities to hold two teleconferences, per year (funds will be managed by Diabetes UK). Unless agreed otherwise with Diabetes UK, all funds will be managed by Diabetes UK. All meeting costs will be in accordance to the Diabetes UK <u>Volunteer Expenses Policy</u>, and claims are to be made using <u>Volunteer Expense Form</u>.

DRSG face-to-face meetings will be minuted by Diabetes UK. Following approval of minutes and redaction of any confidential information, the minutes will be made publicly available.

An additional process for funding small projects to support DRSG work (up to a maximum of £5,000), is also available. Any DRSG member will be able to submit an application, and all applications will be assessed by the DRSG Leadership Panel.

4. Accountability

Each DRSG is accountable to the DRSG Leadership Panel but the overall responsibility for the activity of each DRSG rests with the Chair and members.

DRSG Chairs, working with DRSG members, will track outputs using a framework which will be provided and managed by Diabetes UK. They will also submit contributions for the DRSG Annual Progress Report, which will be collated by the DRSG team at Diabetes UK.

Diabetes UK, with advice and support from the DRSG Leadership Panel, will monitor the progress of the DRSGs on an ongoing basis and will formally review its investment in DRSGs not less than once every five years. As the sole funder, it reserves the right to review, and make changes to, the structure of the DRSG network and its investment, to ensure that the aims are being met.

5. Membership

The membership of each DRSG must be composed to reflect the various stakeholders involved in the development of priorities within the remit of the group. All membership is undertaken on a voluntary basis.

- Each DRSG should have a Deputy Chair.
- Each DRSG should include multi-professional representation and should include non-research active Healthcare Professionals (HCPs).
- The membership of each group should include a minimum of three people living with or at risk of diabetes (experts by experience).
- Groups should be mindful of the diversity of experience of living with diabetes and
 recruit accordingly. As the membership cannot represent the full diversity in experience
 of living with diabetes, a minimum standard of evidencing that priorities are important
 to people with diabetes will need to be met via involvement or engagement activities
 with the wider community.
- Each DRSG should have representation from as wide a geographical area as possible with each group including at least one member from the devolved nations.
- Group membership should represent a mix of research/clinical experience and seniority.

DRSGs should consider co-opting additional members with relevant expertise from a wide range of disciplines and methodologies when discussing specific project related matters or when developing priorities in new areas. DRSGs should also consider where it is appropriate to co-opt members outside the research arena. Representatives of diabetes research funders and other professional organisations may also attend meetings of the DRSGs with prior agreement and in a non-membership role.

6. Terms of office

The term of appointment for Chairs, Deputy Chairs and members is three years in the first instance, with an option to reapply for a further three years. At the end of a second term of membership, a three year period must elapse before a member can reapply for a further term on the same DRSG, though members will be permitted to apply for other DRSGs if their expertise applies to more than one of the groups. Exceptions to this, should they arise, will be reviewed on a case by case basis by the DRSG Leadership Panel and Diabetes UK staff.

Members who are investigators on key projects in priority areas that have been developed through the DRSG and whose term of office expires before the project has been completed will be asked to maintain links with the group.

7. Declarations of Interest

Members shall be required to complete a declaration of interest form on an annual basis, and within 28 days of becoming aware of any change in their declared interests. The register shall be available for inspection. When the agenda for each meeting is circulated, members shall be required to declare any conflicts of interest relevant to specific agenda items and may be asked to leave the meeting for any sections where this would represent a problem.

8. Recruitment

Chairs and members of the DRSGs will be appointed through an open competitive process of recruitment. Positions will be advertised widely and will be open to all members of the UK diabetes research community and to all UK based people living with diabetes.

9. Data Protection

All parties will comply with the Data Protection Act 2018 (and any guidance issued from time to time by the Information Commissioners Office) in relation to their processing of personal data. All parties will process any personal data collected in relation to DRSG members only for the purposes of achieving the DRSG's objectives and for administering the DRSG. Diabetes UK will be the data controller of the personal data of committee members of the DRSG in relation to the administration of the DRSG and undertakes to comply with its responsibilities in relation to any processing of such personal data.

10. Variation

Diabetes UK reserves the right to amend these Terms of Reference at any time at its discretion, or make any necessary alterations to the way the groups are running temporarily due to extraordinary circumstances. Diabetes UK will publish any permanent change to the Terms of Reference on the Diabetes UK website and will notify DRSG Chairs that a change has taken effect.