



National Registry for Radiation Workers Data Governance Group

The NRRW epidemiology cohort study aims to provide direct evidence for the effects of long-term occupational exposure to radiation on the health of workers.

This evidence is used by national and international standards setting bodies to ensure that radiation protection regulations and guidelines provide an appropriate level of protection for UK radiation workers and the public.

This group is established to provide governance and oversight of the epidemiology work proposed using data from the study.

Membership

1. Independent Chair – A senior academic or medically qualified (but not necessarily still registered to practice) or senior scientist (appointed by UKHSA with agreement of NDA to serve a maximum first term of five years with the option of a second two-year term by agreement of the committee)
2. UKHSA management representative(s) with responsibility for the study
3. UKHSA scientific lead for the study
4. UKHSA secretariat (RCE's Radiation Effects Department)
5. NDA management representative(s)
6. Representatives from other employers – 3 or 4 at one time
7. Workforce representatives – ideally three from the unions who represent employees with participating organisations and a cohort representative
8. At least one occupational health physician from a significant participating organisation

Other individuals with required expertise as determined by the committee may be invited to specific meetings.

Terms of Reference

The remit of this group is to provide independent governance and oversight of research proposed using the NRRW cohort.

The approval of this group will be a pre-requisite to the use of NRRW data for research.

The group will review proposals to use data taking account of the following:

- The purpose of the study and the question being asked
- Design and conduct of the study
- Data security
- Protection of participants' confidentiality
- Provision of appropriate information about the study to cohort members
- Participants' right to withdraw
- The impact of the potential results of the study on cohort members and the wider workforce of radiation workers.
- Reputational risks to UKHSA, NDA and other stakeholders.

This Group will only approve studies that have been subject to appropriate ethical review and approval.

This Group will have the power to veto any given research proposal or, in appropriate circumstances, to require the cessation of any ongoing project.

This Group will have the option to seek independent advice from experts as appropriate to ensure it can adequately review proposals.

This Group will be sent research papers at the point of submission for information and will ensure that key stakeholders, including employers and study participants, are appropriately briefed prior to publication or other dissemination.

This Group will ensure that the programme of work is effectively communicated, for example by means of an annual report of work undertaken that is made accessible to study participants and to encourage publication of research findings.

This group will support/encourage the flow of data into the NRRW from employers.

The group will meet two times a year with an aim that one of these will be face-to-face and the other 'online'. Additional meetings can be added if a need arises.

A quorum for the group is defined as the chair, one member from each of UKHSA, workforces (unions) and Occupational Health and at least two data providers.

An agenda item, to formally review the Terms of Reference, will be scheduled annually.