



Diabetes Research Network (DRN) Portfolio Database Guide:

Benefits for DRN-adopted studies and Information for research study teams

Background

The UKCRN has been established to provide support for clinical research; further information is available at www.ukcrn.org.uk. The Diabetes Research Network (DRN) is one of several topic specific networks which make up the UKCRN. Studies, current and future, adopted by the DRN are part of the UKCRN Portfolio of Studies; therefore, information on each study needs to be entered onto the UKCRN Portfolio Database.

When a study is added to the UKCRN Portfolio Database it means that UKCRN funded staff within the DRN can work on that study. Assistance from the DRN is wide and varied, for example, assistance with research governance procedures and Clinical Studies Officer (CSO) assistance with recruitment.

What is required from research teams coordinating studies?

Once accepted into the DRN portfolio each research study team will be required to input study information directly into the UKCRN Portfolio Database. On a monthly basis an accrual contact nominated by each study will be required to submit accrual data on each participant recruited to the UKCRN.

What information is required?

A minimum dataset is required before a study can go live on the UKCRN website. The minimum dataset includes information on areas such as study design, funding body and contacts. Once the minimum dataset has been entered the study can be approved and go live on the website.

If you have been added as a Study Coordinator you are able to obtain a UKCRN log-in and password in order to access the main dataset and maintain the information about your study on the database. Activity-based funding is driven by the data which is held on the UKCRN Portfolio Database and is therefore essential that your study record is kept up-to-date.

Why is study information required?

The Department of Health requires all UKCRN studies to be registered in the UKCRN Portfolio Database, providing a central repository of information. This facilitates access to study information and activity across the UKCRN that is required for many purposes, including producing responses to Parliamentary Questions. The Portfolio Database is a central resource which will support

performance management of the UKCRN, the topic specific networks, and eventually the Comprehensive Research Network.

Confidentiality

Individual research participant data is non-identifiable. Some study information will be available to the UKCRN and individual study team only.

What are the benefits?

Service Support Costs

In future only studies registered on the UKCRN portfolio database will be eligible to access NHS service support costs.

Searchable Portfolio Database

The Portfolio Database provides central searchable access to study information for service users/public.

World Health Organisation (WHO) Registration

Guidelines released by the International Committee of Medical Journal Editors require that certain clinical research studies need to be registered on an acceptable Internet based registry before they can be considered for publication in any member journals. The Portfolio Database has been developed to meet the minimum data requirements set by the ICMJE (International Committee of Medical Journal Editors). The criteria are also the same as the proposed minimum dataset for registration on the WHO International Trials Registry Platform and it is anticipated that trials registered in the Portfolio Database will become registered with the WHO International Trials Registry Platform at no additional cost or work to the study team.

Central Store of Study Information

When all study information is entered onto the database it will provide a concise record of essential study information. Study Coordinators will be able to login and access information for their study from any computer with Internet access. Not all study information is available to the general public via the UKCRN website.

Study Promotion

The portfolio database is an excellent way of promoting research studies and is easily accessed via the Internet providing a resource for the research community and service users. Promotion of studies through the Portfolio Database will be especially useful for studies that are able to accept self referrals.

Data checks

Monthly accrual data provided to the UKCRN are validated. This is useful as simple errors such as a date of birth out of range can be corrected at an early stage.

Portfolio Database – Key Functions

- Central register of UKCRN studies – promotes studies within the portfolio, updated daily, users can search for and access information about studies.
- Central database of accrual data – stores UK-wide recruitment data (access to detailed accrual data is password protected).
- Reports are available that describe recruitment across the networks and different types of study.
- Enables the UKCRN to performance manage the networks so that they can continue to develop and improve.

Further information

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