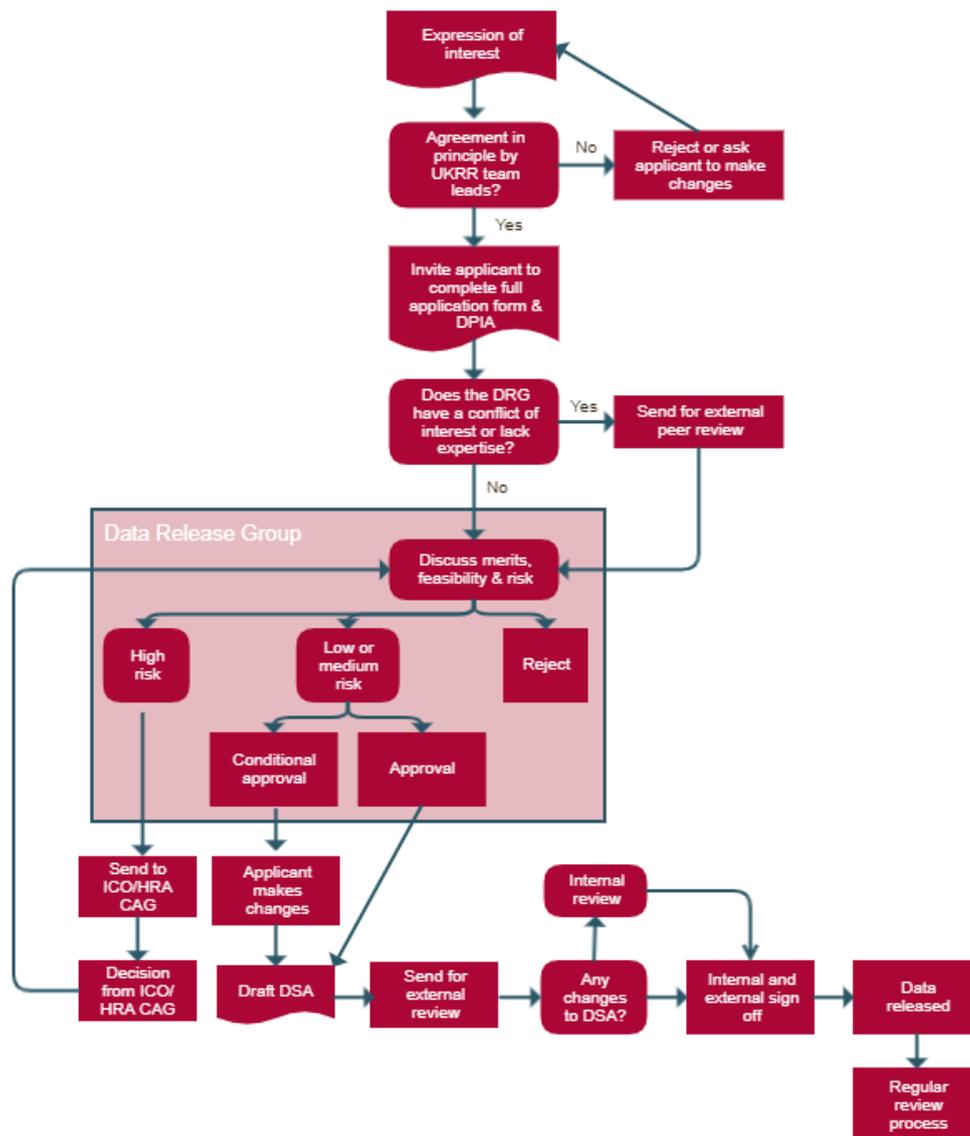# UK Renal Registry Data Release Group – terms of reference

1) The role of the Data Release Group

The UK Renal Registry's (UKRR) Data Release Group (DRG) is a fundamental part of the process for researchers to apply to access pseudonymised patient level data held in the UKRR database (figure 1 – DRG highlighted in pink).

Figure 1 The process to apply to access pseudonymised patient level data held in the UKRR database

DPIA – data protection impact assessment; DRG – Data Release Group; DSA – data sharing agreement; HRA-CAG – Health Research Authority Confidentiality Advisory Group; ICO – Information Commissioner's Office

2) Chair and membership of the DRG

The chair of the DRG is the UK Kidney Association's (UKKA's) medical director.

Membership of the DRG includes the UKKA's director of informatics research, the data protection officer and senior members of the statistical team, the IT team, the finance team and the research team, as well as representatives from the British Association for Paediatric Nephrology (BAPN).

3) Assessment of data applications

All applications are assessed by the DRG, apart from those where it is identified prior to the DRG meeting that there is a conflict of interest or that expertise outside that of the DRG's members is required. In these instances the application is sent to an external peer reviewer and that person's comments are shared when that application is discussed at the DRG.

Any application for paediatric data must involve the input of a BAPN representative.

Using information submitted on the application form and data protection impact assessment (DPIA), members of the DRG discuss the scientific and methodological merits of each application and assess the level of risk for patient re-identification. All high risk applications are referred to the Information Commissioner's Office (ICO) and the Health Research Authority Confidentiality Advisory Group (HRA CAG) for their guidance, while applications of low or medium risk are processed internally.

The chair leads the discussion about each application and completes the assessment form. The discussions end with a vote, which must include input from all teams that make up the DRG. The majority decision is upheld – if it is a tie the chair's vote is the decider.

Applications are either rejected, conditionally approved or approved. Applicants are notified and feedback provided.

4) DRG meetings

Four meetings of the DRG, lasting two hours, are held each year in Bristol at the UKKA's office and/or via an online platform. The meetings are organised by the UKKA's business team.

The UKKA's research manager oversees the entire application process and ensures all applications are circulated to members of the DRG at least two weeks prior to each meeting.

5) Review of DRG terms of reference

The DRG reviews the terms of reference on an annual basis.