*Table 5: Recommendations to Improve Access to Routinely Recorded Data for Research*

|  |
| --- |
| **General** |
| Routinely recorded data are being used to measure RCT outcomes with the agreement, additional benefits and cost-efficiency of such data compared to data recorded through standard RCT methods being unknown.  ***Further research should be performed to assess the agreement, additional benefits and cost-efficiency of accessing routinely recorded data to measure RCT outcomes compared to data collected through standard RCT methods.*** |
| The costs required for data access from routine data sources vary widely, although all reportedly operate on a cost recovery, not-for-profit basis.  ***Costs should be standardised and rationalised between routine data sources.*** |
| The time lag before data is available in routine data sources represents a significant limitation to the access of routinely recorded data for prospective research, including RCTs.  ***The infrastructure and procedures should be developed to reduce the time lag seen in routinely recorded data sources.*** |
| The requirement for linkage between sources of routinely recorded data has been observed and improvements are on-going, for example with the establishment of the ADRN.  ***A standardised set of identifying variables could be recorded by all (clinical and non-clinical) data sources to improve the accuracy of data linkage, similar to a Core Outcome Set for clinical trials [44].*** |
| The public mistrust in the sharing and linking of routinely recorded data will hamper future efforts to develop routinely recorded databases, despite the likely benefits to individual patients and the population.  ***Further research and public engagement should be undertaken to define the issues of most importance to the public and develop strategies to address these.*** |
| **Clinical Routine Data Sources** |
| There are numerous requirements prior to application and criteria to fulfil on submission of an application, yet the guidance and support during development of an application remains limited.  ***Formalise and improve access to guidance and review of study materials during the ‘pre-application stage’.*** |
| There is national coverage of routinely recorded secondary care data, yet primary care coverage remains patchy, based on geographical area or GP IT system.  ***Develop the primary care data sources to provide national coverage, either through collaboration of existing sources and data linkage or development of national data sources, such as the General Practice Extraction Service.*** |
| **Non-Clinical Routine Data Sources** |
| Access to non-clinical data sources to inform clinical research was not possible during this study, despite the significant potential to inform Health Technology Assessment and the increasing importance of such assessments in a healthcare system where resources are increasingly limited.  ***To assist with Health Technology Assessment and particularly the analysis of health economic outcomes, urgent research is required to consider facilitating access to individual-level identifiable data from non-clinical sources. This would include:***   1. *Research regarding the public perception and acceptability of using their personal economic data for clinical research.* 2. *Internal review within non clinical sources such as the DWP and HMRC to assess the feasibility and limitations of permitting access to data for clinical research.* 3. *Formalisation of the approval processes through the independent party, the ADRN for access to non –clinical administrative data – currently, following internal approval the ADRN then negotiate access to administrative data on a project by project basis.* |