UNLOCK
A summary of governance and working arrangements

Background

In 2010 the IPCRG published a protocol summary for UNLOCK (Uncovering and Noting Long-term Outcomes in COPD and asthma to enhance Knowledge) in the Primary Care Respiratory Journal.1 UNLOCK is an international collaboration between primary care researchers to coordinate and share datasets of relevant diagnostic and follow-up variables for COPD and asthma management in primary care. By Summer 2013 the UNLOCK Group included members from 13 countries: Sweden, Spain, Ukraine, Canada, Greece, UK, Netherlands, Norway, Australia, Portugal, Belgium, India and Chile.

Governance arrangements

• The IPCRG Board has overall responsibility for UNLOCK’s progress and performance, both financially and scientifically.

• The IPCRG Board delegates responsibility to the IPCRG Research Sub-committee to ensure that the UNLOCK Group works within the framework of the IPCRG’s research standards and of its research needs statement and priorities and to review the content of proposals for individual studies.

• Two reviewers independent of the proposed study review each proposals for its:
  o Connection to the IPCRG’s research needs and the work of the UNLOCK Group
  o Originality: ie not covered by any other IPCRG or UNLOCK study
  o Quality: the question and analysis are robust
  o Feasibility: uses data variables held by UNLOCK members on their existing datasets
  o Value: value to practising primary care in terms of improving outcomes

• The UNLOCK Steering Group (which is made up of the Chair of the UNLOCK Group, two other members of the UNLOCK Group and the IPCRG Executive Director) approves applications from new members, makes recommendations to the IPCRG Board on which proposed UNLOCK studies should be prioritised for funding and ensures the progress of the UNLOCK work programme.

• First authors of UNLOCK studies funded by the IPCRG each have a contract with the IPCRG, using IPCRG standard terms and conditions for research. The intellectual property and database rights clauses are required to be explicitly agreed. The default clause: “The database right in any database or data in the work [project title] shall belong to the funder of the research from which that database or data is derived. If IPCRG funded the creation of a database, it would own the rights. However, if it funded an analysis but not a database, it would own the analysis.”

Working arrangements

- Research questions are proposed by members of the UNLOCK Group at their twice yearly meetings and in on-going discussions using a private virtual forum hosted on the IPCRG web platform.
- Those research questions which are considered important by members and for which data is available are prioritised.
- The UNLOCK member who undertakes the analysis usually acts as the first author of a study, with those members who contribute data acting as co-authors, according to the authorship criteria agreed by the UNLOCK Group.
- Low-cost fixed funding for analysis and publication charges is made available from the UNLOCK budget to support first authors in undertaking data analysis.
- Technical support in the form of syntax development, data exchange platforms and sharing standards is available through the Rosetta project.
- The UNLOCK Group also seeks to maximizes opportunities for getting findings into practice through publishing and presenting studies and through peer education.
- The UNLOCK Group is supported by a part time project manager.

Criteria for membership of the UNLOCK Group

- Have an independently managed COPD and/or asthma dataset that is funded;
- The dataset is from a primary care population that has given informed consent\(^1\) as appropriate [recognising national rules do not always exist, and where they do, are inconsistent between countries];
- The dataset is longitudinal in nature; and
- The dataset includes a minimum set of variables including
  - symptoms
  - lung function and
  - quality of life.

\(^1\) Informed consent to be included in a dataset that will be kept and used for decades for research to improve patient care