About the UNLOCK Group

What is UNLOCK?

UNLOCK (Uncovering and Noting Long-term Outcomes in COPD and asthma to enhance Knowledge) 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. It was set up by members of the International Primary Care Respiratory Group. The protocol summary was published in the Primary Care Respiratory Journal in 2010 (see UNLOCK PCRJ.pdf) and the report of the findings to 2018 (npjPCRM 2018).

The UNLOCK Group currently includes members from 15 countries: Sweden, Spain, Ukraine, Canada, Greece, UK, Netherlands, Norway, Australia, USA, Portugal, Germany, India, Uganda and Chile.

What is UNLOCK for?

The IPCRG Research Need Statements identified the need for evidence to underpin the primary care approach to diagnosis, assessment and broad management strategies.[1][2] This evidence is required to address current concerns including variations in care and outcomes, the difference between the results of clinical trials and real outcomes in primary care and the need for clinical guidelines that are relevant and useful for primary care. Furthermore, there is growing consensus that additional evidence is needed on the process of translating basic scientific discoveries into clinical practice, known as the "bench to bedside continuum". [3]

The primary purpose of UNLOCK is, therefore, to contribute to meeting these research needs through the evaluation of the burden of disease (symptoms, limitations and exacerbations), the natural history of disease, treatment and follow-up, and co-morbidities in unselected primary care populations from diverse contexts. The unique value of UNLOCK is that data is drawn from primary care databases so there is the potential for longitudinal as well as cross-sectional studies. In addition, as they are primary care populations there is the potential to consider multiple morbidity. Moreover, because there are already 15 countries involved, data can be drawn from a variety of contexts.

How does UNLOCK work?

Participants from leading universities and research institutes across 15 countries collaborate in the UNLOCK Group to progress UNLOCK studies. The UNLOCK Group:

- Discusses and agrees research questions
- Develops and approves study protocols
- Publishes protocols in npj Primary Care Respiratory Medicine
- Registers protocols on the ENCePP registry[4]
- Discusses and challenges emerging findings
- Publishes findings in peer-reviewed journals
- Presents findings nationally and internationally

UNLOCK members provide relevant data from their existing primary care datasets for analysis to answer relevant research questions in one of two ways, depending on the ethical approval and data protection requirements of their own datasets: either they analyse their own data using agreed variables and provide this analysis to the lead researcher; or they provide the data to the lead researcher undertaking the study for centralised analysis. Each member maintains their own database and data is not kept in a merged form in order to maintain the integrity of individual datasets.

Analysis undertaken depends on specific research questions and usually includes includes comparison of patient characteristics (age, gender, smoking status, socio-economic status) and disease severity (FEV1%, exacerbations, quality of life, comorbidities) and retrospective cross-sectional analysis in primary care datasets from different UNLOCK countries.

The UNLOCK Group meets twice a year in person to define research questions and discuss emerging findings. In between meetings, virtual discussions take place and work is progressing using the IPCRG web platform. The work of the UNLOCK Group is supported by a researcher and a project manager.

How is UNLOCK managed?

A small UNLOCK Steering Committee oversees its work. This works within the framework of the IPCRG’s research standards and of its research needs statement and priorities. The IPCRG Board has overall responsibility for UNLOCK’s progress and performance, both financially and scientifically. The UNLOCK Group has agreed guidelines for authorship. These can be viewed at: 13-5-24 Guidelines for authorship.pdf

What type of issues does UNLOCK explore?

To date UNLOCK has used data from different countries to undertake a variety of different studies. You can read about these in the following publications:

Articles

Protocols

- Cragg L, Williams S, van der Molen T, Thomas M, Correia de Sousa J, Chavannes NH. Fostering the exchange of real-life data across different countries to answer primary care research questions: a protocol for an UNLOCK study from the IPCRG. Npj Prim Care Respir Med [Internet]. The Author(s); 2016 Sep 22;26:16048. Available from: http://dx.doi.org/10.1038/npjpcrm.2016.48

Other


What type of datasets do UNLOCK members have?

UNLOCK members have access to a range of datasets including:

- Those collected through routine primary care consultations
- Those collected as part of real-life cohort studies
- Those collected as part of pragmatic clinical trials in primary care.

Through these datasets, UNLOCK has the potential to include data from over 216,000 patients with COPD, over 800,000 patients with asthma and over 3.8 million routine primary care patients.

Data variables included in the datasets of UNLOCK members vary depending on its purpose, with some datasets being large and "shallow" and others being small and "deep". Minimum variables required for participation include: longitudinal data covering symptoms, lung function and quality of life.

Is UNLOCK open to new members?

Yes. Interested researchers are invited to join the group. A condition of membership is the ability to contribute primary care patient data on COPD and asthma which meet minimum inclusion criteria of having a funded and independent COPD and / or asthma dataset with informed consent as appropriate which includes longitudinal data and minimum variables including symptoms, lung function and quality of life.

For more information contact Liza Cragg, the UNLOCK project manager, at cragg.liza@gmail.com.

[3] Drolet, B et al. Translational research: understanding the continuum from bench to bedside