How can IMI leverage your communication?
Support for patients with respiratory diseases

13/03/2019

IMI’s PRO-active project has developed new patient-centred tools and approaches to help people with chronic obstructive respiratory disease (COPD) get more personalised treatments - a means to boost their activity levels, health and well-being.

COPD affects 1 in 10 of all people aged 50 and over and is a leading cause of death. The disease is characterised by breathlessness, coughing and often excessive mucus production, all of which make any physical activity uncomfortable and difficult for sufferers. In Europe alone, some 300,000 Europeans die each year from COPD.

Physical inactivity is a key predictor of death in patients with COPD. The IMI project PRO-active has developed new tools to help researchers and clinicians measure the impact of the disease on patients experience with physical activity and the physical difficulties patients encounter. This information can now be used to assess the impact of effective treatments on an outcome that is directly relevant to patients.

‘Lack of physical activity is an indicator of mortality,’ says project coordinator Thierry Troosters of the Katholieke Universiteit Leuven in Belgium. Patients with COPD who drop their physical activity levels are more likely to die than people who maintain these levels. We could already measure physical activity, but now we have a tool that captures how patients experience it.’

The new tools are providing doctors, nurses and other healthcare workers and researchers with unique information on the effect of treatments on their patients, he adds. They will also feed into the way new medicines and other interventions are assessed and benchmarked, based on patients’ experiences.
IMI website: project factsheet and catalogue tools

Catalogue of project tools

In order to help scientists outside of our projects in their research efforts, we have started building a catalogue of accessible tools generated by our projects. Please keep in mind that this list is not comprehensive.

If you know of a tool which should be included in this catalogue please contact us.

Summary

Although lack of physical activity is one of the most common predictors of mortality in patients with chronic obstructive respiratory disease, there are no validated tools to measure the impact of the disease on how patients experience physical activity. The PROactive project developed new, innovative patient reported outcome tools to capture both the experienced amount of physical activity and the difficulties during activity, opening the way for the development of more effective treatments. The project also developed innovative ways to enhance physical activity, both as it is objectively measured and as it is experienced by patients. Furthermore, the project succeeded in placing physical activity higher on the agendas of clinicians, patient organisations and researchers, and patients are already reaping the benefits.

Achievements & News

ProACTiVe concludes telecoaching study for COPD patients
May 2015

The ProACTiVe project has successfully concluded testing in its telecoaching study on physical activity in patients with chronic obstructive pulmonary disease (COPD).

PROactive researcher wins COPD award
September 2014

Professor Milo Puhan, a researcher from IMI’s PROactive project on chronic obstructive pulmonary disease (COPD) has been awarded the European Respiratory Society (ERS) COPD Research Award 2014.

PROactive trials for lung disease patients underway
July 2014

IMI’s PROactive project on chronic obstructive pulmonary disease (COPD) has launched a number of trials and studies using its innovative tools for accurately capturing the impact of COPD on patients’ physical activity levels.

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Horizon 2020
@EU_H2020 · Mar 7

Low physical activity levels can lead to premature deaths in lung disease sufferers
An #H2020 project has developed patient-centred tools to help people with chronic obstructive respiratory disease #COPD get + personalised treatments #EUHealthResearch

europa.eu/IpT94YM
At the end of 2018, IMI had maintained 2,398 newsletter subscribers.
IMI Events organised by IMI

- Gave the floor to 162 speakers
- Attracted over 1,060 participants from diverse audiences
External events with IMI involvement

P Stoffels slide for the BIO 2016 IMI session

IMI at ESOF 2018

IMI took part in ESOF 2018 with a session on the (re)-use of health data on Wednesday 11 July. ESOF (the EuroScience Open Forum) 2018 was held in Toulouse, France from 9 to 14 July inclusive. The IMI session was part of the Scientific Programme under the ‘Health in our societies’ theme. In addition, IMI was present at the European Commission stand in the exhibition.

IMI session: ‘My health, my data? A role-playing game surrounding the (re)-use of health data’

Wednesday 11 July 13:30-14:45
Group members reached the figure of 4,974 at the end of 2018
IMI in the media

Homepage with 25,000 unique monthly pageviews
Science|Business bi-weekly newsletters- opt-in list of 18,000
Social media promotion with total outreach of 12,000 followers
IMI next steps

- BIO two IMI sessions:
  - ‘Getting to grips with data quality issues through international neuroscience initiatives’ - IMI’s EQIPD project,
  - ‘Building a brighter future for children: How will large paediatric trial networks help to deliver safe, effective medicines - IMI’s C4C project

- Results Pack on the digital future of Brain research: EU-AIMS, PRISM and AETIONOMY

- SF 2019 on ‘Brain health and disease in the digital era - 2020 & beyond’. Several speakers from related IMI projects

- … and focus results, results, results. Help us demonstrate IMI impact!