

European study provides new insight into public interest in medicines research

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Researchers at The University of Manchester and Central Manchester University Hospitals NHS Foundation Trust (CMFT) have published data for the first time about public knowledge of and interest in the process of medicines research and development (R&D).

The study, which is part of the wider European Patients' Academy on Therapeutic Innovation (EUPATI) project, is believed to be the largest peer-reviewed survey of its kind and was published today in the *BMJ Open*.

Medicines R&D describes the entire process of bringing a new medicine to patients – from laboratory studies to clinical studies, then regulatory approval and further evaluation during clinical use.

The data, which is segmented by type of medicines R&D (e.g. safety, clinical trials, patients' roles), demographics, country, and level of previous experience in the subject area, will help to improve communications with the [public](#) about the field.

By providing an extensive insight into people's knowledge and interests, the [researchers](#) hope the data will help drive public involvement in medicines R&D, which is the main objective of the EUPATI project. Increased engagement and involvement of patients in research has been shown to increase study recruitment/retention and improve patient experience, supporting the delivery of better healthcare through the development of new diagnostics, medicines and devices. It is thought

that the information will also be useful to pharmaceutical companies wishing to involve the public in medicines research.

Dr Lode Dewulf, Chief Patient Affairs Officer at UCB, partner in the project, commented: "We need better studies to answer more relevant questions more efficiently and faster. Collaboration between study sponsors and (future and experienced) study participants is needed for this. But we often lack the required understanding to have such collaboration for all studies. Thus, this survey and its findings greatly contribute to the understanding we need."

A key finding of the EUPATI research, led by Bella Starling, Director of Public Programmes at CMFT, and Kay Warner, Focus on the Patient Manager at GlaxoSmithKline plc, is that those who had previous experience of medical research were almost five times more likely to report having good or very good knowledge of medicines R&D. People also indicated that they are keen to learn more, particularly about medicines safety (50%), and personalised and predictive medicine (47%).

"We are all potential patients," said Kathy Oliver, Co-Chair of EUPATI's Project Advisory Board and Chair of the International Brain Tumour Alliance. "This possibility emphasises the crucial need for the general public to really understand the numerous stages of medicines development and realise the complex processes that take place before a medicine is available for general use. EUPATI's newly-published paper throws a fascinating light on what people already know, and where their learning gaps are. In addition, the paper's findings are of great value to us as patient advocacy groups because they validate the need for organisations like ours to help increase [public knowledge](#) and awareness about medicines research and development."

The study which surveyed almost 7,000 people across Europe is part of

the European Patients' Academy on Therapeutic Innovation (EUPATI), a patient-led project, which involves a unique European team of academia, patient advocacy organisations and the pharmaceutical industry. EUPATI has been established to provide scientifically reliable, objective, comprehensive information to the public on the research and development process of medicines to both patients and members of the public. EUPATI is supported by the Innovative Medicines Initiative (IMI), a partnership between the European Union and the European pharmaceutical industry.

Suzanne Parsons, Health Researcher at The University of Manchester and Central Manchester University Hospitals NHS Foundation Trust and lead researcher for the study, explained: "The survey reveals that over 75 percent of respondents had no or less than good knowledge about medicines research. Previous studies have focused on public interest in clinical research, but this is the first time that medicines research has been looked at as a whole and we are able to provide a more holistic view of the subject.

"The data generated through our study will be a powerful tool for the EUPATI project and others who want to engage and involve [patients](#) and the public in a specific area of medicines research."

More information: "What the public knows and wants to know about medicines research and development: a survey of the general public in six European countries." *BMJ Open* 2015;5:e006420 [DOI: 10.1136/bmjopen-2014-006420](#)

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