# Giving patients a voice in drug development

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The patient perspective is important in all medical research, and particularly in drug development. This month, a public private research initiative called PREFER, is launched to assess when and how patient preferences on benefits and risks should be incorporated in decisions on medicinal products.

Drugs are developed for patients and there is an emerging consensus that they should be involved in determination of benefit-risk considerations during the life cycle of medicinal products. The patient voice is becoming increasingly important, not only for the companies that develop new therapies, but also for the authorities that assess, regulate and decide which drugs are effective, well tolerated and cost-effective for patients and the community.

Industry, regulatory authorities, health technology assessment bodies, reimbursement agencies and patient organisations are in agreement regarding the high value of patient preferences. However, there is little guidance on conducting and using such studies in pharmaceutical industry, regulatory and reimbursement decision environment. PREFER will provide a set of systematic methodologies and recommendations to assess, engage and include patient perspectives during the development, approval, and post-approval of new therapies.

PREFER is a five year project funded by the Innovative Medicines Initiative (IMI), to evaluate different preference elicitation methods and test them in a clinical setting.

"Almost all decisions taken in research, trials and approval somehow affect patients, which is why we involve patients directly as partners in the PREFER project. We have also created patient advisory groups to make sure the project gets input from a wider patient community," says Mats G. Hansson, Professor of Biomedical Ethics at Uppsala University's Centre for Research Ethics & Bioethics (CRB).

"We have put a lot of effort into building close collaborations between academic and industry researchers, health and technology assessment bodies, payers, regulators and patients to investigate how patient preference studies can best address everybody's needs. We believe that PREFER will provide recommendations that can support the development of guidelines for industry, regulatory authorities and HTA bodies for all medicinal products," says Conny Berlin, Global Head of Quantitative Safety and Epidemiology at Novartis Pharma AG.

PREFER will conduct patient preference studies in three disease areas where patient and clinical research partners have expertise: cancer, rheumatoid arthritis and neuromuscular disorders. Industry partners will provide additional patient preference studies, covering disease areas from their fields of expertise.

**More information:** To find out more, please visit the PREFER website: www.imi-prefer.eu/

Provided by Uppsala University

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