Inspired by patients.
Driven by science.

Patient Data for Developing Innovative and Valuable Treatments

In the past decade, there has been expansion in the range and quantity of collectible information that can inform treatments, particularly driven by digitization. This personal data may originate from patients and caregivers, healthcare providers, or others, all of which are covered by data protection laws. This growing volume of data – both produced by UCB and externally owned – drives opportunities and challenges in healthcare and has transformed the way healthcare systems approach clinical development, treatment pathways, and innovative processes. These advancements have led to new possibilities such as collecting new endpoints, conducting decentralized clinical trials, and improving diversity in clinical trial participation, benefiting patients through enhanced decision-making in clinical development and treatment.

These data are subject to strict data protection laws to protect patients, such as the European Union (EU) General Data Protection Regulation (GDPR). This essential information contributes to innovation and advancements in health products for prevention, patient care, and treatment of disease.

UCB's Values

At UCB, we value the ethical and responsible treatment of data above all else. We are a question-led company, focusing on gathering useful data to answer questions that are the most important to patients. We create a strong technology foundation that connects people, systems, and data and we build strategically to unleash the full potential of data to benefit patients and their caregivers. We believe that the responsible sharing of data from our studies can allow other qualified researchers to conduct additional research on anonymized patient-level data, contributing to medical advances and improved outcomes for patients.

UCB's Approach

At UCB, we use data analysis to generate evidence which informs better decisions for, with, and by patients and caregivers in need. While we only collect data necessary to meet each trial or study's goals, we strive to make these goals and the requisite data collection patient-oriented through inclusion of patient reported outcomes (PROs) and similar endpoints. We put strong safeguards in place to preserve privacy for patients. These include applying privacy by design principles which ensure that collection and treatment of data is lawful, fair, and transparent. We only collect and process data that is necessary for purpose and minimize further processing where possible, and we ensure that the data we use is accurate and up-to-date.

The results of our clinical studies are publicly available online via our clinical studies index. The regularly updated list discloses information regardless of study outcome or location(s) and includes

information about UCB's ongoing clinical trials. This type of information can help patients and caregivers to make better informed decisions about their current healthcare and potential treatment options and is also a way to acknowledge the people who participated in our trials.

Leveraging Data for Better Patient Outcomes

Digitalization of data provides researchers with new opportunities to leverage data science and generate valuable evidence and insights that can improve patients' lives. By harnessing the power of data, we can accelerate the process of discovering and developing medicines and better understand the patient experience of an illness or treatment, ultimately contributing to our goal of improving healthcare outcomes to patients in a timely way. UCB responsibly collects, uses, and shares data to better understand our treatments and how they impact patients' lives, as well as the lives of their carers.

Fairness and Diversity Through Data Collection

At UCB, we want to ensure participants in UCB clinical trials reflect the populations that will ultimately benefit from our medicines. As we continue to deliver value to patients, we deploy new innovations in clinical trial practices that drive the inclusion of a broader spectrum of the population, such as decentralized clinical trials (DCTs). We use supplemental Real-World Data (RWD), and the evidence generated from it, as it can be key to understanding the impact of our treatments on real-world experiences, especially in areas such as rare diseases where there are limited patient populations. We aim to collect data that enables our treatments and activities to be fairer and more diverse where we can, but we recognize that there is much more that we can do.

Data Sharing

Sharing clinical trial data with other researchers and stakeholders such as patient communities, when done in a responsible way with strong safeguards in place to preserve privacy for patients can lead to scientific advances, uncover new discoveries and treatments, and ultimately benefit patients. At UCB, we see our work in this area as part of a broad trend towards maximizing openness. We comply with data protection regulations and ensure that anyone we share data with respects the same standards.

UCB participates in global data sharing initiatives to support the wider research community to advance science, such as DataCelerate and Vivli, leading to new discoveries and treatments.

Our Commitments

UCB follows standards set by pharmaceutical industry associations in the European Union and United States including:

- Principles for Responsible Clinical Trial Data Sharing from the European Federation of Pharmaceutical Industries and Associations & Pharmaceutical Research and Manufacturers of America (**EFPIA/PhRMA**) and International Federation of Pharmaceutical Manufacturers & Associations (**IFPMA**)
- **Good Publication Practice**
- **Recommendations of the International Committee of Medical Journal Editors**
- **Recommendations from the Joint International Society Pharmacoeconomics and Outcomes Research (ISPOR)-International Society for Pharmacoepidemiology (ISPE) Special Task Force** on Real-World Evidence in Health Care Decision Making