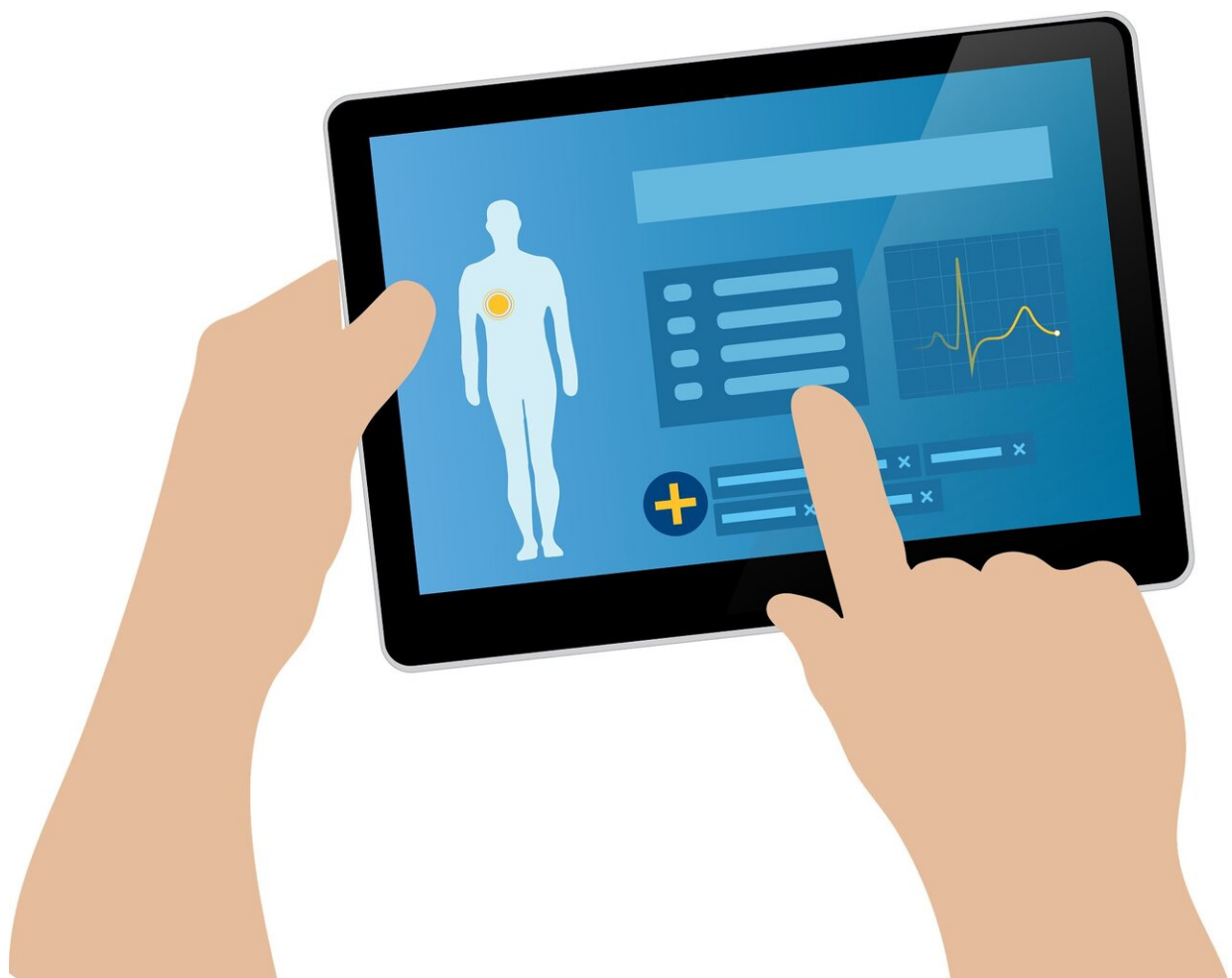


# Long-term collection of patient-reported outcome data in oncology trials: Important and feasible

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Patient-reported outcome (PRO) data are collected in oncology trials to determine patients' perspectives of cancer treatment—unfortunately often too briefly, for example only up to the point when an X-ray shows tumor growth and treatment is discontinued. As a result, it is not possible, for example, to reliably assess the impact on patients' lives of disease progression seen on X-rays or the long-term side effects of cancer treatment.

The reasons given for this are organizational difficulties or patients' lack of interest in long-term follow-up. But is this really the case?

These and similar questions were discussed at a roundtable in 2020 that brought together 16 stakeholders from academia, [clinical practice](#), patient representatives, international regulatory agencies, HTA bodies, and the pharmaceutical industry. The German Institute for Quality and Efficiency in Health Care (IQWiG) was represented by Beate Wieseler, Head of the Drug Assessment Department. The results have now been published in a scientific journal.

## **A clear plan and good explanations needed**

All parties agreed that it is important to understand the long-term effects of treatments on patients in [clinical trials](#)—even after treatment has been discontinued. This information is important for decisions by regulators, payers, physicians and patients.

To make the best use of PRO data collected after the study treatment has ended, clinical trial sponsors must define clear research questions before [data collection](#) begins. Anything less is unethical and a waste of resources and patients' valuable time.

According to patient representatives, patients are willing to invest time in the collection of PRO data if it is made clear why their input is valuable.

This shows that the long-term collection of such data is not an unrealistic academic pipe dream, but is feasible with good planning—and not at all against the interests of patients.

The work is published in the journal *Value in Health*.

**More information:** Bellinda L. King-Kallimanis et al, Perspectives on Patient-Reported Outcome Data After Treatment Discontinuation in Cancer Clinical Trials, *Value in Health* (2023). [DOI: 10.1016/j.jval.2023.06.019](https://doi.org/10.1016/j.jval.2023.06.019)

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