“The key is professional, full-time coordination”



In the interview: Stefanie Frenz (left), spokesperson for the WTZ Patient Advisory Board and patient representative for “breast cancer” and “melanoma”, and Dr Maria Josten, Patient Engagement at the West German Tumour Centre (WTZ) in Essen.

© HEI_UKM

Stefanie Frenz, spokesperson for the WTZ Patient Advisory Board and patient representative for “breast cancer” and “melanoma”, and Dr Maria Josten, Patient Engagement at the West German Tumour Centre (WTZ) Essen and Patient Coordinator at NCT West, share their views with “Monitor Versorgungsforschung” on the work of the Patient Council in light of the current Medical Research Act. Stefanie Frenz emphasises that “working together as equals to improve the quality of individual patient care and clinical trials” is the stated common goal. A key factor in this is professional, full-time coordination between patients and researchers.

>> Patient involvement is not yet a matter of course in Germany. Section 140f of the German Social Code, Book V (SGB V) provides for structural participation, such as the right of patient representatives to be consulted (without voting rights) in the Joint Federal Committee. However, patient involvement is not the focus of the Medical Research Act, which came into force at the end of 2024; during the debate on the Act, some critics argued that patient involvement in digital research had remained a ‘blind spot’. What is the

current

status?

Frenz: The studies and projects in which we are currently involved as a patient advisory board began years ago. In that respect, the impact of the Medical Research Act is not yet particularly obvious or practically noticeable for us.

Josten: It is good that the Act creates a structural basis for participation, even if this certainly needs to be developed more consistently. From discussions with colleagues at the hospital, I have gathered that the acceleration of the approval process enabled by the Act does indeed allow studies to start noticeably sooner. Particularly in view of the rapid developments in digital research, this is an important first step. I think the next four to five years will show whether this will also lead to a shorter overall duration of studies.

Nevertheless, the current Medical Research Act provides for approaches that are also in the interests of patients, for instance by optimising the feasibility of clinical trials (for example through provisions in Section 42e on academic research), which is intended to facilitate the conduct of clinical trials. Were there any reservations from the research community at the outset? How has acceptance changed and developed, if at all?

Josten: There were no noticeable reservations; quite the opposite. The integration of patients' experiences of illness and a practical focus, as well as study design based on patients' needs, ultimately lead to optimised patient involvement. In two respects: on the one hand, recruitment becomes easier. On the other hand, patient adherence and compliance are increased. Both are very much in the interests of researchers. When patients and doctors see themselves as a team from the outset and work together as equals to pursue the goal of improving quality in the medical research landscape, this also creates added value. In the long term

,

the whole of Germany as a research hub could even benefit from this.

"Working together as equals to improve the quality of individual patient care and of studies. That is the declared common goal."

Stefanie Frenz, spokesperson for the WTZ Patient Advisory Board

. Laypeople and experts are supposed – at least in theory – to exchange views on medical issues for studies. In a sense, this brings two worlds together. How can we balance the different perspectives on research and its objectives, as well as differing levels of experience and knowledge?

Frenz: It takes time and structures to enable an exchange on equal terms. We try to break down barriers through clearly defined procedures and processes designed to ensure transparency and trust.

Josten: I see breaking down reservations and uncertainty on both sides as one of the central tasks in my role as coordinator. Patients are allowed to ask questions that would otherwise not be asked in scientific discourse. This can sometimes be disruptive to the system at first, but it is always helpful in the end. I try to encourage patients to do so. At the same time, researchers often feel uncertain about how and with what expectations they can approach patients.

And what is the reality? At the West German Cancer Centre of Essen University Hospital, for example, a patient advisory board has been working closely with researchers and clinical teams since 2020. How did the advisory board come to be established? What goals have been pursued jointly since then?

Frenz: To work together as equals to improve the quality of individual patient care and clinical trials. That is the stated shared goal. And this goes far beyond the involvement of self-help groups. For instance, the experiences and needs of the patient advisory board are already incorporated into study planning, and it checks study documents for clarity, for example.

Josten: As early as ten years ago, patient representatives were appointed to the board of the West German Cancer Centre (WTZ) on an equal footing for the first time. The aim was to improve the patient experience surrounding the disease. Inspired by experiences from visits to American cancer centres, it was then decided to further develop the concept. Patient representatives with different disease backgrounds were invited to establish the Patient Advisory Board, and at the same time, professional contacts with experience of cancer were appointed.

How exactly does this collaboration work? Are there clearly defined processes for this?

Josten: We have developed a procedural model in the style of a classic Standard Operating Procedure (SOP). It has been in force since 2024 and governs the early incorporation of the patient perspective into the development of clinical trials, thereby ensuring trust and confidence – among patients and researchers alike. This procedural model ensures that the Patient Advisory Board provides input from the outset

.

This may

include

relevant questions regarding

quality of life and the acceptance of new procedures. But the management of side effects is also an important issue that we address.

Frenz: The SOP stipulates that, as a first step, the Patient Advisory Board must receive a brief description of each research project, including a specific research question. As a second step, the Board is obliged to offer a meeting within 20 days. It may then decide on the extent of the collaboration. Regardless of the outcome of this decision, the researchers are in turn obliged to provide ongoing updates on the study's progress and ultimately to deliver a brief summary of the results that is accessible to the general public.

"The participation formats still need to be

further

developed."

Dr Maria Josten, Patient Participation at the WTZ Essen and

Patient

Coordinator at NCT West

. Making patient involvement part of medical training would certainly break down barriers in this regard, but also in terms of the general approach to patient representatives in a scientific context.

Are there practical examples of how the Patient Advisory Board actually influences research? For instance, research questions or study designs that might not otherwise have existed?

Josten: Through direct feedback from the patients' perspective, research can address more relevant questions, such as those concerning quality of life, the management of side effects, or the acceptance of new procedures, as well as – very importantly – prioritisation

. How can different patient groups be represented – for example, by age, social background or clinical presentation?

Josten: I currently still see this as a weak point. At present, the educational level of patients who actively participate is still above average, and certain clinical conditions are also represented more frequently than others. That needs to change in future. In fact, everyone should have the opportunity to participate, and that shouldn't even be up for debate. We still have a long way to go.

Frenz: For me personally, for example, medical English is a challenge. We are trying to break down barriers and support and encourage patients through appropriate training programmes and regular interaction with one another. In our view, collaborative learning, respect and structured cooperation form the basis of patient-centred cancer research.

Communication on an equal footing requires specific skills on both sides. How can these be ensured?

Frenz: This is a crucial point for us as patients, as concerns about a lack of specialist expertise deter many from actively engaging in research. To be able to communicate on an equal footing with researchers, we as laypeople need additional skills, for example in clinical research, study design and medical terminology. We teach these basic skills in our Patient Expert Academy (PEAK) at NCT level.

Josten: Yes, particularly when it comes to technical terminology, we need to understand endpoints such as progression-free survival.



Stefanie Frenz *is spokesperson for the WTZ Patient Advisory Board, a lawyer and patient representative for metastatic breast cancer and melanoma. Among other things, she is involved with the Women's Cancer Self-Help Group and Melanom Info Deutschland.*



Dr Maria Josten *is a physiotherapist and a biologist with a PhD and a background in clinical research. She currently coordinates patient involvement, advisory boards and self-help groups at the WTZ and NCT. Previously, she managed clinical trials.*

In which areas of the healthcare system is the patient perspective still particularly lacking?

Frenz: Research generally focuses on new drugs, the applications of active substances or treatment regimens. There are still too few studies dealing with the long-term effects of cancer and long-term survival. How does the disease affect those affected and their families? What happens in particular when a child or teenager develops cancer? What impact does this have on later life? Questions such as these, which concern both the physical and psychological as well as social side effects and long-term consequences, are still not sufficiently addressed in Germany. Currently,

after five relapse-free years, one is simply considered healthy.

Josten: I would like to add that there is also potential for optimising procedures and processes to reduce additional stress during the already very challenging period of treatment. Can one or two additional blood tests or examinations be avoided? Does every doctor's appointment have to take place in person, or is a phone call or video conference sufficient? These are all issues that affect quality of life during treatment, which plays a very important role for patients.

What advice would you give to organisations looking to set up a patient advisory board for the first time?

Frenz: In my view, professional, full-time coordination between patients and researchers is a key factor in the success of the patient involvement concept. In addition, clearly defined procedures and processes for communication are needed.

Where do you currently see the greatest challenges regarding patient involvement in Germany?

Josten: We are still not managing to adequately reflect the diversity of patients so that different experiences and needs can be taken into account. The participation formats therefore need to be further developed.

Frenz: In a way, this is also about a cultural shift, and as we know, that takes time above all else. Patient involvement has already developed significantly in recent years, but structural challenges remain. For example, we are currently involving patients on a voluntary basis. This means we have to manage our resources extremely carefully. Not all patients are able to commit to a project over several years due to their illness. The level of patient involvement also varies greatly depending on the region.

Thank you very much for the interview. <<

The interview was conducted by MVF Editor-in-Chief Peter Stegmaier.

New guidance service from Thieme TeleCare

>> For many patients, a particularly sensitive phase begins after a hospital stay for depression: the period leading up to outpatient follow-up treatment. It often takes several months even today to find a therapy place – recent decisions to reduce fees for outpatient therapies, which came into force recently, could extend this period even further. However, during this gap in care, the risk of relapse increases significantly. Hybrid aftercare services combining personal psychological support with digital assistance can help stabilise patients during this period. This is because those affected wait an average of around 20 weeks for further outpatient treatment. As reimbursement for psychotherapeutic services is set to be reduced by 4.5 per cent from 1 April 2026, there is also a fear that it will now become even more difficult for those with statutory health insurance to secure an outpatient therapy place. "The period following discharge is a critical juncture," says Wolfgang Weber, Senior Vice President at Thieme TeleCare. "If patients are left on their own during this phase, the likelihood of them needing to be readmitted for inpatient treatment increases."

This is precisely where Thieme TeleCare's hybrid aftercare programme comes in: following discharge, patients are assigned a dedicated,

psychologically trained health coach who provides regular telephone support for up to 12 months. The approach follows a clear guiding principle: to place patients more firmly at the centre of care and support them in actively managing their own health.

“Many patients initially feel overwhelmed after discharge,” says psychologist and Thieme health coach Franziska Köhnecke. “Together, we look at specific everyday situations and strengthen their ability to take early countermeasures.” The conversations are not about therapy in the strict sense. They are about everyday life, about situations that can take a turn for the worse. About early warning signs. About concrete steps to take when their mood starts to slip again. In addition, participants use the Thieme TeleCoach app, which features structured health pathways, exercises and clearly presented information. They can monitor symptoms, track their progress and receive practical tips for everyday life. An AI-supported feature also provides quick and reliable answers to individual questions based on medically verified content.

Evaluations show that participants in such programmes report a better quality of life and fewer depressive symptoms. At the same time, the likelihood of further hospital admissions drops significantly. This also has economic implications: if relapses are prevented and costly readmissions avoided, expenditure within the healthcare system falls noticeably. “This takes the strain off not only hospitals, but also payers and healthcare structures as a whole,” says Weber. So far, however, such services are not available nationwide and are only regulated through selective contracts with individual health insurance funds. <<

Citation

Frenz, S., Josten, M., Stegmaier, P.: “The key is professional, full-time coordination”, in “Monitor Versorgungsforschung” (03/26), pp. 42–45. http://doi.org/10.24945/MVF.03.26.1866-0533.2830

Literature:

Long waiting times: Health insurers call for centralised appointment booking for psychotherapy | G+G Accessed: 26 February 2026 https://hohpublica.uni-hohenheim.de/items/3c0f921c-0e4e-41fb-b95c-88eba3a9a789 Accessed: 26 February 2026