



# Giving Patients a Voice

10 years of patient representation  
in the Federal Joint Committee

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Patient involvement specialist team of the G-BA

## Our voice for better healthcare

» Germany has one of the best, if not the best, healthcare system in the world. But there's still a lot that can be improved: the system is burdened by oversupply, undersupply, and inappropriate care. Inequality in the allocation of services is a real issue.

Patient representation was established on 1 January 2004 to give the more than 70 million members of the statutory health insurance funds in Germany a voice in the decision processes of the Federal Joint Committee. Its legal foundation is section 140f, paragraph 2 of the German Social Code, Book Five.

The Federal Joint Committee (Gemeinsamer Bundesausschuss or G-BA) is the highest decision-making body of the joint self-government of physicians, dentists, psychotherapists, hospitals, and health insurance funds in Germany. It defines the healthcare services offered to persons insured under statutory health insurance (SHI) in Germany, and sets quality assurance standards for inpatient and outpatient care.

Around 250 competent persons from nationally recognized patient organizations serve as patient representatives in G-BA sessions, taking part in discussions and exercising the right of these organizations to submit petitions. They represent the interests of patients as well as chronically ill and disabled persons on a federal level.

## The value of experience

As committed members of a wide range of different patient and self-help organizations, the patient representatives have extensive knowledge in their respective fields. Some of them are affected directly by a particular illness, either personally or in their families. Others have expertise in healthcare systems or specialty fields. They work together to combine their knowledge and develop strategies for their work on the G-BA committees.

It's not always easy to reach workable solutions in the G-BA. Sometimes there is a gap between patient needs and scientific study results, or between the law and everyday reality in healthcare. And beyond finding facts and defining solutions, it's also important to balance financial, professional, and political interests. Some compromises seem fair, others feeble. But the patient representatives always try to strike a balance between individual interests and responsibility for the overall system.

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## We're here for everyone

The patient representatives are familiar with nearly every disease and treatment imaginable. Asthma, diabetes, psoriasis, high blood pressure, rheumatism, cancer, pain, epilepsy, thyroid diseases, gastrointestinal disorders, macula degeneration, cystic fibrosis, thrombosis, stroke, osteoporosis, hepatitis C, HIV, depression, Alzheimer's disease, Parkinson's disease, tuberculosis, multiple sclerosis – those are just a few of the syndromes we confront in our everyday work.

The various subcommittees focus on the issues faced by people and families grappling with these diseases. The G-BA assesses medicinal products, evaluates new examination and treatment methods, and looks into assistive technologies, remedies, and sociotherapy. It also

focuses on medical needs planning, disease management programmes, specialized outpatient care, quality assurance, psychotherapy, and health-care provision by contracted physicians.

On every G-BA committee, we advocate the needs and demands of patients.

» Is there anything that hasn't come up in the pharmaceuticals subcommittee? Probably not. We're involved in every issue imaginable.«

## 10 years of ongoing growth

» We'll never forget that first meeting back in Siegburg in western Germany. Completely unprepared and without even understanding what types of people, institutions, and processes we would encounter, the patient representatives made their way to the meeting room. When we arrived, the meeting was already in full swing – without us. Not a chair was empty. Nobody was waiting for us with bated breath. And we had the distinct feeling that we were in the way. [...] Now, 10 years later, we can laugh about that.

Patient involvement in the G-BA would never have been possible without the self-help movement that started in Germany in the 1970s. Then in 2003, the SHI Modernization Act laid the foundation for patient involvement, and a new board for joint self-government was born: the Federal Joint Committee, or G-BA. The G-BA was also commissioned to involve persons insured under SHI closely in its decision-making processes, and thereby ensure that the decisions it takes have grassroots support. Relevant organizations that represent the interests of patients and chronically ill or disabled persons in Germany were therefore given the right to take part in discussions and submit petitions in the G-BA.

The right to submit petitions gives patient and self-help organizations influence in recognizing new examination and treatment methods, and in adding new medical techniques to the catalogue of services paid for under SHI.

## A dedicated, competent network -

In that first year, a small number of patient representatives faced a much larger number of committees and boards. But as the number of patient representatives grew, the importance of patient representation has changed as well. Over the past ten years, it has evolved from a rather passive commentator to a full stakeholder. Better communication amongst one another, targeted planning and coordination meetings, and the possibility to contract expert opinions all make the work of the patient representative more organized, efficient, and competent.



An important milestone in achieving more influence was the passage of the Act to Enhance Competition in Statutory Health Insurance on 26 March 2007. It obliges the G-BA to support patient organizations in exercising their rights of involvement, and marked the launch of the patient involvement specialist team. Its members are responsible for supporting patient representatives in exercising their rights to take part in discussions and submit petitions (German Social Code, Book Five, section 140f, paragraph 6).

The specialist team also organizes numerous seminars and training sessions on topics such as pharmaceutical and methods assessment, quality assurance procedures, needs planning, and the principles of evidence-based medicine. These empower patient representatives to become familiar with G-BA processes and thus strengthen their influence.

*Public meeting of the G-BA plenum with patient representatives*



## Our work makes a difference

» We're the ones (and often the only ones) who know what the healthcare situation is really like in real life. That is apparent over and over again. That's what makes us strong!

Through dedication, hard work, and perseverance, the patient representatives have been able to achieve significant improvements in the healthcare situation in Germany over the past ten years. They also work to prevent any negative impact of decisions on patients. Their real-life experience enables them to understand what effect a directive will have on patient care.

But often their suggestions and petitions are ignored, even though they are backed up by solid reasoning, facts, experience, and expert opinions. Patient representatives often feel that negotiations are not conducted in an appropriate manner, or that important findings are not applied to improve the healthcare situation for patients. And if they are, it usually takes far too long before these improvements are incorporated into G-BA directives – and even longer before patients begin to benefit from them.

This is where we want to see real change, and are working to achieve that.

### **Success comes in small, incremental steps. Here are a few we have achieved for patients across Germany:**

- The right to assisted reproductive technology for couples affected by HIV
- Better availability of bone density measurement as an SHI benefit
- Barrier-free access as a topic in hospital quality reports and the Needs Planning Directive
- Successful petition on off-label use
- Outpatient nursing in day or night facilities
- Provision of remedies in day facilities for children and adolescents with severe, long-term disabilities
- The right of patient representatives to take part in discussions on state-level quality assurance committees
- MRSA decontamination in outpatient nursing



- Quality improvements in the care of newborns and premature infants
- Quality assurance in cardiac surgical care for children and adolescents
- Subcutaneous infusions for the treatment of exsiccosis in outpatient nursing
- Improvements in access to psychotherapy for children and adolescents as part of needs planning

**Ongoing proceedings we've initiated in the G-BA:**

- Liposuction for lipoedema
- Pulse oximetry screening for severe congenital heart defects
- Systematic treatment for periodontopathy
- Ultrasound screening for abdominal aortic aneurysms

» Sometimes what we hear is almost Orwellian Newspeak, for example when cutting benefits is referred to as “needs planning”.«

## Our voice is growing stronger

» Ten years down the road, patient involvement has become a trusted “brand” that stands for competence, experience, and insight into the needs of patients.

We’re dedicated to ensuring that people have access to patient-oriented care that is as safe and effective as possible. That includes strengthening the roles of narrative medicine and of effective, patient-based quality assurance. We want to achieve better healthcare and reduce unnecessary suffering for patients in Germany.

We are working towards a healthcare system that ensures inclusive, barrier-free, and equal access for everyone in all areas – including the right to choose treatments and caregivers, and to receive medical information and communication in a form that is understandable for laypeople. Our goal is a healthcare system that truly focuses on the patient.

Most of our work is done by volunteers, many of whom are themselves affected by disease. That means that the resources we have to achieve our goals can in no way compare to those of the member organizations of the G-BA.

### **To enable us to achieve our targets, we call for:**

- Ongoing improvement of patient representative resources and infrastructure
- More rights for patient representatives, including voting rights in G-BA proceedings and the right to receive a written justification if a petition is rejected
- Better patient representative resources and infrastructure at the state level

» Progress moves at a snail’s pace in the G-BA as well. «

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## We have a say

- » We aim to achieve clear public recognition and the acceptance of our suggestions and reasoning so that a serious discussion takes place. We also want less bureaucracy and more flexibility!

Patient representation is a successful form of citizens' involvement. The approach of sending representative from "below" instead of appointing them from "above" has also garnered international acclaim.

The respective patient and self-help organizations mutually appoint competent persons as patient representatives to take part in G-BA discussions. This is a legal mandate in accordance with SGB V, section 140f.

The patient and self-help organizations have agreed on nomination criteria to ensure that nomination is conducted mutually. These criteria relate to the representatives themselves and to the organizations they come from. The goal is to ensure patient involvement in the G-BA that is unified and transparent. Appointments can be made for committees and agenda items.

## Who appoints patient representatives?

The following patient and self-help organizations are currently entitled to appoint patient representatives to the G-BA:

**The German Council of People with Disabilities  
(Deutscher Behindertenrat, DBR)**

Contact: c/o Sozialverband Deutschland e.V.,  
Stralauer Strasse 63, 10179 Berlin, Germany  
[www.deutscher-behindertenrat.de](http://www.deutscher-behindertenrat.de)

**The Federal Syndicate of Patient Interest Groups  
(Bundesarbeitsgemeinschaft der PatientInnenstellen, BAGP)**

Contact: Gesundheitsladen München e.V.,  
Walterstrasse 16a, 80337 Munich, Germany  
[www.gesundheits.de/bagp/](http://www.gesundheits.de/bagp/)

**The German Syndicate of Self-Help Groups  
(Deutsche Arbeitsgemeinschaft Selbsthilfegruppen e.V., DAG SHG)**

Contact: NAKOS,  
Otto-Suhr-Allee 115, 10585 Berlin, Germany  
[www.dag-shg.de](http://www.dag-shg.de)

**The Federation of German Consumer Organizations  
(Verbraucherzentrale Bundesverband e.V., vzbv)**

Contact: Markgrafenstrasse 66, 10969 Berlin, Germany  
[www.vzbv.de](http://www.vzbv.de)

These organizations have formed a joint committee that coordinates the work of the patient representatives. Representatives of the relevant patient organizations are members of this coordination committee.

You can find more information on the members of the coordination committee and the patient representative spokespersons at:  
[www.g-ba.de/institution/struktur/patientenbeteiligung/](http://www.g-ba.de/institution/struktur/patientenbeteiligung/)

## The legal basis of our work

Regarding participation in discussions, SGB V, section 140f, paragraph 2 says:

- this right to represent the interests of patients and the self-help for chronically ill and disabled persons is granted to relevant organizations on a federal level;
- it shall be exercised by competent persons (patient representatives);
- the competent persons shall be mutually appointed by those patient and self-help organizations recognized by the patient involvement regulations according to SGB V, section 140g.

Regarding the right to submit petitions, SGB V, section 140f, paragraph 2 says furthermore:

- this right is granted to patient and self-help organizations recognized by the regulations according to SGB V, section 140g;
- this right applies in particular to all directive resolutions of the G-BA.

*First general assembly of the patient representatives*





# The mission of the patient representatives in the Federal Joint Committee (G-BA)

Drafted at the first general assembly of the patient representatives on 7 and 8 June 2013

## I. Purpose

We are a strong community that represents the interests of patients. We represent the full diversity of patients in Germany, whether acutely or chronically ill, mildly or severely handicapped, young or old.

As experts with individual and collective knowledge from experience, we contribute our competence to the consultations of the G-BA and its committees. We see ourselves as the link between the G-BA and the everyday lives of those affected by disease. As consultants and persons directly affected, we are independent of the interests of care providers, statutory health insurance funds, industry, and politics otherwise represented in the G-BA. We are committed solely to the interests of persons affected by disease, and do not allow ourselves to be exploited for other interests.

We are the counterbalance to the other stakeholders in the G-BA. And as the voice for patients, we are indispensable in the healthcare sector.

We make sure that patients are taken seriously at the G-BA and in healthcare delivery.

We're assertive in pursuing patient interests in public policy and in the G-BA. We are persistent in exposing weaknesses in the provision of medical care, and call attention to shortcomings in order to improve the quality of patient care and achieve transparency.

## II. Principles

Our aim is to improve medical safety for patients, and to achieve a healthcare system that continually increases its usefulness for patients in terms of longevity, alleviation of symptoms, and quality of life. We use the best available knowledge, including the individual experience of those affected. We're dedicated to increasing knowledge about good, safe healthcare. The methods of evidence-based medicine help us to examine the reliability of our knowledge about the safety and benefit of treatment methods.

Patient representation is a team effort. Our guiding principles are cooperation,

solidarity, respect, openness, objectivity, transparency, conflict management, consensus, and exchange of knowledge. The interests of patients take precedence over those of associations.

### III. Cooperation

We have organizational structures and workflows that are dependable and ensure a proper flow of information among the representatives.

We provide ongoing induction for new patient representatives and continually expand our own knowledge through training and seminars.

We strive to achieve consensus among the patient representatives. If that is not possible, differing viewpoints shall be communicated respectfully and documented appropriately.

### IV. Aims

As the patient representatives in the Federal Joint Committee, we're dedicated to ensuring that people have access to patient-oriented care that is as safe and effective as possible. That includes strengthening the roles of narrative medicine and of effective, patient-based quality assurance. We want to achieve

better healthcare and reduce unnecessary suffering for patients in Germany.

We are working towards a healthcare system that ensures inclusive, barrier-free, and equal access for everyone in all areas – including the right to choose treatments and caregivers, and to receive medical information and communication in a form that is understandable for laypeople. We promote independent, transparent research that is focused exclusively on patient benefit and that aims to find answers to pressing questions.

We want to achieve better transparency in our own work and greater relevance in public affairs. In G-BA consultations and outside the G-BA, we want to be known as the voice of patients. That requires adequate financial and staffing resources. Our goal is a healthcare system that truly focuses on the patient.

## The patient representatives in the Federal Joint Committee



Deutsche  
Arbeitsgemeinschaft  
Selbsthilfegruppen e.V.



**BAGP**  
BundesArbeits-  
Gemeinschaft der  
PatientInnenstellen  
und -Initiativen

**verbraucherzentrale**  
*Bundesverband*



Deutscher  
Behindertenrat