

Implications of the SARS-CoV-2 pandemic from the perspective of patients, doctors, nursing professionals and scientists

Lessons learned from the pandemic



Lessons learned from the pandemic it's time for change!



Our healthcare system is facing significant challenges. In a field of tension between medical progress, demographic development, and digital transformation, it is essential to ensure high-quality long-term healthcare.

#### Framework conditions:

cohesion.

# Our healthcare system in the 21st century - Opportunities and risks

Our healthcare system is facing significant challenges. In a field of tension between medical progress, demographic development, and digital transformation, it is essential to ensure high-quality long-term healthcare.

The development of a healthcare system that is based on medical progress and at the same time socially fair and economic efficient is one of the greatest challenges of our time. A healthcare system that on the one hand enables broad access to resources and innovations and remains affordable for individuals and for the society is one of the most important foundations for social

In medicine and nursing today, there is unprecedented potential to achieve better precision in diagnostics, therapy and especially in prevention, due to the dynamics of technological developments, research, and the possibilities to collect and analyze large amounts of data. The use of big data should be able to take place with

the patient consent, in compliance with data protection regulations, so that the use of data for the individual and the common good is not prevented. There is a great patients' willingness to use this potential.

At the same time, patients – although rightly -criticize an unequal access to the medical services and a medical progress in Germany that reaches people only with a considerable delay. In addition, the focus of the healthcare system in Germany is on the care of the seriously and chronically ill and the medium- and long-term prevention opportunities are missing.

#### Reform proposals from the patient's perspective:

# The "Roadmap for a for a future-proof healthcare system" from the Pfizer Patient Dialogue

For many years, the research-based pharmaceutical company Pfizer has been engaged in a productive and innovative exchange with patients and patient organizations within the framework of the Pfizer Patient Dialogue. The focus of the exchange is on current topics and issues in health, research, and care.

The patients' wish was appreciated and supported to not only develop health information together in a patient-oriented way, but also to address the political framework together with many experts from medicine, nursing, science, and politics. Thus, the Pfizer Patient Dialogue resulted in the "Roadmap for a for a future-proof healthcare system" with 10 contributions to reforms in healthcare.

The Roadmap brings together the complex knowledge of experts from medicine, nursing, health policy and patient work. These contributions explain which changes and improvements in the healthcare system are necessary and possible. They are not theoretical ideas, but concrete recommendations for action. Central concerns include promoting doctor-patient communication, improving health literacy, better working conditions for nursing professionals, better coordination of the sectors of the healthcare system, improve access to medical care with shorter waiting times, strengthening patient participation in the healthcare system, and digital transformation with patient orientation.

#### Common goals:

#### From Roadmap to White Paper

Central ideas and concerns from the Roadmap have been incorporated into this "White Paper for a Sustainable Healthcare System". In addition, the contents of the Roadmap were discussed and further developed in form of a digital patient convent with representatives from medicine and science. The compatibility of the approaches from patient work, medicine and science led to the commitment to pursue a joint approach and to formulate corresponding recommendations for action in this white paper.

Also, a so-called "Innovation Challenge" was used to create an additional opinion, focusing on the perspective of the younger generation. Within the framework of

the Innovation Challenge, teams of students were called to develop their own proposals and approaches for reforms of the healthcare system that from their perspective were necessary. The submissions of the Innovation Challenge clearly show that the topic of a sustainable and patient-oriented healthcare system is also supported by the younger generation. The high interest of the students has also shown that especially young adults are open towards involvement in the integrative process of establishing a sustainable healthcare system and that many young adults demand better participation opportunities in the health policy which also include informed decision making, health advocacy, policy development and implementation and evaluation of services.

#### SARS-CoV-2 pandemic:

#### Health becomes top issue on the political agenda

The SARS-CoV-2 pandemic has immediately brought the importance of health for society and for each individual into focus. At the same time, like a burning glass, the pandemic has highlighted the challenges that a sustainable healthcare system must overcome and the areas of the system that need improvements. The current pandemic challenges our healthcare system in an unprecedented way to become more robust, flexible, innovative and adaptable even in crisis situations, and thus also offers an opportunity for a positive further development of the system.

The fight against the SARS-CoV-2 pandemic has made it clear that there is a fundamental solidarity for vulnerable groups in society, which must be upheld while respecting their sovereignty.

The efforts to overcome the crisis, which will probably accompany us for a longer period, has shown that communication, transparent dialogue also in controversial points, and the cooperation of many committed people are key factors to succeed.

For the further development of the healthcare system, the continuous dialogue of all stakeholders is essential, whereby the patients as those affected and the citizens as potentially affected are the most important stakeholders. However, in the German healthcare system and also at the European level, the perspective of the patients is not sufficiently reflected and not taken into account in the developments of the healthcare system. Although the German healthcare system has proven its resilience quite well in the pandemic, it still needs to be strengthened. This means much more than improving and specifying crisis plans and processes. The continuous further development of the German healthcare system is crucial to provide a high-performing and at the same time patient -oriented healthcare system that is better prepared for future crises against the background of constantly changing framework conditions for all people.

THIS PROCESS RAISES ESSENTIAL QUESTIONS:

- » What reforms are needed in the healthcare system to strengthen its sustainably?
- » What new alliances of stakeholders in the healthcare system are needed to implement reforms?
- » What is the role of progress in medicine and nursing and the digital transformation?
- » How can sustainable solutions be found that better meet the concrete needs of patients and care recipients?
- » How can a staged regional and supra-regional care be established, that uses the available resources efficiently and in a patient-oriented manner?

#### Patient orientation:

#### central guideline for reforms

Patient orientation must be guaranteed when formulating recommendations for action for improvements in the healthcare system. The "patient centricity" must not be a phrase in health policy discourse, but it must be a consistent procedural model and integrate patients' perspective. The perspective of relatives who take on supportive and caring tasks must also be considered.

The perspective of patients and / or care recipients must play a more important role in the discussion and implementation of main future issues in the healthcare system in the future. Therefore, we need a democratization of the healthcare system and better participation opportunities for patients. A systemic approach in the development of care, research and innovation is necessary for patients and civil society. In the German healthcare system, there is not a lack of knowledge, but a lack of action or implementation. Therefore, new alliances among science, clinical medicine, care, and patients are needed.

Patients' rights are citizens' rights. Not the profit but the patient and social cohesion must be the starting point and focus for any further development of the healthcare system.

It is particularly important to improve access to needsbased and comprehensive medical and/or nursing care. Medical professionals report from practice that patients in our open and diversified healthcare system often worry that they will not be able to receive the most appropriate care either by chance or due to system shortages. This uncertainty results into a parallel and often redundant claim of available resources (e.g. multiple diagnostics with different imaging procedures). The other reason is also an unbalanced regional distribution of care. For some time now, there have been various efforts and measures to improve medical care services in structurally weak areas, e.g. in rural areas, or in areas with special needs, e.g. demographic change. This awakes an urgent need to develop a strong structural concept for multitiered medical care in Germany.

Patients address the following shortcomings: Long waiting times for appointments in specialized medical care with the consequence of repeated diagnostic and therapeutic measures that do not lead to the goal, contradictory prognostic assessments and avoidable emergency situations or wrong treatments in an emergency situation or in the case of a complex disease, as well as insufficient staffing in hospitals and care facilities. The pandemic acts as an amplifier of many problems by reducing resources for non-acute events.

#### For a sustainable healthcare system:

#### recommendations for action

On the way to a sustainable healthcare system, the following goals and measures have a high priority. When implementing measures, it is particularly important to take the patient perspective into account, to actively involve patients in the relevant processes and to improve the opportunities for patient participation.

#### THE RECOMMENDATIONS FOR ACTION ARE THEREFORE:

- » Improve access to specialist and specialized care. (p. 10)
- » Improve patient care through cross-sector coordination (p. 11)
- » Regional structuring of emergency care with the participation of university medicine (p. 12)
- » Recognise trustful communication between doctors, patients, nurses and care recipients as the most important pillar of medical care. (p. 13)
- » Not only talk about digitalization, but also implement it (p. 14)
- » Improve framework conditions for the provision of nursing care (p. 15)
- » Make financing more needs-based (p. 16)

# Improve access to specialist and specialized care

Despite existing resources, patient care in the German healthcare system shows surmountable hurdles and regional deficits.

- » Reduction of waiting times through:
  - Promoting awareness and efficiency of the already existing appointment service centers
  - Doctor-led or trainee-led coordination of specialist consultation requests
  - Best practice orientation: for instance, A- /B-referral procedure of the Association of Statutory Health Insurance (KV)Mecklenburg-Western Pomerania
- » Simplification of appointment allocation by practices (through online services with standardized questions on anamnesis/symptoms, use of software solutions).
- » Improve care routines in the outpatient and inpatient sectors to reduce waiting times in doctors' practices and hospitals.
- » Initial assessment through telemedicine tools (especially in rural areas or for patients with language barriers)
- » Mapping of the regionally available medical services and specialists in navigation systems
- » Incentivization (motivational support) for practices: incentives for patient-oriented care solutions and services
- » Improve access (nationwide) to the latest therapies and associated diagnostics (e.g. marker-based, stratified cancer therapies).

## Improve patient care through cross-sector coordination

Information is lost between inpatient and outpatient care. The lack of networking here goes hand in hand with the waste of resources.

- » Cross-sectoral communication and cooperation between service providers (e.g. through the introduction and use of the electronic patient file (ePA))
- » Establishment of regional centers and care networks (e.g. networking of university hospitals with maximum care providers, specialist clinics, general practitioners or on specific topics)
- » Transfer the idea of the digital tumor board or case conferences for rare diseases to other fields of application to integrate care for chronically ill patients and avoid unnecessary visits to specialists or therapies
- » Better information for patients on the medication plan because this enables cross-sectoral orientation on medication care
- » Stronger focus on prevention through appropriate measures for chronic diseases in all age groups, e.g.:
  - Easy access to "health training" by university clinics in cooperation with the health insurance funds in the area with an incentive for the participation of insured persons (certificate)
  - Target group-oriented, evidence-based prevention measures for the older generation
  - prevention-related bonus system in health insurance also for people with pre-existing conditions (secondary prevention)
  - Implementation of adolescent doctors, school nurses and school psychologists in schools/school centers (Scandinavian model)
  - Continuous monitoring and scientific support of population-based screening programs in gynecology and pediatrics and adolescent medicine
- » Prompt implementation of the GBA resolution

- of Dec. 5th, 2019, on the establishment of crosssectoral, structured centers for interdisciplinary care of patients with special needs, e.g. for rare diseases, cancer diseases, etc. (analogous to emergency care, cf. point 3).
- » Involvement of the public health service (ÖGD) in health education measures as well as in the recording and care of infectious spread as well as addictive diseases.
- » Example Corona: Numerous patients need long-term aftercare and rehabilitation after treatment in hospital. Corresponding structures involving hospitals, outpatient care and rehabilitation clinics with special expertise have not been established yet, which leads to many uncertainties among patients. It is hence important to have a continuous care for patients after discharge from inpatient treatment by "corona trainees" as a supplement to general practitioners (in the light of long-term consequences of the disease). Beyond the SARS-CoV-2 pandemic, "case trainees" would generally contribute to improving the health situation of psychologically ill patients, patients with severe oncological diseases or to the follow-up of major orthopedic operations.
- » Web-based reminder and information tools could be developed and used for regular or prospectively scheduled appointments.

# Regional structuring of emergency care with the participation of university medicine

The reform of regional emergency care system that has been initiated must be implemented consistently.

- » Structural reform of emergency care including the involved sectors:
  - Medical on-call service of the Associations of Statutory Health
  - Interdisciplinary emergency rooms of the hospitals
  - Rescue services
- » Stronger integration of university medicine into regional care planning: university medicine offers the full spectrum of maximal medical care as well as comprehensive emergency care, especially for those patients with additional needs for specialized knowledge with regard to underlying diseases
- » Regional assessment and planning of emergency care according to need and available expertise:
  - Structuring of regional emergency care for special diseases
     (e.g. for patients with rare diseases or limited social and cognitive abilities) by naming specialized centers/clinics
  - Structuring of regional emergency care according to existing expertise for special forms of care (analogous to severe burn care, e.g. for severe pulmonary emergency situations with oxygen deficiency)
- » A draft law for the reform of emergency care was already presented by the Federal Ministry of Health in 2019 and the need for the reform was again emphasized and confirmed by Federal Health Minister Jens Spahn in October 2020

# Recognise trustful communication between doctors, patients, nurses and care recipients as the most important pillar of medical care.

Interpersonal trust remains the foundation for good care even in a digitalized medicine. In addition to the professional expertise of the medical staff, it is important for patients, care recipients and, if applicable, relatives seeking advice to have a relationship with the medical and nursing staff that is characterized by mutual trust and sufficient time for counselling sessions.

- » Patient participation in decision-making ("shared decision making"): Promoting patient participation through transparent and comprehensive information, if desired
- » Promoting the health literacy of patients through patient-centered information to support shared decision making and also to achieve better adherence to treatment
- » Better information for patients by medical staff on the right to a second opinion: in the case of very complex and innovative therapy measures or serious diagnoses, it is particularly important to make clear the right to a second opinion (also as a telemedical option)
- » Appropriate remuneration for time-intensive individual counselling activities ("talking medicine") also in prevention, rehabilitation and palliative care
- » Greater inclusion of telemedicine/video consultations in medical communication and care (also as an offer for high-risk patients to avoid infection risks)
- » Improve communication between nurses and doctors, promote rapid feedback from nurses to doctors (also digital)
- » Recognition of the communication services of nurses as communicative mediators between doctors and patients
- » Appropriate remuneration for time-intensive individual counselling activities ("talking care") also in prevention, rehabilitation and palliative care

- » Communication training for medical and nursing staff:
  - Greater consideration of the topics of communication/interaction/telemedicine in medical training (in general and with a thematic focus, e.g. palliative medicine, geriatrics, pediatrics and adolescent medicine, care for people with a migration background)
  - Continuation of communication training for doctors even after licensure
  - Target group-specific training for nurses in complex communication situations with different interlocutors: Patients, relatives, care recipients, medical staff
- » Communication training for patients with reference to different media/formats:
  - Patient-doctor communication in the classical consultation hour
  - Patient-doctor communication online in the video consultation
  - Patient-care communication (analogue and digital)

# Not only talk about digitalization, but also implement it

Increasingly, patients see telemedicine applications and the availability of existing data as great opportunities for better care, as long as they can decide on the use of the data themselves.

- » Standardization and interoperability of systems and tools as a basis for digitization (if necessary, through predefined standardization)
- » Introduction and use of an electronic patient file as quickly as possible (can be established immediately as a pdf collection, if necessary, also with software for data use), which can be used across sectors
- » Introduction and use of an electronic health professional card for nursing professionals as soon as possible and better connection of nursing to the telematics infrastructure
- » Ensuring data sovereignty for patients: Data should be always accessible and patients should be able to decide themselves on the use and further use of their data
- » Promote patient information and dialogue on the electronic health card/patient file so that patients can use it confidently
- » Patient participation in the further design and functional enhancements of the electronic patient file
- » Ensure the use of patient data in research:
  - Use of patient data for medical research after careful patient information and subject to patient consent
  - Linking healthcare data with research data (using experience from the field of oncology, where more targeted therapies with already approved drugs are developed by combining biological data of the tumors with already existing clinical data)

- » Develop new, performance-based reimbursement models that encourage the use and development of digital applications (reimbursement of digital applications and services, such as telemedicine consultations, which has been insufficient to date).
- » Creation of the necessary infrastructure: Nationwide introduction of the 5G standard in data transmission to enable broad application of telemedicine applications
- » Monitoring the success and further development of Digital Health by evaluating the measures for the introduction of digital technologies

# Improve framework conditions for the provision of nursing care

The shortage of nursing staff (including intensive care, geriatric care and palliative care) has become a critical factor in maintaining care. It is important to have a future-oriented nursing policy that combines targeted measures to secure skilled labor with quality assurance in nursing care and better pay for nursing professionals.

- » The social and monetary upgrading of nursing professions is a priority:
  - Fairer remuneration structure in professional nursing, increase of the minimum starting salary and all following salary groups for nursing professionals
  - Transparent training and further education opportunities
  - Extension of the action competence for nursing professionals: Transfer of tasks to the healthcare professions that have been attributed only to the doctors so far (e.g. prescription, prescribing and billing authority for certain services and nursing interventions as well as aids, nursing supplies and medical devices)
- » Further development of the training pathways:
  - Reducing staff shortages through increased training of skilled nursing staff in Germany
  - The same training standards (state examination) for teachers in nursing training as for all other teachers in the Federal Republic of Germany, including the corresponding remuneration.
  - Promotion of opportunities for specialization:
     Differentiation of training paths and professional qualifications based on generalist nursing training that meets the needs of various patient groups and settings of the healthcare system, with special attention to patient safety/resident safety.
  - Academization: Promote higher education for nurses to provide care with specialized knowledge, increase the number of study places for nursing in initial education and post-graduate for specialization.

- » Promoting political participation: Strengthening the nursing professions in the healthcare system through improved rights of voice and co-determination.
- » Stronger involvement of nursing in health policy decision-making processes: Participation of nursing professionals in federal and state crisis staffs, entitlement to comment in the legislative context.
- » Implement patient-friendly pandemic solutions for visits to hospitals and care facilities: Access for relatives must be possible, bans on visits to care facilities (especially for the seriously ill and dying) must be avoided, care professionals must be involved in the implementation and monitoring of appropriate solutions

#### Make financing more needs-based

The current narrow sector-based financing of the healthcare system has led to an orientation of service provision on maximizing revenues. Therefore, a gradual transformation with stronger quality orientation, greater transparency and less sector dependency is necessary.

- » Further development of the overall system is required so that improved and individualized patient care and therapy can be provided:
  - Link inpatient and outpatient care in funding planning, create incentives for outpatient treatment, e.g. for pre- and aftercare
  - The holding costs for specialized treatment must be more fully reflected in the remuneration, so that treatment is based on need rather than case numbers
  - Quality-oriented remuneration with focus on the patient's well-being
  - Better remuneration and more incentives needed for "talking medicine" and interdisciplinary exchange, e.g. in the form of case conferences
  - Strengthening the attractiveness of digital treatment offers, among other things, through appropriate reimbursement of corresponding care services.
- » Example hospital: SARS-CoV-2 pandemic has shown the limits of the current DRG system (Diagnosis Related Group) in hospital care
  - The remuneration for the treatment of corona patients in intensive care units does not cover costs in many cases. Also, necessary outpatient follow-up care is not included in the financing planning so far
  - Goal: Further develop flat rates per case to avoid unnecessary treatments and operations and instead achieve that doctors can take more time for their patients again

- » Example nursing: Existing differences in the remuneration of nurses in nursing and long-term care cannot be justified in terms of qualification, workload and responsibility
  - Demand of the Federal Chamber of Nursing of Nov. 11th 2020: Conclusion of a collective agreement in long-term care that is oriented towards the collective agreement of the public service (TVöD) or the guidelines (AVR) of the confessional hospital operators
  - Increase in the minimum starting salary for nurses
- » Example Outpatient care: Reimbursement of digital applications / services, e.g. telemedical consultation, insufficient so far
  - Develop new performance-based remuneration models that encourage the use and development of digital applications and are at least equivalent to "classic" personal treatment.

Our common goal is to consider the pandemic as a starting point for changes. That is why we do not want to let the process end here, but rather enter a discourse to modify the current system step by step. This goal and the implementation of the above mentioned measures can only succeed together. We see a window of opportunity to bring the interests of patients and citizens into the political discussion at national and European level in a targeted manner, and we want to use it together.

#### The authors and supporters of the white paper::

#### Representatives of science / doctors / nursing

Jens Albrecht

Member of the Board of the Nursing Chamber Establishment Committee of North Rhine-Westphalia

Prof. Dr. Annette Grüters-Kieslich Charité - Universitätsmedizin Berlin / Member of the National Academy of Sciences Leopoldina

Sandra Postel Chairperson of the Establishment Committee of the North Rhine-Westphalia Nursing Chamber

Prof. Dr. Clemens Wendtner Head Physician Munich Schwabing Clinic

#### **Patient representatives**

Ludwig Hammel

Managing Director of the German Bekhterev's Disease Association (Deutsche Vereinigung Morbus Bechterew e.V. Bundesverband)

Dr Barbara Keck Managing Director BAGSO Service Gesellschaft

Simone Pareigis

leader of the self-help group for leukaemia and lymphoma patients in Halle an der Saale and initiator of the project "meine.WEGA" for the development of an ePA

Doris C. Schmitt board member of the PATH Foundation and communication trainer for doctorpatient communication

#### More supporters

Peter Albiez

Chairman of the Management Board Pfizer Germany

Wolfgang Branoner Managing Partner SNPC GmbH

Christina Claussen Director Alliance Management & Patient Relations, Pfizer Germany

**Transparency Notice:** The contents of this white paper were discussed and prepared jointly by the signatories. The signatories involved have contributed their time and effort free of charge. The editorial work was carried out with the kind support of the research-based pharmaceutical company Pfizer.



We would like to thank the authors who have contributed to the preparation of the white paper free of charge and with great commitment.

#### Jens Albrecht

Member of the Board of the Nursing Chamber Establishment Committee of North Rhine-Westphalia

#### Prof. Dr. Annette Grüters-Kieslich

Charité - Universitätsmedizin Berlin / Member of the National Academy of Sciences Leopoldina

#### **Ludwig Hammel**

Managing Director of the German Bekhterev's Disease Association (Deutsche Vereinigung Morbus Bechterew e.V. Bundesverband)

#### Dr Barbara Keck

Managing Director BAGSO Service Gesellschaft

#### Simone Pareigis

leader of the self-help group for leukaemia and lymphoma patients in Halle an der Saale and initiator of the project "meine.WEGA" for the development of an ePA

#### Sandra Postel

Chairperson of the Establishment Committee of the North Rhine-Westphalia Nursing Chamber

#### **Doris C. Schmitt**

board member of the PATH Foundation and communication trainer for doctor-patient communication

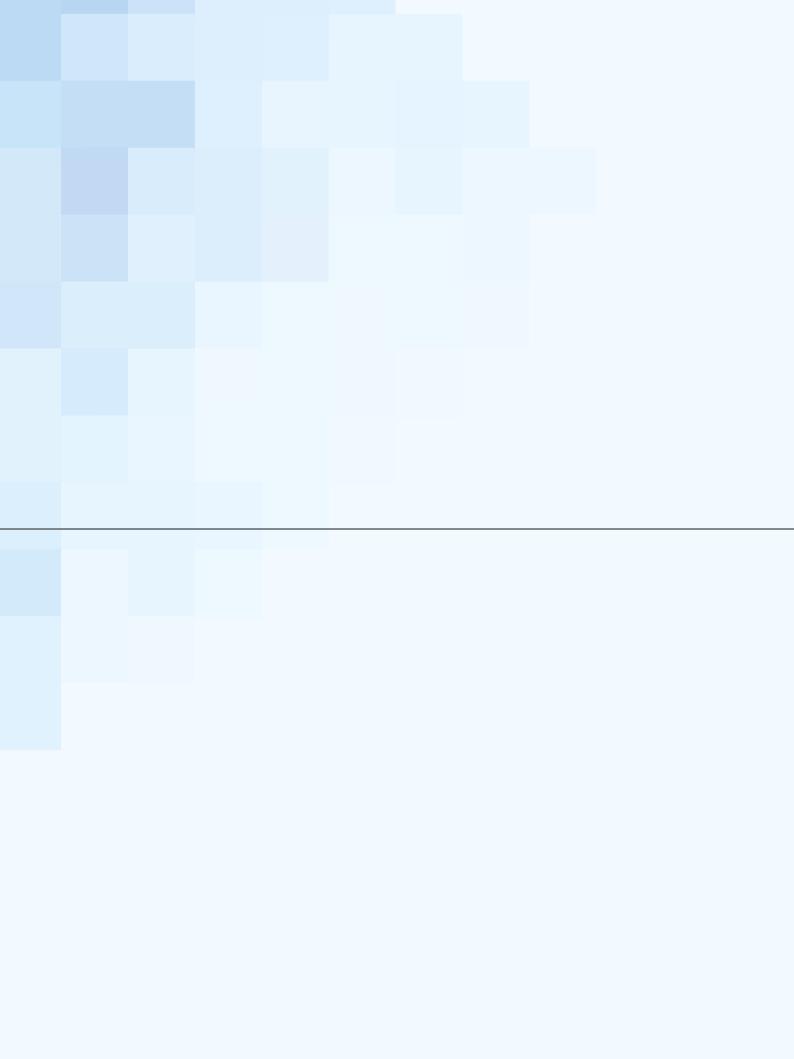
#### Prof. Dr. Clemens Wendtner

Head Physician Munich Schwabing Clinic

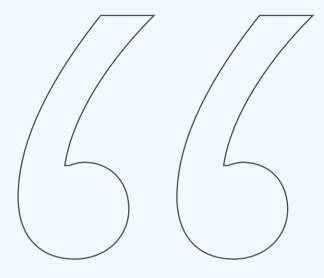




Alliance for Health: Approaches from the field



# Impulses for a Health Agenda 2022



Events like the COVID-19 pandemic, which shake us to the core, have far-reaching effects and change many things. Among these changes is the perception of health and its importance to society - an issue of the highest priority. The pandemic presents an opportunity to rethink and improve health care - an opportunity that no country should miss. Initiatives such as the White Paper for a future-proof healthcare system can contribute and provide valuable impulses.

Dr Hans Henri P. Kluge, WHO Regional Director for Europe

## White Paper for a future-proof healthcare system: Broad alliance for reform

Under the impact of the Corona pandemic, an interdisciplinary group of authors produced the "White Paper for a future-proof healthcare system" in the winter of 2020/2021."

The white paper is the start of a joint initiative with the aim of bringing important topics and positions from practice into the political process in close cooperation with science, medicine, patients, and care.

To this end, the editors and authors of the paper have presented the contents in various formats and initiated a productive exchange with other stakeholders from the healthcare sector.

From the outset, the group of authors aimed to expand the circle of reformers and form new alliances to generate even more support for the reform approaches.

#### Our White Paper in the political discussion: New partners and alliances

The "White Paper for a future-proof healthcare system" was presented for the first time in January 2021 in a digital discussion round, with the participation of the authors and accompanied by numerous stakeholders from health policy, including the then Chairman of the Health Committee in the German Bundestag, Erwin Rüddel.

In the months that followed, the contents were discussed in various formats and introduced into the health policy debate. Numerous politicians from various fields were involved, including the Federal Government's Representative for Nursing Care, Andreas Westerfellhaus, the Federal Government's Patient Representative, Professor Dr. Claudia Schmidtke, and Karin Maag, impar-tial member of the Federal Joint Committee (G-BA) and former health policy spokesperson for the CDU/CSU parliamentary group in the Bundestag.

In addition, the white paper was presented several times at congresses and major events and discussed in front of a broad audience - for example, at the Pfizer Patient Dialogue in May, at the Neustart! Health Summit of the Robert Bosch Stiftung in June and at the ideas workshop from the Pfizer Patient Dialog "5 for Health" in October.

At the Pfizer Patient Dialogue, which was broadcast via livestream in 15 countries, the authors drew a positive interim balance of their political work, with around 500 viewers, including representatives of numerous patient organizations, following the debate. At the New Start Initiative's Health Summit, the White Paper was shared with numerous members of the scientific and medical communities. Here, a broad consensus emerged, particularly about the importance of greater patient participation in the system. To put it exaggeratedly: The German healthcare system is sick, and it has lost sight of the patients.

In addition to the reform proposals from the White Paper, further initiatives and impulses for better care were presented at the "5 for Health" ideas workshop. There was a great deal of agreement on the need for change and willingness to play an active role in shaping it. It also became clear that substantial improvements in the system are possible through the impulses and ideas of committed "lateral entrants". We do not have a knowledge problem - we have an implementation problem.

Against this background, health appears to be a challenge for society, in which many can and must participate.

Existing initiatives - such as the National Decade Against Cancer - can provide important pointers for shaping a broad participation process and implementing the common goals set out in this White Paper. The Decade is an example of how a broad-based participation process can be constructively designed and consolidated.

The intensive discussions that followed the launch of the white paper for a future-proof healthcare system led to the development of numerous new contacts and alliances with other reform projects that pursue similar goals to those of the white paper.

This has given rise to the idea of launching a joint appeal in the context of the federal elections, backed by a broad alliance of signatories »

#### Bundestag election 2021: Setting the course for the healthcare system

The federal election, the ensuing coalition negotiations and the formation of a new federal government have brought movement into health policy. The historical coincidence of the Corona pandemic and political upheaval creates a special window of opportunity.

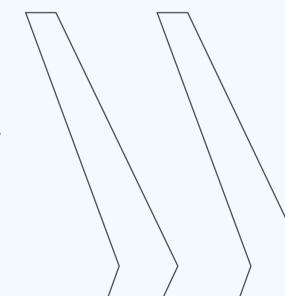
The task now is to implement the lessons learned from the pandemic and set a new course for health policy. What is needed are clearly defined, sustainable development goals that are developed on a broad social basis - the authors of this paper make a substantial contribution to this with their ideas and proposals. We urgently call for a master plan for further development with clear health and care goals. We also advocate that any goals, resources expended, and results be presented transparently in a timely and comprehensible manner.

It has become clear that health policy decisions made before the Bundestag elections (e.g., the Health Care Further Development Act, GVWG) fall far short of the need for reform.

For example, nursing care: Unfortunately, representatives of the nursing care sector were not even involved in the drafting of the GVWG, this must change. Further shaping of nursing self-administration, political participation of nursing and improvement of working conditions (in terms of content, structure, and money) remain central tasks for the coming federal government. Bold decisions are needed to ensure high quality of care in practice in the long term, rather than care reforms and the usual "business as usual".

The signatories of the White Paper see the further development of the healthcare system as a task for society that can no longer wait. That is why we must act now.

Reforms now!



# Sustainable Development Goals: What matters now.

Together, the signatories of the call are committed to:

1) We now use the lessons learned from the Corona crisis to create healthier living environments - for all people, whether urban or rural, young or old, or, sick or healthy.

It is especially important to grasp the full complex implications of the Corona Crisis and learn from them consistently. We are living through not only an infectious disease crisis, but also a psychological crisis. The Corona Crisis means an increase in mental distress and chronic stress in the population, worry, sleep disturbance, and exhaustion. We are also seeing more and more people affected by depression and loneliness because of the pandemic.

2) We improve the framework conditions for access to care to eliminate, as much as possible, the dysfunctional division of our healthcare system into sectors that are partly in competition instead of cooperation, and to enable faster and more efficient diagnoses and therapies.

This is particularly true in rural regions and in certain medical fields, e.g., rare diseases. It also applies to the care of children and adolescents, which varies from region to region and is inadequate in some cases.

It must be considered here that young people are particularly burdened by the Corona pandemic. It has been shown that younger age groups are particularly affected by mental stress, anxiety, and depression during the pandemic, despite the lower risk of severe corona. It has also become clear that the care systems do not offer enough support in this regard.

3) We promote a digital transformation that is oriented toward patient-centered care.

To this end, it is necessary to involve patients more closely in shaping the digital transformation and to make use of their ideas, their experiential knowledge and their expertise in the design, development, and handling of technologies. It is also important to take their concerns seriously, in addition to their constructive suggestions. This concerns, for example, the issue of access to personal data. It is important to promote digital transformation while ensuring that patients receive and retain sovereignty over their personal data. It is also important to anchor the use of digital health applications more firmly in medical training.

4) We are open to the participation of different stakeholders in health policy discussions and decisions. To this end, we need a new culture of communication on health issues that does not only take place in the scientific-political space, but specifically includes the relevant patient perspectives and is open to different positions, including those of "lateral entrants". Because only together can we find good solutions.

A good communication culture includes the promotion of health literacy at various levels of society - from health education in schools to the promotion of health awareness in the working world (corporate health) to the academic qualification of patient voices to promote the professional participation of patient advocates in the healthcare system. It is also important to have a stronger focus on doctor-patient communication and empathic care in medical education.

5) We need to think about all solutions and reforms in the healthcare system from the patient's perspective and improve the opportunities for patient participation.

A good healthcare system puts patients at the center and gives qualified patients more opportunities to participate in the healthcare system themselves, to sit on appropriate committees and to be part of the healthcare policy discourse. Patients must be included in all discussions that affect them. Patient orientation must be the overriding guideline so that the various stakeholders in the healthcare system can work together to achieve sustainable solutions that contribute to the common good.

#### Bibliography:

Klaus Piwernetz, Edmund Neugebauer: Strategiewechsel jetzt! Die Corona-Pandemie als Chance für eine Neuausrichtung unseres Gesundheitssystems, Verlag deGruyter 2020 Robert Bosch Stiftung (Hg.): Die Neustart! Zukunftsagenda – für Gesundheit, Partizipation und Gemeinwohl, Stuttgart 2021

Nationale Dekade gegen Krebs: Principles of Successful Patient Involvement in Cancer Research, 2021

#### The authors and supporters of White Paper:

#### Representatives of science/physicians/nurses:

Prof. Dr. Mazda Adli, Chief Physician Fliedner Klinik Berlin, Berlin

Jens Albrecht, Member of the Board "Errichtungsausschuss Pflegekammer Nordrhein-Westfalen", Düsseldorf

Prof. Dr. Annette Grüters-Kieslich, Charité - Universitätsmedizin Berlin/ Member of the National Academy of Sciences Leopoldina, Berlin

Marcus Jogerst-Ratzka, Managing Director Seniorenhaus Renchen, Renchen

Dr. Bernadette Klapper, German Professional Association for Nursing Professions (DBfK), Berlin

Prof. Dr. Edmund Neugebauer, Brandenburg Theodor Fontane Medical School (MHB), Neuruppin

Dr. Dr. Klaus Piwernetz, Managing Director medimaxx health management GmbH, Munich

Sandra Postel, Chairwoman of the Board "Errichtungsausschuss Pflegekammer Nordrhein-Westfalen", Düsseldorf

Prof. Dr. Clemens Wendtner, Chief Physician, Munich Schwabing Clinic; Deputy Chairman of the Ethics Committee of the Ludwig Maximilian University of Munich, Munich

#### **Civil Society**

Irina Cichon, Senior Project Manager Health Robert Bosch Stiftung, Stuttgart

Nikolas Groth, student of human medicine and founder IntensivKontakt, Hamburg

#### Patient Representatives:

Jan Geissler, Managing Director Patvocates GmbH, Munich

Ludwig Hammel, Managing Director of the German Bekhterev's Disease Association, Schwein-furt

Martina Hagspiel, founder Kurvenkratzer-InfluCancer, Vienna

Renate Haidinger, 1st Chairwoman of Brustkrebs Deutschland e.V., Munich

Dr. Barbara Keck, Managing Director BAGSO Service Gesellschaft, Bonn

Simone Pareigis, head of the self-help group for leukemia and lymphoma patients in Halle an der Saale and initiator of the "meine.WEGA" project for the development of an ePA, Halle (an der Saale)

Bernd Rosenbichler, Founder One in a Million - Alström Germany, Munich

Doris C. Schmitt, board member of the PATH Foundation and communication trainer for doctor-patient communication, Constance

Eva Schumacher-Wulf, Editor-in-Chief Mamma Mia! the cancer magazine, Kronberg

#### **Initiators**

Wolfgang Branoner, Managing Partner SNPC GmbH, Berlin (Editor)

Christina Claussen, Director Alliance Management & Patient Relations, Pfizer Germany, Berlin

Aylin Tüzel, Chairwoman of the Board of Pfizer Germany, Berlin

#### **Transparency Notice:**

### We would like to thank the authors who have contributed to the preparation of this white paper free of charge and with great commitment.

#### Prof. Dr. Mazda Adli

Chief Physician Fliedner Klinik Berlin, Berlin

#### Jens Albrecht

Member of the Board "Errichtungsausschuss Pflegekammer Nordrhein-Westfalen", Düsseldorf

#### Irina Cichon

Senior Project Manager Health Robert Bosch Stiftung, Stuttgart

#### Jan Geissler

Managing Director Patvocates GmbH, Munich

#### Nikolas Groth

Founder IntensivKontakt, Hamburg

#### Prof. Dr. Annette Grüters-Kieslich

Charité – Universitätsmedizin Berlin/ Member of the National Academy of Sciences Leopoldina, Berlin

#### Martina Hagspiel

founder of Kurvenkratzer-InfluCancer, Vienna

#### Renate Haidinger

1st Chairwoman of Brustkrebs Deutschland e.V., Munich

#### **Ludwig Hammel**

Managing Director of the German Bekhterev's Disease Association, Schweinfurt

#### Marcus Jogerst-Ratzka

Managing Director Seniorenhaus Renchen, Renchen

#### Dr. Barbara Keck

Managing Director of BAGSO Service Gesellschaft, Bonn

#### Dr. Bernadette Klapper

German Professional Association for Nursing Professions (DBfK), Berlin

#### Prof. Dr. Edmund Neugebauer

Brandenburg Theodor Fontane Medical School (MHB), Neuruppin

#### Simone Pareigis

head of the self-help group for leukemia and lymphoma patients in Halle an der Saale and initiator of the "meine.WEGA" project for the development of an ePA, Halle

#### Dr. Dr. Klaus Piwernetz

Managing Director medimaxx health management GmbH, Munich

#### Sandra Postel

Chairwoman of the "Errichtungsausschuss Pflegekammer Nordrhein-Westfalen", Düsseldorf

#### Bernd Rosenbichler

Founder One in a Million - Alström Germany, Munich

#### Doris C. Schmitt

Member of the Board of the PATH Foundation and communication trainer for doctor-patient communication, Constance

#### Eva Schumacher-Wulf

Editor-in-Chief of Mamma Mia! the cancer magazine, Kronberg

#### Prof. Dr. Clemens Wendtner

Chief Physician, Munich Schwabing Clinic; Deputy Chairman of the Ethics Committee of the Ludwig Maximilian University of Munich, Munich

