

Questionnaire on Focus Area 1 for the thirteenth session of the United Nations' Open Ended Working Group on Ageing

Guiding questions for the thirteenth session. Focus area 1: Right to health and access to health services

National legal and policy framework

1. What are the legal provisions and policy frameworks in your country that guarantee the right of older persons to the enjoyment of the highest attainable standard of physical and mental health, including access to promotive, preventive, curative, rehabilitative and palliative health facilities, goods and services?

The German health care system provides universal access to health for all people residing in Germany. Individuals are insured either in the private or statutory health insurance system, independent of age or other demographic or socio-economic characteristics. The overarching aim of the 2015 Preventive Health Care Act is to prevent NCDs before they manifest themselves by strengthening prevention and health promotion in different settings, in particular where people live, learn and work, focusing strongly on common risk factors and health inequalities. The Act takes a disease-unspecific approach and aims to strengthen people's health resources and potential. These Act strengthens the basis for enhanced co-operation among the social security institutions, the Laender, and the local authorities in the areas of prevention and health promotion – for all age-groups and in multiple life settings.

In order to cover the risk of developing long-term care needs, a statutory long-term care insurance (LTCI) was introduced in 1995 as a fifth independent branch of Germany's social insurance system. A guiding principle of German LTCI is to give those in need of long-term care the opportunity to decide for themselves how and by whom they will be cared for. LTCI thus offers a variety of insurance benefits that people in need of care and their relatives can make use of, spanning from benefits for home care to benefits for care in residential LTC facilities.

2. What steps have been taken to ensure that every older person has access to affordable and good quality health care and services in older age without discrimination?

The dual health care system - consisting of statutory health insurance (SHI) and private health insurance (PHI) - gives all persons residing in Germany access to health care by law, regardless of age and state of health. In statutory health insurance, the same benefits are available to all insured people. Contributions are paid based on economic capacity. Privately insured persons receive benefits according to their insurance contract. They can switch to the basic tariff of private health insurance, which corresponds in type and scope to the benefits of SHI. If the insured person is in need of financial support, a health insurance subsidy is paid.

Germany's long-term care insurance is constructed as a comprehensive compulsory insurance for all members of the (mandatory) statutory or private healthcare insurance system. All members of the statutory healthcare insurance scheme are automatically insured via the statutory long-term care insurance scheme. All persons with a private healthcare insurance must take out private long-term care insurance. As the need for long-term care can generally exist in all phases of life, age is not a necessary criterion for receiving LTCI benefits. Through a long-term care needs assessment, the so-called care degree of a person and the eligibility to receive LTCI benefits is determined depending on the extent of the limitations of independence and abilities.

3. What data and research are available regarding older persons' right to health and access to health care and services? Please indicate how national or sub-national data is disaggregated by sex, age and inequality dimensions, and what indicators are used to monitor the full realization of the right to health of older persons.

The German health care system provides universal access to health with mandatory health insurance regulated by law. Individuals are insured either with private or statutory health insurance companies thus reaching a health care coverage of nearly 100%, independent of age or other demographic or socio-economic characteristics.

RKI studies collect a variety of information on health care of older persons. Direct questions on the right to care are not included, but topics such as the use of inpatient and outpatient care. Health care use indicators provide information on realized access which can be influenced by both, systematic access barriers and patient preferences. Analyses can be disaggregated by variables of socio-economic status (education, labour status, income). The educational attainment level is defined according to the International Standard Classification of Education 2011 (ISCED 2011).

Recent studies at the Robert Koch Institute which include questions concerning access to health care and services are German Health Update (GEDA 2019/2020-EHIS) and the study on health of older people in Germany (Health 65+).

GEDA 2019/20-EHIS

GEDA 2019/20-EHIS was carried out between April 2019 and September 2020. The study used a questionnaire based on the third wave of the European Health Interview Survey (EHIS), which was carried out in all EU member states. GEDA-EHIS 2019/20 includes 6,048 participants aged 65–79 years and 1,809 aged 80 years and beyond. Included is European Health Care Module (EHCM) which collects data on the use of health care services (use of inpatient and day care, use of ambulatory and home care, medicine use, preventive services) and the unmet needs for health care.

Health 65+

Health 65+ is a population-based longitudinal epidemiological study to provide representative data on the health situation of people aged 65 years and older in Germany. The baseline survey was carried out between June 2021 and April 2022. It includes 1,525 participants aged 65–79 years and 2,169 aged 80 years and beyond. Health-care related indicators at baseline include polypharmacy, hospital and emergency room admissions, vaccination against flu, presence of a long-term care grade, health literacy (2 questions from the European Health Literacy Survey (HLS-EU)), and quality indicators for ambulant care.

4. What steps have been taken to provide appropriate training for legislators, policymakers, health and care personnel on the right to health of older persons?

The federal legal basis for training or studying in a health profession basically enables graduates to work with people of all ages, especially older persons.

5. What steps have been taken to align macroeconomic policies and measures with international human rights law, to use maximum available resources for the realization of older persons' right to health, such as through expanding fiscal space, adopting targeted measures and international cooperation?

The German system of solidarity and universal health care coverage provides a high level of benefits based on the needs of the individual and not her or his economic capability. While there is no

financial cap in benefits to the individual, contributions are based on economic capacity (i.e. personal income) which is also the basis of firm caps on e.g. co-payments. Benefits in this system go well beyond the mere insurance of cases of sickness and the treatment thereof but rather include rehabilitation efforts, the provision of medical devices and technologies aimed at alleviating the burdens associated with sickness and disability as well targeted services/ preventive efforts intended to promote healthy living for the elderly among other groups.

(e.g.: <https://www.gkv-buendnis.de/buendnisaktivitaeten/bundesweite-aktivitaeten/auf-leben/>)

While this contribution-based system is financed to a disproportionately larger degree by contributions from the working-age population, the expenditure is disproportionately benefitting the older shares of the insured population which is typically at a higher risk of temporary and chronic sickness as well as disability. Hence, the system has a non-negligible, intergenerational distributional impact at the macro-economic level.

6. What are the challenges faced by older persons in their enjoyment of the right to health, including the impact of intersectional discrimination and inequality based on age, gender, disability and other grounds?

Baer et al (2016) describe availability, accessibility, acceptability, and quality as factors that influence the enjoyment of health and access to quality services. Availability refers to a sufficient quantity of functioning public health and health care facilities, goods, and services, as well as programs. Accessibility (of health facilities, goods, services, and programs) has four subdimensions: nondiscrimination, physical accessibility, economic accessibility (or affordability), and information accessibility. Acceptability includes a consideration, for example, of whether services are age friendly or responsive to older people's needs, taking into account the diversity of older people, as they are not a homogeneous group but face varying health risks and circumstances. Adequately skilled, competent and empathetic health workers are an important component of assuring good-quality health services.

A literature review of the German Federal Anti-Discrimination Agency suggests several challenges older people face when exercising their right to health. Negative stereotypes concerning (older) age influence access to as well as the quality of health care. Older patients are less often offered e.g. long-term therapies or rehabilitative care. Also, diagnostics is influenced by discrimination based on age if health conditions are ascribed to age-related morbidity instead of offering differentiated diagnostics. Furthermore, the review suggests that cost-intensive health services are less often offered to older people due to the limited time of life that is expected to remain. Another problem is limited knowledge of the specific needs of older people among medical personal due to a lack of the topic of geriatrics in (medical) curricula. Besides, clinical studies examining the effectiveness of (new) medicals or therapies among people of old age are lacking.

A study of the examined socioeconomic inequalities in health and perceived unmet needs for healthcare and explores the dynamics of health inequalities with age among elderly people in Germany. Results show that socially disadvantaged elderly people perceive greater barriers to accessing healthcare services than those who are better off.

7. What measures have been taken to eliminate ageism and discrimination based on age, including discriminatory laws, policies, practices, social norms and stereotypes that perpetuate health inequalities among older persons and prevent older persons from enjoying their right to health?

With the General Equal Treatment Act ("AGG"), the German legislator has introduced standards that are intended to prevent imminent discrimination and eliminate existing discrimination. In § 1,

the legislator has listed specific characteristics, in the presence of which different treatment is prohibited. Age is one such prohibited discriminatory characteristic. According to this, discrimination is generally prohibited. Exceptionally this can be permissible in accordance with § 10 AGG. This norm refers however to the entrance to professions. In this respect, the AGG also protects older persons when concluding contracts with medical practitioners and supports them in exercising their right to health.

8. What measures have been taken to ensure that older persons are able to exercise their legal capacity on an equal basis with others, including making an informed consent, decisions and choices about their treatment and care?

According to § 630d of the German Civil Code (BGB), the treating party is obliged to obtain the patient's consent prior to a medical measure. The prerequisite for this is an explanation in accordance with Section 630e of the German Civil Code (BGB). More on this below. The background to this is that the patient is not the object of the treatment, but can decide on the treatment as an autonomous subject. This also applies to older patients.

According to § 630e of the German Civil Code (BGB), the treating doctor is obliged to inform the patient of all circumstances essential for consenting to the intervention. The information provided must be comprehensible to the specific patient. This is measured in terms of both language and content by the patient's understanding. In this respect, the doctor is also obliged to adapt to the respective cognitive abilities of the patient.

If a person is lacking his or her legal capacity of consenting to or denying a medical treatment, for example due to an age-related medical condition, the competent court (“Betreuungsgericht”) may appoint a legal representative that supports the person concerned in making the decision needed (section 1814 paragraph 1 Bürgerliches Gesetzbuch (BGB)). He or she is supposed to recognize and realize the adult’s wishes. These wishes must be followed, as long as their realization does not cause an immediate danger for the adult himself, his financial situation, or the wish cannot be expected to be followed by the legal representative (section 1821 BGB). The court-appointed (legal) representative is given the task to support the adult in exercising his or her rights also regarding treatments and medical care and to protect him or her from harming him- or herself. A substitute decision shall only be made if the adult is not capable of acting with assistance.

Informed consent, decisions and choices about treatment and care can also be given or made by an advanced medical directive, a legal instrument codified in section 1827 paragraph 1 BGB. Any adult who is capable of consenting can determine in writing, for the contingency that he or she is not capable of consenting anymore, which examinations of the state of his or her health, therapeutic treatments or operations he or she consents to or prohibits. In general, such an advanced directive is legally binding for all persons involved in a medical treatment. The Federal Consumer Service Center offers an easy accessible legal tech tool that helps to create such a binding advanced medical directive also explaining its risks and consequences

Within Germany’s long-term care insurance (LTCI) system there are on a statutory basis yearly quality inspection visits of all LTC services and LTC nursing homes. The results of those inspections and of additional information on core quality items (with a stress on outcome quality) are open to users and the general public on the internet platforms of the LTCI providers, so that persons in need of care and their relatives can make informed choices on that basis. Furthermore, LTCI supports those in need of care and their relatives by providing individual and free care counselling services. In addition to that, so-called care support bases (“Pflegestützpunkte”) in which persons in need of care and their relatives find advice and support in finding and organising their home care setting exist in many regions.

9. What judicial and non-judicial mechanisms are in place for older persons to complain and seek redress for the denial of their right to health?

:In cases of suspected errors in treatment, patients of all ages can turn to the expert commissions and arbitration boards set up by the Medical Associations (Ärzttekammern) for clarification of the suspicion. Independent physicians and lawyers assess whether there has been an error in treatment for which the physician is accountable and which has led to damage to the patient's health. The procedure is free of charge for patients. Regardless of the outcome of the proceedings, the patients may still take legal action. Patients can also address complaints about physicians to the relevant Medical Association, which is responsible for ensuring that physicians comply with their professional duties. In the case of violations, the Medical Associations may, if necessary, issue reprimands or refer the matter to a disciplinary court.

Depending on the exact contract of the medical measure and depending on the exact circumstances, §§ 19 et seq of the AGG may be applicable. According to § 21 AGG, disadvantaged persons can demand the elimination of the impairment in the event of a conflict with the prohibition of discrimination (...). Furthermore, in the event of a violation of the prohibition of discrimination, the discriminating party is generally obligated to compensate for the resulting damage.

10. What mechanisms are in place to ensure the effective and meaningful participation of older persons living in different geographic areas of the country in the planning, design, implementation and evaluation of health laws, policies, programmes and services that affect them?

Within the framework already determined by law (see answer to question no. 1) the Joint Federal Committee (G-BA) defines which specific healthcare services are paid for by statutory health insurance. Among other responsibilities, the G-BA is involved in the planning, design, implementation and evaluation of health programmes and services. The G-BA is a public legal entity comprising the four leading umbrella organizations of the self-governing German healthcare system: the National Associations of Statutory Health Insurance Physicians and Dentists, the German Hospital Federation, and the Central Federal Association of Health Insurance Funds.

Leading nationwide advocacy groups that represent patient interests or facilitate self-help for people in Germany who are chronically ill or have disabilities are entitled to take part in discussions and submit petitions. 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, The Federal Syndicate of Patient Interest Groups, The German Syndicate of Self-Help Groups and the Federation of German Consumer Organisations. These groups and the people they represent reflect the rich diversity of patient and self-help organizations in Germany.

Effective and meaningful participation opportunities within the framework of the G-BA consultation process are not limited to the above-mentioned organisations though. Older people's perspectives are regularly heard both in the hearings and in the involvement of external expertise, be it from a scientific (e.g. German Society for Geriatrics) or a more holistic point of view (e.g. European Association for Vitality and Active Ageing).

Furthermore, the German Federal Anti-Discrimination Agency has since last year also the right to be consulted by the government in all matters regarding its mandate. Hence the agency can influence directly health legislation and other legislation if matters of the prevention of discrimination based on age are concerned.