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Summary of the Statement

Data-driven Dementia Prevention

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With this statement, the Academies would like to stimulate societal discussion by highlighting the complex interrelationships which have an impact on dementia risk and how such insights can be used for prevention.

- A wealth of knowledge is already available about risk factors and indicators for dementia and this knowledge makes it possible to detect indications of an increased risk of dementia long before the onset of the condition and to modify this risk.
- Making good use of technology and data is the cornerstone for targeted behavioural prevention and for deriving effective structural prevention measures.
- In the short term, better use must be made of existing data and the scope of data collection and utilisation for research must be widened in order to enhance its potential in dementia prevention.
- Effective dementia prevention additionally requires changes to the policy framework and should be seen as part of an overall strategy for disease prevention and health promotion.

Summary

Dementia as a Societal Challenge in Germany

Dementia is one of the greatest societal challenges of our times and will only become more significant in future. In 2023, there were around 1.8 million people living with dementia in Germany and extrapolations would suggest that this number will rise to some 2.74 million by 2050. The impact on the quality of life, health and daily lives of those directly affected is sometimes dramatic but dementia also has other negative effects: according to billing data from healthcare funding providers, dementia was already costing the German healthcare system around 20 billion euro in medical costs in 2020. However, since only around 40 per cent of people with dementia receive a diagnosis, these costs have probably been underestimated.

There are also other indirect costs: a large proportion of people with dementia receive "informal" care from relatives. The burden of care often results in these relatives reducing their working hours and sometimes even taking early retirement. According to estimates for 2020, the overall social costs of dementia in Germany therefore amount to around 83 billion euro and these costs could rise as high as 141 billion euro by 2040.

The various forms of dementia are a group of conditions whose aetiology is still not fully understood. Only in around five per cent of cases are the causes known and in still fewer cases can dementia in principle be remedied, for instance in the case of autoimmune diseases, vitamin deficiencies or infections. Approved drugs are already available for specific types of dementia, but the corresponding preparations have so far only provided symptomatic relief or slowed progression in the early stage of the disease. While intense research activity does mean that causal treatments may indeed become available in the long term, there is currently no cure or effective causal treatment for dementia on the horizon for many parts of the population.

Potential of prevention

Prevention has great potential for reducing the burden of disease caused by dementia thanks to the technical possibilities that are now available. This relates, on the one hand, to the avoidance of dementia, in particular "secondary dementia", which can be prevented or regressed if diagnosed in good time. On the other hand, targeted prevention can also enable those with more advanced or irreversible dementia to participate more in society by mitigating or slowing the progression of the condition. The focus of this statement is on an increasingly data-driven prevention concept based on individualised risk profiles.

According to the current epidemiological evidence base, various modifiable risk factors play a major role in the occurrence of dementia. For instance, up to 45 per cent of all dementia cases worldwide are theoretically preventable if 14 modifiable risk factors were eliminated from the population: low level of education, hearing loss, high LDL cholesterol, depression, traumatic brain injury, physical inactivity, diabetes, smoking, high blood pressure, obesity, excessive alcohol consumption, social isolation, air pollution and vision loss. For Germany, estimates from 2023 based on the eleven best-studied risk factors at the time also showed that 38 per cent of all dementia is attributable to modifiable risk factors. Even a reduction of just 15 per cent in the prevalence of these risk factors through individual behavioural and public structural prevention measures could reduce case numbers by up to 138,000, i.e. by seven percentage points, by 2033.

In addition to the stated risk factors, the evidence base also provides pointers, albeit less clearly and comprehensively, to further factors which appear to have a positive or negative influence on dementia risk. These include anxiety disorders, low income, contact with solvents, consumption of ultraprocessed food, air pollution in an individual's living environment, chronic kidney disease, poor sleep quality, post-operative neurocognitive disorders and circadian rhythm disorders. Modification of the risk profile in terms of dementia prevention can also be supplemented with medication, for example antibody therapies. Although dementia is not an inherited condition in the majority of cases, there are genetic factors, such as the presenilin genes, the APP gene and the ApoE gene, which do have a significant impact on dementia risk.

Over and above the risk factors, various risk indicators for dementia are also known and are already in use today for diagnosing dementia. Some indicators can point to an increased risk as early as 20 to 30 years before onset of the condition. Indicators differ in significance and the effort required for data collection and can be broadly divided into three categories: biomarkers, which are collected by image-based diagnostics and by cerebrospinal fluid or blood analyses; digital biomarkers, which are based on data evaluation from wearables, implants or smartphones; and cognitive status assessments, in which various cognitive capabilities are tested using paper-based or digital methods.

Building blocks of data-driven dementia prevention in Germany

Individualised risk profiles are one possible tool for developing tailored prevention measures. Such profiles ideally include all the relevant data relating to a person's existing risk factors and risk indicators. Specifically, these data cover lifestyle factors, genetic factors, medical history and cognitive and physiological status. These risk profiles also need to be regularly updated to reflect changes in circumstances and individual risk factors.

Full risk profiles are not as yet available for dementia prevention at population level. Furthermore, the individual interplay between different risk factors has not yet been sufficiently researched. However, current evidence would suggest that even rudimentary individualised risk profiles could enable initial practical prevention recommendations to be developed and measures to be planned and implemented. Moreover, such profiles can also provide a basis for predicting and simulating disease progression in different scenarios.

In addition to new possibilities for behavioural prevention, risk profiles also offer a better basis for decision-making for effective structural prevention. The two types of preventive healthcare should always be considered together because the interaction between behavioural and structural prevention measures strengthens not only an individual's resilience and self-efficacy but also the resilience of the healthcare system and of other areas of society that are of relevance to health. However, when collecting the data, it must be ensured that the individual's rights to voluntary participation and to remain in ignorance are taken into account and appropriately weighed up against society's entitlement to the best possible prevention of dementia and use of available resources. This is particularly the case where there are no specific therapeutic measures for the risk factors in question or the condition. In this context, it must also be weighed up which data can appropriately be used for research while taking account of these individual rights.

Two-stage dementia risk screening might in future provide a framework for integrating individualised risk profiles into everyday care as a tool for prevention. The first step would be to identify people with an increased risk of dementia by means of an inexpensive, widely applicable method such as a

prevention app for collecting digital biomarkers. The second step would be to use more specific methods such as diagnostic imaging to observe the identified individuals for relevant dementia-related pathological changes.

Individualised risk profiles are not only helpful in determining personal dementia risk but also provide starting points for specific prevention measures. If prevention is actually to contribute to reducing disease burden, information from risk profiles has thus also to be communicated to the individuals involved and translated into suitable interventions. A number of initial steps have been taken in this direction, but some significant basic research is still lacking for effective individualised risk factor management, personalised approaches to dementia prevention and suitable structural prevention measures.

Approaches to promoting data-driven dementia prevention

Effective dementia prevention which can appreciably alleviate both the individual and societal burden of disease is already possible today. If Germany is to be able to make better use of this potential, existing health data should be made available for medical research and healthcare in the short term. In addition, dementia-specific data for research and care purposes should in future also be systematically collected on a broad scale, while data-based research findings must in turn be quickly translated into individualised and general prevention measures. In the long term, prevention campaigns for other conditions such as obesity, cardiovascular disease, cancer or diabetes could also benefit from such a data-driven approach.

The existing National Dementia Strategy should also be carried on beyond 2026 as a “Decade for Brain Health” and be further developed in terms of prevention, digitalisation and participation. The aim should be to establish fundamentally data-driven dementia prevention in Germany which should also be accompanied by other prevention approaches such as promoting mental health. Data-driven dementia prevention is an interdisciplinary field, which is why the corresponding framework has to be created at federal level through interministerial cooperation. In the longer term, the dementia prevention outlined here should also be incorporated into an overall national strategy for disease prevention and health promotion.

The effectiveness of dementia prevention increases, the more health-related data from different areas of a person’s life can be linked up and put to medical use. This involves firstly making the data “FAIRer” as defined in the National Research Data Infrastructure, namely the data must be Findable, Accessible, Interoperable and Reusable. In this context, it would be ideal to establish a national ecosystem for prevention and research which provides access to all relevant data for deriving specific prevention measures as a function of individual risk profile. The introduction of a unique identifier (UID) permitting unique identification of an individual is central to the effective linkage of personal health data from different sources (record linkage). Since Germany does not yet have a UID for health data, it should be introduced as soon as possible. Moreover, it is not only individual health data that are of relevance to dementia prevention — public administration data (e.g. social, environmental and mobility data) can also provide information about risk factors, correlations, and prevention needs and potential and should therefore be factored in when creating individual risk profiles.

Further research is also needed if the potential of data-driven dementia prevention is to be fully exploited in future. Key research perspectives include the question of how far statements about dementia risk and status based on digital biomarkers and lifestyle factors can be confirmed by classical, i.e. molecular and cellular, biomarkers. This could potentially enable more accurate prediction of dementia

risk based on digital biomarkers as a surrogate for molecular biomarkers. Tools for research, diagnostics and prevention planning which permit meaningful integration of data from various biomarkers on the different organisational levels of the brain and interacting organs such as the immune system should also be developed on the basis of increased research into molecular and cellular biomarkers. Data from different organisational levels must be integrated and validated on the basis of theory-driven mechanistic models (simulations, digital twins) to enable individualised predictions of the effect of risk factors on brain health.

In addition to the effectiveness of specific measures for individual dementia prevention, another currently open field of research concerns the health economics of different prevention measures. In addition, nuanced feasibility studies are needed to determine which specific prevention services work for those affected in their respective life situations, and to identify the target groups, especially particularly vulnerable population groups, for which new programmes may need to be developed.

Given the large numbers affected, dementia is an issue for the entire population. Beyond regulatory and technical measures for data use and research, there is thus a need for suitable concepts for actively and bidirectionally involving the population in dementia prevention, similarly to citizen science projects. One major problem in this context is the stigmatisation of dementia in public perception. Destigmatisation campaigns, such as those already being carried out in the psychiatric/psychological context, should therefore be an important component in dementia prevention. Because people should not be forced or coerced for social or economic reasons to deal with the possible or certain onset of a disease before they have to, the emphasis here should be on education. The aim of such a campaign should therefore be to raise awareness of the possibilities of dementia prevention and, without applying pressure, to boost willingness to provide data and participate in research projects.

There is additionally a need for a national research and prevention app or, alternatively, an ecosystem of apps to ensure the continued development of dementia prevention in the future. The app or app ecosystem should collect digital biomarkers as well as individual risk factors and a person's cognitive status using a questionnaire function and make them available to a Germany-wide data ecosystem for dementia research and care. Such an ecosystem of apps should go beyond existing offerings: they should be scientifically sound, function across healthcare sectors and disciplines and enable simple and low-threshold use so that vulnerable, less digitally savvy and less health-aware population groups can also be reached. The corresponding research activities and the development of the data ecosystem for dementia prevention should be securely funded for at least a decade, be comprehensively evaluated and further developed and successful elements should ideally be made permanent. Prevention demands long-term plans and thus also long-term funding.

Since the risk factors themselves cannot be completely eliminated, effective dementia prevention also requires structural prevention, i.e. an improvement in the social framework to promote healthy lifestyles. Beyond dementia-specific goals, targeted structural prevention can also simultaneously reduce risk factors for a variety of diseases, which is why it should ideally be planned comprehensively and holistically as part of an overall prevention strategy. So far, the evidence primarily supports the benefit of restrictive structural prevention measures such as higher duties on alcohol and tobacco. The potential of more participatory approaches cannot yet be estimated on the basis of current data and there is a need for further research into indirect prevention effects and "co-benefits". Data-driven dementia prevention should in future therefore also include the development of structural prevention measures using a broader pool of data and with the participation of people at increased risk of dementia. In this way, support measures can be designed depending on particular living conditions and, if necessary, with the involvement of healthcare professionals.

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