Aus der Abteilung Allgemeinmedizin und Versorgungsforschung
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From data need to data use: Exploring the potential of data use for equitable policymaking in long-term care for persons with dementia in the German state of Baden-Wuerttemberg

Inauguraldissertation
Zur Erlangung des Doctor scientiarum humanarum (Dr. sc. hum.)
an der
Medizinischen Fakultät Heidelberg
der
Ruprecht-Karls-Universität

vorgelegt von
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2023

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List of Abbreviations

CCI	Charlson Comorbidity Index
CI	Confidence interval
GISD	German Index of Socioeconomic Deprivation
HITS	Heidelberg Institute for Theoretical Studies
ICC	Intraclass correlation coefficient
ICD-10	International Statistical Classification of Diseases and Related Health Problems, Revision 10
ICD-10-GM	International Statistical Classification of Diseases and Related Health Problems, Revision 10, German Modification
LoCD	Level of care dependency
LTC	Long-term care
OECD	Organisation for Economic Cooperation and Development
OR	Odds ratio
PwD	Persons with dementia
SES	Socioeconomic status
SGB	Social Code (Sozialgesetzbuch)
WHO	World Health Organisation

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1 Introduction

This dissertation refers in large parts to 2 publications, which resulted from this dissertation. This concerns the work on study 1 (Wronski et al. 2021a) and study 3 (Wronski et al. 2021b), which are further outlined in section 1.2. If sections of the doctoral thesis are reproduced in whole or in part in the publications, this is indicated at the beginning of the respective section of the doctoral thesis and the corresponding publication is cited. Own contributions to data collection, analysis, and own publications are presented in section 7.

In section 1.1 individual sentences in terms of content about the *Model Project Cross Sectoral Healthcare* and health system indicators can also be found in (Wronski et al. 2021a) and (Wronski et al. 2021b). In sections 1.3.1.1 and 1.3.1.2 individual paragraphs can also be found in (Wronski et al. 2021b).

1.1 Problem statement

According to the German Social Code (SGB) XI § 69 long-term care (LTC) insurance has to ensure equitable care for the insured. This aim is challenged by current population developments: there is an expected rise in the number of people in need of LTC due to an ageing population, which comes along with an increased number of persons being affected by age associated chronic conditions such as dementia, an acquired disturbance of the memory function and other cognitive functions which leads to significant constraints in activities of daily living. Life expectancy so far played a major role in terms of absolute dementia prevalence compared to lifestyle and other factors: despite observed decreases of prevalence rates of dementia, absolute case numbers are increasing (Doblhammer et al. 2015). Without a significant breakthrough in prevention this trend is expected to continue at least until 2050, when the baby boomer generation reached the highest age group (Deutsche Alzheimer Gesellschaft 2019). For 2018, the number of persons with dementia (PwD) was estimated at circa 1.5 million (Deutsche Alzheimer Gesellschaft 2019) and is expected to increase to a total number between 1.9 and 2.4 million (Milan and Fetzer 2019). PwD have a 10 times higher risk for care dependency than persons without this diagnosis, dementia is the most frequent diagnosis care dependency is based on within the German system of statutory LTC insurance (van den Bussche et al. 2014). In terms of costs, dementia might be one of the most expensive brain disorders (Gustavsson et al. 2011) with total annual costs of $70,911 per patient in a global context (Schaller et al.

2015). The observed increase of LTC need partly exceeds the development of the corresponding supply side. The number of full-time equivalent nurses in outpatient LTC per 100,000 persons in need of care in Germany decreased from 12 in 2007 to 10 in 2017 (Rothgang et al. 2020). If similar ratios were to be maintained until 2050, circa 65 % more LTC professionals would be needed, which would be 965,628 in total (Jacobs et al. 2019).

There exist multiple definitions of needs-based supply of care (Scholten et al. 2016) and multiple approaches to measure equitable healthcare (Hernández-Quevedo and Papanicolas 2013). Since the research by Wennberg and Gittelsohn in 1973 it has been shown that healthcare delivery varies regionally (Wennberg and Gittelsohn 1973). This means that spatial factors should be considered in analyses of equity. In Germany, regional variation in healthcare provision has been increasingly studied in health services research in recent years, not least against the background of increasingly sparsely populated rural regions and demographic change and the associated increase in age-associated diseases. It is often unclear whether observed regional differences are the result of (vertical) equity of need or whether regionally distributed barriers to access play a role. With the increasing availability of health data in Germany, especially administrative data of the statutory health and long-term care insurance, the possibility has arisen to use such data to inform healthcare planning in the sense of 'evidence-informed health policymaking'. Among other things, administrative data offer the advantage of regionalised analyses as they comprise large populations.

In view of these developments, the Ministry of Social Affairs and Integration of the German state Baden-Wuerttemberg together with various health system stakeholders such as citizens, patients, health care providers, and payers formulated guiding principles ('*Gesundheitsleitbild*') (Landesgesundheitskonferenz Baden-Württemberg 2014) on how to manage challenges posed to the health system (Wronski et al. 2021a). There are three main approaches to the guiding principles: (1) decisions on healthcare and LTC structures should be orientated on need, (2) be conducted on the regional level of administrative districts, and (3) these decisions should be informed by regional data analyses (Landesgesundheitskonferenz Baden-Württemberg 2014). These principles pose several questions for operationalisation: how is need defined and how can it be measured in general and on a small area level? What data do regional health planners consider as important? A variety of health system indicators and associated conceptual frameworks exist. But indicators and frameworks of other health systems and regions often cannot be transferred to the own setting, e.g. because health systems are organised differently or simply because certain data are not yet available. This is evident, for example, within Germany. There is a state-organised system of health reporting and associated with it about 300 indicators, of which only about 37 % are held by all federal states and are suitable for comparisons between them (Arbeitsgemeinschaft der Obersten Landesgesundheitsbehörden 2003). Besides, there are many other sources of indicators and data providers which causes a sort of "*indicator chaos*" (Saskatchewan Health Quality Council 2011), a problem also experienced in other countries such as Canada (Wronski et al. 2021a). This requires local healthcare planners to make a selection of indicators (Wronski et al. 2021a). Finally, how is the data uptake by health planners once the data become available? Specifying these questions could shed more light onto the potential towards the stated political aims of data- and needs-based healthcare planning on a small area level.

1.2 Research questions and structure of thesis

The aim of this thesis is to analyse the potential of needs- and data-based policymaking exemplary on the case of the German state Baden-Wuerttemberg and the area of LTC for PwD and the political normative goal of equity. As there are many aspects about data-based policymaking, this thesis focusses three main aspects along a pathway from data need of potential users, which includes any health system stakeholder involved in health care planning and policymaking, via data production to data use for needs-based policy-making (Figure 1).

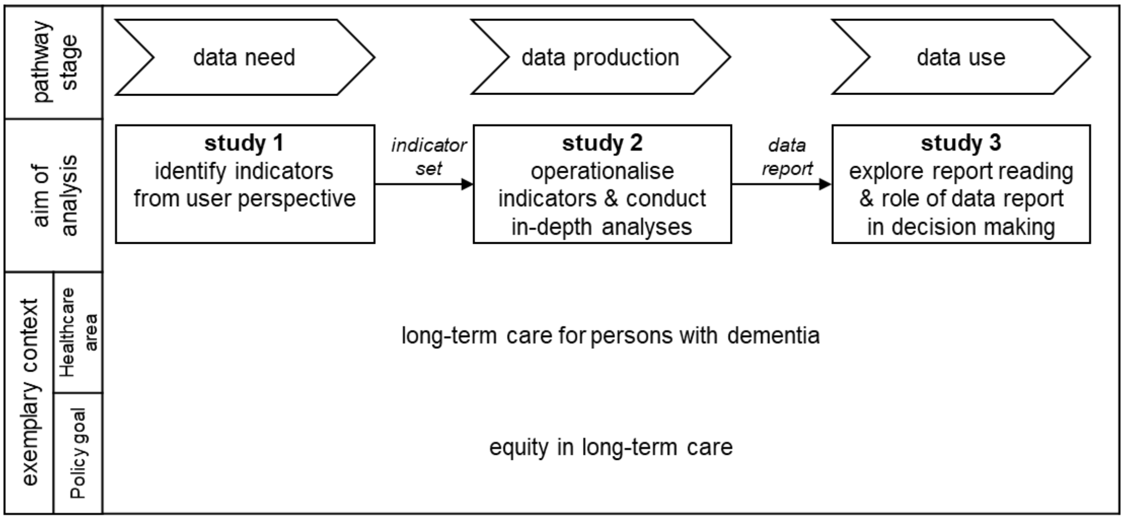

Figure 1: Thesis overview along a pathway from data need to data use (own figure)

Each of the three pathway stages was examined in an according study. Study 1 aimed to identify health system indicators, which health system stakeholders consider as relevant for making policy decisions in long-term care for persons with dementia in Baden-Wuerttemberg. Possibilities and challenges of data-based policymaking on the stage of data production are examined in study 2. This comprises two approaches based on secondary data analyses: (1) LTC need in PwD was approximated on the basis of indicators identified in study 1 on a small area level and (2) equity of LTC in PwD was analysed for Baden-Wuerttemberg. In study 3, data use was examined by exploring, how individuals actually read a data report and what role it has in their decision making. Therefore, a data report was created, which partly uses data from study 2 to describe needs and demands in long-term care exemplary in the Rhine-Neckar district of Baden-Wuerttemberg. This leads to the following research questions:

1. What data do stakeholders of the health system in Baden-Wuerttemberg consider as relevant for planning needs-based long-term care for persons with dementia?
2. What evidence for equity in long-term care among persons with dementia can in Baden-Wuerttemberg on a small-area level can be found?
3. How is a data report on regional needs-based planning of long-term care for persons with dementia used by individual decision makers?

In the following sections of the introduction, definitions and concepts of evidence-informed policy and equity underlying this thesis are presented. Further, the policy context of LTC will be shortly introduced.

The methods as well as the results section both are structured around the three studies each addressing one of the presented research questions. Study 1 reports a survey to identify health system indicators among different stakeholder groups of the health system in Baden-Wuerttemberg. The survey was part of a subproject initiated by the MSAI to explore current and future healthcare need on state and small area level along a selection of epidemiologically relevant chronic conditions to develop an indicator set, which should provide data to inform cross-sectoral, needs-based, health planning in the state's districts. This subproject, *Subproject 1*, was part of a larger program, the *Model Project Cross-Sectoral Healthcare* (Ministerium für Soziales 2018), and should further deliver regional data for the development of a cross-sectoral and needs-based healthcare concept within a model region. While the survey focussed on eight chronic conditions (anorexia nervosa, chronic lower back pain, colorectal cancer, diabetes type 1 and 2, stroke, depression, and dementia) and health(care) sectors from prevention to medical and palliative care, the presentation of indicators in study 1 will focus on indicators related to long-term care and dementia. Study 2 is also based on *Subproject 1* and aims to produce data on LTC for persons with dementia in Baden-Wuerttemberg which could be used to inform data-based healthcare planning, based on available secondary data by a) operationalising indicators on a small area level selected by a group of health system stakeholders in study 1 and b) conducting in-depth analyses on equity in long-term care among PwD. Study 3 is based on the *QuantEV* project (*influence of quantitative data reports on decisions in healthcare planning*). This project takes up on *Subproject 1* and the quantitative data report, which was produced in this proceeding project. The aim of QuantEV was to explore how a quantitative data report is used by individuals for health policy decision making using innovative methods. In the discussion section the three presented studies will be assessed in the light of the aim of this thesis. What conclusions can be drawn from these studies about the potential of data-based health policy making in Baden-Wuerttemberg in the area of long-term care for persons with dementia? Further, applied materials and methods, results, and literature of the particular studies are discussed, as they hold certain advantages and disadvantages in investigating the thesis's aim.

1.3 Concepts, definitions, and context of long-term care

In this section, first, the concepts and definitions of data-based policymaking in healthcare, which build the frame of this thesis's aim (section 1.2), are presented. Following this, the main concepts and definitions to investigate this aim, which underlie the three conducted studies, are described. Simultaneously, current knowledge and practices in the fields of indicator development (study 1), equity assessment (study 2), and data use (study 3) are briefly presented in general and in the context of the long-term care system for PwD in Germany.

1.3.1 Data-based policymaking in healthcare

At first sight, data-informed policymaking may simply refer to the use of data within decisions in policymaking, e. g. in healthcare. It can be subsumed under the broader term of evidence-based or, less misleading (Tannahill 2008), evidence-informed policymaking (EIP), where data refers to a specific form of evidence. To specify the potential of evidence use, the type of evidence one refers to needs to be defined as well as what actually is meant by 'using' it.

1.3.1.1 Type of evidence

The term of evidence proposed by Bowen and Zwi can be the result from a wide range of sources ranging from research with its different paradigms and study designs, e.g. presented in peer-reviewed scientific journal articles to knowledge and information found in published documents or reports including statistical analyses (Bowen and Zwi 2005). Evidence can be either provided by researchers, who may produce and report evidence in charge of a policymaker or on own merits, or by policymakers and their affiliated institutions. This broad definition of evidence goes beyond the idea of evidence often used in the research of EIP, where evidence refers to research produced by scientists only, published in peer-reviewed journals (Oliver et al. 2014b).

When it comes to data informed health system monitoring for the purpose of health system development and performance improvement, measures are needed. Since health and health system aspects, especially in the area of performance or quality are not measurable directly, indicators based on theoretical frameworks are used to approximate these latent constructs. Therefore, the subject of evaluation, e.g. the health system in a region, is presented in a system of categories. The individual categories are usually formed on the basis of theoretical concepts. A framework is a transparent starting point for a structured process of compiling a set of indicators. Many countries are motivated to evaluate their health systems to improve their performance. This may facilitate the achievement of targets such as equity of healthcare and helps to manage challenges, such as an increasing need for care (Kelley and Hurst 2006). Some countries have developed frameworks for indicators to measure performance in the healthcare system. The advantage of such frameworks is that they clarify how the performance of a healthcare system can be measured across its various dimensions and how these dimensions relate to the objectives of a health system (Canadian Institute for Health Information 2013). The OECD has compiled an overview of frameworks for measuring the performance of the health system and healthcare provision (Table 1). A distinction was made between frameworks that relate to the health system and those that relate only to healthcare as part of the health system.

Table 1: Overview of existing health and healthcare systems (Arah et al. 2006)

	Framework for health system performance	**Framework for healthcare system performance**
United Kingdom	✓	✓
Canada	✓	
Australia	✓	
United States of America		✓

European Community Health Indicators Project (ECHI)	✓	
The Commonwealth Fund's International Health Indicators Project		✓
World Health Organisation (WHO)	✓	
Organisation for Economic Co-operation and Development (OECD)	✓	

There has been some research on the question, what type of evidence or presentation format policymakers prefer. Evidence summaries are preferred over systematic reviews (Petkovic et al. 2016). Moreover, formats are proposed that are simultaneously orientated towards different user preferences (Wronski et al. 2021b). One such format under consideration is the 1:3:25 model. This format incorporates concise summaries for policymakers who prefer reading abstracts and conclusions, along with more extensive information that includes methodological background (Lavis et al. 2005). Findings based on empirical evidence from selected Australian public health decision-making entities indicate a higher reliance on internal data and reports compared to research evidence, with the latter being the least utilised (Zardo and Collie 2015). Similar trends are observed in research conducted in the context of US health policy (Dodson et al. 2015) (Wronski et al. 2021b).

1.3.1.2 Evidence use

Although there is a substantial amount of evidence being generated, there is limited understanding of how this evidence is put into practice by policymakers (Orton et al. 2011). Some guidance on analysing how policymakers use evidence is provided by Bowen and Zwi (Bowen and Zwi 2005). They identified the following three stages of use along the dimension of its processing: introduction, interpretation, and application. On the introduction stage a problem is specified and a wide range of questions is discussed. The interpretation stage comprises the uptake of evidence, e.g. by reading. In the application stage, sourced evidence is prioritised and weighted (Bowen and Zwi 2005).

Regarding the two stages of interpretation and application, there is a large body on EIP research concentrated on obstacles and supporting factors of evidence use (Oliver et al. 2014a; Orton et al. 2011; Tricco et al. 2016; van de Goor et al. 2017). The primary objective was to "bridge the gap" between the evidence produced by scientists and its utilisation by policymakers (Choi et al. 2016; Langlois et al. 2016; Mitton et al. 2007). The ‘*availability and access to research/improved dissemination*’ has been identified as the paramount barrier and facilitator of evidence utilisation concurrently (Oliver et al. 2014a). The focal point of this research is also subjected to critical discussion due to its inherent risk of neglecting other valid factors in policymaking. Notably, the examination of negotiating conflicting values within societies is perceived as an integral component of evidence-based policymaking (Cairney and Oliver 2017; Klein 2000; Saretzki 2019). This differentiates this concept from the evidence-based medicine (EbM) approach, marked in 1972 by Archie Cochrane (Cochrane 1972; Oliver et al. 2014b), which EIP is often linked to. Another critical point is, again, the type of evidence EbM refers to, which is usually based on randomised controlled trials and mainly delivers information on efficacy and effectiveness, which is not the only information needed in policy processes and decision making (Klein 2000; Tannahill 2008).

The analysis of how individuals engage with reports subsequent to their attainment of availability and accessibility has been comparatively underexplored. Nevertheless, such an examination may shed light on the prioritisation of information that influences their decision-making processes.

While the earlier mentioned research focus has been investigated mostly with means like questionnaires and interviews, there is a small but growing body of research exploring the reading of quantitative data or data reports by applying eye-tracking. Vass et al. (2018) investigated potential applications of eye-tracking technology to enhance the comprehension of outcomes derived from discrete choice experiments within the context of a breast screening program. Their utilisation of eye-tracking data aimed to corroborate self-reported attribute non-attendance and to scrutinise the influence of risk communication on the decision-making strategies of respondents (Vass et al. 2018). Similarly, King et al. (2020) employed eye-tracking methodology to examine the reading behaviour of clinicians perusing electronic health records for patients undergoing critical care. The eye-tracking data demonstrated potential efficacy as an alternative to manual selection in training a model designed to proficiently navigate an electronic health records system, thereby presenting pertinent information (King et al. 2020).

Adopting a rational choice perspective, one might anticipate policymakers to systematically evaluate the quality of provided information and integrate the most optimal available information into their decision-making processes. Nonetheless, decision-makers often deviate from a strictly rational approach, opting instead for an optimised decision-making strategy within the confines of cognitive limitations, a concept referred to as 'bounded rationality' (Battaglio et al. 2018; Simon 1955).

1.3.2 Financing, governance and data for policymaking in German LTC

This section focusses on the financing and governance of the German LTC system, and data to inform policymaking. Further information on LTC provision and need is presented within the introduction of the concepts of equity and need in sections 1.3.3 and 1.3.4.

Until the 1990ies LTC provision in Germany was primarily the task of the family. Additionally, social assistance schemes provided means tested benefits for people who could not afford LTC (Schulz 2010). In 1995 the German government introduced a system of LTC insurances. Since then, LTC insurances partly pay the cost of LTC benefits with the aim of covering basic LTC needs. According to the principle "LTC insurance follows health insurance" members of statutory health insurance automatically are a member of statutory LTC insurance, while members of private health insurance are obliged to contract with a private scheme (Schulz 2010). Accordingly, the majority (circa 90 % (Bundesministerium für Gesundheit 2023b; Statistisches Bundesamt 2023a)) of persons living in Germany is insured with the statutory scheme.

In general, statutory LTC insurance is funded by income-based insurance contributions (since July 2023: 3,4 % of gross income) (Bundesministerium für Gesundheit 2023a). Additionally, members without children pay 0,6 % (status: July 2023) of their gross income. Members of private schemes pay premiums related to their age and health state. In both schemes, statutory and mandatory private, employers pay circa half of their employee's contribution resp. premium.

The public law (mainly formulated in SGB XI) sets the frame for the self-administered statutory LTC insurance funds and – as there are many stakeholders in the pluralistic LTC system – emphasises regional cooperation e. g. by building regional networks (§ 12 Abs. 1 SGB XI). The responsibility of LTC insurance funds is to ensure the provision of LTC for their members, i.e. capacity planning, monitoring, organisation of care provision, assessment of LTC, and quality control. LTC insurances negotiate services and prices (usually collectively on federal level) and contract with specific providers. LTC insurance responsibilities are partly shared with the federal states (Länder) as they are responsible for a sufficient LTC structure. How planning and support of LTC facilities is realised in particular is regulated by law on the level of the Länder. There it is defined, e. g. to what extend a federal state pays for investment costs of nursing homes, which in the end also decides about the share of these costs forwarded from providers to their residents.

Guidelines for quality controls in LTC facilities are defined by the Medical Advisory Board [Medizinischer Dienst Bund] (before 2020 known as the Medical Advisory Board of the Health Insurance Funds) together with public bodes such as the Confederation of Municipal Authorities' Associations [Bundesvereinigung der kommunalen Spitzenverbände] and Federal Working Group of Supraregional Social Welfare Agencies [Bundesarbeitsgemeinschaft der überörtlichen Träger der Sozialhilfe]) as well as with the Federal Association of LTC Providers, and the Association of Private Insurances Funds (Schulz 2010).

An example of data use in LTC policymaking is the context of quality control. Medical Advisory Boards regularly assess the quality of LTC facilities in cooperation with other quality assessing bodies such as public surveillance authorities for accommodations offering LTC [Heimaufsicht] and document the results in reports within the Länder. These quality assessment reports are forwarded to LTC insurance funds. Depending on the extent and duration of quality deficiencies assessors observe, different measures are taken. These measures can range from proposals for quality-improvement to termination of the contract by the LTC insurance funds (Schulz 2010).

An important data base to inform LTC policymaking in Germany is the LTC statistics provided by the Federal Statistical Office and the Statistical Offices of the Länder. Since 1999 the Statistical Offices of the Länder survey the outpatient and inpatient care facilities every two years, while the Association of the Statutory Health and LTC Insurance Funds together with the Association of Private Health and LTC Insurers provide information on the recipients of LTC cash-benefits – i.e. persons in need of care who are mostly cared for by relatives. The aim of the LTC statistics is to obtain data on the supply and demand for LTC to inform capacity planning and it is also needed for the further planning and development of the LTC Insurance Act, the legal frame of the LTC system (Statistisches Bundesamt 2023b).

1.3.3 Equity in healthcare

Generally, equity means a just distribution of goods. To answer the question, to what extent a health system is equitable, requires at least two considerations: First, what is the good that is distributed? Second, what makes a distribution just?

Regarding the first consideration, health could be the intuitive good. But health is determined not only by social factors and therefore cannot be distributed by a society. For example, the risk for getting the Alzheimer's disease as one of the most frequent causes of dementia is partly explained by genetics. Given that healthcare contributes to health, distributing healthcare, as the chance for better health (Daniels 2012), seems more appropriate as it can be produced and the resources for production quantified and distributed.

A just distribution depends on its accordance to a normative principle or ethical paradigm. When it comes to the distribution of healthcare, egalitarianism seems to be the predominant normative principle. The choice of egalitarianism in healthcare as preferred normative principle has been expressed in many ways, e.g. in the human right for medical care defined in the Universal Declaration of Human Rights, the World Health Organisation (WHO)'s aim of universal health coverage (UHC), where "UHC means all people receiving the health services they need […]" (World Health Organization 2015), and specifically in the context of this thesis, in the German social code as stated earlier. These examples also show another element of equity based on egalitarianism: a feature which defines individuals as equal, which in the context of healthcare mostly is defined as need for health(care) (Wagstaff and van Doorslaer 2000). On this conceptual and normative basis, a healthcare distribution is defined as equitable, when equals in terms of healthcare need are treated equally irrespective of other characteristics, which is also referred to as horizontal equity, and unequals are treated appropriately unequally (vertical equity) (O'Donnell et al. 2008; Olsen 2011; van Doorslaer et al. 2000; Wagstaff and van Doorslaer 2000). Hence, horizontal equity means that healthcare distribution should be independent of other characteristics (non-need factors), such as an individual's ability to pay or its income, its socioeconomic status, or place of living (O'Donnell et al. 2008; Olsen 2011; van Doorslaer et al. 2000; Wagstaff and van Doorslaer 2000; (Wagstaff et al. 1991).

Need is a construct which cannot be measured directly but can only be approximated. From a health services research perspective there are three main elements which constitute healthcare need: one element is ‘subjective’ need which refers to an individual’s wish or preference for a certain health service (Sachverständigenrat für die Konzentrierte Aktion im Gesundheitswesen 2001). Another element is called ‘objective’ need which is given, when a health professional diagnoses a disease or dysfunctionality based on scientific criteria. Lastly, there can be only need for healthcare, if there exists a treatment or health technology to address a disease or dysfunctionality effectively (Sachverständigenrat für die Konzentrierte Aktion im Gesundheitswesen 2001).

1.3.4 Horizontal equity in long-term care among persons with dementia

After having introduced the concept of horizontal equity, in this section it is outlined how healthcare need and non-need factors translate to need for LTC in persons with dementia in general and specifically in the context of the German social LTC system. This is meant to set a conceptual starting point for the measurement of horizontal equity in LTC in persons with dementia in Baden-Wuerttemberg and to provide some current knowledge from other studies.

Dementia, according to the International Statistical Classification of Diseases and Related Health Problems, Revision 10 (ICD-10) definition, is a clinical syndrome following a chronic or progressive brain disease. Patients usually suffer from the decline and loss of cognitive functions and everyday life skills such as lack of temporal and spatial orientation, communication skills as well as autobiographic identification and personality traits. In the severe stage the consequence often is the complete dependency from others. Persons with dementia are typically affected with comorbidities and have a shorter life expectancy. Dementia symptoms often place a high emotional burden on relatives and dependants. Furthermore, there is a physical burden from taking care of a patient’s personal hygiene and from the disruption of patients’ day-night-rhythm which results in a higher risk of mental and physical diseases for dependants of persons with dementia.

Therapeutic options are not able to provide a full remission for persons with dementia. Current therapy aims to treat cognitive and mental symptoms in order to maintain patients’ everyday life competencies and health related quality of life as long as possible. In the end, disease progression mostly cannot be stopped, so that patients are affected by care dependency in the course of their disease. Persons with dementia (PwD) have a 3 to

10 times higher risk for care dependency than persons without this diagnosis and dementia is one of the most frequent diagnoses care dependency is based on within the German system of statutory LTC insurance (Beekmann et al. 2012; van den Bussche et al. 2014). In summary, there is an essential need for LTC in PwD.

Within the statutory LTC system persons in need of care, once their care dependency has been determined in a formal process, have access to mainly three types of benefits: in-cash benefits to compensate informal caregivers, the reimbursement of expenses for an outpatient care service, and finally care provided in a nursing home. The first two options both refer to the home setting and can be utilised and reimbursed either separately or combined.

Depending on how much support and care a person needs, one is assigned a specific level of care dependency (LoCD), which determines how much benefits are covered by LTC insurance. As mentioned earlier, this also means that insurance coverage is capped, covered amounts increase with LoCD, but usually not all LTC expenses of insured are covered, out-of-pocket payments are required by design (Rothgang 2010).

The criteria for care dependency to be eligible for benefits from the statutory LTC insurance as well as the corresponding benefits changed with LTC reforms of the past years (Forstner et al. 2019). At first, only physical need for activities and limitations of instrumental activities in daily living (ADL) were regarded as relevant criteria to be eligible for benefits from LTC insurance. Persons affected with cognitive impairments such as PwD often fell through the cracks of these eligibility criteria, although they experience limitations in their everyday competence. This partly changed with the Act to Realign Long-Term Care (*Pflege-Neuausrichtungs-Gesetz*) in 2013, which allowed persons with limited everyday competence such as PwD to utilise in-kind and in-cash benefits for homecare, although they were not assigned to a LoCD (so-called ‘LoCD 0‘). In 2017 a new definition of LTC need was introduced, which also includes cognitive impairments as eligibility criterion, replacing the three LoCD by a five-level system (*Zweites Pflegestärkungsgesetz – PSG II*).

A main principle of LTC insurance services is “outpatient care before inpatient care” preferring home-based care, either provided by informal caregivers such as family members or provided by an outpatient care service over inpatient care (Schulz 2010). In Baden-Wuerttemberg this preference was also expressed in the so-called '*Gesundheitsleitbild*', which are guidelines for future design changes of the health and LTC system in the federal state defined by a broad range of health and LTC system stakeholders such as patients, citizens, service providers, payers, local health authorities, and other state bodies (Landesgesundheitskonferenz Baden-Württemberg 2014).

While an institutional care setting seems to be most appropriate for PwD in higher stages of the disease, there are preferences and interventions to postpone the transition from home to the institutionalised setting as far as possible because of manifold reasons: the transition yields risks for the well-being of PwD, such as anxiety, depression, and frailty, and is often experienced as losing the own home, the familiar neighbourhood and circle of acquaintances (Brodaty et al. 2001; Fazio et al. 2018; Scocco et al. 2006; Sury et al. 2013). From the perspective of statutory LTC insurance, homecare for PwD is less costly than a nursing home (Michalowsky et al. 2019). Nevertheless, it has been observed that a dementia diagnosis comes along with a higher utilisation of LTC, but to a lesser degree of homecare, when compared with a similar population without dementia (Forma et al. 2011). Evidence on the appropriateness of other housing options such as assisted living in a flat sharing community is scarce.

In the case of homecare for persons with dementia horizontal equity means that access to homecare services and in-cash benefits to compensate informal carers should primarily be driven by need for LTC and factors associated with it such as a dementia diagnosis, high age, and comorbidities and should be independent of other factors than need.

Research on non-need factors

Previous research on the utilisation of LTC and healthcare has identified different factors other than need which were associated with utilisation. Among persons with dementia older men were observed to attend specialised physicians more likely than their female counterparts (Albert et al. 2002; Eisele et al. 2010; Schubert et al. 2007). That older men – in contrast to older women - are more likely to live with a spouse who takes charge of the husband's consultations is discussed as an explanation for this observation (Eisele et al. 2010). In Germany, citizenship has been identified as another non-need factor for being entitled to LTC and utilizing institutionalised LTC among persons with dementia in favour of persons with German citizenship (Stock et al. 2018). In Spain it has been found that utilization of formal LTC among disabled persons was higher among the better-off

(Garcia-Gomez et al. 2015). With regard to LTC entitlements and utilisation of homecare, in the Netherlands there have been observed differences due to place of residence (Tenand et al. 2020).

2 Materials and Methods

Almost the whole description of materials and methods provided in section 2.1 can also be found in (Wronski et al. 2021a) except information referring to dementia and LTC in section 2.1.3. The whole description of materials and methods in section 2.3 can be found in (Wronski et al. 2021b).

2.1 Study 1: Survey on indicator selection from the perspective of health system stakeholders in Baden-Wuerttemberg

This study is part of *Subproject 1*, which was dedicated to establishing an indicator database providing information on the level of administrative districts to facilitate local needs-based policymaking in Baden-Wuerttemberg. Embedded within a larger program initiated by the Ministry of Social Affairs and Integration of the German state Baden-Wuerttemberg, the project sought to explore the operationalisation of regional policymaking aligned with the objectives outlined in the *Gesundheitsleitbild*. embedded in the *Model Project Cross Sectoral Healthcare* initiated by the Ministry of Social Affairs and Integration of the German state Baden-Wuerttemberg. The project predominantly concentrated on 8 prevalent chronic diseases: anorexia nervosa, chronic lower back pain, colorectal cancer, dementia, depression, type 1 and type 2 diabetes mellitus, and stroke. By emphasising these specific chronic conditions, the project endeavoured to approximate the concept of health need, principally through disease-specific morbidity (Scholten et al. 2016). The temporal scope of the project spanned from January 2016 to April 2018 (Wronski et al. 2021a).

2.1.1 Study design

The stakeholder online survey followed the format of the initial round of a Delphi study. Originating as a method designed to facilitate decision-making in scenarios characterised by either insufficient or overwhelming information, the Delphi method involves soliciting input from numerous experts concurrently, typically through the administration of a postal or online questionnaire, and occasionally supplemented by meetings if regarded necessary (Jones and Hunter 1995; Linstone and Turoff 1975) (Wronski et al. 2021a).

In study 1, institutions representing key stakeholder groups within the state's health system were invited to evaluate the relevance and comprehensibility of systematically researched indicators using a standardised online questionnaire. The methodological framework employed in this endeavour drew inspiration from the RAND/UCLA Appropriateness Method (RAM) (Fitch et al. 2001), a methodology routinely utilised for the selection and development of healthcare quality indicators. This method has also found application in German quality indicator development and healthcare planning, notably in specific healthcare sectors such as the emergency rescue service in Baden-Wuerttemberg (SQR-BW Stelle zur trägerübergreifenden Qualitätssicherung im Rettungsdienst Baden-Württemberg 2014) (Wronski et al. 2021a).

The Delphi element of the RAM was particularly apt for the study's initial context, given the imperative of choosing from a large set of available indicators. Participants in the online survey received written information elucidating the study's context, data collection procedures, and data security measures. Participation was voluntary and contingent upon participants providing informed consent. Data was collected and analysed at an individual level in an anonymous manner. Notably, the research ethics committee of Heidelberg University Hospital granted a waiver for ethics approval for *Subproject* 1, within which study 1 was situated (Wronski et al. 2021a).

The stakeholder survey was preceded by the formulation of a conceptual framework for indicators and a systematic search for indicators. The comprehensive procedural steps, spanning from the initial problem definition to the ultimate selection of indicators, are delineated in Figure 2 (Wronski et al. 2021a).

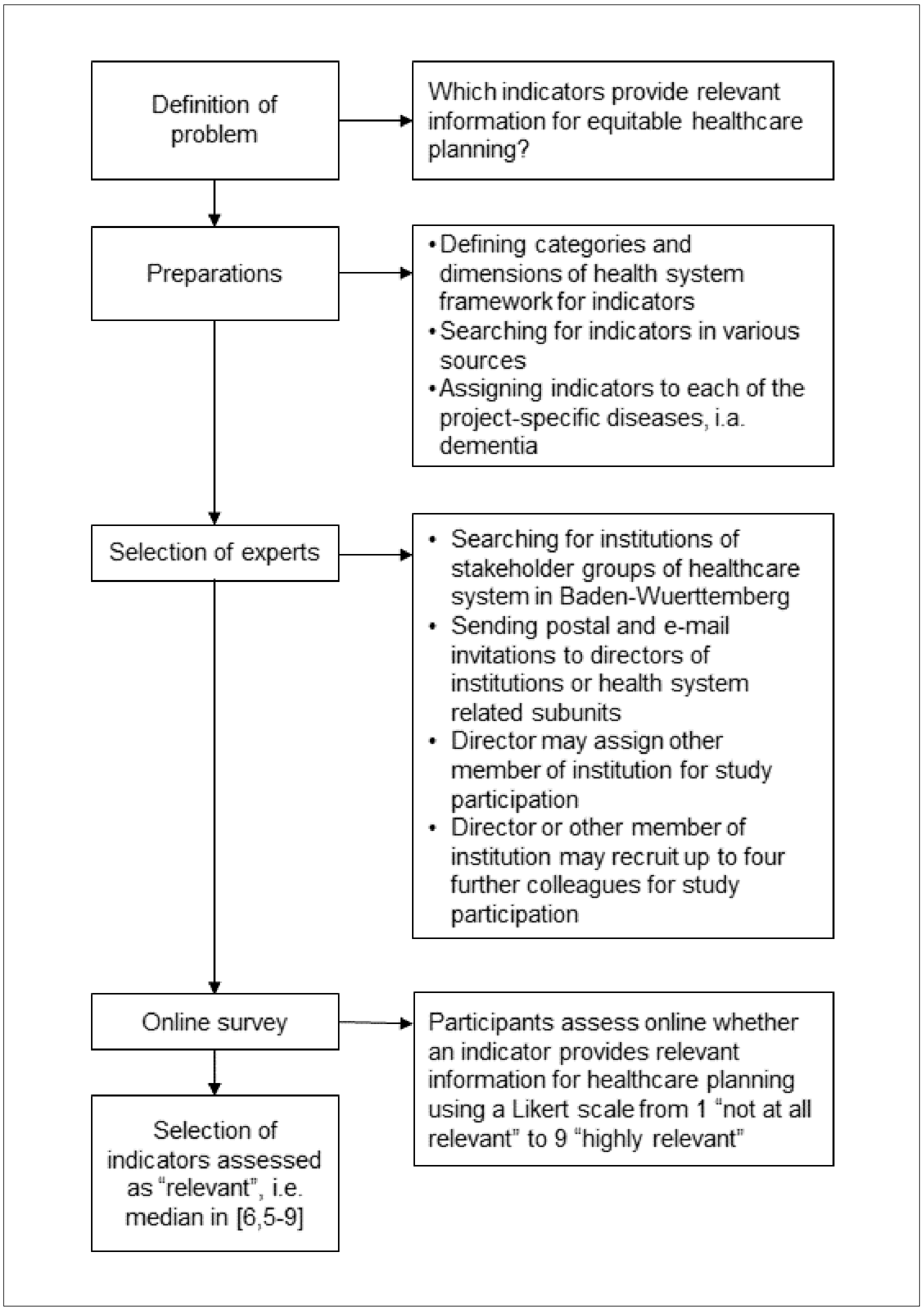

Figure 2: Process of indicator selection (own figure based on (Wronski et al. 2021a))

2.1.2 Conceptual framework and its development process

To facilitate the systematic search and selection of indicators, *Subproject 1* undertook the development of a conceptual framework in collaboration with the project group from the *Model Project Cross-sectoral Healthcare in Baden-Wuerttemberg*. This project group comprised representatives from 8 institutions, namely the Ministry of Social Affairs and Integration of the German state Baden-Wuerttemberg, a state-level population health organisation, 3 district-level population health organisations, and academic colleagues from two universities. The objective was to create a comprehensive conceptual framework that encompassed all facets of the health system, including medical care in hospitals, primary prevention, and health promotion. The framework aimed to be descriptive, predominantly listing health system dimensions and organising them hierarchically, aligning with the project's predefined objectives (Wronski et al. 2021a).

The initial version of the framework was developed through collaborative efforts within the study group. The starting point involved an international preselection of 8 existing health (care) system frameworks, as enumerated by (Arah et al. 2006). This preselection seemed adequate, as it offered diverse dimensions arranged in various manners. The resultant initial framework drew heavily from the Canadian Health Indicators Framework (Canadian Institute for Health Information 2013), as it aligned most closely with the project's goal of comprehensive and descriptive arrangement of dimensions. The Canadian framework not only categorises health system performance indicators but also encompasses indicators of public health, aligning well with the project's aim to provide data on healthcare needs and corresponding supply, inclusive of primary prevention and health promotion. As the project embraced a broad concept of cross-sectoral healthcare, encompassing non-medical determinants of health, the Canadian framework's inclusion of such data was deemed essential. This preliminary framework, comprising 4 dimensions, underwent further refinement based on feedback obtained during project meetings and individual input from project group members, resulting in the final version unanimously endorsed by the project group (Wronski et al. 2021a).

In Table 2 the final version of the framework is presented together with a description for each sub-dimension.

Table 2: Structure and definitions for sub-dimensions of the framework for indicators of the health system in Baden-Wuerttemberg (Wronski et al. 2021a)

Framework sub-dimension	**Description**
Non-medical determinants of health	
Health behaviours	This sub-category includes self-harming and positive health behaviours. Actions of healthcare planning may aim to promote positive health behaviours.
Social determinants	Social determinants of health embrace the two sub-categories living and working conditions and environmental factors of the Canadian framework. According to the WHO, social determinants of health describe conditions individuals are born, grow up, live, work, and grow old with.
Demographic factors	Population characteristics such as age and gender fall under this sub-category.

Framework sub-dimension	Description
Health status	
Morbidity	In this sub-category, primarily indicators concerning frequency of diseases focused in the project are included.
Mortality	Information on mortality was to be collected mainly for the calculation of health system performance indicators but also to approximate regional health status.
Utilisation of the health system	
Prevention and health promotion	Through indicators assigned to this sub-category, utilisation of prevention or health promotion services and structures is measured.
Outpatient care	This sub-category includes the utilisation of services offered in practices, ambulatory healthcare centres, and domestic setting.
(Semi-residential) inpatient care	This sub-category subsumes the utilisation of services offered in hospitals, rehabilitation clinics, and nursing homes.
Health system performance	
Accessibility	Derived from the OECD's Health Care Quality Indicators Framework accessibility defines how easy healthcare services are accessible. Access can be physical, financial, or psychological and requires the existence of the particular healthcare service.
Patient centeredness	Patient centeredness is achieved, when healthcare provision is orientated on patients' wishes, expectations, and satisfaction.
Continuity	Continuity describes the degree to which healthcare provision for specific users is coordinated between health professionals and other institutions.
Effectiveness & efficiency	Effectiveness describes the degree to which a healthcare service achieves a desired result whereas efficiency means the optimal use of available resources to achieve maximum benefit.
Safety	Safety describes the degree to which healthcare processes avoid, prevent, or improve adverse events resulting from healthcare itself.
Healthcare provision	
Facilities	This sub-category includes a variety of health facilities with a focus of those which are especially relevant for patient groups selected in the project.
Professionals	Indicators of this sub-category were meant to include all health professionals having direct contact to either patients or their dependants such as physicians, psychologists, and nurses.
Technology	This sub-category subsumes health related products such as medical machines like computer tomography scanner, and telemedicine.
Honorary office	Besides health professionals health related support is also provided by other patients, e.g. in self-help groups or other patient organisations, and by other persons on a voluntary basis.
OECD: Organisation for Economic Cooperation and Development; WHO: World Health Organisation	

The final iteration of the framework exhibits notable distinctions from its initial version, incorporating the following modifications: the addition of utilisation of the health system as the fifth dimension. Unlike the Canadian framework, where utilisation is dispersed across various dimensions, the proposed framework emphasizes utilisation as a distinct dimension. This emphasis is attributed to the necessity of the indicator set to facilitate analyses of cross sectoral patient paths and an approximation of future healthcare demand (Wronski et al. 2021a).

Furthermore, several additional changes were implemented, encompassing the introduction of new sub-dimensions such as social determinants and mortality. Notably, separate sub-dimensions were designated for professionals, technology, and honorary office. Examining the arrangement of dimensions in the resulting framework through the lens of a health production process, health status occupies a central position. This centrality is twofold, influenced by non-medical determinants of health and health system factors, including the utilisation of services, the performance of the health system, and the structure of health supply (Wronski et al. 2021a).

2.1.3 Search for indicators

Utilising the framework in its final version, a structured search for indicators was undertaken. Initially, indicator sources were delineated based on types described by the aQua Institute, a German research institution specialising in quality indicator development (aQua – Institut für angewandte Qualitätsförderung und Forschung im Gesundheitswesen GmbH 2015). Subsequently, indicators were chosen from these sources if they aligned with at least one sub-dimension of the framework. In cases where indicators pertained to more than one possible sub-dimension, assignment to the final sub-dimension was carried out by a second member of the study group. An overview of identified indicators, categorised by the type of source from which they were extracted, is presented in Table 3, encompassing all project diseases (including dementia) and health sectors, with specific attention to dementia and/or long-term care. Table 21 (Appendix) comprises a detailed list of indicators and their respective sources related to dementia and/or LTC (Wronski et al. 2021a). A comprehensive list of all proposed indicators is provided by Wronski et al. as supplementary information (Additional file 1) (Wronski et al. 2021a).

Table 3: Number of identified indicators by type of indicator source in total and for dementia and/or LTC (own table)

Type of indicator source	**No. of identified indicators**	
	Total	**Dementia and/or LTC**
indicator sets of German and international institutions and agencies	211	12
clinical practice guidelines	50	4
data bases	35	13

Type of indicator source	No. of identified indicators	
	Total	**Dementia and/or LTC**
published literature	35	25
indicator databases	25	0
other sources	18	10
Sum	374	64
LTC: long-term care		

Across all framework dimensions 374 indicators were identified, with 65 of these specifically pertaining to dementia within the dimensions of non-medical determinants of health and health status (e.g. "most common comorbidities in patients with dementia") and/or LTC within the dimensions of utilisation of the health system, performance, and provision (e.g. "inhabitants per and number of out-patient nursing facility"). Predominantly, the indicators were sourced from indicator sets provided by German and international institutions and agencies, constituting 56 % (N = 374) of the total indicators. Notably, dementia and LTC-related indicators were predominantly sourced from published literature, comprising 42 % (N = 65) of the identified indicators. The category "other sources" encompasses indicators obtained through requests from an academic project partner affiliated with the 3 district-level public health authorities within the project group, as well as suggestions from the study team that were not derived from a specific indicator source (Wronski et al. 2021a).

2.1.4 Recruitment of stakeholders

The target group of the indicator survey was defined as stakeholders within the health system of Baden-Wuerttemberg. Given the expansive scope of indicator aspects, the objective was to involve stakeholders familiar with at least one dimension of the developed framework for indicators, without necessitating comprehensive knowledge of all dimensions. The study delineated 5 key stakeholder groups: (1) patients/citizens, (2) healthcare providers, (3) population health organisations, (4) financing agencies, and (5) quality assurance agencies/statistical office (Wronski et al. 2021a).

The sampling strategy employed was purposive sampling of institutions, as outlined by (Battaglia 2008). Certain institutions, exclusively from population health organisations, were already integrated into the project group. The patient/citizen category comprised representatives from self-help groups and other voluntary institutions offering patient support, specifically targeting individuals affected by one of the 8 focal diseases. The stakeholder list encompassed institutions specialising in all 8 diseases or domains related to these diseases. Additionally, institutions representing citizens engaged in the living environment of other vulnerable groups were approached, with the expectation that their expertise would be particularly valuable for indicators pertaining to non-medical determinants of health. Within the financing agencies group, the largest in terms of membership, were social and private health insurers, social pension schemes, and social accident insurances operating in Baden-Wuerttemberg. Healthcare providers were identified through their representative organisations, predominantly relevant for delivering healthcare to patients with one of the 8 diseases. This included professionals such as physicians, psychologists, nurses, physiotherapists, and occupational therapists. Quality assurance agencies/statistical office encompassed disease-specific registers, for example (Wronski et al. 2021a).

Invitations for study participation were sent to 54 institutions were, comprising 13 patient/citizen representatives, 6 population health organisations, 10 financing agencies, 21 healthcare providers, and 4 quality assurance agencies/statistical offices. All invitations were disseminated via both postal mail and a 3-day delayed e-mail recruitment strategy. The invitations included comprehensive descriptions of the online survey. The directors of the invited health institutions or relevant subunits were the primary addressees. Considering the considerable number of indicators and diverse topics involved, with the assessment potentially exceeding 3 hours for an individual, directors were afforded the option to nominate up to 4 additional members from their institution to partake in the survey (Wronski et al. 2021a).

2.1.5 Questionnaire

The online platform employed for the stakeholder survey was developed and overseen by the research group's department. This platform provided explicit study information detailing the primary objective, which was to assess the relevance of proposed indicators for informing healthcare planning across sectors. Participating institutions were requested to specify the number of representatives from their respective organisations who would be taking part in the survey (Wronski et al. 2021a).

The assessment page for a single indicator encompassed its identification number, the designated dimension and sub-dimension it was intended to operationalise, and a summarising name indicating the content of the indicator. As a consequence of accommodating the extensive number of indicators, the names of many indicators were more comprehensive than their original sources. This compromise was necessitated by the need to include additional information in indicator names while forgoing further specifications, such as operationalisation. Given that one of the primary objectives of the study was to involve stakeholders in the reduction of the collected indicators, aiming for a reduction of approximately one-third, stakeholders were tasked with assessing the relevance of each indicator. This assessment was conducted using a Likert scale ranging from 1 (not relevant at all) to 9 (highly relevant). An illustrative example of the assessment view is provided in Figure 18 (Appendix) (Wronski et al. 2021a).

The global criterion of 'relevance' encompasses various definitions. In the RAM process, a comparable concept to relevance is appropriateness, which pertains to the benefits and harms that a medical intervention may pose for patients (Fitch et al. 2001). Carinci et al. defined an indicator as relevant when it "[measures] an aspect of quality with high clinical importance, a high burden of disease or high health care use [...]" (Carinci et al. 2015). In the context of this study, where the focus is on selecting indicators not only for health system performance but also for other health system dimensions, such as non-medical determinants of health, relevance is understood as the indicator's ability to measure an aspect perceived as important for comprehensive healthcare planning by stakeholders. This aligns with the initial point of the definition provided by Carinci et al. (Wronski et al. 2021a).

Another aspect considered was the comprehensibility of the indicators, indicated by a 'yes' or 'no' response. This inquiry pertained to the clarity of an indicator's name, aiming to gauge whether stakeholders perceived a clear understanding of the aspect intended to be measured by the proposed indicator. The results of this assessment were intended for use post-indicator selection, with the aim of identifying indicator names that might require revision. To serve this purpose, a 'yes or no' assessment was deemed sufficient. Additionally, stakeholders were given the opportunity to provide comments for each indicator, offering a more nuanced perspective on their comprehension and potential concerns (Wronski et al. 2021a).

At the end of the survey, participants were prompted to categorise their institution into one of the specified stakeholder groups. Subsequently, they were requested to rank each stakeholder group based on the perceived relevance of the role each group should play in healthcare planning. This ranking was done on a scale ranging from 1 (low) to 7 (high). The purpose of this question was to establish weights for each stakeholder group, intending to assign significance to the relevance ratings of the institutions based on their associated stakeholder group. This approach aimed to capture and incorporate the diverse perspectives and priorities of the various stakeholder groups in the healthcare planning process (Wronski et al. 2021a).

To mitigate potential challenges associated with the substantial number of indicators to be assessed, several adjustments were made in the question mode to minimise withdrawal rates and uphold data quality. Participants were afforded the option to activate a filter, restricting the assessment to indicators relevant for one or more selected diseases emphasised in the project. Moreover, indicators that had already been assessed by any participant from the same institution could be filtered. Additionally, participants had the flexibility to exit the assessment area and rejoin during the field phase, retaining information about processed indicators from previous sessions (Wronski et al. 2021a).

2.1.6 Data Analysis

The survey data underwent processing and analysis using IBM SPSS Statistics Version 24 and Microsoft Excel 2010. The assessments of indicators were analysed at the institutional level, while the closing questions regarding stakeholder ratings were analysed at the individual level (Wronski et al. 2021a).

The sole selection criterion for an indicator in this study was relevance, aligning with the objective of identifying relevant indicators for healthcare planning from a stakeholder perspective. Similar to other contexts of indicator development, relevance is frequently employed as a central selection criterion (aQua – Institut für angewandte Qualitätsförderung und Forschung im Gesundheitswesen GmbH 2015). Adhering to the approach of the RAM, an indicator was categorised as 'relevant' if its median score fell within the range of 6.5 to 9, classified as 'uncertain' for scores ranging from 4 to 6, and deemed 'not relevant' for scores in the range of 1 to 3. The selection process, from problem definition to the identification of 'relevant' indicators, is illustrated in Figure 2 (Wronski et al. 2021a).

Comprehensibility was specifically analysed for indicators categorised as 'relevant.' If an indicator received at least one rating indicating a lack of comprehensibility, metadata adjustments were made for the model project's final report. These adjustments primarily focused on refining the indicator's name and providing a concise description to enhance clarity and understanding. This process aimed to ensure that indicators deemed relevant were not only meaningful but also conveyed their intended meaning clearly to stakeholders (Wronski et al. 2021a).

The content of comments was analysed to gather insights that could guide adjustments to the measurement and names of 'relevant' indicators. As part of this analysis, comments were specifically examined for 'relevant' indicators where no operationalisation was provided in the indicator's source. Additionally, comments were scrutinised for 'relevant' indicators that received a rating of 'not comprehensible' from at least one institution (Wronski et al. 2021a).

The identification of an institution's stakeholder group was accomplished by analysing its pseudonyms, which were also provided to institutions for logging into the online assessment area. Prior to dissemination, the pseudonyms had been categorised according to the corresponding stakeholder groups (Wronski et al. 2021a).

2.2 Study 2: Secondary data analyses on long-term care in persons with dementia and its equity in Baden-Wuerttemberg

Two sets of secondary data analyses were conducted to explore possibilities and limitations of available regional secondary data in measuring LTC need in PwD and its equity in Baden-Wuerttemberg.

First, regional LTC need in PwD was approximated by indicators from the two dimensions health status and utilisation. Indicators originate from study 1. Here, only indicators, which were classifiable as relevant for healthcare planning from a health system stakeholder perspective, were measured cross-sectionally with secondary data on the level of districts in Baden-Wuerttemberg. These selected indicators at the same time are part of the results of study 1. A list of indicators related to dementia and LTC is provided in Table 21 (Appendix).

The other set of secondary data analyses explored possibilities and limitations of analysing equity in LTC among persons with dementia on a small area level following the concept of horizontal equity introduced in sections 1.3.3 and 1.3.4. Due to the policy emphasis on homecare as outlined in section 1.3.4, these analyses focussed on this LTC-setting.

Both analysis sets are embedded in the same project (subproject 1) as study 1 and are partly based on the same data sources.

2.2.1 Indicators on long-term care need in persons with dementia

Criteria for the measurement of indicators on dementia and LTC were mainly derived by the underlying subproject 1 of the model project. There, secondary data sources were used to measure indicators, when they met the following criteria:

- They were available on the level of districts.
- They were collected regularly.
- Different secondary data sources should refer to the same year of observation.
- As far as possible, they comprised information about different dimensions of the framework for indicators (Table 2).

At the time of the search most secondary data sources referred to the observation year 2013. This was mainly because of the Long-Term Care Statistics, which are collected every two years. Further information on the measurability, operationalisation, used data sources and their data providers of each indicator dementia and LTC related indicator is provided in Table 22 (Appendix)

All LTC need indicators were measured with administrative data from the statutory health insurance company “Allgemeine Ortskrankenkasse” (AOK) Baden-Wuerttemberg. On this basis age and sex specific rates were extrapolated to the according populations of the administrative districts and Baden-Wuerttemberg in total. An overview on the percentage of inhabitants insured with the AOK for each administrative district and Baden-Wuerttemberg is provided in Figure 3, which was taken from the final report of the model project (Ministerium für Soziales 2018).

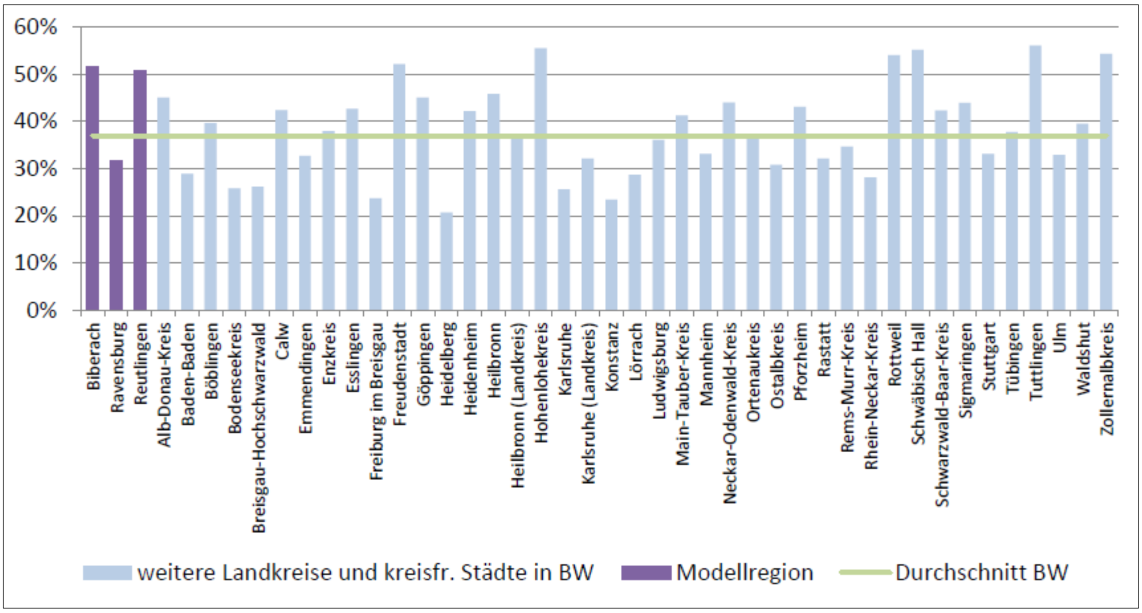

Figure 3: Portion (%) of persons insured with the AOK in the resident population in 2013 in administrative districts of Baden-Wuerttemberg, taken from the final report of the model project (Ministerium für Soziales 2018)

2.2.2 Horizontal equity in LTC for persons with dementia in Baden-Wuerttemberg

2.2.2.1 Study design

This study was designed as a retrospective cross-sectional study based on claims-based data on LTC utilisation of a large statutory health insurance company, official sources of population statistics, and other secondary data. Most data were related to the German state Baden-Wuerttemberg in the year 2013.

2.2.2.2 Study population

The study population was composed of people insured by the statutory health insurance company AOK Baden-Wuerttemberg, who were diagnosed dementia (see ICD-10 German Modification[GM] codes below), aged 65 and older, continuously insured with AOK in 2013, not living in a nursing home, and could be assigned by postal code to an association of municipalities in Baden-Wurttemberg.

Dementia diagnoses were defined by using claims data from the years 2012 to 2014 from inpatient and outpatient care as displayed in Table 4. Outpatient diagnoses were internally validated by using only confirmed diagnoses, which were documented for at least two quarters. Diagnoses were based on the International Classification of Diseases in the 10th revision of the German modification (ICD-10-GM) and defined as dementia diagnosis using the ICD-10-GM-codes F00, F01, F02, F03, F05.1, G30, G31.0, and G31.82.

Table 4: Criteria to identify persons with a documented dementia diagnosis (own table based on (Forstner et al. 2019))

Outpatient diagnoses
• only confirmed diagnoses **and** • outpatient diagnoses in at least 2 quarters of 2013 **or** • outpatient diagnoses in at least 2 quarters of 2012 **or** • outpatient diagnoses in 1 quarter in 2012 AND 1 quarter in 2013 **or** • outpatient diagnoses in at least 1 quarter in 2014 AND 1 quarter in 2013 **or** • outpatient diagnoses in 1 quarter in 2012 AND at least 1 quarter in 2014
Inpatient diagnoses
• at least one case with dementia diagnosis as main diagnose in 2012 **or** 2013 at discharge
Cross-sectoral diagnoses
• 1 outpatient diagnose and 1 inpatient secondary diagnose at discharge in 2012 **or** 2013 • 1 outpatient diagnosis in 2012 **and** 1 inpatient secondary diagnose in 2013 and vice versa • 1 outpatient diagnosis in 2013 **and** 1 inpatient secondary diagnose in 2014 and vice versa

2.2.2.3 Data sources

Data were collected from a number of different data sources. First, data on patient characteristics and long-term care utilisation were provided by the AOK Baden-Wuerttemberg on individual level for the years 2013 as observation period and 2012 to 2014 for the validation of diagnoses. These claims data were originally processed for scientific use within the evaluation of general practitioners-centred care (Laux 2017). The AOK-Baden-Wuerttemberg approved the use of this data within the associated project of this study. For the evaluation of general practitioners-centred care several data protection measures were obtained to meet requirements of European data protection laws. These include pseudonymisation of insured and healthcare providers by coarsening data on identifying characteristics to such a degree making re-identification so extensive that it is nearly impossible.

Secondly, socioeconomic data aggregated on the level of municipalities associations was retrieved from the data source *German Index of Socioeconomic Deprivation (GISD) Version 1.0* (Kroll and Robert Koch-Institut 2017). This data source was generated by researchers from the Robert Koch Institute, a central governmental scientific institution in the fields of biomedicine and public health in Germany. The GISD dataset is available online for free and provided by the SowiDataNet – datorium. This research data repository is run by the GESIS Leibniz Institute for the Social Sciences and allows researchers to share their primary and secondary data with the scientific community.

The third data source was the List of Long-Term Care Facilities in Baden-Wuerttemberg (*Pflegeverzeichnis Baden-Württemberg*) on the level of addresses provided by and purchased from the Statistical Office of the Federal State Baden-Wuerttemberg. This list is only available for the year 2013 and includes data about outpatient LTC services and nursing homes, which agreed to publication and comprises almost all service providers.

Further data on characteristics of municipalities associations were retrieved from the Regional Database Germany GENESIS of the Federal Statistical Office and the Statistical Offices of the Länder. This data source is available online for free.

For sensitivity another SES-variable was used. It is based on microdata for the population and households in Baden-Wuerttemberg from the Microcensus (*Mikrozensus*), which is an official statistical survey provided by the Federal Statistical Office. It is based on a representative sample of one percent of the German population and households and includes multiple subjects such as population structure, economic and social situation of the population, employment, occupation, and living conditions (Research Data Centres of the Statistical Offices of the Federation and the federal states 2019). Microcensus data were accessed through on-site use in a safe centre (*Gastwissenschaftlerarbeitsplatz, GWAP*) of the Federal Statistical Office and the Statistical Offices of the Länder.

The *GISD Version 1.0* data source refers to 2012. Further data sources refer to the year of 2013. Aggregated data were linked with claims data on the level of municipalities associations, which appeared to be the smallest regional level possible given the available data. Data processing for the presented analyses and data linkage were conducted with MariaDB Server 10.1.5 (64 Bit).

2.2.2.4 Measures

The central outcome in the study is the utilisation of homecare by an individual. Based on claims data, utilisation was operationalised as utilisation of a professional outpatient LTC service or the receipt of in-cash benefits from the health insurer in December 2013 and was coded binary. In-cash benefits from the health insurer are thought to compensate informal caregivers. A distinction between professional services and in-cash benefits was not made in the data. Eligibility for homecare was the model's second outcome variable, because it partly determines the accessibility of homecare, though it is not equal to utilisation. On the other hand, it can be partly regarded as proxy for need for LTC as eligibility for LTC is assessed professionally. For descriptive purposes, LoCD had five codes including all possible LoCD (0 to 3) and no LoCD. For analysis purposes eligibility for homecare was coded binary, whereby the LoCD 0 to 3 were summarised into one category and no LoCD was used as reference category.

A number of predictors were included in the study. The individual's measures age and comorbidity were regarded as proxies for the 'objective' need for LTC. Other predictors were regarded as factors indicating potential inequity in case they correlate with the utilisation of homecare or LoCD. These were sex and citizenship. The same applies to selected characteristics of the geographic area (municipalities associations) in which the individual lives: socioeconomic deprivation, population size, and the density of outpatient care services.

Age was measured on individual level and was included as continuous variable in the regression analysis. Comorbidity was measured with the Charlson Comorbidity Index (CCI) and categorised into the groups mild, moderate, and severe as described elsewhere (Forstner et al. 2019). Citizenship was operationalised binary with the categories German and other citizenships. Among the persons with non-German citizenship might be persons who had in fact the German citizenship at the time of the study, as citizenship is only registered at the time of entry to a statutory health insurance company, changes of citizenship are not documented (Stock et al. 2018). SES was included as a regional characteristic. Therefore, the German index of socioeconomic deprivation (GISD) developed by Kroll et al. (Kroll et al. 2017) was used. The index was developed to support analyses on and public health monitoring of regional socioeconomic inequalities in health. The GISD is conceptually orientated on the SES: it summarises the three dimensions of education, occupation, and income, which are used equally in the construction of the index, and can take values in the range between 3 and 21 points, whereas a lower GISD value represents lower socioeconomic deprivation. Five out of eight indicators used for the construction of the index were not available on the level of municipalities associations and therefore were estimated by regression analyses based on available indicators. As a result, the index is subject to more uncertainty at this regional level than at higher regional levels (Kroll et al. 2017). Population size of the place of living was based on the Regional Database Germany GENESIS and operationalised as the number of inhabitants. Density of outpatient care services was measured as the number of outpatient care services per 100,000 inhabitants, using data from the List of Long-Term Care Facilities in Baden-Wuerttemberg. The list provides a 6-digit municipality code for each outpatient care service, which was used to aggregate the number of services on the level of municipalities associations.

The SES-variable used in sensitivity analyses based on the Microcensus was calculated as the aggregated mean value for the insured's place of living on the level of municipal associations. Further, SES was operationalised as proposed by Winkler and Stolzenberg (range of SES value between 3 to 21) by building an index based on educational and occupational qualification, occupational status, and equivalent household disposable income (Winkler and Stolzenberg 1999). Lampert et al. provided an orientation for the classification (low, middle, high) and corresponding cut-off values of SES (1st quintile: 3.0 to 7.9; 2nd to 4th quintile: 8.0 to 13.8; 5th quintile: 13.9 to 21.0) for the German population using data from the GEDA study (Lampert et al. 2013).

2.2.2.5 Analysis

Base case analyses

Two analytical approaches were taken. To explore whether factors associated with inequity correlate with the utilisation and eligibility of homecare, multiple binary logistic multilevel regressions were estimated. The degree of horizontal inequity in the utilisation of homecare and eligibility was quantified on the basis of horizontal inequity indices (O'Donnell et al. 2008; Pulok et al. 2020; van Doorslaer and van Ourti 2011). Concentration curves were constructed to visualise potential inequalities (Wagstaff et al. 1991).

Concentration curves were constructed with aggregated data on the regional level of municipalities associations for utilisation of homecare with the non-need variables GISD, number of inhabitants, and outpatient care service density. Utilisation was aggregated as utilisation rate among the study population according to their place of living. Similarly, concentration curves were constructed for eligibility for homecare, which was aggregated as eligibility rate, with the non-need variable GISD. For plotting the concentration curves, utilisation and eligibility, both were transformed into their cumulative proportions after sorting the data by the according non-need variable from lowest to highest value, while non-need variables represent the cumulative proportion of municipalities associations ranked by the according non-need variable from lowest to highest value.

Horizontal inequity indices included similar variables as used for concentration curves: utilisation rate of homecare and eligibility rate for homecare in an association of municipalities were used as outcome variables, non-need variables were included accordingly to concentration curve analyses. Horizontal inequity indices were calculated in two steps: first, by running a regression model, beta-coefficients were estimated for the outcome variable with a ranked non-need variable as predictor and for the need-predicted outcome with comorbidity rate and mean age as need-variables. Secondly, the beta-coefficient for the need-predicted outcome was subtracted from the beta-coefficient using a ranked non-need variable as predictor. In this way, concentration indices of indirectly need-standardised healthcare utilisation and eligibility were estimated (Pulok et al. 2020; van Doorslaer and van Ourti 2011). Quintile-based confidence intervals were estimated via bootstrapping using 1,000 iterations.

The logistic regression analyses considered individuals nested in municipalities associations (hierarchical data structure) and thus included municipalities associations as random factors at level 2. In the analysis of homecare utilisation ‘no utilisation’ served as reference category and in case of eligibility for homecare ‘no eligibility’ was set as reference category. The regional characteristics density of outpatient care services and number of inhabitants were excluded from the eligibility model, because there was no theoretical ground that being assigned a LoCD is related to these factors. Tests for significance were conducted by using an alpha-level of $p < 0.05$.

Concentration curves and horizontal inequity indices were constructed and calculated by using RStudio Version 1.0.143. Logistic regression analyses were conducted using IBM SPSS Statistics Version 26.

Sensitivity analyses

Two sets of sensitivity analyses were conducted. The first set replaced GISD by SES in the construction of concentration curves and in the logistic regression analyses, in each case for both outcome variables, utilisation of homecare and eligibility for homecare. The idea behind replacing GISD by SES was to analyse whether constructing this measure on individual level versus aggregated data on the level of municipalities associations impacts their association with homecare utilisation and homecare eligibility.

As there are only a few municipalities associations in Baden-Wuerttemberg with more than 100,000 inhabitants, a second set of sensitivity analyses was conducted to analyse the impact of these outlier municipalities associations. Therefore, municipalities associations with more than 100,000 inhabitants were excluded from the logistic regression analyses.

SES was calculated for municipalities associations based on survey data. In some regions there were no survey participants at all or very few. A survey participant number of at least 30 was considered appropriate to calculate SES for a municipality association. Therefore, insured persons who lived in a municipality association with less than 30 survey participants were excluded from sensitivity analyses including SES.

2.3 Study 3: Exploratory study on data use in a hypothetical scenario for policy-making in long-term care for persons with dementia

2.3.1 Study design

The computer-assisted laboratory study comprised a computer-based quantitative data report along with observational measures, including an eye tracker, a questionnaire, and a semi-structured interview. Given the exploratory nature of the study, the design adopted was observational. Ethical approval for this study was obtained from the research ethics committee of Heidelberg University Hospital, with the assigned ethics approval number being S-857/2018 (Wronski et al. 2021b).

2.3.2 Study population

The study population comprised current and potential future healthcare professionals actively engaged in local healthcare policy-making, either as a primary responsibility or in conjunction with other tasks. Current healthcare professionals encompassed individuals working for health insurance schemes, physicians in executive roles, employees of health facilities in administrative capacities, and scientists specialising in health services research. The group of future healthcare professionals referred to students of academic programmes in the field of health sciences and medicine. Inclusion criteria for participants involved being at least 18 years old and possessing a native-level proficiency in the German language. Additionally, participants for the eye-tracking measures were required not to be blind and not to have implanted artificial lenses. For the exploratory study, a sample size ranging from 40 to 60 participants was deemed sufficient. Recruitment was conducted across three distinct groups: starting students, advanced students, and professionals within the healthcare domain (Wronski et al. 2021b).

Starting students were recruited from the first two semesters of the study programmes in human medicine and the bachelor program in interprofessional healthcare (IPG) offered by the medical faculty of the University of Heidelberg. The IPG programme allows students to combine a university programme with vocational training in nursing or allied health professions such as physiotherapy or speech therapy. Advanced students were recruited from the Master of Science programme in health services research and implementation science in healthcare, as well as from the 7th semester and beyond in the medical students' curriculum. Students were invited to participate in the study via email, sent by the study programme coordinators or the programme's secretary. Additional recruitment methods included the use of posters on campus and brief presentations in bachelor's and master's classes. At the time of recruiting, there were 364 first-year students and 1,520 advanced students enrolled in the eligible study programmes and semesters (Universität Heidelberg, 2019) (Wronski et al. 2021b).

Professionals were purposively selected from the working environment of the study team and the region of the research setting. This comprised former project partners engaged in public health administration, colleagues from both within and outside the study team's organisation, and individuals involved in healthcare policy-making within the region of the research setting who were not personally acquainted with the study team. The latter group was identified through the webpage of the communal health conference of the study team's administrative district, which provided information on participating organisations and their representatives in the communal working group for LTC. The communal health conference serves as a networking platform for local health system stakeholders, allowing them to organise themselves into communal working groups to collaboratively enhance local healthcare in specific areas. The intervention in Study 3 is embedded in a hypothetical scenario related to the working group for LTC. Professionals identified through an internet search received study invitations by post (n = 8), while others were invited via email (n = 20) (Wronski et al. 2021b).

An equal representation of the three participant groups — starting students, advanced students, and professionals — was sought for the study. The research was conducted in a laboratory setting, necessitating participants to travel to the university's campus. Starting students and advanced students received a remuneration of 15 € each after participation. Professionals were offered compensation for their travel costs (Wronski et al. 2021b).

2.3.3 Data collection and research setting

Data collection for the study occurred in the Eye Tracker Laboratory within the Scientific Database and Visualisation group at the Heidelberg Institute for Theoretical Studies (HITS) between April 2nd and November 20th, 2019. Before the data collection started, participants received information in both a written form and a face-to-face conversation about the study context, the data collection procedure, and data security. Participation in the study was voluntary, and participants had the option to withdraw from the study at any point until the collected data was anonymised (Wronski et al. 2021b).

Participants received instructions both verbally and in written form on the computer screen before the commencement of data collection. Each participant underwent 4 distinct measurements: computer-assisted eye-tracking while performing the reading and decision task, two computer-assisted questionnaires, and finally a face-to-face interview. The duration of all measurements for each participant was anticipated to be between 60 to 90 minutes. Throughout the data collection process, 2 members of the study team were present in the laboratory. One team member provided instructions before data collection and conducted the interviews, while the other team member, possessing expertise in the scientific use of eye trackers, performed a 5-point calibration before each data collection to ensure a satisfactory accuracy of data acquisition. In case calibration proved unattainable, the experiment was not conducted (Wronski et al. 2021b).

Eye-tracking was conducted using the Tobii-X1 light (Tobii Technology AB 2014), a desktop-mounted and binocular eye-tracker. The Tobii eye-tracker software (version 3.4.8) facilitated the collection of eye-tracking data. This device emits infrared lights directed towards the center of the eyes, producing pupil and corneal reflection patterns. Image sensors then detect these reflection patterns, enabling the computation of the eyes' position and gaze points. The Tobii X1 light eye tracker operates at around 30 (±2) frames per second (FPS). Data from both eyes were utilised to calculate average values for eye-tracking measures. During calibration before data collection, the recommended distance between participants' eyes and the eye tracker device, approximately 65 cm, was captured and instructed to be maintained by participants throughout the session. The laboratory was well-lit, with curtains covering windows. In instances where participants wore glasses, curtains were opened to allow natural sunlight into the room. Interviews were audio-recorded and subsequently transcribed for analysis (Wronski et al. 2021b).

2.3.4 Intervention

In Study 3, the primary type of evidence utilised for analysing data use was a data report. The original language version in German as well as a version translated to English is provided in the Appendix. This report comprised information predominantly on the epidemiology of LTC, encompassing aspects such as LTC need in PwD supply, and scenarios of future developments, based on indicators identified in Study 1 and operationalised in Study 2. The policy and decision context specified in the study pertains to LTC care for PwD within the region of Baden-Wuerttemberg during the data use stage, specifically during the phases of reading and interpretation (Wronski et al. 2021b).

The intervention in this study served the function of simulating a decision scenario within the realm of LTC policymaking. Participants were presented with a quantitative data report, and their task involved making a decision based on the information provided in the report (Wronski et al. 2021b).

Before presenting the data report, participants were introduced to a hypothetical decision scenario on the computer screen. In essence, participants were cast as members of a communal working group focussed on regional LTC. They were instructed to maintain their real-life roles, such as student, nurse, physician, or a child of a parent in need of LTC, as the participation in this working group, in reality, is not only composed of professional representatives from health system institutions but is also open to all local citizens. The envisaged task of this working group was to provide advice to the local district administrator regarding the allocation of additional funds for LTC, particularly for PwD. The scenario outlined that the working group had previously agreed on a preselection of options for the use of additional funds. For the upcoming meeting, the goal was for the members to reach a consensus on one option to recommend to the local district administrator. As working group members, study participants were tasked with preparing for this meeting and advocating for one of the preselected options. For participants, this meant making an individual choice. Additionally, it was emphasised that the decision involved only one step, i.e. there was a single decision to be made, which needed to be made only once. To aid participants in their meeting preparation, a quantitative data report on the supply and demand for LTC in PwD in the community was provided by the working group. The scenario description did not specify a particular aim for the decision, but it was articulated that the working group's interest was in allocating additional funds where they were most needed. A summarised depiction of the decision scenario is presented in Table 5 (Wronski et al. 2021b).

Table 5: Summary of decision scenario (Wronski et al. 2021b)

Decision component	**Specification**
Decision problem	One-step: How to spend additional funds for long-term care in community?
Given options	A. more support for informal carers B. more ambulant nursing capacity C. more nursing home capacity
Potential consequences	A: lowest cost, most people reached B: medium cost, medium number of people reached C: highest cost, least people reached
Decision maker	Individual (study participant makes decision alone)
Aim/goal	Not defined explicitly (implicitly, aim of working group stated in scenario description: ‘use additional funds where they are needed most’)

The quantitative data report was presented on the computer screen alongside a tick box, prompting participants to select one of the proposed options. Additionally, participants had the opportunity to provide comments. Instructions specified that participants should allocate no more than 20 minutes to the decision task and the reading of the report. The displayed report was written in German, spanning 13 pages (4,111 words), and followed a structure similar to a concise project report, encompassing a title page, table of contents, introduction (approximately 1.5 pages), methods section (approximately 3.5 pages), results section (approximately 4.5 pages), and a discussion and conclusion section (circa 1 page). To access all pages of the report, participants were required to scroll down. The introduction section featured a brief description of the 3 options preselected by the working group for the allocation of additional funds for LTC in the community (Table 5). The quantitative data presented in the report consisted of real descriptive figures detailing the current and projected demand and supply of LTC services in the region of interest, derived from secondary data analyses of authentic data emerging from the *Model Project Cross Sectoral Healthcare* (Ministerium für Soziales 2018) (Wronski et al. 2021b).

2.3.5 Measures

Data collection comprised the following 3 methods: eye-tracking based, questionnaires, and interviews (Wronski et al. 2021b).

2.3.5.1 Eye-tracking

Based on the eye-tracking data, 5 measures were extracted, and mean values were calculated across report sections and the three report figures. The time spent (in minutes) reading the report and completing the task was recorded based on the recorded sessions. The following 3 pupil-based measures were derived: diameter (in mm), dilation (in mm), and response (in mm). Diameter served as a standard measure of pupil size, while dilation represented the increase in pupil size and was calculated as the difference between the largest and smallest pupil diameter within an individual during the processing of a report section. Pupillary response is a composite measure that summarised changes in pupil size resulting from both dilations and constrictions (decrease in pupil size) by summing these two types of pupil size changes. These 3 pupillometric measures are considered indicators of cognitive load during task performance (Hartmann and Fischer 2014; Hess and Polt 1964). The 5th eye-tracking measure was the average fixation duration (in milliseconds), utilised as an indicator of attention when processing information from the report (Rayner 2009) (Wronski et al. 2021b).

Heatmaps depicting reading behaviour were generated to descriptively illustrate attention patterns. These heatmaps visualise fixations during the reading of the report (Holmqvist et al. 2015). A greater number of fixations on a particular part of the report is represented by red colours, indicating more attention, while fewer fixations are denoted by green colours (Deubel and Schneider 1996). Since the range of fixations represented by colours was individually defined for each study participant, a visual comparison of different colour shades is only applicable within a single heatmap and cannot be compared across individuals (Wronski et al. 2021b).

To investigate whether the recorded fixations were a result of attention rather than daydreaming, fixations on white space were visually estimated through an analysis of gaze plots from all participants. Gaze plots depict the location of gaze points and the duration of fixations by circles plotted over the stimulus in the time sequence in which fixations occurred (Wronski et al. 2021b).

2.3.5.2 Questionnaire

A questionnaire was developed specifically for this study. It is provided in the original German version and in an English version (Appendix). Participants were requested to provide individual characteristics hypothesised to influence the reading and decision-making task, including demographic information, educational background, and practical experience in healthcare or LTC. Tolerance of ambiguity, as the data in reports comes with a certain level of uncertainty, was measured using the validated 8-item test (Reis 1997), employing adapted wordings (Dalbert 1999). Participants were required to rate each item on a 6-point scale from 'absolutely true' to 'absolutely not true,' where a higher score indicates higher tolerance of ambiguity. Additionally, participants' understanding of information presented in graphs in the quantitative data report was tested using 5 items. The question type of the items was adapted from Galesic et al., who assessed general graph literacy (Galesic and Garcia-Retamero 2011). For study 3, scoring was conducted by summing the number of correct answers, resulting in a range of 0 to 5 possible points. Statistical numeracy or risk literacy was measured using the validated Berlin numeracy test, a 4-item paper-and-pencil version in the German language (Cokely et al. 2012). A score was calculated by determining the proportion of correct answers, resulting in a range of 0 to 1. To aid in assessing the quality of eye-tracking data, participants were asked about their use of visual aids, such as contact lenses, during the report-reading task. Finally, participants were asked to assess each section of the report (introduction, methods, results, discussion, and conclusion) in terms of their understandability and helpfulness during the decision-making task, both on a 10-point Likert scale from 1 ('not helpful at all') to 10 ('very helpful') (Wronski et al. 2021b).

2.3.5.3 Interviews

To explore the experiences of participants regarding the completion of the task, two members of the QuantEV study group conducted face-to-face interviews using a semi-structured question guide. The interview questions were developed by the QuantEV study group and were revised after the first six participants to encourage study participants to speak more openly about their experiences, particularly about the way they had read the report. For the revision of the question guide, the study group consulted two colleagues, both of whom are experienced researchers (a sociologist and a health scientist), especially in developing question guides for qualitative research. An opening question was added to the question guide, and all questions were reformulated. The final version of the guide in

German language as well as a translated English version, can be found in the Appendix. The interview transcripts were not returned to participants for correction or comments (Wronski et al. 2021b).

2.3.6 Analysis

In all analyses, study participants were considered the unit of analysis. IBM SPSS Statistics Version 25 was used to analyse questionnaire and eye-tracking data. The latter data was prepared for analyses with Tobii eye-tracker software. Descriptive analyses were performed to report on the appreciation of report sections based on questionnaire data, as well as fixation-based and pupillometric data obtained from eye-tracking. Furthermore, Pearson correlations were calculated to investigate the relationship between fixation, pupillometric, and questionnaire measures for report sections separately. Given the explorative nature of the study, a p-value < 0.10 was considered significant (Wronski et al. 2021b).

In the analysis of the interviews, a qualitative content analysis was conducted to explore the reasons participants mentioned for giving more or less attention to a specific report section for decision-making. A conventional approach was used, where categories (in this case, mentioned reasons) were derived from the collected data rather than from a pre-existing theory (Hsieh and Shannon 2005). The qualitative content analysis involved 3 members of the QuantEV study team, 2 of whom were also involved in data collection. The analysis began by extracting relevant text passages from interview transcripts for all participants, using ATLAS.ti version 7.5.10. Simultaneously, extracts were coded with the concerned report section. To enhance interrater reliability, a coding plan was developed. Subsequent steps were (a) paraphrasing, (b) formulating short forms of paraphrases, and (c) categorizing short forms. Paraphrasing aimed to reduce extracts to the core of the statement (Mayring 2014). Formulating short forms of paraphrases involved reducing extracts to a statement not directly related to report content. If short forms appeared synonymous in content, they were aggregated. Finally, the coding team grouped short forms into themes related to the content of the short forms. For each theme, quotations from interviews were selected to exemplify the meaning of that theme (Gläser and Laudel 2013) (Wronski et al. 2021b).

The pilot study of the entire data collection procedure involved 3 employees from Heidelberg University Hospital. Its purpose was to test and, if necessary, revise the measures and ensure the technical functionality of the eye-tracking software in combination with the survey tool (Wronski et al. 2021b).

3 Results

Almost the whole description of results provided in section 3.1 can also be found in (Wronski et al. 2021a) except information referring to dementia and LTC in section 3.1.2. The whole description of results in section 3.3 can be found in (Wronski et al. 2021b).

3.1 Study 1: Survey on indicator selection from the perspective of health system stakeholders in Baden-Wuerttemberg

3.1.1 Participating stakeholders

Study participants had the opportunity to assess indicators via the online platform between December 12th, 2016, and the end of January 2017. Of the institutions invited, a total of 22 (41 %) took part in the study with a total of 35 individuals. Group specific response rates were as follows: 100 % for population health organisations and quality assurance agencies/statistical office, 60 % for financing agencies, 24 % for healthcare providers, and 8 % for patients/citizens. From most institutions, a single individual participated in the study, while from 8 institutions more than 1 person agreed to participate in the study. Among these were 4 institutions with 2 participants, 3 institutions with 3 potential persons, and 1 institution with a total of 4. An overview on the composition of participating stakeholders is provided in Table 6 (Wronski et al. 2021a).

Table 6: Composition of participating stakeholders (Wronski et al. 2021a)

	Individuals	**Institutions**	
Stakeholder group	**N**	**N**	**% of all participating stakeholders**
Patients/citizens	1	1	4.5
Healthcare providers	8	5	22.7
Financing agencies	8	6	27.3
Population health organisations	11	6	27.3
Quality assurance agencies/statistical office	7	4	18.2
Total	35	22	100.0

The average number of indicators assessed for relevance by a participant was around 269, with a range from 14 to all 374 proposed indicators, in both cases by 1 institution. The average number of institutions an indicator was assessed by for its relevance was 15.8 with a range from 7 to 22. Regarding the level of stakeholder groups, population health organisations, financing agencies, and healthcare providers assessed the relevance of all indicators while the group of quality assurance agencies/statistical office left 27 indicators without a relevance assessment. These indicators were related to the sub-dimension of effectiveness and efficiency. The number of assessed indicators was lowest for the group of patients/citizens with n = 55 (15 %). The indicators were related to the dimensions non-medical determinants of health and health status (Wronski et al. 2021a).

The average number of indicators a participant assessed for comprehensibility was around 270 with 1 institution assessing a minimum of 13 and another institution assessing a maximum of all 374 indicators. An average number of comprehensibility assessments from 16 institutions per indicator was observed ranging from 9 to 22 institutions (Wronski et al. 2021a).

Among participants, circa 57 % of 35 respondents from 73 % of institutions provided responses to the query regarding the importance of one of the 5 proposed stakeholder groups in healthcare planning in Baden-Wuerttemberg. Notably, none of the participants from the patients/citizens group addressed this particular question. The median values for stakeholder relevance in healthcare planning exhibited similarity across all stakeholder groups, ranging from 5.0 to 6.0. In light of this uniformity and the substantial number of missing values in the stakeholder rating, a decision was made to refrain from constructing weights based on these ratings. Consequently, stakeholders' assessments on the relevance of indicators were not differentially weighted (Wronski et al. 2021a).

3.1.2 Selected indicators

Out of the 374 indicators initially proposed, 212 were deemed 'relevant' and subsequently included in the final selection. The remaining 162 indicators were divided between those categorised as 'uncertain' (n = 153) and 'not relevant' (n = 9), leading to their exclusion from the ultimate indicator set (Wronski et al. 2021a).

Of 16[1] proposed indicators related to dementia and / or LTC 14 were classified as ‘relevant’. This results in a higher proportion of selected indicators (88 %) than the proportion of selected indicators in total (57 %). Figure 4 shows the number of selected and proposed indicators for each framework sub-dimension.

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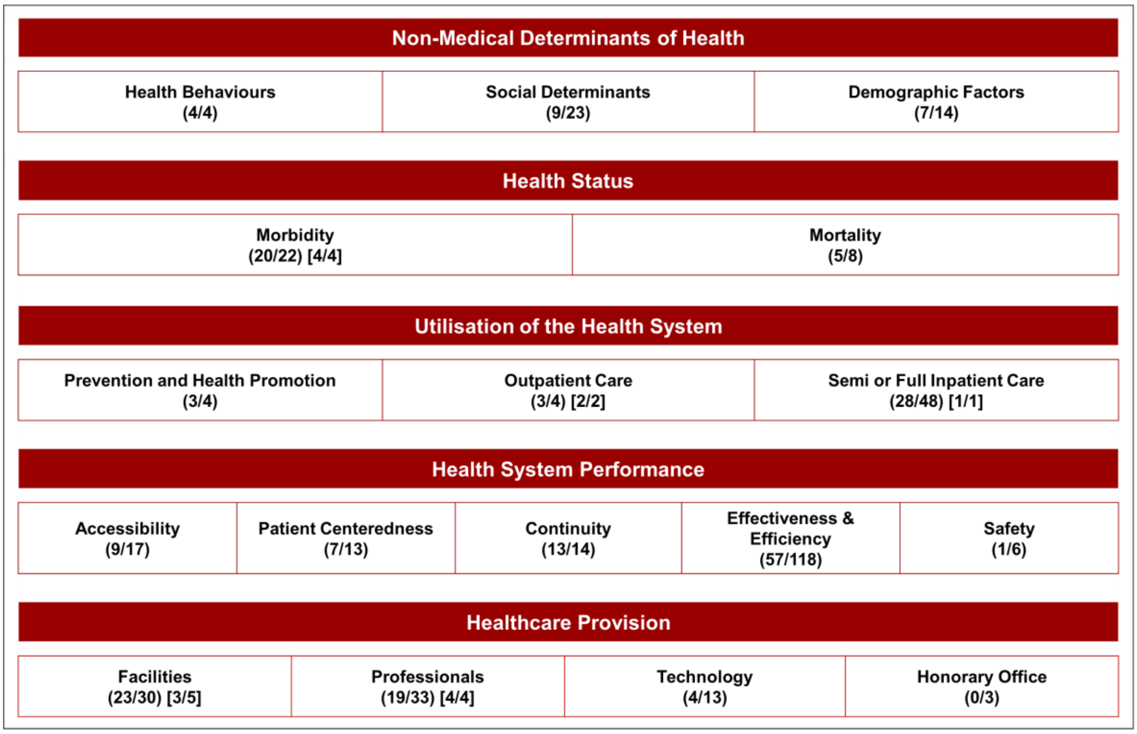
[1] Indicators of non-medical determinants of health were regarded as being related to health status in general and therefore not included in the count of dementia and / or LTC related indicators.



Results are displayed as number of selected indicators/number of proposed indicators in total () and dementia and / or LTC related []. The latter are not displayed, when there were no proposed indicators (concerns prevention and health promotion, accessibility, patient centeredness, continuity, effectiveness and efficiency, technology, and honorary office).

Figure 4: Framework for indicators of the health system in Baden-Wuerttemberg (own figure based on (Wronski et al. 2021a)

Physical activity was the only indicator that received a median score of nine, signifying high relevance. Predominantly, relevant indicators pertained to the sub-dimension of effectivity and efficiency within health system performance (27 %), followed by semi or full inpatient care (13 %) as a sub-dimension of health system utilisation, and facilities (11 %) as a sub-dimension of healthcare provision. Notably, over 90 % of the proposed indicators within the sub-dimensions of health behaviours, continuity, and morbidity were deemed relevant. In contrast, none of the three proposed indicators from the sub-dimension of honorary office was selected, and less than a third of the proposed indicators were chosen from the sub-dimensions of patient safety and technology (Wronski et al. 2021a).

Table 7 presents a consolidation of institutions' relevance ratings for indicators, categorised by framework sub-dimensions. Owing to the extensive number of indicators, detailed relevance assessments for each indicator can be found in a publication of Wronski et al. as supplementary information (Additional file 1) (Wronski et al. 2021a). For indicators related to dementia and/or LTC the detailed relevance assessments are provided in Table 21 (Appendix).

Table 7: Relevance ratings of institutions (n = 22) by framework sub-dimensions ([mean/min./max.] median per indicator) (Wronski et al. 2021a)

	All indicators (n = 374)				**Mean** selected[a] (n = 212)	**Mean** not selected[a] (n = 162)	**Difference** selected - not selected
Sub-dimension	**Mean**	**SD**	**Min.**	**Max.**			
health behaviours	7.9	0.7	7.0	9.0	7.9	-[b]	-
social determinants	5.8	1.6	2.0	8.0	7.3	4.8	2.5
demographic factors	6.7	1.0	5.0	8.0	7.6	5.8	1.9
morbidity	7.3	0.7	6.0	8.0	7.4	6.0	1.4
mortality	6.8	0.7	6.0	8.0	7.2	6.0	1.2
prevention & health promotion	7.3	0.8	6.0	8.0	7.7	6.0	1.7
outpatient care	7.0	0.7	6.0	8.0	7.3	6.0	1.3
semi or full inpatient care	6.5	0.8	6.5	8.5	7.1	5.8	1.3
accessibility	6.2	1.1	6.5	8.0	7.1	5.2	1.9
patient centeredness	6.1	1.2	3.5	7.5	7.0	5.0	2.0
continuity	7.4	0.6	6.0	8.0	7.5	6.0	1.5
effectiveness & efficiency	6.1	1.4	3.0	8.0	7.3	5.0	2.3
safety	6.0	1.0	5.0	8.0	8.0	5.6	2.4
facilities	6.8	0.7	5.0	8.0	7.1	5.8	1.3
professionals	6.5	0.8	4.5	8.0	7.1	5.7	1.4
technology	5.7	0.9	4.0	7.0	6.8	5.3	1.5
honorary office	6.0	0.2	5.5	6.0	-[b]	5.8	-

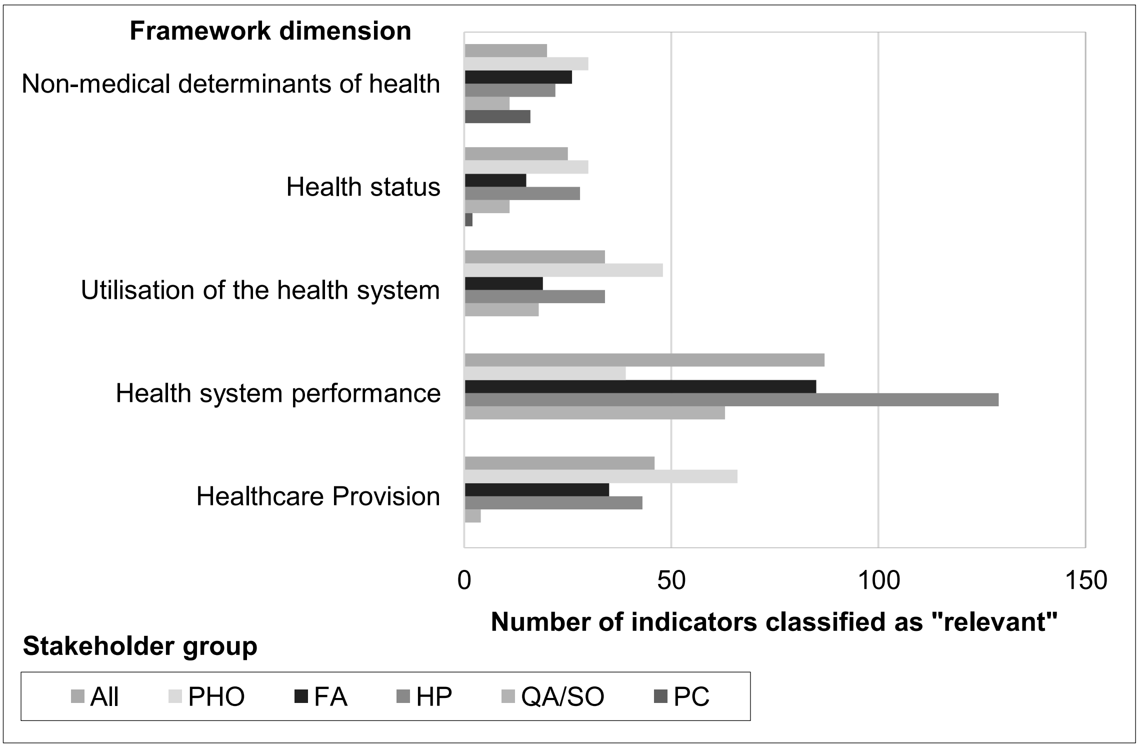
The figures presented in this table are based on the median value per indicator resulting from the relevance assessment of participating institutions. E.g. for the sub-dimension *health behaviours* the mean value over the median value for the 4 indicators of this subdimension is 7.9. Likert-type scale for relevance ratings (1 = *not relevant at all* to 9 = *highly relevant*).

a. Formal consent about the selection i.e. relevance of an indicator was defined by a median in [6.5-9].
b. Either all or none of the indicators were selected.

SD: standard deviation

Among the framework sub-dimensions, health behaviours exhibited the highest mean value (7.9) across its 4 indicators, while safety and honorary office showed the lowest (6.0). The range between minimum and maximum median values, coupled with the disparity in mean values over the median between selected and not selected indicators, provides an approximation of consensus regarding indicator relevance. This variance was most pronounced for social determinants (2.5) and least for health behaviours, where all indicators were selected, and honorary office, where no indicator received selection (Wronski et al. 2021a).

Figure 5 presents the number of relevant indicators among the 5 stakeholder groups arranged by the 5 framework dimensions (Wronski et al. 2021a).



FA: financing agencies; HP: health providers; PC: patients/citizens; PHO: population health organisations; QA/SO: quality assurance/statistical office

Figure 5: Number of relevant indicators by stakeholder group and framework dimension (Wronski et al. 2021a)

Most (90 %) of the indicators classified as 'relevant' received a maximum of 5 comments. The number of comments per indicator ranged between 0 and 12, which concerned 2 indicators in each case. The substance of all comments was construed as guidance for indicator measurement and the reformulation of an indicator's name. For instance, study participants provided notes to specify the indicator, and raised questions regarding its unit (Wronski et al. 2021a).

3.2 Study 2: Secondary data analyses

3.2.1 Regional long-term care need in persons with dementia

LTC need in PwD was assessed for all 44 administrative districts, of which 9 were classified as urban and the others as rural with a population size ranging between 53,012 inhabitants in Baden-Baden and 604,297 inhabitants in Stuttgart on the reporting date of 31 December 2013 according to the population update of the Baden-Wuerttemberg Statistical Office (Statistisches Landesamt Baden-Württemberg 2019).

Figure 6 shows the administrative prevalence of dementia as the share of persons diagnosed with dementia in administrative districts in 2013. For Baden-Wuerttemberg with a population size of 10,631,278 (Statistisches Landesamt Baden-Württemberg 2019) this results in circa 180,730 persons diagnosed with dementia and an administrative prevalence of 1.7 %. This percentage varied within the regions ranging between 1.1 % in the rural district Tuebingen and 2.4 % in the city of Baden-Baden.

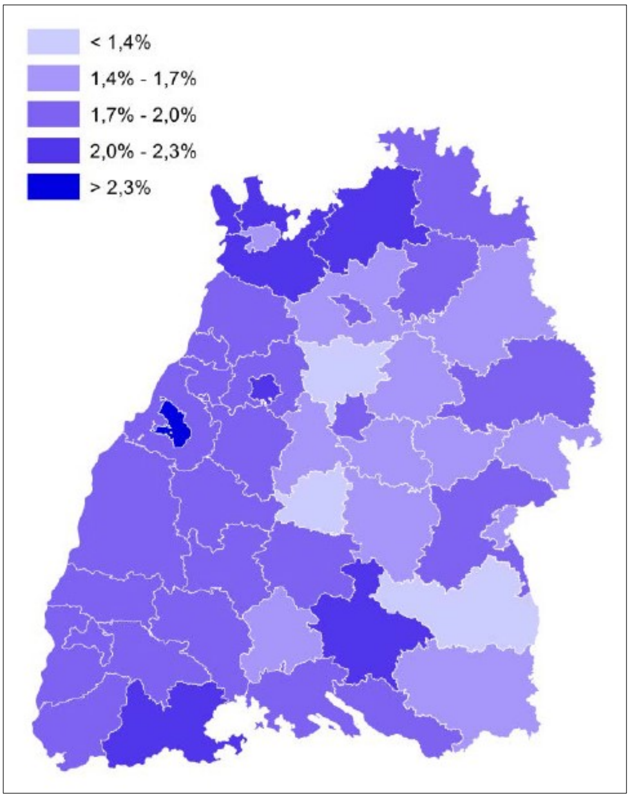


Figure 6: Administrative prevalence of dementia in administrative districts of Baden-Wuerttemberg in 2013 (own figure)

Figure 7 shows the distribution of age- and sex-specific prevalence rates of persons diagnosed dementia among inhabitants of Baden-Wuerttemberg aged 65 years and older. The frequency of dementia increases many times over within the age groups considered: while the prevalence in the 65 to 69 age group is still between 1 % and 2 %, it is more than 10 times higher at an age of ≥ 90 years, for both, the male and female population. Another difference can be observed among sex groups. Within the age groups between 65 years and 79 years prevalence rates are almost similar, being slightly higher within the male population (e.g. 65 years to 69 years of age: 1.9 % versus 1.4 %). In higher age groups, this relation switches and the difference between sexes even increases up to prevalence rates of 25.7 % (male) and 33.2 % (female) within the population aged 90 years and more.

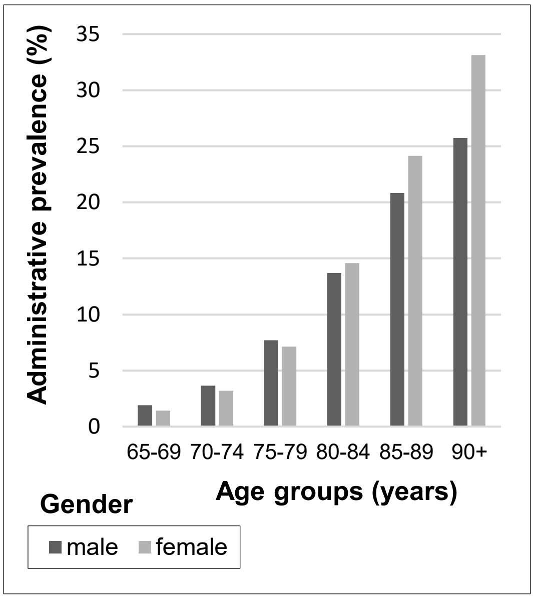
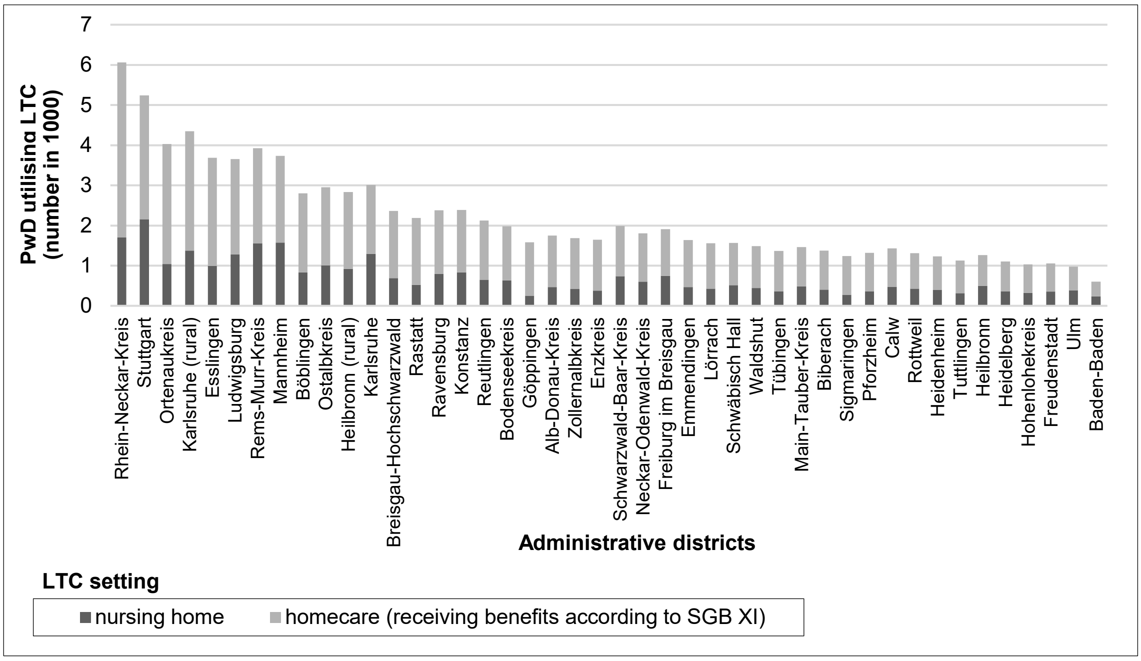


Figure 7: Administrative prevalence of dementia in Baden-Wuerttemberg in 2013, grouped by age and sex (own figure)

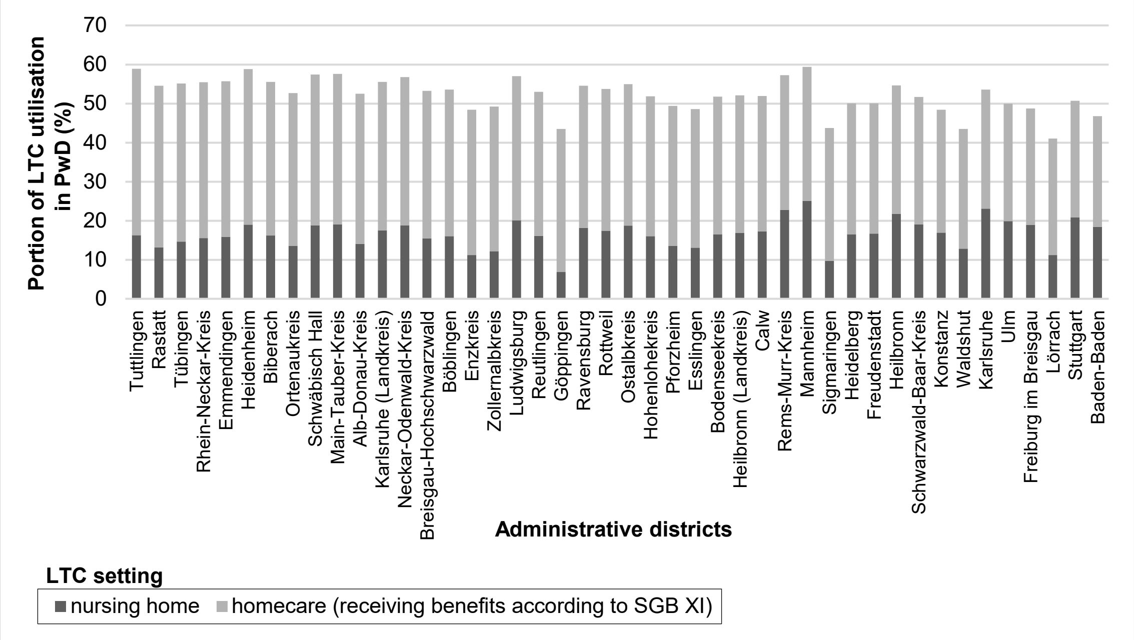
In another analysis on state level the three most common concomitant diagnoses on the level of the 3-digits ICD-10 codes in 2013 within PwD were identified. With around 71 % hypertension (codes I10 to I15) was the most documented concomitant diagnose, followed by metabolic disorders (codes E70 to E90) with around 45 %, and 41 % of PwD were diagnosed with other forms of heart disease (codes I30 to I52).

LTC utilisation by persons diagnosed with dementia in the administrative districts is presented in absolute numbers (Figure 8) and as portion in persons diagnosed with dementia (Figure 9). In both figures, LTC utilisation is differentiated by the two settings of nursing home and homecare. The latter includes either receiving in-cash benefits to compensate for informal carers, utilisation of outpatient care services, or semi-outpatient care, whereby all the three benefits can also be utilised in combination. In absolute terms (Figure 8), most PwD and LTC utilisation (circa 6,000 persons) were counted in the Rhein-Neckar-Kreis, although this administrative district does not have the most inhabitants. A tenth of this number of PwD utilising LTC was estimated for Baden-Baden with the lowest number. In relative terms (Figure 9), the percentage of LTC utilisation within PwD ranged between 41 % in Loerrach and 59 % in Heidenheim and Mannheim. In all administrative districts, the most frequently utilised LTC setting was homecare ranging between 28 % in Baden-Baden and 43 % in Tuttlingen, while nursing home utilisation within PwD was lowest in Goeppingen (7 %) and highest in Mannheim (25 %).



Administrative districts were arranged by the number of PwD in homecare setting in decreasing order
LTC: long-term care; PwD: persons with dementia; SGB: Social Code

Figure 8: Absolute LTC utilisation in PwD in administrative districts in Baden-Wuerttemberg in 2013 (own figure)



Administrative districts were arranged by the portion of PwD in homecare setting in decreasing order
LTC: long-term care; PwD: persons with dementia; SGB: Social Code

Figure 9: Percentage of LTC utilisation in PwD in administrative districts in Baden-Wuerttemberg in 2013 (own figure)

3.2.2 Analyses on equity in long-term care for persons with dementia in Baden-Wuerttemberg

3.2.2.1 Study population

The study population (Table 8) consists of 55,483 insured PwD aged 65 years and older, who were living in a community setting. The mean age within the study population is 81.6 years, the largest age group (27 %) is between 80 to 84 years old. Study participants were largely female (64.4 %) and mostly had German citizenship (94.6 %). The showed none or mild comorbidity for the majority of the study population (59.5 %). Almost two thirds of study participants had a LoCD. Among participants with LoCD the most frequent levels were LoCD 1 (44.7 %) and LoCD 2 (34.2 %). Though, the majority of participants (60.4 %) was eligible for the utilisation of homecare, only 43.9 % utilised it.

455 out of 462 municipalities associations could be included in the analyses. Number of inhabitants ranged from 2,843 to 604,297. The association of municipalities' GISD values did not vary much (range: 5.000 to 7.460). Most regions (87 %) were in the two least deprived quintiles in Germany, while there was no region in the most deprived quintile. Mean density of outpatient care services was 9.6 per 100,000 inhabitants, whereby almost one fifth of municipalities associations did not offer any outpatient care services.

Table 8: Characteristics of study population (individual level) and place of living (level of municipalities associations) (own table)

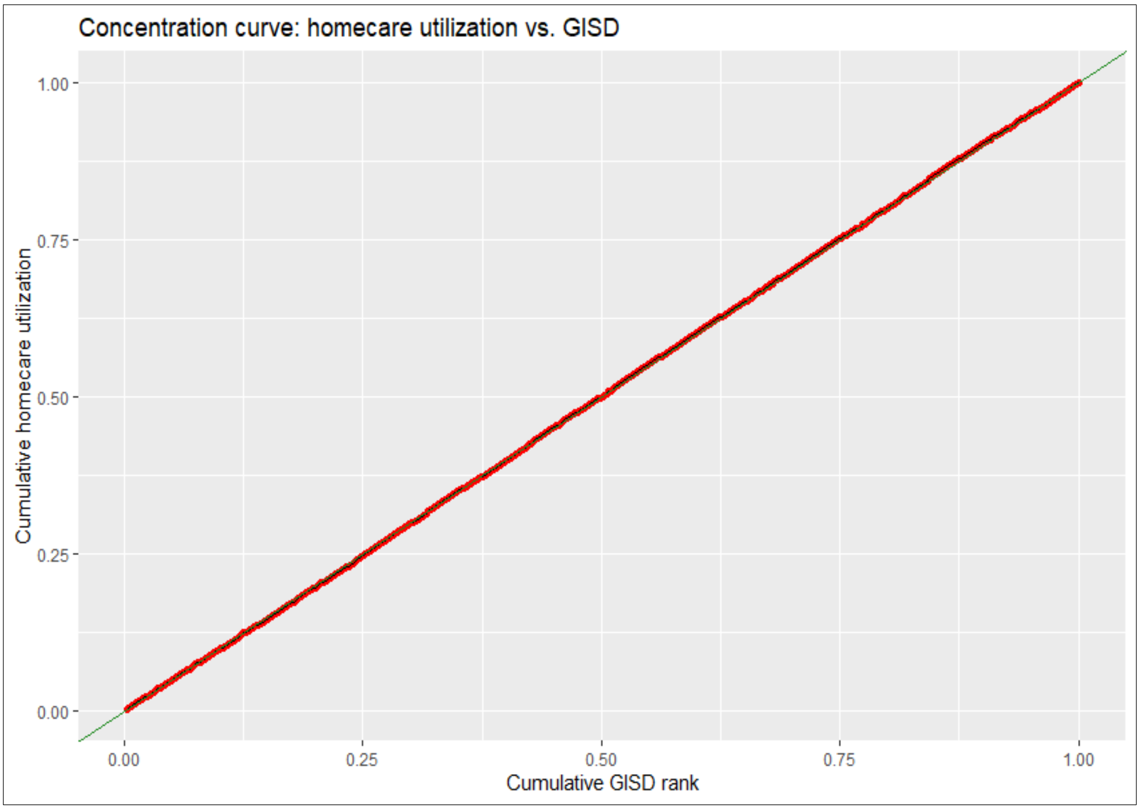
	Individuals (n = 55,483)
Age [mean (standard deviation); range]	81.6 (6.8); 65-107
Age in categories [n (%)]	
65-69 years	2,322 (4.2)
70-74 years	6,302 (11.4)
75-79 years	12,528 (22.6)
80-84 years	14,965 (27.0)
85-89 years	12,361 (22.3)
90-94 years	5,939 (10.7)
95 years and older	1,066 (1.9)
Sex [n (%)]	
Female	35,772 (64.4)
Male	19,761 (35.6)
Citizenship [n (%)]	
German	52,482 (94.6)
Other	2,814 (5.1)
Missing	187 (0.3)
Charlson comorbidity index [n (%)]	
None	15,334 (27.6)
Mild	17,706 (31.9)
Moderate	12,100 (21.8)
Severe	10,343 (18.6)
LoCD [n (%)]	33,500 (60.4)
No LoCD	21,983 (39.6)
LoCD 0	2,508 (4.5)
LoCD 1	15,001 (27.0)
LoCD 2	11,445 (20.6)
LoCD 3	4,546 (8.2)
Utilisation of homecare [n (%)]	24,365 (43.9)
	Associations of municipalities (n=455)
Utilisation rate of homecare [mean (standard deviation); range]	0.454 (0.091); 0.13-0.76
LoCD rate [mean (standard deviation); range]	0.611 (0.091); 0.24-0.85
Number of inhabitants [mean (standard deviation); range]	23,249 (39,355.069); 2,843- 604,297
	Associations of municipalities (n = 455)
GISD [mean over municipalities associations (standard deviation); range]	6.445 (0.376); 5.000-7.460

GISD distribution over quintiles based on all German municipalities associations [n (%)]	
1	174 (38.2)
2	222 (48.8)
3	45 (9.9)
4	14 (3.1)
5	-
Number of outpatient care services per 100,000 inhabitants [mean (standard deviation); range]	9.568 (7.725); 0.000-47.540
GISD: German Index of Socioeconomic Deprivation; LoCD: level of care dependency	

3.2.2.2 Results of base case analyses

Analysis of inequality and horizontal inequity

Figure 10 to Figure 13 display concentration curves (bold lines) for the outcome variables utilisation of homecare (Figure 10 to Figure 12) and eligibility (Figure 13). The y-axes show the cumulative portion (from 0 to 1) of an outcome variable against the cumulative portion of municipalities associations (from 0 to 1), ranked by a non-need variable from its lowest to highest value (x-axes). In case of Figure 10, for instance, the cumulative portion of homecare utilisation rates of municipalities associations (y-axis) is plotted against the cumulative portion of municipalities associations, ranked by their GISD from lowest to highest value (x-axis). The concentration curves lie on the respective diagonals (equality lines), which indicates an equal distribution of homecare utilisation and eligibility among municipalities associations. Only when ranked by the density of outpatient care services (Figure 11), utilisation of homecare seems to be distributed slightly unequal in favour of municipalities associations with fewer outpatient cares services per 100,000 inhabitants as the concentration curve slightly runs above the equality line. The vertical course of the concentration curve displayed on the left side of Figure 11 results from several association municipalities not having any outpatient care services at all. Therefore, this part of the concentration curve is not considered in the appraisal of inequality.



GISD: German Index of Socioeconomic Deprivation

Figure 10: Concentration curve for cumulative portion of homecare utilisation among municipalities associations ranked by GISD (own figure)

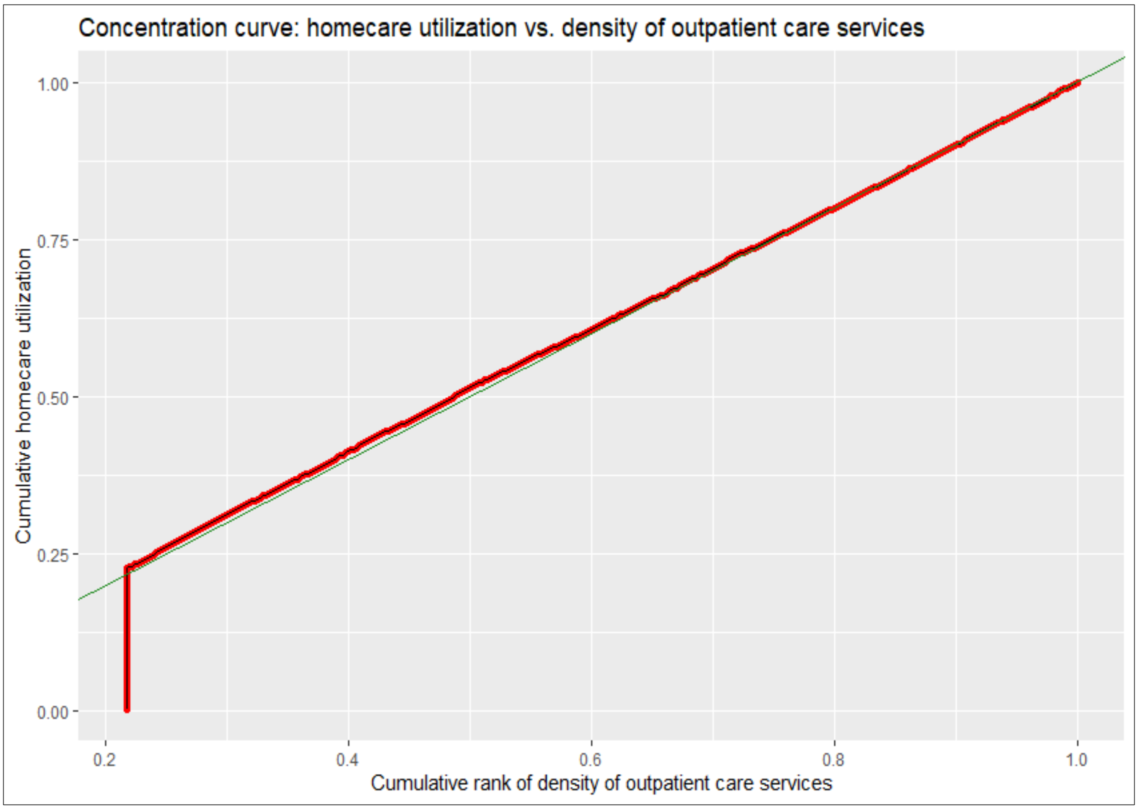


Figure 11: Concentration curve for cumulative portion of homecare utilisation among municipalities associations ranked by density of outpatient care services (own figure)

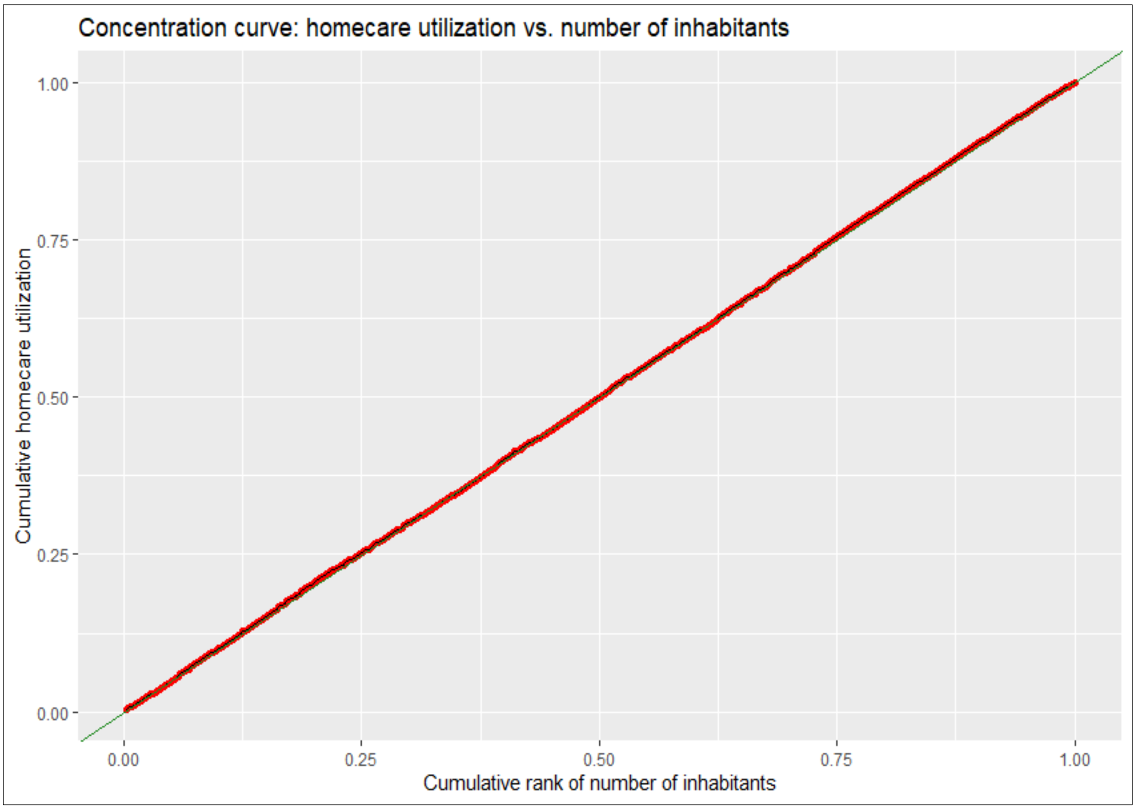


Figure 12: Concentration curve for cumulative portion of homecare utilisation among municipalities associations ranked by number of inhabitants (own figure)

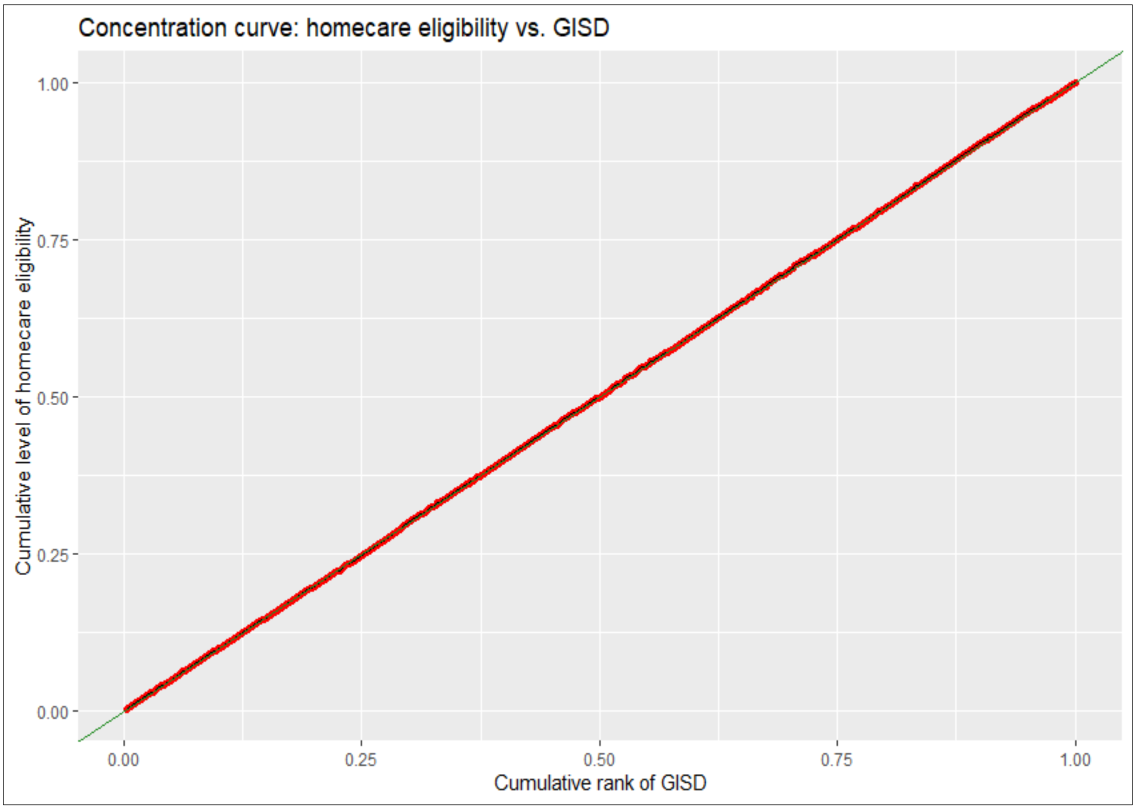


Figure 13: Concentration curve for cumulative portion of eligibility for homecare among municipalities associations ranked by number of inhabitants (own figure)

The results for the concentration index and the horizontal inequity index (Table 9) are in line with the concentration curves: they do not show any concentration of neither homecare eligibility nor utilisation except for a slight concentration of utilisation in favour of regions with lower density of outpatient care services.

Table 9: Concentration index and horizontal equity index for GISD, number of inhabitants, and outpatient care service density (n = 455) (own table)

Analysis	**Concentration index (outcome)**	**Concentration index (need-predicted outcome)**	**Horizontal inequity index (outcome)**
Homecare utilisation			
GISD	-0.010 [-0.102;0.086]	0.056 [-0.034;0.148]	-0.066 [-0.192;0.062]
number of inhabitants in place of living	-0.040 [-0.124;0.056]	-0.0480 [-0.140;0.038]	0.013 [-0.110;0.144]
number of outpatient care services per 100,000 inhabitants in place of living	-0.120 [-0.217;-0.023]	0.057 [-0.041;0.157]	-0.177 [-0.328;-0.036]

Homecare eligibility			
GISD	-0.011 [-0.101;0.084]	0.047 [-0.051;0.136]	-0.058 [-0.186;0.074]
In brackets: 95 % confidence intervals, computed by bootstrapping using 1,000 replications. GISD: German Index of Socioeconomic Deprivation			

Factors associated with homecare utilisation and eligibility (multilevel analyses)

Table 10 shows the results of the multilevel regression analysis of the utilisation of homecare. In community dwelling PwD, the likelihood of utilising homecare was higher, when they had a comorbidity and were of higher age (OR=1.050). The strongest predictor for the utilisation of homecare among proxy measures of need were comorbidities with the highest CCI category ‘severe’, being associated with a 1.681 times higher likelihood of utilizing homecare compared to no comorbidity. Among the individual factors indicating inequity, a higher likelihood of homecare utilisation for female PwD (OR = 1.098) and PwD with a non-German citizenship (OR=1.271) were found. Interclass correlation was very low and indicated that only 0.1 % of the chance to utilise homecare was explained by between-region differences. This is in line with almost none associations between non-need factors measured on the level of municipalities associations. PwD living in a region with a higher outpatient care services density had a slightly lower likelihood to utilise homecare (OR = 0.994).

Table 10: Multilevel logistic regression analysis of the utilisation of homecare among PwD living in community setting (own table)

	OR	p	95 % CI
Factors associated with LTC need			
CCI (reference: no comorbidity)[a]			
mild	1.124	0.000	[1.074;1.176]
moderate	1.357	0.000	[1.291;1.426]
severe	1.689	0.000	[1.689;1.603]
age[a]	1.050	0.000	[1.047;1.053]
Non-need factors			
sex (reference: male)[a]	1.103	0.000	[1.062;1.145]
citizenship (reference: German)[a]	1.265	0.000	[1.167;1.371]
GISD in place of living[b]	0.962	0.364	[0.883;1.047]
number of inhabitants in place of living[b]	0.999	0.017	[0.999;1.000]
number of outpatient care services per 100,000 inhabitants in place of living	0.994	0.008	[0.990;0.998]

ICC	0.001		
N	55,296		
[a]measured on individual level (level 1 variable) [b]measured on level of municipalities associations (level 2 variable) CCI: Charlson Comorbidity Index; CI: confidence interval; GISD: German Index of Socioeconomic Deprivation; ICC: Intraclass Correlation Coefficient; LTC: long-term care; OR: odds ratio; PwD: persons with dementia			

Results of the multilevel model using eligibility for homecare as outcome variable is presented in Table 11. Interclass correlation was slightly higher (ICC = 0.002) compared to the utilisation model but still very low. The associations between the independent variables to the outcome variable were largely similar to the first model. Only the magnitude of effects was slightly higher than in the first model for almost all independent level 1 variables but non-German citizenship which did not show statistically significant results.

Table 11: Multilevel logistic regression analysis of eligibility for homecare among PwD living in community setting (own table)

	OR	**p**	**95 % CI**
Factors associated with LTC need			
CCI (reference: no comorbidity)[a]			
mild	1.159	0.000	[1.107;1.213]
moderate	1.473	0.000	[1.399;1.552]
severe	1.866	0.000	[1.766;1.973]
age[a]	1.087	0.000	[1.084;1.091]
Factors indicating inequity			
sex (reference: male)[a]	1.279	0.000	[1.231;1.329]
citizenship (reference: German)[a]	1.023	0.535	[0.942;1.109]
GISD in place of living[b]	0.995	0.319	[0.871;1.046]
ICC N	0.002 55,296		
[a]measured on individual level (level 1 variable) [b]measured on level of municipalities associations (level 2 variable) CCI: Charlson Comorbidity Index; CI: confidence interval; GISD: German Index of Socioeconomic Deprivation; ICC: Intraclass Correlation Coefficient; LoCD: level of care dependency; LTC: long-term care; OR: odds ratio; PwD: persons with dementia			

3.2.2.3 Results of sensitivity analyses

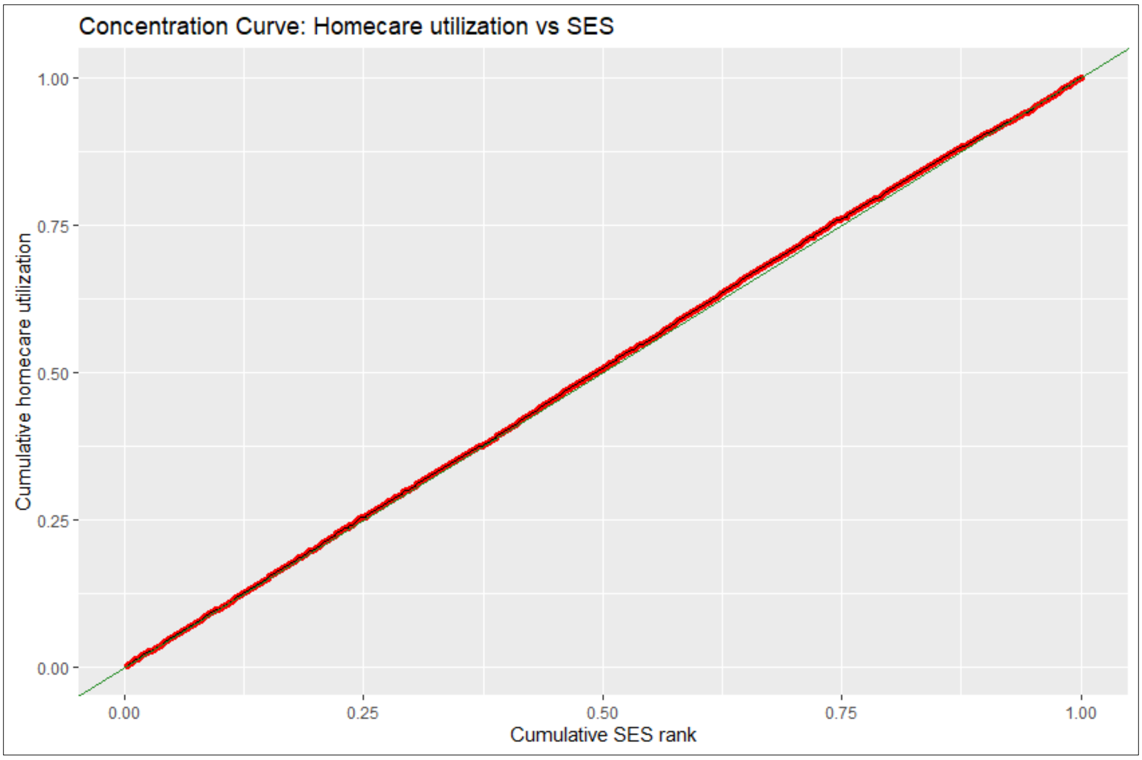
SES instead of GISD

The calculation of the mean SES for a municipalities association required that at least 30 persons from the respective region participated in the Microcensus. This condition was fulfilled by 428 out of 455 earlier identified municipalities associations for the base case analyses (section 3.2.2.1). The mean SES range between 8.9 and 14.9 in municipalities associations as well as its distribution over terciles is displayed in Table 12.

Table 12: SES mean and terciles over municipalities associations in Baden-Wuerttemberg in 2013, using Microcensus data (own table)

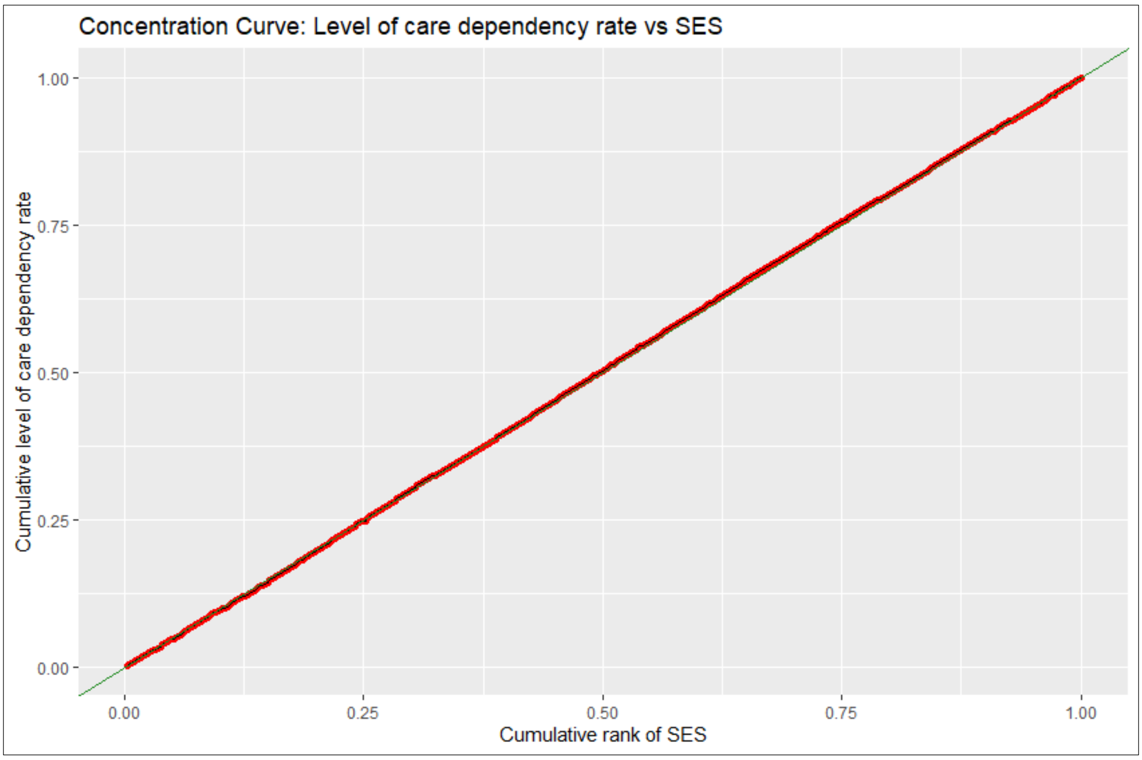
	Municipalities associations (N = 428)
SES [mean over municipalities associations (standard deviation); range]	11.5 (0.99); 8.9-14.9
SES mean terciles (ranges)	
1st tercile	8.9-11.1
2nd tercile	11.2-11.8
3rd tercile	11.9-14.9
SES: socioeconomic status	

The following two figures show concentration curves using mean SES in municipalities associations against the utilisation of homecare (Figure 14) and against eligibility for homecare operationalised over the rate of PwD with an assigned LoCD (Figure 15). The use of mean SES instead of GISD for the construction of concentration curves shows a slight difference for the utilisation of homecare as outcome variable (Figure 14). Here, the concentration curve slightly runs above the equality line indicating that the utilisation of homecare is distributed slightly unequal in favour of municipalities associations with a lower mean SES. Eligibility for homecare seems to be distributed equally among municipalities associations either ranked by mean SES (Figure 15) or GISD.



SES: socioeconomic status

Figure 14: Concentration curve for cumulative portion of homecare utilisation among municipalities associations ranked by SES (own figure)



SES: socioeconomic status

Figure 15: Concentration curve for cumulative portion of level of eligibility of homecare among municipalities associations ranked by SES (own figure)

GISD was also replaced by mean SES as a non-need factor in the multilevel logistic regression analyses with utilisation of homecare (Table 13) and homecare eligibility (Table 14) as outcome variables. The results point to a similar direction as the concentration curves: While the homecare eligibility model shows similar associations for need and non-need factors, the homecare utilisation model (Table 14) results in a statistically significant association for SES ($p < 0.05$) with a higher mean SES value of a PwD's municipality association, i.e. place of living being associated with a slightly lower likelihood of utilising homecare (OR = 0.962).

Table 13: Multilevel logistic regression analysis of the utilisation of homecare among PwD living in community setting, using SES instead of GISD (own table)

	OR	**p**	**95 % CI**
Factors associated with LTC need			
CCI (reference: no comorbidity)[a]			
mild	1.123	0.000	[1.073;1.175]
moderate	1.354	0.000	[1.287;1.423]
severe	1.681	0.000	[1.595;1.772]
age[a]	1.050	0.000	[1.047;1.053]
Non-need factors			
sex (reference: male)[a]	1.098	0.000	[1.057;1.140]
citizenship (reference: German)[a]	1.271	0.000	[1.172;1.379]
SES mean value in place of living[b]	0.962	0.031	[0.930;0.997]
number of inhabitants in place of living[b]	0.999	0.068	[0.999;1.000]
number of outpatient care services per 100,000 inhabitants in place of living	0.994	0.014	[0.990;0.999]
ICC	0.001	0.000	
N	54,308		

[a]measured on individual level (level 1 variable)
[b]measured on level of municipalities associations (level 2 variable)

CCI: Charlson Comorbidity Index; CI: confidence interval; GISD: German Index of Socioeconomic Deprivation; ICC: Intraclass Correlation Coefficient; LTC: long-term care; OR: odds ratio; PwD: persons with dementia; SES: socioeconomic status

Table 14: Multilevel logistic regression analysis of eligibility for homecare among PwD living in community setting, using SES instead of GISD (own table)

	OR	**p**	**95 % CI**
Factors associated with LTC need			
CCI (reference: no comorbidity)[a]			
mild	1.160	0.000	[1.107;1.125]
moderate	1.469	0.000	[1.394;1.548]
severe	1.863	0.000	[1.762;1.971]
age[a]	1.087	0.000	[1.084;1.090]
Factors indicating inequity			
sex (reference: male)[a]	1.279	0.000	[1.084;1.090]
citizenship (reference: German)[a]	1.025	0.556	[0.944;1.113]
SES mean value in place of living[b]	0.986	0.466	[0.949;1.024]
ICC	0.002	0.000	
N	54,308		

[a]measured on individual level (level 1 variable)
[b]measured on level of municipalities associations (level 2 variable)

CCI: Charlson Comorbidity Index; CI: confidence interval; GISD: German Index of Socioeconomic Deprivation; ICC: Intraclass Correlation Coefficient; LoCD: level of care dependency; LTC: long-term care; OR: odds ratio; PwD: persons with dementia; SES: socioeconomic status

Excluding large municipalities associations from multilevel logistic regression analyses

In total 10 municipalities associations were identified as large (more than 100,000 inhabitants) and therefore were excluded from the multilevel logistic regression analyses for homecare utilisation (Table 15) and homecare eligibility (Table 16) as outcome variables. The exclusion of large municipalities associations did not show any significant differences compared to the base case analyses.

Table 15: Multilevel logistic regression analysis of the utilisation of homecare among PwD living in community setting, municipalities associations with > 100,000 inhabitants excluded (own table)

	OR	**p**	**95 % CI**
Factors associated with LTC need			
CCI (reference: no comorbidity)[a]			
mild	1.130	0.000	[1.075;1.187]
moderate	1.356	0.000	[1.284;1.431]
severe	1.657	0.000	[1.565;1.755]
age[a]	1.051	0.000	[1.048;1.055]

	OR	p	95 % CI
Non-need factors			
sex (reference: male)[a]	1.111	0.000	[1.067;1.157]
citizenship (reference: German)[a]	1.218	0.000	[1.106;1.342]
GISD in place of living[b]	0.954	0.300	[0.872;1.043]
number of inhabitants in place of living[b]	0.999	0.254	[0.997;1.001]
number of outpatient care services per 100,000 inhabitants in place of living	0.994	0.009	[0.990;0.999]
ICC	0.001	0.000	
N	46,230		
[a]measured on individual level (level 1 variable) [b]measured on level of municipalities associations (level 2 variable) CCI: Charlson Comorbidity Index; CI: confidence interval; GISD: German Index of Socioeconomic Deprivation; ICC: Intraclass Correlation Coefficient; LTC: long-term care; OR: odds ratio; PwD: persons with dementia			

Table 16: Multilevel logistic regression analysis of homecare eligibility among PwD living in community setting, municipalities associations with > 100,000 inhabitants excluded (own table)

	OR	p	95 % CI
Factors associated with LTC need			
CCI (reference: no comorbidity)[a]			
mild	1,167	0,000	[1,109;1,228]
moderate	1,456	0,000	[1,376;1,541]
severe	1,831	0,000	[1,723;1,946]
age[a]	1,090	0,000	[1,086;1,093]
Factors indicating inequity			
sex (reference: male)[a]	1,289	0,000	[1,236;1,344]
citizenship (reference: German)[a]	1,008	0,869	[0,914;1,112]
GISD in place of living[b]	0,949	0,293	[0,862;1,046]
ICC	0.002		
N	46,230		
[a]measured on individual level (level 1 variable) [b]measured on level of municipalities associations (level 2 variable) CCI: Charlson Comorbidity Index; CI: confidence interval; GISD: German Index of Socioeconomic Deprivation; ICC: Intraclass Correlation Coefficient; LoCD: level of care dependency; LTC: long-term care; OR: odds ratio; PwD: persons with dementia			

3.3 Study 3: Exploratory study on data use in a hypothetical scenario for policy-making in long-term care for persons with dementia

A total of 46 individuals participated in the study, with students comprising 85 % and professionals making up the remaining 15 % (Table 17). While the intended number of student participants was achieved, the distribution between starting students (circa 20 %) and advanced students (65 %) deviated from the planned balance. Recruiting professionals proved challenging due to the intervention and data collection burden, resulting in a response rate of 22 %. Additionally, the professionals willing to participate were already affiliated with the same campus and were acquainted with parts of the study team. All participants contributed data through the questionnaire, eye-tracking, and the interview. The findings indicate that all participants possessed some practical experience in healthcare provision. Moreover, the majority demonstrated comprehension of the information presented in two of the graphs featured in the report. However, risk numeracy was limited, as only a small number of participants provided correct answers to all 4 items. Regarding the decision task on the allocation of additional funds for LTC, more than two-thirds of participants opted for 'more nursing home capacity,' while the other 2 options garnered similar levels of support (Wronski et al. 2021b).

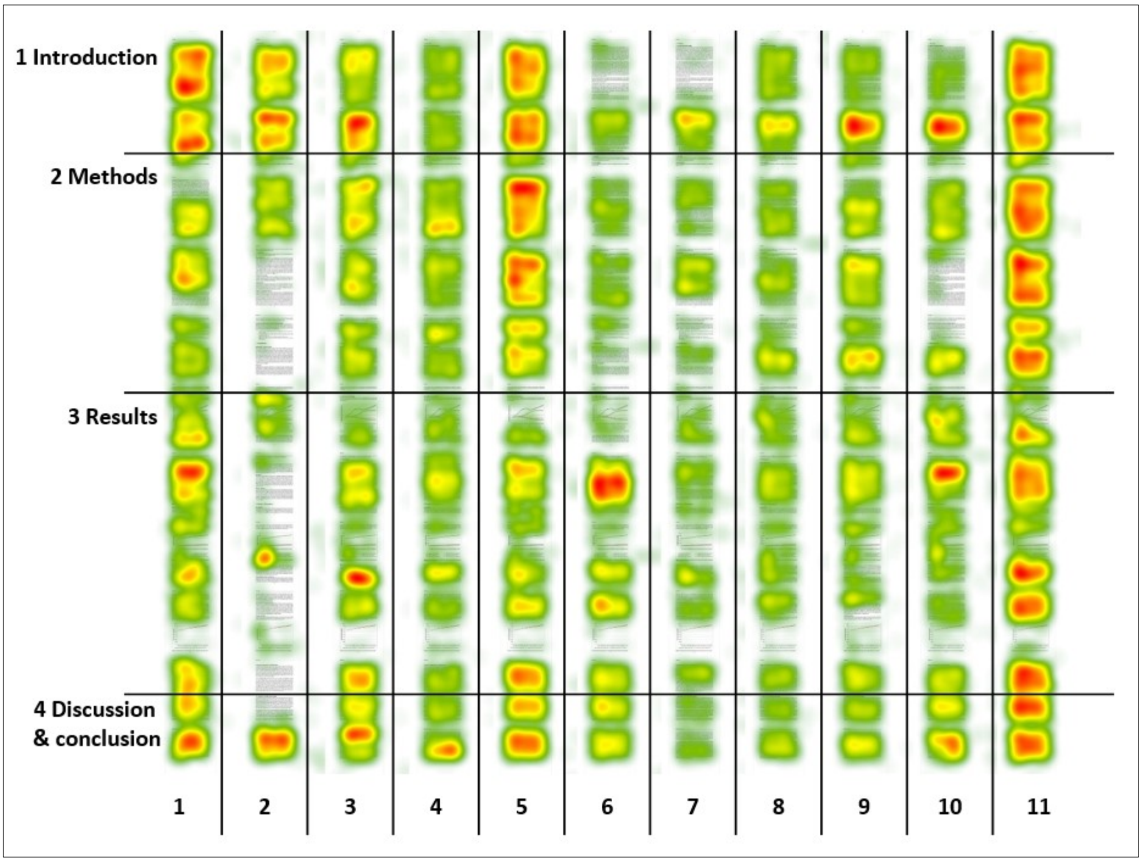
Table 17: Study population / individual characteristics (Wronski et al. 2021b)

N = 46	**n**	**Mean / %**	**SD***
sex (% female)	37	80.4	
age (mean)		25.74	5.42
field (%)			
medicine	27	58.7	
health sciences (graduate & undergraduate)	16	34.8	
other	3	6.5	
level of expertise (%)			
starting	9	19.6	
advanced	30	65.2	
professional	7	15.2	
tolerance of ambiguity (range between 1 and 6)		3.53	0.68
risk numeracy (range between 0 and 1)		0.59	0.36
decision (How to spend additional funds for long-term care in community?)			
option A: support for informal carers	6	13.0	
option B: ambulant nursing capacity	9	19.6	
option C: nursing home capacity	31	67.4	
SD: standard deviation			

The visual examination of gaze plots revealed minimal instances of white space fixations, predominantly occurring on the blank right side of the report picture during scrolling. This observation suggests that participants did not lose focus on the task at hand and were not engaging in 'daydreaming' (Wronski et al. 2021b).

3.3.1 Heatmaps

Figure 16 visually presents heatmaps for 11 randomly selected participants, offering an illustrative representation of the varying visual attention given to different sections of the report. Upon initial inspection, the heatmaps indicate disparities in attention both across report sections and among participants. For instance, heatmap 2 suggests that the methods and results sections received less attention compared to the introduction and conclusion parts, while heatmap 11 indicates a relatively even appreciation of all report sections. Nearly all heatmaps highlight a predominant focus on the second part of the introduction, whereas the 3rd figure located towards the end of the results section garnered limited visual attention (Wronski et al. 2021b).



Average fixation duration in seconds over the 11 participants whose heatmaps are displayed above: red: 0.31 - more / yellow: 0.30 - 0.24 / green 0.23-less.

Figure 16: Heatmaps of 11 participants (columns) after reading the data report (rows), scaled by fixation duration (in seconds) (Wronski et al. 2021b)

The heatmaps of all 46 participants are provided in Figure 19 (Appendix)

3.3.2 *Quantitative appraisal of report sections*

Table 18 provides a descriptive comparison of measures derived from eye-tracking data and responses from the questionnaire, specifically focussing on perceived understandability and helpfulness for decision. The information is organised by report sections and the 3 figures presented in the results section (Wronski et al. 2021b).

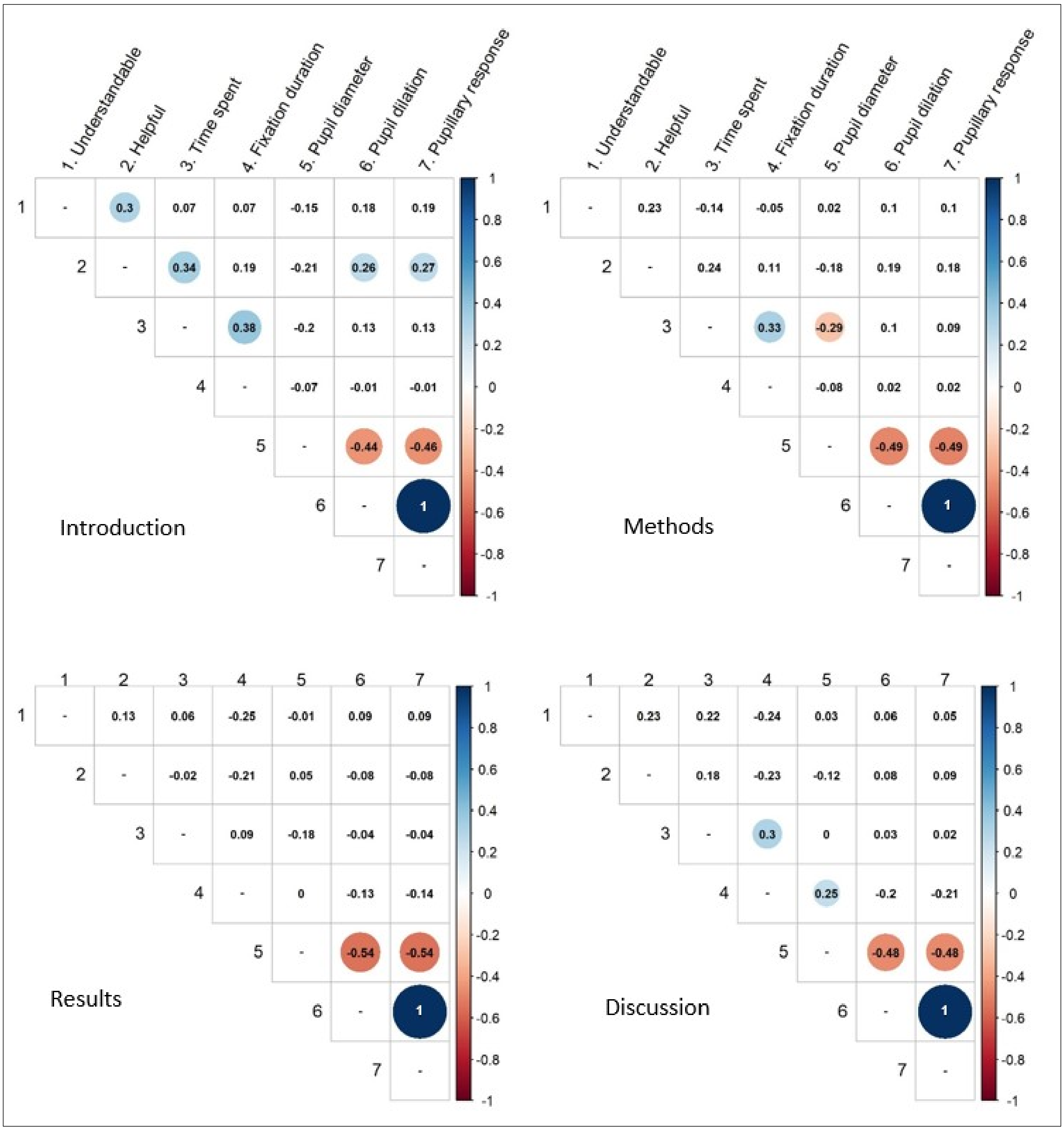
Table 18: Feedback on report sections, all measures in mean values with [standard deviation], N = 46, source: (Wronski et al. 2021b)

	Eye tracking					**Questionnaire**	
Report section and length[a] (in %)	**Time spent (in minutes)**	**Average fixation duration (in ms)**	**Pupil diameter (in mm)**	**Pupil dilation (in mm)**	**Pupillary response (in mm)**	**Under-standable (1 to 10)**	**Helpful for decision (1 to 10)**
Introduction 18.8	2.9 [1.4]	433 [527]	2.71 [0.29]	0.016 [0.007]	0.033 [0.013]	9.0 [1.0]	6.2 [2.5]
Methods 32.4	3.7 [2.5]	380 [452]	2.70 [0.28]	0.017 [0.007]	0.034 [0.015]	7.0 [1.9]	4.6 [2.1]
Results 37.2	4.9 [2.3]	430 [338]	2.70 [0.29]	0.017 [0.007]	0.034 [0.014]	8.1 [1.5]	7.6 [1.6]
Figure 1 2.0	0.4 [0.2]	600 [875]	2.72 [0.27]	0.017 [0.007]	0.034 [0.014]	8.2 [1.8]	6.7 [2.5]
Figure 2 2.0	0.3 [0.1]	447 [434]	2.70 [0.32]	0.018 [0.009]	0.036 [0.019]	8.0 [2.0]	7.4 [2.3]
Figure 3 1.2	0.1 [0.0]	402 [559]	2.67 [0.24]	0.020 [0.009]	0.038 [0.017]	8.3 [1.6]	6.4 [2.8]
Discussion 11.6	1.9 [0.8]	589 [941]	2.69 [0.31]	0.018 [0.008]	0.035 [0.015]	7.8 [1.2]	6.4 [2.3]

a. Length of report sections is approximated by percentage of words from sum of words over all report sections (n=4,042). For figures 1 to 3 words in the labelling of the axes and in captions were counted, each graph was counted as one word.

The average time participants dedicated to reading the report was 13.9 minutes, with a standard deviation of 4.9 minutes. The majority of participants was spending less minutes than the pre-set maximum reading time limit of 20 minutes while 4 reached this maximum. The time spent on each report section roughly corresponded to the length of the respective sections, resulting in similar durations for all sections. Variability among participants in time spent exhibited discrepancies between report sections, notably with a higher standard deviation in the method section compared to the other sections. Participants allocated more time to report figures with higher data density (*figure 1*) than to figures with lower density (*figure 3*). This pattern was similarly reflected in the average fixation duration. Across report sections, the methods section recorded the lowest average fixation duration, while the discussion and conclusion section registered the highest. Pupillometric measures displayed minimal variation among report sections, suggesting no difference in cognitive load. Participants perceived all report sections as understandable, with the methods part receiving the lowest rating (7.0), while the introduction part was deemed the most understandable (9.0). Regarding helpfulness for decision-making, the methods section was perceived as relatively less helpful (4.6), while the results section garnered the highest perceived helpfulness rating (7.6) (Wronski et al. 2021b).

Examining the correlations between measures (Figure 17), there was a notable lack of correlation between measures across the two data sources, questionnaire and eye-tracking. However, some exceptions were identified. In the introduction section, moderate positive correlations were observed for reported helpfulness. Participants perceived the introduction as more helpful when they spent more time reading it (r = 0.34) and when pupil dilation (r = 0.26) and pupil response (r = 0.27) showed higher values. Additionally, the perceived helpfulness of the introduction section was positively associated with its perceived understandability (r = 0.30). Across different sections of the report, the correlation patterns between measures appeared largely similar. The strongest correlations (r = 0.44 and higher) were found between the 3 pupillometric measures, all indicative of cognitive load. Another consistent pattern across most report sections (introduction, methods, discussion, and conclusion) was observed between eye-tracking measures, specifically average fixation duration and time spent. The more time participants spent with these report sections, the more information they processed. Two additional correlations were identified for specific report sections involving pupil diameter and other non-pupillometric eye-tracking measures. A smaller pupil diameter was associated with more time spent on the methods section (r = -0.29). Conversely, for the discussion and conclusion sections, participants exhibited a larger pupil diameter with a longer fixation duration (r = 0.25), indicating increased information processing (Wronski et al. 2021b).



Questionnaire based measures: understandable, helpful for decision. Eye tracking measures: time spent, pupil diameter, pupil dilation, pupillary response. Coloured figures: $p < 0.10$.

Figure 17: Pearson correlations between questionnaire and eye tracking based measures appreciating report sections (Wronski et al. 2021b)

3.3.3 Qualitative analysis

The average duration of the interviews was 17 minutes, with the shortest interview lasting 7 minutes and the longest lasting 31 minutes. Through qualitative content analysis, 29 distinct reasons were identified as explanations for why participants allocated more or less attention to a report section during the reading and decision task. These reasons were categorised into 4 themes: type of information use, perceived understandability, decision-making, and expectations towards report sections. Table 19 provides a summary of these themes and the identified reasons within each theme. While some categories relate to all 4 report sections, certain themes are specific to individual report sections, and others pertain to more than one or all report sections. Additionally, Table 19 indicates the direction of attention towards a report section, clarifying whether a theme was associated with an increase or decrease in attention to a specific section (Wronski et al. 2021b).

Table 19: Reasons for report section attention identified by qualitative content analysis (Wronski et al. 2021b)

Category	Theme (report section theme relates to)[a, b]	Description of category	Illustrative quote per category
Type of information use	+ establish comprehension (3, 4) + facilitates reflective thinking (1, 3, 4) + form an opinion based on given information (3, 4) + learn about authors' view (4) + personal relation to topic (3) + previously made choice was confirmed (2, 3, 4) ± credibility of text part is important (2) ± get overview (1, 3, 4)	• themes describe participants' purposes of information use and mostly relate to importance of a report section for decision task • category addressed by most participants	*"[...] I looked through the conclusion to see whether I did not miss anything, any important information I did not read, yet."* (participant 20, advanced student)
Perceived understandability	+ text part was short (4) + written understandably (4) + figures enhance comprehension of contents (3) ± figures not understandable (3) ± figures quickly understandable (3) ± no link between information and decision (1, 2, 3) - more information provided then needed (2) - too little previous knowledge for understanding the information (2)	• themes reflect understandability of report sections in connection with more or less attention to a report section • category addressed by some participants	*"A graphic provides a nice overview and oneself can, you can see what the development is and so on, you do not need to look at the corresponding text, this saves time when one is under time pressure [...]."* (participant 10, advanced student)
Decision	+ figures generally important (3) + information helpful for weighing up options (3) + text part contains important information (3) + text part relevant (1, 2, 3) ± information less important under time pressure (1-4) ± text more important than figures (3) ± text part not relevant (1, 2) - already decided before reading (3, 4)	• themes relate to decision-making process • category addressed by most participants	*"I knew, I only have 20 minutes, and whether this is routine data or data from a primary data collection is not so important for me, for such a spontaneous decision, this may not be a perfect answer, but in that situation it was not so important for me and therefore I did not read it so much."* (participant 27, advanced student)
Expectations towards report sections	+ desired information was given (1, 4) ± other information desired (2-4) - expected information (3, 4) - information already known from previous knowledge (1, 2, 3) - information already known from report (3, 4)	• themes relate to participants' expectations and anticipations towards information given in report sections • category addressed by some participants	*"Well, actually I was looking for information on effectivity of measures and I did not find it. Therefore, I thought 'okay I will glance at the graphics, wanted to scroll down to the information I actually was looking for, which so to say, never came."* (participant 42, professional)

a. Report sections are indicated by their numbering: 1. Introduction, 2. Methods, 3. Results, 4. Discussion & conclusion
b. Reason / theme was reported to either result in more (+) or less (-) attention to report section or some participants reported a reason / theme to result in more and others to less attention (+-)

3.3.3.1 Type of information use

The majority of participants articulated their actions or intentions regarding the information acquired from specific report sections, delineating how they utilised the information. These rationales were largely linked to the significance of a report section for the decision task, encompassing aspects such as forming an opinion or obtaining an overview. Some participants specifically noted the use of the methods section to evaluate the credibility of other parts of the report. Interestingly, this particular reason was cited by participants who both allocated more attention to the methods section and those who allocated less attention to it (Wronski et al. 2021b).

3.3.3.2 Perceived understandability

When participants elucidated the reasons for allocating more attention to a specific report section compared to others, some also deliberated on the perceived understandability of those sections. This rationale was invoked to elucidate both the decision to devote more and less attention to a particular report section. Participants who indicated that the figures in the results section augmented their comprehension of the section's content mentioned that they allocated more attention to these figures, especially when they could not directly link them to the decision task. Acknowledging the time constraints for reading, some participants valued the fact that the figures in the results section provided a wealth of information in a succinct and clearly presented manner, facilitating rapid comprehension. Consequently, less time was spent on reading the text of the results section, with more attention directed towards the figures (Wronski et al. 2021b).

3.3.3.3 Decision

The reasons cited by most participants for paying attention to a particular report section were directly tied to the decision-making process. Across participants, each reason was associated with either allocating more or less attention to a section. Participants who emphasised the general importance of figures, perceived the provided information as valuable for assessing options, or felt that a report section contained crucial information tended to allocate more attention, particularly to the results section. Perceived relevance for decision-making was another common reason for allocating more attention and applied to all report sections except the methods section. Conversely, some participants viewed the methods section as irrelevant to decision-making and consequently allocated less attention to it (Wronski et al. 2021b).

3.3.3.4 Expectations towards report sections

Another category of reasons mentioned by participants for paying attention to a report section, was identified as expectations towards that report section. Participants expressed that they anticipated the information provided in a specific text part or felt that the scanned information was already known to them, either due to prior knowledge before reading the report or information obtained in an earlier processed part of the report. Participants who articulated these self-observations also mentioned allocating less attention to report sections from which they did not expect to gather new information. These expectations were primarily associated with the results and discussion and conclusion sections (Wronski et al. 2021b).

Beyond the information presented in the report, participants mentioned other factors influencing their decision-making. Qualitative content analysis identified 3 types of categories and 12 sub-categories, as shown in Table 20. Participants mentioned the sub-category relationship/domestic environment most frequently, cited by 31 participants. In this category, participants reflected on the impact of homecare on the relationship between individuals in need of care and their caregiving dependents, as well as the broader consequences of a domestic environment. Participants reflected on situations where they observed instances where caregiving dependents were overwhelmed with providing informal care, while individuals in need of care felt supported and strengthened by their dependents. The 2nd most common sub-category was preference or attitude, as participants described considering their personal preferences or attitudes in making their decision. Additionally, many participants mentioned that their private environment and experience played a significant role in their decision-making. The most prevalent perspective included in participants' decision-making was at the societal level, encompassing thoughts about the opportunity costs for society that may result from informal care (Option A) (Wronski et al. 2021b).

Table 20: Aspects included in decision-making other than report identified by qualitative content analysis (Wronski et al. 2021b)

Source Categories under this heading refer to other sources besides the data report which participants mentioned to have included in their decision-making	**Perspective taken** These categories describe the perspective, from which participants reported aspects included in their decision-making	**Content of aspect** These categories summarise the content of other aspects which participants reported to have included in their decision-making
Preference or attitude	Society	Professionalism

(e.g. general preference of home care)	(e.g. thoughts about opportunity costs for society which may result from informal care)	(e.g. quality of professional care is higher than informal care)
Education (e.g. knowledge aquired at university)	Nursing staff (e.g. thoughts about working conditions of nursing staff)	Capacity (e.g. nursing homes are full)
Experience • *in job environment* (e.g. in nursing home) • *in private environment* (e.g. from dependents)	Concerned persons (in need of care and dependents) (e.g. will of persons in need of care should be considered)	Relationship / domestic environment • *benefits* (e.g. dependents give support and strength to person in need of care) • *burdens* (e.g. dependents are overburdened with informal care)
Other (e.g. information obtained from the media)	Oneself (e.g. how one wants to act oneself in the future)	Reservations about nursing home (e.g. persons in need of care receive insufficient care)

4 Discussion

In this section the results of the present study are discussed. In order to answer the research questions results will be embedded in the current state of research. Furthermore, the methodological approach across and within the 3 presented studies is reflected. Knowledge gained from this study as well as its limitations are discussed and conclusions are derived in the end of this section.

The present study explored the potential of data use for equitable policymaking in LTC for persons living with dementia in Baden-Wuerttemberg. In the study process, 3 aspects are in focus: data need from a policymaker perspective, data production by analysing need and equity, and data use with a focus on information uptake and using it for decision making. Accordingly, these 3 aspects will be thematised in the discussion.

Those parts of the sections 4.1.4 and 4.2 which refer to study 3 can be found in (Wronski et al. 2021b).

4.1 Discussion of results

The discussion of results is structured along the 3 aspects of data need, data production, and data use. Data need is discussed in section 4.1.1 and focusses on indicators related to dementia and data-related possibilities and limitations of available secondary data. The aspect of data production is discussed by focussing the results on analysing long-term care for persons living with dementia (section 4.1.2) and equity in long-term care (section 4.1.3). Data use is discussed in section 4.1.4 by focussing the individual uptake of information on dementia and LTC in decision making. The section also reflects on the use of identified dementia and LTC indicators in the context of the *Model Project Cross-Sectoral Healthcare* where the survey on indicator selection was embedded in. Operationalised indicators were used in the development of a cross-sectoral and needs-based healthcare concept in a model region in subproject 2.

4.1.1 Data need

Health system stakeholders in Baden-Wuerttemberg identified in total 14 indicators related to dementia and/or LTC for regional needs-based LTC policymaking. Additionally, 20 indicators of non-medical determinants of health were identified. Nevertheless, not all framework dimensions were covered by indicators, i.e. the dimension of health system performance. Already during the search of indicators, in this dimension none were found.

One reason could be that there were not sufficient indicators established in Germany during the time of the study (2017), even though regular quality assessments are part of the LTC-system (section 1.3.2). The so called “Pflegenoten”, which were introduced in 2009 to publicly report the quality of LTC facilities, have been highly criticised and major conceptual limitations have been identified (Sunderkamp et al. 2014). “Pflegenoten” are an aggregated presentation of the results from regular quality assessments using German school grades, and were conducted on a small sample of care recipients in nursing homes and outpatient facilities. Since January 2023, in inpatient LTC facilities, this quality reporting system has mainly been replaced by a set of 15 quality indicators (e.g. on pressure ulcer formation). These indicators are generally measured for all care recipients in a facility and have a focus on outcome quality. Among these indicators, there are at least 2 which are only measured within persons with cognitive impairment and therefore relate more to PwD. These indicators are the use of straps to secure persons to the wheelchair or bed and the use of bed side panels. The use of straps and bed side panels is controversially discussed as it restricts the independence of those affected and may cause mental and emotional stress for them. Therefore, use of straps and bed side panels among persons in need of care, who are regarded as unable to decide for themselves, is focussed in quality assessments and should be as low as possible (GKV-Spitzenverband et al. 2023a; GKV-Spitzenverband et al. 2023b). In outpatient LTC the introduction of new quality indicators is being prepared to replace the “Pflegenoten” accordingly.

Apart from the dimension of health system performance, no dementia-specific indicators in the dimension of healthcare provision were found which would describe features of professionals, facilities, or technologies addressing dementia-specific aspects of LTC. Language skills are one example of these aspects. In 2021, circa 1.4 million people were living in Baden-Wuerttemberg (Statistisches Landesamt Baden-Württemberg 2022), who migrated from another country. This means for LTC that there will be a significant number of persons in need of care, whose native language is not German. In the study sample of PwD aged 65 years or older already 5.1 % (section 3.2.2.1) had another citizenship than German. This may become crucial when dementia progresses and PwD may revert to their native language in the course of their disease. Lacking language alternatives in LTC settings may reduce the well-being of those affected and was shown to increase the risk of agitation (Chejor et al. 2023; Cooper et al. 2018). Regularly collected comprehensive data on such features of nursing facilities were not available for the year of 2013.

Available data proved to be sufficient for approximating LTC need in PwD on a small area level, such as administrative districts (section 3.2.1) and could be assessed on a regular basis for needs-based policymaking. Administrative data have been regarded as sufficient for dementia related public health as prevalence rates were comparable to those of other sources such as field studies like EuroCoDe, when extrapolated to the population in Baden-Wuerttemberg in terms of age and sex (Deutsche Alzheimer Gesellschaft 2019), or international meta-studies (Bacigalupo et al. 2018; Doblhammer et al. 2015). Also, regional equity analyses were generally possible with regularly available data (section 3.2.2).

Despite the cross-sectional perspective in this thesis, available data also allow for future projections of prevalence and utilisation rates. One of the main risk factors of dementia is an older age and age specific prevalence rates show an increase (section 3.2.1). Since claims data provides this information on a small area level, future projections of prevalence rates in administrative districts are possible. By using regional population projections provided by the Federal Statistical Office, the sole effect of local population age structure on prevalence can be modelled to give local health policymakers an idea of the future development of LTC need in their region. On the basis of prevalence and utilisation rates presented in this thesis for the year of 2013, an increase of absolute numbers was projected for 2023 in all administrative districts in Baden-Wuerttemberg taking into account life expectancy, birth rates, and migration (Ministerium für Soziales 2018). Especially medium-term projections should provide a good orientation of future need, since the population generations concerned were born already and have reached an age, where certain risk factors can only be influenced to a limited extent as dementia may manifests years before it reaches a pathological level.

Nevertheless, both secondary data analyses showed significant limitations considering data use on a regular basis on a small area level.

First, the differentiation between formal and informal LTC care utilised in the home setting was not possible. Nonetheless, further analyses could provide further information on equity in this politically highly preferred care setting (as stated in the Social Code XI) as results from Spain suggest. Here, it was observed that in a disabled population formal care was more likely to be used by the better of and vice versa (Garcia-Gomez et al. 2015).

The main data source of the secondary data analyses was claims data from the AOK Baden-Wuerttemberg, i.e. a single statutory health and LTC insurance. Although a significant share of the population in Baden-Wuerttemberg was insured with the AOK in 2013 (between 20 % and 55 % of the population in administrative districts (Ministerium für Soziales 2018)), the representativity of this data for the general population is not clear in some aspects. The AOK population consists of more persons with a low SES and fewer with a high compared to the other LTC insurances (both privately insured and the insured of other statutory health and LTC insurances) (Hoffmann and Koller 2017). A solution to this limitation could be data made available by the Health Data Lab at the Federal Institute for Drugs and Medical Devices comprising claims data from all statutory health and LTC insurances for research and health policy purposes. However, the Health Data Lab is still under construction and data may be first accessed by the end of 2024 (Federal Institute for Drugs and Medical Devices 2023).

A limitation the Health Data Lab will not solve is the lack of socioeconomic data in administrative claims data. As this information is essential for equity analyses, in this study socioeconomic data was approximated on regional level instead. However, this is another concept than SES on the individual level. Nevertheless, this data source harbours potential, especially through the linkage at person level of clinical data from electronic patient records. For example, it may be possible to obtain information on the stage of dementia that is missing from administrative data.

4.1.2 Long-term care for persons living with dementia

A quantitative assessment of LTC need among PwD was possible in terms of regional variation of prevalence and utilisation in different settings (home versus nursing home), LoCD, comorbidities, age, and sex (section 3.2.1).

The prevalence of dementia as well as the utilisation of LTC (nursing home, in-cash benefits to compensate for informal carers, outpatient care services, semi-outpatient care) varied across administrative districts, both in absolute terms and in relation to population size. Interestingly, the highest absolute LTC utilisation was not observed in the largest administrative district in terms of population size. As regional variation and its explanatory factors relate to equity aspects, LTC utilisation is discussed in section 4.1.3.

The prevalence of dementia shows regional variation throughout Germany with highest rates in mostly East German administrative districts (Thyrian et al. 2020). Also in other countries, such as Denmark, variation exists, even if prevalence rates are standardised by age and sex (2.5 % to 3.6 % in Denmark in 2015 throughout 5 regions) (Zakarias et al. 2019). The exact reason for this variation is still unclear, but underdiagnosing is discussed as diagnostic rates are higher in field studies than administrative data (Zakarias et al. 2019).

LTC need in PwD was in this study mainly analysed in terms of quantity, such as utilisation rate of LTC and its setting in general, due to data availability. However, this approach does not capture all the LTC need special to PwD. Due to symptoms, such as reduced orientation, communication skills, or attention, LTC for PwD requires more time and comes with a higher burden for carers compared of persons without dementia (Georges et al. 2023). The management of behaviours such as agitation, aggression, and anxiety was identified as one of the most important needs in PwD in a systematic review (Cadieux et al. 2013). Non-pharmaceutical interventions such as listening to music may reduce agitation (Hicks-Moore 2005; Sung et al. 2010). A psychosocial behaviour management programme to support care providers in identifying unmet needs and implementing according action plans reduced challenging behaviour in home-dwelling PwD (Nakanishi et al. 2018).

Comorbidities of PwD partly describe additional special LTC need of PwD and partly result from unmet care need. Common comorbidities reported in section 3.2.1 apply also to the general elderly population. When compared to this population, fluids and electrolyte disorders, insomnia, incontinence, pneumonia, fractures and injuries were observed more often in PwD (Bauer et al. 2014).

4.1.3 Equity in long-term care

In the present study, (horizontal) inequity in access to LTC services in community dwelling PwD in Baden-Wuerttemberg aged at least 65 years was analysed by using claims data of the AOK and statistics on PwD's place of living by linking this data on the level of municipalities associations (section 3.2.2). Concentration and horizontal inequity index analyses mostly did not identify inequitable distributions of homecare utilisation and eligibility among municipalities associations. Though, homecare utilisation was slightly concentrated in favour of regions with a lower density of outpatient care services, which was also illustrated by the concentration curves. Multilevel logistic regression analyses included individual level data additionally to regional characteristics. The latter were the same non-need characteristics as used in concentration and horizontal inequity index analyses, pointing in the same direction. Homecare included LTC provision by informal and formal carers, a differentiation was not possible due to data availability. Among home dwelling persons eligible for LTC benefits according to Social Code XI in general, the majority (65 %) received care only by informal carers (Baden-Württemberg 2023). It should be further investigated whether utilisation of informal care is higher in regions with lower outpatient care service density.

For individual characteristics of study participants logistic regression analyses showed higher likelihoods among female PwD to utilise homecare, while female PwD additionally had a higher likelihood to be eligible for homecare, also when controlled for the need-factors of comorbidity and age. This is in line with results from health inequity analyses of homecare utilisation and eligibility in the general Dutch population aged at least 65 years (Tenand et al. 2020). There, having a partner was found to make a difference in homecare utilisation and eligibility: elderly women with a partner were found to use less homecare compared to men, while for men having a partner did not reduce the likelihood to be eligible for homecare (Tenand et al. 2020).

PwD with non-German citizenship showed also higher likelihoods to utilise homecare compared to no benefits according to Social Code XI in the logistic regression analyses after controlled for need-factors. A possible reason could be underdiagnosing among this population. An analysis of data from AOK data in another West German region observed lower age and sex standardised administrative prevalence rates of dementia among insured persons with non-German citizenship (Stock et al. 2018). Stock et al. discuss underdiagnosing in this population as one of the possible reasons and point out that persons with non-German citizenship have less contact with health professionals who could help to recognise the presence of dementia (Stock et al. 2018). Also, results from Denmark show that diagnostical workups for dementia have been completed less often in ethnic minorities than in the general population (Nielsen et al. 2011).

GISD neither lead to statistically significant results in the logistic regression analyses nor did concentration curves show any inequalities in the distribution of LTC utilisation and eligibility. In contrast to this, SES at the level of a person's place of residence showed a slight concentration of LTC utilisation towards municipalities associations with a lower SES. The logistic regression analysis pointed in a similar direction with PwD living in a municipality association with a higher SES having a lower likelihood to utilise homecare. Results from England point in a similar direction: Hu et al. found homecare utilisation to be distributed pro-poor based on a sample of the English Longitudinal Study of Ageing (ELSA) using equivalised income and wealth as socioeconomic non-need variables (Hu et al. 2022). While access to health care in England is universal, public support for LTC follows a means-test.

4.1.4 Data use in decisions of policymaking in long-term care

This study produced data on the epidemiology of dementia and LTC which has been used explicitly in 2 ways: First, it was used to inform local needs-based policymaking in the *Model Project Cross Sectoral Healthcare* and its model region in the south of Baden-Wuerttemberg during meetings of local health system stakeholders who were developing a cross-sectoral healthcare concept for their region. Second, the data was used in a hypothetical decision scenario to investigate its use by (future) health decision-makers in terms of reading (study 3).

Study 3 describes the use of a quantitative data report by (future) decision-makers (Wronski et al. 2021b). Study participants were observed in a laboratory setting using innovative methods while they read the report and subsequently had to make a decision on the distribution of financial resources for LTC (Wronski et al. 2021b). It was found that the (future) decision-makers spent a similar amount of time reading the report sections (introduction, methods, results, discussion) and were highly focussed. Only when reading the methods section were the study participants less focussed. In addition, the time that the study participants spent on this part of the report showed the most variation (Wronski et al. 2021b). The observation that the methods section was read less intensively can be viewed critically insofar as the methods section contains information that enables an assessment of the quality and significance of the results (Wronski et al. 2021b). The question therefore arose whether reading behaviour would change if the methods section were presented in a different format. A further study investigated whether adding a summarising textbox of the methods would attract more participants to read the methods section and to pay more attention to it (Koetsenruijter et al. 2022). The results of 35 medical students were compared in a non-randomised study design, some of whom were presented with a version of the quantitative data report with a summary textbox and a control group with a report version without a summary textbox. However, the addition of the text box did not result in the method section being read more attentively (Koetsenruijter et al. 2022).

Following the reading and decision-making task, interviews were conducted with the study participants (Wronski et al. 2021b). Qualitative content analysis revealed that the reasons for the level of attention paid to the report sections varied. Furthermore, it became clear that people also have other aspects and approaches in mind when making a decision that go beyond the information that can be found in a quantitative data report. For example, an attempt was made to adopt the perspectives of different groups of people affected, to draw on their own prior knowledge and experience on the topic, or to think beyond other aspects that were less presented in the report, such as the subjective needs of people in need of care and their relatives (Wronski et al. 2021b).

Identified indicators on dementia and long-term care that were collected at administrative district level (sections 3.1 and 3.2.1) were embedded in the *Model Project Cross Sectoral Healthcare*. This project which focussed on patient groups from 7 other indication areas in addition to PwD, as well as other areas of care in addition to LTC. Within this overarching model project, the results were part of Sub-Project 1. With regard to data for policymaking, data on the indicators was provided in Sub-Project 1 in a comprehensive final report, which is freely available on the website of the Baden-Wuerttemberg Ministry of Social Affairs, Health and Integration (Ministerium für Soziales 2018). Decision-makers in Baden-Wuerttemberg were informed about the model project in various ways, including at a state health conference, at a press conference organised by the minister and by means of brochures which were sent to all health authorities in Baden-Wuerttemberg. In addition to the final report, the regionalised health data was also provided to the Ministry in the form of an Excel file, which was made available to interested parties on request to the Ministry. In fact, the Excel file was requested by individual health authorities. However, the pilot project did not provide for a scientific evaluation of the use of the data immediately after it was made available in 2018. As there were also no plans to update the indicators, which relate to data from 2013 with projections for the year 2023, it can be expected that the data is hardly or no longer requested and that an evaluation of regional data use, for example by health authorities, no longer makes sense. The NHS Atlas of Variation in Healthcare in England, for example, is a different case. Since 2010, regionalised healthcare data on expenditure and outcomes has regularly been made available to decision-makers in the healthcare system. In an email survey and subsequent interviews with 53 healthcare decision-makers, Schang et al. analysed the use of the NHS Atlas (Schang et al. 2014). Approximately half of the study participants stated that they did not use the atlas. Reasons included a lack of awareness of the atlas and a lack of staff capacity to use it. Furthermore, some non-users felt that the atlas was not applicable for local decisions. Users of the atlas stated that they used it to gain a better understanding of regional differences and as a visual aid when communicating with clinicians (Schang et al. 2014). In Baden-Wuerttemberg as well, it can be assumed that limited personnel capacities represent a constraint to the integration of regional health data in local policy-making as health authorities in administrative districts are differently equipped in this respect. While some health authorities are able to carry out their own data analyses, other health authorities are reliant on existing services, such as the *Gesundheitsatlas* provided by the State Statistical Office. This service is mainly based on data from official statistics, but data on disease-specific need is scarce. For example, there is no regionalised information on the prevalence of dementia or the use of LTC by PwD (Baden-Württemberg 2022).

In addition to the final report of the model project, some of the data from Sub-Project 1 was integrated into Sub-Project 2. The aim of Sub-Project 2 was to develop a cross-sectoral care concept in the 3 administrative districts of the model region (Biberach, Ravensburg and Reutlingen) (Ministerium für Soziales 2018). The concept was developed primarily in district-specific and disease-specific (including dementia) working groups consisting of local healthcare stakeholders under the coordination of the respective health authority. In each working group (e.g. working group on dementia in the district of Reutlingen), a total of 3 meetings were held in which the current care situation was first analysed, followed by a target analysis. Finally, a target-actual comparison was carried out in which potential for improvement and cross sectoral healthcare problems were identified. As part of the working group meetings, the participants were presented with data (tables, figures and a location map with care services) on current morbidity, utilisation and their respective future development as well as current care services in their district by representatives of the respective health authorities. This served as a starting point for further deliberations in the working group on the question of whether the current care services will continue to be sufficient in the future, whether the services should be expanded or supplemented, and how the current healthcare services could be optimised to meet future healthcare need (Ministerium für Soziales 2018).

4.2 Reflection on the methodological approach

This section reflects on methodological and conceptual aspects related to the potential of data use along the 3 conducted studies.

The survey that was used to identify indicators (study 1) was embedded in a broader setting comprising 7 other diseases. Moreover, it aimed at identifying indicators not only in the sector of LTC but across all health sectors, from primary prevention and health promotion to palliative care. This broad approach may have led to less focus when it comes to the identification of indicators specifically for dementia and LTC.

Only a fraction of the study participants were experts who deal with LTC of PwD. However, as there was only a comparatively low number of indicators in this area and almost all of the proposed indicators relating to dementia and LTC were selected by the participants, the composition of the study participants appears to play a minor role.

Apparently, the high number of indicators to be assessed (and therefore very time-consuming task) seemed to have had little influence on the selected indicators on dementia and LTC, as nearly all were selected. A problem of the "indicator chaos" (Saskatchewan Health Quality Council 2011) mentioned at the beginning (section 1.1), i.e. the challenge for decision-makers to make a selection from many indicators, does not appear to apply to the care area under consideration. Instead, there may be a lack of indicators here as even more, if available, might have been selected.

Furthermore, the search for indicators was focussed on a broad spectrum of morbidity and care. As a result, the search for indicator sources focussed less specifically on the LTC of people with dementia. It cannot be ruled out that relevant indicators may not have been identified as a result. However, this method should still have captured a large part of the relevant and also measurable (regionalised data collected at regular intervals) indicators.

The secondary data analyses (section 3.2) largely comprised regionalised data at an administrative district level (section 3.2.1) and municipal association level (section 3.2.2). This raises the question of which regional level is most appropriate. In principle, more data, especially official statistics, are available at district level. As already mentioned, the number of inhabitants varies less at this regional level than at municipal association level, making comparisons between districts more valid. However, the results of the equity analysis were robust to the exclusion of municipalities associations with a comparatively high population.

Although the GISD was designed as the regionally aggregated counterpart of SES, i.e. includes the same dimensions and spectrum of values (3 to 21 points) (Kroll et al. 2017), it led to statistically not significant results in contrast to SES. This might be explained by a difference in variance between the two measures: the difference from lowest to highest value was 2.46 points for GISD and 6.00 points for SES. Standard deviation was also higher for SES. Differing variances in turn might be explained by the different measurement of the two variables. GISD is based on already aggregated official statistics data which were only partly available on the level of municipalities associations. SES on the other hand was measured with survey data based on a sample. Study samples were not constructed for the level of municipalities associations, so that higher variance in SES values may reflect sample uncertainty.

Since SES was used as a regional characteristic, results of the equity analyses could be biased by a difference in insurance patterns. It is known that in regions with higher SES fewer people are insured with the AOK or statutory health and LTC insurance in general. In Germany, employees with high working income, self-employed, and civil servants are exempt from compulsory insurance and can be insured within a private scheme. This insurance agreement usually continues after retirement age (65 years), so that it still could apply to the sample of this study.

A highly discussed but unsolved conceptual question in the measurement of equity in healthcare is about what should be regarded as the good that is distributed. There is mainly discussed health itself as the “ultimate upstream variable” (Wagstaff and van Doorslaer 2000), access to healthcare, which is closer to the idea of equality in opportunity, and healthcare utilisation, which on the other hand is often used to operationalise the concept of access.

A further question in the, compared to medical care, previously less researched field of equity in LTC concerns the operationalisation of LTC needs and the choice of needs factors. Eligibility was not used as a need factor in this study, but was treated as an indicator of utilisation. However, it can also be argued that eligibility and correspondingly LoCD should be used as a needs factor, as this represents the result of a formal assessment of LTC need.

The use of a quantitative data report for health policy decisions was mainly analysed in study 3 (Wronski et al. 2021b). The data was collected using a computer-assisted questionnaire, eye-tracking, and interviews. The different data collection methods also appear to have led to different and therefore complementary findings on the use of the data report (Wronski et al. 2021b). This could possibly be inferred from the fact that, for example, the assessment of the comprehensibility and helpfulness of the report sections collected via the questionnaire hardly correlated with indicators that were collected using eye-tracking (Wronski et al. 2021b). The heatmaps provided a quick overview of which parts of the report were fixated to a higher or lesser degree. Fixational and pupillometric measures could be used to support the further interpretation of the heatmaps and provide information on whether the report sections were actually read and not just looked at. Finally, the interviews provided more in-depth information about possible reasons for paying more or less attention to a report section (Wronski et al. 2021b).

Limitations of the study should be mentioned in particular with regard to the study sample. The intention was to recruit actual decision-makers in addition to students of health sciences and medicine as potential future decision-makers in the healthcare sector. However, this proved difficult. After all, participation involved a visit to the laboratory and the use of an eye tracker. Therefore, the recruitment of actual decision-makers followed a pragmatic approach, so that mainly scientists whose work only indirectly involves policymaking were recruited (Wronski et al. 2021b).

It should also be mentioned that the sample size was comparatively small. This was sufficient for the exploratory approach of the study and also corresponded to the planned number of participants. However, smaller effects could not be sufficiently analysed in this way (Wronski et al. 2021b).

In addition, the rather artificial context of the data collection must be taken into account: the participants read the report in a study laboratory and made their decision in a hypothetical scenario that was constructed as realistically as possible but was not, for example, associated with real consequences for LTC or the participants themselves (Wronski et al. 2021b).

4.3 Conclusion

Date-based equitable policymaking that takes regional characteristics into account is a declared guiding principle in Baden-Württemberg. Against this background, this study analysed the potential of data-supported and needs-based policymaking in Baden-Wuerttemberg using the example of LTC for PwD. A comprehensive approach was chosen, in which the data need of healthcare decision-makers were determined, the possibilities for analysing existing secondary data sources were examined and the way in which such data is ultimately incorporated into decisions was explored.

The indicator selection and secondary data analysis showed that basic data is available in the area of LTC of PwD to estimate the objective need for LTC in PwD at a small-area level, essentially via indicators of morbidity and utilisation. However, the framework for indicators developed with decision-makers of the healthcare system in Baden-Wuerttemberg also suggests that not all of the required information is yet available. For example, it is currently almost impossible to provide valid data-based information on the performance of LTC in administrative districts, and even less on dementia-specific aspects of regional LTC. Compared to medical care, ensuring the equitable provision of LTC as a responsibility of the state and LTC insurances was introduced later by law. The availability of regularly collected nationwide LTC data differs accordingly, although it is constantly improving, for example through reforms in the quality control of LTC and scientifically supported model projects as well as through large scale study programmes such as the National Cohort. However, a similar gap between policymaking in medical care and LTC can also be observed in other European countries. Equity of LTC was analysed in this study using a health economic approach based on the concept of horizontal equity. For the area of outpatient LTC for Baden-Wuerttemberg, it was shown that access to care for PwD is basically equitable, but a differentiation between formal and informal care in the data would be particularly important for a better understanding. A regional analysis, for example at the level of the administrative districts, of horizontal equity, was not possible as key SES indicators were not available at the level of individuals. The use of quantitative data was explored using innovative methods. This showed that (future) decision-makers in the healthcare system generally read the whole quantitative data report. How carefully a report section was read varied most in the methods section. The information generated via various data collection methods, in particular eye-tracking, complemented each other in this study.

5 Summary / Zusammenfassung

English version

Pamela Wronski
Dr. sc. hum.

From data need to data use: Exploring the potential of data use for equitable policymaking in long-term care for persons with dementia in the German state of Baden-Wuerttemberg

Subject/Department: General Practice and Health Services Research
Supervisor: Prof. Dr. Michel Wensing

According to SGB XI § 69, long-term care in Germany should be organised according to need. A particular challenge here is the increasing need for long-term care, especially due to age-related illnesses such as dementia. For those affected, this is associated with increasing restrictions on activities of daily living and usually leads to a need for care. Dementia is one of the most common diagnoses requiring nursing care. In Baden-Wuerttemberg, the aim is to meet these challenges with data-based care planning that is orientated towards regional care needs in accordance with the "*Gesundheitsleitbild*". Particularly over the last two decades, administrative data from health and long-term care insurers throughout Germany has been increasingly made available and their potential for use in regionalised analyses, especially for medical care, have been developed. The growing number of data sources and indicators present local decision-makers with the challenge of selecting relevant indicators for policymaking. However, studies also show that data availability alone is not enough for policymaking to be data-based. And even if reports are available, there is little knowledge about how decision-makers use and read these quantitative data reports, a common format in which data is provided.

This dissertation explores the potential of data-based policymaking in Baden-Wuerttemberg using the example of needs-based long-term care for people with dementia. To this end, it was investigated (1) which data decision-makers consider relevant for regional policymaking in this area, (2) which data is available, in particular for assessing the need

for care and its adequacy on a small-area level, and (3) how this data is used in the format of a report by individual decision-makers. Indicators on the absolute and relative frequency of dementia and comorbidities, on care utilisation, and on existing care services were identified as relevant indicators from the perspective of decision-makers in an online survey. The estimation of regional care needs on the basis of secondary data revealed differences between the administrative districts, both in absolute terms and relative to the size of the population. It was found that access to long-term homecare is fundamentally orientated towards need factors such as comorbidity and age. In addition, access to care was to a lesser extent also linked to factors such as sex, nationality and the density of outpatient care services. It could not be clearly determined whether there also is a relation between access to care and the social status of the place of residence of persons with dementia. A quantitative data report on care needs and services as part of a hypothetical decision scenario was generally read in full, but less attention was paid to the methods section. When prioritising the different care settings in the hypothetical allocation of financial resources, other sources of knowledge and personal aspects played a role alongside the information from the report. Also, an attempt was made to adopt different perspectives when making the decision. Overall, it was found that for data-based regional care planning the necessary information on the care needs of people with dementia and whether this care is equitable is available, however with significant data gaps. Available data on the care situation of people with dementia is used in regional settings, but it is unclear to what extent this goes beyond pilot projects. Finally, there are indications that information on data quality plays a subordinate role for (future) decision-makers.

German version

Pamela Wronski
Dr. sc. hum.

From data need to data use: Exploring the potential of data use for equitable policymaking in long-term care for persons with dementia in the German state of Baden-Wuerttemberg

Fach/Einrichtung: Allgemeinmedizin und Versorgungsforschung
Doktorvater: Prof. Dr. Michel Wensing

Gemäß SGB XI § 69 soll die pflegerische Versorgung in Deutschland bedarfsgerecht gestaltet sein. Eine besondere Herausforderung dabei ergeben sich aus einem zunehmenden Pflegebedarf, insbesondere durch altersassoziierte Erkrankungen wie Demenz. Diese ist für Betroffene mit zunehmenden Einschränkungen von Aktivitäten des täglichen Lebens betroffen und mündet meist in Pflegebedürftigkeit. Demenz ist eine der häufigsten pflegebegründenden Diagnosen. In Baden-Württemberg will man diesen Herausforderungen gemäß Gesundheitsleitbild mit einer datengestützten Versorgungsplanung begegnen, die am regionalen Versorgungsbedarf orientiert ist. Besonders innerhalb der letzten zwei Dekaden wurden deutschlandweit Routinedaten der Kranken- und Pflegeversicherungen und ihr Nutzungspotenzial für regionalisierte Analysen vor allem zur medizinischen Versorgung zunehmend erschlossen. Dabei stellt das wachsende Angebot an Datenquellen und Indikatoren lokale Entscheidungsträger vor die Herausforderung, eine Auswahl an Indikatoren für die Versorgungsplanung zu treffen. Untersuchungen zeigen aber auch: Datenverfügbarkeit alleine reicht nicht aus, damit Versorgungsplanung datengestützt stattfindet. Zudem gibt es bisher wenige Erkenntnisse darüber, wie Entscheidungsträger quantitative Datenberichte, ein häufiges Format in dem Daten bereitgestellt werden, nutzen und Lesen.

In dieser Dissertation wird das Potenzial datengestützter Versorgungsplanung in Baden-Württemberg am Beispiel einer bedarfsgerechten langzeitpflegerischen Versorgung von Menschen mit Demenz exploriert. Hierzu wurde untersucht (1) welche Daten Entscheidungsträger für die regionale Versorgungsplanung in diesem Bereich für relevant halten, (2) welche Daten verfügbar sind insbesondere zur Einschätzung des Versorgungsbedarfs sowie dessen Bedarfsgerechtigkeit auf kleinräumiger Ebene und (3) wie diese Daten im

Format eines Berichts von individuellen Entscheidungsträgern genutzt werden. Als relevante Indikatoren aus Sicht der Entscheidungsträger wurden im Rahmen einer Online-Befragung Indikatoren zur absoluten und relativen Häufigkeit von Demenz und Komorbiditäten, zur Pflegeinanspruchnahme und zu bestehenden Pflegeangeboten identifiziert. Die Schätzung des regionalen Versorgungsbedarfs auf Basis von Sekundärdatenanalysen ergab Unterschiede in den Stadt- und Landkreisen, sowohl absolut als auch relativ gesehen zur Bevölkerungszahl. Es zeigte sich, dass der Zugang zu häuslicher Langzeitpflege grundsätzlich an Bedarfsfaktoren wie Komorbidität und Alter orientiert ist. Darüber hinaus stand der Zugang in geringerem Maße auch in Zusammenhang mit Faktoren wie Geschlecht, Staatsangehörigkeit und der Angebotsdichte ambulanter Pflegedienste. Nicht eindeutig geklärt werden konnte, ob auch ein Zusammenhang mit dem sozialen Status des Wohnortes von Menschen mit Demenz besteht. Ein quantitativer Datenbericht zum Pflegebedarf und -angebot wurde im Rahmen eines hypothetischen Entscheidungsszenarios in der Regel vollständig gelesen, der Methodenteil erhielt dabei jedoch weniger Aufmerksamkeit. Bei der Priorisierung verschiedener Pflegesettings bei der hypothetischen Zuteilung finanzieller Mittel spielten neben den Informationen aus dem Bericht auch andere Wissensquellen und darüberhinausgehende Aspekte eine Rolle. Bei der Entscheidung wurde zudem versucht, unterschiedliche Perspektiven einzunehmen. Insgesamt zeigte sich, dass für eine datengestützte und regionale Versorgungsplanung grundlegende Informationen zum pflegerischen Versorgungsbedarf von Menschen mit Demenz und für die Einschätzung der Bedarfsgerechtigkeit verfügbar sind, aber signifikante Datenlücken bestehen. Verfügbare Daten zur pflegerischen Versorgungssituation von Menschen mit Demenz werden regional genutzt, jedoch ist unklar, inwieweit dies über Modellprojekte hinaus geschieht. Dabei es Anhaltspunkte dafür, dass Angaben zur Datenqualität bei (zukünftigen) Entscheidungsträgern eine untergeordnete Rolle spielen.

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7 Eigenanteil an Datenerhebung und –auswertung und eigene Veröffentlichungen

Diese Arbeit wurde im Rahmen der beiden Projekte (1) Teilprojekt 1 des Modellprojektes Sektorenübergreifende Versorgung (gefördert vom Ministerium für Soziales, Integration und Gesundheit Baden-Württemberg) und (2) Einfluss von quantitativen Studien auf Entscheidungen in der Versorgungsplanung – QuantEV (gefördert von der Klaus Tschira Stiftung gGmbH) erstellt. Dabei entstand die in der Arbeit als Studie 1 (study 1) bezeichnete Untersuchung im Rahmen des Teilprojektes 1. Die Sekundärdatenanalysen (study 2) sind ebenfalls im Rahmen von Teilprojekt 1 entstanden. Dabei sind die Analysen zu „Inequity“ (Abschnitte 2.2.2 und 3.2.2) zusätzlich auf meine Initiative hin entstanden. Studie 3 (study 3) entstand im Rahmen des QuantEV-Projektes. Die Arbeiten im Rahmen des QuantEV-Projektes erfolgten in enger Kooperation mit dem Heidelberger Institut für Theoretische Studien (HITS). Die Räumlichkeiten und technische Ausstattung des HITS, insbesondere ein Eye-Tracker, wurden zudem für das Computer- und Eye-Tracking-Labor genutzt.

Mein Eigenanteil an der Datenerhebung und -auswertung bei den einzelnen Studien (Studie 1 bis 3) ist in der nachfolgenden Tabelle dargestellt. In den Projekten gab es keine weiteren Doktoranden. Das Datenmaterial aus Studie 3 wurde neben mir auch von Herrn Dr. Koetsenruijter (Projektmitarbeiter von QuantEV) und Frau Dr. Ghosh (Kooperationspartnerin am HITS) für die Erstellung von gemeinsamen Publikationen genutzt.

Studie 1 Online-Indikatorenbefragung	
Datenerhebung	
Entwicklung des Rahmenwerkes für Indikatoren	Entwurf durch mich mit beratender Unterstützung durch Herrn PD Dr. Ose. (leitender Projektmitarbeiter zu Projektbeginn) und Herrn Prof. Dr. Wensing (Projektleitung); Feedbackeinholung in der Projektgruppe des Modellprojektes und Finalisierung des Rahmenwerkes erfolgt durch mich
Indikatorenrecherche	Durchführung durch mich mit beratender Unterstützung durch Herrn Prof. Dr. Wensing
Fragebogenentwicklung	Durchführung durch mich mit beratender Unterstützung von Herrn Prof. Dr. Wensing und Herrn Prof. Dr. Szecsenyi. (ebenfalls Projektleiter)
Rekrutierung der Studienteilnehmenden	Auswahl der einzuladenden Personen durch mich mit beratender Unterstützung von Herrn Prof. Dr. Wensing;

	Erstellung des Rekrutierungsmaterials und Administration der Antworten von eingeladenen Personen durch mich mit Unterstützung von Frau Spektor (von mir betreute Praktikantin im Projekt)
Aufbau der Online-Plattform für die Indikatorenbefragung	Konzeption von Design, Aufbau und Inhalt durch mich mit Unterstützung von Frau Spektor; technische Umsetzung durch Herrn Allutis (Mitarbeiter an der Abteilung, an die die Doktorarbeit geknüpft ist)
Datenauswertung	
Auswertungen, die alle Indikatoren betreffen	erfolgte durch mich mit beratender Unterstützung von meinem Doktorvater und Unterstützung bei der Aufbereitung eines Teils der Daten durch Frau Spektor
Auswertungen zu Indikatoren mit Bezug zu Demenz und Langzeitpflege	erfolgte durch mich
Studie 2 Sekundärdatenanalysen	
Datenerhebung	
Datenbeschaffung	Beantragung der Nutzung sämtlicher Datenquellen durch mich und Download von online frei verfügbaren Daten ebenfalls durch mich
Datenauswertung	
Indikatorenbasierte Auswertung	erfolgte durch mich; technische Umsetzung der Choroplethenkarte durch Herrn Qreini (Projektmitarbeiter); Beratung bei der Arbeit mit dem HZV-Evaluationsdatensatz der AOK Baden-Württemberg durch Herrn Prof. Dr. Laux (Mitarbeiter an der Abteilung, an die die Doktorarbeit geknüpft ist)
Inequity-Analysen	erfolgte durch mich in Zusammenarbeit mit Herrn Dr. Koetsenruijter (Projektmitarbeiter und Mitarbeiter an der Abteilung, an die die Doktorarbeit geknüpft ist)
Studie 3: Computergestützte Laborstudie	
Datenerhebung	
Fragebogenentwicklung	erfolgte durch mich in Zusammenarbeit mit Herrn Dr. Koetsenruijter zu gleichen Teilen mit beratender Unterstützung von Herrn Prof. Dr. Wensing (Projektleitung des QuantEV-Projektes)
Erstellung des Projektberichts für das hypothetische Entscheidungsszenario	Erstellung des Berichtstextes durch mich mit beratender Unterstützung durch Herrn Prof. Dr. Wensing; Erstellung der Abbildungen durch Herrn Dr. Koetsenruijter
Entwicklung des Interviewleitfadens	erfolgte durch mich mit beratender Unterstützung von meinem Doktorvater, Frau Dr. Ullrich. und Frau Dr. Poß-Doering (Mitarbeiterinnen an der Abteilung, an die die Doktorarbeit geknüpft ist)
Rekrutierung der Studienteilnehmenden	Auswahl der einzuladenden Personen mit Erfahrung im Bereich der Versorgungsplanung und Wissenschaftler aus

	dem Bereich der Gesundheitswissenschaften sowie Administration der Rekrutierung durch mich mit beratender Unterstützung von Herrn Prof. Dr. Wensing; Rekrutierung von Studierenden durch mich mit Unterstützung der Studiengangskoordinatorinnen und -koordinatoren der beteiligten Studiengänge und Herrn Gärttner. (wissenschaftliche Hilfskraft an der Abteilung, an die die Doktorarbeit geknüpft ist und Projektmitarbeiter)
Entwicklung der Online-Plattform für die computergestützte Datenerhebung im Labor	Konzeption von Design, Aufbau und Inhalt durch mich; technische Unterstützung durch Herrn Qreini (Kooperationspartner der Abteilung, an die die Doktorarbeit geknüpft ist)
Durchführung der Datenerhebung im Labor	erfolgte durch mich und zu gleichen Teilen durch Herrn Gärttner: Aufklärung und Instruktion der Studienteilnehmenden und Interviews; Frau Dr. Ghosh: Kalibrierung des Eye-Tracking-Systems und Instruktion der Teilnehmenden hinsichtlich des Eye-Trackings
Datenauswertung	
Eye-Tracking-basierte Daten	erfolgte primär durch Frau Dr. Ghosh in Abstimmung mit mir und Herrn Dr. Koetsenruijter
Daten aus der computergestützten Befragung	erfolgte gemeinsam mit Herrn Dr. Koetsenruijter
transkribierte Interviews	gemeinsame Auswertung mit Herrn Dr. Koetsenruijter und Herrn Gärttner.

Teilergebnisse (Studie 1 und Studie 3) wurden in folgenden Aufsätzen vorab publiziert:

1. Studie 1: Wronski, P., Koetsenruijter, J., Ose, D., Paulus, J., Szecsenyi, J. and Wensing, M. (2021a). **Healthcare planning across healthcare sectors in Baden-Wuerttemberg, Germany: a stakeholder online survey to identify indicators**. BMC Health Serv Res *21 (1)*, 510, doi: 10.1186/s12913-021-06514-0.
2. Studie 3: Wronski, P., Wensing, M., Ghosh, S., Garttner, L., Muller, W. and Koetsenruijter, J. (2021b). **Use of a quantitative data report in a hypothetical decision scenario for health policymaking: a computer-assisted laboratory study**. BMC Med Inform Decis Mak *21 (1)*, 32, doi: 10.1186/s12911-021-01401-4.

3. Koetsenruijter, J., Wronski, P., Ghosh, S., Muller, W. and Wensing, M. (2022). **The Effect of an Additional Structured Methods Presentation on Decision-Makers' Reading Time and Opinions on the Helpfulness of the Methods in a Quantitative Report: Nonrandomized Trial**. JMIR Med Inform *10 (4)*, e29813, doi: 10.2196/29813.

Publikation 1 basiert auf den Ergebnissen aus dem Dissertationskapitel 3.1. und einzelnen Aspekten aus dem Dissertationskapitel 1.1. Mein Eigenanteil erstreckt sich auf die Datenerhebung (siehe Tabelle oben) und die Erstellung des gesamten Manuskriptentwurfs und die Einarbeitung des Feedbacks der Co-Autoren sowie sämtliche Auswertungen der Daten (siehe Tabelle oben).

Publikation 2 basiert in seiner Einleitung größtenteils auf den Dissertationskapiteln 1.3.1.1 and 1.3.1.2. Der Methoden- und Ergebnisteil basiert vollständig auf den Dissertationskapiteln 2.3 und 3.3. Mein Eigenanteil an der Datenerhebung erstreckt sich auf circa 60 %. Bei der Datenerhebung waren außerdem Frau Dr. Ghosh und Herr Gärttner beteiligt. Die Datenauswertung erfolgte insgesamt zu circa 50 % durch mich (vor allem Daten aus dem Fragebogen und Interviews sowie gemeinsame Betrachtung der verschiedenen Datenquellen). Die Datenauswertung erfolgte außerdem durch Frau Dr. Ghosh (vor allem Eye-Tracking-basierte Daten), Herrn Dr. Koetsenruijter (Daten aus dem Fragebogen und Interviews) und Herrn Gärttner (Interviews). Mein Eigenanteil erstreckt sich zudem auf das Erstellen des gesamten Manuskriptentwurfs und die Einarbeitung des Feedbacks der Co-Autoren.

Publikation 3 ist im Rahmen des QuantEV-Projektes entstanden und basiert auf den dort erhobenen Daten (Fragebogen und Eye-Tracking-Daten). Die Ergebnisse der Publikation werden kurz in Kapitel 4.1.4 diskutiert. Mein Eigenanteil an der Datenerhebung erstreckt sich auf circa 50 %. Bei der Datenerhebung im Labor waren außerdem Frau Dr. Ghosh und Herr Gärttner beteiligt. Die Datenauswertung erfolgte zusammen mit Herrn Dr. Koetsenruijter, Frau Dr. Ghosh und mir. Den Text der Publikation hat im Wesentlichen Herr Dr. Koetsenruijter verfasst. Mein Anteil am Manuskripttext erstreckt sich auf circa 20 % (insbesondere zum Hintergrund). Die Erarbeitung des Konzepts für das Manuskript erfolgte gemeinsam mit Herrn Dr. Koetsenruijter und mir.

Die Darstellung von Inhalten der Publikationen 1 und 2 in dieser Arbeit erfolgte unter Einhaltung der folgenden Lizenzvereinbarung: https://creativecommons.org/licenses/by/4.0/.

Weitere Publikationen mit Co-Autorenschaft (alphabetisch sortiert):

4. Bossert, J., Ludwig, M., Wronski, P., Koetsenruijter, J., Krug, K., Villalobos, M., Jacob, J., Walker, J., Thomas, M. and Wensing, M. (2021). **Lung cancer patients' comorbidities and attendance of German ambulatory physicians in a 5-year cross-sectional study**. NPJ Prim Care Respir Med *31 (1)*, 2, doi: 10.1038/s41533-020-00214-8.
5. Daniel, T., Koetsenruijter, J., Wensing, M. and Wronski, P. (2022). **[Chronic low back pain-user types of ambulatory care : Cluster analysis of the utilization of ambulatory health care resources with administrative data of the AOK Baden-Wurttemberg]**. Schmerz *36 (5)*, 326-332, doi: 10.1007/s00482-021-00565-2.
6. Eckert, T., Wronski, P., Bongartz, M., Ullrich, P., Abel, B., Kiss, R., Wensing, M., Koetsenruijter, J. and Hauer, K. (2021). **Cost-Effectiveness and Cost-Utility of a Home-Based Exercise Program in Geriatric Patients with Cognitive Impairment**. Gerontology *67 (2)*, 220-232, doi: 10.1159/000512748.
7. Forstner, J., Wensing, M., Koetsenruijter, J. and Wronski, P. (2019). **Claims data-based analysis of the influence of individual and regional characteristics on the utilisation of long-term care by people with dementia in Baden-Wurttemberg, Germany**. BMC Geriatr *19 (1)*, 358, doi: 10.1186/s12877-019-1370-1.

Appendix

Appendix 1: Proposed and selected indicators on dementia and long-term care

Table 21: List of proposed and selected indicators on dementia and long-term care (own table based on (Wronski et al. 2021a))

Indicator ID	**Indicator name (German, original)** ***Indicator name (English, translated)***	**Framework category/ dimension**	**Indicator source (type of source)**	**Indicator relevant? Median in [6,5 - 9]**	**Indicator is measurable**
43	Administrative Prävalenz Demenz *Administrative prevalence of dementia*	Health status/morbidity	Klauber J, Günster C, Gerste B, Robra B-P, Schmacke N (Hrsg.). Versorgungs-Report 2013/2014. Schwerpunkt: Depression. Stuttgart: Schattauer GmbH; 2014. (published literature)	yes	yes
53	Zahl der Pflegebedürftigen je Einwohner *Number of long-term care recipients per inhabitant*	Health status/morbidity	Albrecht M. Nachvollziehbare Bedarfskennzahlen? Konzepte und Indikatoren zur Abbildung des Versorgungsbedarfs. In: 14. Deutscher Kongress für Versorgungsforschung; 2015; Berlin, Deutschland. (published literature)	yes	yes
54	Anzahl Pflegebedürftige nach Pflegestufe *Number of long-term care recipients by care level*	Health status/morbidity	Statistisches Bundesamt (Hrsg.). Pflegestatistik 2013, Pflege im Rahmen der Pflegeversicherung, Deutschlandergebnisse. Wiesbaden. 2015. (data sources)	yes	yes
56	Häufigste Begleiterkrankungen Patientinnen und Patienten mit Demenz *Most common comorbidities in patients with dementia*	Health status/morbidity	Gesundheitsatlas Baden-Württemberg [Internet]. Stuttgart: Landesgesundheitsamt Baden-Württemberg. [last accessed 2019 Sep 24]. Available from: http://gesundheitsatlas-bw.de/ (data sources)	yes	yes
79	Ambulante Pflegeleistungen nach SGB XI; pflegeergänzende Leistungen *Outpatient nursing care services in accordance with the social code XI; care-complementing services*	utilisation of the health system/outpatient care	Indicator is based on suggestion of study team and was not found in a specific indicator source. (other)	yes	no
80	Anzahl Pflegebedürftige in häuslicher Pflege *Number of persons in need of long-term care receiving home care*	utilisation of the health system/outpatient care	Gesundheitsatlas Baden-Württemberg [Internet]. Stuttgart: Landesgesundheitsamt Baden-Württemberg. [last accessed 2019 Sep 24]. Available from: http://gesundheitsatlas-bw.de/	yes	yes

			(data sources)		
128	Auslastung verfügbarer Plätze in stationären Pflegeeinrichtungen in Prozent *Occupancy rate in percent of available places in residential nursing care facilities*	utilisation of the health system/ semi or full inpatient care	Statistisches Bundesamt (Hrsg.). Pflegestatistik 2013, Pflege im Rahmen der Pflegeversicherung, Deutschlandergebnisse. Wiesbaden. 2015. (data sources)	yes	yes
318	Einwohner je und Anzahl ambulante Pflegedienste (gesamt) *Inhabitants per and number of outpatient nursing facilities (total)*	healthcare provision/facilities	Arbeitsgemeinschaft der Obersten Landesgesundheitsbehörden (AOLG). Indikatorensatz für die Gesundheitsberichterstattung der Länder. Düsseldorf: Ministerium für Gesundheit, Soziales, Frauen und Familie des Landes Nordrhein-Westfalen (Hrsg.); 2003, 3. Fassung. (indicator sets of German and international institutions and agencies)	yes	yes
319	Einwohner je und Anzahl ambulante Pflegedienste nur Leistungen nach SGB XI *Inhabitants per and number of outpatient nursing facilities (only services according to social code XI)*	healthcare provision/facilities	Arbeitsgemeinschaft der Obersten Landesgesundheitsbehörden (AOLG). Indikatorensatz für die Gesundheitsberichterstattung der Länder. Düsseldorf: Ministerium für Gesundheit, Soziales, Frauen und Familie des Landes Nordrhein-Westfalen (Hrsg.); 2003, 3. Fassung. (indicator sets of German and international institutions and agencies)	yes	yes
320	Einwohner je und Anzahl ambulante Pflegedienste mit weiteren Sozialleistungen neben SGB XI *Inhabitants per and number of outpatient nursing facilities with additional social services besides social code XI*	healthcare provision/facilities	Arbeitsgemeinschaft der Obersten Landesgesundheitsbehörden (AOLG). Indikatorensatz für die Gesundheitsberichterstattung der Länder. Düsseldorf: Ministerium für Gesundheit, Soziales, Frauen und Familie des Landes Nordrhein-Westfalen (Hrsg.); 2003, 3. Fassung. (indicator sets of German and international institutions and agencies)	yes	no
323	Einwohner je und Anzahl ambulanter Pflegeeinrichtungen als eigenständiger Dienst an einer Wohneinrichtung (Altenheim, Altenwohnheim, betreutes Wohnen) *Inhabitants per and number of outpatient nursing care facilities as independent services at residential*	healthcare provision/facilities	Arbeitsgemeinschaft der Obersten Landesgesundheitsbehörden (AOLG). Indikatorensatz für die Gesundheitsberichterstattung der Länder. Düsseldorf: Ministerium für Gesundheit, Soziales, Frauen und Familie des Landes Nordrhein-Westfalen (Hrsg.); 2003, 3. Fassung.	no	-[a]

	facility (retirement home, residential home for the elderly, assisted living)		(indicator sets of German and international institutions and agencies)		
325	Einwohner je und Anzahl ambulante Pflegeeinrichtungen als eigenständige Dienste an einem Pflegeheim (mehrgliedrige Einrichtungen) *Inhabitants per and number of outpatient nursing facilities as independent services at nursing home (multi-unit facilities)*	healthcare provision/facilities	Arbeitsgemeinschaft der Obersten Landesgesundheitsbehörden (AOLG). Indikatorensatz für die Gesundheitsberichterstattung der Länder. Düsseldorf: Ministerium für Gesundheit, Soziales, Frauen und Familie des Landes Nordrhein-Westfalen (Hrsg.); 2003, 3. Fassung. (indicator sets of German and international institutions and agencies)	no	-[a]
341	Einwohner je und Anzahl Gesundheits- und Krankenpfleger und -pflegerinnen in ambulanten Pflegeeinrichtungen *Inhabitants per and number of nurses in outpatient nursing care facilities*	healthcare provision/professionals	Arbeitsgemeinschaft der Obersten Landesgesundheitsbehörden (AOLG). Indikatorensatz für die Gesundheitsberichterstattung der Länder. Düsseldorf: Ministerium für Gesundheit, Soziales, Frauen und Familie des Landes Nordrhein-Westfalen (Hrsg.); 2003, 3. Fassung. (indicator sets of German and international institutions and agencies)	yes	yes
342	Einwohner je und Anzahl Krankenpflegehelfer und helferinnen in ambulanten Pflegeeinrichtungen *Inhabitants per and number of nursing assistants in outpatient nursing care facilities*	healthcare provision/professionals	Arbeitsgemeinschaft der Obersten Landesgesundheitsbehörden (AOLG). Indikatorensatz für die Gesundheitsberichterstattung der Länder. Düsseldorf: Ministerium für Gesundheit, Soziales, Frauen und Familie des Landes Nordrhein-Westfalen (Hrsg.); 2003, 3. Fassung. (indicator sets of German and international institutions and agencies)	yes	yes
345	Einwohner je und Anzahl stationärer Pflegeeinrichtungen nach Art der Pflegeeinrichtung (z.B. Pflegestufen, Zielgruppen) *Inhabitants per and number of residential nursing care facilities by care facility type (e.g. level of care, target groups)*	healthcare provision/professionals	Arbeitsgemeinschaft der Obersten Landesgesundheitsbehörden (AOLG). Indikatorensatz für die Gesundheitsberichterstattung der Länder. Düsseldorf: Ministerium für Gesundheit, Soziales, Frauen und Familie des Landes Nordrhein-Westfalen (Hrsg.); 2003, 3. Fassung. (indicator sets of German and international institutions and agencies)	yes	yes

346	Einwohner je und Anzahl verfügbarer Plätze in stationären Pflegeeinrichtungen nach Art der Pflegeeinrichtung *Inhabitants per and number of available places in residential nursing care facilities by care facility type*	healthcare provision/professionals	Arbeitsgemeinschaft der Obersten Landesgesundheitsbehörden (AOLG). Indikatorensatz für die Gesundheitsberichterstattung der Länder. Düsseldorf: Ministerium für Gesundheit, Soziales, Frauen und Familie des Landes Nordrhein-Westfalen (Hrsg.); 2003, 3. Fassung. (indicator sets of German and international institutions and agencies)	yes	yes
a. Measurability was only assessed for indicators classified as relevant.					

Appendix 2: Indicator assessment questions (example)

Befragung

(Teil-)Stationäre Versorgung

Bitte bewerten Sie die Relevanz und Verständlichkeit des folgenden Indikators:

Indikator-ID084	Krankenhausfälle Darmkrebs nach Wohnort Patient
Ist der Indikator für das Thema relevant?	○1 ○2 ○3 ○4 ○5 ○6 ○7 ○8 ○9
Relevanz	1 = überhaupt nicht relevant 9 = sehr relevant
Ist der Indikator klar und verständlich formuliert?	○ Ja ○ Nein
Optional: Anmerkungen zur Relevanz und Verständlichkeit des Indikators	

Figure 18: Exemplary assessment view for an indicator from the online survey on indicator selection (study 1)

Appendix 3: Quantitative data report based on hypothetical decision scenario

Quantitative data report
- based on hypothetical decision scenario

Original language version (German): p. 2-14
English version (translated by the authors): p. 15-27

Situation der Langzeitpflege im Rhein-Neckar-Kreis

Bericht der Arbeitsgruppe Versorgung im ländlichen Raum der Kommunalen Gesundheitskonferenz des Rhein-Neckar-Kreises

Situation der Langzeitpflege im Rhein-Neckar-Kreis

Bericht der Arbeitsgruppe Versorgung im ländlichen Raum der Kommunalen Gesundheitskonferenz des Rhein-Neckar-Kreises

1. Einleitung

1.1 Aktuelle Herausforderungen

Der Rhein-Neckar-Kreis möchte seinen Bürgerinnen und Bürgern aktuell und zukünftig eine gute und qualitativ hochwertige Versorgung mit Langzeitpflege anbieten. Unter Langzeitpflege fallen sämtliche Pflegemaßnahmen, die über einen längeren Zeitraum oder auf Dauer erbracht werden. Bei der Kommunalen Gesundheitskonferenz (CHC) 2018 des Rhein-Neckar-Kreises berichteten Pflegebedürftige, ihre Angehörigen, aber auch Mitarbeiter aus ambulanten Pflegediensten und Pflegeheimen von wachsenden Schwierigkeiten, den aktuellen Bedarf an Pflegeleistungen zu decken. Es wurde unter anderem berichtet von steigenden Wartezeiten für einen Platz der vollstationären Dauerpflege, mehr Pflegebedürftigen einerseits und weniger Zeit für die Pflege durch Pflegekräfte. Pflegende Angehörige berichten, dass sie oft stark belastet sind durch die Pflege, sich gezwungen sehen, ihre berufliche Tätigkeit zu reduzieren oder vollständig aufzugeben und oft weniger Zeit haben für die Selbstsorge, z.B. weniger Kontakt zu Freunden haben und stärker gesundheitlich beeinträchtigt sind.

Der bundesweite demografische Wandel steht auch im Rhein-Neckar-Kreis bevor bzw. findet bereits statt und birgt vielfältige Herausforderungen für die Langzeitpflege. Es wird erwartet, dass zukünftig mehr ältere Menschen und damit mehr Pflegebedürftige im Kreis leben werden. Ebenso erwartet wird die Zunahme von Menschen mit Demenz, deren Pflege mit besonderen Anforderungen an Pflegeangebote geknüpft ist. Auf der anderen Seite werden weniger Pflegende erwartet sowohl unter den Angehörigen von Pflegebedürftigen als auch unter Fachkräften. In Deutschland werden derzeit viele Pflegebedürftige durch ihre Kinder gepflegt. Immer mehr Menschen bleiben in ihrem Leben jedoch kinderlos. Ebenfalls übernehmen meist Frauen die Pflege von Angehörigen. Die Zahl der berufstätigen Frauen ist gestiegen, was bedeutet, dass sie weniger Kapazitäten für die Pflege von Angehörigen haben werden. Im Bereich der Fachkräfte haben bereits jetzt immer mehr Einrichtungen Schwierigkeiten, Personal für die Pflege zu gewinnen. Durch den demografischen Wandel wird eine Verschärfung dieser Situation erwartet.

Auch aus den Nachbarregionen des Rhein-Neckar-Kreises werden Schwierigkeiten bei der Vorhaltung bedarfsgerechter Angebote der Langzeitpflege berichtet und auch zukünftig erwartet, sodass Bürgerinnen und Bürger derzeit und in den nächsten Jahren keine Möglichkeit haben, auf Angebote aus benachbarten Regionen auszuweichen.

Die Langzeitpflege steht bundesweit vor den genannten Herausforderungen. Daher wurden bereits einige Maßnahmen umgesetzt, deren Wirksamkeit vor Ort abzuwarten ist. Um dem Fachkräftemangel zu begegnen sollen mit der Beitragssteigerung in der Pflegeversicherung im Jahr 2019 bundesweit 13.000 neue Stellen für Pflegekräfte geschaffen werden, die Pflegeausbildung reformiert und Pflegekräfte besser bezahlt werden. Mit den drei Pflegestärkungsgesetzen (PSG I-III) wurden u.a. Maßnahmen zur Verbesserung des Pflegeschlüssels in Pflegeheimen, unterstützende Maßnahmen für pflegende Angehörige (z.B. kostenlose Beratungsangebote, bessere soziale Absicherung) und mehr Leistungsansprüche für Pflegebedürftige eingeleitet.

1.2 Zusätzliche Mittel für die Pflege

Im Anschluss an die CHC 2018 hat der Landrat des Rhein-Neckar-Kreises angekündigt, zusätzliche finanzielle Mittel für die Langzeitpflege bereitzustellen und möchte bei der Mittelverwendung Empfehlungen der CHC berücksichtigen. Die Mittel sollen von 2020 bis 2030 jährlich ausgezahlt werden. Die genaue Höhe der Mittel ist noch nicht bekannt. Des Weiteren können die Mittel nur für eine von drei bereits festgelegten Optionen verwendet werden. Diese werden nachfolgend mit einer kurzen Einschätzung ihrer budgetären Konsequenzen vorgestellt.

Option A: Aufstockung von Mitteln für Unterstützungsmaßnahmen pflegender Angehöriger (z.B. Geldleistungen, Beratungsangebote, niedrigschwellige Betreuung, Aufstockung von Plätzen der Kurzzeitpflege in Pflegeheimen). Dies ist die pro Kopf gerechnet kostengünstigste Option. D.h. die meisten Pflegebedürftigen würden von dieser Option profitieren. Professionelle Pflegeleistungen sind von dieser Option ausgeschlossen.

Option B: Aufstockung von Pflegeplätzen der vollstationären Dauerpflege. Diese Option ist pro Kopf gerechnet die teuerste Variante, d.h. im Vergleich zu den anderen Optionen würden die wenigsten Pflegebedürftigen profitieren.

Option C: Aufstockung von Kapazitäten in der ambulanten Pflege. Durch diese Option können ambulante Pflegedienste ihre Kapazitäten erhöhen, um mehr Pflegebedürftige zu versorgen und/oder ihre Leistungen je Pflegebedürftigem auszuweiten, z.B. in Form von mehr Pflegezeit. Diese Option ist pro Kopf gerechnet günstiger als Option B und teurer als Option A, gleich verhält es sich mit der Anzahl der Pflegebedürftigen, die von dieser Option profitieren würden.

1.3 Ziele der vorliegenden Analyse

Die Arbeitsgruppe „Versorgung im ländlichen Raum“ der CHC Rhein-Neckar-Kreis sieht sich verpflichtet, ihren Beitrag für Empfehlungen an den Landrat zur Verwendung der geplanten zusätzlichen Mittel für die Langzeitpflege zu geben. Für eine datengestützte Empfehlung wurde daher der vorliegende Bericht von Mitgliedern der AG erstellt. Ziel des Berichtes ist eine zusammenfassende Darstellung der aktuellen und Schätzung der zukünftigen Versorgungssituation im Bereich der Langzeitpflege im Rhein-Neckar-Kreis anhand verfügbarer Daten. Da das Krankheitsbild Demenz zu besonderen Pflegebedarfen bei Betroffenen führt, sollten hierzu ebenfalls Analysen erstellt werden. Folgende Fragestellungen sollen mit dem vorliegenden Bericht für den Rhein-Neckar-Kreis bearbeitet werden:

- Wie viele Pflegebedürftige (insbesondere mit Demenz) leben derzeit und zukünftig im Kreis?
- Wie ist die derzeitige und zukünftige Inanspruchnahme von ambulanten Pflegediensten und Plätzen der vollstationären Dauerpflege?
- Wie ist die bisherige Entwicklung des Pflegeangebotes und dessen Auslastung?

2. Methodik

Die durchgeführten Analysen basieren zum einen auf Sekundärdatenauswertungen der AG-Mitglieder. Dort, wo keine Daten zur Verfügung standen, wurden Ergebnisse aus anderen Berichten oder Studien für den Ergebnisteil herangezogen.

2.1 Datenquellen

Für die Sekundärdatenanalyse wurden verschiedene Datenquellen ausgewertet, die nachfolgend vorgestellt werden.

Routinedaten der AOK Baden-Württemberg (AOK BW): Daten zur aktuellen und Projektion der Inanspruchnahme von Pflegeleistungen sowie demenzbezogene Analysen basieren auf Abrechnungsdaten der gesetzlichen Kranken- und Pflegekasse AOK BW aus dem Zeitraum 01.01.2013 bis 31.12.2013. In diesem Zeitraum waren rund 28% der Wohnbevölkerung im Rhein-Neckar-Kreis bei der AOK BW versichert. Damit ist die Stichprobe dieser Datenquelle sehr umfassend. Dennoch ist mit historisch entstandenen Unterschieden zwischen der AOK Versichertenpopulation und der Gesamtbevölkerung im Rhein-Neckar-Kreis zu rechnen, die die Repräsentativität der Daten limitieren können. Die Sicherung der Datenqualität gemäß aktueller Standards (Gute Praxis Sekundärdatenanalyse 2012) erfolgte durch das aQua-Institut für angewandte Qualitätsförderung und Forschung im Gesundheitswesen. Im Rahmen der Berichterstellung durch die AG der CHC wurden diese Daten anschließend über sichere Verbindungen an die AG übermittelt. Für die Kodierung der Versichertendiagnosen wurde die Internationale statistische Klassifikation der Krankheiten und verwandter Gesundheitsprobleme in der zehnten Revision nach der deutschen Modifikation (ICD-10-GM) verwendet.

Pflegestatistik: Daten zum Pflegeangebot, zu bisherigen Entwicklungen bei den Pflegebedürftigen und der Inanspruchnahme von Pflegeleistungen durch Pflegebedürftige basieren auf Daten der Pflegestatistik des Statistischen Landesamtes Baden-Württemberg. Die Statistik ist eine Vollerhebung und wird seit 1999 zweijährlich zum Stichtag 15. Dezember eines Jahres erhoben. Zweck der Statistik ist die Erfassung von Angebot und Nachfrage im Bereich der Pflege für die Planung der Versorgung. Der Zugang zu den Daten erfolgte online über die Regionaldatenbank des Statistischen Landesamtes Baden-Württemberg.

Regionalisierte Bevölkerungsvorausrechnung: Projizierte Daten basieren auf der Regionalisierten Bevölkerungsvorausberechnung des Statistischen Landesamtes Baden-Württemberg. Die aktualisierte und im vorliegenden Bericht verwendete Vorausberechnung wurde im Jahr 2016 veröffentlicht und anlässlich des besonders hohen Zuzugs von Flüchtlingen im Jahr 2015 für die Jahre 2014 bis 2060 auf Landesebene und bis zum Jahr 2035 in der regionalisierten Variante erstellt. Berücksichtigte Parameter in der Vorausberechnung beziehen sich auf natürliche Wanderungsbewegungen (Geburten, Sterbefälle), Wanderungsbewegungen innerhalb des Landes und mit dem Ausland. Je nach Parameter wurden unterschiedlich lange Stützzeiträume verwendet, deren Obergrenze das Jahr 2014 bildet. Bis zu diesem Jahr lagen auf dem Zensus 2011 basierende Statistiken zum fortgeschriebenen Bevölkerungsstand vor. Es wurden drei verschiedene Entwicklungskorridore für den Rhein-Neckar-Kreis berechnet, die sich in ihren Annahmen unterscheiden. Der Hauptvariante liegen folgende Annahmen zugrunde:

- Bei der Lebenserwartung der Frauen wird von einer weiteren Zunahme um 2,1 Jahre bis zum Jahr 2035 ausgegangen, bei den Männern leicht höher mit 2,4 Jahren.
- Es wird von einem leichten Anstieg der Geburtenrate ausgegangen von 1,46 auf 1,5. Hierzu wird ferner für die nächsten 10 Jahre angenommen, dass sich der Trend, Kinder später zu bekommen, fortsetzt und dann konstant bleibt.
- Es wird ein Wanderungsgewinn von 125.000 Personen angenommen für das Land Baden-Württemberg, der für jedes Folgejahr abnimmt.

Die drei Varianten der Bevölkerungsvorausrechnung unterscheiden sich nur in den Annahmen zu Fort- und Zuzügen in den Landkreis. In der Hauptvariante wird für den Zeitraum zwischen 2015 bis 2060 ein Wanderungssaldo von 62.870 Personen angenommen, für die untere Variante 47.901 Personen und die obere Variante 97.299 Personen.

2.2 Definitionen

Die Definition der im Bericht betrachteten Pflegeleistungen sowie der Pflegebedürftigkeitsbegriff beruhen auf dem Pflegeversicherungsgesetz (SGB XI).

Pflegebedürftigkeit

Gesetzlich Pflegeversicherte gelten dann als pflegebedürftig, wenn dies gutachterlich festgestellt wurde. Hierzu wird auf Antrag bei der Pflegekasse ein Gutachter bestellt, i.d.R. vom Medizinischen Dienst der Krankenversicherung. Die Begutachtung orientiert sich dabei am gesetzlich festgelegten Pflegebedürftigkeitsbegriff. Bis einschließlich des Jahres 2016 bezog sich die Pflegebedürftigkeit vorrangig auf körperliche Beeinträchtigungen und den damit verbundenen zeitlichen Hilfebedarf bei überwiegend körperlichen Verrichtungen. Je nach Ausmaß des festgestellten Pflegebedarfs erfolgte eine Zuteilung zu einer von drei Pflegestufen und zusätzlich die Feststellung einer „erheblich eingeschränkten Alltagskompetenz“, der sogenannten Pflegestufe 0, zum Beispiel aufgrund einer Demenz. Mit dem Pflegestärkungsgesetz wurde zum 1. Januar 2017 ein neuer und weiter gefasster Pflegebedürftigkeitsbegriff eingeführt. Hierüber sollen geistig bzw. psychisch bedingte Beeinträchtigungen stärker als bisher berücksichtigt werden. Die Einstufung des Pflegebedarfs erfolgt in fünf Pflegegraden. Der vorliegende Bericht beruht hauptsächlich auf Daten vor 2017, sodass die Darstellung der Pflegebedürftigkeit hier auf der Definition vor 2017 basiert.

Vollstationäre Dauerpflege

Das Angebot stationärer Pflegeeinrichtungen (Pflegeheime) wird unterschieden zwischen Kurzzeitpflege in einer vollstationären Einrichtung bis zu acht Wochen im Jahr, teilstationärer Pflege in Form von Tages- und/oder Nachtpflege und vollstationärer Dauerpflege. Die Auswertungen in diesem Bericht beziehen sich auf die vollstationäre Dauerpflege.

Ambulante Pflege

Pflegebedürftige, die in häuslicher Umgebung leben, können ambulante Pflegedienste nutzen. Die Leistungen umfassen körperbezogene Pflegemaßnahmen wie waschen, anziehen, beim Essen helfen, pflegerische Betreuungsmaßnahmen sowie Hilfe bei der Haushaltsführung, z.B. einkaufen oder kochen. Diese sogenannten Pflegesachleistungen dürfen nur zugelassene Pflegedienste erbringen, mit denen Pflegekassen einen Versorgungsvertrag abgeschlossen haben.

Demenzen – Definition und Einteilung

Eine Demenz (lat. *dementia* = ohne Verstand) wird derzeit definiert als ein psychopathologisches Syndrom. Dieses setzt sich zusammen aus einer erworbenen Störung von Gedächtnisfunktionen und mindestens einer weiteren kognitiven Beeinträchtigung des Denkens, der Orientierung, der Auffassung, des Rechnens, der Lernfähigkeit, der Sprache und des Urteilsvermögens. Dazu kommen Veränderungen der emotionalen Kontrolle, des Sozialverhaltens und der Motivation. Kognitive Beeinträchtigungen sind bei Demenzen so stark ausgeprägt, dass sie eine Verschlechterung gegenüber einem vormals höheren Leistungsniveau darstellen und Einschränkungen in der Alltagskompetenz mit sich bringen. Von Demenzen abzugrenzen ist das Delir, bei dem kurzfristige kognitive Einbußen auftreten.

Es gibt verschiedene Ursachen für eine Demenz. Je nach Ursache spricht man von einer primären oder sekundären Demenz. Bei der ersteren und häufigeren Form liegt der Schwerpunkt der Erkrankung hauptsächlich im Gehirn. Die häufigste Ursache einer primären Demenz ist die Alzheimer-Krankheit. Bei sekundären Demenzen ist das Gehirn nur mittelbar in das Krankheitsgeschehen einbezogen, der Schwerpunkt der Krankheitsursache wird außerhalb des Gehirns verortet. Zerebrale Durchblutungsstörungen sind die häufigste Ursache einer sekundären Demenz.

Falldefinition für Menschen mit Demenz bei Routinedatenanalysen

Eigene Berechnungen zur Häufigkeit von Demenzerkrankungen basieren auf Abrechnungsdaten der AOK BW aus der ambulanten und stationären medizinischen Versorgung. Diagnosen werden dort mit der Internationalen statistischen Klassifikation der Krankheiten und verwandter Gesundheitsprobleme, 10. Revision, German Modification (ICD-10-GM) dokumentiert. Ein Versicherter wurde dann als Betroffener gezählt, wenn die folgenden Kriterien erfüllt waren:

- Mindestens eine der folgenden Diagnosen nach ICD-10-GM lag vor: F00, F01, F02, F03, F05.1, G30, G31.0, G31.82.
- Die Demenz-Diagnose lag als ambulant gesicherte Diagnose in mindestens zwei Quartalen des Beobachtungsjahres vor
- ODER die Demenz-Diagnose lag als stationäre Hauptdiagnose bei Entlassung vor
- ODER die Demenz-Diagnose lag als stationäre Nebendiagnose in mindestens zwei stationären Aufenthalten vor.

2.3 Analysemethoden

Administrative Prävalenz der Demenz

Bei Prävalenzschätzungen, die auf der Grundlage von Routinedaten durchgeführt wurden, spricht man auch von der administrativen Prävalenz. Damit wird u. a. betont, dass nur diejenigen „Fälle“ erfasst werden, bei denen eine Erkrankung zu einer Inanspruchnahme von Leistungen - im vorliegenden Fall der gesetzlichen Krankenversicherung - führte. Die Population der AOK BW-Versicherten kann von der Struktur der Wohnbevölkerung im Rhein-Neckar-Kreis abweichen. Deshalb wurden Berechnungen zur administrativen Prävalenz der Demenz angepasst an die Alters- und Geschlechtsstruktur der Wohnbevölkerung des Rhein-Neckar-Kreises mittels Daten der Bevölkerungsfortschreibung des Statistischen Landesamtes Baden-Württemberg. Bis auf die Gruppe der 90-Jährigen und höher erfolgte die Altersadjustierung nach Altersjahren. Aufgrund der Datenverfügbarkeit erfolgte diese Anpassung für die Gruppe der 90-Jährigen und älter nicht in Altersjahren sondern als eine Altersgruppe. Die Adjustierung nach weiteren sozioökonomischen Variablen wie dem sozioökonomischen Status, der in Zusammenhang mit gesundheitsrelevanten Aspekten steht, war aufgrund der verfügbaren Daten nicht möglich.

Projektionen

Projektion bedeutet, dass aktuelle Verhältnisse, z.B. Inanspruchnahme- oder Prävalenzraten auf die künftige Bevölkerung übertragen werden. Die einzige sich ändernde Variable ist demnach die Bevölkerungsstruktur. Die Projektion von Prävalenzen und Inanspruchnahmeraten in den vorliegenden Analysen erfolgte in zwei wesentlichen Schritten. In einem ersten Schritt wurden für jede Alters- und Geschlechtsgruppe (Alter nach Jahren bis zum Alter von 89, danach eine Gruppe für die Altersjahre 90+) jeweils Prävalenz- oder Inanspruchnahmeraten auf Grundlage von Routinedaten der AOK BW ermittelt. Anschließend wurden die alters- und geschlechtsspezifischen Raten mit dem Anteil der vorausberechneten Alters- und Geschlechtsgruppe im Rhein-Neckar-Kreis multipliziert. Die Daten zur vorausberechneten Bevölkerungsstruktur wurden vom Statistischen Landesamt Baden-Württemberg bereitgestellt.

3. Ergebnisse

3.1 Bevölkerungsentwicklung

Erste Hinweise für die zukünftige Entwicklung der Zahl der Pflegebedürftigen und formellen sowie informellen Pflegenden kann die Entwicklung bestimmter Altersgruppen im Rhein-Neckar-Kreis (Abbildung 1) geben.

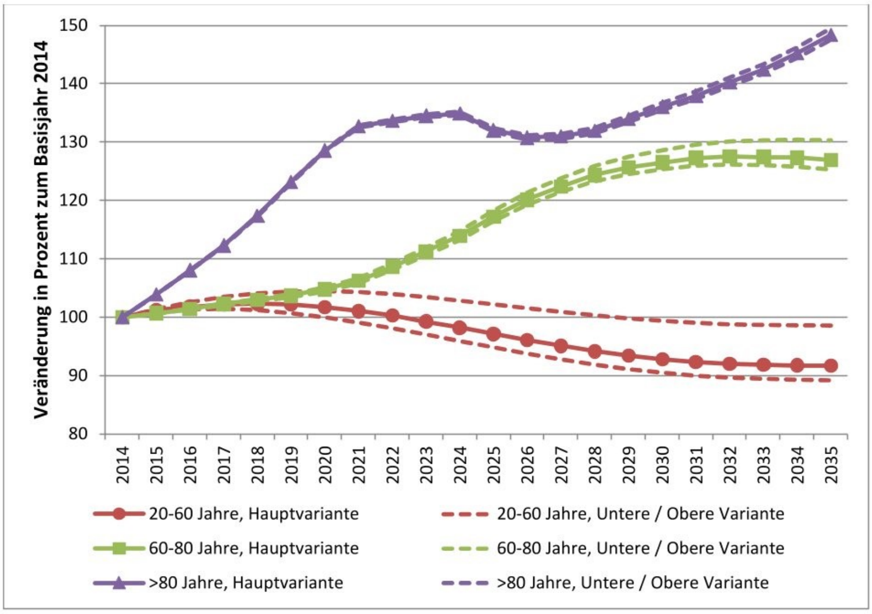

Abbildung 1: Vorausberechnung der Bevölkerungsstruktur im Rhein-Neckar-Kreis nach Altersgruppen von 2014 bis 2035.

In der Altersgruppe der über 80-Jährigen ist das Risiko einer Pflegebedürftigkeit höher als in darunter liegenden Altersgruppen. Ausgehend vom Jahr 2014 wird die Zahl dieser Altersgruppe bis zum Jahr 2035 um fast 50 Prozent zunehmen. Damit ergeben sich für diese Altersgruppe die größten Veränderungen. Anhand der Altersgruppe der 60 bis 80-Jährigen lassen sich erste grobe Schätzungen zur Entwicklung sowohl der Zahl Pflegebedürftiger als auch potenziell pflegender Angehöriger machen. Auch in dieser Gruppe wird zwischen 2014 bis 2035 eine Zunahme erwartet um circa 25 Prozent. In der Altersgruppe der 20 bis 60-Jährigen, die vor allem potenzielle Pflegende umfasst, wird für den Vorausberechnungszeitraum eine Abnahme zwischen ein bis zehn Prozent erwartet.

3.2 Pflegeangebote

Ambulante Pflegedienste

Zwischen 2003 und 2015 nahm die Anzahl der ambulanten Pflegedienste von 48 auf 56 leicht zu. Ebenso wurde ein Anstieg des Personals in den ambulanten Pflegediensten verzeichnet. Kamen im Jahr 2003 im Durchschnitt 21 Beschäftigte auf einen ambulanten Pflegedienst (u.a. Verwaltung, examinierte Gesundheits- und Krankenpflege, Pflegehelfer), waren es 2015 mit 29 etwas mehr. Ein genaueres Maß der absoluten Kapazitäten stellt das Personal ambulanter Pflegedienste in Vollzeitäquivalenten dar. Diese lagen 2013 bei 985. Die Bertelsmann Stiftung geht in ihrer Vorausberechnung für das Jahr 2030 von einem Rückgang auf 931 aus. Basis dieser Vorausberechnung ist die Entwicklung der Bevölkerung im Alter zwischen 20 bis 64 Jahren.

Pflegeheime

Die Zahl der verfügbaren Plätze in Pflegeheimen mit vollstationärer Dauerpflege lag im Jahr 2003 bei 3.900 und hat bis 2015 um 28 Prozent zugenommen. Für die relativen Kapazitäten gemessen in Plätzen der vollstationären Dauerpflege je 1.000 Pflegebedürftige ergibt sich eine Abnahme der Kapazitäten von 328 Plätzen je 1.000 Pflegebedürftige in 2003 auf 267 in 2015. In allen Pflegeheimen insgesamt hat die Zahl des Personals (darin enthalten u.a. Verwaltung, examinierte Alten- und Krankenpflege, Pflegehelfer) im selben Zeitraum um 43 Prozent zugenommen. Die absoluten Kapazitäten der Pflegeheime gemessen in Personal im stationären Pflegedienst in Vollzeitäquivalenten lagen 2013 bei 3.184. Die Bertelsmann Stiftung geht in ihrer Vorausberechnung für das Jahr 2030 von einem Rückgang auf 3.010 aus.

Pflegende Angehörige

Da für den Rhein-Neckar-Kreis keine tiefergehenden Informationen über pflegende Angehörige gefunden werden konnten, werden an dieser Stelle Ergebnisse einer deutschlandweiten Umfrage der gesetzlichen Krankenkasse BARMER, publiziert in ihrem Pflegereport 2018, vorgestellt. Demnach waren zwei Drittel der pflegenden Angehörigen weiblich. Knapp die Hälfte der Hauptpflegepersonen war zwischen 50 und 70 Jahre alt. Ein Drittel der pflegenden Angehörigen gab an, erwerbstätig zu sein, jeder Vierte habe aufgrund der Pflege Arbeit reduziert oder vollständig aufgegeben. Etwa die Hälfte der Hauptpflegepersonen gab an, ihren Partner zu pflegen, danach folgen als Hauptpflegepersonen die Kinder pflegebedürftiger Eltern mit rund 28 Prozent und mit rund zwölf Prozent Eltern, die ihre Kinder pflegen.

3.3 Nachfrage von Pflegeangeboten

Pflegebedürftige

Seit Inkrafttreten der Pflegeversicherung beschreibt die Pflegestatistik eine stetige Zunahme der Zahl der Pflegebedürftigen. Im Rhein-Neckar-Kreis ist diese zwischen 2003 und 2015 um mehr als 50 Prozent gestiegen von rund 11.900 Personen auf 18.700. Bis zum Jahr 2035 ergibt sich ein weiterer deutlicher Anstieg auf rund 26.000 Pflegebedürftige (Abbildung 2). Von den derzeit Pflegebedürftigen sind 64 Prozent weiblich. Im Jahr 2013 konnte erstmals Pflegestufe 0 (erheblich eingeschränkte Alltagskompetenz) vergeben werden. Der Anteil der Pflegebedürftigen in dieser Pflegestufe war am niedrigsten und lag bei vier Prozent. Für die meisten Pflegebedürftigen wurde Pflegestufe 1 vergeben (54 Prozent), gefolgt von Pflegestufe 2 mit 32 Prozent und Pflegestufe 3 mit 10 Prozent.

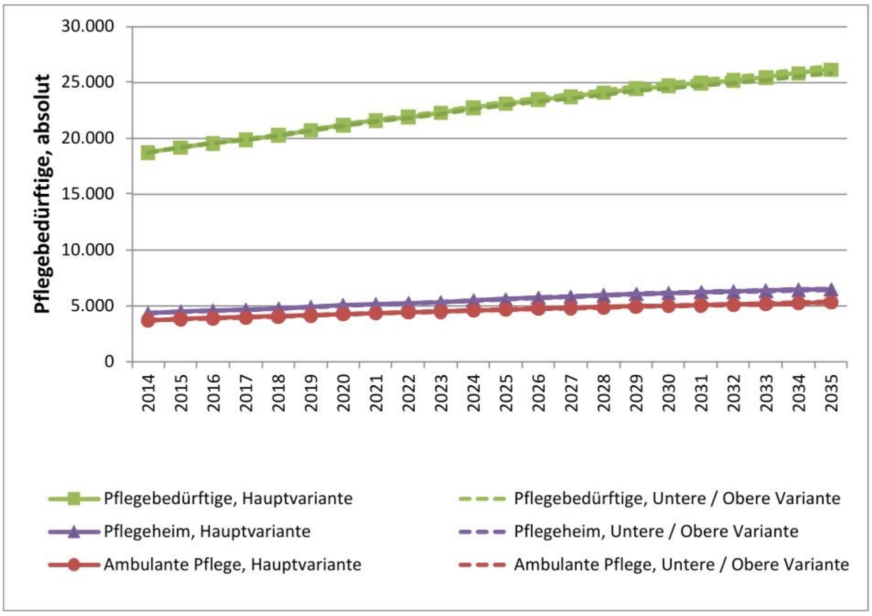

Abbildung 2: Projizierte Entwicklung der Zahl der Pflegebedürftigen und Inanspruchnahme ausgewählter Pflegeangebote im Rhein-Neckar-Kreis von 2014 bis 2035.

Pflege durch Angehörige

Berechnungen der Bertelsmann Stiftung zufolge wurden im Rhein-Neckar-Kreis 53,5 Prozent der Pflegebedürftigen ausschließlich durch Angehörige gepflegt. Für das Jahr 2030 wird ein leichter Rückgang auf 50,7 Prozent erwartet. Einen Einblick in den Pflegeaufwand gibt die BARMER-Versichertenbefragung 2018 für ihre Versicherten in Deutschland insgesamt. Von den befragten pflegenden Angehörigen gaben 85 Prozent an, sich täglich um die pflegebedürftige Person zu kümmern. Die Hälfte davon gab an, sich mehr als zwölf Stunden täglich zu kümmern. Dabei erstreckt sich der Hilfebedarf nicht nur auf Tageszeiten. Etwa zwei Drittel der befragten Hauptpflegepersonen gaben an, sich auch nachts um den Pflegebedürftigen zu kümmern.

Inanspruchnahme ambulanter Pflegedienste

Im Rhein-Neckar-Kreis wurden 2015 rund 20 Prozent der Pflegebedürftigen durch einen ambulanten Pflegedienst versorgt. In den betrachteten Vorjahren (2003 bis 2013) unterlag dieser Anteil leichten Schwankungen, die alle einen niedrigeren Anteil ausweisen mit dem niedrigsten Anteil im Jahr 2005 mit 18 Prozent. Zusammen mit der Zahl der Pflegebedürftigen hat auch die Zahl derjenigen, die einen ambulanten Pflegedienst nutzen, deutlich zugenommen von 2.216 im Jahr 2003 zu 3.715 in 2015. Abbildung 2 zeigt u.a. die projizierte Entwicklung der Zahl der Pflegebedürftigen im Rhein-Neckar-Kreis, die ambulante Pflegedienste in Anspruch nehmen. Demnach würde sich der bisherige Trend der kontinuierlichen Zunahme im projizierten Zeitraum (2014 bis 2035) in allen drei Varianten der

Vorausberechnung fortsetzen. Im Jahr 2035 wären dann circa 5.215 Pflegebedürftige zu erwarten, die durch ambulante Dienste gepflegt würden.

Inanspruchnahme der stationären Pflege

Etwa 23 Prozent der Pflegebedürftigen im Rhein-Neckar-Kreis lebten im Jahr 2015 dauerhaft in einem Pflegeheim und erhielten dort vollstationäre Pflege. Im Vergleich zu den ambulanten Pflegediensten unterlag der Anteil der vollstationären Dauerpflege in den Jahren zwischen 2003 und 2015 größeren Schwankungen. Zunächst war eine kontinuierliche Zunahme zu beobachten, die 2009 einen Höhepunkt fand mit rund 30 Prozent. Danach sank der Anteil kontinuierlich. In absoluten Dimensionen war, wie im Bereich der ambulanten Pflege auch, eine kontinuierliche Zunahme der Pflegebedürftigen in vollstationärer Dauerpflege zu beobachten von 3.340 im Jahr 2003 zu 4.364 in 2015. Auch zukünftig ist mit einer weiteren kontinuierlichen Zunahme zu rechnen (siehe Abbildung 2), die im Jahr 2035 bei etwa 6.383 Pflegebedürftigen in Pflegeheimen läge.

Menschen mit Demenz

Im Rhein-Neckar-Kreis leben derzeit etwa 11.000 Menschen mit einer Demenz. Bis zum Jahr 2035 werden es schätzungsweise 15.000 Betroffene sein (Abbildung 3). Die Schätzungen auf Basis der drei Varianten der Bevölkerungsvorausberechnung liegen dabei nah beieinander.

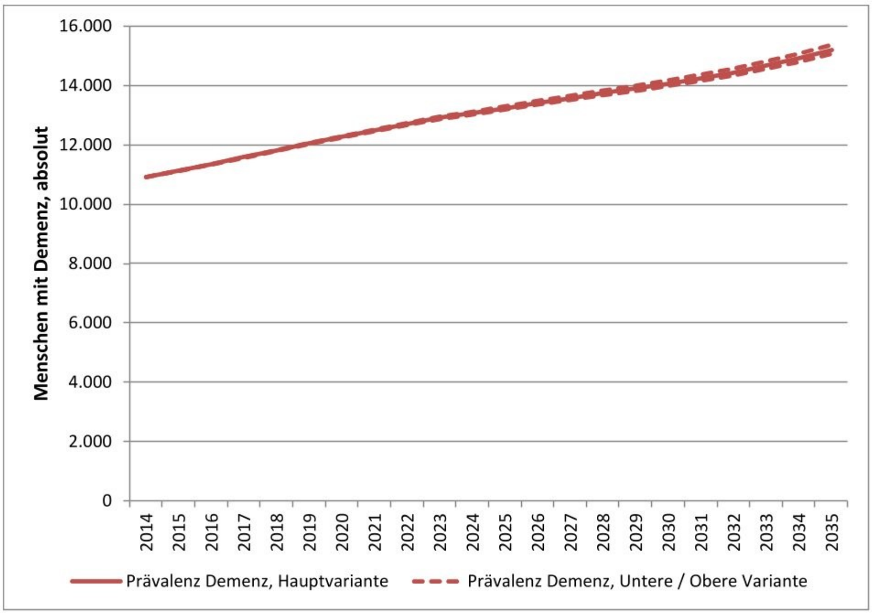

Abbildung 3: Projizierte Entwicklung der Anzahl von Menschen mit Demenz im Rhein-Neckar-Kreis von 2014 bis 2035.

Demenz und Inanspruchnahme von Pflegeleistungen

Umfangreiche Darstellungen zur Inanspruchnahme von Leistungen der gesetzlichen Pflegeversicherung durch Menschen mit Demenz finden sich bei Doblhammer et al. auf Basis von deutschlandweiten

Daten der AOK aus dem Jahr 2007. Die nachfolgenden Ausführungen beziehen sich auf diese Quelle. Das Risiko für Menschen mit Demenz pflegebedürftig zu sein ist groß. Etwa 41 Prozent der an Demenz erkrankten Frauen zwischen 65 und 70 Jahren erhält Pflegeleistungen. Mit dem Alter steigt dieser Anteil kontinuierlich an und stagniert im Alter von 100 Jahren bei circa 93 Prozent. Der Verlauf über das Alter hinweg ist bei Männern ähnlich, ihre Inanspruchnahme unterscheidet sich leicht. So ist der Anteil der Männer mit Demenz, die Pflegeleistungen erhalten, zwischen dem 65. und 75. Lebensjahr mit etwa 47 Prozent höher als bei den Frauen.

Von den pflegebedürftigen Menschen mit Demenz wird ein Großteil durch Pflegeheime versorgt, davon ist die Mehrheit weiblich. Im Alter von 65 Jahren sind die Anteile bei Männern und Frauen noch ähnlich mit jeweils rund 50 Prozent. Danach sinkt der Anteil der im Pflegeheim lebenden pflegebedürftigen Menschen mit Demenz bis zu einem Alter zwischen 75 und 80 Jahren. Bei den Frauen liegt der Anteil hier bei rund 45 Prozent, bei den Männern ist dieser Anteil mit rund 35 Prozent deutlich niedriger. Mit zunehmendem Alter steigt der Anteil bei beiden Geschlechtern und liegt im Alter von 100 Jahren bei mehr als 65 Prozent (Frauen) bzw. rund 50 Prozent (Männer). Eigene Analysen für den Rhein-Neckar-Kreis ergaben, dass circa 40 Prozent der Pflegeheimbewohner über alle Altersgruppen hinweg in vollstationärer Dauerpflege an einer Demenz erkrankt sind. Hoffmann et al. kommen in ihrer Analyse zu dem Schluss, dass für Heimbewohner ab einem Alter von 65 Jahren in Deutschland die Prävalenz der Demenz mit rund 52 Prozent noch höher ist.

4. Diskussion und Schlussfolgerungen

Zusammenfassend zeigen die vorliegenden Analysen, dass für den Rhein-Neckar-Kreis davon auszugehen ist, dass sich bisher beobachtbare Trends sowohl in der Nachfrage als auch im Angebot von Pflegeleistungen fortsetzen werden in den nächsten zehn bis fünfzehn Jahren. Zu berücksichtigen ist, dass die ermittelten Veränderungen aufgrund der Bevölkerungsentwicklung im Kreis zu erwarten ist. Welchen Einfluss aktuelle und zukünftige Maßnahmen wie Gesetzesänderungen und veränderte Lebensweisen haben werden, lässt sich nur schwer abschätzen. Da es sich jedoch um einen vergleichsweise kurzen Zeitraum für die Projektion handelt und die entscheidenden Generationen der Pflegefrage bereits geboren sind, bietet die vorliegende Analyse hilfreiche Informationen über Entwicklungen und ihre Größenordnung von Angebot und Nachfrage von Pflegeleistungen im Kreis.

Die Nachfrage von formeller und informeller Langzeitpflege wird weiterhin zunehmen. Rund 7.000 Pflegebedürftige mehr werden es im Jahr 2035 im Vergleich zu 2014 voraussichtlich sein. Zudem ist zu erwarten, dass unter den Pflegebedürftigen mehr Menschen von einer Demenz betroffen sein werden als bisher. Denn das Risiko an einer Demenz zu erkranken sowie das Risiko für einen Menschen mit Demenz pflegebedürftig zu sein steigt mit dem Alter. Gleichzeitig sind die über 80-Jährigen diejenige Altersgruppe, in der der höchste Bevölkerungszuwachs bis 2035 erwartet wird.

Offen bleibt, wie sich die zunehmende Nachfrage von Pflegeleistungen auf Angehörige, ambulante Pflegedienste und Pflegeheime verteilen. Die Bevölkerungsentwicklung ist hier nur ein Faktor von vielen. Betrachtet man nur die Projektionen aufgrund der Bevölkerungsentwicklung, ergeben sich für die Aufteilung der Pflege kaum Änderungen. Andere Entwicklungen wie die Zunahme von Einpersonenhaushalten und die Tendenz, weniger Kinder zu bekommen, aber auch die Zunahme von Pflegebedürftigen mit höherem Pflegebedarf etwa durch die Zunahme von Pflegebedürftigen mit einer Demenz, legen nahe, dass die Nachfrage nach formeller Pflege stärker zunehmen könnte als die Nachfrage nach informeller Pflege. Demgegenüber steht der Wunsch vieler Pflegebedürftiger, möglichst lange im häuslichen Umfeld zu verbleiben und durch Angehörige gepflegt zu werden.

Der zunehmenden Nachfrage von Pflegeleistungen steht ein zu erwartender Rückgang der Pflegenden gegenüber. Die Bevölkerungsvorausberechnung liefert hier hilfreiche Informationen. Der vorausberechnete Rückgang des Bevölkerungsanteils von 20 bis 60-Jährigen bedeutet auch einen Rückgang potenzieller professioneller Pflegekräfte. Ob es bis 2035 jedoch zu diesem Rückgang kommt, ist nicht sicher, die Spanne zwischen den drei Vorausberechnungsvarianten reicht hier von einer geringen Abnahme in der oberen Variante bis zu einer Abnahme von rund zehn Prozent gemäß der unteren Variante. Diese Schwankung spiegelt die Unsicherheit über Ab- und Zuwanderung aus bzw. in den Landkreis durch diese Personengruppe wider. Die Entwicklung der formellen Pflegekapazitäten hängt zudem davon ab, wie viele Menschen einen Pflegeberuf als attraktiv ansehen und dementsprechend in diesem Beruf verbleiben bzw. eine Ausbildung beginnen. Geht man nach den gesundheitlichen, beruflichen und finanziellen Belastungen, die pflegende Angehörige derzeit berichten, lässt sich schließen, dass bereits jetzt weitere Unterstützungsangebote zur Entlastung pflegender Angehöriger erforderlich sind. Durch die Zunahme der Pflegebedürftigen insgesamt wird dieser Bedarf in den nächsten Jahren weiter zunehmen.

Situation of long-term care in the Rhine-Neckar district

Report of the Working Group on Care in Rural Areas of the Rhine-Neckar District Communal Health Conference

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1. Introduction

1.1 Current challenges

The Rhine-Neckar district would like to offer its citizens a good and high-quality supply of long-term care currently and in the future. Long-term care includes all care measures that are provided over a longer period of time or on a permanent basis. At the 2018 Communal Health Conference (CHC) of the Rhine-Neckar district, people in need of long-term care, their relatives, and also employees from outpatient care services and nursing homes reported growing difficulties in covering the current demand for long-term care services. Among other things, they reported increasing waiting times for a place in full-time permanent care, more people in need of care on the one hand, and less time for care by caregivers on the other. Family caregivers report that they are often heavily burdened by caregiving, feel forced to reduce or completely abandon their professional activities, and often have less time for self-care, e.g., have less contact with friends and are more impaired in health.

The nationwide demographic change is also imminent or already taking place in the Rhine-Neckar district and poses a variety of challenges for long-term care. It is expected that more elderly people and thus more people in need of care will live in the district in the future. It is also expected that there will be an increase in the number of people with dementia, whose care is linked to special requirements for care services. On the other hand, fewer caregivers are expected, both among the relatives of those in need of care and among professionals. In Germany, many people in need of care are currently cared for by their children. However, more and more people remain childless in their lives. Likewise, it is mostly women who take on the care of relatives. The number of working women has increased, which means that they will have less capacity to care for relatives. In the area of skilled workers, more and more facilities are already having difficulty recruiting personnel for care. Demographic change is expected to exacerbate this situation.

Difficulties in the provision of needs-based long-term care services are also reported from neighboring regions of the Rhine-Neckar district and are also expected in the future so that citizens currently and in the coming years will not have the opportunity to switch to services from neighboring regions.

Long-term care is facing the aforementioned challenges throughout Germany. For this reason, a number of measures have already been implemented, the effectiveness of which remains to be seen on the ground. In order to counter the shortage of skilled workers, the increase in contributions to long-term care insurance in 2019 is to create 13,000 new positions for care workers nationwide, reform care training, and pay care workers better. The three Care Strengthening Acts (PSG I-III) introduced measures to improve the care ratio in nursing homes, support measures for family caregivers (e.g., free counseling services, better social security), and more benefit entitlements for people in need of care.

1.2 Additional funds for long-term care

Following the CHC 2018, the district administrator of the Rhine-Neckar district announced that additional financial resources would be made available for long-term care and would like to take recommendations of the CHC into account when allocating the funds. The funds are to be disbursed annually from 2020 to 2030. The exact amount of the funds is not yet known. Further, the funds can only be used for one of three options already identified. These are presented below with a brief assessment of their budgetary consequences.

Option A: Increase funding for support measures for family caregivers (e.g., cash benefits, counseling services, low-threshold care, increase capacity for short-term care in nursing homes). This is the most cost-effective option on a per capita basis. That is, most people in need of care would benefit from this option. Professional nursing services are excluded from this option.

Option B: Increase nursing home capacity for permanent inpatient care. This option is the most expensive option on a per capita basis, i.e., compared to the other options, the fewest care recipients would benefit.

Option C: Increase capacity in outpatient care. This option allows outpatient care services to increase their capacity to care for more care recipients and/or expand their services per care recipient, e.g., in the form of more care time. This option is cheaper per capita than option B and more expensive than option A, but the same applies to the number of people in need of care who would benefit from this option.

1.3 Objectives of the present analysis

The working group "Healthcare in rural areas" of the CHC Rhine-Neckar district feels obliged to give its contribution for recommendations to the district administrator for the use of the planned additional funds for long-term care. Therefore, the present report was prepared by members of the AG for a data-based recommendation. The aim of the report is to summarize the current and estimate the future supply situation in the field of long-term care in the Rhine-Neckar district on the basis of available data. Since the clinical picture of dementia leads to special care requirements for those affected, analyses should also be prepared for this. The following questions are to be dealt with in this report for the Rhine-Neckar district:

- How many people in need of care (especially with dementia) live in the district at present and in the future?
- What is the current and future utilization of outpatient care services and places of permanent inpatient care in nursing homes?
- What has been the development of long-term care services and their utilization to date?

2. Methods

The analyses carried out are based on the one hand on secondary data analyses by the working group members. Where no data were available, results from other reports or studies were used for the results section.

2.1 Data sources

For the secondary data analysis, various data sources were analyzed, which are presented below.

Routine data of the AOK Baden-Wuerttemberg (AOK BW): Data on the current and projected utilization of long-term care services as well as dementia-related analyses are based on billing data of the statutory health and long-term care insurance company AOK BW from the period 01.01.2013 to 31.12.2013. In this period, about 28% of the resident population in the Rhine-Neckar district were insured with AOK BW. Thus, the sample of this data source is very comprehensive. Nevertheless, historically developed differences between the AOK insured population and the total population in the Rhine-Neckar district are to be expected, which may limit the representativeness of the data. Data quality assurance according to current standards (Good Practice Secondary Data Analysis 2012) was performed by the aQua-Institute for Applied Quality Promotion and Research in Health Care. As part of the reporting process by the CHC working group, these data were then transmitted to the working group via secure connections. The International Statistical Classification of Diseases and Related Health Problems in the tenth revision according to the German modification (ICD-10-GM) was used for coding the insured diagnoses.

Long-term Care Statistics: Data on the provision of long-term care, previous developments in the number of people in need of care and the utilization of care services are based on data from the Long-term Care Statistics of the Baden-Wuerttemberg State Statistical Office. The statistics are a complete survey and have been collected biennially since 1999 on December 15 of each year. The purpose of the statistics is to record supply and demand in the field of long-term care for the purpose of planning resources. The data is accessed online via the regional database of the Baden-Wuerttemberg Statistical Office.

Regionalized population projection: Projected data are based on the regionalized population projection of the Baden-Wuerttemberg Statistical Office. The updated projection used in this report was published in 2016 and was prepared on the occasion of the particularly high influx of refugees in 2015 for the years 2014 to 2060 at the state level and up to 2035 in the regionalized variant. The parameters taken into account in the projection refer to natural migration (births, deaths), migration within the country and with other countries. Depending on the parameters, support periods of different lengths were used, the upper limit of which is the year 2014. Up to this year, statistics based on the 2011 census were available for the updated population level. Three different development corridors were calculated for the Rhine-Neckar district, which differ in their assumptions. The main variant is based on the following assumptions:

- Life expectancy for women is assumed to increase by a further 2.1 years by 2035, for men slightly higher at 2.4 years.
- A slight increase in the birth rate from 1.46 to 1.5 is assumed. It is also assumed for the next 10 years that the trend toward having children later will continue and then remain constant.
- A migration gain of 125,000 persons is assumed for the state of Baden-Wuerttemberg, which decreases for each subsequent year.

The three variants of the population projection differ only in the assumptions on outward and inward migration to the district. In the main variant, a net migration of 62,870 persons is assumed for the period between 2015 and 2060, 47,901 persons for the lower variant, and 97,299 persons for the upper variant.

2.2 Definitions

The definition of the care services considered in the report and the concept of need for care are based on the German Long-Term Care Insurance Act (SGB XI).

Need for care

People with statutory long-term care insurance are considered to be in need of care if this has been determined by an expert. To this end, an expert is appointed upon application to the long-term care insurance fund, usually by the Medical Service of the Health Insurance Fund. The assessment is based on the statutory definition of the need for long-term care. Up to and including 2016, the need for care primarily related to physical impairments and the associated need for time-consuming assistance with predominantly physical activities. Depending on the extent of the need for care determined, the person was assigned to one of three care levels and additionally determined to have "significantly limited everyday competence", the so-called care level 0, for example, due to dementia. With the Care Strengthening Act (Pflegestärkungsgesetz), a new and broader definition of the need for care was introduced on January 1, 2017. This is intended to take greater account than before of mental and psychological impairments. The need for care is classified into five degrees of care. This report is mainly based on data prior to 2017, so the presentation of the need for care here is based on the definition prior to 2017.

Full inpatient permanent care

The range of inpatient care facilities (nursing homes) is differentiated between short-term care in a fully inpatient facility for up to eight weeks a year, day care in the form of day and/or night care, and fully inpatient permanent care. The evaluations in this report refer to fully inpatient permanent care.

Outpatient care

People in need of care who live in a home environment can use outpatient care services. The services include body-related care measures such as washing, dressing, helping with meals, nursing care measures, and help with household management, e.g., shopping or cooking. These so-called care benefits in kind may only be provided by licensed care services with which care insurance funds have concluded a care contract.

Dementia - definition and classification

Dementia (lat. dementia = without mind) is currently defined as a psychopathological syndrome. It consists of an acquired disturbance of memory functions and at least one further cognitive impairment of thinking, orientation, perception, calculation, learning ability, language, and judgment. In addition, there are changes in emotional control, social behavior, and motivation. In dementias, cognitive impairments are so pronounced that they represent a deterioration compared to a previously higher level of performance and entail limitations in everyday competence. Delirium, in which short-term cognitive impairment occurs, must be distinguished from dementia.

There are various causes of dementia. Depending on the cause, one speaks of primary or secondary dementia. In the former and more common form, the focus of the disease is mainly in the brain. The most common cause of primary dementia is Alzheimer's disease. In secondary dementias, the brain is only indirectly involved in the disease process, the focus of the disease cause is located outside the brain. Cerebral circulatory disorders are the most common cause of secondary dementia.

Case definition for people with dementia in routine data analyses.

Own calculations on the frequency of dementia are based on administrative data of the AOK BW from outpatient and inpatient medical care. Diagnoses are documented there using the International Statistical Classification of Diseases and Related Health Problems, 10th Revision, German Modification (ICD-10-GM). An insured was counted as a person with dementia if the following criteria were met:

At least one of the following ICD-10-GM diagnoses was present: F00, F01, F02, F03, F05.1, G30, G31.0, G31.82.

- The dementia diagnosis was documented as a confirmed outpatient diagnosis in at least two quarters of the observation year,
- OR the dementia diagnosis was documented as an inpatient principal diagnosis at discharge,
- OR the dementia diagnosis was documented as an inpatient secondary diagnosis in at least two inpatient stays.

2.3 Methods of analysis

Administrative prevalence of dementia

Prevalence estimates based on routine data are also referred to as administrative prevalence. This emphasizes, that only those "cases" are recorded in which a disease led to a claim for services - in the present case, statutory health insurance. The population of AOK BW insurants may differ from the structure of the resident population in the Rhine-Neckar district. Therefore, calculations on the administrative prevalence of dementia were adjusted to the age and gender structure of the resident population of the Rhine-Neckar district using data from the population update of the Baden-Wuerttemberg Statistical Office. Except for the group of 90-year-olds and above, the age adjustment was made according to age years. Due to data availability, this adjustment for the group of 90-year-olds and older was not made in age years but as an age group. Adjustment for other socioeconomic variables, such as socioeconomic status, which is related to health-related aspects, was not possible due to available data.

Projections

Projection means that current conditions, such as utilization or prevalence rates, are applied to the future population. Thus, the only variable that changes is the population structure. The projection of prevalence and utilization rates in the present analyses was done in two main steps. In a first step, prevalence or utilization rates were determined for each age and sex group (age by years up to age 89, then a group for ages 90+) based on routine data from the AOK BW. Subsequently, the age- and sex-specific rates were multiplied by the proportion of the predicted age and sex group in the Rhine-Neckar district. The data on the projected population structure were provided by the Baden-Wuerttemberg State Statistical Office.

3. Results

3.1 Population development

The development of certain age groups in the Rhine-Neckar district (Figure 1) provides initial indications for the future development of the number of people in need of care and formal as well as informal caregivers.

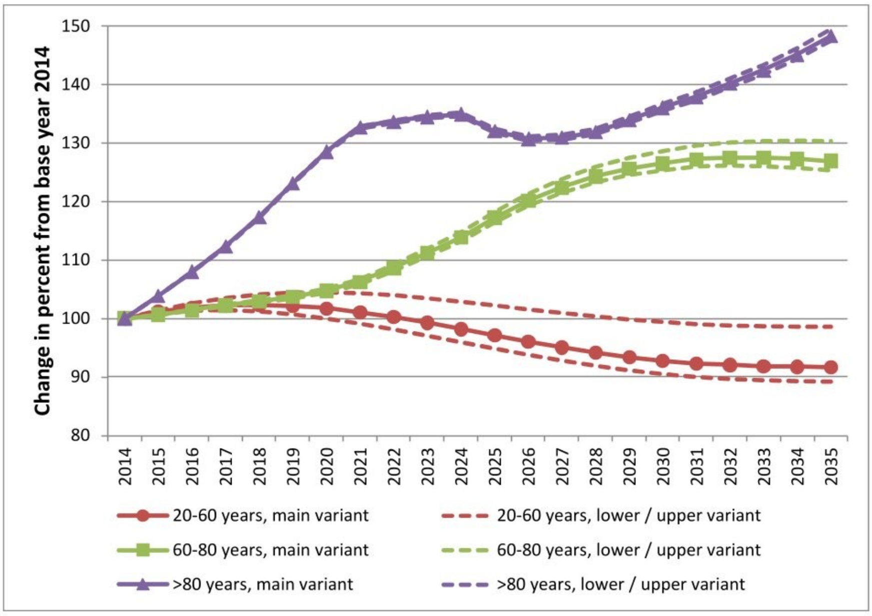


Figure 1: Projection of the population structure in the Rhine-Neckar district according to age groups from 2014 to 2035.

The risk of needing long-term care is higher in the over-80 age group than in the age groups below. Starting from 2014, the number of people in this age group is expected to increase by almost 50 percent by 2035. This means that the greatest changes will occur in this age group. The 60 to 80 age group provides an initial estimate of the development of both the number of people in need of care and the potential number of informal caregivers. In this group, too, an increase of around 25 percent is expected between 2014 and 2035. In the 20 to 60 age group, which mainly comprises potential formal and informal caregivers, a decrease of between one and ten percent is expected for the projection period.

3.2 Long-term care supply

Outpatient care services

Between 2003 and 2015, the number of outpatient care services increased slightly from 48 to 56. Likewise, there was an increase in the number of staff in outpatient care services. Whereas in 2003 there was an average of 21 employees per outpatient care service (including administration, registered health and nursing care, nursing assistants), in 2015 the figure was slightly higher at 29. A more accurate measure of absolute capacity is the number of full-time equivalent staff in outpatient care services. In its projection for 2030, the Bertelsmann Stiftung assumes a decline to 931. This projection is based on the development of the population aged between 20 and 64.

Nursing homes

The number of available places in nursing homes with full inpatient permanent care was 3,900 in 2003 and had increased by 28 percent by 2015. For the relative capacities measured in places of full inpatient permanent care per 1,000 persons in need of care, there is a decrease in capacities from 328 places per 1,000 persons in need of care in 2003 to 267 in 2015. In all nursing homes as a whole, the number of staff (including, among others, administration, registered geriatric nurses, nursing assistants) has increased by 43 percent in the same period. The absolute capacity of nursing homes, measured in full-time equivalent inpatient nursing staff, was 3,184 in 2013. In its projection for 2030, the Bertelsmann Stiftung assumes a decline to 3,010.

Informal caregivers

Since no more in-depth information on caring dependents could be found for the Rhine-Neckar district, results of a Germany-wide survey by the statutory health insurance company BARMER, published in its Long-Term Care Report 2018, are presented here. According to the survey, two-thirds of informal caregivers were female. Just under half of the main caregivers were between 50 and 70 years old. One-third of informal caregivers reported being employed, and one in four had reduced or completely given up work due to caregiving. Around half of the main caregivers stated that they cared for their partner, followed by the children of parents in need of care as the main caregivers with around 28 percent and parents caring for their children with around 12 percent.

3.3 Demand for long-term care services

Persons in need of care

Since long-term care insurance came into force, the long-term care statistics describe a steady increase in the number of persons in need of long-term care. In the Rhine-Neckar district, this number has increased by more than 50 percent between 2003 and 2015, from around 11,900 people to 18,700. By 2035, there will be a further significant increase to around 26,000 persons in need of care (Figure 2). Of those currently in need of care, 64 percent are female. In 2013, care level 0 (significantly impaired daily living skills) was awarded for the first time. The proportion of persons in need of care in this care level was the lowest, at four percent. Care level 1 was awarded to most care recipients (54 percent), followed by care level 2 with 32 percent and care level 3 with 10 percent.

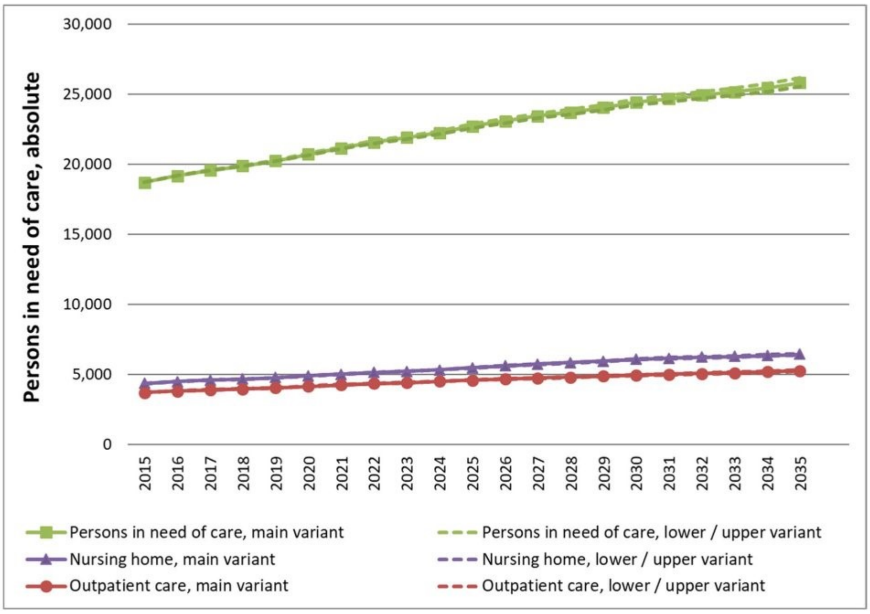


Figure 2: Projected development of the number of persons in need of long-term care and utilization of selected long-term care services in the Rhine-Neckar district from 2014 to 2035.

Care by dependents

According to calculations by the Bertelsmann Stiftung, 53.5 percent of those in need of care in the Rhine-Neckar district were cared for exclusively by their dependents. A slight decline to 50.7 percent is expected for 2030. An insight into the amount of care required is provided by the 2018 BARMER survey of insured persons in Germany as a whole. Of the informal caregivers surveyed, 85 percent said they cared for the person in need of care on a daily basis. Half of them said they cared for more than twelve hours a day. The need for help does not only extend to daytime. Around two-thirds of the main caregivers surveyed also said they looked after the person in need of care at night.

Use of outpatient care services

In the Rhine-Neckar district, around 20 percent of those in need of care were cared for by an outpatient care service in 2015. In the previous years under review (2003 to 2013), this share was subject to slight fluctuations, all of which showed a lower share with the lowest share in 2005 at 18 percent. Along with the number of persons in need of care, the number of those using an outpatient care service has also increased significantly from 2,216 in 2003 to 3,715 in 2015. Figure 2 shows, among other things, the projected development of the number of persons in need of care in the Rhine-Neckar district who use outpatient care services. According to this, the previous trend of continuous increase would continue in the projected period (2014 to 2035) in all three variants of the projection. In 2035, approximately 5,215 people in need of long-term care would then be expected to be cared for by outpatient services.

Use of inpatient care

In 2015, around 23 percent of those in need of care in the Rhine-Neckar district lived permanently in a nursing home and received full inpatient care there. Compared to outpatient care services, the share of full-time inpatient permanent care was subject to greater fluctuations in the years between 2003 and 2015. Initially, there was a continuous increase, which peaked in 2009 at around 30 percent. Thereafter, the share declined continuously. In absolute terms, as in the area of outpatient care, there was a continuous increase in the number of people in need of long-term inpatient care, from 3,340 in 2003 to 4,364 in 2015. A further continuous increase can be expected in the future (see Figure 2), which would amount to around 6,383 people in need of long-term care in nursing homes in 2035.

Persons with dementia

There are currently about 11,000 people living with dementia in the Rhine-Neckar district. By 2035, there will be an estimated 15,000 affected persons (Figure 3). The estimates based on the three variants of the population projection are close to each other.

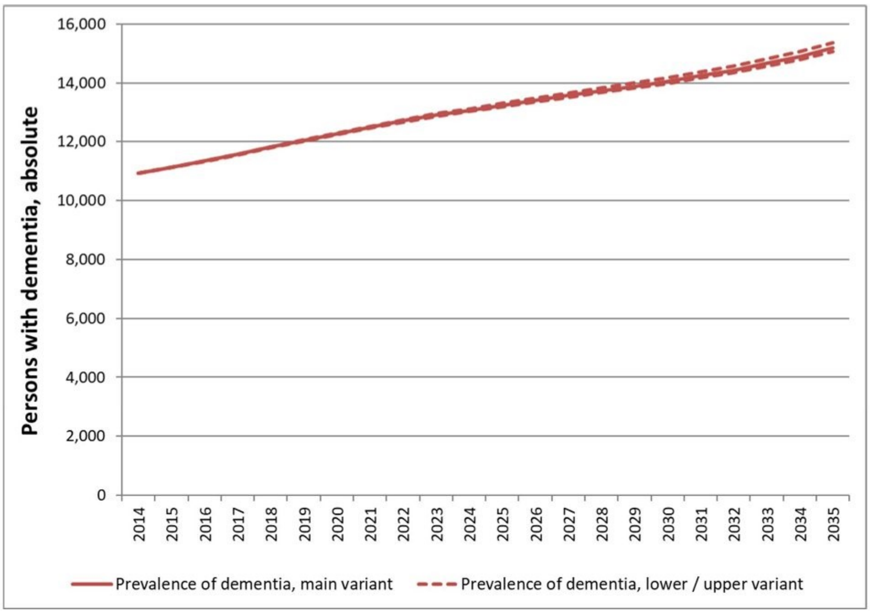


Figure 3: Projected development of the number of persons with dementia in the Rhine-Neckar district from 2014 to 2035.

Dementia and utilization of care services

Doblhammer et al. provide extensive information on the use of long-term care services by persons with dementia, based on nationwide data from the AOK in 2007. The following comments refer to this source. The risk for persons with dementia to be in need of care is high. About 41 percent of women between the ages of 65 and 70 who are affected by dementia receive care services. This proportion increases steadily with age and stagnates at around 93 percent at age 100. The trend across age is similar for men, but their utilization differs slightly. The proportion of men with dementia receiving care between the ages of 65 and 75 is higher than for women, at around 47 percent.

Of the people with dementia who need care, a large proportion are cared for by nursing homes, the majority of whom are female. At age 65, the proportions are still similar for men and women, at about 50 percent each. Thereafter, the proportion of people with dementia in need of care living in a nursing home decreases until they are between 75 and 80 years old. For women, the proportion here is around 45 percent; for men, the proportion is significantly lower at around 35 percent. With increasing age, the proportion rises for both sexes and is more than 65 percent (women) and around 50 percent (men) at the age of 100. Our own analyses for the Rhine-Neckar district showed that about 40 percent of nursing home residents across all age groups in full inpatient permanent care suffer from dementia. In their analysis, Hoffmann et al. conclude that the prevalence of dementia is even higher for nursing home residents aged 65 and older in Germany, at around 52 percent.

4. Discussion and conclusions

In summary, the present analyses show that for the Rhine-Neckar district, it can be assumed that previously observable trends in both the demand and the supply of care services will continue over the next ten to fifteen years. It must be taken into account that the changes determined are to be expected due to the population development in the district. It is difficult to estimate what influence current and future measures such as changes in legislation and changing lifestyles will have. However, since it is a comparatively short period of time for the projection and the decisive generations of the care issue have already been born, the present analysis provides helpful information about developments and their magnitude of supply and demand of care services in the district.

The demand for formal and informal long-term care will continue to grow. About 7,000 more people in need of long-term care are expected in 2035 compared to 2014. In addition, it is expected that more people will be affected by dementia among those in need of long-term care than in the past. This is because the risk of developing dementia and the risk of a person with dementia needing care increases with age. At the same time, the over-80s are the age group in which the highest population growth is expected by 2035.

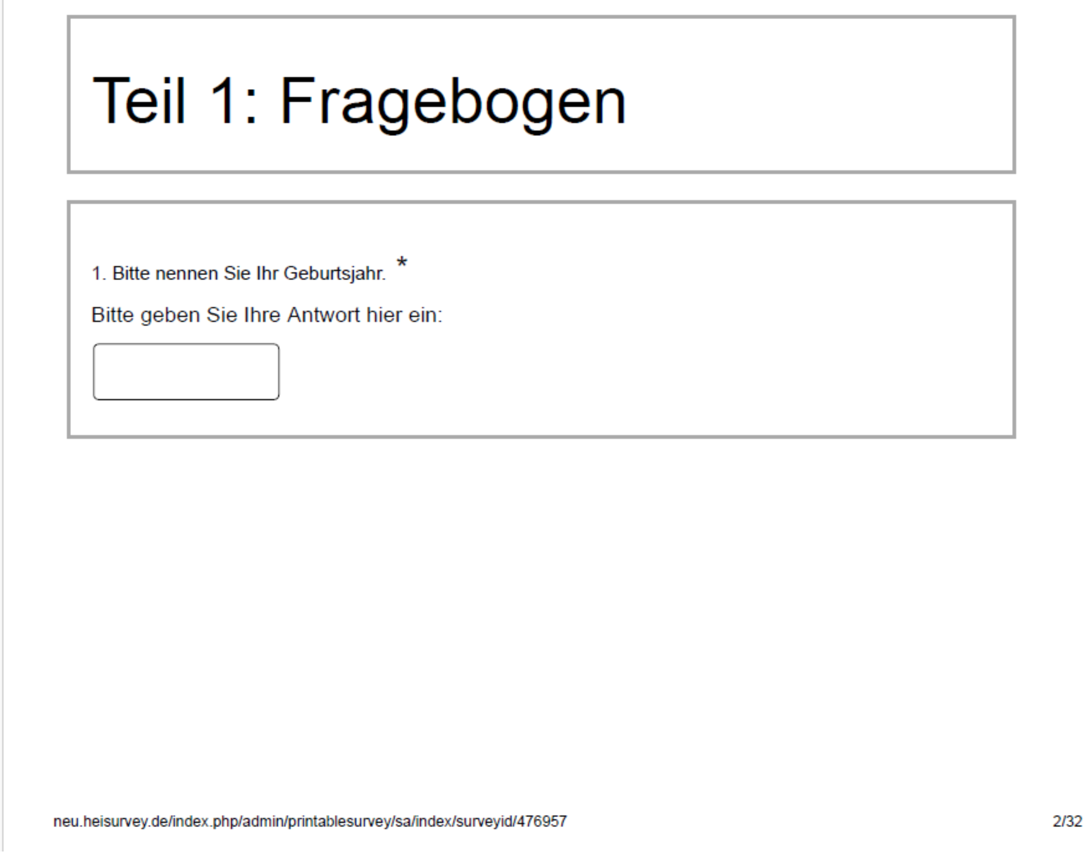
It remains to be seen how the increasing demand for care services will be distributed among relatives, outpatient care services and nursing homes. Population development is only one factor of many, here. If we look only at the projections based on population development, there are hardly any changes in the distribution of care. Other developments, such as the increase in single-person households and the tendency to have fewer children, but also the increase in people in need of care with higher care requirements, for example due to the increase in people in need of care with dementia, suggest that the demand for formal care could increase more than the demand for informal care. This contrasts with the desire of many people in need of care to remain in their home environment for as long as possible and to be cared for by relatives.

The increasing demand for care services is offset by an expected decline in the number of people needing care. The population projection provides helpful information here. The predicted decline in the proportion of the population aged 20 to 60 also means a decline in potential professional caregivers.

However, it is not certain whether this decline will occur by 2035; the range between the three projection variants here is from a small decrease in the upper variant to a decrease of around ten percent according to the lower variant. This fluctuation reflects the uncertainty about the outflow and inflow of this group of persons to and from the district. The development of formal nursing capacities also depends on how many people regard a nursing profession as attractive and accordingly remain in this profession or start training. Judging by the health, professional, and financial burdens that caregivers currently report, it can be concluded that further support services are already needed to ease the burden on caregiving dependents. Due to the overall increase in the number of persons in need of care, this need will continue to grow in the coming years.

Appendix 4: Questionnaire used in computer-assisted laboratory study (study 3)

- Original language version (German)
- English version (translated)



Teil 1: Fragebogen

1. Bitte nennen Sie Ihr Geburtsjahr. *

Bitte geben Sie Ihre Antwort hier ein:

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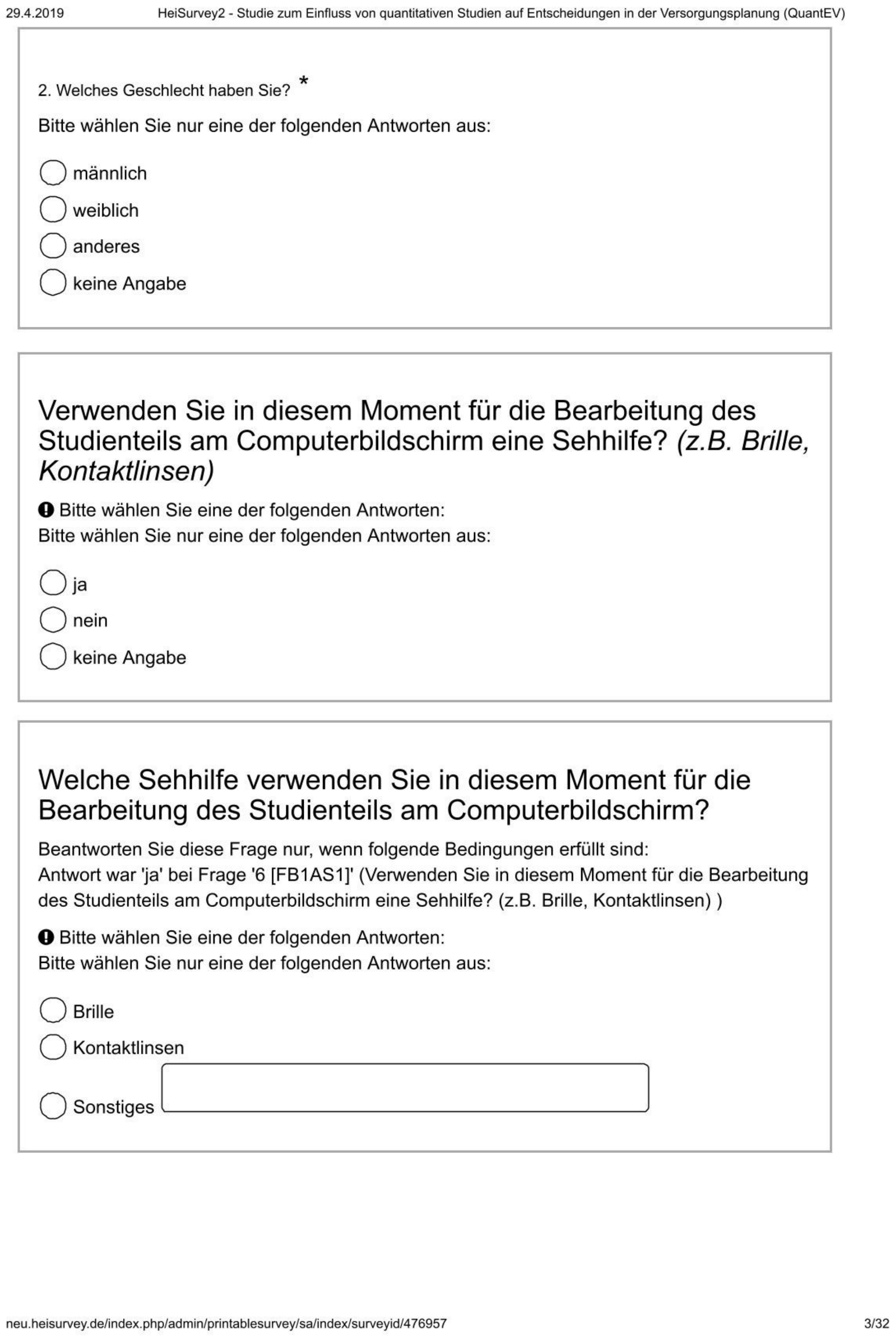


2. Welches Geschlecht haben Sie? *

Bitte wählen Sie nur eine der folgenden Antworten aus:

- ○ männlich
- ○ weiblich
- ○ anderes
- ○ keine Angabe

Verwenden Sie in diesem Moment für die Bearbeitung des Studienteils am Computerbildschirm eine Sehhilfe? *(z.B. Brille, Kontaktlinsen)*

❗ Bitte wählen Sie eine der folgenden Antworten:
Bitte wählen Sie nur eine der folgenden Antworten aus:

- ○ ja
- ○ nein
- ○ keine Angabe

Welche Sehhilfe verwenden Sie in diesem Moment für die Bearbeitung des Studienteils am Computerbildschirm?

Beantworten Sie diese Frage nur, wenn folgende Bedingungen erfüllt sind:
Antwort war 'ja' bei Frage '6 [FB1AS1]' (Verwenden Sie in diesem Moment für die Bearbeitung des Studienteils am Computerbildschirm eine Sehhilfe? (z.B. Brille, Kontaktlinsen))

❗ Bitte wählen Sie eine der folgenden Antworten:
Bitte wählen Sie nur eine der folgenden Antworten aus:

- ○ Brille
- ○ Kontaktlinsen
- ○ Sonstiges

Über wie viel Dioptrien verfügt Ihre Sehhilfe?

Falls Sie sich nicht sicher sind über die Dioptrienwerte, bitten wir Sie zu schätzen, welche Werte mindestens zutreffen könnten.
Falls Ihnen eine Antwort trotzdem nicht möglich ist oder diese Frage nicht zutreffend ist für Sie (z.B. aufgrund einer Sehhilfe, die nicht auf den Ausgleich von Dioptrien abzielt) , tragen Sie bitte „0 " in das Antwortfeld ein.

Beantworten Sie diese Frage nur, wenn folgende Bedingungen erfüllt sind:
Antwort war 'ja' bei Frage '6 [FB1AS1]' (Verwenden Sie in diesem Moment für die Bearbeitung des Studienteils am Computerbildschirm eine Sehhilfe? (z.B. Brille, Kontaktlinsen))

❗ Nur Zahlen dürfen in diese Felder eingegeben werden.
Bitte geben Sie Ihre Antwort(en) hier ein:

Dioptrien linkes Auge ☐

Dioptrien rechtes Auge ☐

Aus welchem Material ist die Linse Ihrer Sehhilfe?

Beantworten Sie diese Frage nur, wenn folgende Bedingungen erfüllt sind:
Antwort war 'Kontaktlinsen' bei Frage '7 [FB1AS2]' (Welche Sehhilfe verwenden Sie in diesem Moment für die Bearbeitung des Studienteils am Computerbildschirm?)

❗ Bitte wählen Sie eine der folgenden Antworten:
Bitte wählen Sie nur eine der folgenden Antworten aus:

- ○ Glas
- ○ Kunststoff
- ○ weiß nicht
- ○ keine Angabe
- ○ Sonstiges ☐

Sind Ihre Kontaktlinsen...

Beantworten Sie diese Frage nur, wenn folgende Bedingungen erfüllt sind:
Antwort war 'Kunststoff' bei Frage '9 [FBAS4]' (Aus welchem Material ist die Linse Ihrer Sehhilfe?)

❗ Bitte wählen Sie eine der folgenden Antworten:
Bitte wählen Sie nur eine der folgenden Antworten aus:

○ hart
○ weich
○ weiß nicht
○ keine Angabe

3. Haben Sie einen Hochschul-/Fachhochschulabschluss? *

Bitte wählen Sie nur eine der folgenden Antworten aus:

○ ja
○ nein (Sie werden weitergeleitet zu Frage 6)
○ keine Angabe (Sie werden weitergeleitet zu Frage 6)

Falls Sie einen Hochschul-/Fachhochschulabschluss haben:

4. Welchen höchsten Hochschul-/Fachhochschulabschluss haben Sie?

Beantworten Sie diese Frage nur, wenn folgende Bedingungen erfüllt sind:
Antwort war 'ja' bei Frage '11 [FB1A3]' (3. Haben Sie einen Hochschul-/Fachhochschulabschluss?)

Bitte wählen Sie nur eine der folgenden Antworten aus:

○ Bachelor
○ Master, Diplom, Magister, Staatsprüfung, Lehramtsprüfung
○ Promotion
○ Habilitation
○ Sonstiges ☐

Falls Sie einen Hochschul-/Fachhochschulabschluss haben:

5. Welcher Fachrichtung gehört Ihr höchster Studienabschluss an?

(Mehrfachantworten möglich)

Beantworten Sie diese Frage nur, wenn folgende Bedingungen erfüllt sind:
Antwort war 'ja' bei Frage '11 [FB1A3]' (3. Haben Sie einen Hochschul-/Fachhochschulabschluss?)

Bitte wählen Sie alle zutreffenden Antworten aus:

☐ Gesundheitswissenschaften
☐ Humanmedizin/Zahnmedizin
☐ Naturwissenschaften
☐ Geisteswissenschaften
☐ Sozialwissenschaften
☐ Wirtschaftswissenschaften
☐ Sonstiges: ☐

6. Haben Sie sich schon einmal praktisch mit dem Gesundheitswesen befasst?

(z.B. Berufstätigkeit, Berufsausbildung, Nebentätigkeit z.B. als Wissenschaftliche Hilfskraft, Praktikum, Zivildienst, Ehrenamt, freiwilliges soziales Jahr)

*

Bitte wählen Sie nur eine der folgenden Antworten aus:

○ nein
○ ja, und zwar:

Bitte schreiben Sie einen Kommentar zu Ihrer Auswahl

☐

Falls Sie einen Hochschul-/Fachhochschulabschluss haben:

5. Welcher Fachrichtung gehört Ihr höchster Studienabschluss an?

(Mehrfachantworten möglich)

Beantworten Sie diese Frage nur, wenn folgende Bedingungen erfüllt sind:
Antwort war 'ja' bei Frage '11 [FB1A3]' (3. Haben Sie einen Hochschul-/Fachhochschulabschluss?)

Bitte wählen Sie alle zutreffenden Antworten aus:

☐ Gesundheitswissenschaften
☐ Humanmedizin/Zahnmedizin
☐ Naturwissenschaften
☐ Geisteswissenschaften
☐ Sozialwissenschaften
☐ Wirtschaftswissenschaften
☐ Sonstiges:

6. Haben Sie sich schon einmal praktisch mit dem Gesundheitswesen befasst?

(z.B. Berufstätigkeit, Berufsausbildung, Nebentätigkeit z.B. als Wissenschaftliche Hilfskraft, Praktikum, Zivildienst, Ehrenamt, freiwilliges soziales Jahr)

*

Bitte wählen Sie nur eine der folgenden Antworten aus:

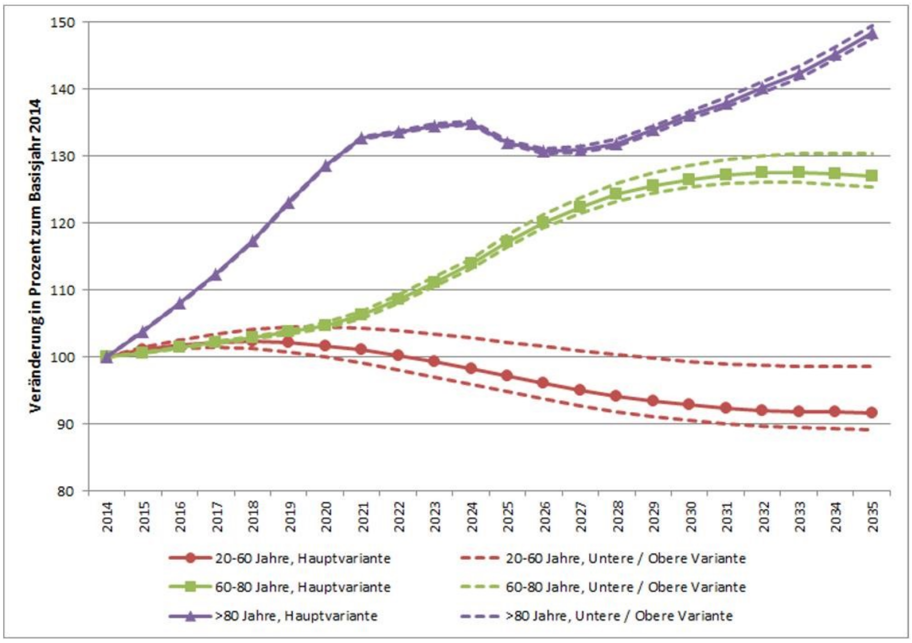
○ nein
○ ja, und zwar:

Bitte schreiben Sie einen Kommentar zu Ihrer Auswahl

Bitte kreuzen Sie an, inwiefern die folgenden Aussagen für Sie zutreffen. Wenn Sie unsicher sind, kreuzen Sie bitte die Kategorie an, die am ehesten zutrifft. *

Bitte wählen Sie die zutreffende Antwort für jeden Punkt aus:

	stimmt überhaupt nicht	**stimmt weitgehend nicht**	**stimmt eher nicht**	**stimmt ein wenig**	**stimmt weitgehend**	**stimmt genau**	**keine Angabe**
Ich probiere gerne Dinge aus, auch wenn nicht immer etwas dabei herauskommt.	○	○	○	○	○	○	○
Ich beschäftige mich nur mit Aufgaben, die lösbar sind.	○	○	○	○	○	○	○
Ich mag es, wenn unverhofft Überraschungen auftreten.	○	○	○	○	○	○	○
Ich lasse die Dinge gerne auf mich zukommen.	○	○	○	○	○	○	○
Ich habe es gerne, wenn die Arbeit gleichmäßig verläuft.	○	○	○	○	○	○	○
Ich warte geradezu darauf, dass etwas Aufregendes passiert.	○	○	○	○	○	○	○
Wenn um mich herum alles drunter und drüber geht, fühle ich mich so richtig wohl.	○	○	○	○	○	○	○
Ich weiß gerne, was auf mich zukommt.	○	○	○	○	○	○	○

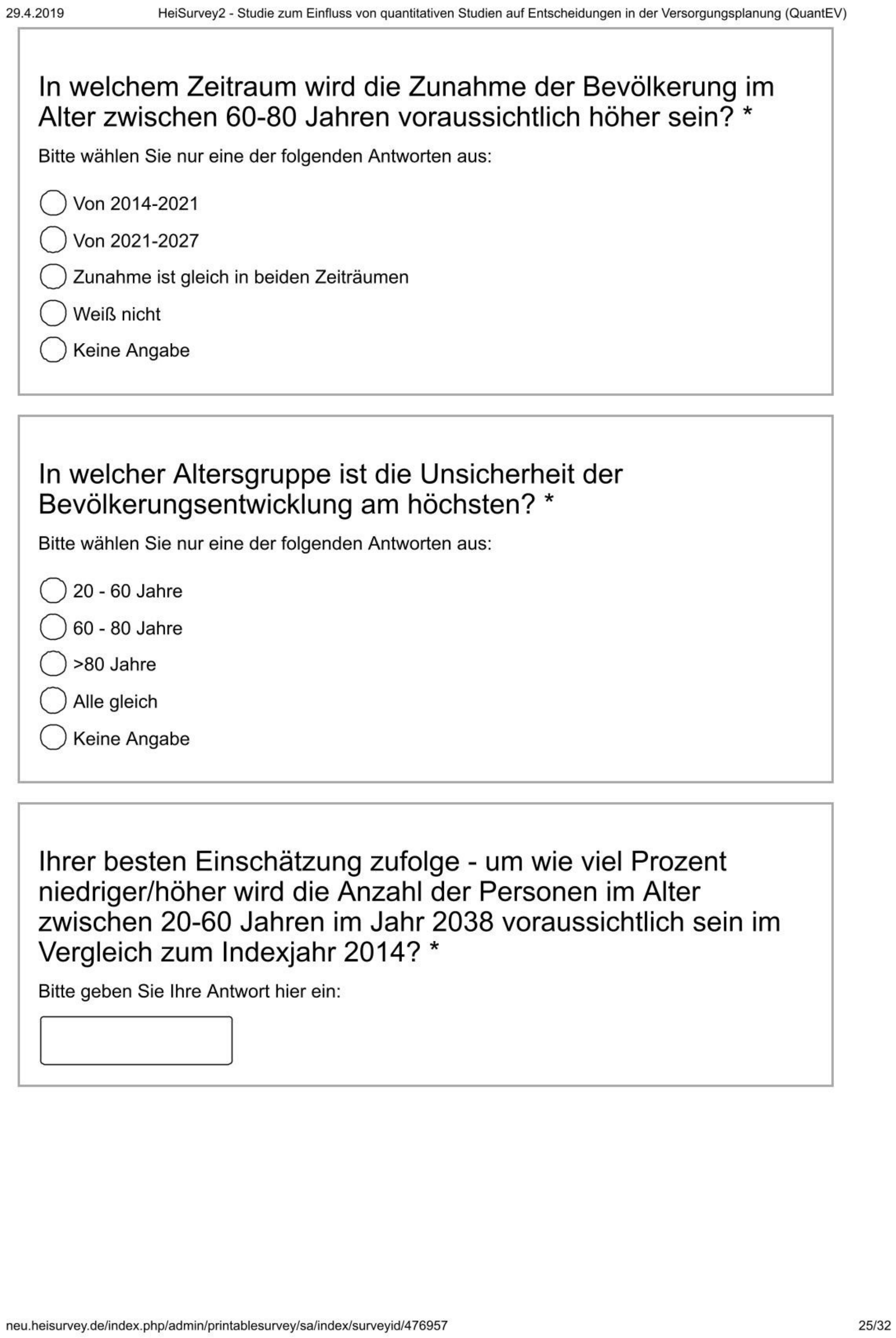


Im Vergleich zum Indexjahr 2014 - um wie viel Prozent niedriger/höher wird die Anzahl der Personen im Alter zwischen 20-60 Jahren im Jahr 2022 voraussichtlich sein? *

❗ In dieses Feld dürfen nur Zahlen eingegeben werden.

Bitte geben Sie Ihre Antwort hier ein:

☐



29.4.2019 HeiSurvey2 - Studie zum Einfluss von quantitativen Studien auf Entscheidungen in der Versorgungsplanung (QuantEV)

In welchem Zeitraum wird die Zunahme der Bevölkerung im Alter zwischen 60-80 Jahren voraussichtlich höher sein? *

Bitte wählen Sie nur eine der folgenden Antworten aus:

○ Von 2014-2021
○ Von 2021-2027
○ Zunahme ist gleich in beiden Zeiträumen
○ Weiß nicht
○ Keine Angabe

In welcher Altersgruppe ist die Unsicherheit der Bevölkerungsentwicklung am höchsten? *

Bitte wählen Sie nur eine der folgenden Antworten aus:

○ 20 - 60 Jahre
○ 60 - 80 Jahre
○ >80 Jahre
○ Alle gleich
○ Keine Angabe

Ihrer besten Einschätzung zufolge - um wie viel Prozent niedriger/höher wird die Anzahl der Personen im Alter zwischen 20-60 Jahren im Jahr 2038 voraussichtlich sein im Vergleich zum Indexjahr 2014? *

Bitte geben Sie Ihre Antwort hier ein:

☐

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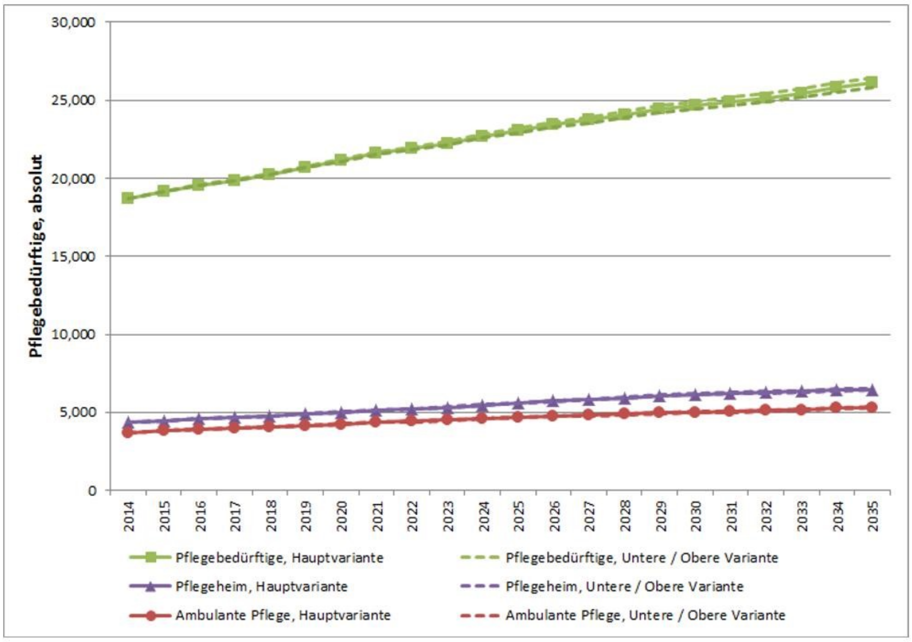
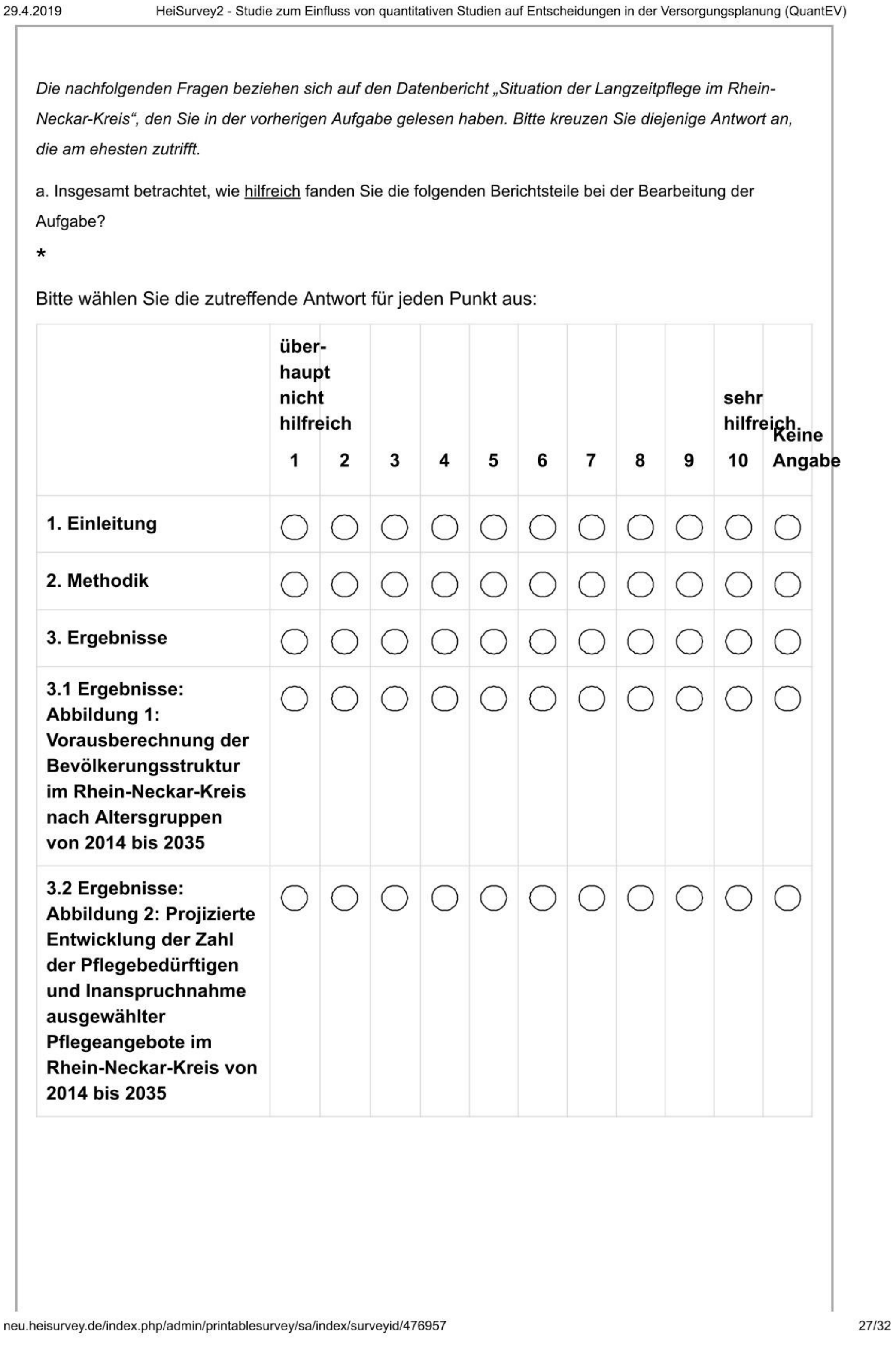
Wird im Zeitraum zwischen 2014 und 2035 voraussichtlich die Anzahl derjenigen stärker ansteigen, die ambulante Pflege in Anspruch nehmen oder die Anzahl der Pflegebedürftigen? *

Bitte wählen Sie nur eine der folgenden Antworten aus:

○ ambulante Pflege
○ Pflegebedürftige
○ die Anzahl steigt gleich stark an
○ weiß nicht
○ keine Angabe





29.4.2019 HeiSurvey2 - Studie zum Einfluss von quantitativen Studien auf Entscheidungen in der Versorgungsplanung (QuantEV)

Die nachfolgenden Fragen beziehen sich auf den Datenbericht „Situation der Langzeitpflege im Rhein-Neckar-Kreis“, den Sie in der vorherigen Aufgabe gelesen haben. Bitte kreuzen Sie diejenige Antwort an, die am ehesten zutrifft.

a. Insgesamt betrachtet, wie hilfreich fanden Sie die folgenden Berichtsteile bei der Bearbeitung der Aufgabe?

*

Bitte wählen Sie die zutreffende Antwort für jeden Punkt aus:

	überhaupt nicht hilfreich 1	2	3	4	5	6	7	8	9	sehr hilfreich 10	Keine Angabe
1. Einleitung	○	○	○	○	○	○	○	○	○	○	○
2. Methodik	○	○	○	○	○	○	○	○	○	○	○
3. Ergebnisse	○	○	○	○	○	○	○	○	○	○	○
3.1 Ergebnisse: Abbildung 1: Vorausberechnung der Bevölkerungsstruktur im Rhein-Neckar-Kreis nach Altersgruppen von 2014 bis 2035	○	○	○	○	○	○	○	○	○	○	○
3.2 Ergebnisse: Abbildung 2: Projizierte Entwicklung der Zahl der Pflegebedürftigen und Inanspruchnahme ausgewählter Pflegeangebote im Rhein-Neckar-Kreis von 2014 bis 2035	○	○	○	○	○	○	○	○	○	○	○

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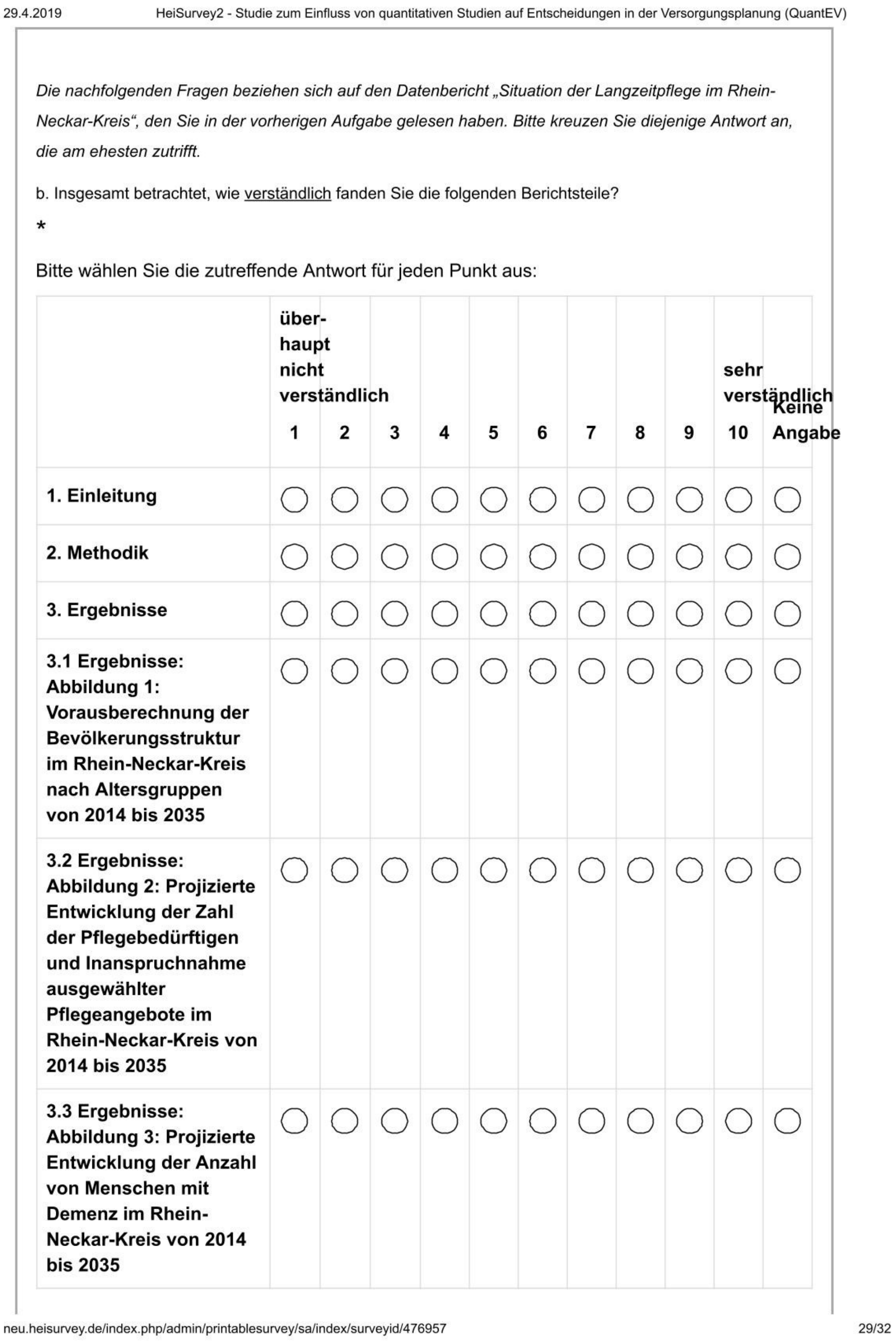
	über-haupt nicht hilfreich **1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**sehr hilfreich** **10**	**Keine Angabe**
3.3 Ergebnisse: Abbildung 3: Projizierte Entwicklung der Anzahl von Menschen mit Demenz im Rhein-Neckar-Kreis von 2014 bis 2035	○	○	○	○	○	○	○	○	○	○	○
3.4 Ergebnisse: Textliche Beschreibung	○	○	○	○	○	○	○	○	○	○	○
4. Diskussion und Schlussfolgerungen	○	○	○	○	○	○	○	○	○	○	○



29.4.2019 HeiSurvey2 - Studie zum Einfluss von quantitativen Studien auf Entscheidungen in der Versorgungsplanung (QuantEV)

Die nachfolgenden Fragen beziehen sich auf den Datenbericht „Situation der Langzeitpflege im Rhein-Neckar-Kreis“, den Sie in der vorherigen Aufgabe gelesen haben. Bitte kreuzen Sie diejenige Antwort an, die am ehesten zutrifft.

b. Insgesamt betrachtet, wie verständlich fanden Sie die folgenden Berichtsteile?

*

Bitte wählen Sie die zutreffende Antwort für jeden Punkt aus:

	über-haupt nicht verständlich **1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**sehr verständlich** **10**	**Keine Angabe**
1. Einleitung	○	○	○	○	○	○	○	○	○	○	○
2. Methodik	○	○	○	○	○	○	○	○	○	○	○
3. Ergebnisse	○	○	○	○	○	○	○	○	○	○	○
3.1 Ergebnisse: Abbildung 1: Vorausberechnung der Bevölkerungsstruktur im Rhein-Neckar-Kreis nach Altersgruppen von 2014 bis 2035	○	○	○	○	○	○	○	○	○	○	○
3.2 Ergebnisse: Abbildung 2: Projizierte Entwicklung der Zahl der Pflegebedürftigen und Inanspruchnahme ausgewählter Pflegeangebote im Rhein-Neckar-Kreis von 2014 bis 2035	○	○	○	○	○	○	○	○	○	○	○
3.3 Ergebnisse: Abbildung 3: Projizierte Entwicklung der Anzahl von Menschen mit Demenz im Rhein-Neckar-Kreis von 2014 bis 2035	○	○	○	○	○	○	○	○	○	○	○

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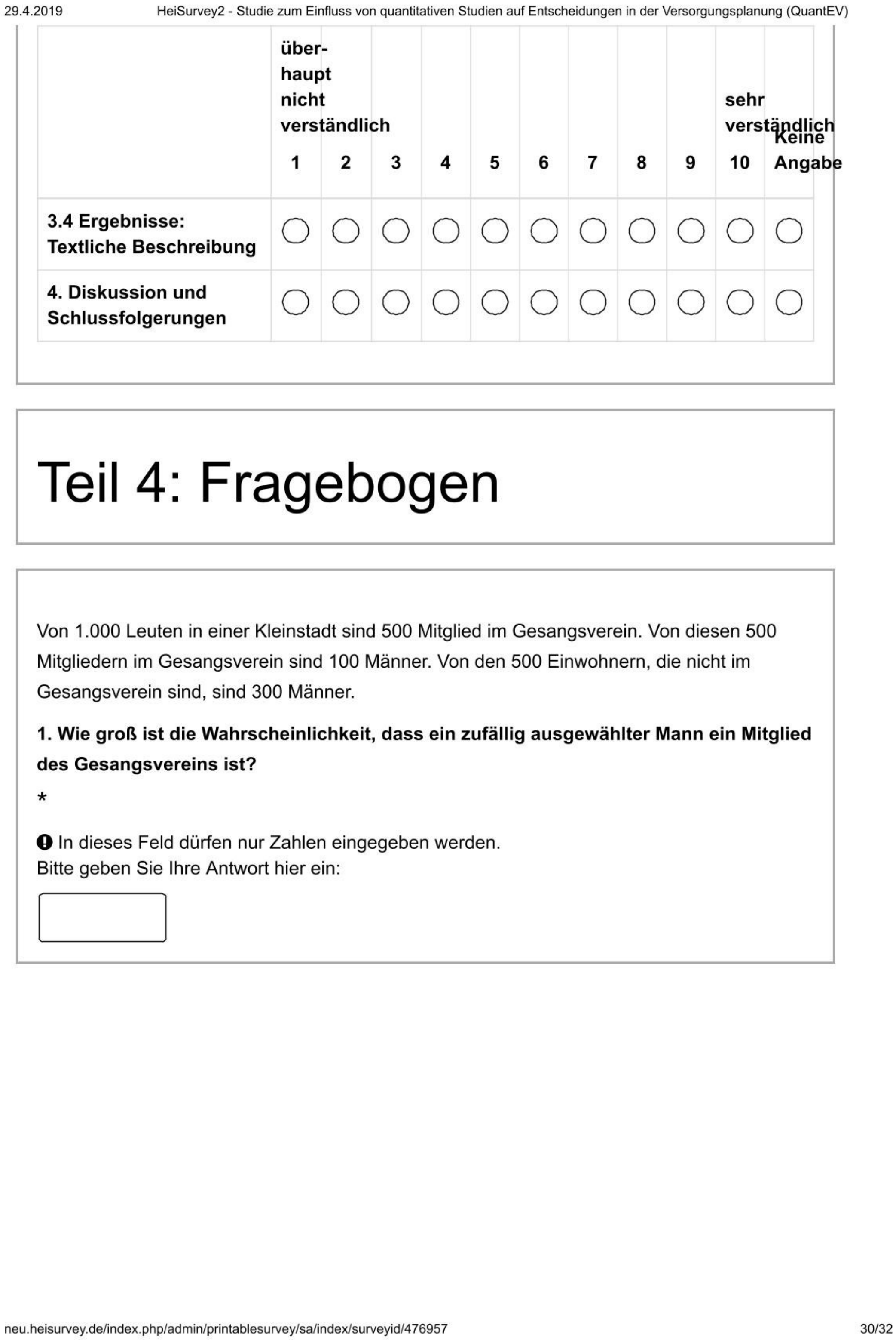


	über-haupt nicht verständlich **1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**sehr verständlich** **10**	**Keine Angabe**
3.4 Ergebnisse: Textliche Beschreibung	○	○	○	○	○	○	○	○	○	○	○
4. Diskussion und Schlussfolgerungen	○	○	○	○	○	○	○	○	○	○	○

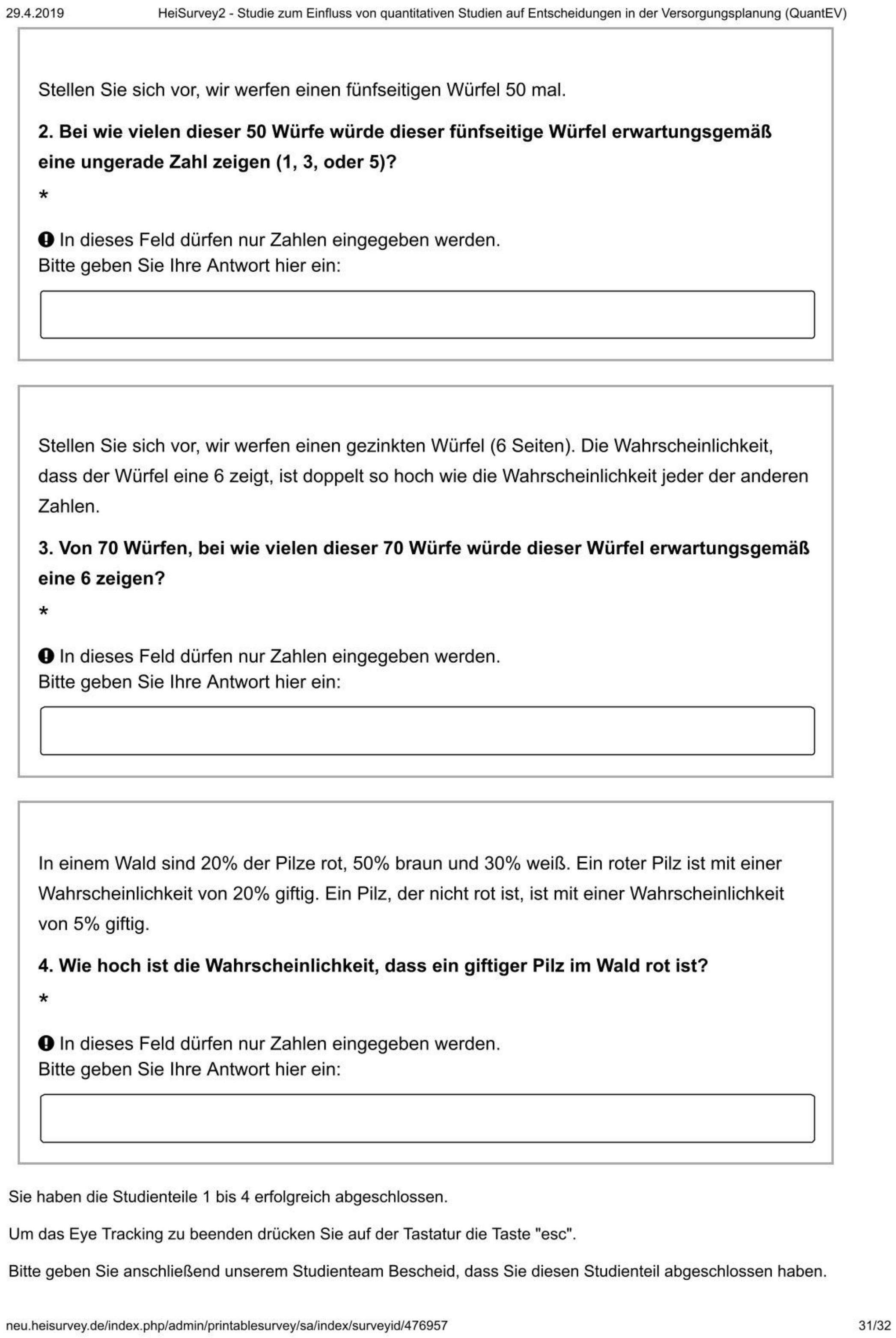
Teil 4: Fragebogen

Von 1.000 Leuten in einer Kleinstadt sind 500 Mitglied im Gesangsverein. Von diesen 500 Mitgliedern im Gesangsverein sind 100 Männer. Von den 500 Einwohnern, die nicht im Gesangsverein sind, sind 300 Männer.

1. Wie groß ist die Wahrscheinlichkeit, dass ein zufällig ausgewählter Mann ein Mitglied des Gesangsvereins ist?

*

❗ In dieses Feld dürfen nur Zahlen eingegeben werden.
Bitte geben Sie Ihre Antwort hier ein:



Stellen Sie sich vor, wir werfen einen fünfseitigen Würfel 50 mal.

2. Bei wie vielen dieser 50 Würfe würde dieser fünfseitige Würfel erwartungsgemäß eine ungerade Zahl zeigen (1, 3, oder 5)?

*

❗ In dieses Feld dürfen nur Zahlen eingegeben werden.
Bitte geben Sie Ihre Antwort hier ein:

Stellen Sie sich vor, wir werfen einen gezinkten Würfel (6 Seiten). Die Wahrscheinlichkeit, dass der Würfel eine 6 zeigt, ist doppelt so hoch wie die Wahrscheinlichkeit jeder der anderen Zahlen.

3. Von 70 Würfen, bei wie vielen dieser 70 Würfe würde dieser Würfel erwartungsgemäß eine 6 zeigen?

*

❗ In dieses Feld dürfen nur Zahlen eingegeben werden.
Bitte geben Sie Ihre Antwort hier ein:

In einem Wald sind 20% der Pilze rot, 50% braun und 30% weiß. Ein roter Pilz ist mit einer Wahrscheinlichkeit von 20% giftig. Ein Pilz, der nicht rot ist, ist mit einer Wahrscheinlichkeit von 5% giftig.

4. Wie hoch ist die Wahrscheinlichkeit, dass ein giftiger Pilz im Wald rot ist?

*

❗ In dieses Feld dürfen nur Zahlen eingegeben werden.
Bitte geben Sie Ihre Antwort hier ein:

Sie haben die Studienteile 1 bis 4 erfolgreich abgeschlossen.

Um das Eye Tracking zu beenden drücken Sie auf der Tastatur die Taste "esc".

Bitte geben Sie anschließend unserem Studienteam Bescheid, dass Sie diesen Studienteil abgeschlossen haben.

Part 1 – At the beginning of data collection

1. **Please state your year of birth.**
   Please enter your answer here:
   ☐

2. **What is your gender?**
   Please select only one of the following answers:
   ○ male
   ○ female
   ○ other
   ○ no answer

3. **Are you using a visual aid at this moment to work on the study part on the computer screen? (e.g. glasses, contact lenses)**
   Please select only one of the following answers:
   ○ yes
   ○ no
   ○ no answer

4. **Which visual aid are you using at this moment to work on the study part on the computer screen?**
   Answer this question only if the following conditions are met: Answer was 'yes' to question '3' (Are you using a visual aid at this moment to work on the study part on the computer screen? (e.g. glasses, contact lenses))
   Please select only one of the following answers:
   ○ *glasses*
   ○ *contact lenses*
   ○ *other* ☐

5. **How many diopters does your vision aid have?**
   Answer this question only if the following conditions are met: Answer was 'yes' to question '3' (Are you using a visual aid at this moment to work on the study part on the computer screen? (e.g. glasses, contact lenses))
   If you are not sure about the diopter values, we ask you to estimate which values could be the minimum. If you are still unable to find an answer or if this question does not apply to you (e.g. due to a visual aid that is not designed to compensate for diopters) please enter "0" in the answer field.
   Only numbers may be entered in these fields.
   Please enter your answer here:
   Diopters left eye
   ☐
   Diopters right eye
   ☐

6. **What material is the lens of your visual aid made of?**
Answer this question only if the following conditions are met:
Answer was 'contact lenses' in question '4 ' (Which visual aid are you using at this moment to work on the study part on the computer screen?)
Please select only one of the following answers:
   - ○ glass
   - ○ plastic
   - ○ don't know
   - ○ no answer
   - ○ other ☐

7. **Are your contact lenses...**
Answer this question only if the following conditions are met:
Answer was 'plastic' in question '6 ' (What material is the lens of your visual aid made of?)
Please select only one of the following answers:
   - ○ hard
   - ○ soft
   - ○ don't know
   - ○ no answer

8. **Do you have a university/non-university degree?**
Please select only one of the following answers:
   - ○ yes
   - ○ no
   - ○ no answer

9. **What is the highest university/non-university degree that you have attained?**
Answer this question only if the following conditions are met:
Answer was 'yes' in question '8 ' (Do you have a university/non-university?)
Please select only one of the following answers:
   - ○ bachelor's degree
   - ○ master, master's degree, state examination, teaching examination
   - ○ doctoral degree
   - ○ habilitation
   - ○ other ☐

10. **What is the field of study of your highest university/non-university degree?**
Answer this question only if the following conditions are met:
Answer was 'yes' in question '8 ' (Do you have a university/non-university?)
Please select all applicable answers:
   - ○ health sciences
   - ○ human medicine/dentistry
   - ○ natural sciences
   - ○ humanities
   - ○ social sciences
   - ○ economic sciences
   - ○ other ☐

11. Have you ever dealt with healthcare in practice?

(e.g. professional activity, vocational training, part-time work e.g. as a research assistant, internship, civilian service, honorary office, voluntary social year)

Please select only one of the following answers:

○ no
○ yes:
Please write a comment to your selection

12. If you summarize all activities, how long was that approximately?

Answer this question only if the following conditions are met:

Answer was 'yes' in question '11 ' (Have you ever dealt with healthcare in practice?)

Please enter your answer here:

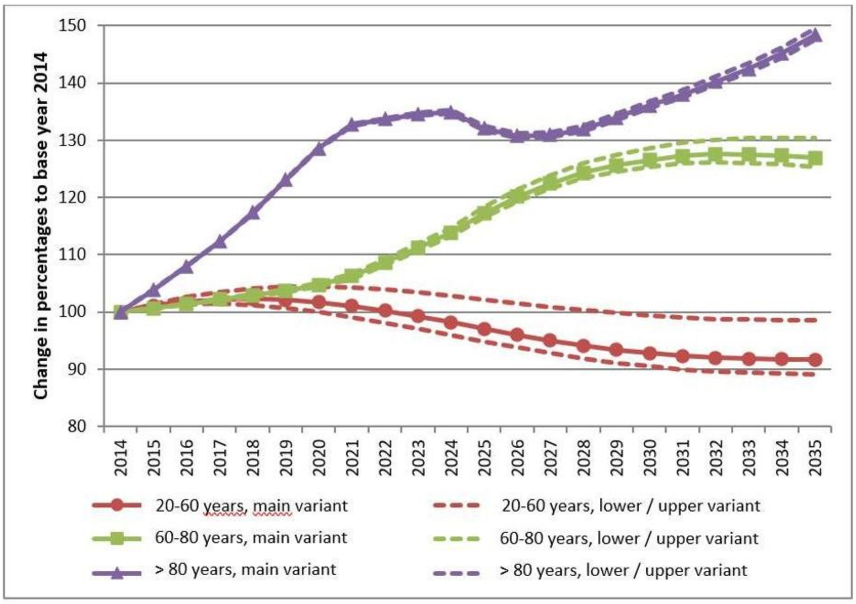
years

If you want to enter month details, please enter them as decimal numbers. Example: 3 months correspond to 0.25.

Please mark, which of the following statements apply to you. If you are unsure, please select the answer that applies most.

	is completely not true	is largely not true	is unlikely to be true	is a little bit true	is largely true	is true exactly	no answer
13.1 I like to try things out, even if something doesn't always come out of it.	○	○	○	○	○	○	○
13.2 I only deal with tasks that can be solved.	○	○	○	○	○	○	○
13.3 I like it when unexpected surprises occur.	○	○	○	○	○	○	○
13.4 I like to let things slide.	○	○	○	○	○	○	○
13.5 I like the work to be even.	○	○	○	○	○	○	○
13.6 I'm just waiting for something exciting to happen.	○	○	○	○	○	○	○
13.7 When everything goes haywire around me, I feel really good.	○	○	○	○	○	○	○
13.8 I like to know what's in store for me.	○	○	○	○	○	○	○

Part 2 – After decision and reading task



Compared to the index year 2014 - by how many percent lower/higher is the number of people aged 20-60 expected to be in 2022?

Only numbers may be entered in this field.

Please enter your answer here:

☐

15. **In which period is the increase of the population aged 60-80 years expected to be higher?**

    Please select only one of the following answers:

    - ○ from 2014 to 2021
    - ○ from 2021 to 2027
    - ○ increase is equal in both periods
    - ○ don't know
    - ○ no answer

16. **In which age group is the uncertainty of population development highest?**

    Please select only one of the following answers:

    - ○ 20 – 60 years
    - ○ 60 – 80 years

---

[1] Author's note: Questions no. 14 to 17 relate to figure 1. In the computer-assisted version of this questionnaire, questions no. 14 to 17 were displayed together only with figure 1.

- ○ > 80 years
- ○ all equal
- ○ don't know
- ○ no answer

17. According to your best estimate - by how many percent lower/higher is the number of people aged 20-60 expected to be in 2038 compared to the index year 2014?

Please enter your answer here:

☐

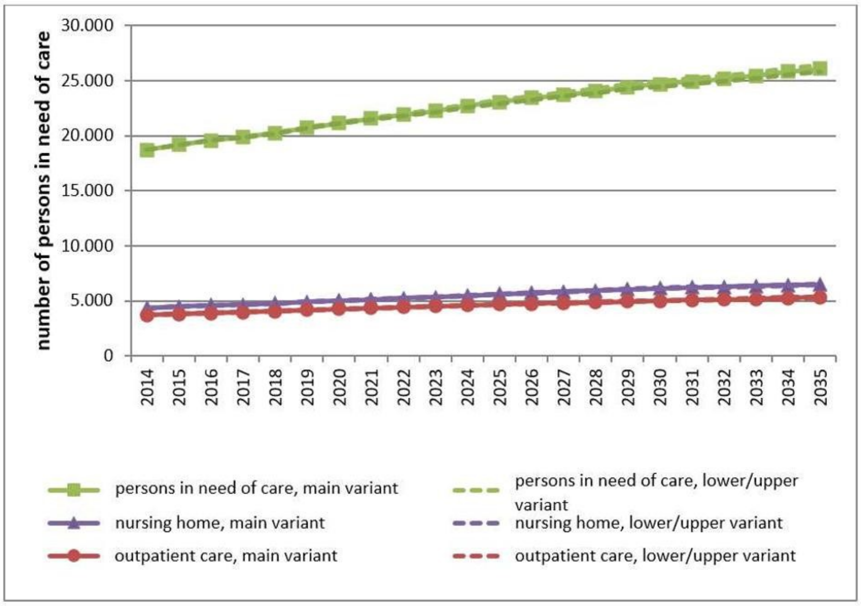


Figure 2[2]: Projected development of the number of persons in need of long-term care and use of selected care services in the Rhine-Neckar district from 2014 to 2035.

18. In the period between 2014 and 2035, is it likely that the number of persons using outpatient care or the number of persons in need of care will increase more strongly?

Please select only one of the following answers:

- ○ outpatient care

---

[2] Author's note: Question no. 18 relates to figure 2. In the computer-assisted version of this questionnaire, question no. 8 was displayed together only with figure 2.

- ○ persons in need of care
- ○ the number increases at the same rate
- ○ don't know
- ○ no answer

The following questions refer to the data report "Situation of long-term care in the Rhine-Neckar district", which you read in the previous task.

19. Overall, how <u>helpful</u> did you find the following parts of the report in completing the task?
Please select the appropriate answer for each item:

	not helpful at all 1	2	3	4	5	6	7	8	9	very helpful 10	no answer
1. Introduction	○	○	○	○	○	○	○	○	○	○	○
2. Methods	○	○	○	○	○	○	○	○	○	○	○
3. Results	○	○	○	○	○	○	○	○	○	○	○
3.1 Results: Figure 1:	○	○	○	○	○	○	○	○	○	○	○
3.2 Results: Figure 2: Projected development of the number of persons in need of long-term care and use of selected care services in the Rhine-Neckar district from 2014 to 2035	○	○	○	○	○	○	○	○	○	○	○
3.3 Results: Figure 3: Projected development of the number of people with dementia in the Rhine-Neckar district from 2014 to 2035	○	○	○	○	○	○	○	○	○	○	○
3.4 Results: Textual description	○	○	○	○	○	○	○	○	○	○	○
4. Discussion and conclusions	○	○	○	○	○	○	○	○	○	○	○

The following questions refer to the data report "Situation of long-term care in the Rhine-Neckar district", which you read in the previous task.

20. Overall, how <u>understandable</u> did you find the following parts of the report?
Please select the appropriate answer for each item:

	not understandable at all 1	2	3	4	5	6	7	8	9	very understandable 10	no answer
1. Introduction	○	○	○	○	○	○	○	○	○	○	○
2. Methods	○	○	○	○	○	○	○	○	○	○	○
3. Results	○	○	○	○	○	○	○	○	○	○	○
3.1 Results: Figure 1:	○	○	○	○	○	○	○	○	○	○	○
3.2 Results: Figure 2: Projected development of the number of persons in need of long-term care and use of selected care services in the Rhine-Neckar district from 2014 to 2035	○	○	○	○	○	○	○	○	○	○	○
3.3 Results: Figure 3: Projected development of the number of people with dementia in the Rhine-Neckar district from 2014 to 2035	○	○	○	○	○	○	○	○	○	○	○
3.4 Results: Textual description	○	○	○	○	○	○	○	○	○	○	○
4. Discussion and conclusions	○	○	○	○	○	○	○	○	○	○	○

21. **Out of 1,000 people in a small town 500 are members of a choir. Out of these 500 members in the choir 100 are men. Out of the 500 inhabitants that are not in the choir 300 are men. What is the probability that a randomly drawn man is a member of the choir?**
Only numbers may be entered in this field.
Please enter your answer here:

22. **Imagine we are throwing a five-sided die 50 times. On average, out of these 50 throws how many times would this five-sided die show an odd number (1, 3 or 5)?**
Only numbers may be entered in this field.
Please enter your answer here:

☐

23. **Imagine we are throwing a loaded die (6 sides). The probability that the die shows a 6 is twice as high as the probability of each of the other numbers. On average, out of these 70 throws, how many times would the die show *the* number 6?**
Only numbers may be entered in this field.
Please enter your answer here:
☐

24. **In a forest 20% of mushrooms are red, 50% brown and 30% white. A red mushroom is poisonous with a probability of 20%. A mushroom that is not red is poisonous with probability of 5%. What is the probability that a poisonous mushroom in the forest is red?**
Only numbers may be entered in this field.
Please enter your answer here:
☐

Appendix 5: Interview guide (study 3)

- Original language version (German)
- English version (translated)

Leitfaden

Einführung

- Bedanken für bisherige Teilnahme
- Vorstellung Studienteil: Umgang mit dem Bericht und der damit verbundenen Aufgabe (entscheiden zwischen drei Optionen)
- Vorgehen: Gespräch ca. 20 Minuten, Gespräch über persönliche Eindrücke und Sichtweisen, daher gibt es weder richtige noch falsche Antworten
- Vertraulichkeit und Datenschutz: Tonbandaufnahme (Gerät zeigen), alle persönlichen Daten werden anonymisiert, Transkription – danach löschen der Tonbandaufnahme, wiederholt auf Freiwilligkeit der Teilnahme hinweisen, Einverständnis wiederholt einholen (mündlich)
- Fragen des Interviewpartners

>>TESTAUFNAHME MACHEN

>>AUFNAHME STARTEN

Einstiegsfrage: Wie ist das eigentlich - unabhängig von heute - welche Berührungspunkte hatten Sie bisher zu solchen Berichten?

1 Als Sie vorhin den Bericht gelesen haben – was war so Ihr erster Eindruck?

- Was hat Ihnen gut gefallen?
  (Welches Beispiel fällt Ihnen dazu [noch] ein? / Wie meinen Sie das genau?)
- Was hat Ihnen weniger gut gefallen?
  (Welches Beispiel fällt Ihnen dazu [noch] ein? / Wie meinen Sie das genau?)

2 An so einen Bericht kann man ja ganz unterschiedlich rangehen. Manche lesen z.B. nur die Schlussfolgerung. Wie haben Sie das vorhin gemacht?

- Welchen Teilen im Bericht haben Sie besondere Aufmerksamkeit geschenkt?
  (Warum sind Sie so vorgegangen? / Wie meinen Sie das genau?)
- Wie ausführlich haben Sie sich mit Texten befasst?
  (Warum sind Sie so vorgegangen? / Wie meinen Sie das genau?)
- Wie ausführlich haben Sie sich mit Grafiken befasst?
  (Warum sind Sie so vorgegangen? / Wie meinen Sie das genau?)
- Und wie gehen Sie sonst so vor, wenn Sie einen Datenbericht lesen? So wie heute?

3 Bei dem Bericht vorhin sollten Sie sich ja für eine von drei Optionen entscheiden. Wie haben Sie den Bericht dabei berücksichtigt?

- Welche Informationen aus dem Bericht waren für Ihre Entscheidung wichtig?
  (Welcher Textabschnitt/Abbildung genau? / Warum genau war das für Sie wichtig?)
- Welche Informationen waren weniger wichtig?
  (Welche Abschnitte/Abbildungen meinen Sie genau? / Warum war das weniger/nicht wichtig für Sie?)
- Wann haben Sie sich für die Option entschieden?
  (Z.B. noch bevor Sie den Bericht gelesen haben, nachdem Sie einen Teil gelesen haben / Nach welchem Teil vom Bericht war das? / Was meinen Sie - warum haben Sie sich dann entschieden?)
- Was floss – unabhängig vom Bericht – in Ihre Entscheidungsfindung mit ein?
  (Können Sie das genauer erläutern? / Was war Ihnen sonst noch wichtig bei Ihrer Entscheidung?)

4 Wenn Sie Personen, die solche Datenberichte erstellen, drei Dinge für die nächsten Berichte mit auf den Weg geben könnten – was wäre das?

- Welche Informationen haben Sie gerne in Berichten?
  (Welche Art von Kennzahlen? / Wie sieht es mit Informationen zu Unsicherheit aus? / Welche Art von Aussagen? / Warum?)
- Wie sollten diese Informationen dargestellt sein?
  (Wie detailliert? / Wie sieht es mit Text aus / Wie sieht es mit Grafiken aus? / Welche Arten von Grafiken? / Wie sieht es mit Tabellen aus? / Warum?)

Abschlussfrage: Jetzt habe ich noch eine allerletzte Frage: Gibt es etwas zum Bericht, was wir nicht angesprochen haben, Sie uns aber gerne noch sagen möchten?

>>AUFNAHME BEENDEN

- Vielen Dank, dass Sie sich die Zeit für dieses Gespräch genommen haben!

Interview Guide

(translated from German to English language)

Introduction

- Thank you for participation so far
- Presentation of the study part: How to deal with the report and the associated task (decision between three options)
- Procedure: Conversation circa 20 minutes, conversation about personal impressions and views, therefore there are neither right nor wrong answers
- Confidentiality and data security: tape recording (show device), all personal data will be made anonymous, transcription - then delete the tape recording, repeatedly point out the voluntary nature of participation, repeatedly obtain consent (verbally)
- Questions of the interview partner

>>TEST RECORDING

>>START RECORDING

Introductory question: What is it actually like - independent of today - what points of contact have you had with such reports so far?

1 When you read the report earlier - what was your first impression?

- What did you like about it?
  (What other example comes to your mind? / What do you mean by that exactly?)
- What did you like less?
  (What other example comes to your mind? / What do you mean by that exactly?)

2 One can approach such a report in many different ways. For example, some people only read the conclusion. How did you do that earlier?

- Which parts of the report did you pay special attention to?
  (Why did you proceed in this way? / What do you mean exactly?)
- How extensively did you deal with texts?
  (Why did you proceed in this way? / What do you mean exactly?)
- How extensively have you dealt with graphics?
  (Why did you proceed in this way? / What do you mean exactly?)
- And how else do you proceed when reading a data report? Like today?

3 When you read the report earlier, you had to choose one of three options. How did you consider the report in your decision?

- Which information from the report was important for your decision?
  (Which text section/illustration exactly? / Why exactly was it important for you?)
- Which information was less important?
  (Which section/illustration do you mean exactly? / Why was that less / not important for you?)
- When did you decide on this option?
  (e.g. before you read the report, after you read a part / After which part of the report was that? / What do you think - why did you decide then?)
- What - independent of the report - was included in your decision making?
  (Can you explain this in more detail? / What else was important to you in your decision?)

4 If you could give three suggestions to people who produce such data reports for the next reports - what would they be?

- What information do you like to have in reports?
  (What kind of key figures? / What about information on uncertainty? / What kind of statements? / Why?)
- How should this information be presented?
  (How detailed? / What about text? / What about graphics? / What types of graphics? / What about tables? / Why?)

Final question: Now I have a very last question: Is there anything to report that we have not mentioned but you would like to tell us?

>> FINISH RECORDING

- Thank you very much for taking the time for this interview!

Appendix 6: Indicators identified in study 1 and their operationalisation

Table 22: Operationalisation of identified indicators on dementia and long-term care

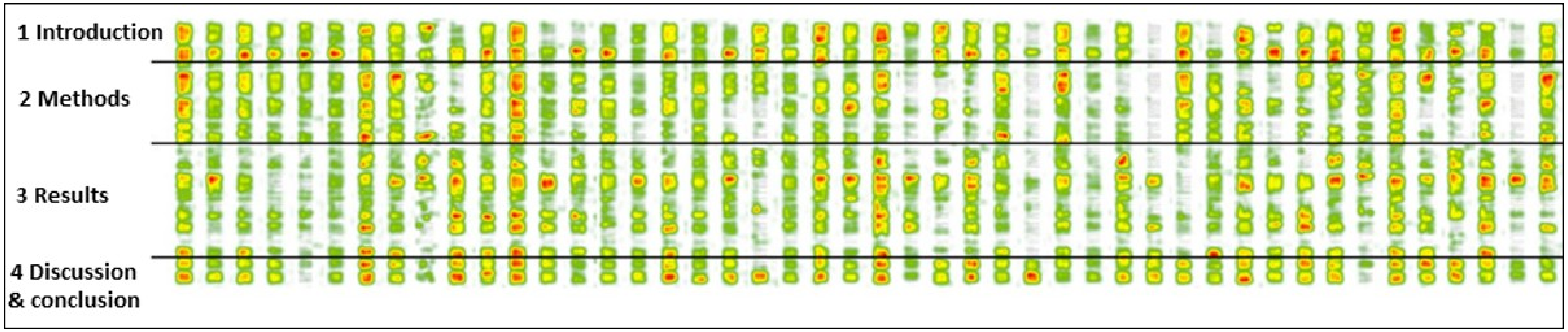
ID	Indicator name (German, original) *Indicator name (English, translated)*	Description and operationalisation of indicator	Data source (data holder)
43	Administrative Prävalenz Demenz *Administrative prevalence of dementia*	The indicator describes the proportion of the population diagnosed with dementia (ICD-10 codes F00.0, F00.1, F00.2, F00.9, F01.0, F01.1, F01.2, F01.3, F01.8, F01.9, F02.0, F02.1, F02.2, F02.3; F02.4, F02.8, F03, F05.1, G30.0, G30.1, G30.8, G30.9, G31.0, G31.82) in inpatient and/or outpatient care. Outpatient diagnoses were only considered if they were labelled as "confirmed" and were present in at least two quarters of the observation year. Inpatient diagnoses were only considered if they were either the main diagnosis or a secondary diagnosis in at least two hospitalisations within the observation year. Since the prevalence is based on administrative health data, it is also referred to as "administrative" prevalence. Administrative prevalence observed in administrative data was adjusted according to age (in years) and sex of a regions' inhabitants. The group of 90-year-old persons was not included in the adjustment in years of age but as an age group.	AOK Routinedatensatz zur Evaluation der HZV in Baden-Württemberg (AOK Baden-Württemberg); Fortschreibung des Bevölkerungsstandes (Statistisches Landesamt Baden-Württemberg https://www.statistikbw.de/)
53	Zahl der Pflegebedürftigen je Einwohner *Number of long-term care recipients per inhabitant*	The indicators represents the number of people with a level of care dependency as defined in SGB XI in relation to 100,000 inhabitants.	Pflegestatistik; Fortschreibung der Bevölkerung (Statistisches Landesamt Baden-Württemberg https://www.statistik-bw.de/)
54	Anzahl Pflegebedürftige nach Pflegestufe *Number of long-term care recipients by care level*	The indicator represents the number of long-term care recipients stratified by level of care dependency as defined in SGB XI with 0 "permanently significantly limited everyday competence", 1 "level of care dependency 1", 2 "level of care dependency 2", and 3 "level of care dependency 3".	Pflegestatistik (Statistisches Landesamt Baden-Württemberg https://www.statistik-bw.de/)
56	Häufigste Begleiterkrankungen Patientinnen und Patienten mit Demenz *Most common comorbidities in patients with dementia*	The indicator shows the three most common comorbidities diagnosed in patients with dementia according to the ICD-10. Diagnoses were measured on a three-digit-level of ICD-10 codes.	AOK Routinedatensatz zur Evaluation der HZV in Baden-Württemberg (AOK Baden-Württemberg)
80	Anzahl Pflegebedürftige in häußlicher Pflege	The indicator shows the number of people in need of care who receive outpatient care services and/or in-cash benefits as defined by SGB XI in relation to 1000 inhabitants.	Pflegestatistik (Statistisches Landesamt Baden-Württemberg https://www.statistik-bw.de/)

ID	**Indicator name (German, original)** ***Indicator name (English, translated)***	**Description and operationalisation of indicator**	**Data source (data holder)**
	Number of persons in need of long-term care receiving home care		
128	Auslastung verfügbarer Plätze in stationären Pflegeeinrichtungen in Prozent *Occupancy rate in percent of available places in residential nursing care facilities*	The indicator shows the occupancy rate of available places in all residential nursing care facilities located in the respective region.	Pflegestatistik (Statistisches Landesamt Baden-Württemberg https://www.statistik-bw.de/)
318	Einwohner je und Anzahl ambulante Pflegedienste (gesamt) *Inhabitants per and number of outpatient nursing facilities (total)*	The indicator shows inhabitants per and the number of outpatient nursing facilities offering long-term care services and other care services.	Pflegestatistik (Statistisches Landesamt Baden-Württemberg https://www.statistik-bw.de/)
319	Einwohner je und Anzahl ambulante Pflegedienste nur Leistungen nach SGB XI *Inhabitants per and number of outpatient nursing facilities (only services according to social code XI)*	The indicator shows inhabitants per and the number of outpatient nursing facilities which offer long-term care services (services according to SGB XI) only.	Pflegestatistik (Statistisches Landesamt Baden-Württemberg https://www.statistik-bw.de/)
341	Einwohner je und Anzahl Gesundheits- und Krankenpfleger und -pflegerinnen in ambulanten Pflegeeinrichtungen *Inhabitants per and number of nurses in outpatient nursing care facilities*	The indicator shows the number (in total and per inhabitants) of nursing staff in outpatient nursing facilities. Trainees are not included.	Pflegestatistik (Statistisches Landesamt Baden-Württemberg https://www.statistik-bw.de/)
342	Einwohner je und Anzahl Krankenpflegehelfer und -helferinnen in ambulanten Pflegeeinrichtungen	The indicator shows the number (in total and per inhabitants) of nursing assistants (nursing assistants and state-recognised recognised geriatric nursing assistants) in outpatient nursing facilities.	Pflegestatistik (Statistisches Landesamt Baden-Württemberg https://www.statistik-bw.de/)

ID	**Indicator name (German, original)** ***Indicator name (English, translated)***	**Description and operationalisation of indicator**	**Data source (data holder)**
	Inhabitants per and number of nursing assistants in outpatient nursing care facilities		
345	Einwohner je und Anzahl stationärer Pflegeeinrichtungen nach Art der Pflegeeinrichtung (z.B. Pflegestufen, Zielgruppen) *Inhabitants per and number of residential nursing care facilities by care facility type (e.g. level of care, target groups)*	The indicator shows the number (in total and per inhabitants) of inpatient nursing facilities in a region.	Pflegestatistik (Statistisches Landesamt Baden-Württemberg https://www.statistik-bw.de/)
346	Einwohner je und Anzahl verfügbarer Plätze in stationären Pflegeeinrichtungen nach Art der Pflegeeinrichtung *Inhabitants per and number of available places in residential nursing care facilities by care facility type*	The indicator shows the number of places available in residential nursing care facilities. These include, for example, nursing care places for full inpatient long-term care, places for short-term care and day and night care places.	Pflegestatistik (Statistisches Landesamt Baden-Württemberg https://www.statistik-bw.de/)

ID: identification number of the indicator

Appendix 7: Heatmaps of all participants from study 3



Average fixation duration in seconds over the 46 participants whose heatmaps are displayed above: red: 0.31 - more / yellow: 0.30 - 0.24 / green 0.23-less.

Figure 19: Heatmaps of all 46 participants (columns) after reading the data report (rows), scaled by fixation duration (in seconds) (Wronski et al. 2021b)

Danksagung

Besonderen Dank schulde ich Herrn Prof. Dr. Wensing. Ich danke für die Unterstützung bei der Themenerarbeitung dieser Arbeit, die ausgezeichnete Betreuung und sehr inspirierende Unterstützung meiner wissenschaftlichen Ausbildung. Vielen Dank auch für das hohe Maß an Geduld und entgegengebrachtes Vertrauen. Ich bin dankbar für die Zusammenarbeit, die meine wissenschaftliche Ausbildung sehr geprägt hat. Vielen Dank.

Herrn Dr. Koetsenruijter danke ich für seine große Hilfsbereitschaft, insbesondere bei statistischen Auswertungen. Es war eine sehr inspirierende und schöne Zeit der Zusammenarbeit, die ich nicht missen möchte. Bedanken möchte ich mich auch für die Motivation mit Rat und Tat an meiner Dissertation dranzubleiben. Des Weiteren bedanke ich mich auch für die persönliche Unterstützung durch das „Rücken freihalten“ in sämtlichen Lebenslagen, was mir sehr dabei half, die Dissertation fertigzustellen.

Frau Dr. Ghosh vom HITS danke ich sehr für die wunderbare Zusammenarbeit im QuantEV-Projekt und das Einbringen ihrer Erfahrung im Bereich des Eye-Tracking, ohne die das QuantEV-Projekt so nicht möglich gewesen wäre.

Herrn Prof. Dr. Szecsenyi danke ich insbesondere für die Möglichkeit an Teilprojekt 1 zu arbeiten und das dort entgegengebrachte Vertrauen.

Herr Priv.-Doz. Dr. Müller vom HITS danke ich für die Ermöglichung der Kooperation im Rahmen des QuantEV-Projektes.

Herrn Prof. Dr. Laux und Herrn Qreini danke ich für die Unterstützung bei meiner Einarbeitung zum Umgang mit dem HZV-Evaluationsdatensatz und die Unterstützung bei der Datenaufbereitung mit SQL.

Frau E. Schmidt danke ich persönlich sehr für die vielen virtuellen gemeinsamen Schreibtage, die mich zur Fertigstellung meiner Doktorarbeit motiviert haben.

Frau Dr. Charlotte Ullrich und Frau Dr. Poß-Doering danke ich für die Unterstützung bei der Entwicklung des Interviewleitfadens.

Zu guter Letzt danke ich Frau R. Schmidt und ihrem an Alzheimer erkranktem Mann für die Inspiration, überhaupt erst an dem Thema Demenz zu arbeiten.

Eidesstattliche Versicherung

Bei der eingereichten Dissertation zu dem Thema

From data need to data use: Exploring the potential of data use for equitable policymaking in long-term care for persons with dementia in the German state of Baden-Wuerttemberg

handelt es sich um meine eigenständig erbrachte Leistung.

2. Ich habe nur die angegebenen Quellen und Hilfsmittel benutzt und mich keiner unzulässigen Hilfe Dritter bedient. Insbesondere habe ich wörtlich oder sinngemäß aus anderen Werken übernommene Inhalte als solche kenntlich gemacht.

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