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## Informal and formal care preferences and expected willingness of providing elderly care in Germany: protocol for a mixed methods study

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5 **Informal and formal care preferences and expected willingness of providing**  
6 **elderly care in Germany: protocol for a mixed methods study**  
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## ABSTRACT

**Introduction:** In Germany, the number of elderly people in need of care is expected to increase from 2.4 million in 2015 to 3.2 million in 2030. The subsequent rise in demand for long-term care facilities is unlikely to be met by the current care structures and available staff. Additionally, many Germans still prefer to be cared for at home for as long as possible. In light of recent changes, such as increasing employment rates of women and growing geographical distances of family members, informal caregiving becomes more challenging in the future. The aim of this study is to explore preferences for informal and formal care services in the German general population, as well as the expected willingness of providing elderly care.

**Methods and analysis:** A mixed methods approach will be used to explore care preferences and expected willingness of providing elderly care in the German general population. A systematic literature review will be performed to provide an overview of the current academic literature on the topic. Qualitative interviews will be conducted with informal caregivers, care consultants and people with no prior caregiving experiences. A labelled discrete choice experiment will be designed and conducted to quantitatively measure the preferences for informal and formal care in the German general population. People between 18 and 65 years of age will be recruited in cooperation with a (regional) statutory health insurance (AOK Lower Saxony). A mixed multinomial logit regression model and a latent class finite-mixture model will be used to analyse the data and test for subgroup differences in care preferences.

**Ethics and dissemination:** The study has been approved by the Committee for Clinical Ethics of the Medical School in Hannover. Data will be treated confidential to ensure the participants anonymity. The results will be discussed and disseminated to relevant stakeholders in the field.

### Strengths and limitations of this study

- This is the first study based on a (labelled) discrete choice experiment design to elicit care preferences of the German general population, as well as the expected willingness of providing elderly care.
- However, the study focuses on the German general population. Transferability of the results need to be tested with transnational comparisons.

## INTRODUCTION

Demographic developments towards an increasingly ageing population place significant pressure on national health systems to adequately prepare for future challenges. More specifically, health systems will likely face growing healthcare costs due to rising numbers of chronic diseases and people in need of care, while reductions in revenues for long-term care insurance are expected as a consequence of lower birth rates [1]. The latest statistics for the year 2015 found that 2.4 million Germans aged 65 years and older were in need of care [2, 3]. While a need of care can arise at any age, we will only focus on elderly's growing dependency on care in this study. Future projections estimate an increase of people in need of care to 3.2 million by 2030 and 4.4 million by 2060 [3–5].

Of the currently 2.4 million elderly people in need of care, the majority of Germans are being cared for at home through relatives or friends and/or outpatient services [2, 6]. To exemplify, 79% of the age group 60 to 69 and 57% of elderly aged 90+ are being cared for at home [6]. It is often reported that the majority of people in need of care prefer to stay in their familiar surroundings for as long as possible to maintain a high degree of autonomy and their social ties [7, 8]. Home care is also encouraged by German health policy and political efforts, as it is less costly for the state and the social security system [9]. However, these political efforts do not necessarily coincide with the required support and incentives of providing care at home.

Different economic theories exist that aim to explain the decision to provide informal care. This needs to be seen against the background that several studies have stressed the extreme burden caregivers are under as a result of time-consuming and straining work [10, 11]. Others have also found positive outcomes of providing informal care, such as increased self-esteem [12]. In a model of altruistic behaviour, the benefits or utility of caregiving (e.g. increased self-esteem) need to outweigh the costs and burden to warrant the decision to provide informal care. Other behavioural models are based on strategic exchanges between parents and their children in the form of financial incentives for caregiving to explain the decision-making process [13].

In light of changing family dynamics, such as increasing employment rates of women and growing geographic distances of family members, some experts expect the rates of informal caregiving to decrease in the future [8, 9]. However, the subsequent increase in demand for long-term care facilities is unlikely to be met by the current number of facilities and qualified staff members. Thus, as informal caregiving will likely become more challenging to provide and with the number of people in need of care continuously increasing, sustainable solutions are needed.

## Aims

The objective of this study is to explore preferences for informal and formal (out-patient) care services in the German general population, as well as the expected willingness of providing elderly care. Firstly, we would like to survey the general population's preferences for informal and formal care services for their relative(s) in need of care. Secondly, we seek to explore any differences in preferences between an own hypothetical dependency on care compared to their relatives' need of care. Lastly, we look to find and provide recommendations on ways to optimise care by considering people's preferences. We will place particular emphasis on the analysis of subgroup differences in care preferences, such as age, gender, previous caregiving experiences, migration background or occupation. This study will be the first to use a discrete choice experiment as a validated stated preference method to measure the care preferences of the German general population. Analysing people's preferences presents an important source of information and indication towards better tailoring current care structures and payment systems.

## METHODS AND ANALYSIS

A mixed methods approach will be used to explore informal and formal care preferences and expected willingness of providing elderly care in Germany. In particular, a systematic literature review, face-to-face interviews and a discrete choice experiment (DCE) will be conducted to assess people's care preferences. Face-to-face interviews will be used to ascertain a range of experiences and explore challenges people face when it comes to caregiving. These insights will then be used to inform the design of the DCE. The ISPOR Guidelines for Good Research Practices for conjoint analysis in health will be followed for the DCE [14].

### Systematic literature review

To create a guideline for the qualitative interviews and design the DCE, we will perform a systematic literature review on published academic studies researching preferences for informal and formal care services. The review will be carried out in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [15]. The selection process will be based on pre-defined inclusion and exclusion criteria. The electronic databases PubMed, Scopus and Dimdi (German Institute of Medical Documentation and Information) will be used with a predefined search strategy. A list of search terms of the three main concepts "informal and formal care", "preferences" and "age of interest" will be created and connected with the Boolean operators AND and OR. Truncations (\*) will be used to find all forms of the word. English and German search terms will be employed in the database search. No specific timeframe will be set for the database search. After removing duplicates, two independent reviewers will perform the selection process. A first selection of

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3 articles will be based on screening the titles and abstracts. If the inclusion criteria are met, the full  
4 text of the articles will be read and checked for final inclusion. In case of disagreement, a third re-  
5 viewer will be consulted. The database search will additionally be complemented by hand searching  
6 the reference lists of the included literature. The quality of the systematic literature review will be  
7 tested with the PRISMA checklist [15].  
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### 10 **Face-to-face interviews**

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12 Semi-structured, guideline-based face-to-face interviews will be conducted in the region of Hanno-  
13 ver, Germany to explore people's views and caregiving preferences. Eligible interviewees will receive  
14 detailed information beforehand concerning the aim and scope of the study, as well as any data  
15 management issues. Interviews will only be conducted after a written informed consent was signed.  
16 For the interviews, informal caregivers, care consultants and people with no prior caregiving experi-  
17 ences will be recruited. For this purpose, primarily self-help groups, care consultancies and care sup-  
18 port points will be identified in the region of Hannover and subsequently contacted. Maximum varia-  
19 tion purposive sampling will be utilized to identify heterogeneous participants for the qualitative  
20 interviews [16]. Approximately 20 to 30 interviews will be conducted, however the total sample size  
21 will be based on the principle of theoretical saturation, meaning no new views on the topic are ex-  
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31 One experienced researcher will conduct all interviews to ensure homogeneity. The researcher will  
32 make sure beforehand that each participant is familiar with the study's aims and the voluntary na-  
33 ture of participating in it. The guideline will be used for each interview and continually revised to  
34 incorporate new points of interest identified during the interviews. Each interview will be audio-  
35 recorded and subsequently transcribed. In order to analyse the transcripts of the audio recording  
36 context-oriented, interviewees will be asked to fill out a questionnaire following the interview, dis-  
37 closing essential sociodemographic factors such as age, gender, profession, previous and/or current  
38 caregiving experiences as well as the geographical distance to the person in need of care. The  
39 planned expenditure of time is set at 30 minutes, as the target audience of informal caregivers is  
40 unlikely to be able to spare too much time for participating in interviews.  
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48 The guideline interview questions will be based on information collected by means of the systematic  
49 literature review. To test the comprehensibility of the interview questions, a group of experts and  
50 randomly selected lay people will be consulted. During the interviews, we will ask participants about  
51 the current structure of care they provide and if this type of care reflects their wishes as well as the  
52 wishes of the person in need of care. We additionally seek to know perceived challenges of providing  
53 care and any observed effects on their time and cost structure. One central question will be people's  
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3 wishes and preferences for their own hypothetical care and any perceived differences to the provi-  
4 sion of care for their relatives. An interesting sub-question at this point will be the responsibility for  
5 providing care, i.e. if people perceive this to be a familial or societal obligation. In the execution of  
6 care, we seek to ask people's preferences for care provided by other people versus potential tech-  
7 nical support. Furthermore, we will ask people for suggestions for improving the current care struc-  
8 ture in Germany.  
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### 12 **Interview analysis**

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15 With the permission of each participant, all interviews will be recorded, transcribed and subsequent-  
16 ly analysed. All transcripts will be entered into MAXQDA Version 11 and reviewed line by line. For the  
17 analysis of the transcripts, a qualitative content analysis will be performed by two independent re-  
18 searchers based on Mayring [17]. The content analysis will take on a directed approach, making use  
19 of deductive categories identified in the interview guide, while at the same time leaving room for  
20 further inductive categories generated during the analysis [18]. A codebook will additionally be cre-  
21 ated. Findings will be crucial in informing the design of the DCE, in particular the generation of at-  
22 tributes for the DCE.  
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### 28 **Discrete choice experiment**

#### 29 Description of the DCE

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32 The DCE is a stated preference method, combining knowledge from random utility theory, experi-  
33 mental design theory, consumer theory and econometric analysis [19]. The method of DCE has been  
34 increasingly applied and deemed useful in the field of healthcare research to elicit people's prefer-  
35 ences [20]. In a DCE, people are asked to choose between two or more alternative scenarios. The  
36 underlying assumptions of a DCE are that any intervention or service looked at can be described by  
37 its attributes or characteristics and that people value these attributes differently depending on their  
38 levels [21]. The attributes and its different levels are then comprised to several scenarios, of which  
39 people are asked to choose one based on their preference. This method enables an inferability to the  
40 relative importance and value people place on different attributes, as these need to make trade-offs  
41 between the several attributes and their levels in their decision-making process [14].  
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#### 48 Design of the DCE

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51 We will perform a DCE to measure the care preferences in the German general population. In the  
52 process of constructing an optimal or nearly optimal experimental design, two statistical issues need  
53 to be examined. Namely, identification meaning the ability to obtain independent and unbiased pa-  
54 rameter estimates and efficiency as the precision with which such effects are estimated [22]. Several  
55 authors argue that design identification should take priority, as efficiency can be improved later by  
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3 for instance increasing the sample size. However, identification errors in the design cannot be altered  
4 retrospectively and are likely to produce biased and confounded results [22–24]. Statistical efficiency  
5 and response efficiency need to be balanced to maximise the precision of parameter estimates [25].  
6 We will use the D-efficiency criterion as a measure of statistical efficiency, while blocking certain  
7 choice sets will be used to increase response efficiency by reducing the information load of partici-  
8 pants. A full factorial design is generally regarded as an optimal design to estimate all main effects as  
9 well as all interaction effects. However, a full factorial design is rarely feasible depending on the final  
10 number of attributes and levels. Thus, we might have to opt for the largest possible fractional facto-  
11 rial design with a high D-efficiency. We will use the Statistical Analysis Software (SAS) to construct the  
12 choice sets of the DCE. We chose to construct a labelled DCE for our study, which uses specific labels  
13 or titles for the different alternatives, thus already conveying information to the study participants.  
14 For this study, the label “type of care” will be used, categorised into “only informal care”, “mix of  
15 informal and formal/out-patient care” and “only formal/out-patient care”. While labelled DCEs are  
16 currently less frequently used in health economics, alternatives will be less abstract and more realis-  
17 tic for respondents, adding to the validity of the results [26].  
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27 Results from the systematic literature review, as well as the interviews, will be used to establish the  
28 attributes for the DCE. In total, four to six attributes will be created on the basis of their relevance to  
29 the research question and decision context [14]. In the creation of the attributes, particular focus will  
30 be placed on the independence of attributes. We would like to respectively include at least one at-  
31 tribute connected to cost (or time). Other potential attributes might be quality of care or retention of  
32 autonomy. With the selection of included attributes, the corresponding range of levels for each at-  
33 tribute will also be decided on and discussed with experts. No opt-out option will be included in the  
34 profiles to ensure the complete estimation of preference structures and trade-offs made between  
35 choice sets. Additionally, the option of not providing needed care is no realistic scenario in this case.  
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#### 41 42 Data collection and sampling strategy 43

44 For the sample, people between 18 and 65 years of age will be recruited from the German general  
45 population with no own need of care. Study participants will be recruited in cooperation with a statu-  
46 tory health insurance (AOK Lower Saxony) by random selection of insured Germans in the chosen age  
47 range. Particular attention will be placed on the population group 45 to 64 years of age, as they most  
48 likely have own informal caregiving experiences. The primary mode of administration will be a mail  
49 survey. Study participants will receive detailed information about the study and the data manage-  
50 ment plan beforehand. Data will only be used after written informed consent by all study partici-  
51 pants. Based on first estimations, the targeted sample size is approximately 250 per questionnaire  
52 version [27]. Calculating with two questionnaire versions and estimating with a response rate of 1/3,  
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3 we would send out about 1,500 questionnaires. To verify these first estimations, we will use the  
4 sample size calculations by de Bekker-Grob et al. (2015). This approach consists of five elements that  
5 are deemed necessary for calculating the required sample size of a DCE. Particularly, the significance  
6 level, the statistical power, the statistical model used in the DCE, initial beliefs about parameter val-  
7 ues and the DCE design itself are needed [19].  
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11 Once all the attributes, descriptions and levels, as well as the different choice sets have been estab-  
12 lished, we will perform a pre-test ( $n = 20$ ) to make sure the questionnaire is understandable for study  
13 participants. Next to the understanding of attributes and their levels, we will also test the length and  
14 complexity of the DCE questionnaire. A rationality test will be included in the survey to make sure  
15 study participants understand the questions. After making any necessary adjustments to the ques-  
16 tionnaire following the pre-test, we will be able to send out the final survey. Next to the DCE choice  
17 sets, we will ask participants to disclose a number of important sociodemographic factors, as well as  
18 provide an assessment of their perceived quality of life. This data will then be used in the analysis of  
19 the questionnaires. To measure the quality of life of study participants, we will use the instrument  
20 WHOQOL-BREF, consisting of 26 items in total [28]. This instrument is a valid and reliable abbreviated  
21 version of the WHOQOL-100 questionnaire and covers the domains physical health, psychological  
22 health, social relationships and environment [28]. To reduce the burden on participants, we might  
23 opt for asking only certain excerpts of the instrument.  
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### 32 **Data analysis of DCE**

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34 Following data collection, we will analyse the data with descriptive statistics and conduct several  
35 logistic regression analyses to determine factors that influenced the choices made by the study par-  
36 ticipants. The core of the statistical analysis rests on the random utility theory, in which choices can  
37 be divided into an explainable component and a random component and people's preferences are  
38 summarised by their utility function [19]. The random component can be due to different types of  
39 error, unobservable attributes or preference variation [22]. The assumption is that people choose the  
40 option with the highest utility. For the multivariate analyses, we will use a mixed multinomial logit  
41 regression model and a latent class finite-mixture model. Both multivariate analyses are appropriate  
42 to compare subgroups and see if factors such as gender, age and previous caregiving experience in-  
43 fluence the choices made. We chose to perform a multinomial logit model, as our dependent varia-  
44 ble (type of care) has more than two levels. Additionally, we will conduct a latent class finite-mixture  
45 model, which allows the identification of latent classes or subgroups within the sample with different  
46 preference weights [29]. With the statistical analyses, we aim to investigate if certain sociodemo-  
47 graphic characteristics or previous caregiving experiences influence the choices made by the study  
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3 participants with regard to care preferences. The statistical program R will be used to perform all  
4 statistical analyses.  
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## 6 **ETHICAL CONSIDERATIONS AND DISSEMINATION**

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8 The study has been approved by the Medizinische Hochschule Hannover (MHH)'s Committee for  
9 Clinical Ethics (Reference number 09.05.17/La). Additionally, the study has been registered at the  
10 German Registry of Clinical Trials (DRKS) and is already visible on the WHO International Clinical Trials  
11 Registry Platform. A contact person will be provided for all participants in the event of questions or  
12 later withdrawal from the study. The results of the study will be discussed and disseminated to rele-  
13 vant stakeholders in the field. Important experts are for instance payers, care providers and lobby-  
14 ists. Outcomes in the form of recommendations regarding a more efficient use of the limited re-  
15 sources available will also be made by taking into consideration the preferences of the German gen-  
16 eral population. We will subsequently publish the results in peer-reviewed scientific journals.  
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## 23 **DISCUSSION**

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25 Elderly people in need of care are expected to increase from 2.4 million in 2015 to 4.4 million in 2060  
26 due to changing demographics, rising numbers of multi-morbidities and increasing life expectancy. Of  
27 the 4.4 million elderly Germans in need of care in 2060, the group aged 80+ is projected to make up  
28 74% in total [3]. At the same time, current demographic and societal changes will likely make infor-  
29 mal caregiving more challenging in the future and the subsequent demand for long-term care facili-  
30 ties is unlikely to be met. To reduce the growing expenses of the long-term care insurance in Germa-  
31 ny, political efforts have previously encouraged informal caregiving and the use of out-patient ser-  
32 vices to prolong caregiving at home. In the most recent care support act of 2017, the state increased  
33 monetary support for caregiving at home and aimed to facilitate the agreement of caregiving and  
34 professional responsibilities for informal caregivers. However, insufficient research has been done in  
35 Germany to see if political efforts match the wishes and needs of informal caregivers and to repre-  
36 sentatively measure the preferences of (potential) informal caregivers.  
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45 The results from this study will provide an important source of information towards improving the  
46 German care structures and payment systems to accommodate future demographic and societal  
47 trends. Our analysis will address the aims of this study by providing estimates of the importance of  
48 each attribute/care characteristic for the overall preference of the type of care. Additionally, the  
49 study will provide an indication to which extent people are willing to trade-off between attributes.  
50 Several logistic regression models will be used to analyse subgroup differences in preferences, such  
51 as socio-demographic factors, previous informal caregiving experiences or migrant background. The  
52 outputs of the study will be critically discussed and disseminated to stakeholders in the field to spark  
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3 political debate. Suggested solutions will be made to improve the current care structures and use  
4 available resources more efficiently. Available care services for informal caregivers can be improved  
5 preference-based to further encourage and facilitate caregiving at home. Additionally, the surveyed  
6 willingness to provide care and willingness to pay for services of the German general population can  
7 be used to better tailor existing services. This study will be the first in Germany to use a (labelled)  
8 DCE to elicit people's preferences for care characteristics such as time and cost.  
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For peer review only

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**Author's contributions**

LDJ was responsible for drafting the manuscript. All authors approved the final study design and were involved in revising the manuscript.

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**Competing interests**

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# BMJ Open

## Informal and formal care preferences and expected willingness of providing elderly care in Germany: protocol for a mixed methods study

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5 **Informal and formal care preferences and expected willingness of providing**  
6 **elderly care in Germany: protocol for a mixed methods study**  
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## ABSTRACT

**Introduction:** In Germany, the number of elderly people in need of care is expected to increase from 2.4 million in 2015 to 3.2 million in 2030. The subsequent rise in demand for long-term care facilities is unlikely to be met by the current care structures and available staff. Additionally, many Germans still prefer to be cared for at home for as long as possible. In light of recent changes, such as increasing employment rates of women and growing geographical distances of family members, informal caregiving becomes more challenging in the future. The aim of this study is to explore preferences for informal and formal care services in the German general population, as well as the expected willingness of providing elderly care.

**Methods and analysis:** A mixed methods approach will be used to explore care preferences and expected willingness of providing elderly care in the German general population. A systematic literature review will be performed to provide an overview of the current academic literature on the topic. Qualitative interviews will be conducted with informal caregivers, care consultants and people with no prior caregiving experiences. A labelled discrete choice experiment will be designed and conducted to quantitatively measure the preferences for informal and formal care in the German general population. People between 18 and 65 years of age will be recruited in cooperation with a (regional) statutory health insurance (AOK Lower Saxony). A mixed multinomial logit regression model and a latent class finite-mixture model will be used to analyse the data and test for subgroup differences in care preferences.

**Ethics and dissemination:** The study has been approved by the Committee for Clinical Ethics of the Medical School in Hannover. Data will be treated confidential to ensure the participants anonymity. The results will be discussed and disseminated to relevant stakeholders in the field.

### Strengths and limitations of this study

- This is the first study based on a (labelled) discrete choice experiment design to elicit care preferences of the German general population, as well as the expected willingness of providing elderly care.
- However, the study focuses on the German general population. Transferability of the results need to be tested with transnational comparisons.

## INTRODUCTION

Demographic developments towards an increasingly ageing population place significant pressure on national health systems to adequately prepare for future challenges. More specifically, health systems will likely face growing healthcare costs due to rising numbers of chronic diseases and people in need of care, while reductions in revenues for long-term care insurance are expected as a consequence of lower birth rates [1]. The latest statistics for the year 2015 found that 2.4 million Germans aged 65 years and older were in need of care [2, 3]. While a need for care can arise at any age, we will only focus on elderly's growing dependency on care in this study. Future projections estimate an increase of people in need of care to 3.2 million by 2030 and 4.4 million by 2060 [3–5].

Of the currently 2.4 million elderly people in need of care, the majority of Germans are being cared for at home through relatives or friends (informal care) and/or outpatient services [2, 6]. To exemplify, 79% of the age group 60 to 69 and 57% of elderly aged 90+ are being cared for at home [6]. It is often reported that the majority of people in need of care prefer to stay in their familiar surroundings for as long as possible to maintain a high degree of autonomy and their social ties [7, 8]. Home care is also encouraged by German health policy and political efforts, as it is less costly for the state and the social security system [9]. However, these political efforts do not necessarily coincide with the required support and incentives of providing care at home.

Different economic theories exist that aim to explain the decision to provide informal care. This needs to be seen against the background that several studies have stressed the extreme burden caregivers are under as a result of time-consuming and straining work [10, 11]. Others have also found positive outcomes of providing informal care, such as increased self-esteem [12]. In a model of altruistic behaviour, the benefits or utility of caregiving (e.g. increased self-esteem) need to outweigh the costs and burden to warrant the decision to provide informal care. Other behavioural models are based on strategic exchanges between parents and their children in the form of financial incentives for caregiving to explain the decision-making process [13]. Studies have found determining factors of making use of home care services to include having children, previous experience in providing informal care, as well as the proximity of family resources [8, 13–15].

In light of changing family dynamics, such as increasing employment rates of women and growing geographic distances of family members, while male labour participation and involvement as informal caregivers has remained nearly consistent, some experts expect the rates of informal caregiving to decrease in the future [8, 9]. However, the subsequent increase in demand for long-term care facilities is unlikely to be met by the current number of facilities and qualified staff members [9]. Thus, as informal caregiving will likely become more challenging to provide and with the number of people in need of care continuously increasing, sustainable solutions are needed.

## Aims

The objective of this study is to explore preferences for informal and formal (out-patient) care services in the German general population, as well as the expected willingness of providing elderly care. Firstly, we would like to survey the general population's preferences for providing informal and formal care services for their relative(s) in need of care. Secondly, we seek to explore any differences in preferences between an own hypothetical dependency on care compared to their relatives' need for care. Lastly, we look to find and provide recommendations on ways to optimise care by considering people's preferences. We will place particular emphasis on the analysis of subgroup differences in care preferences, such as age, gender, previous caregiving experiences, migration background or occupation. This study will be the first to use a discrete choice experiment (DCE) as a validated stated preference method to measure the caregiving preferences of the German general population [16, 17]. Analysing people's preferences presents an important source of information and indication towards better tailoring current care structures and payment systems.

## METHODS AND ANALYSIS

A mixed methods approach will be used to explore informal and formal care preferences and expected willingness of providing elderly care in Germany. In particular, a systematic literature review, face-to-face interviews and a DCE will be conducted to assess people's care preferences. Face-to-face interviews will be used to ascertain a range of experiences and explore challenges people face when it comes to caregiving. These insights will then be used to inform the design of the DCE. The ISPOR Guidelines for Good Research Practices for conjoint analysis in health will be followed for the DCE [18].

### Systematic literature review

To create a guideline for the qualitative interviews and design the DCE, we will perform a systematic literature review on published academic studies researching preferences for informal and formal care services. The review will be carried out in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [19]. The selection process will be based on pre-defined inclusion and exclusion criteria. The electronic databases PubMed, Scopus and Dimdi (German Institute of Medical Documentation and Information) will be used with a predefined search strategy. A list of search terms of the four main concepts "informal and formal care", "long term care", "preferences" and "age of interest" will be created and connected with the Boolean operators AND and OR. Truncations (\*) will be used to find all forms of the word. English and German search terms will be employed in the database search. No specific timeframe will be set for the database search. After removing duplicates, two independent reviewers will perform the selection process. A

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3 first selection of articles will be based on screening the titles and abstracts. If the inclusion criteria  
4 are met, the full text of the articles will be read and checked for final inclusion. In case of disagree-  
5 ment, a third reviewer will be consulted. The database search will additionally be complemented by  
6 hand searching the reference lists of the included literature. The quality of the systematic literature  
7 review will be tested with the PRISMA checklist [19].  
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### 10 11 **Face-to-face interviews**

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13 Semi-structured, guideline-based face-to-face interviews will be conducted in the region of Hanno-  
14 ver, Germany to explore people's views and caregiving preferences. Eligible interviewees will receive  
15 detailed information beforehand concerning the aim and scope of the study, as well as any data  
16 management issues. Interviews will only be conducted after a written informed consent was signed.  
17 For the interviews, informal caregivers, care consultants and people with no prior caregiving experi-  
18 ences will be recruited. For this purpose, primarily self-help groups, care consultancies and care sup-  
19 port points will be identified in the region of Hannover and subsequently contacted. Maximum varia-  
20 tion purposive sampling will be utilized to identify heterogeneous participants for the qualitative  
21 interviews [20]. The total sample size will be based on the principle of theoretical saturation, mean-  
22 ing no new views on the topic are expressed [21].  
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30 One experienced researcher (LDJ) will conduct all interviews to ensure homogeneity. The researcher  
31 will make sure beforehand that each participant is familiar with the study's aims and the voluntary  
32 nature of participating in it. The guideline will be used for each interview and continually revised to  
33 incorporate new points of interest identified during the interviews. Each interview will be audio-  
34 recorded and subsequently transcribed. In order to analyse the transcripts of the audio recording  
35 context-oriented, interviewees will be asked to fill out a questionnaire following the interview, dis-  
36 closing essential sociodemographic factors such as age, gender, profession, previous and/or current  
37 caregiving experiences as well as the geographical distance to the person in need of care. The  
38 planned expenditure of time is set at 30 minutes, as the target audience of informal caregivers is  
39 unlikely to be able to spare too much time for participating in interviews.  
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47 The guideline interview questions will be based on information collected by means of the systematic  
48 literature review. To test the comprehensibility of the interview questions, a group of experts and  
49 randomly selected lay people will be consulted. During the interviews, we will ask participants about  
50 the current structure of care they provide and if this type of care reflects their wishes as well as the  
51 wishes of the person in need of care. We additionally seek to know perceived challenges of providing  
52 care and any observed effects on their time and cost structure. One central question will be people's  
53 wishes and preferences for their own hypothetical care and any perceived differences to the provi-  
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3 sion of care for their relatives. An interesting sub-question at this point will be the responsibility for  
4 providing care, i.e. if people perceive this to be a familial or societal obligation. In the execution of  
5 care, we seek to ask people's preferences for care provided by other people versus potential tech-  
6 nical support. Furthermore, we will ask people for suggestions for improving the current care struc-  
7 ture in Germany.  
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### 10 **Interview analysis**

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12 With the informed consent of each participant, all interviews will be recorded, transcribed and sub-  
13 sequently analysed. All transcripts will be entered into MAXQDA Version 11 and reviewed line by  
14 line. For the analysis of the transcripts, a qualitative content analysis will be performed by two inde-  
15 pendent researchers based on Mayring [22]. The content analysis will take on a directed approach,  
16 making use of deductive categories identified in the interview guide, while at the same time leaving  
17 room for further inductive categories generated during the analysis of the interview transcripts [23].  
18 A codebook will additionally be created for the two researchers performing the analysis. Findings will  
19 be crucial in informing the design of the DCE, in particular the generation of attributes for the DCE.  
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### 26 **Discrete choice experiment**

#### 27 Description of the DCE

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29 The DCE is a stated preference method, combining knowledge from random utility theory, experi-  
30 mental design theory, consumer theory and econometric analysis [24]. The method of DCE has been  
31 increasingly applied and deemed useful in the field of healthcare research to elicit people's prefer-  
32 ences [25, 26]. In a DCE, people are asked to choose between two or more alternative scenarios. The  
33 underlying assumptions of a DCE are that any intervention or service looked at can be described by  
34 its attributes or characteristics and that people value these attributes differently depending on their  
35 levels [27]. The attributes and its different levels are then comprised to several scenarios, of which  
36 people are asked to choose one based on their preference. This method enables an inferability to the  
37 relative importance and value people place on different attributes, as these need to make trade-offs  
38 between the several attributes and their levels in their decision-making process [18].  
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#### 46 Design of the DCE

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48 We will conduct a DCE to measure the caregiving preferences in the German general population. In  
49 the process of constructing an optimal or nearly optimal experimental design, two statistical issues  
50 need to be examined. Namely, identification meaning the ability to obtain independent and unbiased  
51 parameter estimates and efficiency as the precision with which such effects are estimated [17]. Sev-  
52 eral authors argue that design identification should take priority, as efficiency can be improved later  
53 by for instance increasing the sample size. However, identification errors in the design cannot be  
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3 altered retrospectively and are likely to produce biased and confounded results [17, 28, 29]. Statisti-  
4 cal efficiency and response efficiency need to be balanced to maximise the precision of parameter  
5 estimates [30]. We will use the D-efficiency criterion as a measure of statistical efficiency, while  
6 blocking certain choice sets will be used to increase response efficiency by reducing the information  
7 load of participants. The D-efficiency criterion has been increasingly used to measure statistical effi-  
8 ciency when aiming to create optimal designs with an efficiency of 100%. Thus, we will create choice  
9 sets that minimise the D-error, which respectively maximises the D-efficiency [26, 28]. A full factorial  
10 design is generally regarded as an optimal design to estimate all main effects as well as all interaction  
11 effects. However, a full factorial design is rarely feasible depending on the final number of attributes  
12 and levels. Thus, we might have to opt for the largest possible fractional factorial design with a high  
13 D-efficiency. We will use the Statistical Analysis Software (SAS) to construct the choice sets of the  
14 DCE. We chose to construct a labelled DCE for our study, which uses specific labels or titles for the  
15 different alternatives, thus already conveying information to the study participants. For this study,  
16 the label “type of care” will be used, categorised into “only informal care”, “mix of informal and for-  
17 mal/out-patient care” and “only formal/out-patient care”. While labelled DCEs are currently less  
18 frequently used in health economics, alternatives will be less abstract and more realistic for respond-  
19 ents, adding to the validity of the results [31].

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30 Results from the systematic literature review, as well as the interviews, will be used to establish the  
31 attributes for the DCE. In total, four to six attributes will be created on the basis of their relevance to  
32 the research question and decision context [18]. In the creation of the attributes, particular focus will  
33 be placed on the independence of attributes. We would like to respectively include at least one at-  
34 tribute connected to cost (or time). The willingness to pay for services will be integrated as an attrib-  
35 ute in the DCE. Other potential attributes might be quality of care or retention of autonomy. With  
36 the selection of included attributes, the corresponding range of levels for each attribute will also be  
37 decided on and discussed with experts. No opt-out option will be included in the profiles to ensure  
38 the complete estimation of preference structures and trade-offs made between choice sets. Addi-  
39 tionally, the option of not providing needed care is no realistic scenario in this case.

#### 40 41 42 43 44 45 46 Data collection and sampling strategy

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49 For the sample, people between 18 and 65 years of age will be recruited from the German general  
50 population with no own need for care. The aim of the age limit is the ascertainability of a group of  
51 people of working age with no own dependency on care. Occupational and familial obligations are  
52 expected to influence the individual willingness to provide care for relatives. Study participants will  
53 be recruited in cooperation with a statutory health insurance (AOK Lower Saxony) by random selec-  
54 tion of insured Germans in the chosen age range. Particular attention will be placed on the popula-  
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3 tion group 45 to 64 years of age, as they most likely have own informal caregiving experiences. The  
4 primary mode of administration will be a mail survey. Study participants will receive detailed infor-  
5 mation about the study and the data management plan beforehand. Data will only be used after  
6 written informed consent by all study participants. In accordance with the new European General  
7 Data Protection Regulation, the statutory health insurance will be in charge of recruitment and con-  
8 tacting potential study participants. We will only receive the filled out questionnaires of study partic-  
9 ipants after written informed consent has been obtained. All personal data, i.e. sociodemographic  
10 characteristics, will be provided to us in a pseudonymised manner [32]. Based on first estimations,  
11 the targeted sample size is approximately 250 per questionnaire version [33]. Calculating with two  
12 questionnaire versions and estimating with a response rate of 1/3, we would send out about 1,500  
13 questionnaires. To verify these first estimations, we will use the sample size calculations by de Bek-  
14 ker-Grob et al. (2015). This approach consists of five elements that are deemed necessary for calcu-  
15 lating the required sample size of a DCE. Particularly, the significance level, the statistical power, the  
16 statistical model used in the DCE, initial beliefs about parameter values and the DCE design itself are  
17 needed [24].

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Once all the attributes, descriptions and levels, as well as the different choice sets have been estab-  
lished, we will perform a pre-test ( $n = 20$ ) to make sure the questionnaire is understandable for study  
participants. Next to the understanding of attributes and their levels, we will also test the length and  
complexity of the DCE questionnaire. A rationality test will be included in the survey to make sure  
study participants understand the questions. After making any necessary adjustments to the ques-  
tionnaire following the pre-test, we will be able to send out the final survey. Next to the DCE choice  
sets, we will ask participants to disclose a number of important sociodemographic factors, as well as  
provide an assessment of their perceived quality of life. This data will then be used in the analysis of  
the questionnaires. To measure the health-related quality of life of study participants, we will use the  
standardised EQ-5D-5L instrument, consisting of the five dimensions mobility, self-care, usual activi-  
ties, pain/discomfort and anxiety/depression. Next to the descriptive system of the instrument, com-  
prised of the five dimensions with five severity levels each, respondents will also be asked to judge  
their current health state on a visual analogue scale from 0 to 100 [34].

### **Data analysis of DCE**

Following data collection, we will analyse the data with descriptive statistics and conduct several  
logistic regression analyses to determine factors that influenced the choices made by the study par-  
ticipants. We will analyse and compare the distribution of mean age and sex between the included  
respondents of the DCE and the people who did not respond. The core of the statistical analysis rests  
on the random utility theory, in which choices can be divided into an explainable component and a

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3 random component and people's preferences are summarised by their utility function [24]. The ran-  
4 dom component can be due to different types of error, unobservable attributes or preference varia-  
5 tion [17]. The assumption is that people choose the option with the highest utility. For the multivari-  
6 ate analyses, we will use a mixed multinomial logit regression model and a latent class finite-mixture  
7 model. Both multivariate analyses are appropriate to compare subgroups and see if factors such as  
8 gender, age and previous caregiving experience influence the choices made. We chose to perform a  
9 multinomial logit model, as our dependent variable (type of care) has more than two levels. Addi-  
10 tionally, we will conduct a latent class finite-mixture model, which allows the identification of latent  
11 classes or subgroups within the sample with different preference weights [35]. With the statistical  
12 analyses, we aim to investigate if certain sociodemographic characteristics or previous caregiving  
13 experiences influence the choices made by the study participants with regard to care preferences.  
14 The statistical program R will be used to perform all statistical analyses.

### 21 22 **Patient and Public Involvement**

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24 The development of the research question and outcome measures were informed by the current  
25 demographic changes and political efforts in Germany, as well as the lack of preference studies in the  
26 field of elderly care in Germany. No patients or members of the public were involved in the design of  
27 the study. The public will be involved during the design of the questionnaire, as well as the conduc-  
28 tion of the DCE. The results of the face-to-face interviews will be sent and disseminated to the study  
29 participants. The results of the systematic literature review and the DCE will be published in open-  
30 access journals.

### 36 **ETHICAL CONSIDERATIONS AND DISSEMINATION**

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38 The study has been approved by the Medizinische Hochschule Hannover (MHH)'s Committee for  
39 Clinical Ethics (Reference number 09.05.17/La). Additionally, the study has been registered at the  
40 German Registry of Clinical Trials (DRKS) and is already visible on the WHO International Clinical Trials  
41 Registry Platform. A contact person will be provided for all participants in the event of questions or  
42 later withdrawal from the study. The results of the study will be discussed and disseminated to rele-  
43 vant stakeholders in the field. Important experts are for instance payers, care providers and lobby-  
44 ists. Outcomes in the form of recommendations regarding a more efficient use of the limited re-  
45 sources available will also be made by taking into consideration the preferences of the German gen-  
46 eral population. We will subsequently publish the results in peer-reviewed scientific journals.

### 53 **DISCUSSION**

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55 Elderly people in need of care are expected to increase from 2.4 million in 2015 to 4.4 million in 2060  
56 due to changing demographics, rising numbers of multi-morbidities and increasing life expectancy. Of  
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3 the 4.4 million elderly Germans in need of care in 2060, the group aged 80+ is projected to make up  
4 74% in total [3]. At the same time, current demographic and societal changes will likely make informal  
5 caregiving more challenging in the future and the subsequent demand for long-term care facilities  
6 is unlikely to be met. To reduce the growing expenses of the long-term care insurance in Germany,  
7 political efforts have previously encouraged informal caregiving and the use of out-patient services  
8 to prolong caregiving at home. In the most recent care support act of 2017, the state increased  
9 monetary support for caregiving at home and aimed to facilitate the agreement of caregiving and  
10 professional responsibilities for informal caregivers. However, insufficient research has been done in  
11 Germany to see if political efforts match the wishes and needs of informal caregivers and to representatively  
12 measure the preferences of (potential) informal caregivers.  
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19 The results from this study will provide an important source of information towards improving the  
20 German care structures and payment systems to accommodate future demographic and societal  
21 trends. Our analysis will address the aims of this study by providing estimates of the importance of  
22 each attribute/care characteristic for the overall preference of the type of care. Additionally, the  
23 study will provide an indication to which extent people are willing to trade-off between attributes.  
24 Several logistic regression models will be used to analyse subgroup differences in preferences, such  
25 as socio-demographic factors, previous informal caregiving experiences or migrant background. The  
26 outputs of the study will be critically discussed and disseminated to stakeholders in the field to spark  
27 political debate. Suggested solutions will be made to improve the current care structures and use  
28 available resources more efficiently. Available care services for informal caregivers can be improved  
29 preference-based to further encourage and facilitate caregiving at home. Additionally, the surveyed  
30 willingness to provide care and willingness to pay for services of the German general population can  
31 be used to better tailor existing services. This study will be the first in Germany to use a (labelled)  
32 DCE to elicit people's caregiving preferences for care characteristics such as time and cost.  
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**Author's contributions**

LDJ, KD, MP and JZ were involved in the design of the study. JTS and SE were responsible for the design of the recruitment process. LDJ was responsible for drafting the manuscript. All authors approved the final study design and were involved in revising the manuscript. All authors agree to be accountable for all aspects of the work.

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**Competing interests**

The authors report no conflicts of interest.

# BMJ Open

## Informal and formal care preferences and expected willingness of providing elderly care in Germany: protocol for a mixed methods study

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## ABSTRACT

**Introduction:** In Germany, the number of elderly people in need of care is expected to increase from 2.4 million in 2015 to 3.2 million in 2030. The subsequent rise in demand for long-term care facilities is unlikely to be met by the current care structures and available staff. Additionally, many Germans still prefer to be cared for at home for as long as possible. In light of recent changes, such as increasing employment rates of women and growing geographical distances of family members, informal caregiving becomes more challenging in the future. The aim of this study is to explore preferences for informal and formal care services in the German general population, as well as the expected willingness of providing elderly care.

**Methods and analysis:** A mixed methods approach will be used to explore care preferences and expected willingness of providing elderly care in the German general population. A systematic literature review will be performed to provide an overview of the current academic literature on the topic. Qualitative interviews will be conducted with informal caregivers, care consultants and people with no prior caregiving experiences. A labelled discrete choice experiment will be designed and conducted to quantitatively measure the preferences for informal and formal care in the German general population. People between 18 and 65 years of age will be recruited in cooperation with a (regional) statutory health insurance (AOK Lower Saxony). A mixed multinomial logit regression model and a latent class finite-mixture model will be used to analyse the data and test for subgroup differences in care preferences.

**Ethics and dissemination:** The study has been approved by the Committee for Clinical Ethics of the Medical School in Hannover. Data will be treated confidential to ensure the participants anonymity. The results will be discussed and disseminated to relevant stakeholders in the field.

### Strengths and limitations of this study

- This is the first study based on a (labelled) discrete choice experiment design to elicit care preferences of the German general population, as well as the expected willingness of providing elderly care.
- This method enables an inferability to the relative importance and value people place on different care characteristics, as they need to make trade-offs between a number of attributes and their levels in deciding between two hypothetical care scenarios.
- Results can be used to better tailor existing care structures and payment systems in Germany.
- However, the study focuses on the German general population. Transferability of the results need to be tested with transnational comparisons.
- The design of the discrete choice experiment demands participants to make decisions based on what they think and thus might not predict real behaviours.

## INTRODUCTION

Demographic developments towards an increasingly ageing population place significant pressure on national health systems to adequately prepare for future challenges. More specifically, health systems will likely face growing healthcare costs due to rising numbers of chronic diseases and people in need of care, while reductions in revenues for long-term care insurance are expected as a consequence of lower birth rates [1]. The latest statistics for the year 2015 found that 2.4 million Germans aged 65 years and older were in need of care [2, 3]. While a need for care can arise at any age, we will only focus on elderly's growing dependency on care in this study. Future projections estimate an increase of people in need of care to 3.2 million by 2030 and 4.4 million by 2060 [3–5].

Of the currently 2.4 million elderly people in need of care, the majority of Germans are being cared for at home through relatives or friends (informal care) and/or outpatient services [2, 6]. To exemplify, 79% of the age group 60 to 69 and 57% of elderly aged 90+ are being cared for at home [6]. It is often reported that the majority of people in need of care prefer to stay in their familiar surroundings for as long as possible to maintain a high degree of autonomy and their social ties [7, 8]. Home care is also encouraged by German health policy and political efforts, as it is less costly for the state and the social security system [9]. However, these political efforts do not necessarily coincide with the required support and incentives of providing care at home.

Different economic theories exist that aim to explain the decision to provide informal care. This needs to be seen against the background that several studies have stressed the extreme burden caregivers are under as a result of time-consuming and straining work [10, 11]. Others have also found positive outcomes of providing informal care, such as increased self-esteem [12]. In a model of altruistic behaviour, the benefits or utility of caregiving (e.g. increased self-esteem) need to outweigh the costs and burden to warrant the decision to provide informal care. Other behavioural models are based on strategic exchanges between parents and their children in the form of financial incentives for caregiving to explain the decision-making process [13]. Studies have found determining factors of making use of home care services to include having children, previous experience in providing informal care, as well as the proximity of family resources [8, 13–15].

In light of changing family dynamics, such as increasing employment rates of women and growing geographic distances of family members, while male labour participation and involvement as informal caregivers has remained nearly consistent, some experts expect the rates of informal caregiving to decrease in the future [8, 9]. However, the subsequent increase in demand for long-term care facilities is unlikely to be met by the current number of facilities and qualified staff members [9]. Thus, as informal caregiving will likely become more challenging to provide and with the number of people in need of care continuously increasing, sustainable solutions are needed.

## Aims

The objective of this study is to explore preferences for informal and formal (out-patient) care services in the German general population, as well as the expected willingness of providing elderly care. Firstly, we would like to survey the general population's preferences for providing informal and formal care services for their relative(s) in need of care. Secondly, we seek to explore any differences in preferences between an own hypothetical dependency on care compared to their relatives' need for care. Lastly, we look to find and provide recommendations on ways to optimise care by considering people's preferences. We will place particular emphasis on the analysis of subgroup differences in care preferences, such as age, gender, previous caregiving experiences, migration background or occupation. This study will be the first to use a discrete choice experiment (DCE) as a validated stated preference method to measure the caregiving preferences of the German general population [16, 17]. Analysing people's preferences presents an important source of information and indication towards better tailoring current care structures and payment systems.

## METHODS AND ANALYSIS

A mixed methods approach will be used to explore informal and formal care preferences and expected willingness of providing elderly care in Germany. In particular, a systematic literature review, face-to-face interviews and a DCE will be conducted to assess people's care preferences. Face-to-face interviews will be used to ascertain a range of experiences and explore challenges people face when it comes to caregiving. These insights will then be used to inform the design of the DCE. The ISPOR Guidelines for Good Research Practices for conjoint analysis in health will be followed for the DCE [18].

### Systematic literature review

To create a guideline for the qualitative interviews and design the DCE, we will perform a systematic literature review on published academic studies researching preferences for informal and formal care services. The review will be carried out in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [19]. The selection process will be based on pre-defined inclusion and exclusion criteria. The electronic databases PubMed, Scopus and Dimdi (German Institute of Medical Documentation and Information) will be used with a predefined search strategy. A list of search terms of the four main concepts "informal and formal care", "long term care", "preferences" and "age of interest" will be created and connected with the Boolean operators AND and OR. Truncations (\*) will be used to find all forms of the word. English and German search terms will be employed in the database search. No specific timeframe will be set for the database search. After removing duplicates, two independent reviewers will perform the selection process. A first selection of articles will be based on screening the titles and abstracts. If the inclusion criteria are met,

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3 the full text of the articles will be read and checked for final inclusion. In case of disagreement, a third  
4 reviewer will be consulted. The database search will additionally be complemented by hand searching  
5 the reference lists of the included literature. The quality of the systematic literature review will be  
6 tested with the PRISMA checklist [19].  
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### 10 **Face-to-face interviews**

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12 Semi-structured, guideline-based face-to-face interviews will be conducted in the region of Hannover,  
13 Germany to explore people's views and caregiving preferences. Eligible interviewees will receive  
14 detailed information beforehand concerning the aim and scope of the study, as well as any data  
15 management issues. Interviews will only be conducted after a written informed consent was signed.  
16 For the interviews, informal caregivers, care consultants and people with no prior caregiving  
17 experiences will be recruited. For this purpose, primarily self-help groups, care consultancies and care  
18 support points will be identified in the region of Hannover and subsequently contacted. Maximum  
19 variation purposive sampling will be utilized to identify heterogeneous participants for the qualitative  
20 interviews [20]. The total sample size will be based on the principle of theoretical saturation, meaning  
21 no new views on the topic are expressed [21].  
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30 One experienced researcher (LDJ) will conduct all interviews to ensure homogeneity. The researcher  
31 will make sure beforehand that each participant is familiar with the study's aims and the voluntary  
32 nature of participating in it. The guideline will be used for each interview and continually revised to  
33 incorporate new points of interest identified during the interviews. Each interview will be audio-  
34 recorded and subsequently transcribed. In order to analyse the transcripts of the audio recording  
35 context-oriented, interviewees will be asked to fill out a questionnaire following the interview,  
36 disclosing essential sociodemographic factors such as age, gender, profession, previous and/or current  
37 caregiving experiences as well as the geographical distance to the person in need of care. The planned  
38 expenditure of time is set at 30 minutes, as the target audience of informal caregivers is unlikely to be  
39 able to spare too much time for participating in interviews.  
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48 The guideline interview questions will be based on information collected by means of the systematic  
49 literature review. To test the comprehensibility of the interview questions, a group of experts and  
50 randomly selected lay people will be consulted. During the interviews, we will ask participants about  
51 the current structure of care they provide and if this type of care reflects their wishes as well as the  
52 wishes of the person in need of care. We additionally seek to know perceived challenges of providing  
53 care and any observed effects on their time and cost structure. One central question will be people's  
54 wishes and preferences for their own hypothetical care and any perceived differences to the provision  
55 of care for their relatives. An interesting sub-question at this point will be the responsibility for  
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3 providing care, i.e. if people perceive this to be a familial or societal obligation. In the execution of  
4 care, we seek to ask people's preferences for care provided by other people versus potential technical  
5 support. Furthermore, we will ask people for suggestions for improving the current care structure in  
6 Germany.  
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### 10 **Interview analysis**

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12 With the informed consent of each participant, all interviews will be recorded, transcribed and  
13 subsequently analysed. All transcripts will be entered into MAXQDA Version 11 and reviewed line by  
14 line. For the analysis of the transcripts, a qualitative content analysis will be performed by two  
15 independent researchers based on Mayring [22]. The content analysis will take on a directed approach,  
16 making use of deductive categories identified in the interview guide, while at the same time leaving  
17 room for further inductive categories generated during the analysis of the interview transcripts [23].  
18 A codebook will additionally be created for the two researchers performing the analysis. Findings will  
19 be crucial in informing the design of the DCE, in particular the generation of attributes for the DCE.  
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### 26 **Discrete choice experiment**

#### 27 Description of the DCE

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29 The DCE is a stated preference method, combining knowledge from random utility theory,  
30 experimental design theory, consumer theory and econometric analysis [24]. The method of DCE has  
31 been increasingly applied and deemed useful in the field of healthcare research to elicit people's  
32 preferences [25, 26]. In a DCE, people are asked to choose between two or more alternative scenarios.  
33 The underlying assumptions of a DCE are that any intervention or service looked at can be described  
34 by its attributes or characteristics and that people value these attributes differently depending on their  
35 levels [27]. The attributes and its different levels are then comprised to several scenarios, of which  
36 people are asked to choose one based on their preference. This method enables an inferability to the  
37 relative importance and value people place on different attributes, as these need to make trade-offs  
38 between the several attributes and their levels in their decision-making process [18].  
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#### 48 Design of the DCE

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50 We will conduct a DCE to measure the caregiving preferences in the German general population. In  
51 the process of constructing an optimal or nearly optimal experimental design, two statistical issues  
52 need to be examined. Namely, identification meaning the ability to obtain independent and unbiased  
53 parameter estimates and efficiency as the precision with which such effects are estimated [17]. Several  
54 authors argue that design identification should take priority, as efficiency can be improved later by for  
55 instance increasing the sample size. However, identification errors in the design cannot be altered  
56 retrospectively and are likely to produce biased and confounded results [17, 28, 29]. Statistical  
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3 efficiency and response efficiency need to be balanced to maximise the precision of parameter  
4 estimates [30]. We will use the D-efficiency criterion as a measure of statistical efficiency, while  
5 blocking certain choice sets will be used to increase response efficiency by reducing the information  
6 load of participants. The D-efficiency criterion has been increasingly used to measure statistical  
7 efficiency when aiming to create optimal designs with an efficiency of 100%. Thus, we will create choice  
8 sets that minimise the D-error, which respectively maximises the D-efficiency [26, 28]. A full factorial  
9 design is generally regarded as an optimal design to estimate all main effects as well as all interaction  
10 effects. However, a full factorial design is rarely feasible depending on the final number of attributes  
11 and levels. Thus, we might have to opt for the largest possible fractional factorial design with a high D-  
12 efficiency. We will use the Statistical Analysis Software (SAS) to construct the choice sets of the DCE.  
13 We chose to construct a labelled DCE for our study, which uses specific labels or titles for the different  
14 alternatives, thus already conveying information to the study participants. For this study, the label  
15 “type of care” will be used, categorised into “only informal care”, “mix of informal and formal/out-  
16 patient care” and “only formal/out-patient care”. While labelled DCEs are currently less frequently  
17 used in health economics, alternatives will be less abstract and more realistic for respondents, adding  
18 to the validity of the results [31].  
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20 Results from the systematic literature review, as well as the interviews, will be used to establish the  
21 attributes for the DCE. In total, four to six attributes will be created on the basis of their relevance to  
22 the research question and decision context [18]. In the creation of the attributes, particular focus will  
23 be placed on the independence of attributes. We would like to respectively include at least one  
24 attribute connected to cost (or time). The willingness to pay for services will be integrated as an  
25 attribute in the DCE. Other potential attributes might be quality of care or retention of autonomy. With  
26 the selection of included attributes, the corresponding range of levels for each attribute will also be  
27 decided on and discussed with experts. No opt-out option will be included in the profiles to ensure the  
28 complete estimation of preference structures and trade-offs made between choice sets. Additionally,  
29 the option of not providing needed care is no realistic scenario in this case.  
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#### 31 Data collection and sampling strategy

32 For the sample, people between 18 and 65 years of age will be recruited from the German general  
33 population with no own need for care. The aim of the age limit is the ascertainability of a group of  
34 people of working age with no own dependency on care. Occupational and familial obligations are  
35 expected to influence the individual willingness to provide care for relatives. Study participants will be  
36 recruited in cooperation with a statutory health insurance (AOK Lower Saxony) by random selection of  
37 insured Germans in the chosen age range. Particular attention will be placed on the population group  
38 45 to 64 years of age, as they most likely have own informal caregiving experiences. The primary mode  
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3 of administration will be a mail survey. Study participants will receive detailed information about the  
4 study and the data management plan beforehand. Data will only be used after written informed  
5 consent by all study participants. In accordance with the new European General Data Protection  
6 Regulation, the statutory health insurance will be in charge of recruitment and contacting potential  
7 study participants. We will only receive the filled out questionnaires of study participants after written  
8 informed consent has been obtained. All personal data, i.e. sociodemographic characteristics, will be  
9 provided to us in a pseudonymised manner [32]. Based on first estimations, the targeted sample size  
10 is approximately 250 per questionnaire version [33]. Calculating with two questionnaire versions and  
11 estimating with a response rate of 1/3, we would send out about 1,500 questionnaires. To verify these  
12 first estimations, we will use the sample size calculations by de Bekker-Grob et al. (2015). This approach  
13 consists of five elements that are deemed necessary for calculating the required sample size of a DCE.  
14 Particularly, the significance level, the statistical power, the statistical model used in the DCE, initial  
15 beliefs about parameter values and the DCE design itself are needed [24].

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Once all the attributes, descriptions and levels, as well as the different choice sets have been established, we will perform a pre-test (n = 20) to make sure the questionnaire is understandable for study participants. Next to the understanding of attributes and their levels, we will also test the length and complexity of the DCE questionnaire. A rationality test will be included in the survey to make sure study participants understand the questions. After making any necessary adjustments to the questionnaire following the pre-test, we will be able to send out the final survey. Next to the DCE choice sets, we will ask participants to disclose a number of important sociodemographic factors, as well as provide an assessment of their perceived quality of life. This data will then be used in the analysis of the questionnaires. To measure the health-related quality of life of study participants, we will use the standardised EQ-5D-5L instrument, consisting of the five dimensions mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Next to the descriptive system of the instrument, comprised of the five dimensions with five severity levels each, respondents will also be asked to judge their current health state on a visual analogue scale from 0 to 100 [34].

### **Data analysis of DCE**

Following data collection, we will analyse the data with descriptive statistics and conduct several logistic regression analyses to determine factors that influenced the choices made by the study participants. We will analyse and compare the distribution of mean age and sex between the included respondents of the DCE and the people who did not respond. The core of the statistical analysis rests on the random utility theory, in which choices can be divided into an explainable component and a random component and people's preferences are summarised by their utility function [24]. The random component can be due to different types of error, unobservable attributes or preference



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3 variation [17]. The assumption is that people choose the option with the highest utility. For the  
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5 multivariate analyses, we will use a mixed multinomial logit regression model and a latent class finite-  
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7 mixture model. Both multivariate analyses are appropriate to compare subgroups and see if factors  
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9 such as gender, age and previous caregiving experience influence the choices made. We chose to  
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11 perform a multinomial logit model, as our dependent variable (type of care) has more than two levels.  
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13 Additionally, we will conduct a latent class finite-mixture model, which allows the identification of  
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15 latent classes or subgroups within the sample with different preference weights [35]. With the  
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17 statistical analyses, we aim to investigate if certain sociodemographic characteristics or previous  
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19 caregiving experiences influence the choices made by the study participants with regard to care  
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21 preferences. The statistical program R will be used to perform all statistical analyses.

### 22 **Patient and Public Involvement**

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24 The development of the research question and outcome measures were informed by the current  
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26 demographic changes and political efforts in Germany, as well as the lack of preference studies in the  
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28 field of elderly care in Germany. No patients or members of the public were involved in the design of  
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30 the study. The public will be involved during the design of the questionnaire, as well as the conduction  
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32 of the DCE. The results of the face-to-face interviews will be sent and disseminated to the study  
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34 participants. The results of the systematic literature review and the DCE will be published in open-  
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36 access journals.

### 37 **ETHICAL CONSIDERATIONS AND DISSEMINATION**

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39 The study has been approved by the Medizinische Hochschule Hannover (MHH)'s Committee for  
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41 Clinical Ethics (Reference number 09.05.17/La). Additionally, the study has been registered at the  
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43 German Registry of Clinical Trials (DRKS) and is already visible on the WHO International Clinical Trials  
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45 Registry Platform. A contact person will be provided for all participants in the event of questions or  
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47 later withdrawal from the study. The results of the study will be discussed and disseminated to relevant  
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49 stakeholders in the field. Important experts are for instance payers, care providers and lobbyists.  
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51 Outcomes in the form of recommendations regarding a more efficient use of the limited resources  
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53 available will also be made by taking into consideration the preferences of the German general  
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55 population. We will subsequently publish the results in peer-reviewed scientific journals.

### 56 **DISCUSSION**

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58 Elderly people in need of care are expected to increase from 2.4 million in 2015 to 4.4 million in 2060  
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60 due to changing demographics, rising numbers of multi-morbidities and increasing life expectancy. Of  
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62 the 4.4 million elderly Germans in need of care in 2060, the group aged 80+ is projected to make up  
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64 74% in total [3]. At the same time, current demographic and societal changes will likely make informal

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3 caregiving more challenging in the future and the subsequent demand for long-term care facilities is  
4 unlikely to be met. To reduce the growing expenses of the long-term care insurance in Germany,  
5 political efforts have previously encouraged informal caregiving and the use of out-patient services to  
6 prolong caregiving at home. In the most recent care support act of 2017, the state increased monetary  
7 support for caregiving at home and aimed to facilitate the agreement of caregiving and professional  
8 responsibilities for informal caregivers. However, insufficient research has been done in Germany to  
9 see if political efforts match the wishes and needs of informal caregivers and to representatively  
10 measure the preferences of (potential) informal caregivers.  
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17 The results from this study will provide an important source of information towards improving the  
18 German care structures and payment systems to accommodate future demographic and societal  
19 trends. Our analysis will address the aims of this study by providing estimates of the importance of  
20 each attribute/care characteristic for the overall preference of the type of care. Additionally, the study  
21 will provide an indication to which extent people are willing to trade-off between attributes. Several  
22 logistic regression models will be used to analyse subgroup differences in preferences, such as socio-  
23 demographic factors, previous informal caregiving experiences or migrant background. The outputs of  
24 the study will be critically discussed and disseminated to stakeholders in the field to spark political  
25 debate. Suggested solutions will be made to improve the current care structures and use available  
26 resources more efficiently. Available care services for informal caregivers can be improved preference-  
27 based to further encourage and facilitate caregiving at home. Additionally, the surveyed willingness to  
28 provide care and willingness to pay for services of the German general population can be used to better  
29 tailor existing services. This study will be the first in Germany to use a (labelled) DCE to elicit people's  
30 caregiving preferences for care characteristics such as time and cost.  
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**Author's contributions**

LDJ, KD, MP and JZ were involved in the design of the study. JTS and SE were responsible for the design of the recruitment process. LDJ was responsible for drafting the manuscript. All authors approved the final study design and were involved in revising the manuscript. All authors agree to be accountable for all aspects of the work.

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**Competing interests**

The authors report no conflicts of interest.